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# Online Communities For People Who Stutter: An Ethnographic Study Of A Facebook Social Networking Support Group

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**ONLINE COMMUNITIES FOR PEOPLE WHO STUTTER:  
AN ETHNOGRAPHIC STUDY OF A *FACEBOOK*  
SOCIAL NETWORKING SUPPORT GROUP**

by

**ERIK X. RAJ**

**DISSERTATION**

Submitted to the Graduate School

of Wayne State University,

Detroit, Michigan

in partial fulfillment of the requirements

for the degree of

**DOCTOR OF PHILOSOPHY**

2015

MAJOR: COMMUNICATIONS SCIENCES  
AND DISORDERS

Approved By:

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Advisor Date

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## **DEDICATION**

This dissertation is dedicated to my wife, Natalie Dallavalle, and people who stutter.

## ACKNOWLEDGMENTS

This dissertation is the result of the support, guidance, and encouragement of many individuals. I would like to thank the 9 participants who were members of the stuttering support *Facebook* group that was created. I appreciate your willingness to be a part of this study. The words that you all have shared have truly shed new light on the power of digitally connecting with one another to share thoughts, feelings, experiences, and information about stuttering.

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## TABLE OF CONTENTS

<b>Dedication .....</b>	<b>ii</b>
<b>Acknowledgments .....</b>	<b>iii</b>
<b>List of Tables .....</b>	<b>x</b>
<b>List of Figures.....</b>	<b>xi</b>
<b>Chapter 1: Introduction .....</b>	<b>1</b>
Definition of Terms.....	7
<b>Chapter 2: Review of Literature .....</b>	<b>10</b>
Stuttering as a Multidimensional Disorder .....	10
Overt Aspects of Stuttering.....	11
Covert Aspects of Stuttering.....	13
Openly Talking About Talking.....	16
Psychosocial Aspects of Stuttering.....	17
The Legitimacy of Psychosocial Evidence .....	22
Support Group Environments .....	24
Online Support Environments Unrelated to Communication	
Difficulties .....	25
Online Support Environments Related to Communication	
Difficulties .....	27
An Inside Look at Social Networking Sites Today .....	31
Digital Sharing Online for People Who Stutter .....	34
Web 1.0 Digital Sharing Before the Year 2000 .....	35

Web 2.0 Digital Sharing After the Year 2000 .....	38
Benefits Associated With Digital Sharing Via Social Networking Sites .....	41
Challenges Associated With Digital Sharing Via Social Networking Sites .....	45
Statement of the Problem.....	47
Purpose of Study .....	48
Research Questions .....	48
<b>Chapter 3: Method.....</b>	<b>50</b>
Overview of Methodology .....	50
Development of the Participant Site Selection .....	52
Participants Recruited for the Study .....	60
Data Collection Methods .....	62
Data Analysis Methods .....	67
Credibility and Trustworthiness (Validity and Reliability) .....	70
Ethical Framework.....	73
Significance of Study .....	73
Subjectivity Statement .....	74
<b>Chapter 4: Results.....</b>	<b>76</b>
Themes Related to Benefits .....	78
Sense of Family.....	78
Feelings of Safety and Acceptance .....	78
Thought-Provoking .....	79
Convenience Through Accessibility .....	80

Supplemental.....	80
Themes Related to Challenges.....	81
Limited Number of Members .....	81
Sense of Disconnect.....	82
Fear of Misinterpretations.....	82
Lack of Instantaneous Communication .....	83
Lack of Any Responses to a Question .....	83
Themes Related to Support Through Providing Information .....	85
Upcoming Meetings.....	85
Internet Articles .....	87
Themes Related to Support Through Posing Questions .....	91
Weekly Conversation Starters.....	91
Social Gathering Questions.....	92
Themes Related to Support Through Giving Encouragement.....	93
Text-Based .....	93
Like Button-Based .....	94
Themes Related to Support Through Engaging in Humor .....	96
Self-Deprecating .....	96
Sarcasm .....	98
Theme Related to Healthy Debate .....	99
Theme Related to Honest and Varied Opinions .....	100

<b>Chapter 5: Discussion .....</b>	<b>105</b>
Benefits .....	105
Challenges.....	112
Support Through Providing Information .....	117
Support Through Posing Questions .....	119
Support Through Giving Encouragement.....	121
Support Through Engaging in Humor .....	123
Healthy Debate.....	125
Honest and Varied Opinions.....	127
Interpretation of Results in Relation to Previous Research .....	128
Limitations and Strengths of Study.....	129
Implications for Speech-Language Pathologists and Stuttering Support Group Organizers.....	132
Implications for Speech-Language Pathologists.....	133
Implications for Stuttering Support Group Organizers.....	133
Conclusion .....	134
<b>Appendix A: Institutional Review Board Approval .....</b>	<b>135</b>
<b>Appendix B: Permission to Conduct the Study.....</b>	<b>142</b>
<b>Appendix C: Letter of Assurance.....</b>	<b>143</b>
<b>Appendix D: <i>Facebook</i> Posts.....</b>	<b>144</b>
<b>Appendix E: Semi-Structured Interview Protocol.....</b>	<b>158</b>
<b>Appendix F: Interview Transcripts.....</b>	<b>159</b>

<b>Appendix G: Written Questionnaire Protocol .....</b>	<b>196</b>
<b>References .....</b>	<b>199</b>
<b>Abstract.....</b>	<b>214</b>
<b>Autobiographical Statement .....</b>	<b>216</b>

## LIST OF TABLES

Table 3.1: Examples of Public and Closed <i>Facebook</i> Groups Discovered .....	58
Table 3.2: Participant Information .....	61
Table 3.3: Data Collection Schedule .....	62
Table 4.1: Major Themes and Subthemes of the Participants' Experiences of Participating in an Online Community for Stuttering.....	77
Table 4.2: Major Themes and Subthemes of the Ways in Which an Online Community for Stuttering Offers Support to People Who Stutter .....	84
Table 4.3: Total Number of Posts, Replies, and Likes .....	95

## LIST OF FIGURES

Figure 4.1: Group meeting information example.....	86
Figure 4.2: First Internet article example. ....	88
Figure 4.3: Second Internet article example.....	89
Figure 4.4: Third Internet article example. ....	90
Figure 4.5: <i>BuzzFeed</i> article screenshot.....	97

## **CHAPTER 1**

### **INTRODUCTION**

The National Stuttering Association (2009), the American Speech-Language-Hearing Association (1995), and numerous researchers in the field of speech-language pathology have agreed that stuttering is a multidimensional disorder of communication (Daniels, Hagstrom, & Gabel, 2006; Healey, Trautman, & Susca, 2004; Quesal, 1989; Van Riper, 1971; Yaruss, 2001, 2010). That is, stuttering affects not only a person's speech patterns but also one's overall quality of life (Beilby, Byrnes, Meagher, & Yaruss, 2013; Klompas & Ross, 2004; Plexico, Manning, & Levitt, 2009). A number of studies have explored the impact of stuttering on the speaker's quality of life and have found that people who stutter often reported having negative thoughts, feelings, and emotions that were directly related to their overt and covert communication difficulties (Corcoran & Stewart, 1998; Daniels, Gabel, & Hughes, 2012; Gabel, Colcord, & Petrosino, 2002; Plexico, Manning, & DiLollo, 2005; Hughes, Gabel, Goberman, & Hughes, 2011).

One of the ways in which people who stutter have been able to gain support for negative thoughts, feelings, and emotions has been experiencing support group environments. For example, face-to-face self-help conferences for people who stutter, which typically occur once a year in a designated city, have been found to improve the well-being and self-esteem of attendees (Trichon & Tetnowski, 2011). In addition, individuals who attended local, face-to-face self-help monthly meetings for people who stutter have reported that those gatherings positively impacted their self-image and acceptance of themselves as people who stutter (Yaruss et al., 2002). These findings

suggest that the act of connecting and sharing with other people who stutter is filled with numerous benefits that help to increase the overall quality of life of those who stutter.

In the past, most support groups of any kind usually required all individuals to be physically together in the same location to gain the full benefits associated with the meetings. This traditional, face-to-face approach was the standard method that allowed people to connect and share with one another. However, advances in Internet technologies have enabled a new genre of support groups to be born. Digital support groups, or online communities, exist on the Internet in various forms and allow for individuals to connect digitally and share with others at a distance. For example, online support groups have been explored with individuals diagnosed with breast cancer (Collie et al., 2007; Orgad, 2005), caregivers of family members with dementia (Garcia, Marziali, & Meyers, 2011), adults suffering from depression (Lazzari, Egan, & Rees, 2011), individuals attempting to lose weight (Leggatt-Cook & Chamberlain, 2012), and individuals living with other specific health conditions (Rains & Keating, 2011). All of the data from these studies have revealed that participants communicated significant decreases in the negative thoughts, feelings, and emotions associated with their particular life situation. In addition, a majority of participants reported a reduction in loneliness. It is presumed that because the Internet allowed those individuals to connect digitally and share with others, they were able to experience an increase in their overall quality of life, regardless of their physical location. Therefore, online support groups can be just as impactful, if not more so, than traditional face-to-face support groups.

As early as 1995, people who stutter and those interested in stuttering have begun to embrace the Worldwide Web as a means for obtaining stuttering information and digitally connecting and sharing with others online (Brundage, 2007; Kuster, 1995; Kuster & Kuster, 1995; Meredith, Miller, & Simmons, 2012; Packman & Meredith, 2011; Stoudt & Ouellette, 2004; Snyder, Reitzes, & Jackson, 2009; Tellis, Gabel, Smith, & Tellis, 2002). For example, a study by Stoudt and Ouellette (2004) examined a number of text-based thoughts, feelings, and experiences that people who stutter posted on a designated Internet stuttering forum. This digital location acted as a type of asynchronous, stuttering self-help group meeting point where members actively engaged in public conversations about stuttering that included giving advice, empathizing with others' experiences with the disorder, and sharing their own experiences. By collectively coming together in this digital environment to converse with one another about stuttering, the participants of this Internet stuttering forum encountered positive experiences that helped them to better define and redefine what it means to be a person who stutters.

Furthermore, Packman and Meredith (2011) described a collection of Internet technologies that could potentially provide valid support and self-help opportunities for people who stutter. For example, *Second Life* is a web-based virtual world that could allow people who stutter to easily interact and synchronously communicate with other members in a designated virtual area on the Worldwide Web. Therefore, a virtual world such as this might create numerous opportunities for positive interactions to be had online through in-the-moment discourse about stuttering and real-time socializing with other people who stutter.

Additionally, Meredith et al. (2012) described how people who stutter could use such web-based virtual worlds to increase their effective communication abilities by verbally practicing numerous speaking techniques during a virtual role-playing session. This action may help individuals feel more confident and comfortable with their communication intents, thus increasing their overall quality of life. Examples of role-playing sessions included answering questions at a job interview, ordering food at a restaurant, and speaking on the telephone. After these scenarios were attempted, the users were able to digitally discuss their experiences in a support group setting. These scenarios are often difficult for people who stutter, so practicing them in a controlled environment online could prove to have a healthy number of outcomes that benefit a speaker's self-esteem and psychosocial well-being.

Online communities for people who stutter that exist on the Internet allow for active conversations to take place on the subject of stuttering. The intentional act of openly talking about communication is beneficial for people who stutter (Quesal, 1989); however, research findings unrelated to online communities for people who stutter have found that numerous people who stutter rarely took the opportunity to talk about anything related to their communication difficulty (Beilby et al., 2013; Blood, Blood, Tellis, & Gabel, 2003; Corcoran & Stewart, 1998; Hughes, et al., 2011). For example, Blood et al. (2003), who explored the self-esteem of 48 adolescents who stutter, revealed that more than half of the participants rarely or never talked about their stuttering to other people. In addition, while investigating the experiences of adults who stutter, Corcoran and Stewart (1998) found that several participants made comments about the shame associated with stuttering and their

choice not to discuss it with anyone. For example, one participant stated, “[my stuttering] it was just never mentioned. It’s sort of like having a member of a family who is an alcoholic, and that problem is never mentioned” (p. 255). It could be concluded that the attempt to conceal stuttering by not talking about it might be a natural response of individuals who do not wish to be rejected or stereotyped because of the self-perceived stigma associated with stuttering.

Similarly, Hughes et al. (2011) further illustrated a perceived stigma associated with stuttering, in that 4 of their 7 adult participants who stutter also mentioned considerable concerns about publicly discussing their stuttering, especially to their family members. One participant stated the following, in regards to not talking about stuttering in the home setting: “it was just not something we discussed or talked about, it was just an unspoken topic” (p. 51). This unspoken rule to never mention stuttering at home was also found when Beilby et al. (2013) conducted rich and detailed interviews with the partners of people who stutter. One person stated, “No we never really talked about or discussed his stutter. I didn’t really want him to feel embarrassed about it” (p. 22). The consistent action of dodging the subject of stuttering with others could imply, again, that shame was associated with stuttering and that the individuals feared confronting and preferred not to confront this shame.

It should be mentioned, however, that clients have reported that talking about stuttering and the thoughts, feelings, and emotions that surround the communication difficulty are helpful aspects of stuttering treatment (Irani, Gabel, Daniels, & Hughes, 2012). While exploring client perceptions of an intensive stuttering therapy program that

utilized a multifaceted approach to therapy, Irani et al. (2012) found positive effects of clients actively talking about talking. One participant mentioned, “something that was new and different for me that stood out from any other experience was actually being with other people that stuttered and meeting with them and talking with them” (p. 170). The ability to connect and share thoughts and experiences about stuttering is something that has been found to be powerful within a speech therapy approach that focuses on the affective, behavioral, and cognitive components of stuttering, and it is assumed that the same could be said for digitally connecting and sharing with others within an online community.

As described, online communities are often filled with valuable information and opportunities for people who stutter to digitally connect and share with others. One of the most popular web-based technologies that could prove to be beneficial for people who stutter is social networking sites. These online communication platforms enable individuals to digitally connect and share thoughts, feelings, experiences, and information with one another (Subrahmanyam, Reich, Waechter, & Espinoza, 2008). The conversations that occur within social networking sites have been perceived to have more benefits than conversations in traditional, face-to-face meetings. Examples included being better able to share, discuss, and reflect on ideas that are being communicated in the group setting of an online meeting place versus a face-to-face setting (Plumb 2013a; 2013b).

Over the past decade, it has been found that, with each new year, a great percentage of people are choosing to join a social networking site because of the perceived benefits (Duggan & Brenner, 2013; Lenhart, 2009). This steady increase in the adoption of digital social networking implies that the act of connecting and sharing with others online is

starting to become an accepted, new form of common communication. However, few studies have specifically explored social networking sites and their impact on people who stutter. Most published studies that investigate online communities have been conducted in fields unrelated to the study of communication disorders, thus making it clear that there is a need for more evidence-based research in this area. Online communities have shown much promise in past research, and it is crucial that future investigations are attempted to determine whether social networking sites, and the online communities that surround them, are an appropriate means of psychosocial support for people who stutter.

Therefore, the purpose of this study was to explore the experiences of people who stutter who digitally connect and share with other people who stutter within a social networking site, specifically *Facebook*. The chapters are organized as follows. First, this Introduction outlined the rationale for investigating the experiences of people who stutter who engage and interact within an online stuttering community. Chapter 2 is a review of literature that focuses on describing the complexity of stuttering and unraveling the history of social networking sites for people who stutter. Chapter 3 consists of a detailed description of the methodology used to implement the study. Chapter 4 shares the results of the study. Chapter 5 discusses the detailed findings and their implications for people who stutter.

### **Definition of Terms**

*Stuttering.* Stuttering has been defined in a number of ways. Van Riper (1971), for example, defined stuttering as a disruption in communication where the speaker's speech consists of words that are interrupted by repetitions, prolongations, gaps, the insertion of

other inappropriate behaviors into the motor pattern, or some combination thereof. To date, stuttering can be defined as speech characterized by part-word and monosyllabic word repetitions, disrhythmic phonations, which include prolongations of speech sounds, and blocks (Yairi & Ambrose, 2005). Finally, in addition to the behavioral components that are typical for this communication disorder, psychosocial aspects of stuttering exist that include negative thoughts, feelings, and emotions directly related to the temporary disruptions in the forward flow of speech (Quesal, 1989).

*Social networking site.* Cheung, Chiu, and Lee (2011) defined a social networking site as a “virtual community that provides an online social space for individuals to communicate and interact” (p. 1339). As further described by Boyd and Ellison (2008), these communal, web-based services that allow individuals to facilitate a social interaction via the Internet often have three main characteristics that properly categorizes them as a social networking site. The first characteristic is that it allows the user to create a public or semipublic profile within the website. The second characteristic is that it gives the owner of the newly created profile access to other preexisting users within the website that share a given connection. The third characteristic is that the new user is able to view and explore their list of connections. These characteristics allow the users to reach out to and share digital content with those connections, as well as with any other connections that are visible throughout the website.

*Facebook.* As described on its website (Facebook.com), *Facebook* is U.S.-based social networking site that gives its users the ability to share and make the world more open and connected. Once a user creates a *Facebook* account and sets up a profile, that user is

able to “use *Facebook* to stay connected with friends and family, discover what’s going on in the world, and to share and express what matters to [him or her].”

*Facebook group.* A *Facebook* group is a digital location where the website’s users can create an organized forum or message board to share their common interests and express their opinions about a central theme that encompasses the set of users it was made for. The *Facebook* group feature allows for users “to come together around a common cause, issue or activity to organize, express objectives, discuss issues, post photos and share related content” (Pineda, 2010). Once a *Facebook* group is created, the founders of that group have the ability to decide the privacy level of the group. The privacy level could range anywhere from publicly available, where anyone is able to join and view posts, to private, where users must accept an invitation from the group’s members to join to view posts and contribute to conversations.

## **CHAPTER 2**

### **REVIEW OF LITERATURE**

The purpose of this chapter is to discuss literature that focuses on describing the complexity of stuttering and how various aspects of stuttering come together to create a unique, multidimensional communication disorder. In addition, this chapter attempts to unravel the history of social networking sites for people who stutter. It is believed that through highlighting the benefits and challenges associated when people who stutter digitally share thoughts, feelings, experiences, and information online with other people who stutter, a well-informed depiction of digital social networking for people who stutter will be presented.

#### **Stuttering as a Multidimensional Disorder**

Stuttering is a complex and multidimensional disorder that has been known to affect more than just a person's speech patterns. The National Stuttering Association (2009) and numerous investigators have found that a number of people who stutter experience negative emotions as a result of their communication difficulties (Crichton-Smith, 2002; Quesal, 1989; Van Riper, 1971; Yaruss, 2001, 2010). It is not uncommon for people who stutter to state feeling unfavorable emotions such as shame, guilt, inadequacy (Plexico et al., 2005), embarrassment (Hughes et al., 2011) and anxiety (Gabel et al., 2002). These feelings not only have an adverse impact on the person's ability to effectively communicate, but can also interfere with their progress in the stuttering therapy session (Healey et al., 2004).

The American Speech-Language-Hearing Association (1995) has an official statement in regards to the practice of stuttering treatment and the overall complexity that

surrounds the communication disorder. Their stated guidelines indicate that not only could stuttering behaviors be overt in nature, which are characterized by a temporary disruption in the forward flow of speech, but the disorder also could have covert aspects to it. These covert, or concealed, aspects of stuttering could create barriers to social, educational, and vocational life. In some cases, there can be serious emotional disturbance, such as depression or sociopathic behavior. With such complexities, it is important to mention that overt and covert aspects of stuttering could both work together to create issues that are well within the scope of practice for clinicians to help their clients deal with through treatment that explores the psychosocial aspects of the disorder. Therefore, it is crucial that clinicians are fully aware as to what overt and covert stuttering behaviors are to fully understand how stuttering impacts their clients.

### **Overt Aspects of Stuttering**

Past researchers have explored and sorted the differences in the overt, or obvious, speech behaviors of people who stutter in an attempt to better understand how stuttering presents itself (Guitar, 2013; Van Riper, 1971; Yairi & Ambrose, 2005). For example, Van Riper (1971) mentioned that when a person was said to be one who stutters, that individual's speech consisted of words that were broken by repetitions, prolongations, gaps, and/or the insertion of other inappropriate behaviors into the motor pattern. More specifically, Yairi and Ambrose (2005) stated that people who stutter produced part-word and monosyllabic word repetitions, as well as disrhythmic phonations, which included prolongations of speech sounds and arrests in speech, called blocks. For a person who truly stutters, these overt core speech behaviors, or stuttering-like disfluencies (Yairi, 1996;

Yairi & Ambrose, 2005), do not happen occasionally or in small instances; the occurrences are typically characterized by an abnormally high frequency and/or duration of stoppages in the forward flow of speech (Guitar, 2013). Therefore, the described overt core behaviors constitute a communication disorder because the produced speech deviates from that of others, calls attention to itself, interferences with communication intents, and/or causes distress in both the speaker and the listener (Van Riper, 1978).

Stuttering is not homogenous in nature and this communication disorder has been said to come in many dimensions and subtypes (Borden, 1990; Yairi, 2007). In addition to including a wide variety of characteristic interruptions to the forward flow of speech, the overt core speech behaviors of stuttering are also manifested with an assortment of severity levels (Fucci, Leach, McKenzie, Gonzales, 1998). One common way in which clinicians have been found to measure a speaker's stuttering is by listening to the percentage of syllables stuttered. From this information, a speech-language pathologist is able to indicate the proportion of syllables in the speech sample that are associated with unambiguous stuttering (O'Brian, Packman, & Onslow, 2004). In addition, a person's core stuttering severity level could be calculated by administering numerous norm-referenced assessments, such as Riley's Stuttering Severity Instrument (Howell, Soukup-Ascencao, Davis, & Rusbridge, 2011) or the Illinois Clinician Stuttering Scale (Yairi & Ambrose, 2005). These tests are able to provide an individual with a detailed breakdown of the stuttering-like disfluencies produced by a speaker and objectively measure those behavioral components of stuttering. However, the described norm-referenced assessments do not offer a comprehensive representation of the psychological and social impact of the

experience of being a person who stutters, which has been found to be an important piece of communication information regarding an individual (Manning & Gayle, in press). These types of stuttering behaviors often manifest themselves as covert in nature, which are often hidden from the world by the person who stutters and are difficult for a listener to notice.

### **Covert Aspects of Stuttering**

In many cases, the overt core speech behaviors, no matter the severity, tend to occur as a result of a person's unsuccessful attempts to stop the occurrence of stuttering from happening, in the moment (Van Riper, 1971). The overt, or obvious, behaviors are much different from the covert, or hidden, behaviors that sometimes happen. Covert behaviors do not focus on stopping the stuttering in the moment; instead, they aim to avoid it entirely. These behaviors are the discrete actions that people who stutter take to keep their stuttering a secret, or covered up, from the world. Some common covert behaviors include substituting an easier word to say in the place of a word that might cause stuttering-like disfluencies, pretending to not know the answer of a question for fear that by answering, the stuttering would be exposed in the verbal response, and making the decision to appear as if one is a shy person, when in reality, that person is not (Guitar, 2013; Murphy, Quesal, & Gulker, 2007).

In a study by Corcoran and Stewart (1998) that investigated the experiences of eight adults who stutter, one participant explained the following, regarding what covert behaviors allow a person who stutters to do: "our whole reaction to this problem [stuttering] is one of hiding and avoiding. We pretend to go along with other people's opinions. We nod and agree, because it's easier than voicing our opinion or speaking up" (p. 256). The

conscious decision to agree with someone, simply because it involves much less speech to be produced, when compared to disagreeing, is proof that a person who stutters could falsely pass as a fluent speaker, but at the expense of not being able to truly voice what should have, most certainly, been voiced.

As Van Riper (1971) mentioned, one of the most interesting things about the covert aspect of stuttering is that an individual with no background in the field of speech-language pathology might participate in a verbal conversation with a person who covertly stutters and determine that the speaker has no communication difficulty at all. This given assumption would be based on the fact that no overt core speech behaviors would be auditory or physically present, but the silent struggle could be occurring, and that is something that is not easily seen. Therefore, “we cannot always rely on listener judgments in evaluating the severity of stuttering” (p. 220) because stuttering does not always show itself through observable characteristics, such as hearing a repetition or seeing facial tension. It can also exist under the surface, which adds to the complexity of this multidimensional communication disorder (Healey et al., 2004; Yaruss, 2010).

Most of what fluent listeners experience when communicating with a person who stutters are the various behavioral motor difficulties, or overt aspects, that might be shown. However, as has been discussed, stuttering is more complex than the observed surface features. Sheehan (1997) described it best with his Iceberg Analogy that compares stuttering to a floating iceberg in the water. The ice above the surface is the portion that people can see and hear. When compared to stuttering, that small part of the iceberg would be the behavior motor difficulties, the surface features of stuttering. The part that is

underneath the surface is, by far, the largest portion of the iceberg and should not be forgotten about or ignored simply because it is not seen above the surface of the water. When compared to stuttering, that part of the ice below the water, which cannot be seen, is just like the self-defeating thoughts and feelings often experienced by people who stutter. The shame, fear, guilt, and other thoughts, feelings, and emotions that fill a speaker's mind and heart during a moment of stuttering are hidden from the world because they exist internally, or, under the water. This puts the speaker back at square one and perfectly illustrates why creating goals and objectives that focus solely on the behavioral motor issues, or overt aspects of stuttering, are limiting because they may fail to address the psychosocial components of stuttering (Healey et al., 2004).

Because of the importance of acknowledging the covert aspect of stuttering and its impact on communication, instruments for evaluating and quantifying the experience of stuttering from the perspective of individuals who stutter were created. One such instrument is the Overall Assessment of the Speaker's Experience of Stuttering, which collects information about the totality of the stuttering disorder to better categorize the covert stuttering severity of the speaker (Yaruss & Quesal, 2006). This assessment is appropriate for speakers ages 7 and up. Another assessment was created to focus on the younger population of children who stutter called the Communication Attitude Test for Preschool and Kindergarten Children Who Stutter (Vanryckeghem, Brutten, & Hernandez, 2005). By not exclusively focusing on the overt core speech behavioral characteristics of stuttering, these assessments help to provide the evaluator with a severity category that reveals the true impact that stuttering has on the speaker's quality of life and not just a

verbal descriptor, such as the often used terms of “mild,” “mild-moderate,” “moderate,” “moderate-severe,” and “severe.” These measurements of severity seem to be more diagnostically helpful than a measurement of overt core speech behavioral characteristics because “it can never be automatically assumed that a level of stuttering frequency and speech rate observed in one measurement situation will also be observed in another” (p. 47, Howie, Woods, & Andrews, 1982). That is, the frequency of overt core behavioral characteristics of stuttering is known to vary widely from day to day and situation to situation. Whereas, a measurement of severity that focuses on the psychological impact in the form of the distress and impairment experienced by the speaker is less likely to fluctuate (Manning & Gayle, in press).

### **Openly Talking About Talking**

One of the recommendations made by the American Speech-Language-Hearing Association (1995) encourages clinicians to take covert aspects of stuttering into consideration while working with people who stutter. By taking the time to explore and reduce attitudes, beliefs, and thought processes that interfere with fluent speech production or that hinder the achievement of other treatment goals, clinicians are able to fully provide appropriate and effective stuttering therapy that targets all aspects of stuttering. This stance emphasizes how crucial it is for clinicians to realize how self-defeating thoughts and feelings, such as anxieties felt before, during, or after a communication intent, could serve to exacerbate or maintain stuttering behaviors. It highlights the fact that overt and covert aspects of stuttering are often interconnected, thus demonstrating the importance of investigating psychosocial aspects of stuttering because “we shouldn’t only worry about

how a stutterer sounds. We should also focus on how the stutterer has dealt with the disorder” (Quesal, 1989, pp. 156–157).

Manning (2006) mentioned a 14-year-old boy who, at the time, had just begun stuttering therapy. This particular boy was encouraged to openly talk about talking and he described his experience with stuttering as, “it is like I am a butterfly trying to fly, but I am constantly buffered by strong winds. I cannot move forward like I want and it is frustrating” (p. 155). Similarly, an adult participant in a study by Plexico, et al., (2009) described stuttering as, “a momentary suffocation. Because your vocal folds are shut and it’s not allowing air to come through. And so your lungs are building up and you get the feeling that you’re drowning” (p. 94). From these personal narratives, the irritation that this communication difficulty has caused them is clear and one could assume that their current frustrations could result in future self-defeating thoughts and feelings if not discussed. Incorporating psychosocial aspects of stuttering into treatment allows for these frustrations to be addressed. Descriptions like these should not be covered up; they need to be uncovered and spoken about to move forward towards successful communication.

### **Psychosocial Aspects of Stuttering**

Encouraging people who stutter to talk about their stuttering with others has been known to positively help build social support. Hughes et al. (2011) found that a majority of people who stutter did not have conversations with their family members about stuttering, and therefore, they did not have a strong level of reported social support. Though people who stutter mentioned they would like to be a part of a strong support system in which stuttering could have been openly discussed in their homes, this often did not

happen. One participant stated the following, in regards to why no dialogue about stuttering ever took place within the home setting: “I think it’s always been this ‘hush, hush’ kind of issue and I just put up the front that everything’s fantastic” (Hughes et al., 2011, p. 51).

While exploring the self-esteem of adolescents who stutter, Blood et al. (2003) have also discovered that a number of participants rarely or never chose to talk about their stuttering to anyone around them. Instead, they preferred to stay silent on this particular topic. These findings are similar to data collected from Corcoran and Stewart (1998) who found that adult participants who stutter described a large amount of self-reported shame and anxiety that were said to be associated with their communication difficulty. These negative thoughts and feelings forced them to never mention anything that related to the subject of stuttering to anyone. The obvious attempt to shy away from talking about talking seemed to be a clear indicator that there was a strong self-perceived stigma associated with stuttering and a substantial amount of fear related to talking about talking (Beilby et al., 2013; Hughes et al., 2011).

However, Guitar (2013) mentioned that individuals would have a difficult time reducing their fear of stuttering and becoming effective communicators if they continued to avoid it by not talking about or verbally acknowledging it. These fears, if left unmentioned, could trigger a string of circumstances that could exacerbate or maintain stuttering, such as excessive muscle tension. If these negative thoughts and feelings are not diminished, they could become the seeds that might stay with the person who stutters and could eventually grow to keep them from adopting effective communication strategies.

Making the decision to start a conversation about stuttering and actively talking about talking and the thoughts and feelings that surround talking has been found to be a portion of stuttering therapy that clients have reported to be beneficial (Irani et al., 2012). While exploring the client perceptions of an intensive stuttering therapy program that utilized a multi-faceted approach to therapy, Irani et al. (2012) found positive effects of clients actively engaging in purposeful conversations that revolved around the subject of stuttering. The acts of connecting and sharing thoughts and experiences about stuttering with other people who also stutter are aspects of stuttering therapy that have been found to be encouraging because it focused on the affective, behavioral, and cognitive components of stuttering.

It has been found that during verbal communication intents, people who stutter often reported feeling more anxiety than people who did not stutter (Gabel et al., 2002). Clinicians have the ability to incorporate psychosocial aspects of stuttering into treatment by talking about and exploring these anxieties within stuttering therapy sessions. These conversations are essential because speakers who experience communication anxieties tend to subconsciously paint an unrealistic, negative portrait of themselves as communicators. Van Riper (1971) stated, “much of the stutter’s abnormal speech is based on the evaluations of others and the way he perceives them” (p. 204). When people who stutter encounter individuals who react to their stuttering with what is perceived as negativity, such as anxiousness or rejection, communicators could begin to develop negative behaviors of avoidance and struggle. These behaviors often hinder the person’s

ability to effectively communicate by adding an extra layer of unnecessary stress on to the surface features of stuttering (Guitar, 2013).

However, researchers have found that sometimes the perceived negativity that a person who stutters notices while attempting to communicate with a fluent speaker is not always an accurate portrayal of the true public attitudes at large (Hughes, Gabel, Irani, & Schlagheck, 2010; Irani & Gabel, 2008). In an effort to explore the public attitudes towards stuttering, Irani and Gabel (2008) assessed 178 K–12 schoolteachers on their thoughts of people who stutter and found that they did not report overtly negative attitudes towards them. It should also be mentioned that the educational and experiential factors were not found to have an effect on the teachers' overall positive attitudes toward people who stutter. Similarly, in a study by Hughes et al. (2010), it was revealed that a number of university students used positive descriptors when they described a person who stutters. Included words used were: caring, patient, kind, and accepting. In addition, a number of participants indicated that they perceived people who stutter to be no different than fluent speakers. For example, one participant stated, "I believe they are people just like anyone else. People are people that have similar wants, needs, desires, and feelings" (p. 289). These types of results could indicate that the general public, or at least those that exist within the educational realm, are more tolerant and accepting of people who stutter. Therefore, future clinicians would be wise to discuss data such as this to clients who stutter because these findings could prove to be beneficial in possibly helping clients to reexamine past communication interactions where perceived negativity was noted. This emphasis on thinking back to past

moments of communication is an effective way to incorporate psychosocial aspects of stuttering into treatment.

Successful stuttering treatment usually goes beyond working on the surface features of stuttering by including a strong psychotherapeutic component that focuses on psychosocial aspects of stuttering (Manning, 2006). In an effort to explore the thoughts and feelings of stuttering through the words of people who stutter, Plexico et al. (2009) conducted interviews with nine people who stutter that encouraged them to describe a variety of emotions they felt as a result of their communication difficulty. Participants in this study mentioned a great deal of information related to self-defeating thoughts and feelings that were felt, in regards to stuttering. Specifically, it was revealed how they often thought about their listeners' reactions, not only during the verbal communication intents, but also before and after. Repeated descriptions were mentioned that centered on the anxieties and fears of potentially making a negative first impression or being rejected by the listener. For example, one participant stated the following, in regards to the experience of being a person who stutters looking for a job: "and I never really got any interviews. It was just kinda the look they gave me. That kinda of look that once I start stuttering that they seem a little less interested because they made a snap decision. Well this guy stutters he's probably not that bright" (p. 94). Though it is impossible to know, for sure, what that "look" truly meant, one thing that is certain is that this particular person who stutters automatically categorized the "look" as a negative one and made the conclusion that it was because of the stuttering that he did not get the job. This is a clear example of how a self-defeating thought and a negative feeling can cause a speaker to jump to a conclusion

without having any concrete evidence to support it. The act of jumping to a conclusion does not benefit a communicator's self-esteem or well-being.

Continuing on, another participant from the same study mentioned the following in reference to having to say a gas pump number to a gas station attendant: "before I even pull up to the pump I'm thinking about stuttering. I'm thinking about which pump number is the easiest to say and that's the pump I'll pull up to" (p. 96). Similar to the jumping to conclusions example, this particular speaker assumed that he was going to have a difficult time communicating at the gas station before the communication intent was even initiated. This self-defeating thought forced him to make a specific life decision that was directly a result of attempting to avoid a stuttering moment. The habits of jumping to conclusions, making assumptions without any real evidence, and constantly thinking about stuttering, could create a never-ending source of physical and mental exhaustion for people who stutter. However, by taking the opportunity to actively talk about and analyze such examples that contain instances of self-defeating thoughts and feelings within the stuttering therapy setting, the clinician has the ability to educate the speaker on what does and does not constitute effective communication. Because this conversation incorporates psychosocial aspects, it can begin to diminish some of the self-defeating thoughts and feelings and set the stage for improved communication and greater social and emotional connectivity.

### **The Legitimacy of Psychosocial Evidence**

There is often debate over what counts as legitimate evidence in stuttering research and treatment. Is talking about talking legitimate? Are the collected words that describe a

speaker's thoughts, feelings, and emotions, as they relate to stuttering, able to be counted as evidence? As Quesal (1989) described, talking about things and giving examples of ways in which those things have affected the lives of individuals have been found to be difficult to scientifically quantify. Additionally, some researchers have even challenged reports of how feelings affected one's life, thus sometimes even causing the individual who initially described the feelings to question whether the feelings were real or imagined. However, it is imperative to understand that just because the psychosocial aspects of stuttering are difficult to quantify, does not mean a lack of reality.

Yaruss (2004) urges researchers to remember that the published empirical literature on stuttering is not yet complete and more effort should be put into exploring the psychosocial aspects of stuttering, even if it is difficult to do so. Currently, a large amount of existing research literature emphasizes treatment approaches that are designed to evoke fluent speech. These endeavors rarely, if ever, mention the connection that thoughts, feelings, or emotions have on a communicator. A smaller amount of literature targets treatment approaches designed to help people who stutter feel less concerned about their speaking difficulties by actively having conversations about the psychosocial aspects of stuttering. These psychosocial aspects of stuttering are just as important.

Bernstein Ratner (2005) asked the thought-provoking question of can all fields use the same evidence-gathering framework to give something, such as a stuttering therapy approach, the evidence-based stamp of approval? In short, the answer is no. Requiring all evidence in stuttering research to fit within the medical community's current hierarchy of evidence may not be possible for the field of speech-language pathology. One example that

illustrates this is placebo pills and how they are easier to administer than placebo behavioral treatment. Also, washout phases, which assess the effects of removing a treatment, are possible in short-term medication trials, but are simply not possible in stuttering therapy because it is impossible to unlearn techniques, concepts, reactions, and other actions that often occur within the therapy room. With these examples in mind, it is clear to see that speech-language pathology is still in the process of figuring out how to look at evidence to categorize it as legitimate or not.

One way of looking at this situation is to address the client's complaint and to always allow the client to be the judge as to if the treatment is successful or not. As Yaruss (2004) mentioned, different people who stutter all want different things. To say that every person who stutters enters treatment to eliminate their stuttering would be false because it is not that simple. By allowing the client to work together with the clinician to create unique goals that address the client's unique complaint and perspective, both parties involved can collectively view the chosen data to gauge its legitimacy (Yaruss, 2001).

### **Support Group Environments**

Social support groups have been found to be a beneficial means for sharing and connecting with others. Kaplan, Cassel, and Gore (1977) stated that typical support groups usually provide its members with one or more of the following: (a) access to an immediate community of people who can be relied upon, (b) a reciprocal counseling experience that encourage members to become both a counselor and counselee, (c) a positive environment that helps to increase self-esteem and provide validation, (d) an emphasis on improving members' overall health by loving oneself and caring for others, (e) an outlet for exploring

and discussing physical and emotional reactions to stressors, and (f) a safe and nonjudgmental location that allows members to disclose personal information.

While exploring self-help conferences for people who stutter, Trichon and Tetnowski (2011) have collected data that revealed when people who stutter had the opportunity to meet and connect with others who stutter in this type of support group environment, there was a decrease in negative thoughts and feelings related to stuttering. It was found that the reduction in negativity helped participants to communicate more easily with one another. The positive impact of having access to a community of people who stutter prompted Trichon and Tetnowski to recommend that future researchers explore the Internet and how people who stutter participate in digital sharing activities that exist on the Worldwide Web, and more specifically, on social networking sites.

### **Online Support Environments Unrelated to Communication Difficulties**

We are currently living through a time that is highlighted by rapidly growing technological breakthroughs that are affecting all aspects of our personal and professional lives. Advances in Internet technology are enabling us to share thoughts, ideas, and messages to one another in such a way that past generations could not have imagined. The Internet has been found to be a powerful tool that enables individuals with specific health conditions and disorders to digitally connect and share with one another on the Worldwide Web (Brundage, 2007; Leggatt-Cook & Chamberlain, 2012; Orgad, 2005; Rains & Keating, 2011). Because of its ability to allow all users to both learn from the information they read online and contribute to that information, strong communities of like-minded people are able to exist on the Internet in a helpful and supportive manner (Plumb, 2013a).

These digital communities allow individuals the opportunity to gain a deeper understanding of the knowledge they are seeking to comprehend by engaging in online texts and interactions with one another.

Garcia et al. (2011) found that participants who were caring for family members with dementia positively benefited from the opportunity to participate in a psychotherapeutic support group that met online once a week for an hour during a 20-week period. During a typical support session, group individuals joined in on conversations that ranged from caregiver education to strategies for coping with depression symptoms associated with caregiving. This Internet-based support group approach proved to have the same benefits as traditional face-to-face group therapy. In addition, it was found that by sharing emotions and strategies with one another, strong ties were made and positive connections were established between the caregivers, thus eliminating any negative thoughts and feelings that might have been present before interacting within the online support group.

Similarly, Collie et al. (2007) conducted research that was aimed to help women diagnosed with breast cancer who were living in a rural location of the United States. In an effort to provide these women with the psychosocial support that they needed while facing challenges posed by their cancer, an Internet-based support group was formed. The participants engaged in eight group therapy sessions, each lasting 2 hours in length. All parties involved stated that the intervention was valuable because it allowed the women to share information with other women who were also going through the same situation.

Moreover, it was noted that the women developed strong emotional connections with each other.

In addition, a study by Lazzari et al. (2011), which was conducted with adults who were suffering from depression, revealed that all participants involved in their online community rated their experience as “satisfied” or “very satisfied.” One participant stated, “It certainly seemed strange to begin with (videoconferencing) but I soon outgrew this” (Lazzari et al., 2011, p. 561). From data that was collected throughout the weekly hour-long sessions during a 5-week period, it was found that the treatment that was delivered through the online portal produced clinically significant and reliable decreases in depression. Another participant stated, “I’m now able to see that I can move on and once again enjoy life ” (Lazzari et al., 2011, p. 561). This online community, and others like it, could be used to continuously provide psychosocial support for people of all ages all over the world.

### **Online Support Environments Related to Communication Difficulties**

The alternative social environments that exist within the digital landscape of the Internet have started to be adopted by those who have disorders and disabilities that could impact their communication effectiveness (Barak & Sadovsky, 2008). For example, Jordan (2010) and Davidson (2008) have both discussed how people with autism use the Internet to digitally connect and share with other people with autism as a way to gain social support and to learn about, and embrace, the culture of autism. Similarly, people who are considered to be deaf, or hard of hearing, have been found to use the Internet to share text-based communication about deafness to inform, express emotion, and advocate for

collective action by and for the Deaf community (Hamill & Stein, 2011). These examples provide proof that the Worldwide Web has a substantial amount of information on it that pertains to those who may have difficulties with communication. Therefore, it has become a key digital location for interested individuals to connect with others to share knowledge and support with one other.

In regards to stuttering, Meredith et al. (2012), as well as Packman and Meredith (2011), explored a collection of Internet technologies that could have potential for providing people who stutter with a digital framework that enables valid support and self-help to be obtained. Web-based virtual worlds, such as *Second Life*, could allow people who stutter to easily interact and synchronously communicate with other members online. This ability to digitally connect and share creates many opportunities for people who stutter to be a part of in the moment discourse that specifically focuses around stuttering. In addition, such virtual worlds that exist on the Internet could provide people who stutter with an online environment to attempt virtual role-playing sessions where they could practice various stuttering strategies and scenarios and then discuss those experiences in a supportive group manner. The psychosocial support that exists within these virtual worlds give considerable support that the overall self-esteem and well-being of those who stutter could be increased upon interacting with other who stutter online.

A seminal study by Stoudt and Ouellette (2004) was one of the first to uncover and describe how people who stutter use the Internet as a means for obtaining psychosocial support from other people who stutter. Their initial findings indicated that a healthy amount of people who stutter seemed to be using the Internet as a space for open communication

about stuttering, which seemed to positively impact their self-esteem and well-being. For 30 days, these researchers observed a group of people who stutter as they posted text-based thoughts, feelings, and experiences related to their communication disorder on a designated Internet stuttering forum. Examples of commonly typed messages included sharing various personal stories about their stuttering, empathizing with experiences related to stuttering, and giving advice to members in an effort to provide meaningful support and camaraderie.

One Internet stuttering forum member wrote the following reassuring response to another member who was asking the group for dating advice that related to the fact that the member was hiding his stuttering from his new girlfriend: “I know it can be difficult to start a new relationship, especially when you are trying to hide your problem. I was with my boyfriend for over a year before I admitted that I had a stuttering problem. I’m not going to tell you that hiding it is the wrong thing to do . . . but I can tell you that after I told him I felt a huge weight was lifted off me, it was great” (Stoudt & Ouellette, 2004, p. 187). This written response is an example of a community member providing psychosocial support by giving advice while empathizing and sharing a personal story.

The written back and forth content within the Internet stuttering forum showed that digitally connecting and sharing with each other helped the participants to feel as if they are not alone in their struggles to communicate effectively. One contributor even stated, “I have met only one woman who stutters and that was back when I took therapy as a child. I have met many other men, but no other woman. I was a little surprised at the number of women participants on this listserv” (Stoudt & Ouellette, 2004, p. 184). This eye opening and positive realization could assist people who stutter to see that they are not the only

individuals in the world with this communication disorder and that they have the ability to share their thoughts, perceptions, feelings, and attitudes with other people who stutter.

Members who participated in this Internet stuttering forum have consistently mentioned how important it was to explore the thoughts, perceptions, feelings, and attitudes that were associated with stuttering. One member mentioned the following, in regards to psychosocial support: “I honestly feel that there should be counseling of some sort, not only ‘therapy for stutterers’ but also counseling where you can go and talk about the ‘emotions’ that come with stuttering” (Stoudt & Ouellette, 2004, p. 184). It was obvious from the data collected by Stoudt and Ouellette that people who stutter who belonged to an online stuttering community did have the ability to talk and start valid conversations about stuttering, thus increasing their overall self-esteem, well-being, and psychosocial support. Though they were not able to connect face-to-face, such as in the traditional self-help conferences or meetings that Trichon and Tetnowski (2011) wrote about, those who stutter were able to have a digital relationship with one another and from this relationship, all parties involved were able to receive psychosocial support that were both helpful and inspiring.

The increase in online social networking participation within the United States is at an all-time high (Duggan & Brenner, 2013). With more and more people choosing to digitally share thoughts, feelings, experiences, and information with one another on the Worldwide Web, the landscape of the Internet is vastly changing. A small number of professionals in the field of speech-language pathology have started to explore the Internet and its impact on people who stutter. Stoudt and Ouellette (2004) stated that one of the

reasons that makes the Worldwide Web so interesting for people who stutter is because “the Internet is a context in which fluency does not depend on spoken word and relationships do not depend on proxy” (p. 179).

### **An Inside Look at Social Networking Sites Today**

Over the past half-decade, social networking sites such as *Facebook*, *YouTube*, *Twitter* and others have dramatically increased their user base. With an estimated 1.11 billion monthly users (*Facebook*, 2013), *Facebook* is currently the second most visited website in the world. In addition, *YouTube* and *Twitter* have achieved global status by becoming the third and 10 most visited websites on the planet, respectively (Alexa Internet, 2014).

A social networking site has been defined by Cheung, Chiu, and Lee (2011) as a “virtual community that provides an online social space for individuals to communicate and interact” (p. 1339). As further described by Boyd and Ellison (2008), these communal web-based services that allow individuals to facilitate a social interaction via the Internet often have three main characteristics present that properly categorizes a website as a social networking one. The first characteristic is that it allows the user to create a public or semipublic profile within the website. The second characteristic is that it gives the owner of the newly created profile access to other preexisting users within the website that share a given connection. The third characteristic is that the new user is able to view and explore their list of connections.

According to findings from the Pew Research Center’s Internet and American Life Project, Duggan and Brenner (2013) reported that 67% of adult Internet users were likely

to be a part of a social networking site. This percentage is nearly doubled from the 2008 data collected by Lenhart (2009) and the Pew Research Center, which showed that only 35% of American adult Internet users had a profile on a social networking site at the time. This observed increase in the general popularity of online social networking clearly illustrates that joining a social networking site and digitally sharing and connecting with others is starting to become a central feature of the overall Internet experience.

At its very core, social networking is about making meaningful connections with others who share the same interests or experiences. Adults have confessed that they are drawn to social networking sites, such as *Facebook*, because the platform allows for emotional connections to take place, provides a communication hub for expressing opinions, and gives users the ability to establish relationships with like-minded individuals (Ancu, 2012). The overall attitude of adults who choose to digitally share thoughts, feelings, experiences, and information with others through a social networking site is generally a positive one and that affirming attitude reinforces the appropriateness of this reportedly enjoyable activity (McKinney, Kelly, & Duran, 2012; Plumb 2013a; 2013b).

While exploring the most common social networking site activities that individuals participated in, Subrahmanyam et al. (2008) found that adults spend a large amount of time actively connecting and sharing with others. This included reading and responding to friends' private messages, reading and posting comments on friends' profiles, making and accepting friend requests, and updating their statuses so that friends could keep in-the-loop with one another. In addition, it has been found by Lin and Lu (2011) that adults enjoyed sharing links to photos, videos, and articles that they deemed to be worthwhile or

interesting with others on social networking sites. All of these common online activities strengthen the notion that digitally sharing thoughts, feelings, experiences, and information within a social networking site helps individuals to establish connections and maintain intimate and legitimate relationships. By using the web-based communication and sharing tools that a social networking site provided its users with, participants were able to find value in a virtual space and sustain valid interconnections with others.

Like any medium of communication, the Internet and the Worldwide Web can be used to make both positive and negative connections (Barnes, 1996). Though there are considerable amounts of evidence that indicate how connecting and sharing with others online often results in a valuable experience that improves a user's overall self-esteem, well-being, and psychosocial support (Brundage, 2007; Collie et al., 2007; Fox & Rainie, 2014; Garcia et al., 2011; Lazzari et al., 2011; Meredith et al., 2012; Packman & Meredith, 2011; Stoudt & Ouellette, 2004), other researchers have uncovered dangers associated with actively participating within social networking sites (Feinstein et al., 2013; Lannin & Scott, 2013; Ybarra & Mitchell, 2008). Some researchers caution individuals to be aware of potential harassment on social networking sites that could include threats, aggressive comments, or having rumors spread about them (Ybarra & Mitchell, 2008). Additionally, it has been found in some instances that engaging within social networking sites had the potential to cause a user to develop depressive symptoms, due to negatively comparing oneself to other individuals on the website (Feinstein et al., 2013). Moreover, another study mentioned how inadvertent disclosure of certain information on social networking sites could result in risk of liability and harm (Lannin & Scott, 2013).

However, it is important to keep in mind that all Internet technologies are “constantly changing, advancing, and providing greater functionality (Sparks, 1996, p. 437),” and the same goes for social networking sites. They, as a whole, are web-based services that are still in their infancy. Websites like *Facebook*, *YouTube*, and *Twitter* are all new types of digital and social landscapes that are continuing to evolve. Thus, the technology and culture of social networking sites must constantly be examined to make the most informed decisions as to what they can and cannot bring to the lives of people who stutter.

### **Digital Sharing Online for People Who Stutter**

As described by Baehr and Lang (2012), in the mid to early 1990s, the Worldwide Web was often coined to be the era of Web 1.0. Web 1.0’s technologies were set up in a fashion that created a divide between content providers and content consumers. In other words, the structures put in place for the first batch of digital content creators made it difficult for any type of back-and-forth conversation to be had between the author and the reader. However, as the Worldwide Web continued to mature into the 2000s, Web 1.0 began its transition to what is now typically called Web 2.0. This new category marked the beginning of more extensive and sophisticated interactions between authors and readers. Because of Web 2.0 staples, such as social networking sites and advancement of other digital sharing platforms, the line between author and reader began to blur in such a way that both parties were now one in the same. A typical Web 2.0 user could be described as both an author and a reader who embraces participating in numerous and continuous digital sharing activities online.

**Web 1.0 Digital Sharing Before the Year 2000**

Using the Internet to help make connections and build support networks for individuals around the world began to be discussed in the later part of the 20<sup>th</sup> century. One way that healthcare practitioners and professionals were able to use the early Internet to better communicate and digitally share with one another was through electronic mail (e-mail). As described by Pallen (1995), e-mail was one of the earliest and most basic resources on the Internet that allowed transmission of text-based messages between networked computers. This form of digital communication was more appealing than conventional mail through the postal service because a message could be sent and delivered to its recipient in a matter of minutes, as opposed to a matter of days. The utilization of e-mail marked the beginning of digitally sharing between groups of people and paved the way for more organized digital sharing platforms and social networking sites to be created.

Kuster and Kuster (1995) were part of the first wave to report and promote how individuals were using e-mail lists as a way to help people who stutter to digitally connect and share with one another. In the 1990s, e-mail lists provided some of the earliest public and private digital forums for discussing and disseminating information about specific topics relevant to the field of speech-language pathology. An interested person only had to send an e-mail request to join an e-mail list to gain access to all that it had to offer. Typical speech-language pathology e-mail lists at the time ranged from broader topics related to communication difficulties, such as hearing loss and traumatic brain injury, to more specific topics related to stuttering, such as exclusive support groups for people who stutter and the latest stuttering research findings and initiatives. By actively seeking out and

discovering the various e-mail lists that were available to those interested in or impacted by a communication difficulty, Kuster and Kuster were able to reveal that there was early potential for establishing connections with others online by digitally sharing and consuming personal and professional information about stuttering. While taking into consideration the social networking characteristics that Boyd and Ellison (2008) laid out, the digital community that surrounded a specific e-mail list could have been considered to be one of the earliest examples of an online social networking meeting point, in that the users created a profile (i.e., e-mail address) to convene and share with users (i.e., other e-mail addresses) that had a common connection (i.e., the mutual interest in the topic of stuttering).

The earliest adopters of the Internet who were interested in communication sciences and disorders were interested to discover and share knowledge that was relevant to stuttering. In addition to reading and replying to e-mail list information that was delivered directly to e-mail inboxes, people were beginning to create websites that digitally shared a running number of personal and professional stuttering related posts. In 1995, Kuster (in consultation with John Harrison, then the Program Director of the National Stuttering Project) created the first fully public website that was dedicated solely to stuttering information called “The Stuttering Home Page.” The creation of this website was significant because it was an open resource on the Worldwide Web for people who stutter that did not require an individual to have a personal e-mail address to consume information about stuttering or potentially connect with other people who stutter. The Stuttering Home

Page could be accessed by anyone on the planet with an Internet connection and a web browser.

With numerous comparisons to some of the first recognizable social networking sites shared by Boyd and Ellison (2008), The Stuttering Home Page could be considered to be the first proper social networking site for people who stutter for a number of reasons. First, The Stuttering Homepage was an online destination that targeted a certain group of people, those who stutter. Much like the early social networking site *AsianAvenue*, which launched in 1997 to target the Asian American community, or *BlackPlanet*, which launched in 1999 to target the African American community, The Stuttering Homepage provided a specific set of organized information to a specific set of people during a time when there was limited information to be found on the Worldwide Web. Examples of stuttering-related posts shared on this website included answers to frequently asked questions about stuttering, stuttering treatment approaches and resources, and a number of other unique contributions from individuals who had personal insight into stuttering. Second, much like the earliest social networking site, *SixDegrees*, which launched in 1997, The Stuttering Home Page could also have been seen as a tool to help people digitally connect with and send messages to others online. The Stuttering Homepage purposefully encouraged social networking and relationship building through the website by providing online visitors with physical and digital contact information for support organizations for people who stutter both within the United States and beyond. This action helped to plant the seeds that a community of people who stutter that enjoyed sharing with one another did not have to just exist in the “real world,” it could also exist in the “virtual” world, as well.

As the Worldwide Web continued to evolve and new Internet technologies were being introduced to the masses, The Stuttering Home Page embraced the technological advances. Tellis and colleagues (2002) discussed, in 1997, how The Stuttering Home Page added a plethora of chat rooms to the website and encouraged users to digitally connect and share thoughts, feelings, experiences, and information about stuttering with one another. One such example was a chat room for parents and caregivers of children who stutter. These individuals were able to network and interact with each other to digitally discuss topics that pertained to their children's communication. Another specific chat room that was available was for students who stutter. This digital location gave school-aged children of all ages the opportunity to have active conversations about stuttering therapy and problems that they may have encountered, both in and out of school, as a result of their communication difficulty. The addition of chat rooms to The Stuttering Home Page was profound in that it was the first time users had the ability to participate in a synchronous communication experience, as opposed to the asynchronous experience of waiting for new posts to be published online. Ultimately, these chat rooms helped users to realize, in real-time, that they were not alone, and that they could use The Stuttering Home Page as a helpful online destination where instantaneous communication about stuttering could take place. Thus, making it a valid and valuable social networking experience.

### **Web 2.0 Digital Sharing After the Year 2000**

The turn of the century brought an increase in Internet options for digitally sharing thoughts, feelings, experiences and information about stuttering. Now, The Stuttering Home Page was one of many locations that were available for people who stutter to

participate in Internet discourse. One such example that started to become common was online public message threads. Online public message threads could be described as an organized public bulletin board that had a designated theme where participants had the option to add relevant posts to it (Sparks, 1996). These digital forums were used as a way of getting and sharing information, participating in or listening to the exchange of ideas, and building contacts (Rojo & Ragsdale, 1997).

As the years went on and the Internet continued to grow and evolve well into the mid to late 2000s, yet another digital sharing option began to gain popularity – the ability to make and share podcasts. A podcast is a user created audio or video file that is made available for download on the Internet (Beamish & Brown, 2012). Podcasting dates back to around 2004 and the word ‘podcast’ is a neologism derived from the worlds ‘broadcast’ and ‘pod’, as in iPod, the line of portable media players designed and marketed by Apple Inc. (Hobson, 2012). Because of podcasting, people who stutter were able to see that sharing on the Internet no longer had to be just a text-based activity that focused on text-based communication (i.e., e-mail messages, chat room sentences, message thread posts, etc.). It was able to advance into a multidimensional experience that featured interactive digital media, specifically audio and video presentations. Thanks in large part to increased Internet speeds, improved computer operating systems, newly invented media and mobile devices, and more affordable computer equipment, a number of people who stutter were beginning to digitally share online, not just by typing their words on a keyboard, but by using their own voice to speak their words directly into a microphone and/or a video camera. Regardless of their stuttering severity, these people who stutter were now starting

to create and digitally share audio and video files as a new way to distribute stuttering information to others and to better describe their thoughts, feelings, and experiences relating to their communication difficulty (Snyder et al., 2009).

An example of one of the largest stuttering podcasts is called StutterTalk. This audio podcast was started in 2007 and has since published more than 400 weekly podcasts. It frequently highlights in-depth interviews with people who stutter, researchers, speech-language pathologists, leaders in the self help community, and others (StutterTalk, n.d.). Examples of StutterTalk episodes include discussion on topics such as voluntary stuttering, covert stuttering, speaking strategies, acceptance, the role of religion in therapy, talking to parents about stuttering, and more. As described by the creators of StutterTalk, “Listeners hear us stutter and hear us talking about stuttering from healthy, open, and honest perspectives” (Snyder et al., 2009, p. 89).

To further illustrate how the Internet is no longer considered to be a one-dimensional experience that relies solely on reading static text, virtual reality-centered websites have started to show promise as locations where people who stutter can digitally connect and share with one another. It has been found that the lives of people who stutter were enhanced after participating within a three-dimensional virtual environment (Brundage, 2007), such as *Second Life* (Meredith et al., 2012; Packman & Meredith, 2011). *Second Life*, which is one of the leading virtual reality-centered websites, is described as a free online, computer-simulated environment where millions of real people are represented by avatars online (Stewart, Hansen, & Carey, 2010). As described by Meredith et al. (2012), an avatar is a digital depiction of a user that can enable a person to interact and

synchronously communicate with other *Second Life* members in a simulated, real-world environment. Communication in this virtual world can range from text to graphical icons, to visual gestures and voice.

Through the described three-dimensional medium that *Second Life* allots, people who stutter can talk to other people who stutter without leaving the physical location that they are in (Packman & Meredith, 2011). In addition, a person who stutters could also verbally practice numerous speaking techniques during a virtual roleplaying session that may help the individual feel more confident and comfortable. Examples of roleplaying sessions that have been explored included answering questions at a job interview, ordering food at a restaurant, or speaking on the telephone. After these scenarios were attempted, the users were able to digitally discuss the experienced results in a support group setting manner (Meredith et al., 2012).

### **Benefits Associated With Digital Sharing Via Social Networking Sites**

Approximately 3.1 million Americans stutter. After proper calculation, that number equals out to roughly 1% of the country's population (Bloodstein & Bernstein-Ratner, 2008). A similar calculation could be used to show interested individuals the massive number of people who stutter that are part of a social networking site. For example, *Facebook* and *YouTube* both individually have more than 1 billion unique monthly users (*Facebook*, 2013; *YouTube*, n.d.). This reported number of users could potentially be calculated to contain at least 10 million users who stutter who could be digitally sharing important stuttering related links with their online stuttering community. Or *Twitter*, which currently has 115 million active users per month (Statistic Brain, 2013), could essentially

be calculated to have 1.1 million users who stutter who might be actively creating and distributing the next great stuttering podcast for all of the world to experience. These descriptive numbers could be beneficial for people who stutter to see because it could help them to realize that they are not alone. Through social networking sites, they have the ability to meet and digitally share with an enormous community of people who stutter.

Furthermore, using the Internet to meet and digitally share with other people who stutter is not just limited to individuals from a single country. From locations that include the Netherlands, Japan, Australia, Canada, and beyond, it should be mentioned that the Internet contains an international community of individuals interested in digitally sharing knowledge and thoughts about communication disorders (Kuster, 1998), and social networking sites are no exception. *Facebook* and *Twitter* both have language settings on their homepages that are not just American English. Users are able to select from a large list of languages that include ones from Africa and the Middle East, Eastern and Western Europe, and more (*Facebook*, n.d.; *Twitter*, n.d.). In addition, *YouTube* is currently localized in 56 countries and features 61 language choices for its users (*YouTube*, 2013). The fact that these wildly popular social networking sites offer such a wide range of languages for its users to choose from is proof that there is an overwhelming need and a steady stream of visitors from those international places. Thus, an individual's ability to connect with another person who stutters increases because of this global component. This worldwide connection could help to diminish the negative thoughts that are often associated with stuttering, and strengthen self-esteem and overall quality of life.

Likewise, there is strong data to support that creating a profile and keeping active on social networking sites benefits users' thoughts and feelings. Results from a study by Gentile, Twenge, Freeman, and Campbell (2012) found that when undergraduate college students spent time on social networking sites, such as *Facebook*, they reported higher levels of self-esteem and had more instances of positive self-views. After being given numerous tests, it was found that these social networking site users agreed or disagreed with test items that read:

Agreed

- I feel that I am a person of worth, at least on an equal basis with others.
- I feel that I have a number of good qualities.
- I take a positive attitude toward myself
- On the whole, I am satisfied with myself

Disagreed

- I feel that I do not have much to be proud.
- I wish I could have more respect for myself

As a whole, it appeared that there was a potential causal link between the use of social networking sites and positive self-views.

It also should be stated that the short and quick posts that are made on social networking sites could prove to be an efficient way to digitally share and communicate. The length of communication intents that are created on *Facebook* and *Twitter* are quite different when compared to the communicative end product that is typically within an e-mail mailing list message or an online message thread. Messages created specifically for

e-mail mailing lists or online message threads are usually made up of longer pieces of writing, anywhere from a few sentences to a few paragraphs. Whereas *Facebook* and *Twitter* have recently been labeled microblogging platforms that emphasis shorter communication posts of about 1–2 sentences. Microblog posts are brief text-based life updates, such as one’s present thoughts or current experiences, that are meant to inform others online about how that person is feeling or what that person is doing (McFedries, 2007). Updates like this have been described as “useful for keeping a pulse on what is on others’ minds and knowing their personal life up-dates” (Zhao & Rosson, 2009, p. 249).

One could see the benefit that microblogging might have for people who stutter by giving them a simple and quick way to digitally share one’s present thoughts and current experiences, in regards to stuttering. An example of a person who stutters that consistently exercises this form of digital sharing to connect with other people who stutter, is Daniele Rossi. With the *Twitter* username of “stutterdude,” Rossi publicly creates thought provoking microblog post questions, such as, “How would you explain stuttering to an alien?” (stutterdude, 2013a) and “If you were to write a book about stuttering, what would you write about?” (stutterdude, 2013b). Also, he shares personal information that relates to his stuttering, such as, “Needed some comfort food today so I had a mocha during a team meeting. Forgot how much caffeine skyrockets my stuttering :)” (stutterdude, 2013c) and “It’s ok to take a break from trying to control your stuttering and avoiding avoidance once in a while” (stutterdude, 2013d). Each of these microblog posts generated digital conversations and further showed that these types of simple and quick communicative

intents could prove to be beneficial for all parties involved in the *Twitter* conversational exchange.

### **Challenges Associated With Digital Sharing Via Social Networking Sites**

Research has showed that social networking site users in the United States, China, and India have reported to occasionally use fake usernames in the past or admitted to impersonating someone else on a social networking site (Wang, Norice, & Cranor, 2011). This raises concern for individuals' safety while interacting and digitally sharing thoughts, feelings, experiences, and information within a social networking site. As discussed by Packman and Meredith (2011), a website used by people who stutter who are looking to connect, befriend, and digitally share with other people who stutter ideally should have restricted access and be monitored to ensure that all individuals truly are who they say they are. One could only imagine the harm that may occur if a person who does not stutter poses as a person who stutters. An unexpected situation like this would not benefit the person who stutters because it could cause feelings of betrayal and trigger other negative emotions and situations. However, being that social networking sites are generally an open access area, proper verification of all users to ensure safety could prove to be difficult. It is critical that people who stutter, who are new users of social networking sites, tread lightly while they become more accustomed to this type of digital environment.

A potential leak in privacy is another challenge that all users of social networking sites must be mindful of. Most social networking sites allow users to customize their privacy setting to protect their personal information and limit access to their content, if they so choose. However, there is limited technological protection against the employees of the

social networking site from accessing the “private” information themselves (Buehgger, Schiöberg, Vu, & Datta, 2009). Research has found that users are concerned about the potential that employees from their chosen social networking site may have the ability to access all of their personal information and a number of those users have admitted to not fully trusting said employees (Wang et al., 2011). With such a large amount of private information associated with a user’s social networking account, it is important that people who stutter are made aware of the possibilities that what one would consider to be “private” information, might not end up being “private” in certain situations because people with malicious intents.

In addition to safety and privacy challenges, the notion of credibility is also something that should be discussed with people who stutter who are interested in exploring social networking sites to connect with others. These individuals need to be made aware that not all thoughts and information digitally shared online are accurate or helpful. Some thoughts and information could be erroneous or potentially harmful. For example, sometimes people who stutter are brought up in a certain type of culture and might have been exposed to wrong information, or myths, about stuttering (Robinson & Crowe, 1998). This person might not intentionally mean to distribute false information, but because of a lack of correct knowledge on the subject of stuttering, this could occur. Therefore, it is imperative that new users of social networking sites research the stuttering information that is being shared before fully committing to its authenticity. People who stutter should be encouraged to consult with a licensed speech-language pathologist about any claims that are being shared about stuttering theories, information, and treatment (Tellis et al., 2002).

As the world continues to welcome social networking sites with open arms, it is not uncommon to hear of individuals who have developed unhealthy addictions to the Internet. There are only so many hours in a day and some individuals tend to spend too large of an amount of time online (Markham, 1998). The time spent doing “digital life” activities, such as surfing the Internet or constantly checking Internet messages or social networking site status updates, could take away from doing “real life” activities. This could be the start of a habit that could lead to numerous non-beneficial situations. As mentioned by Barnes (1996), workers could begin to neglect their jobs, students could fall behind on assignments, and romantic partners could start to ignore each other. Individuals who develop this type of addiction “spend enormous amounts of time on the net inventing personas and establishing what appears to be electronic friendships. But in reality, the technology becomes a dysfunctional codependency” (p. 35). Like all things in life, moderation is key and it is essential that people who stutter who utilize the powers of social networking sites be made aware of the possibilities of becoming addicted to the Internet.

### **Statement of the Problem**

In summary, people who stutter often have negative thoughts and feelings that are associated with their communication difficulty. Furthermore, these individuals rarely take the opportunity to actively talk about affective and cognitive aspects of their stuttering because there seems to be a stigma associated with speaking about the disorder. The Internet, however, contains numerous online communication platforms where people who stutter are able to digitally connect and share with other people who stutter as a means for psychosocial support. One web-based technology that easily allows users to post thoughts,

feelings, experiences, and information about stuttering on the Worldwide Web is social networking sites. Social networking sites, such as *Facebook*, enable strong communities of like-minded people to exist on the Internet in a helpful and supportive manner that could be considered to be a digital self-help environment. However, limited research is currently available that explores the perceptions that people who stutter have in regards to digitally connecting and sharing with other people who stutter in a social networking site.

### **Purpose of Study**

Trichon and Tetnowski (2011) have observed that when people who stutter connected and shared dialogue about stuttering with other people who stutter during a traditional, face-to-face self-help conference for people who stutter, there was a decrease in negative thoughts and feelings related to stuttering. Also, it was reported that the reduction in negativity helped conference goers to be able to verbally communicate easier with one another. However, it is unknown if the same benefits for people who stutter would be found in a digital environment, such as a social networking site. Therefore, the primary purpose of this qualitative study is to explore the experiences of people who stutter who digitally connect and share with other people who stutter within a social networking site, specifically *Facebook*.

### **Research Questions**

To guide this investigation, the following questions were addressed:

1. In what ways do people who stutter describe their experiences of participating in an online community for stuttering?

2. In what ways does an online community for stuttering offer support to people who stutter?
3. How do people who stutter understand their interactions with other people who stutter in a social network?
4. How do people who stutter understand their communication disorder through their interactions with other people who stutter in a social network?

## **CHAPTER 3**

### **METHOD**

#### **Overview of Methodology**

Based on the goals of this study, ethnography was an appropriate research methodology. This strategy of inquiry has been frequently used by researchers in the field of communication sciences and disorders as a way to gain a better understanding of particular phenomena (Keegan, 2012). It allows for researchers to first discover what people are actually doing and the reasons why they are choosing to do it. Then, the researcher can attempt to interpret those actions and reasons through the understanding or lens of their participants (LeCompte & Schensul, 2010). Ethnography relies on a human observer to observe humans and it emphasizes working with people, rather than treating them as objects (Wolcott, 1999). Because the basic tools of ethnography are the researcher's eyes and ears, systematic observations are able to reveal a large amount of data that can help with making meaning while actively being within the given community (LeCompte & Schensul, 2010).

Ethnography is often considered to be exploratory in nature. That is, it allows for researchers to begin a study with some uncertainty about certain aspects of the research endeavor. As mentioned by LeCompte and Schensul (2013), it is not uncommon for investigators to be somewhat unaware as to which direction the study might take, once it has begun. Sometimes, there might be indecision as to which kinds of data would be most relevant to collect and focus on, which specific populations would be the most appropriate to contact, and even which questions would be the most significant to ask participants. This

research methodology allowed for the principal investigator to modify the project continually during its duration, which helped to better understanding the interactions and experiences of people who stutter that choose to digitally connect and share with other people who stutter in a social network.

Interpretive phenomenological analysis was the primary method exercised throughout this study. As described by Smith, Flowers, and Larkin (2009), this approach “provides a fascinating and very rich way of engaging with, and understanding, other people’s worlds” (p. 205). It also allows researchers to examine how people make sense of their major life experiences and to gather reasonably rich data that contain a high level of personal account. This aids in the ability to show the participants’ involvement in and orientation towards their world, and provides a glimpse into how they make sense of it. It is this aspect of understanding how the participants make sense of their world that makes interpretive phenomenological analysis particularly important within the ethnographic framework.

More specifically to the topic of stuttering, Trichon and Tetnowski (2011) have described interpretive phenomenological analysis as a method that takes into consideration the thinking and sense-making of an individual’s reported experiences, as it relates to stuttering and being a part of a stuttering community. By approaching an investigation with this frame of mind, it enables researchers to use the words of people who stutter to illustrate the interpretations of the collected data. From these words that both describe situations and create conversations, all parties involved are able to explore what their communication difficulty means to them by attaching their own meanings to life events related to stuttering.

By emphasizing the direct experiences, people who stutter could engage in their own constructions of self and social identity (Stoudt & Ouellette, 2004).

### **Development of the Participant Site Selection**

It should be mentioned that this type of investigation presents a major challenge of the sheer quantity of potential relevant social networking sites on the Internet that could be explored to select participants and pertinent data to be analyzed (Leggatt-Cook & Chamberlain, 2012; Mautner, 2005). Because the Internet is home to hundreds, even thousands, of social networking sites that all support a wide range of interests and practices (Boyd & Ellison, 2008), the vast amount of these online writing locations makes it not feasible to attempt to review them all (Leggatt-Cook & Chamberlain, 2012). Therefore, it was determined by the principal researcher to focus on one specific social networking site, *Facebook*, to start to build a foundation of findings for future investigation on this individual platform, and others like it.

*Facebook* is a social networking site that is of particular interest for a number of reasons. First, the data that can be retrieved from this communication platform fits well with the interpretive phenomenological analysis approach described by Smith et al. (2009), in that *Facebook* allows for its users to produce rich, detailed, first person accounts by using computer-mediated communication to freely post words about their experiences. In addition, *Facebook* has achieved global status by becoming the second most visited website (Alexa Internet, 2014) and currently has over one billion active users per month (Statistic Brain, 2014). With this massive amount of people consistently utilizing this social networking site, it is assumed that there is a strong possibility of being able to uncover a

substantial amount of *Facebook* users who stutter that use the platform to digitally connect and share with other similar *Facebook* users.

Furthermore, *Facebook* has language settings on its homepage that is not just American English. Users are able to select from a large list of languages that include ones from Africa and the Middle East, Eastern and Western Europe, and more (*Facebook*, n.d.). This observation implies that there are many countries being represented, thus increasing the ability for people who stutter to connect and share with one another.

Additionally, *Facebook* has a feature that allows for users to set up what is called a *Facebook* group. This is a digital location where users can create an organized forum and message board to enable them to share their common interests, and express their opinions about a central theme that encompasses the set of users it was made for. The *Facebook* group feature allows for users “to come together around a common cause, issue or activity to organize, express objectives, discuss issues, post photos and share related content” (Pineda, 2010). Once a *Facebook* group is created, administrators of that specific group have the ability to decide the privacy level of the group. Currently, a *Facebook* group has three privacy settings. One setting is the public category where anyone is able to see the posts and comments within the group and is able to post their own posts and comments; no permission is needed from the group’s administrators or members. The next setting is the closed category, where anyone can see the name of the group and its description, but in order to see the posts and comments, and to actually add any posts or comments, permission is needed from the group’s administrators and group members. The final setting is the private category, where users must accept an invitation from a group member or

administrator to join the group. Without accepting an invitation, one would be unable to view any posts or contribute to conversations. In fact, a private *Facebook* group is completely hidden from all of *Facebook*'s search options. People who stutter have created numerous stuttering support *Facebook* groups that range in privacy settings. The private category is the *Facebook* group explored in this research study.

The initial idea for this qualitative research study was to explore the experiences of people who stutter who digitally connect and share with other people who stutter within a public or a closed *Facebook* group. However, attempts at these data collection sites were discontinued due to restraints on gaining approval to these sites for research purposes. The data collection used for this study is a private *Facebook* support group that was created in conjunction with an existing face-to-face support group. In collaboration with John, who is the founder of a Pennsylvania face-to-face stuttering support community, and with permission from Misericordia University, the university in which the stuttering support group is affiliated with (see Appendix B for the official permission to conduct the study and Appendix C for the official letter of assurance), a private *Facebook* group was created in October of 2014 as an extension of his already established face-to-face stuttering support group that physically meets the first and third Wednesdays of each month. John and other members of his community have never established a *Facebook* group like this before, and welcomed the idea of collaborating with the principal investigator to launch this private online location where discussions about stuttering could exist between participants.

John's face-to-face stuttering support group started as a National Stuttering Association chapter in March of 2013. The current support group leaders are John and Len.

Since the start of this support group, approximately 35 people who stutter, or have an interest in stuttering, have come to at least one meeting. John's group meets 2 evenings per month for approximately 2 hours at a time. On average, there are usually between four and six people at each gathering, but some meetings have had as many as 10 to 12 individuals. At each meeting, there is always free pizza for members to enjoy while they partake in discussion topics that center on stuttering. John and Len lead the meetings by encouraging the members to introduce themselves and then they present stuttering topics that are used to facilitate group discussion. Throughout the meeting, John and Len maintain or redirect the conversations whenever necessary to keep everything running smoothly.

One of the reasons why the principal investigator felt that John's support group might benefit from the addition of a private *Facebook* group is because of John's willingness to experiment with attaching Internet-based aspects to the inner workings of his stuttering support group. For example, over the last year, John has used *Skype* as a way to help connect people who stutter within his stuttering support group. For example, with the members who are unable to make it to a physical gathering because of weather-related issues or travel plans that take them out of state, John sets up *Skype* on his laptop and has it running during the physical meeting. This allows that particular member to still be able to see, listen, and participate with others, regardless of where that person might be located. Therefore, as long as the member has a *Skype* account and has access to an Internet connection, that person is able to experience and be a part of the gathering.

Prior to the creation and eventual launch of the private *Facebook* group for the aforementioned people who stutter, the principal investigator, along with John, spent a

considerable amount of time actively seeking out other stuttering support *Facebook* groups. The opportunity for them to discover and study these already established online locations of support before creating the brand new one allowed both individuals to gain a better understanding of what typical aspects of support seemed to exist between members within a typical *Facebook* group for people who stutter. Having this information beforehand helped the collaborative process between John and the principal investigator.

In an effort to discover public and closed *Facebook* groups that focused on members engaging in conversations pertaining to stuttering self-help, an extensive Internet search took place that closely followed past procedures by Rains and Keating (2011). Rains and Keating sought to discover self-help blogs that contained a high amount of social support when they exercised two general search strategies to locate their self-help blogs. Therefore, it was assumed that their strategies would aid in the search to discover stuttering support *Facebook* groups.

The first search strategy involved using the built-in search capabilities within *Facebook* to find public and closed *Facebook* groups where members actively engaged with other users on the group page. A number of search phrases were used to conduct the searches. Six terms generally related to this communication disorder were used to ensure that a wide range *Facebook* groups could be reviewed. The search terms were (a) stutter, (b) stutters, (c) stuttering, (d) stammer, (e) stammers, and (f) stammering. The terms stutter, stutters, and stuttering are the common words that individuals within the United States, Canada, and Australia use to describe this targeted communication disorder. The terms stammer, stammers, and stammering are the words that individuals within the United

Kingdom and India sometimes use to describe what is commonly called stuttering in other parts of the world. Each of the mentioned search terms were paired with three qualifiers (i.e., person who; I am a person who; dealing with) to form complete search phrases (e.g., “person who” and “stutters;” “I am a person who” and “stutters;” and “dealing with” and “stammering;” etc.).

The second search strategy used the *Google* search engine to conduct searches to ensure no key *Facebook* groups were mistakenly overlooked during the initial search strategy. Search phrases that were put into the search engines’ search bar included: top stuttering groups on *Facebook*, top communication disorder groups on *Facebook*, and top communication healthcare groups on *Facebook*. Numerous media outlets and people who author blogs tend to write posts from time to time that highlight and promote lists of popular *Facebook* groups. Table 3.1 shows the groups that were discovered by searching the previously mentioned search phrases.

Table 3.1

*Examples of Public and Closed Facebook Groups Discovered*

Group name	Members	Group description
Stuttering Community	3,586	This self-help group for people who stutter promotes itself as an online location where members can vent, post news, and connect with one another. In addition, it encourages members to form connections by utilizing other means of Internet-based technology such as <i>Skype</i> and <i>Google Hangouts</i> .
Stuttering Arena	3,276	This self-help group for people who stutter endorses the idea that this digital space is a location where feelings can and should be shared because “we are all in the same boat.”
Stuttering Hangout	1,898	This self-help group for people who stutter features a healthy collection of stories and experiences where members seem comfortable with honest communication about stuttering. It also makes mention that speech-language pathologists and family members of people who stutter are welcome to join this group.
The Stuttering Lounge	1,204	This self-help group for people who stutter emphasizes the notion that through unity, all members can see that they are “never alone in this stuttering journey.” It also makes mention that speech-language pathologists and other healthcare professionals are welcome to join this group.
Women Who Stutter: Our Stories	501	This self-help group for women who stutter has a main goal of helping females who stutter. With a strong emphasis on providing inspiration to all women who stutter, this group is filled with first-person narratives that relate to being “a minority within the minority of people who stutter.”

Group name	Members	Group description
Voice Unearthed: Supporting Children Who Stutter	221	This self-help group for people who stutter is inspired by a book called "Voice Unearthed: Hope, Help, and a Wake-Up Call for the Parents of Children Who Stutter." It seems to be mostly represented by parents and caregivers of children who stutter who come together to exchange stories and ideas that all revolve around the subject of stuttering. Throughout some conversations, specific chapters or points are referenced from the book that all of these members seem to have read.
Christians that stutter	176	This self-help group for people who stutter consists of members who also share the same religion. The theme of Christianity seems to be prevalent throughout this group in that on several occasions, Bible verses, God, and prayers have been discussed and tied back to stuttering.
Positivity Stutter	129	This self-help group for people who stutter seems to be a collection of inspirational quotes that are posted as a way to bring positive words into the daily lives of its members.
African Stuttering Community	58	This self-help group for people who stutter focuses on the African community and creating stuttering awareness in Africa. Numerous informational links are shared that members are encouraged to read and discuss with one another.
Stuttering Hurts	11	This self-help group for people who stutter seems to have been started by a female senior in high school as a way to confront the frustration of being a person who stutters. It features a mix of informative links to stuttering-related online articles and dialogue between a few members. Ultimately, it was created as a way for this person to be able to meet others who also stutter because "it really helps to know that there are people like me in this world :)"

### **Participants Recruited for the Study**

After numerous public and closed *Facebook* groups for people who stutter were discovered and studied, the group member identification process began. Portions of criteria from Leggatt-Cook and Chamberlain (2012), as well as Rains and Keating (2011), were used as a guide for who might be a good fit to join the face-to-face stuttering support group's brand new private *Facebook* group. To be eligible, the following criteria were considered: (a) the member must be a person who stutters or have an interest in stuttering, (b) the member must have an interest in contributing to the *Facebook* group regularly, and (c) the member must have an interest in creating posts that are focused on connecting and sharing with other people who stutter. After careful consideration, nine people were added to the *Facebook* group, and of the nine members, seven chose to share their demographic information.

Table 3.2 lists demographic information about those participants.

Table 3.2

*Participant Information*

Participant	Age	Gender	Reported occupation	Location	Frequency of <i>Facebook</i> use	How <i>Facebook</i> is accessed
“John” (Founder and co-leader of the group)	21	Male	Student	Pennsylvania	Daily	95% cell phone and 5% laptop
“Len” (Co-leader of the group)	21	Male	Student	Pennsylvania	Daily	70% cell phone and 30% laptop
“Charlie”	25	Female	Speech-language pathologist	Utah	Daily	75% cell phone and 25% computer
“Cornell”	23	Male	Student	Pennsylvania	Daily	Mostly cell phone
“Roth”	22	Male	Student	Pennsylvania	Daily	50% cell phone and 50% computer
“Greg”	26	Male	Student	Pennsylvania	Daily	Mostly cell phone
“Bill”	46	Male	Not reported	Pennsylvania	Every 2 to 3 days	Laptop only

### Data Collection Methods

Ethnographic data are unique in the sense that virtually anything can be defined as such, so long as the elements, which are recorded and collected, present the phenomena through the eyes of those who are involved in the given community (LeCompte & Schensul, 2010). Therefore, the methods that were utilized to record and collect data throughout this study were participant observation, artifact collection and analysis, a written questionnaire, and in-depth ethnographic interviews. The overall timeline for the collection of all data occurred during a 4-month period, between October 2014 and January 2015 (see Table 3.3).

Table 3.3

#### *Data Collection Schedule*

Timeline	Focus
Month 1 (October 2014)	Begin <i>Facebook</i> group observation Begin face-to-face group observation Begin collecting artifacts Begin journaling
Month 2 (November 2014)	Continue <i>Facebook</i> group observation Continue face-to-face group observation Continue collecting artifacts Continue journaling Post written questionnaire Begin looking for themes/codes across data
Month 3 (December 2014)	Finish <i>Facebook</i> group observation Finish face-to-face group observation Finish collecting and analyzing artifacts Finish journaling Finish looking for themes/codes across data
Month 4 (January 2015)	Begin and finish semi-structured interviews Review transcriptions with a peer Begin and finish member-checking with participants

These multimodal methods sought to discover the meaning structures of individuals in whatever forms that were expressed (Wilson, 1977). It is believed that the findings, which were uncovered by these four essential methods for ethnography, were able to successfully begin to answer the research questions of this study with cohesion and integrity.

Participant observation, through the creation and constant upkeep of researcher field notes, was the method used for the purposes of recording situations as they happened within the *Facebook* group and the face-to-face group (LeCompte & Schensul, 2010). The reason why a 4-month time period for observation was chosen was based in part on past research by Stoudt and Ouellett (2004). Those investigators observed participants and kept field notes for 30 days in an already established online community for people who stutter. However, since this *Facebook* group is brand new and because face-to-face support group observation was also planned, it was decided that a longer observation period would result in richer data and more detailed field notes. After 4 months, the principal investigator reached a saturation point where the participants no longer provided new information to the topic of study.

Written field notes have been shown to be an effective method of recording while dialogue begins to unfold in an online environment filled with numerous comments and posts (Markham, 1998). The researcher's ability to keep track of all events observed, as well as the thoughts and experiences that were connected to those events, proved to be a helpful record to look back on during numerous times throughout this study. Considerable reflection was also carried out immediately after each full *Facebook* and face-to-face group

observation came to a close. As described by Sandiford and Seymour (2007), this method enables investigators to revisit the data while the events are still fresh in the researcher's mind, allows for reflection on the data and its collection at a relatively informal level, and subsequently guides future activities related to the study.

As described by LeCompte and Schensul (2010), the method of observation enables investigators to record events, sequences, behaviors, conversations, and interactions between persons as they happen. In addition, it helps the researcher to be able to share the daily lives of the participants and systematically works to attempt to understand their thoughts, feelings, and behaviors (Wilson, 1977). These findings were able to begin to paint a picture as to what the users in the *Facebook* group were doing and why they were choosing to do it. The data collected from this method throughout the study, along with the other three methods, provided the principal investigator with multiple sources of data. All portions were used to either confirm or deny the accuracy of the others.

The collection and analysis of artifacts was the method that exercised for the elicitation of themes or content in a body of written media (LeCompte & Schensul, 2010). Because the participants of this study created digital conversations, which appeared on the wall of their *Facebook* group, the principal investigator had full access to an abundance of relevant textual and visual data for the duration of the study. The text-based interactions between participants were able to serve as valuable bodies of data, in that they were forms of content that could be reviewed and analyzed (Wilson, 1977). This type of content has the ability to inform human conduct and judgment by highlighting the ideas and viewpoints of all who are a part of a social community (Van Maanen, 2011).

Collection and analysis of textual and visual data through the exploration of the text-based and digital photographs posted on the *Facebook* group's wall was a powerful resource for inquiry because that information contained its own story, and was able to trigger other stories, too. The textual and visual data were able to act as vessels, which delivered knowledge, helped foster relationships, and generated conversations between members of the community (Paay, Sterling, Vetere, Howard, & Boettcher, 2009). Therefore, the development and application of analytical categories reflecting the research questions for the study was able to be created because of the textual and visual data which appeared within the *Facebook* group (LeCompte & Schensul, 2010).

A written questionnaire was also created as a means for obtaining statements and responses to inquiries that directly related to the research questions. Questionnaires are a common approach to qualitative data gathering and have the ability to uncover accounts about individuals' reality and social life (Holliday, 2007; Hughes et al., 2010). The open-ended nature of the questions within a written questionnaire gave participants the opportunity to elaborate and provide meaningful detail to help make sense out of described experiences and views (Patton, 1987).

The written questionnaire existed as an anonymous online survey that was posted to the *Facebook* group at the beginning of the second month of the study so members had the ability to share their experiences, if they so chose to. Examples of qualitative prompts that were within the online survey include

1. Describe your experiences of participating in an online community for stuttering.

2. In what ways does an online community for stuttering offer support to you?
3. In what ways have you offered support to others who stutter?

Qualitative questions, such as these, allow for rich descriptions to take place. This rich narrative that comes from the open-ended approach to the online survey puts “flesh on the bones” of collected data, which brings “the results to life,” thus, making the data more able to truly be understood (Patton, 1987, p. 38).

Arguably, the most popular approach to qualitative data gathering is often considered to be participant interviews and its purpose is to give the interviewer a full and detailed account of the interviewee’s given experience with the phenomena (Polkinghorne, 2005). This method allowed the principal investigator to collect in-depth information on selected topics related to the research questions, obtain personal histories, and learn about the cultural knowledge and beliefs of those participants being observed (LeCompte & Schensul, 2010). Conducting interviews toward the end of the 4-month period allowed the principal investigator to understand and interpret the perspectives of the participants about their experiences with the *Facebook* group. Through the conversations that occurred from participant interviews, the principal investigator was able to easily learn about the feelings, attitudes, and meanings that the participants attached to being a part of an online community for people who stutter (Kvale & Brinkmann, 2009). This type of inquiry was adequate to capture the richness and fullness of one’s experience being a part of the *Facebook* group (Polkinghorne, 2005).

The semi-structured online interviews served to collect valuable, in-depth information on certain topics pertaining to being a person who stutters who digitally

connects and shares on a *Facebook* group for people who stutter. The steps for setting up the semi-structured interviews were similar to those described by Markham (1998), in that the principal researcher established contact with the participant and negotiated a date and time for each interview. The interviews were conducted using *Facebook*'s one-on-one chat feature. This instant messaging protocol allows users the ability to perform online chat conversations in real-time with other *Facebook* users (Cheung, Chiu, & Lee, 2011). This function enabled the principal investigator to log and archive the transcript. The questions asked were open-ended in nature to allow for rich descriptions about the phenomenon in question (LeCompte & Schensul, 2010).

Interviews are most often semi-structured for the reason that they allow for the conversation to take on a give-and-take personality. This type of shared dialogue is able to guide interviewers in the direction that interviewees wishes to go. However, it also allows for the interviewer to move the conversational thread closer towards the research questions that are being explored, if a deviation from the subject starts to occur (Polkinghorne, 2005).

### **Data Analysis Methods**

The posts and comments created by the *Facebook* group members and the dialogue collected from their written questionnaires and semi-structured interviews served as the key units of analysis. These types of digital communication, which exist as narratives, were able to provide rich and full language data that are not just a collection of single words. The words were interrelated and combined to reveal meaningful sentences of expression (Polkinghorne, 2005). In addition, the principal investigator was present to observe face-to-face stuttering support meetings and actively took field notes while immersed in that

environment. Therefore, the analytical procedure known as narrative analysis was best for interpreting the described data. Narrative analysis allowed for the principal investigator to study the participants' culture and thinking and allowed the interviewer to hear the interviewees' voices as attempts were made to fully understand the culture in question from the inside (Cortazzi, 1993).

Wiles, Rosenberg, and Kearns (2005) stated that narrative analysis "helps to formulate an understanding of how people talk about experiences and situations as well as what they say" (p. 98). This intentional focus on the narrative produced by a participant allowed the principal investigator to develop a detailed description of a participant's culture, which is able to preserve the words of that speaker (Cortazzi, 1993). Narrating is a powerful way of making sense of those experiences and sharing them with others (Cortazzi, 2001). The analysis of narratives aided in the overall goal to make valid interpretations of the collected data that described the given group of people who stutter and their experiences of digitally connecting and sharing with other people who stutter within a designated *Facebook* group.

While the principal investigator began to arrange the narrative data, Cortazzi's (2001) style of organization was immediately adopted. Cortazzi mentions that true narratives must include the following: an event or series of events, which is what has happened to the person; experiences, which are the thoughts, feelings, and reactions to what has happened to the person; and the narrative functions, which are the audio and/or visual forms of the storytelling that include a plot, sequence, and context. This categorical framework allowed the investigator to move freely within the data to piece together a

flowing description on what it means to be a person who stutters that digitally connects and shares with others on a designated *Facebook* group. Because Cortazzi's style of organization allows for the rearrangement of the order of the various pieces of narrative, it is believed that this approach enabled a clear understanding of the phenomenon.

The process of reading posts made on the *Facebook* group and viewing the written responses from the questionnaires and semi-structured interviews from users who stutter were useful in developing an understanding of how people who stutter choose to make sense of digitally connecting and sharing with other people who stutter online. This informative analytical procedure had the ability to connect the described experiences, thoughts, and feelings in a reflective manner which was used to better depict the digital social relationships that the participants are a part of (Wiles et al., 2005). Through narrative analysis, people are able to learn about, explain, and better organize experiences (Cortazzi, 1993).

In terms of organization, a computer was used to manage the qualitative data. As mentioned by LeCompte and Schensul (2013), computers have the capacity to make an ethnographer's life much easier. They provided a list of principal ways in which a computer could assist in the organization of data that included the ability to save and search for words or phrases in interviews, field notes, and other data documents. In addition, the obtained *Facebook* posts and comments, as well as the semi-structured interview responses were copied and pasted on to a *Microsoft Word* document and further analyzed using the *Microsoft Word* software (Ruona, 2005a, 2005b). Ruona (2005a) pointed out that it has

become increasingly common for qualitative researchers to utilize specific tools within the *Microsoft Word* suite to organize, sort, and retrieve data.

After an in-depth review of the data by the investigator, a colleague with a background in stuttering also conducted a basic analysis. Both analyses were compared to find similarities and dissimilarities. This comparison helped the principal investigator develop a clear and well-thought-out consensus that related to answering the research questions. All colleagues involved were able to discover rich, vivid, and concrete descriptions related to stuttering and digitally connecting and sharing with other *Facebook* group members. These discoveries helped to begin the uncovering of themes and attaching quotes to support the newly realized themes.

### **Credibility and Trustworthiness (Validity and Reliability)**

Qualitative approaches are sometimes criticized because of their perceived lack of rigor and credibility (Decrop, 1999). The data obtained throughout an investigation are only found to be valuable and legitimate if the principal researcher is able to successfully demonstrate the credibility associated with the findings (LeCompte & Goetz, 1982). Creswell and Miller (2000) described three validity procedures, or lens, that should be incorporated when designing research and its ability to contain a healthy amount of trustworthiness. The three entities that should be considered are the lens of the researcher, the lens of study participants, and the lens of people external to the study. Therefore, the described reliability and validity considerations were exercised throughout this investigation.

The lens of the researcher was taken into consideration with the procedure known as triangulation. Triangulation has been used as a way to assess the trustworthiness of a given study that focuses on people who stutter, and it has the ability to bring more soundness to the collected data (Plexico et al., 2005). This procedure urges investigators to consider a single point from three or more different and independent sources (Decrop, 1999). As described by Carlson (2010), the premise of triangulation is that if investigators can provide evidence to support or prove that they have gathered and analyzed data in more than one way, the interpretations and overall conclusions are more likely to be deemed trustworthy. When investigators actively look at the phenomenon or research questions from more than one source, they are better able to have a well-balanced viewpoint because it limits the amount of biases that could exist and increases the amount of generalizability of the study. That is why for this study, several aspects of data were gathered and several researchers interpreted the same body of data. These actions allowed a better ability to either confirm or deny any and all interpretations that were made.

The lens of the study participants was taken into consideration with the procedure known as member checking. Member checking was implemented as an opportunity for members of the study to check specific interpretations of the collected data (Doyle, 2007). From this checking activity, the participants had the chance to either confirm or deny any interpretations of the collected data. Essentially, this beneficial approach enabled the investigator to ask the members of the study if the researcher is currently on the right track with beginning to understand the data or if the researcher properly understood the data in the way it was meant to be (Carlson, 2010). By having these local informants in a study, it

added to the credibility of the study (LeCompte & Goetz, 1982). That is why for this study, participants were allowed and encouraged to take the role of researchers, and were able to review the collected data at numerous points throughout the study's duration. This manner of transparency with the data and its attached interpretations helped the investigator to be able to confirm if the principal investigator's assumptions were shared by the participants.

The lens of the people external to the study (i.e., reviewers, readers) was taken into consideration with the procedure known as the audit trail. The audit trail is designed to get the researcher in the habit of keeping careful documentation of all components of the study for the potential of an external auditor (one formally brought into the study or the readers who examine the narrative account). As described by Carlson (2010), in an effort to create a well-organized and rich collection of documentation, the principal investigator will routinely keep field observation notes, interview notes, journals, records, calendars, and various drafts of interpretation. This was done throughout this study. The goal of the formal audit is to take a detailed look into the process and the product of inquiry. This would help to determine the trustworthiness of the findings because during the audit, numerous questions are able to be explored, such as are the findings grounded in data and are the inferences logical (Creswell & Miller, 2000).

These multiple procedures and sources of information were not seen as unhelpful duplications of effort. They served as clear sources of confirmation or corroboration for each other. The described variations helped to build reliability and validity and were crucial for deepening the overall inquiry and understanding of the phenomenon in question. By intentionally obtaining different types of data and by collecting the findings under different

circumstances and by various investigators, the principal investigator was able to successfully produce different and complementary information on the same topic (LeCompte & Schensul, 2010).

### **Ethical Framework**

Being that the use of the Internet in research is still a relatively new phenomenon, investigators would be wise to be mindful of the confidentiality and anonymity of participants (Holmes, 2009). While looking at the text written messages within an Internet stuttering forum, Stoudt and Ouellette (2004) came to the conclusion that protecting the confidentiality of those who engaged in one of the numerous digital conversations was less of an issue because of the public nature of the forum. Because the users were not forced to use their real names when signing up for an account, Stoudt and Ouellette felt that it would be acceptable to examine and directly quote conversations that appeared on the forum, as long as any possible identifiers were changed or removed. Their conclusion was also applied to this study when exploring the posts created by *Facebook* users because, like the forum users, individuals on *Facebook* are not forced to use their real names during the signup process. However, an added privacy protection, pseudonyms were used for all participants in this study to ensure that none of the findings can be connected back to a single individual (Markham, 1998).

### **Significance of Study**

It is the belief of the principal investigator that the digital communities that often surround a social networking site are valuable context in which to study social support and the potential opportunities created by such communication mediums and social spaces.

These environments facilitate supportive communication and increased self-esteem and psychosocial well-being, therefore, further solidifying its worthiness for exploration. By attempting to understand the thoughts, feelings, and experiences of those who utilize social networking sites to digitally connect and share with other people who stutter, practicing speech-language pathologists have the opportunity to introduce their adult clients who stutter, who have access to the Internet, to a worldwide community that is not limited by physical space.

This qualitative research endeavor attempted to advance the current knowledge and understanding of self-help for stuttering. These findings, which pertain to social networking sites and how people who stutter utilize this new form of common communication, are filled with information that will make a significant contribution to understanding the nature of stuttering and its impact on those affected. Social networking sites are shaping up to be a promising supplement to the traditional face-to-face speech therapy because of the user's ability to connect and start meaningful conversation with a large amount of people who stutter, or to silently watch and consume those meaningful conversations as they unfold.

### **Subjectivity Statement**

The principal investigator of this study wishes to communicate to the reader that he is not a person who stutters. However, as a practicing speech-language pathologist since May of 2006, he has amassed a large amount of knowledge and experience that pertains to stuttering. In addition to providing speech therapy services to close to 100 people who stutter since beginning his career in 2006, he has completed numerous graduate level courses and

continuing education workshops that revolve around the subjects of stuttering and counseling. Also, he has actively been a member in two separate National Stuttering Association sponsored face-to-face support groups for people who stutter in Michigan and Pennsylvania. This consistent opportunity to hear the words and stories from people who stutter, as well as work together with children and adults who stutter, has helped him to grow as clinician to better understand what stuttering is, and what it is not.

Starting around the time of early 2010, this principal investigator began to notice more and more of his adult clients mentioning the fact that they were using the Internet as a means for psychosocial support. A substantial amount of these people who stutter confessed that through e-mail lists, chat rooms, and Internet forums, they were able to connect with and befriend others who also stutter. These confessions started to inspire this investigator to look deeper at the Internet and the benefits and challenges that it might have for people who stutter. This current qualitative research endeavor is an extension of the overall quest to explore and dissect an aspect of the Internet, specifically a *Facebook* group for people who stutter, in an attempt to gauge its usefulness, or lack thereof.

## CHAPTER 4

### RESULTS

The primary purpose of this qualitative study was to explore the experiences of people who stutter who digitally connect and share with other people who stutter within a social networking site, specifically *Facebook*. Four questions guided this research: (1) In what ways do people who stutter describe their experiences of participating in an online community for stuttering; (2) In what ways does an online community for stuttering offer support to people who stutter; (3) How do people who stutter understand their interactions with other people who stutter in a social network; and (4) How do people who stutter understand their communication disorder through their interactions with other people who stutter in a social network? Data collection consisted of textual evidence and artifact collection taken from 3 months worth of *Facebook* group postings (see Appendix D for the full transcript of the postings), semi-structured interviews with seven of the *Facebook* group members (see Appendix E for the semi-structured interview protocol and Appendix F for the seven full transcripts of each semi-structured interview), and anonymous responses from a written questionnaire (see Appendix G for the written questionnaire protocol).

It should be noted that, due to the small sample size, the anonymous responses from the written questionnaire were not taken into consideration during the analysis because only one individual partially completed the questionnaire. Therefore, it has been determined that the insufficient amount of data from the questionnaire should not be analyzed. However, results of the data collection that came from the textual evidence and

artifact collection taken from the *Facebook* group postings, and the semi-structured interviews with seven of the *Facebook* group members, are reported and analyzed in this section.

In this results section, data will be presented in tables, figures, and quotes that relate to specific participants within the study. The figures and quotes used to support the analyzed themes were selected based on the information that was shared and its ability to fit within a created category. The primary investigator made a conscious decision to include quotes from all participants in an effort to provide each member of the private *Facebook* group with a voice that describes the given phenomenon.

Data analysis of the online postings and semi-structured interviews revealed eight major themes. Most of these themes contained numerous subthemes. Table 4.1 presents themes and subthemes of the participants' experiences of participating in an online community for stuttering.

Table 4.1

*Major Themes and Subthemes of the Participants' Experiences of Participating in an Online Community for Stuttering*

Major Themes and Subthemes
1. Benefits
a. Sense of Family
b. Feelings of Safety and Acceptance
c. Thought-Provoking
d. Convenience Through Accessibility
e. Supplemental
2. Challenges
a. Limited Number of Members
b. Sense of Disconnect
c. Fear of Misinterpretations
d. Lack of Instantaneous Communication
e. Lack of Any Responses to a Question

The following sections discuss these themes in more detail. In each section, quotes from participants are provided as a means to further solidify the given themes.

### **Themes Related to Benefits**

This section highlights the ways in which participants within this study believed that the *Facebook* group contained numerous beneficial aspects to it.

#### **Sense of Family**

Most participants in the *Facebook* group conveyed an apparent communal bond to the other members. The following quotes from the semi-structured interviews support this subtheme:

Len: For myself the main benefit of the *Facebook* group is knowing that there is always someone to talk to about my stutter who is willing to listen. While my parents and close friends are always there for me, the group enables me to talk to people who can relate to stuttering. It makes you feel like you are never alone. Trust me I know, when you stutter and are the only person in a large classroom giving a speech who stutters, it is hard not to feel alone. The group is always there for you to fall back on.

Greg: [One word to describe this *Facebook* group would be the word] Belonging. Like Maslow's hierarchy of needs, the group could give someone who stutters and knows no one who stutters, a sense of belonging to society. They could know, for certain, they aren't the only ones like that so they aren't mutant, they aren't weird.

Roth: It just reminds me that there are other people out there that understood where I'm coming from, and it gives me a daily dose of inspiration to keep pushing through the difficult situations or times that come with dealing with stuttering.

#### **Feelings of Safety and Acceptance**

A number of participants communicated feelings of safety and acceptance in regards to participating in online discourse with members of the *Facebook* group. The following quotes from the semi-structured interviews support this subtheme:

Bill: I think [the *Facebook* group is] a good way to communicate to get people's opinions there.

Cornell: I know if I say "wow I ordered a pizza on the phone today and feel pretty good," they're not gonna look at me like I'm high . . .

Roth: I think that the conversations in the group are really great in allowing people who stutter to express themselves in a supportive and understanding environment. Depending on the question raised, I've noticed that different people are able to bring different perspectives to the table and challenge others to view stuttering in a different way, which can be a very positive experience in the process of stuttering acceptance/treatment.

Len: The conversations allow me to express my true thoughts, feelings, emotions and beliefs without the fear of being judged or looked down upon by anyone.

John: I liked the conversation where Greg said that he would always add in a "fucking" to help him through his blocks. I don't remember what the question was but it speaks volumes that a closed private *Facebook* group can have the safety for members to provide completely honest responses . . . [*Facebook* group members] could do so [post opinions] with complete confidence that no one will repeat what is written.

### **Thought-Provoking**

Several participants described the overall activity and conversations within the *Facebook* group as being thought-provoking. The following quotes from the semi-structured interviews support this subtheme:

John: I think that [the *Facebook* group] gets people thinking, at least once a week, about a topic on stuttering.

Cornell: [The *Facebook* group is] insightful in that sometimes my friends from the support group say things that resonate with me.

Roth: I think the question about describing your stuttering in 3 words was a pretty interesting and enlightening experience [to read].

Len: The questions provoke interesting conversations among group members.

### **Convenience Through Accessibility**

Members of this online environment made it clear that always being connected and the convenience of accessing the *Facebook* group through mobile devices or computers increased the overall experience of interacting within the *Facebook* group. This is a key difference when compared to the face-to-face group. The following quotes from the semi-structured interviews support this subtheme:

Charlie: Number one benefit [of the *Facebook* group] I believe is to be connected with others across the nation despite your location . . . it allows us all to stay connected.

John: Anyone, from anywhere can weigh in on things, could post thoughts, or confide in the group.

Len: What the [*Facebook*] group does is essentially take the support group with you wherever you go. Most people can access *Facebook* from their phone and they have their phone with them at all times.

Roth: The biggest positive is that it can be accessed anytime and anywhere. Stuttering is a disorder that can pop up at any point and cause a ton of stress or frustration in any given moment. So, having an online support system that you can turn to whenever you need is a really great resource. Say someone had a really severe block at work or at school and they had a rush of negative feelings about the experience. They could take out their phone or computer and get that support immediately or at least in a much quicker time frame than a 2 times a month support group. I think that's a very powerful thing.

Cornell: If you can't go to a local face-to-face meeting or you live in the backwoods of some shitty Podunk town and stutter, you already feel isolated and now even more. The Internet fixed that, but even then if you stutter, it's less obvious online than in person. With online support groups and online communities for stuttering, it's convenience at a keyboard.

### **Supplemental**

A majority of participants praised the idea of combining the *Facebook* group with face-to-face support meetings that occurred 2 times per month. However, members made

it clear that the face-to-face approach was still their preferred means to obtain stuttering support. The following quotes from the semi-structured interviews support this subtheme:

John: It [the *Facebook* group] definitely has great potential to be a powerful addition to a physical support group.

Bill: [One word to describe the *Facebook* group would be] adjunct because the *Facebook* group seems to be an additional resource, with trying to supplant the idea of having an in person group.

Greg: Replacing [a traditional, face-to-face stuttering support group with an Internet-based one] isn't really possible, supplementing is all a digital medium could do for this kind of thing . . . It might help one person, might be useless for the next . . . So yeah, online help might do something for people who stutter, or it might not. If it helps one person then it's something worth pursuing.

Len: Although the *Facebook* group is more impersonal than the face-to-face meetings, it is absolutely an additional resource other chapters can use to enhance or supplement the face-to-face support group. I think supplement is the key word there. Still having face-to-face meetings is essential for group cohesiveness and the longevity of the group but having a *Facebook* group to supplement the face-to-face group is a great idea.

Roth: I think the online support group model is a really great addition to a face-to-face support group. However, I don't necessarily think that an online group should be used instead of in-person support.

### **Themes Related to Challenges**

This section highlights the ways in which participants within this study believed that the *Facebook* group contained numerous challenging aspects to it.

#### **Limited Number of Members**

Various participants mentioned how the small amount of members within the *Facebook* group was seen as a problem. The following quotes from the semi-structured interviews support this subtheme:

Bill: I think John, the co-leader, does a good job in trying to stimulate conversations- but there's not that many members . . . it would be nice if it were possible to increase the membership [of the *Facebook* group] to get more ideas.

John: I would say that the conversations have been a little stagnant. They started off strong but since we don't have a lot of people that are in the [*Facebook*] group that it doesn't stimulate the conversation enough.

Charlie: Promoting the link to the face-to-face group more often would help to expand the number of members and the number of perspectives taken on discussions.

Len: More people could be added [to the *Facebook* group] to improve it. More people = more people to offer their own unique opinion, thus more conversation would be stimulated.

### **Sense of Disconnect**

A considerable amount of participants mentioned how communicating with each other through the *Facebook* group felt impersonal because they were separated from each other and unable to use their real voices to communicate. The following quotes from the semi-structured interviews support this subtheme:

Cornell: The problem with online communities is there's a sense of disconnect you need to overcome . . . In person support groups make a lot more sense because if you stutter, wouldn't it be more proactive to speak with your voice than through texts? I think so, but everyone has a different comfort zone.

Len: Typing on a screen can be a bit impersonal. Sometimes in tough times you want someone there right by your side to talk to. While the group is a great resource, it cannot teleport people right to your living room couch. At least not yet.

Greg: I like the face-to-face a lot better. The very nature of the support group is about (verbal) dialogue. Stutterers need to have real life interactions to help overcome the symptoms involved with stuttering. Talking about something on an online forum does nothing for the problem I believe. Granted it might be better than doing nothing about it, but still doesn't do much.

### **Fear of Misinterpretations**

Some participants confessed that there was hesitation associated with posting comments in the *Facebook* group because the messages could be misinterpreted by other members. The following quotes from the semi-structured interviews support this subtheme:

Charlie: Personally being somewhat of an introvert, I always hesitate to post on discussions. I fear that someone would judge my words as with, written text, thought can often be misread easily.

Roth: Things can be misinterpreted because you're only reading a block of text instead of hearing someone saying it with context.

Bill: 90% of communication is non verbal- you need to see people's body language, facial expressions and general instantaneous show of emotions.

John: You don't have the emotion of the person [when it is just text within the *Facebook* group].

### **Lack of Instantaneous Communication**

A pair of participants acknowledged that, at times, there was a substantial delay in receiving a response to a comment or question added to the *Facebook* group. The following quotes from the semi-structured interviews support this subtheme:

Len: One challenge [of the *Facebook* group] is that if you post something in the group, people may not respond for a few hours or a few days. If you really want to talk to someone in the group immediately, and don't have their phone number, it can be detrimental.

John: You don't have the back and forth that you have in [face-to-face] meetings.

### **Lack of Any Responses to a Question**

This specific collection of evidence is unique in that a lack of quotes to illustrate the subtheme is, in fact, the data that can be analyzed to support it. On two occasions, questions were asked to the members of the *Facebook* group and no member responded. The following are the pair of questions that were posted to the *Facebook* group that generated no replies and the absence of any responses will serve as data to support this subtheme.

- Post by John (December 7, 2014): We all know that the holiday season can get a bit stressful. Does that holiday stress ever have an impact on your stuttering? If so, please do share with us.
- Post by John (December 22, 2014): Has anyone here been in class before and totally knew the answer that the teacher asked, but you didn't raise your hand because of the possibility of stuttering?

Table 4.2 displays themes and subthemes that describe the ways in which an online community for stuttering offers support to people who stutter.

Table 4.2

*Major Themes and Subthemes of the Ways in Which an Online Community for Stuttering Offers Support to People Who Stutter*

Major Themes and Subthemes
1. Support Through Providing Information <ul style="list-style-type: none"> <li>a. Upcoming Meetings</li> <li>b. Internet Articles</li> </ul>
2. Support Through Posing Questions <ul style="list-style-type: none"> <li>a. Weekly Conversation Starters</li> <li>b. Social Gathering Questions</li> </ul>
3. Support Through Giving Encouragement <ul style="list-style-type: none"> <li>a. Text-Based</li> <li>b. Like Button-Based</li> </ul>
4. Support Through Engaging in Humor <ul style="list-style-type: none"> <li>a. Self-Deprecating</li> <li>b. Sarcasm</li> </ul>

The following sections discuss these themes in more detail. In each section, quotes from participants are provided as a means to further solidify the given theme.

### **Themes Related to Support Through Providing Information**

This section highlights the ways in which participants of this study shared support group meeting details and stuttering-related information with one another within the *Facebook* group.

#### **Upcoming Meetings**

Both co-leaders of the support group utilized the *Facebook* group to post seven messages that promoted upcoming face-to-face support group meetings. The following *Facebook* group posts are four examples of these messages:




- Post by John (October 7, 2014): John created and shared an event. – OCT 15 Support Group Meeting – Wednesday, October 15, 2014 at 7:00pm
- Post by John (October 7, 2014): Terry updated the group photo (see Figure 4.1).
- Post by Len (November 18, 2014): Just a reminder that we will be meeting tomorrow (Wednesday) night at 7PM in our usual meeting location. Hope to see everyone there!
- Post by Len (December 2, 2014): Just a reminder that we will be meeting tomorrow night (Wednesday) in our usual meeting location. Hopefully we will see many of you there!

[REDACTED] updated the group photo.  
October 7, 2014

**If you stutter...  
YOU ARE NOT ALONE!!**

**What:** Show up and you will be a part of a supportive environment where you can meet and speak with others who stutter. This group is run by persons who stutter.

**Who:** People who stutter of all ages, family members of people who stutter, & anyone interested in stuttering

[REDACTED] Chapter

**When:** Every 1st & 3rd Wednesday of each month at 7:00pm

**Contact us at:**  
E-mail: [REDACTED]  
Website: [REDACTED]


 Scan the QR code to follow [REDACTED]

Figure 4.1. Group meeting information example.

### Internet Articles

On three occasions, a participant shared links to stuttering-related Internet articles within the *Facebook* group. The following *Facebook* group posts are three examples of these shared links:

- Post by John (October 22, 2014): Hi Everyone!! Happy ISAD!! Today (October 22nd) is International Stuttering Awareness Day (ISAD)! The following link was posted on the NSA's website a few years back describing what ISAD is and how you can get involved in spreading awareness (see Figure 4.2).
- Post by John (October 31, 2014):  
<http://www.buzzfeed.com/alexisnedd/things-all-people-who-stutter-will-understand?s=mobile> (see Figure 4.3).
- Post by John (November 26, 2014): Check out this article and let us know your thoughts (see Figure 4.4).

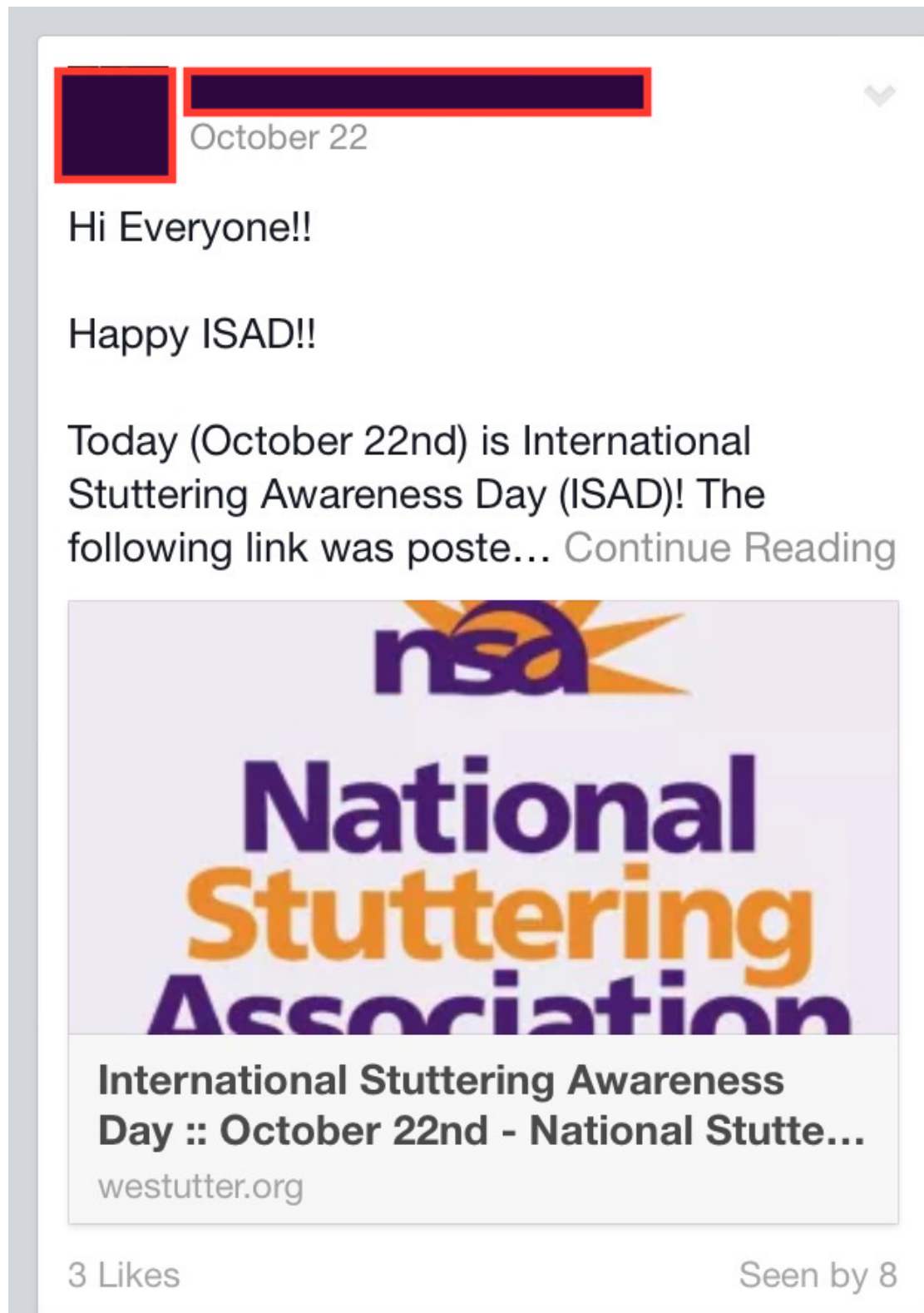


Figure 4.2. First Internet article example.

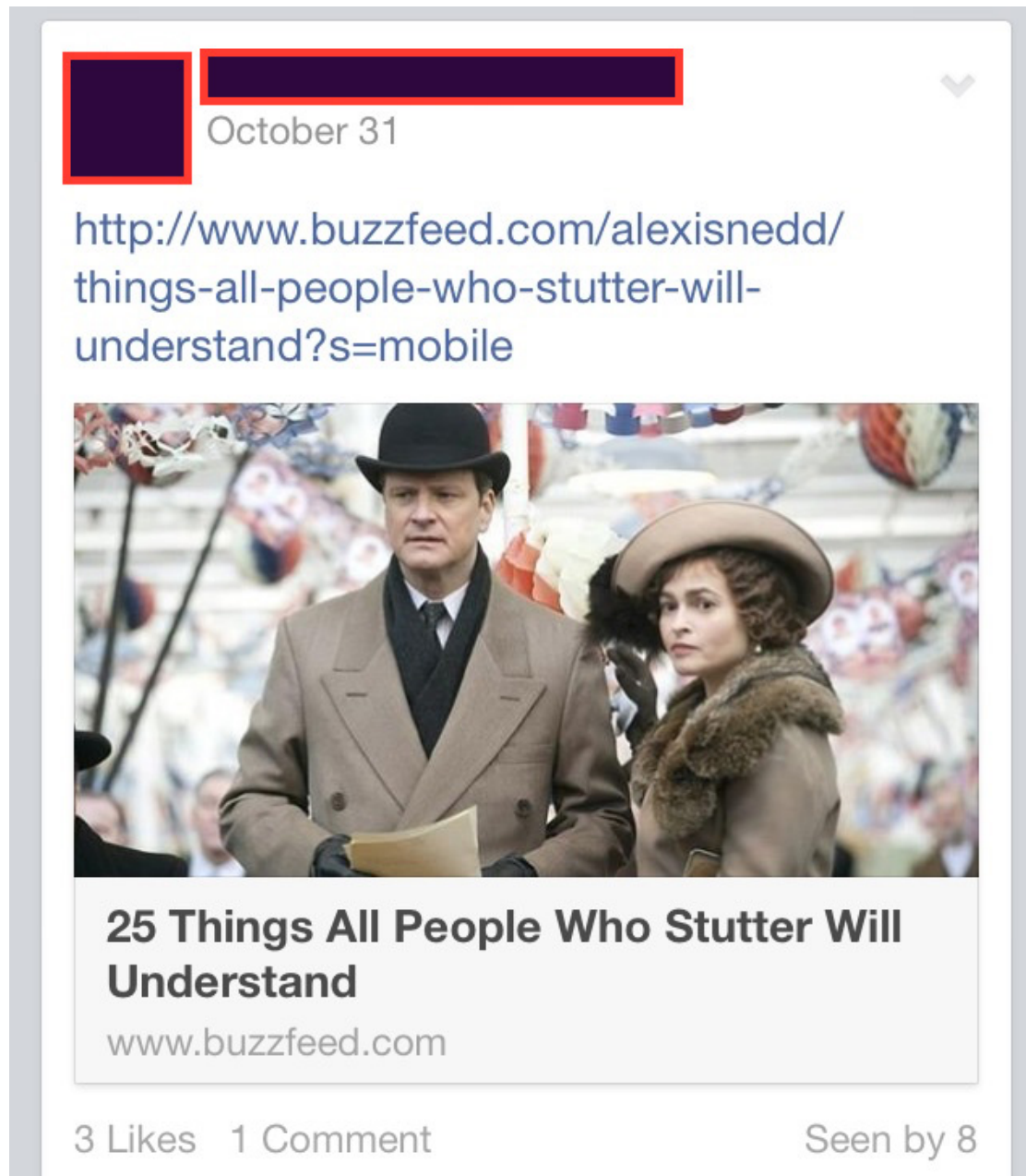





Figure 4.3. Second Internet article example.

 via

**NATIONAL STUTTERING ASSOCIATION**

November 26

Check this article out and let us know your thoughts.



**Why I'm Thankful That I Stutter**  
Stuttering was always considered a fla...  
[www.huffingtonpost.com](http://www.huffingtonpost.com)

2 Likes

Seen by 7

Figure 4.4. Third Internet article example.

### **Themes Related to Support Through Posing Questions**

This section focuses on the ways in which participants used a question-centered approach that presented inquiries to one another within the *Facebook* group as a way to provide support.

#### **Weekly Conversation Starters**

One of the two co-leaders of the support group utilized the *Facebook* group to post 10 stuttering-related questions to members of the *Facebook* group each Sunday during the observation. The following 10 *Facebook* group posts are examples of these stuttering-related questions:

- Post by John (October 26, 2014): If you could describe your stuttering in 3 words, what would they be? Why?
- Post by John (November 2, 2014): When was the last time you felt particularly proud of yourself, in regards to communication? Tell us a bit about it.
- Post by John (November 9, 2014): Do you know of any celebrities that stutter? If so, who?
- Post by John (November 16, 2014): Just curious, are there any people you can think of that you feel you have to hide your stuttering from? If so, why?
- Post by John (November 23, 2014): Just curious, has anyone here ever avoided ordering food at a drive thru because of stuttering? If so, why?
- Post by John (November 30, 2014): This week's topic might be a little controversial. . . . If there was a magic pill that would completely get rid of stuttering, would you take it? Why/why not?

- Post by John (December 7, 2014): We all know that the holiday season can get a bit stressful. Does that holiday stress ever have an impact on your stuttering? If so, please do share with us.
- Post by John (December 15, 2014): Would you rather be called a person who stutters OR a stutterer. Or does it really not make a difference to you? We would love to read your thoughts about that.
- Post by John (December 22, 2014): Has anyone here been in class before and totally knew the answer that the teacher asked, but you didn't raise your hand because of the possibility of stuttering?
- Post by John (December 28, 2014): I once met an adult who told me that for the longest time, he thought that stuttering was caused by parents tickling their child when the child was very young. It amazes me how many silly myths are still floating around out there. Have you heard any other myths like that before?

### **Social Gathering Questions**

One participant utilized the *Facebook* group to ask members a question that related to a possible upcoming social gathering that was separate from the usual face-to-face stuttering support group meetings. The example of this conversation is:

- Post by Bill (December 1, 2014): I have another question- are you guys planning a Christmas get together this year? It would be nice to see everyone in a less rushed atmosphere.
- Post by John (December 22, 2014): Hey Bill, sorry I never got back to you. This post got lost in the shuffle. We are, unfortunately, not going to be holding a

Christmas get together this season. Len and I discussed this but since he is back home out of state, it would be too difficult to plan it with one person. We are however, planning to incorporate Google Hangouts video chat into our meetings so that you or anyone else who is unable to attend due to the travel distance or any other issues will be able to do so. Thank you for reaching out to us with that question. If you have any more, keep them coming.

### **Themes Related to Support Through Giving Encouragement**

This section underlines the ways in which participants gave encouragement to each other within the *Facebook* group as a way to provide support.

#### **Text-Based**

Various participants shared eight encouraging and motivating posts with others within the *Facebook* group. The following eight *Facebook* group posts are examples of these stuttering-related questions:

- Post by Len (October 28, 2014): [in response to a comment by Greg] Never really thought of it like that (stuttering makes you approachable). Cool perspective. Maybe as you said “other people don’t feel as concealed about their flaw” when they see that we are open about our stutter.
- Post by John (November 2, 2014): [in response to a comment by Roth] That’s awesome. I can’t say I’ve ever experienced that before. Does it happen often with you?
- Post by Greg (November 2, 2014): [in response to a comment by John] That’s awesome! Maybe the drinks helped bring out the social John.

- Post by John (November 2, 2014): [in response to a comment by Len] That's awesome man! Glad to see that you faced your fears and stuck with it!! Well done!
- Post by Len (November 16, 2014): [in response to a comment by Cornell] I feel the same way man. For me though I sometimes notice that I try hiding my stutter from my family.
- Post by John (November 24, 2014): [in response to a comment by Greg] That's interesting Greg. I remember I used to use a lot of uhs in my speech so that the person would know I was still there. Couldn't really avoid the McDonald's drive thru because the alternative was going into a fast food restaurant in the middle of a not so good neighborhood... So yeah, sometimes the best thing to do is let it fly.
- Post by John (December 15, 2014): [in response to a comment Greg] That is very interesting. Being an SLP student, we are taught that the "person comes first," that we should only refer to someone who stutters as a stutterer if they want to be called one, so it is interesting that you mention political correctness. I would love to hear everyone's thought on this.
- Post by Len (December 15, 2014): [in response to a comment by Greg] Took the words out of my mouth, Greg.

### **Like Button-Based**

Participants within this study clicked the Like button 112 times as a way to communicate support to members' posts and replies during the observation period. Table

4.3 illustrates the total amount of posts, replies, and likes that were collected within the *Facebook* group.

Table 4.3

*Total Number of Posts, Replies, and Likes*

Activity	Total
Posts	24
Replies	41
Likes	112

The Like button is exclusive to the *Facebook* group and cannot exist in a face-to-face group. Various participants shared their thoughts on what they believed the Like button's role was within the *Facebook* group and how it was a form of support. The following quotes from the semi-structured interviews support this subtheme:

Greg: I guess I see the like button as just a general 'good' kind of thing. Cause when someone puts up something sad or shitty, people still 'like' it but that's not really what it means. I think it's funny when certain things get liked. Like 'my hubbie left me and my kids!' And all the family will like the status just to show they viewed it or something, I don't know lol. Just to show approval but not get involved. Like a random nod of agreement from a crowd lol.

Roth: I think the like button can serve a few different purposes. I think mainly people use it to show that they saw the message and they want you to know that they support its message/can relate to it/feel strongly about it. I think in a way it's a good thing because it allows people to feel like their message is being heard. But on the other hand, I think it runs the risk of becoming a little impersonal, especially in a support group format. I think people need to connect with more than just an acknowledgment like that, especially if that's the only form of communication that they receive time and time again. It doesn't allow people to learn from each other or give people the opportunity to expand on what they want to say.

John: I am not a total fan of the like button. It is a cope out for people to not communicate with one another. Like in the group, people hit like but do not respond. What is the point of that? Especially if we are asking a question. It is a way to show that they saw it but I don't feel it serves much of a purpose. People

might also hit it just to show the other person that they are noticing something that they say.

### **Themes Related to Support Through Engaging in Humor**

This section emphasizes the ways in which participants used aspects of humor within the *Facebook* group as a way to provide support.

#### **Self-Deprecating**

During numerous occasions, participants shared an informational link and/or made specific comments that could both be viewed as a self-deprecating style of humor.

*Facebook* group posts that highlight examples of these interactions are:

- Post by John (October 31, 2014): [Check out this humorous article that was posted on *BuzzFeed*, which is an entertainment and comedy-based website]  
<http://www.buzzfeed.com/alexisnedd/things-all-people-who-stutter-will-understand?s=mobile> (see Figure 4.5).

# 25 Things All People Who Stutter Will Understand

Hands up if you cried during *The King's Speech*.

posted on Oct. 29, 2014, at 1:19 p.m.



**Alexis Nedd**  
BuzzFeed Staff



**1. Not being able to introduce yourself because you get stuck on YOUR OWN NAME.**

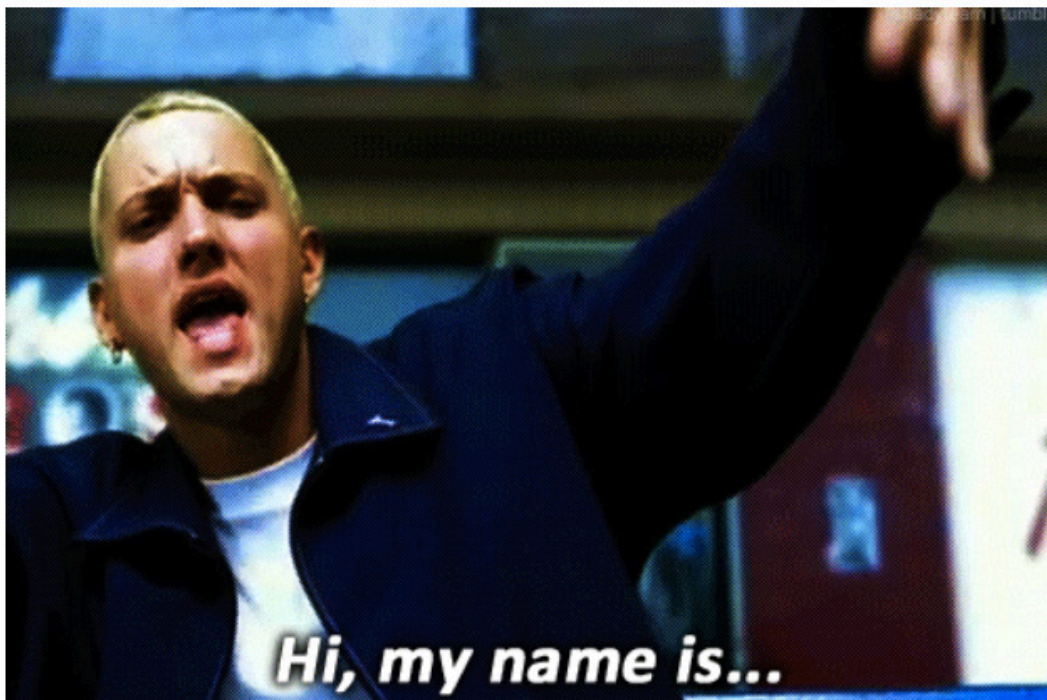


Figure 4.5. BuzzFeed article screenshot.

- Post by Greg (October 31, 2014): [in response to the *BuzzFeed* article link that was shared by John] I actually laughed out loud at the stutter on your own name one lol.
- Post by Greg (November 25, 2014): Filler word. That's perfect! My most used filler is 'fuckin'. It can go in front of anything! Lol. Not classy but oh well
- Post by John (November 30, 2014): [in response to Greg's comment about filler words] Greg, I remember those days. Those are the words that we can say most fluently yet are least acceptable.

### **Sarcasm**

During a conversation that contained four back-and-forth interactions, participants made humorous remarks that could be categorized as sarcastic. *Facebook* group posts that highlight examples of these remarks are:

- Post by John (December 28, 2014): I once met an adult who told me that for the longest time, he thought that stuttering was caused by parents tickling their child when the child was very young. It amazes me how many silly myths are still floating around out there. Have you heard any other myths like that before?
- Post by Greg (December 29, 2014): This is true John. Don't be daft.
- Post by John (December 30, 2014): Yes Greg that definitely explains a lot. I think we just cured stuttering.
- Post by Greg (December 30, 2014): No tickling babies! Who would have thought?

For the question “How do people who stutter understand their interactions with other people who stutter in a social network?” the major theme was Healthy Debate. The following section discusses this theme in more detail. In this section, participants’ quotes from an interaction within the *Facebook* group are provided as a means to further solidify the given theme.

### **Theme Related to Healthy Debate**

This section features a conversation that exemplifies the ways in which participants of this study understand their interactions with other people who stutter within the *Facebook* group. The following *Facebook* group posts, which are a collection of six back-and-forth interactions, highlight the healthy debate among members of the *Facebook* group:

- Post by John (December 15, 2014): Would you rather be called a person who stutters OR a stutterer. Or does it really not make a difference to you? We would love to read your thoughts about that.
- Post by Greg (December 15, 2014): It doesn’t matter. People concerned with political correct nonsense like that have other issues. In the words of my inappropriate grandpa, “Call me anything but asshole”
- Post by John (December 15, 2014): That is very interesting. Being an SLP student, we are taught that the “person comes first,” that we should only refer to someone who stutters as a stutterer if they want to be called one, so it is interesting that you mention political correctness. I would love to hear everyone’s thought on this.

- Post by Greg (December 15, 2014): If a person calls you something you don't like, say something. Demanding things like terminology from the public only garners the community opinion that we're sensitive and need special treatment.
- Post by Len (December 15, 2014): Took the words out of my mouth, Greg.
- Post by John (December 15, 2014): I would rather be called a person who stutters because it follows the person first philosophy. I am someone who stutters but I am not a stutterer. There is more to me than just that.

For the question “How do people who stutter understand their communication disorder through their interactions with other people who stutter in a social network?” the major theme was Honest and Varied Opinions. The following section discusses this theme in more detail. In this section, participants' quotes from an interaction within the *Facebook* group are provided as a means to further solidify the given theme.

### **Theme Related to Honest and Varied Opinions**

This section features a lengthy conversation that exemplifies the ways in which participants of this study understand their communication disorder through their interactions with other people within the *Facebook* group. The following *Facebook* group posts, which is a collection of six back-and-forth interactions, highlights the honest and varied opinions among members of the *Facebook* group:

- Post by John (October 26, 2014): If you could describe your stuttering in 3 words, what would they be? Why?
- Post by Len (October 27, 2014): Frustrating, Powerful, Challenging

Frustrating – At times my stutter is frustrating. Giving a presentation that you have practiced 3 times alone in a classroom, not stuttering once during these 3 times, and then stuttering on every other word during the actual presentation is one of the most frustrating things I have ever experienced.

Powerful – If I let it, my stuttering has the power to debilitate me. It's powerful enough to cause me anxiety and bring me to my knees. However, through these experiences my stutter has also empowered me. It has made me stronger. Perhaps above all else my stutter has given me empathy towards others. Empathy, not sympathy. Sympathy is feeling sorry for someone and giving them your condolences. Empathy is understanding (or trying your best to understand) the pain or frustration someone is going through and being there to help them through it. Looking at my stutter through the right lens, I can see how it has empowered me as much, if not more so, than it has power over me.

Challenging – My stutter is a daily challenge. Even days or times I do not want to address it, my stutter remains constant. It never waivers. Yes, these challenges are hard but they are not impossible obstacles to overcome. Facing these challenges, all of them that my stutter has given me over the years, has shaped my personality, character, and view on life in one way or another. At times, my stutter has won. It has beaten me down time and time again. Strength is measured not by how many times you are defeated, but how many times you pick yourself up and keep going. The challenges my stutter gives me has made me a more perseverant person in all aspects of life.

My thoughts on describing my stutter in 3 words.

- Post by Greg (October 28, 2014): Stuttering is not something I am ashamed of. It makes me stand out as an individual and I make a joke of it so people don't feel awkward. Having a stutter makes you friends with other people who stutter and with people who study it (speech pathology majors for example). Having a stutter makes you approachable. When you display a "flaw" out in the open like that, other people don't feel as concealed about theirs. Just my thoughts
- Post by Len (October 28, 2014): Never really thought of it like that Greg (stuttering makes you approachable). Cool perspective. Maybe as you said "other people don't feel as concealed about their flaw" when they see that we are open about our stutter.
- Post by Roth (October 28, 2014): Empathy – Like Len mentioned, I feel as though stuttering has made me a much more empathic person. I try to keep in mind that everyone I meet may be going through a silent struggle in life, just as I have sometimes struggled with stuttering internally. I think empathy is something that other people can sense, and it attracts others to us. It shows them that we have the ability to be compassionate and understanding, even when others may not be as patient with them. I consider it to be the greatest lesson that I've taken from living with stuttering.

Commitment – Stuttering has taught me that I have to stick with things for the long haul, even if they cause a ton of discomfort at first. There aren't many feelings like the one you get when you achieve a goal you set for yourself.

Whether it's as simple as initiating a conversation with someone, to something as huge as making a 10 minute presentation, you have to commit to achieving it step by step. I think this commitment has carried over into most aspects of my life, and I try to stick with things as long as I feel like the outcome will outweigh the discomfort that may be felt while trying to achieve the goal.

Me – It's taken me a long time to reach the point of feeling okay about stuttering, but I finally see it as just the way that I speak instead of as a hindrance. Growing up, I saw stuttering as the thing that made me different from everyone else, and I was very ashamed of it. While I definitely still have difficult times or moments, I try to focus on all of the positives that stuttering has given me in life. It's a part of me that I don't think I would change if I had the opportunity because it's turned out to be the biggest blessing in disguise I ever could have hoped for in my life. I just wouldn't be me without it.

- Post by John (November 1, 2014): I found it very difficult to pick just three words to describe my stuttering. Stuttering is pervasive and affects a person as soon as they open their mouth to talk. After putting much thought into 3 words to describe my stuttering I came up with: inspiring, challenging, and humbling. My stuttering is inspiring because it led me to pursue a career in speech language pathology and help others who stutter.

My stuttering is challenging because it took a lot of hard work to get to where I am today, in terms of fluency and acceptance. I know that I am still not 100% accepting but I am as close to it as I could be and I am happy with who I am.

My stuttering made me a better and stronger person. All of the challenges that I have faced had a purpose. They shaped my life and made me who I am today. My stuttering is humbling because I know that my current level of fluency might not always be this high. I try to look at things realistically and objectively, knowing that I may have a relapse and be back at square one again.

## CHAPTER 5

### DISCUSSION

The purpose of this study was to explore the experiences of people who stutter who digitally connect and share with other people who stutter within a social networking site, specifically *Facebook*. The primary investigator used the qualitative methodology of ethnography as a means to discover and gather this knowledge. Results revealed themes related to the benefits and challenges of being a part of a private *Facebook* group for people who stutter, the various types of support that existed within that *Facebook* group, as well as the healthy debate and honest and varied opinions that were communicated within that online environment. This chapter will discuss these themes in relation to prior research, discuss limitations and strengths of the study, and mention implications of the findings for speech-language pathologists and stuttering support group organizers.

#### Benefits

Prior research has revealed many benefits associated with online communities and the act of being a member of one. For instance, Stoudt and Ouellett (2004) discovered that through the textual conversations that were found within their observed online community for people who stutter, there seemed to be a healthy and continuous communication loop that was present. Because the members of that Internet-based forum deemed it to be a safe location where personal sharing could exist, this communication loop naturally enabled an individual to share a personal stuttering experience with the group. Then, after the share was initiated, members empathized with the shared experience. Afterwards, honest and

insightful advice was usually given that helped the individual to gain greater acceptance and to carry that experience forward in a new and more positive way.

Another example of this healthy and continuous communication loop can be found in data collected by Leggatt-Cook and Chamberlain (2012). Writers and readers of various weight-loss blogs on the Internet have also been found to champion the Worldwide Web as a safe environment that enables users to share personal experiences with one another that relate to dieting. From this sharing usually came empathy from others, and then a wave of positive feedback and suggestions from individuals who have either been there before or are currently going through similar dieting situations. The words within the textual conversation usually provided valuable and caring knowledge to its recipient. This constant back-and-forth between readers and writers quickly created a like-minded community of support and acceptance.

The findings that were uncovered in these prior studies were also found within this present study of exploring the experiences of people who stutter who digitally connect and share with other people who stutter within a social networking site, specifically *Facebook*. The reported sense of family and ultimate safeness that came from the *Facebook* group fostered a healthy and continuous communication loop so it was able to exist and grow. The loop of conversation helped to diminish feelings of loneliness or isolation that was caused by being a person who stutters living in an environment where a majority of the communicators are not people who stutter. Len described the following:

Len: For myself the main benefit of the *Facebook* group is knowing that there is always someone to talk to about my stutter who is willing to listen. While my parents and close friends are always there for me, the group enables me to talk to people who can relate to stuttering. It makes you feel like you are never alone. Trust

me I know, when you stutter and are the only person in a large classroom giving a speech who stutters, it is hard not to feel alone. The group is always there for you to fall back on.

Throughout this study, it was also noticed that participants expressed enjoyment with reading the postings that were added to the *Facebook* group by the members, as evidenced by numerous quotes. For example, John said, “I think that [the *Facebook* group] gets people thinking, at least once a week, about a topic on stuttering.” Cornell added, “[The *Facebook* group is] insightful in that sometimes my friends from the support group say things that resonate with me.” Roth mentioned, “I think the question about describing your stuttering in 3 words was a pretty interesting and enlightening experience [to read].” The thought provoking nature of the various posts and replies helped to both educate and entertain everyone who was a part of this *Facebook* group.

Similar educational and entertaining parallels can be found in the basic explanations of various stuttering-related online communities and Internet-based locations described by Packman and Meredith (2011) as well as Tellis and colleagues (2002). Those researchers discussed how the Internet, as a whole, contained “almost boundless opportunities for exchanges of information via blogs and chat rooms” (p. 43, Packman & Meredith, 2011) and how that ability is able to empower people who stutter because knowledge, and support, is power. The Internet and online communities contain numerous aspects of shared information that could help a person who stutters to learn more about stuttering. From keeping up-to-speed with the latest developments in stuttering research and treatment by sharing a link to an Internet article, to corresponding with others who stutter for the purpose of sharing specific experiences related to effective communication, all of this seems to have

been happening on the Internet for the past decade and a half. This continues to grow stronger as social networking sites, such as *Facebook*, create more online communities for people to be a part of to digitally connect and share in.

Another benefit that was obvious throughout this study was the fact that accessing the *Facebook* group was extremely convenient because of its availability on mobile devices. This ability to access support cannot be replicated in a face-to-face environment. As long as a person had a cell phone with smart phone capabilities (one that has access to the Internet), the *Facebook* group could be visited at anytime, right from the palm of a user's hand. This is different from the face-to-face group where members had to wait days or weeks in order to access support. Of the seven members who were a part of this study, six of them reportedly used their smart phone to regularly interact within the *Facebook* group. Of the six who did so, five reportedly used their smart phone most of the time to connect to *Facebook* (as opposed to accessing *Facebook* from a desktop or laptop computer). This majority of participants using a smart phone to access the social networking site resembles the latest data collected by Duggan and Brenner (2014) that revealed 67% of American users within the 18- to 29-year-old age demographic use a social networking site on their smart phone. In addition, of the seven participants in this study, six of them reportedly visited *Facebook* daily, and that information closely matches the latest frequency of social media use data that stated 70% of all *Facebook* users engage on the site at least once every 24 hours (Duggan et al., 2015). Roth summed up the convenience of using a mobile device to access the *Facebook* group for support in the following:

Roth: The biggest positive is that it can be accessed anytime and anywhere. Stuttering is a disorder that can pop up at any point and cause a ton of stress or frustration in any given moment. So, having an online support system that you can turn to whenever you need is a really great resource. Say someone had a really severe block at work or at school and they had a rush of negative feelings about the experience. They could take out their phone or computer and get that support immediately or at least in a much quicker time frame than a bi-monthly support group. I think that's a very powerful thing.

Continuing on the subject of convenience through accessibility, members of this study revealed that they appreciated the fact that there was not a set physical location component associated with this piece of the stuttering support group. Because the support existed in a digital way on the Internet, participants did not have to worry about meeting face-to-face at an exact location at a specified time. Regardless of where the members of this study physically were, it was communicated that they were still able to obtain encouragement from each other and continued to develop their friendships. Cornell touched on the power of this type of digital support in the following:

Cornell: If you can't go to a local face-to-face meeting or you live in the backwoods of some shitty Podunk town and stutter, you already feel isolated and now even more. The Internet fixed that, but even then if you stutter, it's less obvious online than in person. With online support groups and online communities for stuttering, it's convenience at a keyboard.

The findings in this study that relate to the mention of location-based limitations are similar to the results collected by Collie et al (2007). These investigators have seen, first hand, the benefits that come along with having an online support environment that takes into consideration how sometimes location limitations can negatively impact a person's ability to physically get to a support group meeting. In their research, they worked together with women diagnosed with breast cancer who were living in a rural location of the United States. These participants engaged in eight group therapy sessions that existed within an

online community and at the conclusion of study, all members stated that they benefited from the Internet-based approach because it allowed the women to share thoughts and feelings with other women who were also going through the same situation. Moreover, it was noted that the women developed strong emotional connections with each other.

Similar findings were discovered by Packman and Meredith (2011) when they discussed how people who stutter were beginning to utilize telehealth services (therapy and support that are provided by the telephone or the Internet as way to reach individuals in rural areas). It was found that many participants who stutter that were a part of a form of telehealth reported positive thoughts associated with that particular way of connecting and sharing with clinicians or other people who stutter. Again, one of the main advantages of this type of therapy or support was that the individuals did not have to travel to a specific location. Because of this, the telehealth sessions could be scheduled at more convenient times for the person who wished to receive the services or support.

A conclusion that designated the *Facebook* group as an appropriate supplement to the traditional face-to-face meetings was also made during this study. Bill called it, “an additional resource” and John stated that it had, “great potential to be a powerful addition to a physical support group.” Members of this online community happily combined the newly established digital component of support, which was the private *Facebook* group, with the more traditional model of physically coming together in a single location during a support group session. The online environment created an additional line of encouragement for those willing to explore the idea of digitally connecting and sharing within the social networking site. However, it should be emphasized that this added

component of support should most likely not take the place of the traditional model of physically coming together coming together in a single location to gain real-time and real-life support. Greg discussed this topic in the following:

Greg: Replacing [a traditional, face-to-face stuttering support group with an Internet-based one] isn't really possible, supplementing is all a digital medium could do for this kind of thing . . . It might help one person, might be useless for the next . . . So yeah, online help might do something for people who stutter, or it might not. If it helps one person then it's something worth pursuing.

This statement resembles Brundage's (2007) stance that virtual reality technologies could benefit people who stutter. In her study, she detailed how virtual reality environments, which can and do exist on the Internet (see Stewart, Hansen, & Carey, 2010; Packman & Meredith, 2011; Meredith et al., 2012), could assist people who stutter in meeting challenges that are often associated with their communication disorder. Because the virtual reality environment could be a controlled and safe space where people who stutter could practice effective communication strategies or participate in conversations that relate to the subject of stuttering with others, this creates another therapy and support feature that could become more widely used in the future. However, it was clearly stated by Brundage (2007) that, "virtual reality is not meant to replace the speech-language pathologist. It is best thought of as a powerful tool for use in the hands of a skilled clinician" (p. 267). It could be suggested that the same could be said for online communities for people who stutter; it is not meant to replace anything and should be viewed as an additional option. Len reinforces this statement in the following:

Len: It [the *Facebook* group] is absolutely an additional resource other chapters can use to enhance or supplement the face-to-face support group. I think supplement is the key word there. Still having face-to-face meetings is essential for group

cohesiveness and the longevity of the group but having a *Facebook* group to supplement the face-to-face group is a great idea.

With all of this beneficial data that was able to be collected throughout this study, it seems highly probable that the *Facebook* group does present itself as a healthy expressive outlet for people who stutter to digitally connect and share with one another. These communities of people who stutter care for each other and willingly want to make lasting and impactful relationships. Therefore, it is assumed that this private *Facebook* group, and other online communities like it, could be described as, “adequate spaces for connection and expression” (p. 180, Stoudt & Ouellette, 2004).

### **Challenges**

Prior research has revealed some challenges associated with online communities and the decision to be a member of one. For example, data collected by Leggatt-Cook and Chamberlain (2012) have discovered that readership and consistent engagement from readers play a pivotal role in the thoughts and feelings of a blogger (one who chooses to share experiences, observations, and/or opinions related to a given subject through written word within an online blogging platform). It was found that when a person wrote a weight-loss blog post, that writer usually shared a deeply personal experience with the Internet. So the author of the weight-loss blog post often expected a certain number of readers to consume the story and a particular amount of comments to be generated. However, sometimes the readership was not as high as what the writer was expecting and this made the author feel as if there was no longer a support system in place. Additionally, a lack of comments often triggered feelings of failure both as a writer and as person struggling to lose weight to improve the chosen healthy lifestyle. A situation like this could cause a

person within an online community to feel abandoned because there is a perceived lack of individuals for a group member to digitally connect and share with.

A similar connection can be made within this present study of exploring the experiences of people who stutter who digitally connect and share with other people who stutter within a social networking site, specifically *Facebook*. A majority of the members in this study confessed that the lack of members in this online space seemed to hinder some conversations from fully expanding. Though there were seven members within this *Facebook* group, participants have made mention that the number was not as high as they had expected and that a higher number was needed to have a larger amount of deeper dialogue within the online community. Bill stated,

Bill: I think John, the co-leader, does a good job in trying to stimulate conversations- but there's not that many members . . . it would be nice if it were possible to increase the membership [of the *Facebook* group] to get more ideas.

When there seems to be a lack of the right amount of members in the online community, or simply not enough members to facilitate a healthy amount of conversation that relates to stuttering, it could negatively impact any members who post messages within the private *Facebook* group. Those members could feel as if they are not receiving the support or encouragement that they need. If these types of feelings continue to exist for a substantial amount of time, the online community will, most likely, cease to exist.

Another challenge that was uncovered in this study was the apparent disconnect that some members felt while digitally connecting and sharing with others in the online environment. Because the conversations were only textual in nature, members were unable to see the body language and hear the voices of the speaker, which in turn hurt the ability

for some individuals to feel a solid connection with others within the private *Facebook* group. Len shared the following words that related to the apparent disconnect:

Len: Typing on a screen can be a bit impersonal. Sometimes in tough times you want someone there right by your side to talk to. While the group is a great resource, it cannot teleport people right to your living room couch. At least not yet.

This sense of disconnect was also found in several past research findings. For example, Collie et al (2007) mentioned how when participants were interacting within an online community that had a videoconferencing component to it, sometimes the lighting was poor. This poor lighting severely impacted the ability of members to be able to see the facial expressions of the given speaker. Thus, it was stated that a higher level of concentration was placed on listening to the speaker's tone of voice, in an effort to make up for not being able to see the face clearly. It could be suggested that this was done in an effort to repair the sense of disconnect that the members were feeling at that moment, due to the lack of being able to see the faces of the individual. This is a perfect example as to how a feeling of disconnect could negatively impact the overall experience of interacting within an online environment with others.

Being that the current study focused on users within a private *Facebook* group, the main mode of communication was text-based. Text-based communication is black and white, in that it lacks the true auditory fingerprint of the writer. It does not have the volume that might be associated with the communication intent. It is absent of any emotion and the chosen tone that belongs to the post. All of this, or rather the lack of all of this, adds to the apparent sense of disconnect that the members mentioned. This might be one of the main reasons why more people are gravitating towards podcasting as a means to digitally connect

and share with other people who stutter. With podcasting, you hear the voice and the stuttering (Snyder et al., 2009).

Misinterpretation was another theme that a number of members within this current study mentioned as a challenge. There was a clear fear associated with the possibility of having written communication intents be misread or taken out of context. This fear caused some members to be cautious with starting conversations within the online community. The fear of possibly having the posted opinion be misinterpreted by other members of the group was a large one. Charlie admitted the following:

Charlie: Personally being somewhat of an introvert, I always hesitate to post on discussions [within the *Facebook* group]. I fear that someone would judge my words as with, written text, thought can often be misread easily.

Similar data relating to misinterpretation could be found in a past study by Rains and Keating (2011) when it was mentioned, “blogs allow asynchronous communication and filter many of the social cues that are present in face-to-face interaction” (p. 528). It could be suggested that because the social cues are filtered, the online writers of textual communication might feel as if their words could be misinterpreted. So as Rains and Keating sought to discover the possible social support one might receive online from blogging about one’s health, one cannot help but think about just how many potential people might have wanted to blog about their health, but chose to opt out of the exercise due to the fear of being misread or misinterpreted. In theory, those who opted out of digitally sharing also missed out on gaining a new system of digital support, and that is a shame.

Continuing on, participants within this study mentioned how the lack of instantaneous communication was seen as a major challenge. Because the nature of the private *Facebook* group is asynchronous, it was not uncommon for a single post to go a full 24 hours before a response was added. One can begin to imagine the frustration that might ensue if a member was seeking to gain advice from the *Facebook* group on a particular subject that was time sensitive. Len echoed this notion in the following:

Len: One challenge [of the *Facebook* group] is that if you post something in the group, people may not respond for a few hours or a few days. If you really want to talk to someone in the group immediately, and don't have their phone number, it can be detrimental.

With online communities for people who stutter, particularly asynchronous ones like the *Facebook* group, responses to posts start off strong, but then start to fade away as members begin to pay attention to other posts (Stoudt & Ouellette, 2004). What if a member needs a response from the group, but the group is either too slow to respond or they have chosen to move onto another post? This would surely be a negative experience for that particular person who stutters.

Instantaneous communication seems to be something that people who stutter frequently request online because it allows them to gain the support that they need, when they need it, with little wait time. This could be why The Stuttering Home Page decided to add numerous chat rooms to the website in the later part of the 1990s. Tellis et al (2002) discussed how, in 1997, The Stuttering Home Page added chat rooms for parents and caregivers of children who stutter, students who stutter, and more. This addition was great in that it gave users the ability to participate in a synchronous communication experience, as opposed to the asynchronous experience of waiting for new posts to be published online.

The last challenge that was discovered during this study was one that had to do with the lack of any responses to accompany a question within the *Facebook* group. On several occasions, a member of the *Facebook* group posted questions to the members who generated zero responses. One could clearly imagine how, just like the frustration felt when there was a lack of instantaneous conversation, the absence of any responses to a particular message would make a person who stutters feel irritated. This irritation would be present because the action of not responding goes against what past research has continually shown, in that people go on social networking sites like *Facebook* to start back-and-forth conversations with friends (Cheung, Chiu, & Lee, 2011).

However, it should be mentioned that on one occasion, a participant did, in fact, read a post by another member, but for whatever reason, chose not to communicate his appreciation for the post. For example, when Cornell was asked by the principal investigator to think back to an insightful post that he enjoyed reading, Cornell responded with, “the drive thru question [was insightful]. Just interesting seeing others, like Greg, talk about their experiences that I feel ridiculous for stressing about—but know I’m not the only one.” This is an example of a passive participant not necessarily engaging in the online community at that moment, but that does not mean that he is still not benefitting from the conversation. He still is, but one cannot help to wonder if making the choice to stay silent is the best way to utilize what the *Facebook* group has to offer, in regards to digital support.

### **Support Through Providing Information**

Past research that looked at the Internet and how people who stutter utilized it as a location for support has consistently shown that that sharing and obtaining information

online were vital pieces to the foundation of the stuttering support structure. For example, Kuster (1995, 1998) was one of the first researchers to highlight how the Internet served to be a beneficial digital environment where people who stutter could share valuable pieces of information, such as articles relating to the communication disorder, contact information of local stuttering support groups, and more. Similarly, Tellis et al (2002) also found the same benefits with how the Internet could be used as a digital location where numerous stuttering-related resources and announcements could be shared with anyone who had access to the Worldwide Web.

In addition, people who are considered to be deaf, or hard of hearing, have been found to use the Internet to share various pieces of information about deafness to inform and educate (Hamill & Stein, 2011). One of the most popular things to do on *Facebook* is to share information with others about upcoming events that pertain to a certain demographic (Cheung, Chiu, & Lee, 2011). Having access to beneficial information like this helps individuals to feel connected and supported because they are able to stay current and up-to-date with whatever community they choose to be a part of online.

The conclusions that were discovered in these prior studies were also found to be true within this present study of exploring the experiences of people who stutter who digitally connect and share with other people who stutter within a social networking site, specifically *Facebook*. In this online environment, both co-leaders of the support group used their *Facebook* group to post numerous messages that promoted upcoming face-to-face support group meetings. Also, they posted links to stuttering-related online articles that they viewed as interesting. By sharing these event reminders and other types of

stuttering information with other members of the group, it could be suggested that they are showing their support for the group through sharing thoughtfully curated information.

### **Support Through Posing Questions**

Past research has touched on the potential benefits of individuals online continuously asking questions to other online community members as a means for social support and engagement. Through this intentional act of posing a series of subject-specific questions, it often enables some members to grow their relationships with others. In addition, these members are able to learn more about themselves and the things that they all have in common with each other. An example of this can be found in research conducted by Hamill and Stein (2011) that looked at how a particular group of members within the Deaf community used the Internet to digitally come together to have active Deaf culture discussions online. While analyzing 416 posts, it was found that a number of those writings posed questions to the online community in an effort to stimulate more Deaf culture conversation. This call for community discussion shows just how important these online community members viewed the power of asking questions to members for the purposes of triggering more questions to be explored together.

In addition, research endeavors by Garcia and colleagues (2011) lead them to create a password-protected online community for participants who were caregivers of family members who had dementia. During the designated meeting times within the online community, questions were consistently shared with all the participants that revolved around basic dementia information and strategies for coping with depressive symptoms associated with providing care to a loved one. It could be suggested that because of the

perceived routine of asking questions to the members of that online community, opinions and responses were able to flow more readily and were able to spark even more questions to discuss.

Similarities between these previously mentioned studies could also be found within this present study of exploring the experiences of people who stutter who digitally connect and share with other people who stutter within a social networking site, specifically *Facebook*. Just like the study by Garcia et al. (2011) where members of their online community posed specific questions once a week to generate conversation, the same was done with this online community for people who stutter. One of the co-leaders of the stuttering support group, John, would post a new stuttering-related question to the *Facebook* group each Sunday evening during the months of October, November, and December 2014. A majority of these questions generated replies and Like button clicks, thus illustrating how the given questions were viewed as worthy of exploration. By exploring these questions together in the safety of the *Facebook* group, it could be concluded that the perceived level of support would have been rated highly by members in the online community.

Continuing on the subject of posing questions to group members, it was also refreshing to notice one member of the *Facebook* group ask a question that related to members getting together for a social event outside of the routinely scheduled 2 times per month face-to-face meetings. An example of this conversation can be found when Bill asked, "I have another question- are you guys planning a Christmas get together this year?"

It would be nice to see everyone in a less rushed atmosphere.” To which John responded with the following:

John: Hey Bill, sorry I never got back to you. This post got lost in the shuffle. We are, unfortunately, not going to be holding a Christmas get together this season. Len and I discussed this but since he is back home out of state, it would be too difficult to plan it with one person. We are however, planning to incorporate Google Hangouts video chat into our meetings so that you or anyone else who is unable to attend due to the travel distance or any other issues will be able to do so. Thank you for reaching out to us with that question. If you have any more, keep them coming.

This example emphasized the importance of questions and how they are all reflections of the support that exists within this *Facebook* group. By asking questions, whether they are stuttering-related or not, users are able to see that their opinions have worth. If their opinions did not have worth, no members would be ever be asking questions or inviting others to share their opinions.

### **Support Through Giving Encouragement**

Providing encouragement to others online has consistently been discovered in a substantial amount of literature. For example, Garcia et al. (2011) experimented with a telehealth approach that incorporated access to an online community for support. The participants within this study were caregivers of family members who had dementia. Being that the participants had access to an online community of others who were also going through the same thing, the caregivers automatically started to provide encouragement to one another during the designated online community meeting times. The members of this study positively expressed benefit with sharing emotions with other members of the group.

Hamill and Stein (2011) have also touched on the benefit that online communities have for the Deaf community and its ability to provide a great deal of text-based support

through acts of encouragement via posts on a weblog. Individuals observed during their study were found to provide comments to one another that positively supported and empowered users. It was not uncommon to see bloggers write posts that urged readers to be welcoming of anyone in the Deaf community and reminders to end Deaf stigma by providing appropriate education to all who need it.

Other examples of text-based encouragement within an online community were found in data collected by Rains and Keating (2011) and Stoudt and Ouellette (2004). Both sets of research teams actively reviewed posts made by their respected participants and found an overwhelming amount of examples that illustrated the members' allegiance to providing as much encouragement to each other as possible. The same could be said for results analyzed during this research study. One of many examples can be seen in the following quote where John responds to a comment by Len with, "that's awesome man! Glad to see that you faced your fears and stuck with it!! Well done!"

Present findings also bring to light a particular aspect of social networking support that has received little to no attention in the current literature. This form of support shows itself not in text-based words, but in the clicking of a Like button. Of the 24 total posts and 41 replies that were added to the *Facebook* group during the observation, an impressive 112 Likes were accumulated. This wordless form of support comes with mixed reviews from members of the group. For example, John stated, "I am not a total fan of the like button. It is a cope out for people to not communicate with one another." Similarly, Greg described the main function of the Like button as, "just to show approval but not get

involved. Like a random nod of agreement from a crowd lol.” Roth clearly described the good and bad of the Like button in the following:

Roth: I think the like button can serve a few different purposes. I think mainly people use it to show that they saw the message and they want you to know that they support its message/can relate to it/feel strongly about it. I think in a way its a good thing because it allows people to feel like their message is being heard. But on the other hand, I think it runs the risk of becoming a little impersonal, especially in a support group format. I think people need to connect with more than just an acknowledgment like that, especially if that’s the only form of communication that they receive time and time again. It doesn’t allow people to learn from each other or give people the opportunity to expand on what they want to say.

It is interesting how the Internet is creating new ways for stuttering support to exist. Two decades ago, text was king on the Worldwide Web. A texted-based message of message of encouragement was used as a way to show support. Now, more abstract ways of showing support are starting to show their faces within online environments. *Facebook’s* Like button is one example of this and as the social networking sites continue to evolve, it would not be surprising to see more variations of this type of support to exist in the future. These are the types of variations that help online communities to be able to differentiate themselves from face-to-face groups.

### **Support Through Engaging in Humor**

Another form of support that is not yet widely discussed in the current online communities literature has to do with gaining support through humor while digitally connecting and sharing with others on the Internet. Hamill and Stein (2011) were able to pick up on the use of humor when it was noticed that bloggers within the Deaf community were making humorous comments that directly related to Deaf culture. Of the 416 posts made on a Deaf culture weblog, 23 of them were categorized as posts with comedic

undertones to them. These types of posts ranged from a funny cartoon picture that showed a boy at the eye doctor finger-spelling all of the letters on an eye exam chart to a more traditional joke with a set up and a punch line, such as “A Deaf man signing with his Deaf friend explains what happened when he came home late last night. . . ‘My wife was wide awake, waiting for me in bed, and she started swearing at me and giving me hell’. ‘So what did you do?’ ‘I turned out the light’” (p. 396). As described by Hamil and Stein, Deaf humor is often set up in a way that often depicts the Deaf person as having an advantage because of the deafness. The ability to see the positives in one’s condition could help to support the person’s feelings about the condition. Also, by being able to view one’s situation as a gift or as strength, it may be an indicator as to where that person is, in regards to the perceived level of self-esteem and well-being.

Though humor is often thought to be extremely subjective, to say the least, data collected by Leggatt-Cook and Chamberlain (2012) could also be considered to be humorous in nature. It was described that humor-based writing could be viewed as a type of writing strategy that helps a person to better understand a given situation. By playing with the situation through writing about it in a good-humored manner, and sharing that playfulness on the Internet, it could help to provide support for people consuming that comedic content. For example, comedic undertones can be found when one weight-loss blogger wrote, “Gas prices killing you? Try losing some weight. Of course, it helps if you have a lot of weight to lose. Most people would have to chop off an arm and a leg to lose as much weight as I have. But gas costs an arm and a leg anyway, so what are you really losing?” (p. 969). Similarities between the previously mentioned studies could also be

found within this present study in that aspects of humor were also communicated to group members within the online community. Within the *Facebook* group, there were times where members all had what read like a supportive conversation filled with laughter that pertained to stuttering. An example of a comedic conversation can be found when John asked the following:

John: I once met an adult who told me that for the longest time, he thought that stuttering was caused by parents tickling their child when the child was very young. It amazes me how many silly myths are still floating around out there. Have you heard any other myths like that before?

Then Greg replied, “This is true John. Don’t be daft.” To which John comes back with, “Yes Greg that definitely explains a lot. I think we just cured stuttering. The closing comedic remark was by Greg when he stated, “No tickling babies! Who would have thought?”

### **Healthy Debate**

Having discussions in which not all members of an online community agree is not something out of the ordinary. Because an online space provides an open area for all to come together to share opinions, it makes sense how there might be, from time to time, some disagreements among members while discussing a given topic of conversation. Disagreements can help to expand the views of others by gently pushing them to rethink a certain stance made on a particular topic. For example, Stoudt and Ouellette (2004) have described how people who stutter within an online community have been observed to share personal opinions that might be, from time to time, misinformed. For example, one male person who was talking about the percentage of females who stutter stated, “About women—well they are less likely to develop this problem—the ratio is 4:1 if I am not

mistaken. . . . I guess that women who stutter tend to have a mild one.” When this male person who stutters mentioned that women who stutter tend to have a more mild frequency of stuttering, this immediately triggered a female person who stutters to join in on the conversation to state her experiences to either approve or disprove the comment he made. She said, “Very kindly, I would like to perhaps straighten this record a bit.” She then went on to explain her disagreement and provided reasons. This is an example of having two different sides come together in a polite manner to discuss stuttering. It does not seem like anyone is being particularly rude with the conversational back-and-forth. All parties involved seem to respect the exercise of healthy debate and they view it as something that makes the online community special.

A example of the conversational back-and-forth that was observed during this study that illustrates healthy debate could be found when John asked, “Would you rather be called a person who stutters OR a stutterer. Or does it really not make a difference to you?” Greg responded with, “It doesn’t matter. People concerned with political correct nonsense like that have other issues. In the words of my inappropriate grandpa, call me anything but asshole.” The exchange went on for a few more interactions and eventually ended with John saying, “I would rather be called a person who stutters because it follows the person first philosophy. I am someone who stutters but I am not a stutterer. There is more to me than just that.” These two group members seemed to have conflicting ideas as to what is right and what is wrong; however, nowhere in this conversation did it show one member being rude to the other. Just as it seemed in the data collected by Stoudt and Ouellette

(2004), members in the *Facebook* group welcomed this type of healthy debate as an opportunity to consider a new point of view while actively defending another.

### **Honest and Varied Opinions**

The different views and judgments formed in the minds of the members of an online community often tend to be quite varied. For example, Davidson (2008) collected data that looked at the online conversations that people with autism were having within an online community. It was found that many members made posts where other members have had the complete opposite opinion on it. From some members claiming to embrace Autistic culture (and some who do not) to others trying to conform their characteristics of autism into ones that are more less than that of autism (and some who do not), these are the types of honest and varied opinions that when shared, could help users begin to possibly redefine what it means to be a person with autism.

Similarly, conversations within the Stoudt and Ouellette (2004) study also highlight members who are honest with their messages online and how that honesty is often as unique as the actual communication disorder of stuttering. Within an online community, people who stutter have been observed to challenge the idea of what the term disability means and if they feel their stuttering is, in fact, a disability. By coming together online and having these types of varied discussions, people are better able to define and redefine certain categories that relate to their own personal definition of what stuttering is.

This current *Facebook* group study also had data that contained a large amount of honest and varied opinions that were shared within the online community. A seemingly simple question posed by John was able to generate a large amount of responses that were

anything but simple. “If you could describe your stuttering in 3 words, what would they be? Why?” Much like the previous research findings by Stoudt and Ouellette (2004) and Davidson (2008), the members of the *Facebook* group were able to think about their communication disorder in a way that they did not do too often. From this personal analysis, they were able to come to a decision and share that decision in an online community that welcomed varied opinion, as long as they were honest.

### **Interpretation of Results in Relation to Previous Research**

The reported experiences of people who stutter who digitally connect and share with other people who stutter within a social networking site, specifically *Facebook*, support previous research that relate to stuttering support and online communities (Brundage, 2007; Kuster, 1995; Kuster, 1998; Packman & Meredith, 2011; Stoudt & Ouellett, 2004; Tellis et al., 2002). As noted in Chapter 2, talking about talking has been something that benefited people who stutter (Daniels, & Hughes, 2012; Irani et al., 2012; Manning, 2006; Plexico, et al., 2009; Quesal, 1989) and this is exactly what members of the private *Facebook* group were able to do; talk about talking. The findings from this study continue to add to the literature that relates to stuttering support and online communities.

Results from this study lend support to the utility of online communities that are specific to stuttering support. Analysis of 3 months of *Facebook* group postings and the semi-structured interviews with seven of the *Facebook* group members revealed numerous benefits and challenges associated with interacting with others within a private *Facebook* group. In addition, it was revealed that there were numerous instances of support that existed within the online space that included support through providing information, posing

questions, giving encouragement, and engaging in humor. Also, the private *Facebook* group included healthy debate and honest and varied opinions. All of these key components emerged as themes within the participants' textual conversations.

The themes that were discovered throughout this study suggest that the utilization of a private *Facebook* group is beneficial as a means for obtaining psychosocial support from other people who stutter. Members of this online community shared their feelings and experiences with interacting in the online space and have communicated their approval with having this additional Internet-based component to the already established face-to-face stuttering support group. This type of research that focused on stuttering support groups and online communities illuminate important knowledge for researchers, clinicians, and stuttering support organizers.

### **Limitations and Strengths of Study**

Qualitative research is an interpretive approach to discovery that allows participants to think about and describe the various experiences that are in reference to a given phenomenon. Although results that came from this study are fascinating and rich with detail, the research is limited in several respects. A first limitation of this study has to do with the smaller number of participants ( $N = 7$ ) within this study. Though Creswell (1998) mentions that having anywhere between 7 and 10 participants in a study is usually able to generate a substantial amount of data, it was the principal investigator's hope, from the start, to have at least 15 users actively engaging within the newly created private *Facebook* group. This might have been able to produce an even larger amount of rich data to be reviewed and analyzed. A second limitation is that the principal investigator presented the

created coding system to the participants of this study for validation purposes. Therefore, one might assume that the coding systems and the discovered themes might have possibly skewed the members' perception of the conversations that occurred within the private *Facebook* group. However, it is believed that any amount of skewedness that might have been present would have, most likely, began to dissipate because they were consistently encouraged to expand upon or delete any of their specifically contributed words if they felt the need to. A third limitation is that results of this study cannot be generalized to all people who stutter. Of the seven participants, six of them all had ages that ranged from 21 to 26 years old. Because a majority of these individuals were all of an extremely similar age demographic, it would not be wise to suggest that these findings would be applicable to people who stutter who were 30 years old or older. However, this lack of diversity can begin to suggest a large amount of information when connected to people who stutter whose ages fall within the 18- to 29-year-old demographic, but again, it cannot and should not be generalized to all people who stutter. A fourth limitation is that the same collection of people made up the *Facebook* and face-to-face group. This resulted in observing examples of support that consistently existed within both environments. Therefore, it could be concluded that if the *Facebook* group members were different from the face-to-face group members it could have resulted in more opportunities to discover the differences between an online community and a face-to-face one.

Though this study does present with limitations, it also has strengths that should be mentioned. Ultimately, this present study creates a solid foundation for more literature to be perused that takes into consideration the experiences of those who stutter that choose to

be a part of an online community for people who stutter. A strength of the current study is that it allowed for detailed words to be shared about experiences with digitally connecting and sharing with other people who stutter within a popular social networking site, *Facebook*. This is an important strength because a limited amount of research has yet to touch on the subject of how individuals with various disorders utilize *Facebook* as a means for obtaining psychosocial support. A large amount of the previously discussed literature has predominantly touched on bloggers using an online blogging platform as a way to digitally connect and share with other like-minded individuals on the Internet. The barrier for entry, with regards to starting and maintaining a blog on the Internet, is much higher than joining a *Facebook* group. With blog creation, a user must usually be somewhat technologically savvy to ensure that the content added to the blog presents itself in a visually pleasing way. Bloggers constantly have to be aware of using the correct fonts, colors, graphics, and hyperlinks. This could be time consuming and cause a substantial amount of frustration to a person who has limited knowledge on the inner workings of blogs. In addition, sometimes there are monetary fees that go along with starting and maintaining a blog, such as domain registration and Internet hosting. This is different from being a part of a *Facebook* group online because it is free to join and almost no prior knowledge is needed with regards to how to get started with digitally connecting and sharing with others. Therefore, the fact that all parties involved with this study made a conscious decision to steer away from stuttering-related blogs, and instead, focused on *Facebook* groups, is viewed as a strength because it helps to expand the literature on this important topic that relates to stuttering support.

In addition, another strength of this study is that it has laid the foundation for future studies, similar to this one, to be designed. Researchers interested in exploring *Facebook* as a means for obtaining psychosocial support from others now have a blueprint to follow that can be easily be changed or expanded upon during future research. Future research in this area could include (a) observing public *Facebook* groups for people who stutter that have over 100 members; (b) incorporating quantitative methods to illustrate the thoughts, feelings, and experiences of being a member of a *Facebook* group for people who stutter; and (c) developing clear principles and guidelines for speech-language pathologists and stuttering support group organizers who are interested in creating a *Facebook* group for people who stutter.

Also, it would be wise to continue to explore other Internet-based locations where people who stutter might be digitally connecting and sharing with other people who stutter. For example, Cornell mentioned how *Reddit* might be a location where future research could look into how people who stutter are actively communicating within that digital space. John and Charlie also added that *Twitter* might be something to look into because of its ability to allow users to create unique hash tags and to effortlessly write out short and motivating messages to your followers right from a smart phone.

### **Implications for Speech-Language Pathologists and Stuttering Support Group Organizers**

The participants in this study provided detailed information about their experiences of digitally connecting and sharing with other people who stutter within a social networking site, specifically *Facebook*. This information has important clinical implications for

practicing speech-language pathologists. In addition, this information can benefit those who are stuttering support group organizers.

### **Implications for Speech-Language Pathologists**

Speech-language pathologists may often be presented with the opportunity to provide speech therapy services to a person who stutters. As a clinician, it is important to keep up-to-speed with all the new Internet-based technologies that are available to help people who stutter gain psychosocial support from other people who stutter (Brundage, 2007; Kuster, 1995; Kuster, 1998; Packman & Meredith, 2011; Stoudt & Ouellett, 2004; Tellis et al., 2002). Information that relate to online communities for people who stutter could be shared with the individual. By being presented with this information, the person who stutters would be able to make a well-informed decision as to if this particular avenue for additional support should be tried out.

### **Implications for Stuttering Support Group Organizers**

Support group organizers, such as volunteers and support group leaders, play an important role in creating and maintaining worthwhile support group meeting experiences. Therefore, it makes sense that these individuals should know as much as possible about online communities in the event that one might want to be added as a supplement to the traditional face-to-face meeting experience. By taking the time to discover if an online community might be right for the members of a particular group, the stuttering support group organizer is actively presenting all members with options that will help increase their overall social support circle.

### **Conclusion**

Prior research has shown many benefits associated with the act of digitally connecting and sharing within an online community for people who stutter. However, it is my belief that, because of the growing popularity of social networking sites, specifically *Facebook*, a body of literature needs to be compiled that explores the experiences of people who stutter who use *Facebook* as way to meet and interact with other people who stutter. It is important to let the voices of these *Facebook* users be heard so that other people who stutter who are not currently using *Facebook* or any other social networking site can see how they are missing a beneficial form of psychosocial support from a welcoming community online.

## APPENDIX A

## INSTITUTIONAL REVIEW BOARD APPROVAL



IRB Administration Office  
87 East Canfield, Second Floor  
Detroit, Michigan 48201  
Phone: (313) 577-1628  
FAX: (313) 993-7122  
<http://irb.wayne.edu>

## NOTICE OF EXPEDITED APPROVAL

**To:** Erik Raj  
Communication Sciences and Disorders  
60 Farnsworth, 207 Rackham Hall

**From:** Dr. Deborah Ellis or designee C. Zolundek/PB.  
Chairperson, Behavioral Institutional Review Board (B3)

**Date:** August 28, 2014

**RE:** IRB #: 071814B3E  
Protocol Title: Online Communities for People Who Stutter: An Ethnographic Study of a Facebook Social Networking Support Group  
Funding Source:  
Protocol #: 1407013205  
**Expiration Date:** August 27, 2015  
**Risk Level / Category:** Research not involving greater than minimal risk

The above-referenced protocol and items listed below (if applicable) were **APPROVED** following *Expedited Review* Category ( #7 ) \* by the Chairperson/designee for the Wayne State University Institutional Review Board (B3) for the period of 08/28/2014 through 08/27/2015. This approval does not replace any departmental or other approvals that may be required.

- Revised Protocol Summary Form (received in the IRB Office 8/20/2014)
- Protocol (received in the IRB Office 7/7/2014)
- A waiver of requirement for written documentation of informed consent has been granted according to 45 CFR 46.116(d). This waiver satisfies: 1) the research involves no more than minimal risk to the participants. Use of observation, anonymous surveys, and de-identified interviews with an adequate plan to protect confidentiality; 2) the research involves no procedures for which written consent is normally required outside of the research context. Written consent is not required for observation, anonymous surveys, or de-identified interviews outside of a research context; 3) the consent process is appropriate and 4) an information sheet disclosing the required and appropriate additional elements of consent disclosure will be provided to participants.
- Research Information Sheet - Survey (dated 8/13/2014)
- Research Information Sheet - Interview (dated 8/13/2014)
- Data Collection Tools: Written Questionnaire and Semi-Structured Interview Protocol

- \* Federal regulations require that all research be reviewed at least annually. You may receive a "Continuation Renewal Reminder" approximately two months prior to the expiration date; however, it is the Principal Investigator's responsibility to obtain review and continued approval **before** the expiration date. Data collected during a period of lapsed approval is unapproved research and can never be reported or published as research data.
- \* All changes or amendments to the above-referenced protocol require review and approval by the IRB **BEFORE** implementation.
- \* Adverse Reactions/Unexpected Events (AR/UE) must be submitted on the appropriate form within the timeframe specified in the IRB Administration Office Policy (<http://www.irb.wayne.edu/policies-human-research.php>).

**NOTE:**

1. Upon notification of an impending regulatory site visit, hold notification, and/or external audit the IRB Administration Office must be contacted immediately.
2. Forms should be downloaded from the IRB website at each use.

**Research Information Sheet**

Title of Study: Online communities for people who stutter: An ethnographic study of a Facebook social networking support group.

Principal Investigator (PI): Erik X. Raj, M.S., CCC-SLP  
Communication Sciences and Disorders  
(732) 995-9836

**Purpose:**

You are being asked to be in a research study that explores the benefits of using a *Facebook* support group for people who stutter because you are a person who stutters who utilizes *Facebook* as a means to digitally connect and share with other people who stutter. This study is being conducted at Wayne State University.

**Study Procedures:**

If you take part in the study you will be asked to complete an anonymous Internet-based survey that contains questions that explore the idea of digitally connecting and sharing with others on an open and public *Facebook* stuttering support group. The survey is voluntary, and will take approximately 20 minutes to complete.

**Benefits**

- As a participant in this research study, there will be no direct benefit for you; however, information from this study may benefit other people now or in the future.

**Risks**

There are no known risks at this time to participation in this study.

**Costs**

- There will be no costs to you for participation in this research study.

**Compensation**

- You will not be paid for taking part in this study.

**Confidentiality:**

- All information collected about you during the course of this study will be kept without any identifiers.

Submission/Revision Date: [08/13/2014]  
Protocol Version #: [2]

Page 1 of 2

Form Date: 10/2013

## Online Communities for People Who Stutter

**Voluntary Participation /Withdrawal:**

Taking part in this study is voluntary. You are free to not answer any questions or withdraw at any time. Your decision will not change any present or future relationships with Wayne State University or its affiliates.

**Questions:**

If you have any questions about this study now or in the future, you may contact Erik X. Raj or one of his research team members at the following phone number (313) 577-8676. If you have questions or concerns about your rights as a research participant, the Chair of the Institutional Review Board can be contacted at (313) 577-1628. If you are unable to contact the research staff, or if you want to talk to someone other than the research staff, you may also call (313) 577-1628 to ask questions or voice concerns or complaints.

**Participation:**

By completing the questionnaire you are agreeing to participate in this study.

**APPROVAL PERIOD**

AUG 28 '14

AUG 27 '15

WAYNE STATE UNIVERSITY  
INSTITUTIONAL REVIEW BOARD

Submission/Revision Date: [08/13/2014]  
Protocol Version #: [2]

Page 2 of 2

Form Date: 10/2013

### Research Information Sheet

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Communication Sciences and Disorders  
(732) 995-9836

#### Purpose:

You are being asked to be in a research study that explores the benefits of using a *Facebook* support group for people who stutter because you are a person who stutters who utilizes *Facebook* as a means to digitally connect and share with other people who stutter. This study is being conducted at Wayne State University.

#### Study Procedures:

If you take part in the study you will be asked to answer questions about your participation in a Facebook support group for people who stutter. You will also be asked questions about your experiences as a person who stutters. The interview will take approximately 60 minutes to complete. You will also be asked to participate in a follow-up interview that will take approximately 30 minutes to complete. The interview is voluntary.

#### Benefits

- As a participant in this research study, there will be no direct benefit for you; however, information from this study may benefit other people now or in the future.

#### Risks

- The proposed study will involve minimal risk of breach of confidentiality based on the measures that are being taken to protect all confidentiality.

#### Costs

- There will be no costs to you for participation in this research study.

#### Compensation

- You will not be paid for taking part in this study.

#### Confidentiality:

- The principal investigator will edit out any and all personal information and identifiers shared within the interview and assign them a pseudonym. A master list will be temporarily kept that will let the principal investigator know whom the pseudonyms are assigned to. Once the interviews are completely analyzed, the master list will be destroyed.

Submission/Revision Date: [08/13/2014]  
Protocol Version #: [2]

Page 1 of 2

Form Date: 10/2013

## Online Communities for People Who Stutter

**Voluntary Participation /Withdrawal:**

Taking part in this study is voluntary. You are free to not answer any questions or withdraw at any time. Your decision will not change any present or future relationships with Wayne State University or its affiliates.

**Questions:**

If you have any questions about this study now or in the future, you may contact Erik X. Raj or one of his research team members at the following phone number (313) 577-8676. If you have questions or concerns about your rights as a research participant, the Chair of the Institutional Review Board can be contacted at (313) 577-1628. If you are unable to contact the research staff, or if you want to talk to someone other than the research staff, you may also call (313) 577-1628 to ask questions or voice concerns or complaints.

**Participation:**

By completing the interview you are agreeing to participate in this study.

**APPROVAL PERIOD**

AUG 28 '14

AUG 27 '15

WAYNE STATE UNIVERSITY  
INSTITUTIONAL REVIEW BOARD

Submission/Revision Date: [08/13/2014]  
Protocol Version #: [2]

Page 2 of 2

Form Date: 10/2013

**Written Questionnaire**

Age \_\_\_\_\_

Gender

☐ Male☐ Female

Current country of residence \_\_\_\_\_

If living in the USA, please provide the state in which you currently reside \_\_\_\_\_

Race/ethnicity

☐ Asian/Pacific Islander☐ Black/African-American☐ Hispanic/Latino☐ Native American☐ White/Caucasian☐ Other

-Relationship status

☐ Married☐ Single☐ Divorced☐ Widowed☐ Separated☐ Partnership☐ Other

-Employment status

☐ Employed☐ Unemployed☐ Student☐ Retired

-If employed, please list your occupation:

-Have you ever received speech therapy for stuttering in the past? Y/N

-If you answered yes, please describe your therapy experiences for stuttering.

-Have you ever attended a face-to-face support group for people who stutter before? Y/N

-If you answered yes, please describe your face-to-face support group experience.

-Do you have a Facebook account? Y/N

-How do you typically log onto Facebook? (check only one)

☐ On my computer (traditional desktop or laptop)

On my digital tablet (iPad, Kindle Fire, Nook, etc)  
 On my mobile device (cell phone or smart phone)  
 Other

-How often do you use Facebook?

Several times a day  
 Once a day  
 Once every few days  
 Once a week  
 Occasionally (less than once week)

-How much time (on average) do you spend on Facebook per day?

Less than 5 minutes  
 5-10 minutes  
 11-30 minutes  
 30+ minutes

-Are you presently a member of any Facebook groups for people who stutter? Y/N

-If yes, please describe your experiences of participating in a Facebook group for people who stutter.

-Prior to joining a Facebook group for people who stutter, please describe support you have received for your experience with stuttering.

-After joining a Facebook group for people who stutter, please describe the support you have received for your experience with stuttering.

-Prior to joining a Facebook group for people who stutter, please describe your self-esteem.

-After joining a Facebook group for people who stutter, please describe level of self-esteem.

-Prior to joining a Facebook group for people who stutter, please describe your feelings about being a person who stutters.

-After joining a Facebook group for people who stutter, please describe your feelings about being a person who stutters.

-What do you think are the benefits and challenges of an online community such as this?

**APPROVED**

AUG 28 2014

WAYNE STATE UNIVERSITY  
 INSTITUTIONAL REVIEW BOARD

## **APPENDIX B**

### **PERMISSION TO CONDUCT THE STUDY**

September 17, 2014

To Whom It May Concern:

I am writing this letter to recommend that Erik Raj be granted permission to conduct his upcoming research at the Misericordia University Speech-Language and Hearing Center. I am aware of the details for his study titled: Online communities for people who stutter: An ethnographic study of a *Facebook* social networking support group. In addition, I am aware that he will be using our on-campus support group for participants.

Sincerely,

A handwritten signature in cursive script, appearing to read "Glen Tellis".

Glen Tellis, Ph.D.

Professor and Chair

**APPENDIX C**

**LETTER OF ASSURANCE**

October 2, 2014

To Whom It May Concern:

I am writing this letter to assure the faculty and staff at Misericordia University that I, Erik Raj, will let all participants know that they will be monitored online during my upcoming and approved research at the Misericordia University Speech-Language and Hearing Center. The title of this research study is: Online communities for people who stutter: An ethnographic study of a *Facebook* social networking support group.

Sincerely,

**E. X. Raj**

Erik X. Raj, M.S., CCC-SLP

**APPENDIX D**

***FACEBOOK POSTS***

COLLECTED FACEBOOK POSTS OCTOBER 1, 2014 – DECEMBER 31, 2014

<John created the group.>

October 4, 2014

<John created an event.>

October 7, 2014

Support Group Meeting

Wednesday, October 15, 2014 at 7:00pm

National Stuttering Association: XXXX Chapter

<John created an event.>

October 7, 2014

Support Group Meeting

Wednesday, November 5, 2014 at 7:00pm

National Stuttering Association: XXXX Chapter

<John created an event.>

October 7, 2014

Support Group Meeting

Wednesday, November 19, 2014 at 7:00pm

National Stuttering Association: XXXX Chapter

<John created an event.>

October 7, 2014

Support Group Meeting

Wednesday, December 3, 2014 at 7:00pm

National Stuttering Association: XXXX Chapter

<John created an event.>

October 7, 2014

Support Group Meeting

Wednesday, December 17, 2014 at 7:00pm

National Stuttering Association: XXXX Chapter

<John updated the description.>

October 7, 2014

Welcome to the private Facebook group of the XXXX Chapter of the National Stuttering Association. We have created this page to act as a digital supplement to the face-to-face meetings that we have on campus here at XXXX University. John is this group's administrator and Erik Raj is monitoring this group. Joining this private Facebook group is optional to join.

<John>

October 7, 2014

Hello there,

We have recently expanded our ability to provide additional support to the members of our XXXX Chapter of the National Stuttering Association by creating and maintaining a private Facebook group for all of us. This private Facebook group will act as a digital supplement to the face-to-face meetings that we have on campus and will result in a digital location where our members could further organize and express their thoughts and feelings about communication and post photos/share relevant content that is related to the subject of stuttering. Joining this private Facebook group is optional.

John, who is currently a speech-language pathology graduate student at XXXX University and the founder of the XXXX Chapter of the National Stuttering Association, is this private Facebook group's administrator. He will be interacting within this page as a way to continue the stuttering support conversation during times when our face-to-face support group meeting is not in session. He will be answering any questions that members might post as well as ask weekly questions to this private Facebook group. These questions aim to start an open conversation about stuttering.

Erik Raj, who is an alumnus of the speech-language pathology graduate program at XXXX University, will also be a part of this private Facebook group. He is currently a Ph.D.

candidate at Wayne State University where he is presently conducting a research study that is beginning to explore the possible benefits of being a part of a Facebook support group for people who stutter. He will be monitoring the activity on this page and gauging its effectiveness as a means for support for people who stutter.

Erik's research is currently titled Online Communities for People Who Stutter: An Ethnographic Study of a Facebook Social Networking Support Group. His research study will have three main portions of data that will be collected and analyzed (all data collected will be anonymous). The first portion will be the textual conversations that are posted within this private Facebook group's wall. The next two portions will be the members' written responses to a voluntary online questionnaire, and the written words that are shared while participating in an optional online interview. Absolutely no personal identifiers will be collected and pseudonyms will consistently be used.

It is the belief of the XXXX Chapter of the National Stuttering Association that the digital communities that often surround a social networking site could be a valuable context in which to study social support and the potential opportunities created by such communication mediums and social spaces. These environments might facilitate supportive communication and increased self-esteem and psychosocial well-being, therefore, further solidifying its worthiness for exploration. By attempting to understand the thoughts, feelings, and experiences of those who utilize social networking sites to digitally connect and share with other people who stutter, practicing speech-language pathologist will have the opportunity to introduce their adult clients who stutter, who have access to the Internet, to a worldwide community that is not limited by physical space.

We'll see you soon,

XXXX Chapter of the National Stuttering Association

<John>

October 22, 2014

Hi Everyone!!

Happy ISAD!!

Today (October 22nd) is International Stuttering Awareness Day (ISAD)! The following link was posted on the NSA's website a few years back describing what ISAD is and how you can get involved in spreading awareness.

International Stuttering Awareness Day :: October 22nd - National Stuttering Association

International Stuttering Awareness Day is right around the corner on October 22nd, and we have several...

WESTTUTTER.ORG

<John>

October 26, 2014

Hey everyone we will be posting weekly questions as ways to spark conversation in the group. Feel free to answer them open and honestly. Hopefully these questions will get some good discussions going.

<John>

October 26, 2014

If you could describe your stuttering in 3 words, what would they be? Why?

<Len>

1) Frustrating 2) Powerful 3) Challenging

1) At times my stutter is frustrating. Giving a presentation that you have practiced 3 times alone in a classroom, not stuttering once during these 3 times, and then stuttering on every other word during the actual presentation is one of the most frustrating things I have ever experienced.

2) If I let it, my stuttering has the power to debilitate me. It's powerful enough to cause me anxiety and bring me to my knees. However, through these experiences my stutter has also empowered me. It has made me stronger. Perhaps above all else my stutter has given me empathy towards others. Empathy, not sympathy. Sympathy is feeling sorry for someone and giving them your condolences. Empathy is understanding (or trying your best to understand) the pain or frustration someone is going through and being there to help them through it. Looking at my stutter through the right lens, I can see how it has empowered me as much, if not more so, than it has power over me.

3) My stutter is a daily challenge. Even days or times I do not want to address it, my stutter remains constant. It never waivers. Yes, these challenges are hard but they are not impossible obstacles to overcome. Facing these challenges, all of them that my stutter has given me over the years, has shaped my personality, character, and view on life in one way or another. At times, my stutter has won. It has beaten me down time and time again. Strength is measured not by how many times you are defeated, but how many times you pick yourself up and keep going. The challenges my stutter gives me has made me a more perseverant person in all aspects of life.

- My thoughts on describing my stutter in 3 words....

October 27, 2014 at 11:00pm

<Greg>

1. Social 2. unique, 3. vulnerable. My stutter is not something I am ashamed of. It makes me stand out as an individual and I make a joke of it so people don't feel awkward. Having a stutter makes you friends with other people who stutter and with people who study it (speech pathology majors for example). Having a stutter makes you approachable. When you display a "flaw" out in the open like that, other people don't feel as concealed about theirs. Just my thoughts

October 28, 2014 at 4:16pm

<Len>

Never really thought of it like that Greg (stuttering makes you approachable). Cool perspective. Maybe as you said "other people don't feel as concealed about their flaw" when they see that we are open about our stutter.

October 28, 2014 at 4:21pm

<Roth>

Empathy – Like Len mentioned, I feel as though stuttering has made me a much more empathic person. I try to keep in mind that everyone I meet may be going through a silent struggle in life, just as I have sometimes struggled with stuttering internally. I think empathy is something that other people can sense, and it attracts others to us. It shows them that we have the ability to be compassionate and understanding, even when others may not be as patient with them. I consider it to be the greatest lesson that I've taken from living with stuttering.

Commitment – Stuttering has taught me that I have to stick with things for the long haul, even if they cause a ton of discomfort at first. There aren't many feelings like the one you get when you achieve a goal you set for yourself. Whether it's as simple as initiating a conversation with someone, to something as huge as making a 10 minute presentation, you have to commit to achieving it step by step. I think this commitment has carried over into most aspects of my life, and I try to stick with things as long as I feel like the outcome will outweigh the discomfort that may be felt while trying to achieve the goal.

Me – It's taken me a long time to reach the point of feeling okay about stuttering, but I finally see it as just the way that I speak instead of as a hindrance. Growing up, I saw stuttering as the thing that made me different from everyone else, and I was very ashamed of it. While I definitely still have difficult times or moments, I try to focus on all of the positives that stuttering has given me in life. It's a part of me that I don't think I would change if I had the opportunity because it's turned out to be the biggest blessing in disguise I ever could have hoped for in my life. I just wouldn't be me without it.

October 28, 2014 at 4:51pm

<John>

I found it very difficult to pick just three words to describe my stuttering. Stuttering is pervasive and affects a person as soon as they open their mouth to talk. After putting much thought into 3 words to describe my stuttering I came up with: inspiring, challenging, and humbling

My stuttering is inspiring because it led me to pursue a career in speech language pathology and help others who stutter.

My stuttering is challenging because it took a lot of hard work to get to where I am today, in terms of fluency and acceptance. I know that I am still not 100% accepting but I am as close to it as I could be and I am happy with who I am. My stuttering made me a better and stronger person. All of the challenges that I have faced had a purpose. They shaped my life and made me who I am today.

My stuttering is humbling because I know that my current level of fluency might not always be this high. I try to look at things realistically and objectively, knowing that I may have a relapse and be back at square one again.

November 1, 2014 at 8:36pm

<John>

October 31, 2014

<http://www.buzzfeed.com/.../things-all-people-who-stutter-wil...>

25 Things All People Who Stutter Will Understand

Hands up if you cried during The King's Speech.

WWW.BUZZFEED.COM|BY ALEXIS NEDD

<Greg>

I actually laughed out loud at the stutter on your own name one lol

October 31, 2014 at 11:58am

<John>

November 2, 2014

When was the last time you felt particularly proud of yourself, in regards to communication? Tell us a bit about it.

<Greg>

Nailed a presentation, but then stuttered at home for the next few days. The irony of speaking fluently in stressful situations and stuttering in comfortable ones is funny at best

November 2, 2014 at 3:34pm

<John>

That's awesome. I can't say I've ever experienced that before. Does it happen often with you?

November 2, 2014 at 7:10pm

<John>

I felt particularly proud of myself this past Friday. I went out to a local bar with a few friends and their extended friend circle. I was very talkative and introduced myself (didn't have someone else initiate the introductions like I usually do) to all of their friends. I started conversations with a lot of my new acquaintances which is something I've struggled to do in the past. All in all it was a very social night!

November 2, 2014 at 7:15pm

<Greg>

That's awesome! Maybe the drinks helped bring out the social John

November 2, 2014 at 8:43pm

<John>

I'd like to think it was all me.. But it probably helped!

November 2, 2014 at 9:06pm

<Len>

This afternoon I had a meeting for the spring break service trip I'm going on. I knew going in I'd have to introduce myself to a group of people...To this day that is one of the things I dread doing the most. I can talk to people casually and not stutter once, but having to formally introduce myself to a group of strangers..... that's when my stutter gets bad. However, I saddled up and went in anyway. I stuttered introducing myself but I got through

it. In times like these I think of a quote by John Wayne. "Courage is being scared to death.... and saddling up anyway." I can't count the times I've been scared so bad in situations I know I will stutter that I can't stop shaking. Even though I'm scared, I push through. Most times this means stepping outside my comfort zone and putting myself in a vulnerable situation. "Saddling up" is something I pride myself on. I am proud of myself for pushing through my group meeting today. Even though I knew I was going to stutter and I did stutter quite a bit, I am proud of myself for having the courage to "saddle up" and face my fear.

November 2, 2014 at 10:57pm

<John>

That's awesome man! Glad to see that you faced your fears and stuck with it!! Well done!

November 2, 2014 at 11:20pm

<John>

November 9, 2014

Do you know of any celebrities that stutter? If so, who?

<Len> Darren Sproles, current running back for the Philadelphia Eagles

November 9, 2014 at 5:28pm

<Len> Did you know that Greg?

November 9, 2014 at 5:31pm

<Bill>

John- is Roth studying under XXX?

November 9, 2014 at 8:17pm

<John>

Yes he is.

November 9, 2014 at 8:18pm

<Greg> Yeah, that's my team too. I'm double proud

November 9, 2014 at 10:28pm

<John>

My boy Darren sproles.....!

November 10, 2014 at 9:15pm

<Cornell>

James Earl Jones, the iconic voice behind Darth Vader & Samuel L Jackson, epitome of cool. Two men that still consider themselves people who stutter, but doesn't let it define them. That's what resonated with me the most; the fact that they came out and openly addressed the fact that it's still something they deal with.

<John>

November 16, 2014

Just curious, are there any people you can think of that you feel you have to hide your stuttering from? If so, why?

<Cornell> For the most part, no. But occasionally if there's a girl I like and I want to approach, I'll hesitate and that always irks me because it's something I've been doing for as long as I can remember. Sometimes it's easier to come off "mysterious and reserved" than someone who openly stutters. But it's something I'm going to change and work on because if you can't accept me for who I am, then I don't care how good you look. I guess the issue is wanting to make a good first impression.

November 16, 2014 at 12:12pm

<Len>

Cornell, I feel the same way man. For me though I sometimes notice that I try hiding my stutter from my family. For the most part I don't stutter around my family members but when I do I notice myself trying to play it off as not "knowing what I wanted to say." I've come to be more open about my stutter with them over the years but do not make it a point to talk about my stutter with my family members (besides my mom and dad).

November 16, 2014 at 3:19pm

<Len>

November 18, 2014

Just a reminder that we will be meeting tomorrow (Wednesday) night at 7PM in our usual meeting location (XXXX Hall). Hope to see everyone there!

<John>

via NATIONAL STUTTERING ASSOCIATION

November 26, 2014

Check this article out and let us know your thoughts.

Why I'm Thankful That I Stutter

Stuttering was always considered a flaw. It was something that I had to live with for the rest of my life. Something that could be fixed -- maybe -- but would take years of effort. Everyone stutters at some point or another but for me it happened mor...

WWW.HUFFINGTONPOST.COM

<John>

November 23, 2014

Just curious, has anyone here ever avoided ordering food at a drive thru because of stuttering? If so, why?

<Greg> All the time. Its one of my worst. I just push through it. Its not like an interview or somethin so I don't care. I just let the stutter fly lol

November 24, 2014 at 12:46am

<John>

That's interesting Greg. I remember I used to use a lot of uhs in my speech so that the person would know I was still there. Couldn't really avoid the McDonald's drive thru bc the alternative was going into an east side fast food restaurant in the middle of a not so good neighborhood... So yeah, sometimes the best thing to do is let it fly.

November 24, 2014 at 6:51am

<Len>

At Dunkin I always order a "Medium regular with whole milk and uhhhh sugar." I make sure to say "whole milk" because if I try to just say "milk" I will usually stutter on the "m" in milk. Saying "whole" acts as a filler word that helps me to say "milk." Also I always need to say "uhhh" before I say "sugar" because if I do not I will stutter badly on the "s" in sugar. Just some techniques I use to help me get through a sentence I need to say quite often.

November 24, 2014 at 4:54pm

<Len>

Whether I should use these techniques to help my fluency or say “screw” the techniques and just stutter completely openly is another story. People may argue that by using these techniques I am trying to cover up my stutter, thus I do not accept it as a part of who I am. I use these techniques simply because they can help me communicate more fluently. Whether this means my acceptance is flawed.... well other people can think what they want. As long as I know where I’m at with acceptance, that’s all that matters.

November 24, 2014 at 5:01pm

<Greg>

Filler word. That’s perfect! My most used filler is ‘fuckin’. It can go in front of anything! Lol. Not classy but oh well

November 25, 2014 at 12:35pm

<John>

Haha Greg, I remember those days. Those are the words that we can say most fluently yet are least acceptable.

November 30, 2014 at 10:27pm

<John>

November 30, 2014

This week’s topic might be a little controversial... If there was a magic pill that would completely get rid of stuttering, would you take it? Why/why not?

<John>

Feel free to reply to this post by creating a new one. If you do this, copy and past the question and put RESPONSE TO: before it. Example--- RESPONSE TO: If there was a magic pill that would completely get rid of stuttering, would you take it? Why/why not?

This way we can have multiple threads going at once. Thanks.

November 30, 2014 at 10:32pm

<Len>

December 1, 2014

RESPONSE: If there was a magic pill that could get rid of your stutter would you take it?

Right or wrong I would take it if I knew it would eliminate my stutter forever. If there was a magic pill that could cure cerebral palsy, and you had cerebral palsy, wouldn't you take it? I am the person I am today in part because of my stutter. I admit this proudly. My stutter has taught me many life lessons, not the least of which is humility. However, if I could communicate more clearly and be able to say things the way I want to say them, I would take the pill.

<Bill>

I have another question- are you guys planning a Christmas get together this year? It would be nice to see everyone in a less rushed atmosphere. I mean I really love the PA turnpike, but not so much that I want to see it twice in 2 hours.

December 1, 2014 at 9:29pm

<John>

Hey Bill, sorry I never got back to you. This post got lost in the shuffle. We are, unfortunately, not going to be holding a Christmas get together this season. Len and I discussed this but since he is back home in out-of-state, it would be too difficult to plan it with one person. We are however, planning to incorporate Google Hangouts video chat into our meetings so that you or anyone else who is unable to attend due to the travel distance or any other issues will be able to do so. Thank you for reaching out to us with that question. If you have any more, keep them coming.

December 22, 2014 at 1:34pm

<Len>

December 2, 2014

Just a reminder that we will be meeting tomorrow night (Wednesday) in our usual meeting location. Hopefully we will see many of you there!

<John>

December 7, 2014

We all know that the holiday season can get a bit stressful. Does that holiday stress ever have an impact on your stuttering? If so, please do share with us.

<John>

December 15, 2014

Would you rather be called a person who stutters OR a stutterer. Or does it really not make a difference to you? We would love to read your thoughts about that.

<Greg>

It doesn't matter. People concerned with political correct nonsense like that have other issues. In the words of my inappropriate grandpa, "Call me anything but asshole"

December 15, 2014 at 12:28pm

<John>

That is very interesting. Being an SLP student, we are taught that the "person comes first," that we should only refer to someone who stutters as a stutterer if they want to be called one, so it is interesting that you mention political correctness. I would love to hear everyone's thought on this.

December 15, 2014 at 12:32pm

<Greg>

If a person calls you something you don't like, say something. Demanding things like terminology from the public only garners the community opinion that we're sensitive and need special treatment.

December 15, 2014 at 1:54pm

<Len> Took the words out of my mouth Greg

December 15, 2014 at 5:25pm

<John>

December 15, 2014

Response to: Would you rather be called a person who stutters OR a stutterer. Or does it really not make a difference to you? We would love to read your thoughts about that.

I would rather be called a person who stutters because it follows the person first philosophy. I am someone who stutters but I am not a stutterer. There is more to me than just that.

<John>

December 22, 2014

Has anyone here been in class before and totally knew the answer that the teacher asked, but you didn't raise your hand because of the possibility of stuttering?

<John>

December 28, 2014 at 7:06pm

I once met an adult who told me that for the longest time, he thought that stuttering was caused by parents tickling their child when the child was very young. It amazes me how many silly myths are still floating around out there. Have you heard any other myths like that before?

<Greg>

This is true John. Don't be daft.

December 29, 2014 at 1:11pm

<Len>

Well I don't know what the word daft means Greg but I know there are a lot of these myths out there about all kinds of things, not only stuttering. Stuff like this is funny because its so far out there. To me, I just laugh at this stuff.

December 29, 2014 at 6:37pm

<John>

Yes Greg that definitely explains a lot. I think we just cured stuttering.

December 30, 2014 at 3:59pm

<Greg>

No tickling babies! Who would have thought?

December 30, 2014 at 5:37pm

**APPENDIX E****SEMI-STRUCTURED INTERVIEW PROTOCOL**

1. How did you find out about the Facebook group for people who stutter?
2. How often do you use the Facebook group?
3. How much time (on average) do you spend on the Facebook group during a typical session?
4. Tell me the reason(s) you decided to join a Facebook group for people who stutter?
5. Tell me, in detail, about your experience with the Facebook group.
  - a. Can you give me some examples of how the group members have supported you?
  - b. Can you give me some examples of how you have supported other people?
6. How would you describe the conversations that take place within the group?
7. What are the benefits and challenges of a group such as this? Please elaborate.
8. Have you ever attended face-to-face support group meetings for stuttering? If so, what was the experience like?
9. Have you ever had speech therapy for stuttering? If so, tell me about the experience.
  - a. What did you like?
  - b. What did you dislike?
10. Tell me what your experiences of stuttering have been like over the years.
  - a. at home
  - b. in school
  - c. on the job
  - d. with friends and family
11. Tell me your thoughts on the support you've received for stuttering over the years.
  - a. from family
  - b. from friends
  - c. from teachers or speech-language pathologists

## **APPENDIX F**

### **INTERVIEW TRANSCRIPTS**

#### **INTERVIEW WITH “LEN” VIA FACEBOOK CHAT**

January 20, 2015

INTERVIEWER: Hi Len!

INTERVIEWER: I am here whenever you are ready for me to start shooting you over some questions.

LEN: Logging on as we speak. Hang on one sec

INTERVIEWER: Coolio.

LEN: Ready buddy!

INTERVIEWER: Thanks so much, Len. And just so you know, anything we chat about will be completely anonymous and pseudonyms will be used for any/all identifiers. You know how research goes

LEN: Yessir got it sounds good!!

INTERVIEWER: How do you typically log onto Facebook? (phone? tablet? computer? etc?)

LEN: Phone usually, computer sometimes

INTERVIEWER: Could you divide it into a percentage?

LEN: 70% of the time phone, 30% of the time laptop

INTERVIEWER: Cool!

INTERVIEWER: How often do you use Facebook?

LEN: Daily. Less than an hour each day

LEN: Probably 20 minutes daily

INTERVIEWER: Perfect.

INTERVIEWER: How did you find out about the Facebook group?

LEN: From you haha. Because I am a co-chapter leader of the group I was informed of it from you.

INTERVIEWER: Are you presently a member of any other Facebook groups for people who stutter, besides the one for the chapter?

LEN: No

INTERVIEWER: How would you describe the conversations that take place within this group?

LEN: Most conversations arise from questions asked by the group leaders. The questions provoke interesting conversations among group members. The conversations are sometimes controversial and members do not always agree. Most importantly, the conversations allow me to express my true thoughts, feelings, emotions and beliefs without the fear of being judged or looked down upon by anyone.

INTERVIEWER: Right on! Could you give me an example of a convo that occurred where you were happy express your true thoughts about something?

LEN: When asked to describe my stutter in 3 words I replied: Frustrating, Powerful, and Challenging. I talked about all the frustrations and challenges I face on a daily basis which was nice for me to be able to get off my chest. Furthermore I discussed how my stutter has made me into the person I am today. It has empowered me to be stronger and made me a more empathetic person. Being able to talk about this really gave me a feeling of satisfaction.

INTERVIEWER: That's awesome. You started to get to this, but I was wondering what would you say are the benefits of a Facebook group such as this?

LEN: For myself the main benefit of the Facebook group is knowing that there is always someone to talk to about my stutter who is willing to listen. While my parents and close friends are always there for me, the group enable me to talk to people who can relate to stuttering. It makes you feel like you are never alone. Trust me I know, when you stutter and are the only person in a large classroom giving a speech who stutters, it is hard not to feel alone. The group is always there for you to fall back on.

INTERVIEWER: That's so cool! Now I gotta ask, what would you say are the challenges of a group such as this?

LEN: One challenge is that if you post something in the group, people may not respond for a few hours or a few days. If you really want to talk to someone in the group immediately, and don't have their phone number, it can be detrimental.

LEN: Furthermore, typing on a screen can be a bit impersonal. Sometimes in tough times you want someone there right by your side to talk to. While the group is a great resource, it cannot teleport people right to your living room couch... At least not yet.

INTERVIEWER: Very true! So with that being said, what do you think could be added to this Facebook group to improve it?

LEN: More people could be added to improve it. More people = more people to offer their own unique opinion, thus more conversation would be stimulated.

LEN: Also, just more conversation in general would make the group feel more personal.

INTERVIEWER: Yea I agree with you. More people always helps to have more conversation and other points of views. Let me take a moment to ask you about your face-to-face support group meetings for stuttering. How often do you go to those, typically how long are they. How many people typically are there. You know the drill. Just tell me a bit about it.

LEN: As a co-chapter leader of the support group I attend every meeting. Living out of state, I skyped in on the meetings over winter break. We meet twice per month for approximately two hours. Typically there are 4-6 people at a meeting. A SLP student is usually there along with people who stutter. We have good conversations about all aspects of stuttering. I have never left a meeting without feeling better than I did going into the meeting.

LEN: If I can help one person then the meetings are worth it. I have gotten a lot out of the face to face meetings.

INTERVIEWER: Do you know of any other chapters who also have a digital component to it? Like this one does?

LEN: No

INTERVIEWER: After seeing this Facebook group and how it coincides with the face-to-face group, do you think it might be worthwhile for other chapters to explore? Why/ why not?

LEN: Absolutely it would be worthwhile for other chapters to explore. What the group does is essentially take the support group with you wherever you go. Most people can access facebook from their phone and they have their phone with them at all times. Although the Facebook group is more impersonal than the face to face meetings, it is absolutely an additional resource other chapter can use to enhance or supplement the face to face support group. I think supplement is the key word there. Still having face to face meetings is essential for group cohesiveness and the longevity of the group but having a Facebook group to supplement the face to face group is a great idea.

INTERVIEWER: This is great Len. I am so sorry this is taking a bit longer than I thought. You are my very first semi-structured interview for this. Do you still have time for a few more questions?

LEN: yeah absolutely take your time

INTERVIEWER: Thanks so much, Len. Drinks on me when I see ya at ASHA next, man!

LEN: hahaha... you'd be better off buying me dinner... it'd be cheaper

INTERVIEWER: HAHAHA!

INTERVIEWER: I wanted to ask you about your experiences with past speech therapy you've had. Could you tell me a bit about it? What did you like? What did you dislike?

LEN: Elementary school speech therapy didn't help me much. I learned techniques like easy onset to help my fluency. While these techniques would work well in the clinicians office, when I tried to apply them to real life situations like giving a speech or reading aloud in class, I was unable to successfully do so. My anxiety would get so high that I would tense up and lose control of my techniques. It is almost as though I became nervous because I knew I was going to stutter and this nervousness crippled me. I had this speech therapy from 1st grade to 6th grade. I attended some private speech therapy in high school and college but never really put much effort in to making it work. I actually made the decision to start therapy here at the university this semester. My first session is next week and I am looking forward to it. now that I know more about stuttering, I am more determined to improve my fluency.

INTERVIEWER: Growing up, did you know any PWS?

LEN: Nope, not until I went to my first support group meeting at the university about 2 years ago

INTERVIEWER: I've heard that time and time again, not knowing another PWS for so long until college or even older. That is one of the reasons I really love social networking. More and more I am speaking to children as young as 12 saying they have friends they met online who are PWS. Being able to make those types of connections are one of the things that really excite me. Ya know what I mean?

LEN: Yup, bottom line.

INTERVIEWER: Ok, 3 more questions. One is a bit longish but the last 2 are quickies.

LEN: shoot em bud

INTERVIEWER: Could you take a moment to tell me a bit about the past support you have gotten from those around you, in regards to being a person who stutters. Like, aside from the members in the chapter and people at MU, how were your friends back home and your parents?

LEN: My parents are the most supportive, loving, and compassionate people. Their love is unconditional. To be honest, I don't really discuss it with my friends back home. No rhyme or reason to it just don't really talk about it.

INTERVIEWER: Totally hear that. Ok, now on to the last 2 quickies. Besides Facebook, is there another social networking site that you use daily? If so, what is it?

LEN: Twitter, just a few minutes daily

INTERVIEWER: What do you typically do on Twitter?

LEN: Tweet haha. Mostly catch up on news and follow athletes I like

INTERVIEWER: Right on! Any stuttering handles you follow?

LEN: Unfortunately not

INTERVIEWER: Cool cool. I'm always lookin for new research ideas, so that's why I asked. PWS hashtags are not as popular on Twitter. Though that might change in the future. Who knows. Ok last question my dude: If you could describe the Facebook group in one word and only one word, what would that word be and why?

LEN: Potential. Possibly the future of support groups. In today's evergrowing global society people are connecting from all over the world from all walks of life. Being able to connect with someone from the other side of the world in a second is amazing... And that access is right at our fingertips. Who knows what the future holds...

INTERVIEWER: Very well said, my man. Very well said. Is there anything else you'd like to add before we peace out?

LEN: That's about all I've got man. Thanks buddy

INTERVIEWER: I was wondering your views on the like button. One of the things I have noticed is how people in our group, and lots of groups in general hit the like button to certain posts. What are your thoughts on that?

LEN: I think the purpose of the like button is to reinforce that you share the same beliefs as someone else or agree with them. Most often in our group people post about their thoughts and feelings. By hitting the like button it shows that you took the time to hear what they had to say and agree with what they say. This is why I think most people hit the like button. To express their agreement.

INTERVIEW WITH “CHARLIE” VIA FACEBOOK CHAT

Date: January 21, 2015

INTERVIEWER: How do you typically log onto Facebook? Like, celly, tablet, etc?

CHARLIE: Most often my cell phone. Also on the computer

INTERVIEWER: Could you divide that into a %

CHARLIE: 75% phone, 25% computer

INTERVIEWER: Right on!

INTERVIEWER: How often do you use Facebook?

CHARLIE: In minutes? Or like rare, sometimes, often, very often?

CHARLIE: Check maybe 2–5 times a day?

INTERVIEWER: like, YEA YEA and then how minutes

INTERVIEWER: total mins per day

CHARLIE: 20 mins

INTERVIEWER: Sweet!

INTERVIEWER: Are you presently a member of any other Facebook groups for people who stutter, besides the one for the chapter?

CHARLIE: Yes

INTERVIEWER: Could you tell me how many?

CHARLIE: Hmmm let me look lol

INTERVIEWER: Cool!

CHARLIE: 12

INTERVIEWER: Nice! How would you describe the conversations that take place within those groups?

CHARLIE: 50% are very active--multiple posts throughout the day. 50% are very inactive--maybe 1–2 posts a month or bi-monthly

INTERVIEWER: And would you consider yourself an active participant or an observer?

CHARLIE: correction: 50% (very active—multiple posts a day), 25% (1–3 posts a week), 25% (1–2 posts a month or bimonthly observer)

INTERVIEWER: Great. Now switching gears to Facebook support groups as a whole, what would you say are the benefits of being a part of an online community?

CHARLIE: Number one benefit I believe is to be connected with others across the nation despite your location

CHARLIE: Quick and easy support access

CHARLIE: Can be both a passive or active avenue of support

CHARLIE: As a clinician, great resource to give to clients

INTERVIEWER: So being that you are a passive observer of this chapter's group, how would you say that just reading these types of interactions benefit you?

CHARLIE: Largely education and ability to take various perspectives

INTERVIEWER: And being that last year you were a huge part of this chapter and now you are super far away, could you explain to me how it feels to watch the conversation unfold? Does it help you to feel like you are still a part of the group, despite being on the other side of the country?

CHARLIE: That is by far the number one reason I like the group...It allows me to still feel connected to the chapter. Gives me an idea of discussions they may be having or concerns a member may have. Being in the hospital largely working without people who stutter, I particularly like seeing the posts about stuttering it in the news, as it makes me able to stay somewhat up-to-date on the stuttering culture.

INTERVIEWER: I agree, groups like this one really do help you to still be connect, no matter how far you are. What about the challenges think come with online communities such as this?

CHARLIE: Hmm...personally being somewhat of an introvert, I always hesitate to post on discussions [within the Facebook group]. I fear that someone would judge my words as with, written text, thought can often be misread easily

CHARLIE: I don't see many downfalls though

CHARLIE: I guess the obvious...that some people don't have Facebook...but that's a caveman idea lol

INTERVIEWER: Great call. I totally undersdtand that. And lol at the “no Facebook” line. Caveman stuff indeed.

INTERVIEWER: Was there a particular interaction or post on the chapter’s page that stuck out to you as interesting or memorable? Could you go into that a bit?

CHARLIE: Yes hold on. I have to look back

INTERVIEWER: Sure!

CHARLIE: “When was the last time you felt particularly proud of yourself, in regards to communication? Tell us a bit about it.”

CHARLIE: It reminded me that these little events can be HUGE, momentous events.

CHARLIE: And how important it is to always provide the right encouragement!

INTERVIEWER: Totally agreed. Now this this group, there is a digital component to is, but not many groups have a digital component to them. Are you aware of any groups that have this type of digital component to them?

INTERVIEWER: Now this this chapter there is a digital component\*

CHARLIE: What do you mean by digital?

INTERVIEWER: Like, this chapter still has the face to face, but now a digital component (FB group). Ya know?

CHARLIE: Ohhhh sorry. Didn’t read the word chapter. Oy vey lol

CHARLIE: I do not believe so

CHARLIE: I know a couple that have websites, but not Facebook groups

CHARLIE: And the NSA has their “20s Something Group”

INTERVIEWER: Yea exactly. Would you say that would be something that could improve the current FB group?

CHARLIE: What would improve it?

INTERVIEWER: Yea, can you think of something that could be done differently or something that could be done that isn’t currently being done in the chapter’s FB group to make it even better?

INTERVIEWER: And by all means, don’t feel like you have to answer.

INTERVIEWER: You might have no idea and thats totally cool.

CHARLIE: Hmmm. Maybe promoting the link to the face to face group more often would help to expand the number of members and the number of perspectives taken on discussions

INTERVIEWER: Yea, so getting those numbers up because currently there are only 9 people, but more than 9 people have been involved from time to time. Got it.

INTERVIEWER: Wow, sorry this is taking so long. I promise I am almost done. Cool?

CHARLIE: No problem

INTERVIEWER: 3 more. One kinda longish and 2 shorties.

CHARLIE: You could ask me 10!

INTERVIEWER: Could you describe to me the typical conversations that take place in a traditional, face-to-face chapter meeting?

CHARLIE: Meetings are held with all members surrounding all sides of a rectangular table. We encourage all members to introduce themselves and provide a brief bio. During discussions, members are encouraged to participate in discussion topics, but not required. Chapter leaders typically lead the meetings, maintaining conversation when appropriate. Sometimes direct questions are posed to particular members if we believe they could provide a particular viewpoint. Sometimes it is hard when a person tries to dominate the conversation but chapter leaders try to move along the conversation...more successfully some nights than others!

INTERVIEWER: So with either bi weekly or weekly meeting scheduled, sometimes people have to miss. How would you think that this digital component (the FB group) might benefit those who can't make the face to face meetings sometimes?

CHARLIE: Helps you stay in touch, helps you stay informed, keeps you updated with events going on in the group, able to reach members even if you may be unable to physically

INTERVIEWER: Great. And last 2 quickies.

INTERVIEWER: Besides Facebook, is another social networking site that you use daily? If so, what is it?

CHARLIE: Twitter and Instagram

INTERVIEWER: If you had to pick one where you think PWS might be able to find some benefit from it, which would it be any why?

CHARLIE: Maybe Twitter. Could be used for quick updates on meeting times, food for thought, inspirational quotes

INTERVIEWER: Yea, that's what I was thinking. Lastly, if you could describe the Facebook group in one word and only one word, what would that word be and why?

CHARLIE: Connection. Always us all stay connected

CHARLIE: Allows us all to stay connected\*\*\*\* please excuse my awful nighttime grammar lol

INTERVIEWER: lol i totally knew what you meant. Thanks for the clarification. Ok, before we end this text party, is there anything you'd like to add that you didnt get a chance to say?

CHARLIE: I don't think so But if I think of anything I won't hesitate to send you a message!

INTERVIEWER: Perfect!

## INTERVIEW WITH “JOHN” VIA FACEBOOK CHAT

Date, January 22, 2015

INTERVIEWER: Hi John! Just a heads up that I am here whenever you want to get rockin.

JOHN: I'm good now man.

INTERVIEWER: Thanks so much, John. And just so you know, anything we chat about will be completely anonymous and pseudonyms will be used for any/all identifiers. You know how research goes. You know the drill.

JOHN: haha yeah. That sounds good.

INTERVIEWER: How do you typically log onto Facebook? (phone? tablet? computer? etc?)

JOHN: I have it on my phone. That's my most frequent one. I also log in from my laptop to work on the support group page and group.

INTERVIEWER: Great. Could you divide that into a percentage? How much phone and how much laptop?

JOHN: 95 % phone 5 % laptop

INTERVIEWER: And how often per day? Minute-wise on average

JOHN: way too much. probably like an hour a day. I hope no more than that.

INTERVIEWER: Gotcha haha same!

INTERVIEWER: Could you give me just a brief history on this chapter? As a founder, I was hoping to get your insight into when it started, why it started, and how far it has come since it has started.

JOHN: Okay. So it started when I was a freshman. Very informally. There was three or four fluency clients that had never spoken to someone else who stuttered. We were all brought together in a somewhat therapy someone support group environment. We all liked it and tried to organize it informally. There would be 3 or 4 people who would say hey yeah we are coming today and then it would be me and one other person. AND this would be a common trend. So that's what drove me to want to formalize it and have a set date and time. March of 2013 was when we formalized the group into an NSA support group. Nov 2012 was when we made it into an advertised group. Since then we have had 35+ people come through our doors. We have had a core group attend meetings in the past and our core has shifted over time. We have a solid core that has great group cohesiveness which makes it a lot of fun. We have a very formalized group but it feels like it is completely

informal. We are planning our 2nd annual 5k this year, we have a budget for our group, supply pizza every meeting, have a website, facebook page, your group... it is a far cry from those meetings where we had one or two members.

INTERVIEWER: So amazing to see how far it has come. You laid a wonderful foundation and I know it will keep on growing and solidifying for years to come. Nice job.

INTERVIEWER: So my next question is, are you aware of any other chapters that have a digital component to their group? Like how you have the face to face AND the private FB group.

JOHN: Thanks man. I hope the group is here to stay. I want to be able to come back in ten years and celebrate the ten year anniversary. No. I know chapters have their own facebook pages but I haven't heard of anything like this.

INTERVIEWER: Yea man, to my knowledge this chapter is the first to be utilizing this digital component, so that's pretty cool. And the whole act of skyping people in when people can't make it, again, this chapter is one of the first for that, too.

INTERVIEWER: When thinking about the FB group, how would you describe the conversations that have been taking place since it started in October?

JOHN: That is very awesome! I hope we are going to be trend setters. I would say that the conversations have been a little stagnant. They started off strong but since we don't have a lot of people that are in the group that it doesn't stimulate the conversation enough. That being said, I think that it gets people thinking, at least once a week, about a topic on stuttering. The conversations also become stagnant depending on the time of year (start of the school year, no one responds...) but it definitely has great potential to be a powerful addition to a physical support group.

INTERVIEWER: Totally! Could you give me an example of a particular interaction that you feel really emulates the idea that a digital location like this holds a lot for the future?

JOHN: I liked the conversation where Greg said that he would always add in a "fucking" to help him through his blocks. I don't remember what the question was but it speaks volumes that a closed private facebook group can have the safety for members to provide completely honest responses.

INTERVIEWER: That's awesome. You started to get to this, but I was wondering what would you say are the benefits of a Facebook group such as this?

JOHN: I would say that anyone, from anywhere can weigh in on things, could post thoughts, or confide in the group with a particular struggle and not have to wait for the meeting, and could do so with complete confidence that no one will repeat what is written. Further more, they could say something without fear of a block and could be useful for

those that are so effected by stuttering that they don't like doing things face to face. Now this group is an extension of one facebook group so of course it wouldnt work exactly like that but it would still be safer than some of those other stuttering groups on facebook.

JOHN: Especially the ones that daily someone asks about a cure for stuttering

INTERVIEWER: I know exactly what you mean. There seems to be a ton of public groups that get a bit crazy at times. That's why I enjoy closed groups. They are more down to Earth and have a better community feel to it.

JOHN: I completely agree.

INTERVIEWER: Now I gotta ask, what would you say are the challenges of a FB group such as this?

JOHN: getting everyone to participate, stimulating the conversation, posting relevant questions, getting people to join. those are the main ones ive seen

INTERVIEWER: Very true! So with that being said, what do you think could be added to this Facebook group to improve it?

JOHN: I know for IRB purposes it has to be 18+ but remove that limitation from it. Also possibly removing the restriction of just our members... there are a few people that i would invite that I know would be great to converse with that aren't a part of our physical group. But when you do that, you risk losing the close knit ness and trust so it could be a balancing act. As it sits right now, I think that we need more people to join which means we need to expand the physical group to expand the digital group

INTERVIEWER: Really nice insight. Totally agree. Let me take a moment to ask you about the face-to-face support group meetings. How often do you do those, typically how long are they. How many people typically are there.

JOHN: first and third wednesday of the month, so 24 times a year. They last anywhere from 1.5 hours to 2.5 hours. We have a steady attendance of 4-6 people a meeting.

INTERVIEWER: Nice! After being a part of this Facebook group and how it coincides with the face-to-face group, was there ever any time in a face to face group meeting when something from the FB group was mentioned? Like, have you noticed any crossover at all? If so, could you give an example?

JOHN: I think it was the opposite. We've had things that we discussed at the meeting that we thought would be great things to post and get opinions, especially from meetings with just a few people. One specifically that coincided with the questions was the one about holiday stress. But I think that in time there will be more cross over.

INTERVIEWER: Very cool! Switching gears just a bit, I wanted to ask you about your experiences with past speech therapy you've had. Could you tell me a bit about it? What did you like? What did you dislike?

JOHN: I've had mixed experiences. Growing up in elementary school, the SLP said i didn't stutter, it must be a problem at home causing it. Then i woked on artic things because i blocked on /w/ so i would say "can you whittle a whistle out of wood." then i was in and out of XXX therapy because the school hadn't a clue but eventually i gave up. I came to XXX march of 2011 and it changed my life. I liked that the students spent the time to build rapport, that they knew what they were talking about... and if they didn't, they had someone to catch their mistakes and fix the path of therapy. Very progressive. That is what our field needs.

INTERVIEWER: Dude exactly! So growing up did you know any PWS?

JOHN: nope. didn't meeting anyone until i came to college.

INTERVIEWER: That's why I love social networking because nowadays, teenagers can meet other PWS no matter where, ya know?

JOHN: yeah man, definitely. it is invaluable. I used to feel as if i was the only one who stuttered so it's definitely cool.

INTERVIEWER: I know it's hard to imagine, but with social networking so much more prevalent now vs when you were a teen, how do you think it could have helped or hindered you as a PWS?

JOHN: I think it would have definitely helped me. I learned of the nsa through the university. I think that if i would have had more resources as a kid stuttering might not have had such a large impact on my life. but we will never know. so my goal is to do everytihng i can to try to take the what ifs from someone else's life. To give them these resources.

INTERVIEWER: Perfectly said! Just a couple more, is that cool?

JOHN: Yeah that's fine!

INTERVIEWER: In regards to making a comparison between the face to face and the digital group. What would you say are the similarities between the two and what are the differences between the two?

JOHN: the similiarities: we plan the meeting around some questions, just as we plan the questions for the facebook group. We have the same vocal players participating in the meetings and in the digital group. There are more differences than similiarities because of the novel nature of the digital group. for one, you don't have the back and forth that you

have in meetings. you don't have the emotion of the person. you don't have the dedicated time that you do with a physical group that makes participation in the posts difficult. these are just a few off the top of my head.

INTERVIEWER: Well said! Ok last 2 quick ones. Besides Facebook, is there another social networking site that you use daily? If so, what is it?

JOHN: thank you! yes, twitter and instagram. I do snapchat too but i don't think that counts.

INTERVIEWER: What do you typically do on twitter? and do you think it might have some potential for PWS?

JOHN: I favorite tons of dog pictures. And reply with smart assed comments to my friend's posts. hahaha. I think it might have a potential for PWS but it is not as "safe." Like following a hashtag would be able to link tons of people together but would require you to put yourself out there to not only the world but your followers, which could be a hard thing to do for people.

INTERVIEWER: Love the dog comment. Ok last one. If you could describe the Facebook group in one word and only one word, what would that word be and why?

JOHN: one word is hard but i'd go with something along the lines of "potential." I'd say this because we have yet to tap the full potential of the group. As you said we believe we are the first to try this. So with the first, you have to figure things out on your own. It has a lot of potential and has lots of room for improvement which again increases its potential because there are so many directions that you can take it in.

INTERVIEWER: Very well said. Is there anything else you'd like to add before we peace out?

JOHN: I can't really think of anything. This was very comprehensive.

INTERVIEWER: I agree! Thanks so much for all of this.

JOHN: It was my pleasure. Best of luck with your dissertation!

JOHN: I am not a total fan of the like button. It is a cope out for people to not communicate with one another. Like in the group, people hit like but do not respond. What is the point of that? Especially if we are asking a question. It is a way to show that they saw it but I don't feel it serves much of a purpose. People might also hit it just to show the other person that they are noticing something that they say. In general, I like the like button when it comes to meaningful posts because your liked posts show up in other peoples feeds, allowing the spread of news. So I guess you could say I have mixed feelings.

## INTERVIEW WITH "CORNELL" VIA FACEBOOK CHAT

January 24, 2015

INTERVIEWER: Hi Cornell! I am here whenever you are ready for me to start shooting you over some questions.

CORNELL: Sure, over text or?

INTERVIEWER: Sweet. Yup over IM like this works perfectly. How do you typically log onto Facebook? (phone? tablet? computer? etc?)

CORNELL: Phone.

INTERVIEWER: So would you say 100% phone?

CORNELL: Most of the time, yes.

INTERVIEWER: On average, how many minutes a day do you think you spend checking out FB?

CORNELL: I don't know. I check throughout the day.

INTERVIEWER: Same. Right on.

INTERVIEWER: Are you presently a member of any other Facebook groups for people who stutter, besides the one for the chapter?

CORNELL: No.

INTERVIEWER: Cool. How would you describe the conversations that you've seen take place within this group?

CORNELL: Sometimes insightful, sometimes drab.

CORNELL: You might want to check out the subreddit /Stutter, too, btw. I think it could help you as well. Whatever I can do to help, too, I'm here for you.

INTERVIEWER: Oh right on. I am starting to get into the whole Reddit culture. So much activity on there. I will totally check out that subreddit though, never did before thanks@ Insightful and drab. Great words. Could you tell me a bit more as to how it could be insightful at times and how it could be drab, too?

CORNELL: No prob, I think it would be useful. Insightful in that sometimes my friends from the support group say things that resonate with me. Drab in that it's usually one person

asking really generic questions. I like John and I comply with this whole group because I want to help, but sometimes the questions make me feel more like a lab rat than a person. The problem with online communities is there's a sense of disconnect you need to overcome. It's easy for us because we see each other in person, too. So we can get a sense of one another's personalities, and we can bust each other's chops too, like a club. In person, support groups make a lot more sense because if you stutter, wouldn't it be more proactive to speak with your voice than through texts? I think so, but everyone has a different comfort zone.

CORNELL: I was going to make an app for people who stutter a while back. I have the URL still, if I ever decide to do anything with it. [www.stutterchat.com](http://www.stutterchat.com)

CORNELL: Where you can type and talk with your voice with other people who stutter in the community — we've got all the time in the world. In essence, I think online communities are important, sure.

INTERVIEWER: Very well said! I like how social networking and the whole Internet, it's all really changing the way we are able to communicate to one another. Sometimes for the better, sometimes for the worse, but hey, I guess the Internet is here so we should roll with it haha. In regards to the chapter's page, what would you say could be something we that could be improved?

INTERVIEWER: Oh that's a great domain. Def hold onto to it for the future!

CORNELL: I think forums would work better but I'm not sure. I think branding is important. But that's just me. Anything I try and do and push, I start with how it's going to look in terms of appearance, and how others will perceive it. Right now, the group doesn't feel that cohesive and the lack of branding; a logo and theme to it would be nice to foster a sense of community and whatnot. In addition, more activities. Maybe we can practice calling each other through Skype one week, or host a "field trip" to visit the NSA with our chapter, like fundraise for it, etc. Stuttering support groups should never just involve people who stutter... It should include everybody.

CORNELL: Right now I feel like it's just people who stutter and SLPs and talking to SLP isn't the same as someone off the street. In a sense, the group needs to train everyone to listen to people who stutter like an SLP — not in finding dysfluencies and flaws but simply waiting and understanding. In part, the group helps its members understand themselves better, and it would be nice if we helped others understand us better as well.

I'm writing a book on stuttering in fact this semester.

INTERVIEWER: Really great suggestions. And I totally love your viewpoints on the branding and user interface/experience. Spoken like a true artist. We should always be

thinking about the aesthetics and the functionality, in regards to digital things (especially a digital hangout like the chapters FB group kinda is).

CORNELL: For sure.

INTERVIEWER: Dude a book? Thats awesome? Is it going to touch on teaching those key listening skills?? I like that idea A LOT!

CORNELL: Yeah. I think it will be useful for SLPs and the “commoner” to read on stuttering. I stutter, and I also write. So using those two things I do, I’ll make lemonade or something out of it right? When life gives you etc.

CORNELL: And mostly, cathartic—for myself.

INTERVIEWER: Yea man, I love that. And sometimes just getting those thoughts out of your mind and onto the paper helps you understand those thoughts that much better. You can take a step back and look at the thoughts through different eyes sometimes. You will rock that book!

In regards to the FB group, was there a particular post that you remember as being particularly insightful?

CORNELL: Yeah, the drivethru question and usually posts with the most comments.  
INTERVIEWER: I also enjoyed the drive thru one. What aspect of that one resonated with you?

CORNELL: Just interesting seeing others, like Greg, talk about their experiences that I feel ridiculous for stressing about—but know I’m not the only one.

INTERVIEWER: Exactly! The drive thru one made me think of a story. Do you remember a thing called Coning? It was this silly internet thing where people would go through drive thrus and order ice cream cones and grab the cones by the ice cream and not the cone. It was a way to surprise the drive thru workers. It was funny i guess. Look it up on youtube. But the crazy thing is my boy and I were going through the drive thru and he stutters. We went over some fluency shaping stuff and he was proud at how he asked for ice cream and then the lady was all like NO NA AH WE ARE NOT GIVING YOU OR ANYONE NO ICE CREAM TONIGHT! TOO MANY OF YOU JERKS ARE CONING US! BYE BYE!

CORNELL: Lmao.

INTERVIEWER: We were both like UMMMM OK? We drove off and were like WELL WE SURE DIDN’T EXPECT THAT! But I guess that goes with all types of communication, expect the unexpected lol

CORNELL: That’s funny.

CORNELL: sundae nazi, like seinfeld no soup for you except ice cream in this case.

INTERVIEWER: NO SOUP FOR YOU! Exactly!!! Would you say there are some benefits that come with digital communities, like especially with distance? If you are too far and whatever?

CORNELL: Yes, that was one of the things I had in mind upon the development of stutterchat. If you can't go to the NSA or you live in the backwoods and some shitty Podunk town and stutter, you already feel isolated and now even more. The Internet fixed that, but even then if you stutter, it's less obvious online than in person. With online support groups and online communities for stuttering, it's convenience at a keyboard.

INTERVIEWER: Right right! So a way for connection to not feel alone. Smart. Def keep toying with that idea. You could def make something cool.

CORNELL: In time perhaps. For now, I got the book... It's for my capstone project I chose over an internship. Props for working towards your PHD man.

INTERVIEWER: Dude I'm so pumped you chose that as your capstone. All too often, I've seen capstones and random thesis papers that are real snoozers. Like, not to be a jerk, but they are usually SOOOO boring and don't really amount to much except for the means to an end of getting the degree. But with yours, I really feel like it would make a serious lasting impression and it would be a fantastic resource for professionals!

INTERVIEWER: Thanks for the PhD props. I love this field and we are getting a lot better with what stuttering is and is not, but we still have lots of work to do. Especially with educating the public! I got some cool ideas I want to do, but first I gotta get this PhD done.

INTERVIEWER: Let me take a moment to ask you about your thoughts on face-to-face support group meetings. How often do you go to those? You started talking about it a bit, and I know that ability to be in the same room with others is awesome, but are there any other aspects that you think are beneficial, besides the obvious?

CORNELL: Yeah, thanks Erik. I appreciate that. And that's cool that you're passionate about it. I go to those every time they're available, Greg drives me. He's a friend I made through the group, aside from the other friends but I'm close with Greg to some extent. So it's a good way to meet new people and make new friends, who coincidentally stutter as well. It's kind of funny, though.

CORNELL: Like "two stutterers walk into a bar" sort of thing.

CORNELL: That's an idea I'd like to do, or see happen. A group of people who stutter order something and everyone has to wait and just to see the scene it causes. Will people laugh and think it's a joke? Will they be more nervous than you?

CORNELL: Just watching other people stutter is fascinating to me, in person.

INTERVIEWER: So rad! Have you seen that one clip on that show called what would you do? The girl was ordering ice cream and she stutters and the reactions around here? <http://youtu.be/Qdyj05-laqY> It's a pretty cool watch.

CORNELL: Yeah I have.

INTERVIEWER: SO cool to see people say WTF U DOING to that bully?

CORNELL: I don't think people are like that anymore, then again, I'm not in high school anymore.

INTERVIEWER: Dude, I'm so sorry, I just noticed this is going a bit long. I know you must be busy so thanks so much for taking the time to chat. Is it cool if I just ask you a couple more quick ones? I don't wanna mess your day up.

CORNELL: Nah, you're good.

CORNELL: Just like talking to a friend.

INTERVIEWER: That's exactly why I didn't even notice the time lol

INTERVIEWER: Boo ya!!!

INTERVIEWER: I wanted to ask you about your experiences with past speech therapy you've had. Could you tell me a bit about it? What did you like? What did you dislike? Things were a lot different therapy wise back in the day when we were kids and all so I'm just curious to hear your take on it.

CORNELL: I was born with a cleft palate. How I learned to speak was done in a very systematic and calculated way. I was trained to enunciate certain sounds as building blocks to adequately say words with less nasality, and better pronunciation. In kindergarten, the teacher couldn't understand me but the kids did and they would essentially tell her what I was saying. I knew very early on I sounded different—weird—not normal. Speech therapy growing up was as good as anyone can be teaching someone the basics. I was born in Brazil and moved here when I was 2; learning a new language in two different ways. I got surgeries and speech therapy up until graduation until middle school and on when I developed a stutter. My speech therapist would give me a paper to read off while she would “send an email real quick.”

CORNELL: I had one good speech therapist in high school, who was more of a friend than anything else. Then I got speech therapy at the university, and that helped a lot but to the extent that it could—clinician room fluency, but step outside and my techniques felt useless. I'm at a better place now and I think it's in part due to speech therapy and myself

and more understanding of stuttering and what it is, and not this vague, imaginary monster. Speech therapy is as useful as the therapist and as proactive as the patient.

INTERVIEWER: Well said man. And reading this response makes me be all like DAMN IT WHEN IS THAT BOOK GOING TO BE DONE? So rediciously interesting. Your background and your experiences have really set you up to be one hell of a teacher. Your words will NO DOUBT teach many people.

INTERVIEWER: One of the things my friends and I always say about stuttering is that, whether we love it or not, it's coming along for the ride with us in this thing called life. So like, sometimes we are at a point in our lives where stuttering actually driving the car, but through conversations about talking, therapy, taking chances, etc. we can usually get the stuttering out of the drivers seat and in the back seat. I don;t know if that makes sense but Im sure you know what I mean. My one boy was even like "somedays are so good that the stuttering isnt even in the car, its tied up and lcked in the trunk. I laughed at that!

CORNELL: Yeah I feel you. I get that, and haha in time. I'm writing about myself and then about other topics, like carl van ripper, Joseph Sheenan, and of course, the man behind the monster study.

INTERVIEWER: OMG YEA YEA that mary the monster study! Jesus, imagine that!

CORNELL: It was really useful in a way though if I understand it correctly.

CORNELL: I could be wrong though, I don't know too much and I'm sure you know more than me.

INTERVIEWER: Yea no you're right, with all research, no matter how wild it might have been, there is always something to be learned. But what's great about today vs the way it was back in the 1950s, is we can just walk into a foster home and start conducting research willy nilly. We need consent, ya know, so thats a good thing LOL. If consent wasnt a factor in this day and age, there would probably be half human half turtles running around or something. lol i guess that would be ninja turtles though and im cool with them but YA KNOW lol

INTERVIEWER: Could you take a moment to tell me a bit about the past support you have gotten from those around you, in regards to being a person who stutters. Like, aside from the members in the chapter and Greg and stuff, how about your parents and stuff? Or was it just something that was never talked about?

CORNELL: That's true. I definitely need to look more into it. I want to interview his son (or grandson I think) and talk about it but I worry he might be apprehensive about talking about this.

CORNELL: We spoke about it. What was spoke about between my parents, I'm not sure but they've always been supportive. My dad always tells me and instills in me I'm more than someone who stutters, and does that typical thing anyone says, "oh it could be worse you know," and goes off tangent about how I could be blind, this and that, and I know he means well and anyone does when they say things like that. My mom has been supportive as well, but we don't talk anymore. Of course, there are times when things are said that shouldn't be said during fights. Your loved ones know exactly what to say to hurt you. Or when people invalidate your experience and say you're being a big baby because you're scared to do something as trivial as say "have a nice day" to someone, so you smile instead.

CORNELL: It's little things like that that is stuttering.

CORNELL: Shifting from one social situation to the next and dealing with how ridiculous it feels coupled with the anxiety and passing as fluent to spare someone the embarrassment.

CORNELL: But my mom has been the one who's always taken me to speech therapy and introduced me to the university through a teacher etc. She's been a mom and a good one.

INTERVIEWER: That's awesome, Cornell. And I totally agree with you 100 million times around the world when you say its our loved one who know what buttons to push. Damn so true.

INTERVIEWER: Aight my buddy, these are the last 2 questions I got for ya:

INTERVIEWER: Besides Facebook, is there another social networking site that you use daily? If so, what is it? (I'm always thinking about new things to possibly look into)

INTERVIEWER: And If you could describe the Facebook group in one word and only one word, what would that word be and why?

CORNELL: Reddit.

CORNELL: Supportive, because it's a support group and I know if I say "wow I ordered a pizza on the phone today and feel pretty good," they're not gonna look at me like I'm high, well, probably not.

INTERVIEWER: HAHHAHA! And yea man, the reddit community does some kick ass things so I am going to totally look into it deeper in the near future. I mean, here and there I will check out the main page of reddit, but like you said, those subreddits could have some real gems so I am going to look at that man. Perfect.

INTERVIEWER: Yo Cornell, mad props for chatting. I should be in the MU area in a few months. Gonna try to plan it out so I come to a Wed meeting. Def try to come out to that

one if you can. We can have some good convo and the pizza is always a plus LOL!  
CORNELL: For sure.

## INTERVIEW WITH “ROTH” VIA FACEBOOK CHAT

Date: January 24, 2015

INTERVIEWER: Hi Roth! I am here whenever you are ready for me to start shooting you over some questions.

ROTH: Hey Erik, sounds good! I'm all ready.

INTERVIEWER: Wonderful! Thanks again for taking the time to chat. You rock!

ROTH: No problem, happy to help!

INTERVIEWER: Ok, here we go. How do you typically log onto Facebook? (phone? tablet? computer? etc?)

ROTH: I'd say it's about a 50/50 split between phone and computer, but I do get notifications sent to my phone if that's an important point

INTERVIEWER: Right on, I'd say same with me 50/50. On average, how many mins a day do you think you spend on FB (phone or comp combined)

ROTH: Too many haha....I'd say 2.5–3 hours sporadically throughout the day. I usually sort of leave it on in the background when I'm online. Or just check it for a few minutes and sign off again.

INTERVIEWER: Haha I totally hear that. One of my new years resolutions was less facebook... im not doing too well HAHAHAAAA!

INTERVIEWER: We are looking to understand the benefits and challenges with online communities for PWS so I was wondering how would you describe the conversations that take place within this chapter FB group?

ROTH: Haha yeah I can totally relate , it's become more or less habitual at this point for me.

ROTH: I think that the conversations in the group are really great in allowing PWS to express themselves in a supportive and understanding environment. Depending on the question raised, I've noticed that different people are able to bring different perspectives to the table and challenge others to view stuttering in a different way, which can be a very positive experience in the process of stuttering acceptance/treatment. I really only have positive things to say about my experience as a member.

INTERVIEWER: That's really cool to hear! I love the ability we have with the Internet to have all these different types of forums to communicate on. Whether it be FB or Twitter or this or that, there are some many options!

INTERVIEWER: Was there any particular question that you thought resonated with you or stopped to make you think?

ROTH: I think the question about describing your stuttering in 3 words was a pretty interesting and enlightening experience. It reinforced the fact that everyone deals with stuttering in their own unique way, and the words that people chose reflected that. I only know a few people in the group personally, so I felt that I was able to get a greater sense of who they are as people and where they're at in regard to their stuttering was a really great way to build up the rapport of the group. And I thought it was a really great activity for myself because it made me sift through all of the different feelings and emotions that I've experienced with stuttering in the past and the present. I could focus on the strengths that living with stuttering has afforded me with instead of the negative aspects of it.

INTERVIEWER: Absolutely! I too enjoyed that question because yes there is that technical way we could describe stuttering, temp disruptions in the forward flow of speech etc etc but it's always interesting to see the personal words used to describe stuttering. Proof that there is a rainbow of ways to look at what stuttering is and is not to various people.

ROTH: We are looking to compare the face-to-face support group feel with the online community feel... I was wondering what you would say are the benefits and challenges with both of those different types of support groups. The face to face and the digital.

INTERVIEWER: I couldn't agree more!

INTERVIEWER: And also, feel free to take your time, I am in no rush friend.

ROTH: Well, I think the online support group model is a really great addition to a face-to-face support group. In my mind, the biggest positive is that it can be accessed anytime and anywhere. Stuttering is a disorder that can pop up at any point and cause a ton of stress or frustration in any given moment. So, having an online support system that you can turn to whenever you need is a really great resource. Say someone had a really severe block at work or at school and they had a rush of negative feelings about the experience. They could take out their phone or computer and get that support immediately or at least in a much quicker time frame than a bi-monthly support group. I think that's a very powerful thing.

ROTH: Also, the online support group can reach out to a wider audience of PWS and maximize the benefits of support for people who may be struggling but unable to attend the group.

ROTH: However, I don't necessarily think that an online group should be used instead of in-person support. Speaking from my own experience, finding the support group and going to my first meeting was an incredibly important part of my journey in dealing with my stuttering. I hadn't had a real conversation with another person who stutters until I was 20 years old and decided to go to a meeting. This thing that I thought I only experienced and

struggled with suddenly became normalized in the group environment, and showing up to that in person was very important. I think people need to hear stuttering and feel that they're making a real connection with others in the group.

ROTH: So, I definitely believe that online support should be utilized in addition to in-person support. Kind of the way that the university group is set up now.

ROTH: I hope that made sense haha

INTERVIEWER: Oops, my bad, my Wifi is acting weird. One sec.

ROTH: No problem, take your time.

INTERVIEWER: Wow! So embarrassing! My wifi never did that before! The box thing went red and I was all like OH NO!

ROTH: Haha not a problem man

INTERVIEWER: And what you said makes perfect sense. One of the key words It should never be a this OR that mentality, face to face and digital should exist together, but face to face should always come first in my opinion because there is nothing better than physically sitting along side someone else. Ya know what I mean? But who know 10 years from now what tech has in store for us. Holograms? Star Trek stuff? HAHA. But you were spot on with what you said!

INTERVIEWER: If you had to dig deep to try to find a negative or a challenge that is associated with being a part of an online community, could you possibly come up with something?

ROTH: I think studies like the one that you're doing now are so important for that very reason. Technology is just going to keep advancing, so finding out the best layouts and approaches to online support is really, really important and worthwhile!

ROTH: Well, I think online communities create the challenge of not being able to connect with others in a face-to-face environment. Things can be misinterpreted because you're only reading a block of text instead of hearing someone saying it with context. It's also a lot easier to slip into the background and not be an active participant in an online forum.

ROTH: Even though people who attend a face-to-face support group and choose not to participate or speak, the facilitator or leader can still gauge how much the person is getting out of the session and figure out ways to better include or involve that person in the process. With a digital format, that really can't happen in the same way because it's easy to lose track of who is in the group and how frequent people are posting.

ROTH: can choose not to\*

INTERVIEWER: Wow! Totally. What your saying really makes sense, especially with how text can be misunderstood because what we see is what we get. It's so static and it lacks the color and art that comes along with face to face communication. The eye contact, the body language, the intonation, all that and more gets lost in text. So true!

INTERVIEWER: After seeing this Facebook group and how it coincides with the face-to-face group, do you know of any other chapters that also have this digital component to their face to face?

ROTH: Hmm. I have friends who lead chapters and I know they have websites for the chapter that include meeting recaps and other information like that. But I can't say I know any other chapters with the same setup as the university group.

INTERVIEWER: Cool cool. I'm always just thinkin' about future research ideas. Guys like us, we can't turn our brains off

INTERVIEWER: I was hoping to ask you about your experiences with past speech therapy you've had. Could you tell me a bit about it? What did you like? What did you dislike?

ROTH: Yeah totally

ROTH: I started going to therapy in the 3rd grade and went on and off for about 5 years, to both my school SLP and other private SLPs/grad students. I was never in a very good place with my stuttering growing up, so I never really had a desire to be there or work on it. Even though I was having a difficult time with it, I couldn't accept it and didn't want to address it in the ways that my therapists encouraged me to. I just saw it as something that made me different and weird, so talking about it and working on it just wasn't an easy thing to do.

ROTH: I was exposed to mostly fluency shaping strategies. They would work pretty flawlessly in the therapy room, but could never transfer over to my everyday life. Because of that, I got pretty discouraged and basically blamed myself for not being able to speak in the way that my therapists told me I could if I kept trying. So, I decided to stop therapy once I reached high school and tried to deal with it (pretty unsuccessfully) on my own.

ROTH: Once I was a junior in college, I felt like I hit my rock bottom with avoiding and trying to hide it from people. So, I made the decision to seek out the university support group and go to a meeting. It was difficult to bring myself to go, but it was a really powerful experience and actually led me to attending an NSA conference. While at the conference, I met a ton of people who went through an intensive program at the American Institute for Stuttering in New York City. So, two summers ago, I went through that 3 week program and had a massive transformation. It was the first time that I was able to address the psychological aspects of stuttering, and did a lot of work in avoidance reduction, desensitization, and stuttering modification. It really changed my life in every aspect, and

it motivated me to go into speech pathology myself. I'm in grad school right now working towards my degree.

INTERVIEWER: I loved hearing about your journey. It's beyond wonderful to hear about that transformation that you went through. The NSA is a wonderful organization and I hear the best things about the Am Institute in NYC. You are one heck of a hard worker and you're just getting started.

ROTH: Yeah it's been a crazy journey but I feel very blessed to be where I'm at with everything right now and having the opportunity to be here.

INTERVIEWER: I know you will go far.

ROTH: Thank you so much, that's really nice of you to say!

INTERVIEWER: Ok, now on to the last 2 quickies. Besides Facebook, is there another social networking site that you use daily? If so, what is it?

ROTH: I'm not sure if it counts, but I use Instagram. Other than that, just Facebook

INTERVIEWER: I like how you said instagram. You are the first to mention that. Now this might be a long shot, but could you foresee any benefit in that photo sharing platform for PWS?

ROTH: Haha not really. If you can find a way to incorporate videos into an account, then maybe. But I don't think it would be very worthwhile

INTERVIEWER: Yea, agreed. Again, this is just my research brain always thinking. LOL

INTERVIEWER: Ok last question my friend: If you could describe the Facebook group in one word and only one word, what would that word be and why?

ROTH: It just reminds me that there are other people out there that understood where I'm coming from, and it gives me a daily dose of inspiration to keep pushing through the difficult situations or times that come with dealing with stuttering

ROTH: understand\*

INTERVIEWER: Love that. So what would be the single word?

ROTH: I guess I would have to say "inspiration."

INTERVIEWER: Nice nice. I dig that.

INTERVIEWER: Ok, that concludes the interview. Is there anything else you might want to add that you might not have had a chance to mention? Or anything you think I missed?

ROTH: No I think I was able to say everything I wanted to!

INTERVIEWER: Perfect. Thank you again.

ROTH: I think the like button can serve a few different purposes. I think mainly people use it to show that they saw the message and they want you to know that they support its message/can relate to it/feel strongly about it. I think in a way its a good thing because it allows people to feel like their message is being heard. But on the other hand, I think it runs the risk of becoming a little impersonal, especially in a support group format. I think people need to connect with more than just an acknowledgment like that, especially if that's the only form of communication that they receive time and time again. It doesn't allow people to learn from each other or give people the opportunity to expand on what they want to say.

## INTERVIEW WITH “GREG” VIA FACEBOOK CHAT

Date: January 25, 2015

INTERVIEWER: Hello Greg! Is now a good time to shoot you over some questions?

GREG: Hey, yeah in a little bit maybe? Watching a movie with the wife, it's almost at the end

INTERVIEWER: Oh yes! Of course! How about I hit you back at 8PM?

GREG: Ah that's not good. We can do it now if you want

INTERVIEWER: haha ok cool sweet

INTERVIEWER: ill get the questions now

INTERVIEWER: How do you typically log onto Facebook? (phone? tablet? computer? etc?)

GREG: Phone

INTERVIEWER: On average, how many minutes do you spend on facebook a day?

GREG: 5–10

INTERVIEWER: 5–10 hours. Cool. Got it.

INTERVIEWER: JK

INTERVIEWER: 5–10 mins

GREG: Lol, yeah I'm not on a whole lot

INTERVIEWER: In regards to the chapter's FB group, how would you describe the conversations that take place within this group?

GREG: Ok. Seems like a lot of classroom like questions posed by SLP students lol

INTERVIEWER: Haha! Yea, some do seem a bit formal. Is there a particular question that you thought was thought provoking?

GREG: The miracle pill to not stutter was funny. No one commented because the answer was a resounding yes I would take a pill to not stutter but admitting that would be admitting we were ashamed of our stutter, which goes against the stuttering teachings

INTERVIEWER: That's really interesting. I like that question, too.

INTERVIEWER: We are looking to compare the face-to-face support group feel with the online community feel... I was wondering what you would say are the benefits and challenges with both of those different types of support groups. The face to face and the digital.

GREG: Well, I like the face to face a lot better. The very nature of the support group is about dialogue. Trying to seek help for stuttering through an online medium is like a drug addict using drugs to help find the answers lol. I can't think of a good analogy. Stutterers need to have real life interactions to help overcome the symptoms involved with stuttering

GREG: Talking about something on an online forum does nothing for the problem I believe. Granted it might be better than doing nothing about it, but still doesn't do much

INTERVIEWER: Ha ha I really like that analogy! I know exactly you're talking about. Face-to-face component is so strong and one that should never try to be replaced by any type of digital means.

GREG: Yeah, replacing isn't really possible, supplementing is all a digital medium could do for this kind of thing

INTERVIEWER: I love the word supplementing.. That is really cool. What about people who might be on the forum just looking at posts but never replying to any posts. Do you think those people could still get some benefit from that? Or do you think there has to always be a back-and-forth conversation for any type of benefit to occur?

GREG: Maybe someone who's still young and stuttering. If we talk about techniques to not stutter or ways to avoid it, etc. they might be able to pick something up. But it's still just little things. Speech pathology is such a soft science, there's hardly any quantifiable or empirical data to base any concrete answers on. It might help one person, might be useless for the next.

INTERVIEWER: Cool cool. In regards to face-to-face meetings, how often do you attend those and how vital do you feel they are for your self-esteem and well-being?

GREG: I attend just about every meeting, they are not vital for my self esteem and well being. I say that because I had speech therapy as a kid, and it didn't work at all. I stuttered like crazy from grade school to about age 20. I attend these meetings because I found out how to get over my stutter, in a psychological sense. It's still there, but not in an anxiety ridden, self deprecating kind of way like it always was in the past.

GREG: I go to the meetings because I like the people there, I like the pizza, and most importantly I like to try and help the younger people with a pronounced stutter learn how to 'flow' their dialogue better

GREG: It's possible to stutter and still get your point across efficiently. Like a dramatic pause before a Star Wars movie.

INTERVIEWER: I totally get what you and I always appreciate a nice Star Wars reference. You're the man! Yes I totally agree that the ability to connect with friends and talk to them about things that they would understand about what is and what is not effective communication is pretty powerful.

INTERVIEWER: I just have a couple more questions, is that okay. I don't want to mess up your night or anything.

GREG: Yeah, that's why I go. No it's ok I'm smokin a cig in my yard

INTERVIEWER: Awesome. You mentioned speech therapy as a child, I was hoping that I could ask you about the support that you received when you were a child. Not necessarily speech therapy, but support from friends and family in regards to stuttering. Did you feel like you were alone? Did you have people to talk to about stuttering that wasn't the clinician?

GREG: Not really, stutterers aren't too abundant, the only other one in my grade even had a stutter AND was severely MR so basically the stutter made kids think it went hand in hand with special needs

GREG: I had support from my mom, a couple different therapists, but nothing worked

GREG: Friend wise we didn't really talk about it. I noticed drinking gave it a humorous effect. Ever see a wicked drunk stutterer? It goes from a social awkwardness to downright hilarious lol

GREG: Speeches and reading from a book were nightmares. They're still not fun. I haven't stuttered once and got all As on every speech I did last semester, but still, every time before the speech I psyche out about how I might stutter like I did when I was a kid and knock over my presentation in front of the whole school and every girl would be silently vowing to never ever sleep with such a nerd.

GREG: Lol, that's the fun part of stuttering.

GREG: It gives you a challenge in life. Something to overcome. I think stuttering adds character. Never met one I didn't like for that matter.

GREG: Sorry, tangent.

GREG: Hope you don't have to write all this down. I could be more vulgar if you want lol

INTERVIEWER: No no this is amazing. I really love your insight.

INTERVIEWER: How about this, and I know its a stretch but I love the way you think. Do you think social networking and the ability to connect with other PWS on the Internet would have benefited you as a teen? Cuz now teens and even younger (scary!) are on social networking sites, so I' curious to see your thoughts on that.

GREG: I can't even imagine it to be honest. I had AIM growing up, there probably was something online back then for it but i never sought the help. I don't think it would have done much good. What works for one stutterer might not do anything for others. For example, I met my first non-MR stutterer when I was like 12. My best friends younger brother. My therapist always told me to write this one sentence 'I am a clear and vivid speaker' over and over and over... Never worked, I thought it was dumb. But I told this kid about it, he did it, and it helped him out a lot. He still brings up to me this day, 14 years later, that he recites that line in his head before every speech or time he gets nervous. Did a fuckload of nothing for me but it was just what he needed

GREG: So yeah, online help might do something for PWS, or it might not. If it helps one person then it's something worth pursuing

INTERVIEWER: Wow! No kidding? That is pretty wild. But ya, I guess that goes to show the whole different strokes for different folks thing.

INTERVIEWER: Ok my friend, we are pretty much wrapping this up. Just one more:

GREG: Yeah, still haven't met a stutterer like me lol

INTERVIEWER: If you could describe the Facebook group in one word and only one word, what would that word be and why?

GREG: John. Just sounds like everything he says and how he talks lol.

INTERVIEWER: Dude, I am literally laughing so hard!

INTERVIEWER: You're hilarious!

GREG: Lol, but really, I would say... 'Belonging'.

GREG: Like Maslows hierarchy of needs, the group could give someone who stutters and knows no one who stutters, a sense of belonging to society. They could know, for certain, they aren't the only ones like that so they aren't mutant, they aren't weird.

GREG: Not just a loan ship

GREG: Lone\* ew that was bad

GREG: USS Sallie Mae. The loan ship

INTERVIEWER: Dude Sallie Mae RIP i think, those jerks are now Navient or something.

INTERVIEWER: HAHA!

INTERVIEWER: You rocked these questions. Before we bounce, is there anything else you wanted to mention that you think I should know?

GREG: No I'm good

INTERVIEWER: As I am thinking about how interactions in forums unfold, I keep thinking about the like button and how people usually press it as a type of "right on" or "cool." But I was curious to hear . . . errr see, your thoughts on that.

GREG: I guess I see the like button as just a general 'good' kind of thing. Cause when someone puts up something sad or shitty, people still 'like' it but that's not really what it means. I think it's funny when certain things get liked. Like 'my hubbie left me and my kids!' And all the family will like the status just to show they viewed it or something, I don't know lol

INTERVIEWER: Yea I know what you mean about the whole 'good' thing. Like it sort of is used as a 'yup I read this thing.' But I wonder what would be the reason(s) why someone would like something but not comment on the thing?

GREG: Just to show approval but not get involved. Like a random nod of agreement from a crowd lol

# INTERVIEW WITH “BILL” VIA FACEBOOK CHAT

Date: January 25, 2015

INTERVIEWER: Hi Bill. Just a heads up that I am here whenever you are ready.

BILL: im here, eik

BILL: i ment erik

INTERVIEWER: Hehe wonderful! How’s the snow?

BILL: round one is cleaned up. not looking forward to round THREE

INTERVIEWER: Ugh! I know. The snow is coming tomorrow. GAH!!!

INTERVIEWER: Ok my friend. Thanks for taking the time to chat for a few. My first question is pretty easy: How do you typically log onto Facebook? (phone? tablet? computer? etc?)

BILL: ijust noticed, my computer clock is off by six hours

INTERVIEWER: Haha! THat’s funny! Gotta fix that

BILL: yep, now what about your research?

INTERVIEWER: My first question is pretty easy: How do you typically log onto Facebook? (phone? tablet? computer? etc?)

BILL: just laptop.

INTERVIEWER: Great. And how many mins per day on average do you check FB?

BILL: somedays i do not check at all. if i do,i try to do whatever i intend to do in one sitting- maybe 20 minutes

INTERVIEWER: That makes sense. Good habit to get into. In regards to the chapter’s FB page, how would you describe the conversations that take place within this group?

BILL: i think John, the co-leader, does a good job in trying to stimulate conversations- but there’s not that many members

INTERVIEWER: Yea I agree. Sometimes it can get tricky to get a back and forth dialogue going. Is there a particular post that the co-chapter leader made that you thought was especially interesting?

BILL: yeh, maybe his last one about what percentage of the population stutters. you could see by my answer of 100% that it depends on how broadly or narrowly you define the term

INTERVIEWER: Oh that's a really interesting point! Sometimes words can be misread or misunderstood. Yea I agree, it's best to be as specific as possible.

BILL: What would you say are the benefits of having this facebook group as an additional way to connect with other group members?

BILL: yeh, well everybody stutters. justwatch the national nnews broadcasters sometimes

INTERVIEWER: Agreed!

BILL: ok what's next

INTERVIEWER: What would you say are the benefits of having this facebook group as an additional way to connect with other group members?

BILL: i think it's good way to communicate to get people's opinions there. i would still rank the face to face meetings as most enjoyable

INTERVIEWER: I agree with you, face to face is best in my eyes too. What do you think is the thing that makes face to face better than the online stuff?

BILL: well, 90% of communication is non verbal- you need to see people's body language, facial expressions and general instantaneous show of emotions.

INTERVIEWER: Oh yea and that is totally lacking when its just text. Good call.

INTERVIEWER: How often do you attend the face to face group?

BILL: is there anything else?

INTERVIEWER: How often do you attend the face to face group?

BILL: well, it's a long commute to face to face meeting (but it would be just as time consuming to attend the next nearest chapter- in the city, with all the not rush hour traffic. I attend more in the summer when there's more daylight time to travel both ways. And then I also attend the National Stuttering Association convention

INTERVIEWER: Oh yes I totally understand that. So I wonder if maybe the online group might be beneficial in the sense that you could keep in touch a bit during those winter months?

BILL: yeh, like responding to the posts.

INTERVIEWER: Do you think it's possible to get something out of the messages being posted in the group even if you are not actively participating in the conversation?

BILL: yeh, it depends on what other people post as a comment. it would be nice if it were possible to increase the membership to get more ideas

INTERVIEWER: Totally agreed. If you could describe the Facebook group in one word and only one word, what would that word be and why?

BILL: can the "why" be more than one word?

INTERVIEWER: Yes, the why can be expanded.

BILL: well, the one word would be "adjunct," because the FB group seems to be an additional resource, with trying to supplant the idea of having an in person group

INTERVIEWER: That's wonderful Bill. I appreciate your time. Those are all the questions I have.

INTERVIEWER: Have a great night and good luck with all the snow.

BILL: great erik- have a non eventful snowstorm.

**APPENDIX G**  
**WRITTEN QUESTIONNAIRE PROTOCOL**

Age\_\_\_\_\_

Gender

☐ Male

☐ Female

Current country of residence \_\_\_\_\_

If living in the USA, please provide the state in which you currently reside \_\_\_\_\_

Race/ethnicity

Asian/Pacific Islander

Black/African-American

Hispanic/Latino

Native American

White/Caucasian

Other

-Relationship status

Married

Single

Divorced

Widowed

Separated

Partnership

Other

-Employment status

Employed

Unemployed

Student

Retired

-If employed, please list your occupation:

-Have you ever received speech therapy for stuttering in the past? Y/N

-If you answered yes, please describe your therapy experiences for stuttering.

-Have you ever attended a face-to-face support group for people who stutter before? Y/N

-If you answered yes, please describe your face-to-face support group experience.

-Do you have a Facebook account? Y/N

-How do you typically log onto Facebook? (check only one)

- On my computer (traditional desktop or laptop)
- On my digital tablet (iPad, Kindle Fire, Nook, etc)
- On my mobile device (cell phone or smart phone)
- Other

-How often do you use Facebook?

- Several times a day
- Once a day
- Once every few days
- Once a week
- Occasionally (less than once week)

-How much time (on average) do you spend on Facebook per day?

- Less than 5 minutes
- 5–10 minutes
- 11–30 minutes
- 30+ minutes

-Are you presently a member of any Facebook groups for people who stutter? Y/N

-If yes, please describe your experiences of participating in a Facebook group for people who stutter.

-Prior to joining a Facebook group for people who stutter, please describe support you have received for your experience with stuttering.

-After joining a Facebook group for people who stutter, please describe the support you have received for your experience with stuttering.

-Prior to joining a Facebook group for people who stutter, please describe your self-esteem.

-After joining a Facebook group for people who stutter, please describe level of self-esteem.

-Prior to joining a Facebook group for people who stutter, please describe your feelings about being a person who stutters.

-After joining a Facebook group for people who stutter, please describe your feelings about being a person who stutters.

-What do you think are the benefits and challenges of an online community such as this?

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**ABSTRACT****ONLINE COMMUNITIES FOR PEOPLE WHO STUTTER:  
AN ETHNOGRAPHIC STUDY OF A *FACEBOOK*  
SOCIAL NETWORKING SUPPORT GROUP**

by

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The purpose of this study was to explore the experiences of people who stutter who digitally connect and share with other people who stutter on a social networking site, specifically *Facebook*. This study used a qualitative, ethnographic approach to gain insight from members of a private *Facebook* group for people who stutter and to collect their opinions as to whether an online community was a beneficial means of obtaining psychosocial support from other people who stutter. The primary investigator collected textual data and artifacts from 3 months of *Facebook* group postings, semi-structured interviews with 7 of the *Facebook* group members, and anonymous responses from a written questionnaire. The primary investigator analyzed all of the data for major and minor themes. To establish credibility, all research findings were consistently shared with participants to validate, clarify, and question the results. Also, they were encouraged expand upon or delete any of their specifically contributed words if they felt the need to. In addition, 3 independent investigators (2 with a background in stuttering and 1 with

expertise in social networking sites) performed separate thematic analyses. Their findings were compared with those of the primary investigator to gauge the consistency of themes. Data analysis revealed 8 major themes, which included the benefits and challenges of participating in an online community for stuttering; the types of support that existed within an online community for stuttering, which included providing information, posting questions, giving encouragement, and engaging in humor; and the healthy debate and honest and varied opinions that members had within the online community. Results suggested that, for people who stutter, digitally connecting and sharing privately on *Facebook* was a useful and impactful way to gain psychosocial support from other people who stutter.

### **AUTOBIOGRAPHICAL STATEMENT**

Erik X. Raj holds a Certificate of Clinical Competence from the American Speech-Language-Hearing Association. Mr. Raj obtained his Bachelor of Science degree in Speech Pathology and Audiology from Stockton University in Galloway, New Jersey in 2006. He then went on to earn his Master of Science degree in Speech-Language Pathology from Misericordia University in Dallas, Pennsylvania in 2008. Mr. Raj's research interests are in fluency and Internet technology. He regularly presents interactive workshops nationally and internationally where he demonstrates how school-based speech-language pathologists can use technology to motivate and teach students on their caseload. As a doctoral student and candidate, he taught numerous undergraduate courses within Wayne State University's Department of Communication Sciences and Disorders. In addition, he was a clinical supervisor at Wayne State University's Intensive Stuttering Clinic.