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## Exploring the Lived Experiences of Adults Who Stutter: A Qualitative Study

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The purpose of this narrative inquiry is to tell the story of two adults who stutter, from the participants' own perspectives. The final narrative explores the lived experience of a person who stutters, thus increasing the reader's understanding of this phenomenon. The study potentially benefits professionals in the field of speech pathology because it will help them to gain perspective on the client's side of therapy and provide insight into the life of the client as an overall picture. Understanding the day to day experience of adults who stutter may provide speech pathologists with a better idea of how to respond. This study ultimately provides a voice to two individual adults who stutter, and even though each person goes through different experiences and makes different choices, this research presents an initial step toward understanding their lives.

The following are the primary research questions for this research study:

Q1: What are the lived experiences of adults who have stuttered since early childhood?

Q2: How is the perspective of an adult who stutters affected when he or she has a friend or family member who also stutters?

### **Review of the Literature**

“The *disability* of stuttering is the limitation it puts on an individual's ability to communicate. The limitation...will be heavily influenced by how a stutterer feels about himself and his stuttering, as well as how listeners react to him” (Guitar, 2006, p. 18). A review of the literature reveals that many people who stutter view their speech disorder negatively and believe that it has impacted many aspects of life (Boyle, 2013b; Blood, Blood, Tramontana, Sylvia, Boyle & Motzko, 2011; Bricker-Katz, Lincoln & Cumming, 2013; Susca & Healey, 2001). Other information suggests that individuals feel they have been able to overcome the disorder and live a relatively normal life (Boyle, 2013a; Beilby, Byrnes, Meagher, & Yaruss, 2013). The only

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general consensus is that stuttering has had an impact on the lived experiences of adults who stutter, whether they view it as positive and/or negative. Stuttering is described as speech disfluency in the field of speech pathology, and will be interchangeably referred to as either disfluency or stuttering in the literature reviewed for this study.

### **Anxiety in Relation to Stuttering**

A study by Blood, Blood, Maloney, Meyer and Qualls (2007) indicated that anxiety levels are often higher in individuals who stutter than those who do not, but they are still within what are considered normal limits. It is widely theorized that anxiety and stuttering have somewhat of a cyclical relationship – anxiety makes stuttering worse in some social situations, and in turn, having more disfluent moments increases anxiety (Craig & Tran, 2014). This is one possible challenge to consider when making attempts to understand the lived experiences of an adult or adolescent who stutters. However, because these findings are likely to vary among individuals, making the generalization that anxiety is a part of someone's life solely because he or she stutters does little to help us gain perspective on an individual level.

The prominence of anxiety among people who stutter could be related to the negative perceptions of many stutterers about the disorder. Beilby (2014) found that many people who stutter have more negative attitudes toward speech in general. It was found that people with moderate to severe stutters believe that stuttering has had an overall negative impact on their quality of life (Koedoot, Bouwmans, Franken, Stolk, 2011), but this may also be influenced by a person's coping style and how they deal with perceived negative experiences in their life. For example, a more anxious person is more likely to view their stutter negatively while an individual who handles stress differently may not have the same attitude.

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While it is possible that there is a relationship between anxiety and stuttering, the personality of an individual can strongly influence how they deal with challenges in their life, and therefore how they might face the challenge of having a stutter. This being said, making the generalization that people who stutter are usually more anxious is too much of a blanket statement and does not take into account the experiences of individual people.

### **Personality Traits and Stuttering**

One factor to consider when exploring the lived experiences of people who stutter is personality type. While it is evident that opinions regarding stuttering persist from adolescence into older adulthood and many individuals maintain that stuttering has a significant effect on their lives, the response may vary based on personality. Bleek, Reuter, Yaruss, Cook, Faber and Montag (2012) tested the prevalence of neuroticism in relation to negative response to stuttering, and the people who scored higher on the neuroticism tests were also shown to struggle more with stuttering and experience greater negative reactions to having the disorder. This research demonstrates that when evaluating the overall quality of life of an individual with a stutter, it is important to consider all aspects of personality including a person's ability to cope with having the disorder and their perception of how their life is affected.

### **Stuttering and Quality of Life**

Another tool used to assess the quality of life of a person who stutters is the *Overall Assessment of the Speaker's Experience of Stuttering (OASES)*, a multi-dimensional assessment instrument, part of which can be used to assess the overall quality of life of an individual who stutters. Through the use of this assessment it has been determined that there are many negative

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feelings associated with having a stutter, but some of these feelings can be alleviated after treatment of the stutter, and it is therefore important to do these assessments on quality of life (Yaruss, 2010).

There are valuable efforts being made to increase the quality of life of individuals who stutter through the use of the OASES assessment tool. These methods help others to understand general feelings experienced by the population of people who stutter, but what they lack are the individual experiences that cannot be explained by a standardized assessment tool. It is important to take the research one step further and examine the individual life experiences of people who stutter to get a better understanding of clients as individual people.

### **Life Experiences of People Who Stutter**

Throughout the literature, there are many different aspects of the life of a person who stutters being analyzed in hopes of learning how stuttering has affected certain important parts of the overall life experience, such as experience in the work environment and social situations in school (Blood, Blood, Tramontana, Sylvia, Boyle & Motzko, 2011; Bricker-Katz, Lincoln & Cumming, 2013).

For people who stutter, the work environment can be somewhat problematic, and may enforce the feeling of negative evaluation by others. Feelings of inadequacy in the work place among people who stutter stem from their own perception of how they are viewed by their normally fluent peers, and the sense that they are being negatively evaluated (Bricker-Katz, Lincoln & Cumming, 2013). This can create barriers for success, especially when a person who stutters is in a career that requires large amounts of communication and he or she feels that communication is more difficult because of this perceived negative reaction by others.

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In a study by Blood, Blood, Tramontana, Sylvia, Boyle, and Motzko (2011), 54% of students who stutter admitted to feeling victimized in school, as opposed to the 9.2% of fluent speakers who felt victimized. The bullying that goes on in schools can have a major impact on the lives of people who stutter, as this victimization correlates to negative self-esteem, lack of life optimism, and negative self-satisfaction (Blood et. al., 2011).

There are many components of life and different experiences that influence the personality, emotions, self-esteem, and personal choices of a person. Looking at these aspects together may help to form a more conclusive idea of what it is like to be a person who stutters.

### **Gaps in the Literature**

While much of the literature provides valuable information regarding the general experiences and challenges of adults who stutter, what it is lacking is a personal account. Many research studies attempt to generalize a sentiment to an entire population by taking averages and combining responses in their reports or interviews. Thus, this narrative inquiry study provided perspectives on the lived experience of adults who stutter and provided an opportunity to explore this speech condition not from a quantitative reported standpoint, but from a personally told story of two adults who are living day to day with stuttering. This research addressed many of the same challenges previously mentioned in other studies and looked at these challenges through a more personal lens in the hope that readers will be able to personally connect with the findings.

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### **Methodology**

#### **Narrative Inquiry**

For this study, a narrative inquiry research methodology (Clandinin & Connelly, 2000) was chosen in order to gain a closer perspective on the lives of adults who stutter through their individual stories. A narrative inquiry focuses on the experiences of the participants, and comprises a story based on those experiences. The researcher, in the process of learning the story of the participants, may relate his or her experiences to those of the participants. From this construction of knowledge comes a research study that readers can relate to their own experiences. Data for this narrative inquiry was gathered in the form of interviews that used questions formulated to better understand the perspective of what gives purpose to a person's life. The data was then compiled into a narrative format, which is a useful form of data presentation because it shows the participants' stories.

#### **Participant Selection**

The participants were chosen based on a convenience sampling method (Salkind, 2010). I already had a personal relationship with both participants, and was able to contact them easily. These participants were also selected because they had both grown up with a stutter. This is important to the research because the purpose of the narrative is to tell the story of the lived experiences of the participants as they were growing up and how having a stutter impacted all aspects of their life. Although there are individuals who may have developed stutters later in life, the participants best suited for this research were adults who had already gone through a significant portion of their lives with a stutter.

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One participant was a female, 21 years old, who recently graduated from college with a degree in theater arts. This participant grew up with a father who also stutters. I met her in my freshman year of high school in 2008. The second participant was a male, 21 years old, who had previously attended college for graphic design. I met him in my eighth grade year, 2007.

In order to maintain confidentiality, participants were allowed to choose pseudonyms to be used throughout the project (Wynne-Davies, 1997). The female participant is referred to as Janine, and the male participant as John.

### **Data Collection**

Interviews were held in the researcher's and participants' homes, either in person or via Skype, and were both video and audio recorded for later analysis. Because it is a narrative inquiry, questions were provided to guide the conversation rather than as part of formal interviews (Clandinin & Connelly, 2000). This approach uncovered valuable insights and information and provided the opportunity to construct knowledge together through conversation.

An initial interview was conducted to get some background information and begin discussion about how stuttering had affected the experiences of the participants. For example, participants were asked to answer questions such as: *What is your family like? What are your favorite hobbies?* as well as more specific questions concerning stuttering: *How did having a stutter affect your education in elementary school? Did that differ from middle school and high school?* (Appendix A). Both participants were interviewed individually for the duration of one and a half to two hours, and then participated in a group interview where they were both present (this allowed for individual perspective as well as shared experiences) which lasted about one hour. During this interview, questions focused more on their friendship. For example,

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participants were asked questions such as *Have you ever had any serious conflicts?* and *Do you feel that you had a different experience stuttering from an early age because of your friendship?* (Appendix B). After the group interview, each participant did one more individual follow-up interview, lasting around fifteen minutes. This interview was used to find out if either participant had any more relevant information to add, that maybe they thought of during or after the group interview (Appendix C).

### **Data Analysis**

Analysis of data consisted of turning the interviews and conversations into stories. Based on the narrative inquiry data analysis method put forth by Creswell (2007), thematic codes were determined in six steps: data managing, reading/memoing, describing, classifying, interpreting, and representing/visualizing (p. 156-157, 2007). In addition to the researcher, a graduate student also coded and interpreted themes. All identified themes were discussed and agreed upon by both parties prior to the construction of the narrative. The participants were given the opportunity to review these themes in the narrative to ensure that their perspectives were accurately represented.

The six steps used for determining themes were broken down into creating audio recording files for the data obtained during the interviews, and then making transcriptions of these audio recordings. Reading and memoing of the transcripts helped to solidify the knowledge and observations gained from the interviews, and lead to further analyses as well as indicated possible instances of bias created by the researcher. Another step in analyzing the transcriptions was to place the stories into chronological order (Creswell, 2007); this served as the beginning of the narrative, although it did not end up being presented entirely in chronological order. To classify the data by different themes, I cut up copies of the transcriptions and put them in theme

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groups that had information in common, in order to interpret meaning from the participants' answers to the questions and the stories that were shared. Finally, the data was compiled to develop a thick, rich description (Creswell, 2007) that helps readers to visualize what it is like to be the participants. Based on the themes identified through the use of codes and the timeline of the story, the experiences of the two participants could be classified into certain main events that make up the basis of the stories, and from this final point the researcher was able to add in interpretations of the larger meaning of the story (Creswell, 2007, p. 155-158).

### **Results**

The interviews conducted focused on understanding the lived experiences of two adult participants who stutter, and how having a friend or family member who also stutters affected those experiences. The following questions were addressed through the interviews by means of questions from an interview guide as well as discussion between the participants and the researcher:

Q1: What are the lived experiences of adults who have stuttered since early childhood?

Q2: How is the perspective of an adult who stutters affected when he or she has a friend or family member who also stutters?

One participant gave very detailed, in depth answers while the other participant was much more brief and vague with the answers he gave. During the group interview, participants were able to discuss their lived experiences together and how their friendship affected their perspectives of stuttering. According to the data analysis procedures outlined above, themes were identified based on the contexts and emotions experienced by the participants in their interactions with people and the situations that influenced and shaped the participants' lives

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(Creswell, 2007). Themes varied between the two participants; the main themes identified during the interviews were friendships, relationship with family, shyness, school and work, childhood experiences, frustration, embarrassment, fear/anxiety, acknowledgement/acceptance, humor/sarcasm, resilience, confidence/pride, therapy, and information about stuttering. The contextual themes were identified based on experiences the participants had because of a certain situation or location they were in, and emotional themes were based on emotions that consistently arose for the participants throughout their answers to the interview questions. For the purpose of this research, the lived experiences of the participants, John and Janine, will be presented in a narrative form divided into three sections: John, Janine, and Both Participants. This will allow the researcher to highlight each participant's experiences as an individual, as well as what both participants have in common, and describe how the participants' friendship affected their experiences.

It is important to note the unique researcher-participant relationship of the research; because I had known both participants for many years prior to conducting the research, they appeared genuinely comfortable sharing such personal information with me. In addition, the narrative inquiry methodology allows for some researcher participation, as the purpose is to construct a new base of knowledge during the interviews that could not happen in any other situation. While the focus of the research is to examine participant perspective of stuttering, the researcher perspective was also taken into account throughout the narrative section of the research.

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### **Limitations of the Present Study**

Although I purposefully selected two participants to take part in this study, it might be seen as a limitation of the study because the stories of two participants cannot be generalized to the entire population of people who stutter. The narrative inquiry methodology often focuses on one individual participant and highlights their story in relation to the researcher. As this research was intended to present a very personal perspective on stuttering and friendship, the participation of these two adults was completely intentional. The fact that their responses cannot be generalized to all people who stutter is within the very nature of narrative inquiry methodology: meaning that this research may not necessarily be relevant or accurate for all people who stutter.

In addition, my relationship to the participants may have been a limitation to the reliability of this particular study. Having a personal relationship with the participants has made it difficult to avoid bias, due to the friendly nature of the conversations and any perceptions of the participants I may have had prior to the research. However, it is my belief that, although this personal relationship may have affected the level of bias involved in the research, it also added to the strength of the content. Without this relationship to the participants, it might have been necessary to spend more time with the participants prior to the research to build a rapport so they would be willing to share personal information during the interviews, and even then the participants might not have been as honest and open with someone who was essentially a stranger prior to the beginning of the research process.

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### John

John, now a 21-year old male in the midst of dropping out of college, stumbled into my life some years ago on an eighth grade trip to Washington D.C. One of my first memories of him is that I, unwittingly, made fun of him for stuttering. During an interview with John, I brought up this memory, only to realize that he does not remember me making fun of him, nor does he remember the fact that he stood up for himself and told me that he had repeated that syllable because he stutters. However, it is a memory that has stayed with me for almost eight years.

**Personal facts about stuttering.** In talking with John, I came to realize a great deal more about how stuttering has affected him throughout his life. A large majority of his memories concerning stuttering seemed to be very negative, demonstrating the extent to which stuttering has been a great challenge to him in his life. He seems, however, to have a more hopeful outlook for the future, and for his life in general.

John's interviews can very clearly be divided into themes. However, many of his answers were very brief: he tended not to go into much depth when describing feelings, emotions, or perspectives.

While interviewing John, I learned a great deal about how he personally views stuttering, and which specific characteristics of stuttering he has experienced. When I asked him to describe his speech, John said:

*It's fine, but every now and then I get blocks, where I can't say anything... Like I can't, my vocal cords won't do it... I can't imagine your thing, like not having that. Just being able to do anything.*

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He mentioned that even in comfortable situations, with people he knows well, he is able to relax a bit but is still very aware of his stutter. He reports using many different techniques to get through sentences more fluently, such as switching to a synonym instead of the word he originally intended, pausing and taking a breath, or saying “um.” However, if he doesn’t plan out what he’s going to say he tends to be more fluent than if he thinks about it a lot beforehand. John also told me that when reading aloud, he is nearly fluent.

**Relationship with family.** John first noticed he stuttered around the age of eight, and when he approached his parents about it, they simply shrugged him off, insisting that “it would pass.” When I asked him how it made him feel when his parents said that it would pass, John told me that it made him upset because “they didn’t care about it.” At that time, John decided to trust his parents, knowing that in general, they were usually right. However, his stutter did not go away, and this lack of acknowledgement from his family is something that has followed him throughout his life. John admitted to me, during our interview, that he has no idea whether or not his brothers even know that he stutters, and continually repeated that his parents do not mention it or act as if they notice that he is stuttering at all. John also stated that his family is not a particularly close one. In describing how his family functions, John explained that they “don’t really talk much,” and if they do talk, it’s about school. School, the most important thing to his parents, is something that John has recently decided he has no interest in (even after going through high school as a very successful student).

**Friendships.** This lack of acknowledgement, when it comes to stuttering, is something that has also translated into John’s relationship with his friends and peers. When asked what he would want a new friend to know about him upon meeting him, John said, “I would like them to know that I’m gay and that I stutter without having to tell them.” He felt, however, that this

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sentiment was too awkward to say when initiating a friendship, even though it is valuable information for someone to know about him. This was a consistent theme throughout my interviews with John. He wants the people in his life to know and acknowledge that he stutters, but he is not willing to bring it up with them himself. Although John never felt that people treated him differently because he stutters, he explained that sometimes his friends would make jokes about him stuttering or “saying something weird,” and he did not find it amusing; rather, even though it was friendly teasing, John felt bothered by his friends’ lack of empathy and understanding about his stutter. He mentioned, however, that it is usually easy for him to move past these feelings of frustration and he does not stay mad about being teased.

**Shyness.** John’s inability to bring up his stutter is not the only thing that he is unable to discuss. When I asked John what he felt might have been different had he not stuttered, he said:

*I would talk a lot...I'd say I'd just talk more. I feel like I don't get to talk, not that I don't want to talk. Or I don't want to not talk, know what I mean?*

Consistently throughout our talks, John mentioned feeling shy, feeling that he couldn’t talk, and decided to be quiet throughout high school. It wasn’t until recent years that John realized he wasn’t actually an introvert. John expressed a strong desire to talk, and mentioned that he likes talking to people very much, even though throughout most of his life he has not felt that he is talkative. In keeping with his hopeful mentality, John mentioned that he is now getting to a place where he is trying to look past the fact that he stutters and just talk, because talking to people is something that he enjoys.

**School and work.** This shyness, or unwillingness to talk, has affected John in many aspects of his life. As mentioned previously, John did not talk much during high school, other than to classmates sitting right next to him. He reportedly would not talk, “like at all,” in front of

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the class, and even to his classmates he still came off as being very shy. He reported multiple instances of school projects that gave him trouble because having to talk in front of the class tended to make his stutter much more severe and hindering. One particular instance was during high school at a government competition, for which the entire class prepared months ahead of time. All John remembers is stuttering through the whole thing and then blocking it out of his memory. This kind of circumstance was something that came up often in work situations as well, because during job interviews John would often get extra nervous and stutter more. He mentioned one instance when he “talked fine” with the employer casually before the interview, but as soon as the interview started, he could hardly put a fluent sentence together. John told me another story about a job interview where the employer asked him about the large gap on his resume, and embarrassed about the real reason, John lied, which caused him to stutter much more than he might have. Even though he was invited back for a second interview, fear and embarrassment kept him from returning.

John currently holds a position doing graphic design work, and feels he is very successful at everything except answering the phone. John mentioned multiple times throughout the interview that he is a very successful artist, and would like to continue along this path and eventually have a job where all he had to do was art.

**Frustration and embarrassment.** Although somewhat apparent throughout the previously-mentioned themes, I feel frustration and embarrassment are worth mentioning in their own category. John said he felt frustrated many times throughout his life, often as a result of stuttering, but as a result of many other things as well. For example, when I first asked him about his childhood, he brought up being frustrated with the fact that he was “fat, gay, [and] stuttering” because “it just added all up.” Later on, during a French pronunciation class, John was faced

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with the difficult decision to either give the wrong answer that he could pronounce, or to try and stutter through the correct answer. He chose to tell the teacher that he “couldn’t do it” and did not give the correct answer even though he knew it, out of frustration with not being able to pronounce it properly. John also expressed frustration in describing situations where his friends either wouldn’t acknowledge his stutter, or people would imitate him (often not knowing what was causing his speech to be disfluent), and he would “just laugh it off.” John referenced his experiences out in public at restaurants with his friends, explaining that he always had to order first because otherwise he felt like he was holding everyone else up. It was also easier to get his order out if he went first, because he didn’t have any time to get nervous about what he was going to say. He did tell me that he always prepared two orders though, just in case when it came his turn to order if he couldn’t say the first one, he had a backup plan to resort to. He summarized all of these experiences well in one sentence when he told me that “it’s just when you need to say it, you can’t say it. That’s what I’ve learned. Summarize everything like that.”

**Acknowledgement, acceptance and/or resilience.** Although it seems at first glance that stuttering has made many aspects of John’s life more difficult for him, he also highlighted some experiences that show he is beginning to accept stuttering as part of his life and acknowledge that it is something he can cope with. When John was describing the situation where he picks out two orders at a restaurant and tries to order first, there was an underlying tone of acceptance in that although he was frustrated about this situation, he knew how to handle it and confidently went first rather than quietly waiting his turn to order. He admires his friend, and the other participant Janine, for being able to call people on the phone and is attempting to do that more often to gain confidence. John also stated that he “is proud of it, kind of, cause it has made [him] who [he] is. Like uh nice and not – [he doesn’t] really have an ego,” and he attributes these characteristics to

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stuttering. He also said that he has become a very patient person, and although he doesn't expect others to do it for him, he is always willing to wait for someone to finish their sentence. He hopes that stuttering will affect him less in the future, and that it will not bring him down; rather, he will be able to be confident in the way he speaks and he will talk to more people.

### **Janine**

Janine, a 21-year old female, was one of my closest friends during high school. I met her through the other participant, John, because they had become very close friends. Janine is someone who, throughout high school, I perceived as being sarcastic to compensate for a lack of confidence. However, after interviewing her just recently, I have come to realize how much she has accepted herself. She has grown into someone who is sarcastic because she is confident, and is so at peace with the fact that she stutters that she hardly even associates herself with the stuttering community. Janine had a unique experience growing up, because in addition to having a friend who stuttered, she also had a father who stuttered. Janine had these two perspectives on stuttering from which to gain insight, in addition to her own experiences, challenges, and triumphs. Janine was immediately willing to share information about her experience and gave very deep and insightful answers to the questions I asked her.

**Personal facts about stuttering.** When I asked Janine to describe her speech and her definition of stuttering, she had an interesting response; in fact, until I explained some of the different characteristics of stuttering, she had no idea what her speech even sounded like. She initially said she did the same thing as John, and that she “unintentionally gets stuck on words”—that was her entire explanation. She described situations in which she tended to use coping mechanisms to get around moments of disfluency, such as during her job as a theater stage

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manager and in school. She mentioned using synonyms to get around words that would give her trouble, and also said that people had made fun of her for stuttering before they knew what it was. But in all her explanations of these situations, none of them seemed to bother her for more than an instant. She reported that talking about stuttering was “like trying to talk about how you breathe or how you walk. It’s like I – I just, you do it!”

**Relationship with family.** When asked about her family, Janine described her parents as being “very much in love” and sarcastically reported that she “didn’t get it.” She said that she and her younger sister had fought as children, and that they weren’t exactly close now but they got along better than they used to. After I asked her how it was to talk with her family. She said that her speech actually tended to get worse because she was so comfortable with them that she didn’t need to constantly reword things. It was different around her family, because Janine’s dad also stuttered, and so “they just got it. And they didn’t care because of that.” Janine also reported feeling this ease with certain friends that she felt very close to, because after a while she considered them family too.

**Friendships.** My first question to both participants concerning friendships was, “If you were to meet a new friend, what would you want them to know about you?” Immediately, Janine’s response was, “I would want them to know that I don’t like playing games.” Upon further investigation, I found out that this was because she “doesn’t like when she can’t have a conversation with someone.” Janine insisted that she “liked talking to people and didn’t like when people have to do things to bond with their friends.” This sentiment was interesting, particularly in contrast with John’s feelings about talking with other people. In this case, the fact that Janine had clearly surpassed any nervous feelings in regards to stuttering is quite clear.

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When meeting a new friend, talking was not something that held her back; in fact, it was annoying to her if she wasn't able to talk with someone when getting to know them.

**School and work.** The first time anyone ever mentioned stuttering or talked to Janine about it, she was in third grade. She said that she was so young that she didn't really know what the problem was; it was just "the way she talked." Her dad did it at the house, so it seemed relatively normal to her to stutter when she spoke. She remembered that there must have been a teacher who brought it up to her family, and then brought it up with her, and that was the first time she was even aware that it was a concern. Up until that point, "it just always was." It wasn't until her transition to middle school that Janine ever felt any sort of apprehension about speaking, because she was in a new school, with new teachers and new classmates, and no one was familiar with the way she spoke; on top of that, she had to introduce herself and say her name in class, and for the first time she felt afraid to speak up. Throughout my conversations with Janine, there was only one true mention of shyness, and that was during her high school years. I asked her what she felt might have been different if she had never stuttered, and she said she thought she would have been a lot more outgoing, but that she didn't know if she was awkward and insecure because she was in high school or because she stuttered.

Janine is currently working as a theater stage manager, which is a job that requires her to make calls using a microphone to alert the cast and crew when to do certain things in a scene, as well as to read actors' lines to them during rehearsal to help them memorize their parts. Janine doesn't feel that stuttering has caused her any big problems in relation to her work, except when she is reading lines with the actors or making calls that are particularly difficult to say. She has ways around these though: if she's "having a bad day with her speech" or the way she is reading lines isn't working, she will hand the book off to someone else to make sure the rehearsal is still

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productive. If a cue is particularly hard for her to say, she will change the way she calls it, but the change will be consistent throughout the show so the crew will still know what she means. She also mentioned that she might prepare a cue before it actually needs to happen, just in case she has trouble saying it.

**Humor/sarcasm.** Something I noticed in particular with Janine, was that she often used sarcasm in her answers to my questions. This personality trait was consistent with my memory of her from high school, but there was a more confident air to her humor during the interviews. For example, when I asked her what her dream job was, her immediate response was, “Oh I don’t know, a singer!” followed by, “To be famous!” However, upon further questioning, I came to find out that she has little serious interest in those ideas, and truly loves the job she already has. After I mentioned that upon meeting new friends I would like them to know that I am sarcastic (not rude), she asked if she could add that to her own answer. She explained that she thinks stuttering is the reason she is sarcastic, because as she got older she acted rude and sarcastic to make people laugh in an attempt to make them forget about the way she stuttered when she spoke. Janine also said that when other people are sarcastic, she thinks they seem much more confident in themselves, or in her words, “You must be funny like in all the ways, and very confident in yourself to be sarcastic.” She also mentioned that both her parents are very funny, and so humor just runs in her genes and she can’t help but be hilarious.

**Acknowledgement and acceptance.** By way of detachment, Janine seems to have been able to gradually accept the fact that she stutters and acknowledge that she still feels occasional fear and anxiety, but it is now less personal. Stuttering is something that is annoying to deal with on a regular basis, and things like reading aloud still bring up an emotional reaction, but it is less about what other people will think about her and more about the fact that, once again, this is

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something she has to worry about. Janine also indicated that stuttering was something that affected her socially and may have made her less outgoing, but she was able to find friends who didn't care about the way she spoke and accepted her as she was. She also stated that although she constantly felt this fear and annoyance about speaking, she didn't let it stop her from talking to people and eventually making friends.

**Confidence and pride.** Although Janine mentioned more than once the fear she felt because of stuttering, and a few instances where it held her back and stopped her from doing things she wanted to do such as acting, she was still able to put a positive spin on these situations and how they benefitted her in some way. Even though, as she said, "it just always sucks to like constantly have that concern... Because it's funny cause when I think about people who don't, I like don't get how they don't have to be worried about it," she later told me that "In good ways, it's made [her] really – [she's] had to work so much more to get where [she] wanted to go." For example, when interviewing for jobs, it takes more preparation for her because she is not only worried about making a good impression to get the job, she is worried about talking to the employer in general. She has found a good support system of friends and family, and once she figured out exactly what she wanted to do, it made the extra effort worth it.

I asked Janine if she had ever been to or considered therapy, and it turned out she tried going to speech therapy two different times, first in elementary school and then again in college. Both times, she felt that:

*It was like correcting something about [her] that wasn't really a problem... It was like trying to learn how to walk a different way, you know. And you know in hindsight, it was probably because [she] didn't need it. So like [she] was, they were trying to fix something that deep down, [she] didn't need to fix. So why put in the work?*

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She realized that she wasn't letting stuttering hold her back, and so without the drive to fix it, therapy was never going to make any difference for her.

**Resilience.** Janine, in contrast to John, showed great amounts of resilience in coping with stuttering. That is not to say that John wasn't making growth in the direction of resilience, only that Janine seemed to already be there. When asked for an example of how she felt she had been resilient, Janine told a story about her final year in college, during her senior seminar class, when the students were required to do mock interviews. It didn't go well for her, because she walked in to do the interview, and she realized that her career could depend on the impression she made. Conversing with me she was able to say, "that experience was like kind of woke me up to being like, 'Oh, I can't let this affect me, I can't like let this prevent me from doing what I wanna do,' ... Like it just became so real at that point... that I was like, 'I can't let this stop me because it just almost did.'" This experience showed a great amount of resilience, but it was one other thing she said to me that really stuck out as an example of how she turned a situation that most people would think incredibly challenging, and made something positive out of it:

*The older I get the more, you know, like I said I have to work so much more for what I want to do. And I've thankfully picked a career that allows me to speak and I have to work with people and I have to talk a lot and I have to present myself a certain way and I have to brand myself, which is all things that people get scared of, um, so... I think it very easily could have put me at a desk job and I'm thankful that it didn't. But I think that's why, too, cause I think I've always like been moving... like I've, like I got into college before our senior year began. I knew exactly what I wanted to do. I did the internship before I began my freshman year of school. I graduated in three years, and then I moved straight to [a new city], like I just always am like moving. And I think that's why, because*

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*I, I didn't want it to affect me. And I didn't want it to just, I didn't want myself to let it be an excuse to just sit back and like stay in [the town I grew up in] at a desk job, where I'm comfortable, you know, cause I've always been so uncomfortable with my speech that I've been moving forward to forget about it.*

Janine stressed the point that stuttering is always going to pose a challenge to her, but she doesn't expect it to affect her future or the choices she makes.

### **Both participants**

Because of the unique relationship between the two participants and the researcher, this study was able to highlight the perspective of an adult who stutters who also has a friend and/or family member who stutters. John and Janine were friends in high school, and so one of the interviews was done with the participants together, to gain more insight into their perspectives on their friendship, and how it affected their individual experiences as people who stutter.

John and Janine met during their freshman year of high school after they were assigned to sit at the same table in science class. Janine reported that she asked John if he stuttered, and when he said yes she commented that she did too, and he didn't believe her at first. Both participants felt that this experience and the common fact that they both stuttered is what helped them bond so quickly. There were instances when their other friends got angry with them for being so close, because they didn't seem to understand the particular bond that John and Janine shared. In fact, John remembered one experience with a group of friends when deciding what movie to watch, when he said, "Oh we own Mamma Mia!" meaning that Janine's family owned it; after so much time together at her house, they considered each other to be family.

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**Friendship.** The most common theme that arose throughout the interviews about how the friendship affected the participants was that they felt comforted by having a friend at the same school as them who also stuttered. They would often vent about things that happened – situations of disfluency, other people misinterpreting stuttering for something funny, daily frustrations – and both participants expressed that they enjoyed having someone to talk to about what they were going through. Janine mentioned during the group interview that after meeting, she had thought, “Oh my God, I’m so glad I’m not crazy, he does it too!” John in particular explained that he was grateful to know another person who stuttered, because Janine was the first person he had met who spoke the same way he did, and he liked having someone to talk to about his speech. He mentioned that he didn’t think he ever would have talked to anyone about stuttering if he hadn’t met Janine. Reflecting on their experience in high school together, both reminisced about the fact that having a friend who also stuttered gave them one less thing to be self-conscious about, at an age when everything seems to make people insecure.

**If they had never met.** When asked how they thought their lives might have been different if they had never met, both participants agreed that high school would have been more difficult for them in the realm of insecurities and friendships. However, they both felt that being apart in college helped them to grow and become more independent, because they weren’t able to use one another as a crutch to lean on when things got rough. Knowing that there were other people out there who stuttered and that they had met each other gave John and Janine some of the confidence they needed to be successful in their lives and to worry just a little bit less about their speech. When asked this same question individually, Janine commented that she hadn’t realized what a huge impact she had had on John; she was the first person he met who also stuttered, whereas she had grown up with her father stuttering, so she wasn’t as starved for

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someone to relate to as he was. She told me that it felt good to know she had impacted someone so much, although it seemed that she hadn't expected to make such a mark on another person's life. She also mentioned that before, when the two of them would talk about their speech, it was often to complain. However, as they had grown up a bit, coming back together to talk about it in the group interview made her realize that they could talk about it now more in a positive light, if they even needed to talk about it at all. While it was still nice to have someone to relate to and share the struggles that came along with stuttering, it was no longer entirely necessary, but just an added perk of their friendship.

### **Discussion**

There is very limited research concerned with the overall lived experience of adults who stutter; there are many studies conducted in the realm of speech-language pathology that evaluate certain aspects of perception of stuttering, self-efficacy and stuttering, and stigma associated with stuttering (Boyle, 2013b; Bricker-Katz, Lincoln & Cumming, 2013; Susca & Healey, 2001). However, none of these studies have the goal of discovering the life experiences of people who stutter on an individual level, as was the purpose of this research. Therefore, it is difficult to compare the results of the present research with the current literature; this is mainly because qualitative research is not common in studies about speech-language pathology.

Through conversations guided by interview questions, the participants revealed a great deal of insight into the lived experiences of adults who stutter. This information is valuable to those in the speech-language pathology field, as it gives them a different perspective on the clients they serve. This research is meant to encourage these professionals to take a holistic view of their clients when creating treatment plans and providing intervention, and to take into

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account all of the lived experiences of their clients. This is not to say that professionals in the field do not already take the time to get to know their clients on a personal level, as many of them do.

The results of the conversations I had with the participants were valuable because they were able to show the resilience of one participant and the growing confidence of the other. Although there were many negative experiences and stories, which were brought up during the interviews, there were also a great number of positive feelings and confident, resilient attitudes. Both participants showed signs of acceptance toward their stuttering, and Janine in particular showed resilience, confidence, and pride when referring to her experience with stuttering. While the participants reported some negative feelings toward stuttering, it is important to note the presence of positive and hopeful feelings as well. These two people were faced with something that many would deem challenging, and some would term a “disability,” and they faced it head on with emotion and grace. I found it remarkable to hear about the participants’ frustrations and fears, and inspiring to realize that they have found ways to conquer the challenge presented to them. For these two participants, the friendship of a person who understood their experience was of the utmost importance. While this may not be the case for all people who stutter, it is certainly noteworthy that friendship, support, and understanding were key components in the coping strategies of both participants.

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### APPENDIX A

#### Conversation Guide Questions First Individual Interview

##### Personal Information:

1. What is your family like?\* Do you have any siblings?\* Are your parents still married?
2. What was your childhood like?\* Did you grow up somewhere else?
3. What is a memory that resonates with you about your life?\*
4. Who was your best friend growing up? Who is your best friend now?
5. Have you had any jobs growing up?\*
6. If you were to meet a new friend, what would you want them to know about you?\*
7. Would that information change after being friends for a long period of time?
8. What would you want a partner to know about you?
9. What is your favorite hobby?
10. What is your least favorite thing to do?
11. What is something you are passionate about?
12. Are you afraid of anything? Why?\*
13. Would you ever consider going on a blind date?
14. Are you currently in a relationship?
15. What's something that not many people know about you? Why don't they know?\*
16. Do you have any regrets?\*
17. What is your dream job?
18. What are your future plans? Career plans?\*

##### More Specifically About Stuttering:

Note: If time allows, all of the questions in this category will be asked.

1. How do you describe your speech?\*
2. When did you first realize you stuttered? Do you remember it or is it something your parents told you?\*
3. What was your initial reaction to learning that you stuttered?
4. How did stuttering affect your education in elementary school? Did that differ from middle school and high school?\*
5. Do you believe stuttering affected you socially? Was it different in school and out of school?\*
6. What impact does stuttering have on your life?\*
7. How might things have been different if you didn't stutter?
8. What was it like to stutter around your family? How did they treat you? Your friends?\*
9. Was there ever a time you wished you didn't stutter?
10. Do you think growing up with a dad and a friend who stutter changed the way you dealt with it?
11. Did you ever go to therapy for stuttering? If so, do you feel that it helped or didn't help?\*

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12. Is there any incident that sticks out to you as being particularly problematic or challenging? What is an experience that really stuck with you while you were growing up that happened because you have a stutter?\*
13. Do you feel you have been able to be resilient when dealing with the challenges of stuttering? Why or why not?\*
14. Do you feel that some aspects of your personality have been affected by stuttering? If so, how?\*
15. What is an experience that really stuck out to you as something you're proud of?
16. Is there anything you like about stuttering?
17. What do you think you have gained by stuttering?\*
18. Do you practice any avoidance behaviors during normal conversation?\*
19. Are you doing anything to improve your fluency?
20. Have you done any activities that would improve your stutter, or do you have any tricks that help you personally in a situation where you would stutter?
21. How do you think it will affect your life in the future?\*
22. Are you worried about job prospects because you stutter? Will stuttering have an effect on your career path? Does your job choice have anything to do with the fact that you stutter?\*

\*Questions considered to be a priority

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### APPENDIX B

#### Conversation Guide Questions Group Interview

1. Can you describe your friendship to me?
2. Is the friendship the two of you have different from your friendships with other people?  
How so?
3. How did you meet? How did you become friends?
4. Tell me a story about a good experience you had together.
5. Have you ever had any serious conflicts?
6. Do you feel that you had a different experience stuttering from an early age because of your friendship? (Why or why not?)
7. Did your perceptions of your stuttering change when you met each other?
8. Do you think you are friends based on the fact that you have a speech disorder in common, or would you have been friends without that common factor?
9. What do you feel might have been different if the two of you hadn't become friends?

\*All Appendix B questions are considered necessary

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### APPENDIX C

#### Conversation Guide Questions Second Individual Interview

1. Did the group interview raise any new perspectives for you about your own life experiences?
2. Do you feel differently about things we discussed earlier after meeting as a group?
3. Is there anything you would be willing to share with me individually that you didn't feel comfortable talking about in the group interview?
4. How do you feel that your friendship with the other participant affected your life positively? Negatively?
5. What do you feel might have been different if the two of you hadn't become friends?
6. Was anything noticeably different about your life before you met the other participant vs. after?
7. Can you describe to me how your perception of your stutter has changed over time? Your perception of yourself?
8. Were there any significant events in your life that you feel changed your perception of your stutter?
9. What is the greatest strength you feel you have as a result of growing up stuttering?
10. Is there anything about yourself that you would consider a weakness as a result of stuttering?
11. Is there anything else you want to share that you haven't gotten a chance to talk about yet?

\*All Appendix C questions are considered necessary

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### APPENDIX D

#### Participant Recruitment E-mail

Hello,

I am writing to ask if you are interested in participating in a research project for my honors thesis. The focus of the research is investigating the lived experiences of young adults who stutter, and because you have stuttered since an early age you are an ideal candidate. There will be an interview process that involves three separate interviews, and one of the interviews will be with the second participant. This will be a unique process, because the second participant will be someone that you already know. This is ideal for the research, because I am looking to gain the perspective that you two share as well as your own individual perspective on what it is like to stutter. Many of the interview questions are very personal because the purpose of the research is to gain an understanding of you as a person as a whole, as well as determine how stuttering has affected the person you are. In order to participate you will be asked to sign a consent form, which will inform you of all risks and benefits involved with your participation.

If you are interested in participating in the study, please contact me at the email address listed below as soon as possible so that we can schedule a time for the first interview. If you would prefer not to participate, please let me know that as well. Thank you for your consideration.

Sincerely,

Emilie Scharf

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**APPENDIX E**

CONSENT FORM FOR HUMAN PARTICIPANTS IN RESEARCH  
UNIVERSITY OF NORTHERN COLORADO

Project Title: Exploring the Lived Experiences of Adults Who Stutter

Researcher: Emilie Scharf

E-mail:

Advisor: Julie A. Hanks, Ed. D., CCC-SLP

Audiology & Speech Language Sciences

University of Northern Colorado

The purpose of this study is to provide insight into the lived experiences of adults who stutter, specifically the stories of the participants in this research. Based on the stories and information obtained through a series of interviews and conversations held, a narrative or story will be created to represent the perspectives of you as the participant in the most accurate manner possible while still maintaining that your identity is confidential. The information gathered in the study will be used for the purpose of fulfilling honors thesis requirements, and may eventually be published.

You will be asked to take part in a series of two individual interviews, as well as one interview with one other person you know. Interviews will be somewhat structured, but should be considered more of an open-ended conversation simply meant to obtain stories about your life. The questions asked in the interviews are of a nature that may be considered quite personal; for example, you may be asked questions such as, *How do you feel about growing up stuttering? Did stuttering in any way affect your abilities to be social with peers, teachers, etc.?* Interviews will take place in a private space, and may last up to four hours in total. They will later be transcribed for research purposes; you will have a chance to review the transcripts to ensure that they accurately represent your answers to the interview questions. Ideally interviews will be video recorded, but if you would prefer that your interview be audio recorded only, please indicate this on the second page.

In an effort to keep information about your identity confidential, you will be given the opportunity to choose a pseudonym for yourself. Throughout the entirety of the research, you will be identified by your pseudonym. The settings of the interviews and your hometown information will be generally described as is necessary to the research, but no specific information will be disclosed in final reports of the research.

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Risks of participation may include mild emotional discomfort or anxiety brought up by personal topics of conversation.

Participation is voluntary. You may decide not to participate in this study and if you begin participation you may still decide to stop and withdraw at any time. Your decision will be respected and will not result in loss of benefits to which you are otherwise entitled. Having read the above and having had an opportunity to ask any questions, please sign below if you would like to participate in this research. A copy of this form will be given to you to retain for future reference. If you have any concerns about your selection or treatment as a research participant, please contact Sherry May, IRB Administrator, Office of Sponsored Programs, 25 Kepner Hall, University of Northern Colorado Greeley, CO 80639; 970-351-1910.

\_\_\_\_\_ I consent to video recording (initial).

\_\_\_\_\_ I consent to audio recording only (initial).

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Participant's Signature

Date

---

Researcher's Signature

Date

## EXPLORING THE LIVED EXPERIENCES OF ADULTS WHO STUTTER

### APPENDIX F

#### Review Protocol

“The data collected in a narrative study need to be analyzed for the story they have to tell, a chronology of unfolding events, and turning points or epiphanies” (Creswell, p. 155, 2007).

Analyze data for:

1. Interaction (personal and social)
2. Continuity (past, present, future)
3. Situation (physical places or the storyteller’s places)

Creswell steps:

1. Data managing: create and organize files for data
2. Reading/Memoing: read through transcripts and make note of common themes (also make note of important quotes). These will serve as the initial codes for themes
  - a. Designate one color for each theme code. (Cut the interviews up and use colored paper to designate theme categories. That way if we decide to change something to a different theme, it will be easy to move.)
  - b. Themes should be both **contextual** and **emotional**
3. Describing: as themes arise, describe how you are defining each one. Also, describe the story chronologically.
4. Classifying: classifying sections of the transcript into different theme categories based on context and emotion; identify stories; locate epiphanies
5. Interpreting: interpret the larger meaning of the story.
  - a. After identifying themes, summarize the meaning of the story in its entirety.
6. Representing/Visualizing: “present narration focusing on processes, theories, and unique and general features of the life” (Creswell, p. 157, 2007).
  - a. This step is really more for me when writing the narrative, so don’t worry about it for now.

Note: Sometimes a part of the story may correspond with more than one theme – that’s okay. Pick the theme you think it fits into most, and make note of the other theme.

\*The above review protocol was sent to a graduate student with the interview transcripts and used by the researcher in reviewing the transcripts to reduce researcher bias.

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### **Acknowledgements**

I would like to thank my thesis advisor, Dr. Julie Hanks, for her guidance throughout the research process. Without her insight, this project would never have become what it is.

I would also like to thank Dr. Sarah Wycaver, without whom I probably would not have finished this research in the first place. Thank you for seeing potential in me when I could not see it in myself.

Finally, I would like to thank my participants, for dedicating so much time to my research and for being willing to share such insightful and personal information with me.