

ATTITUDES OF STUTTERING WITHIN
THE SOCIAL NETWORKS OF
PEOPLE WHO STUTTER

by

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ABSTRACT

This study examined attitudes about stuttering in the social networks of people who stutter. This study included seven people who stutter (PWS) as well as 21 other participants across the social networks of the PWS. The PWS were asked to identify up to five individuals they consider to be close to, constituting the inner “circle” of their social network. These individuals were asked to identify two acquaintances and two strangers of the PWS to also participate in the study, constituting the outer circles of the social network. However, low participation rate made it possible to examine only the inner circle. A series of surveys were administered to the PWS and all recruited participants to assess how attitudes toward stuttering change as a function of the “distance” from the PWS, and to evaluate the prevalence of negative attitudes (i.e., stigma) about stuttering in the network. Results showed that perceived stigma was similar between PWS and those in their social networks. In addition, PWS rated their overall experiences of stuttering and the level of debilitation as less negative than their social networks. The perceived closeness of the individuals did not appear to have a major impact on the attitudes about stuttering. One limitation of the study is that stigma of stuttering proved to be an obstacle to studying the stigma itself. This suggests a need for more communication about stuttering within the networks of PWS.

LIST OF ABBREVIATIONS

PWS	Person who Stutters
WHO	World Health Organization
OASES	Overall Assessment of the Speaker's Experience of Stuttering
AoS	Acceptance of Stuttering as a Disability Scale
4S	Self-Stigma of Stuttering Scale
IOS	Inclusion of the Other in the Self Scale
SLP	Speech-Language Pathologist

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INTRODUCTION

Stuttering is a complex disorder associated with multiple factors that make it difficult to clearly define. Wendell Johnson (1946) was among the first to define stuttering as a disorder by hypothesizing a clear etiology. Particularly, he posited that stuttering occurs when a normally fluent person reacts to negative feedback from adults (i.e., the mother) about their speech disfluency. Consequently, young children attempt to try avoiding speech disfluency which, in turn, causes them to stutter. This is otherwise known as the Diagenetic Theory (Johnson & Associates, 1959), or stuttering originating in the “ear of the listener” (Johnson, 1946). Charles Van Riper, another pioneer of scholarship in the area of speech fluency, described stuttering as an underlying disruption in a person’s speech that could be effectively managed with treatment (Van Riper, 1982). These two viewpoints provide insight into the potential origin of stuttering events (i.e., environmental versus organic).

The World Health Organization (WHO) offered a definition in 1977 that described stuttering as the feeling or experience of the inability to get the words out that one wants to say (World Health Organization, 1977). This definition was unique in that it acknowledged the subjective experience of stuttering as a necessary component of its definition. In 1980, WHO revised their definition to include “personal factors” (World Health Organization, 1980), thus taking into account not only the observable characteristics of the disorder but also those characteristics that are covert. Although there is no known cause of stuttering, there are a number of known factors about its onset and development that could potentially shed light on its

etiology. fluency disorder that most often appears in early childhood. More than 85% of children begin to stutter by 3.5 years of age (Yairi & Ambrose, 2005). While more than 75% of children recover from stuttering in childhood, many children continue to stutter into adulthood and must manage stuttering throughout their lives (Yaruss & Quesal, 2006). The incident of stuttering is greater in males than females, and because more females recover from stuttering, the prevalence is greater in males as well (Kent, 1983). Research has also shown that 30-69% of people who stutter report having at least one family member who also stutters, indicating a strong genetic component (Bloodstein & Bernstein, 2008). Ambrose et al. (1993) identified that children who stutter are 42% likely that someone in their immediate family stutters and 71% likely that someone in their immediate family stutters. Finally, stuttering is associated with other aspects of communication, including language development. Yairi & Ambrose (2005) observed that most children who stutter have average or above average receptive and expressive language skills.

Although stuttering can function as a communication disorder, stuttering has a much broader impact on the social and emotional lives of PWS including affective, behavioral, and cognitive aspects of their daily lives (Yaruss & Quesal, 2006). Research has shown that stuttering can lead to heightened anxiety (DiLollo, Manning, & Neimeyer, 2003), particularly in demanding social contexts (Craig, 1990). It has also been reported that many PWS have lower self-esteem (Wright, 1983). Other negative effects of stuttering include a feeling of helplessness, and a loss of control (De Nardo, Gabel, Tetnowski, & Swartz, 2016; Manning, 2010). When assessing the quality of life of people who stutter, stuttering is related to a decrease in social and emotional functioning and mental health (Craig et al., 2009). To this end, it is the clinician's job to help the person as a whole, effectively dealing with the feelings as well as the behaviors.

Another aspect of stuttering that has recently been a subject of concern is discrimination. In the workplace, one study found that 70% of people who stutter reported that they think their stuttering has prevented them from getting hired or promoted at some point in their career (Klein & Hood, 2004). Another study by Hurst and Cooper (1983) found that when asked to rank the most impairing speech disorders, rehabilitation counselors ranked stuttering as the most impairing. This discrimination extends outside of the workforce. In a college setting, professors and students both rated a hypothetical student who stutters more negatively than one that does not stutter (Dorsey & Guenther, 2000). This discrimination is present in multiple settings and across many professions that are thought to be mindful about discrimination (e.g., Garcia, Laroche, & Barette; Gabel et al., 2004; Walker, Mayo, & Louis, 2016). The perception of discrimination by people who stutter is negatively correlated with self-acceptance and self-esteem (De Nardo et al., 2016). Thus, discrimination affects PWS in the work place and academic settings, both of which can contribute to decreased quality of life.

Treatment of stuttering can result in positive outcomes for people who stutter. Many studies have reported that direct speech therapy increases an individual's fluency (e.g., Conture, 1996). Less conventional approaches to therapy focus on overall quality of life. These two treatment perspectives are referred to as the Medical Model versus the Common Factors Model.

The Medical Model is a perspective in which a disorder can be understood as originating as dysfunction in a particular component of a system, and treatment can be used to fix that component and thus improve the behavior. Within the Medical Model perspective, treatment of stuttering can be directed to any underlying speech or language process that is presumed to be deficient. Often, this perspective does not take into account the spectrum upon which many disorders lie (Raskin & Lewandowski, 2000). With this Medical Model perspective, stuttering

can be viewed, for example, as a motor speech disorder (e.g., Kent, 2000), or a language disorder (e.g., Postma & Kolk, 1993). Thus, stuttering as a motor planning problem could be treated via motor therapies, or stuttering as a language disorder could be treated via language therapies. In either case, the Medical Model focuses on the neurological underpinning of behavior, which would function as a distal target of stuttering treatment. Many researchers, such as the ones reviewed in Ingham (2001), study different forms of brain imaging to capture what occurs at a neurological level within a person who stutters. However, because the Medical Model perspective focuses on what is presumed to be the underlying deficiency instead of the person as a whole, the client is not always treated in the most efficacious way.

In contrast, the Common Factors Model seeks to identify those factors that are common to the experience of stuttering and elevating them as primary objects of treatment. This can include social and emotional factors in the environment that are associated with stuttering experiences. The Common Factors model finds its roots in the “Iowa” school of thought in which scholars originally came to understand stuttering in terms of the social dynamics during early onset and development of stuttering (Zebrowski & Areans, 2009). Zebrowski (2007) reported that there are several similarities between treating people who stutter and psychotherapeutic and counseling approaches found in psychology. This includes addressing emotional issues as playing an important role in stuttering treatment, and developing as a strong, supporting relationship between the clinician and the client. For example, Crichton-Smith (2002) showed that when psychological aspects of stuttering are addressed in the treatment process, PWS are more likely to maintain progress already made. This might include developing a positive self-regard as a communicator.

The self is thought to be a socially constructed phenomenon that begins to take shape in early childhood (Harter, 2012). The emergence and development of the self depend on a child establishing theories about others' thinking, including about one's self. This "theory of mind" is the understanding that others have thoughts, beliefs, information, and ideas that are different from your own (Herrmann, Call, Hernandez-Lloreda, Hare, & Tomasello, 2007). This knowledge allows a person to communicate with others effectively, thus enabling to become part of a social network. Important aspects of the self begin to develop between ages three and four, which coincides with the typical onset of stuttering (Yairi, 1983). As the self continues to take shape into the school-age years, being perceived by others as a "stutterer" can begin to take root in one's self-identity. Indeed, adults who stutter often feel that they are fixed into the "stutterer role", showing that it becomes part of their identity (DiLollo, Manning, & Neimeyer, 2003). However, this identifying feature seems to emerge earlier than adulthood with some individuals. When asked about their own stuttering, school-aged children report that they felt stuttering was one of their defining characteristics, indicating that it is an important factor to them as well (Lau, et al., 2012).

Counseling is an important part of fluency treatment. Backus (1957) stated that the client's relationship with the clinician is the most important aspect of therapy. This often means incorporating a variety of factors into therapy sessions. For example, by addressing a client's self-esteem, it is possible to also increase the self-acceptance of stuttering (De Nardo et al., 2016). By helping a client manage strong emotions about stuttering, it is easier to treat stuttering behaviors. Plexico, Manning, & DiLollo (2005) found that people who stutter who reported having success in their therapy sessions also reported having fewer negative emotions, less intrinsic fear, and less avoidance of uncomfortable situations. For many people who stutter, it is

effective to participate in group therapy sessions to discuss feelings and emotions with people going through similar experiences. Irani, Gabel, Daniels, and Hughes (2012) reported that PWS enjoy being a part of sessions with others who stutter.

Even outside of formal treatment, children who stutter can seek counseling within peer groups. In one study, children who stutter rated their relationships with their parents as being less trusting compared to their peers (Lau, Beilby, Byrnes, Hennessey, 2012). In another study, Evans, Healey, Kawai, and Rowland (2008), reported that school-aged children were more likely to perceive their peers in higher regard, thus utilizing them as a means of social competence.

The social dynamics of stuttering, including attitudes about stuttering as well as one's own identity as a "stutterer" can spread throughout one's social network, particularly as people naturally "influence and copy each other" (Christakis & Fowler, 2009). While for many people who stutter it may seem that others are very concerned or paying close attention to one's own stuttering behavior, that might not be the case. Rather, one might instead interpret ambiguous social feedback as confirming one's own negative views about stuttering (i.e., confirmation bias). This possibility, which deserves more empirical scrutiny, is referred to in psychology as the "spotlight effect." The spotlight effect describes how people, especially in a social setting, tend to think that more people are noticing more about them than they actually are (Gilovich, Medvec, & Savitsky, 2000). This psychological quality begins in childhood forms the center of one's life throughout a lifetime. Gilovich et al. (2000) conducted an experiment that successfully demonstrated this phenomena in college-aged students. The spotlight effect may negatively impact a person with a disability by priming them to think that others notice more than they actually do.

At the same time, prevailing negative attitudes about a disorder could spread throughout a social network and referred to as stigma. WHO defines stigma as “a mark of shame, disgrace, or disapproval that results in an individual being rejected, discriminated against, and excluded from participating in a number of different areas of society” (World, 2001). Stigma is a common when studying a variety of topics such as alcoholism, mental health, and stuttering (Dean & Poremba, 1983; Corrigan, 2004). Negative stigmas about stuttering include stereotypes that have negative correlations with the person’s quality of life (Boyle, 2013). Although a number of studies have looked at the stigma of stuttering (e.g., Woods & Williams, 1976; Cooper & Cooper, 1996), it’s hard to conclude where the stigma comes from. For example, a person who stutters might assume that others think about stuttering the way they do, which might be negative. On the other hand, a prevailing stigma about stuttering could already be present and later adopted by a person who stutters. In either case, a stigma about stuttering results in the “taboo” nature of the disorders and could be off-limits for discussion in many social contexts, thus presenting an obstacle to communication. Indeed, not knowing what one’s closest friends or family members think about stuttering, particularly if they believe the subject is a sensitive topic, prevents one from making the social connections that are necessary for managing the negative feelings about stuttering.

Personal construct theory, developed by Kelly (1955), consists of the continuous hypotheses about everyday experiences as we attempt to find meaning in the world around us. A variety of experiences can be included in our own personal constructs, not only the manner in which we physically present ourselves, but also the way we talk. DiLollo, Manning, and Neimeyer (2003) discussed defining one’s self as a person who stutters, and if that identity is negative, one might attempt to avoid sharing that identity with other people. To this end, one aspect of treatment is to change one’s personal construct away from “stutterer” and all the

limitations are assuming to be part of it, and instead develop a personal narrative that focuses on possibilities. In other words, one's personal identity is changing by modifying how one thinks about others' thinking about you. For stuttering, this can mean re-imagining others' thoughts about you, or reconsider them in a more positive light. This can mean changing one's perceived position in a social network. The nature in which attitudes can spread within a social network is called hyperdyadic spread, as discussed by Christakis and Fowler (2009). This is the idea that social influence can spread across a network of people, many who have never met, merely by the energy of person-to-person social interaction.

As mentioned earlier, stuttering can be associated with negative psychological characteristics including anxiety, depression, shame, and guilt (e.g. Murphy, 1998; Boyle, 2015). Likewise, preschool children who stutter do not exhibit these characteristics, indicating that they are acquired (Alm, 2014), perhaps from the social network as a stigma. The stigma could manifest within a social network due to hyperdyadic spread. However, it is also possible that those within a person who stutter's network are unaware of a self-stigma within the person who stutters.

The aim of this study is to evaluate the attitudes associated with stuttering. By examining the feelings or attitudes of individuals who form the social networks of people who stutter, we hope to better understand how attitudes manifest in their social networks. We also seek to evaluate the accuracy of perceptions about a person who stutters at the center of a social network. Finally, by examining the network of people who stutter, we hope to see how stigma can spread throughout a social network, perhaps to people a person who stutters have never met. By examining such factors, we hope to better understand the stigma of stuttering and see how we can help a person who stutters better understand themselves and how they fit into the world around them.

METHODS

Participants

This study included seven individuals who stutter. Demographic information of the participants is found in Table 1. Each participant was asked to identify five people in their inner circle. These selected individuals were then asked to identify four more people: two who are acquaintances of the PWS and two who are strangers to the PWS. All people identified by the PWS were over the age of 19 and did not stutter. All participants voluntarily signed a consent form approved by the Institutional Review Board at the University of Alabama.

Table 1: Demographics

	PWS	PWNS
Gender		
Male	2	6
Female	5	15
Education		
Some College	1	3
College	1	8
Masters	3	5
Doctorate	2	4
N/A	0	1
Age Group		
18-24	4	4
25-34	2	1
35-44	1	4
45-54	0	4
55-64	0	5
65-74	0	2
N/A	0	1

Testing Instruments

A series of standardized tests were used to assess the participants' views of stuttering. The first measure was the Overall Assessment of the Speaker's Experience of Stuttering (OASES) (Yaruss & Quesal, 2006). The OASES is a formal evaluation that looks at the impact that stuttering has on a person's life. There are four subtests in the OASES: a general information section, reactions to stuttering section, a communication in daily situations section, and a quality of life section. Each participant was asked to rate the truthfulness of the statements and qualities using a 5-point scale (1= never, 5= always), as if they were the PWS.

The next measure was the Acceptance of Stuttering Scale (AoS). The scale, originally called the Acceptance of Disability Scale, is effective in measuring the self-acceptance of a disability (Linkowski, 1971). Instead of using the 50-item survey, we used the modified, 10-question version (Li & Moore, 1998). The version used in this study is modified so that the word "disability" is replaced with "stuttering" to better measure the particular population, as done in De Nardo et al. (2016). This measure also uses a 5-point Likert scale, with 1 being strongly agree and 5 being strongly disagree.

The Self-Stigma of Stuttering Scale (4S) was used to measure the self-stigma of the PWS (Boyle, 2013). To capture all the components of the stigma of stuttering, awareness, agreement, and application were all measured in the survey. Responses were taken from a 5-point Likert scale with 1 being strongly agree and 5 being strongly disagree. For these first three measures, the person who stutters took the surveys as his/her self and the other participants took them as if they were the person who stutters.

The final measure included was the Inclusion of the Other in the Self (IOS) scale (Aron, Aron, & Smollan, 1992). This measure was originally created to determine the level of closeness

felt in a romantic relationship. However, it has been used to rate the closeness of other relationships (Woosnam, 2010; Cameron, 2006). In the present study, the scale was used to convey how close a person feels they are to the PWS. For the IOS, participants were asked to select an image that best defined their relationship with the person who stutters. All seven images include two circles: one representing one depicting “self” and one depicting “other”. The first image has the two circles completely separate and the seventh image has the two circles overlapping. Likewise, the five circles in between are all varying levels of overlap between the two extremes. The person who stutters was asked to select the image that most closely defines their relationship with each of the recruited participants. By comparing these selected images, we were able to see the subjective connectedness of the two individuals.

Procedure

Each PWS was asked to identify five of the closest people in their life, which was specified to include family, friends, or coworkers. A study investigator then contacted the potential participants and asked them to participate in the study as well. Upon agreeing, they were asked to identify two different individuals in their own life, one the PWS was acquainted with and one the PWS had never met. This process completed the second and third of three “circles” around the PWS. Overall, the three circles consisted of people the PWS was close to, one the PWS as acquainted with, and one the PWS do not know at all.

The original five identified people as well as the identified acquaintances were contacted via email to explain the nature of the study. A link to a Qualtrics survey was attached to the email. The first page of the survey included a consent form that required the participant to agree to participate before continuing with the rest of the survey. The first section of the survey was a demographics section, and, upon completion, the surveys followed.

The next section included the four subtests of the OASES (Yaruss & Quesal, 2006). Scores were calculated by finding the overall mean of the four subtests, as suggested in the OASES manual. The scores were then exported to a spreadsheet where the recruited participants' scores were compared to the person who stutters. A higher score on the OASES indicated that stuttering has more of an impact of a person's life. The Acceptance of Stuttering as a Disability (AoS) Scale (Linkowski, 1971) was administered and scored in the same manner, with a higher score indicating more acceptance. The next measure included is the 4S (Boyle, 2013), which was scored in the same manner. In this measure, a higher score indicates a stigma that is more internalized. The IOS (Gächter, Starmer, & Tufano, 2015) was the last scale represented within the survey. The participants chose which of the seven pictures best represented the other party's relationship with them to gather a subjective measure of their closeness. This measure was scored differently, with each recruited participant being compared individually to the person who stutters.

RESULTS

The study was designed for PWS to be the “center” of 25 other people grouped into distinct social categories within their social networks, including 1) close, 2) acquaintance, and 3) stranger. However, unexpectedly, it was very challenging to attract the designed number of study participants to complete the social network. Reasons for this will be discussed later. Rather, only the very first circle of close friends was used, and for many of these participants, less than the desired number of five participants completed the survey. After the initial email and between two to four follow-up emails, the social network of each PWS contained 2-5 people. A total of eight participants completed the survey across the outer two circles across all PWS, meaning that these circles could not be used for the study. Table 1 displays the efforts to attract participants to the study.

Table 2: Progression of Survey Distribution

	Expected	Provided	Sent Email	Started Survey	Completed
PWS	9	-	9	8	7
Friends	35	33	33	24	21
Acquaintances	42	6	6	4	2
Strangers	42	6	6	5	4
Total	182	-	54	41	34

Table 2: Progression of Survey Distribution. *Note: 21 were provided at first but individuals provided additional names that completed survey*

Due to the low response rate, results include only individuals in the PWS’s inner circle. The number of participants across the network of each PWS ranged from 2 to 5. Comparisons between PWS and the inner circle are displayed in Figures 1-7. For the 4S, OASES, and AoS,

the overall means values were obtained. The 4S and the AoS required several items be reverse scored. For the IOS, ratings from the inner circle were compared to each PWS. For purposes of this study, a rating of 7 was considered “very close” with a rating of 1 being “not close at all” (Gächter, Starmer, & Tufano, 2015). Independent factors were intended to be included with each circle, as well as the age and gender of the PWS.

Table 3: Testing Results

	OASES	4S	AoS
PWS	2.03	2.92	1.64
PWNS	2.33	2.93	2.10

Quantitative Analysis

R statistical software version 3.5.3 (R Development Core Team, 2009) was used to compare the means associated with the OASES, 4S, and the AoS between the PWS and the PWNS. Because of the difference in group size, the Mann-Whitney Wilcox test was employed. First, the 4S results showed the PWS (mean=2.92) and PWNS (mean=2.93) did not differ, $W=84.5$, $p=0.5774$.) For the OASES, results of this test showed that PWS (mean=2.03) and PWNS (mean=2.33) did not differ, $W=91.5$, $p=.353$. Finally, the AoS results showed no difference between the PWS (mean=1.64) and PWNS (mean=2.10), $W=90$, $p=0.3934$.

These results do not provide evidence that there was a statistically significant difference between the groups. The quantitative analysis did not examine other explanatory variables across the three measures. However, a qualitative analysis was also employed to look deeper into the data. The remainder of the results section will be dedicated to investigating other patterns in the data.

Qualitative Analysis

The 4S. When examining the results of the 4S, there appeared to be a few trends. The seven PWS were rated between 2.4 and 3.81, indicating variation among individuals. The average score across all participants was 2.98, indicative of a high self-stigma, which is characterized by a score of 3 or higher (Boyle, 2013). The lowest 4S scores were participants 6 and 7, who scored 2.5 or lower. Likewise, both had significantly higher scores reported from their inner rings (P6's ring=3.25; P7's ring=2.94), suggesting the stigma may be more prevalent in their network than they realize.

Variability between PWS and the members of their inner circles is also evident in the 4S. A difference of only 0.32 between the PWS and this first ring indicates similar perception of stigma within a network, which is best exemplified by figures 3 and 5. Participants 1 and 3 and their inner circles rated a high stigma. Likewise, participants 2, 4, 5, and 7 and their inner circles rated a low stigma. Participant 6, however, rated a "low" stigma of 2.5 while their inner circle rated 3.25, showing a discrepancy of perceived stigma within that network.

The OASES: On the OASES, there was more variation between PWS and their inner circle. Two PWS reported a "mild" overall impact, two reported a "mild-moderate" impact, and three reported a "moderate" impact (Yaruss & Quesal, 2006). The inner circles reported overall higher impact ratings when imagining being a PWS; ten reported a "mild-moderate" impact rating, eight reported a "moderate" impact rating, two reported a "moderate-severe" impact rating, and one reported a "severe" impact rating. These findings suggest that people who do not stutter may perceive the overall experience of PWS to be more negative than PWS themselves.

Participants 1 and 3 had the least variation in comparison to their inner circles. In fact, participant 1 differed by only 0.03 compared to the inner circle. Participant 4 had the highest

variation, rating 1.11 lower than the inner circle. This suggested that people making up the inner circle was not aware of the impact that stuttering has on the PWS's overall experience.

Interestingly, participant 4 had limited variation between scores on the 4S and AoS scale. This difference on the OASES measure could be due to the limited communication about feelings, quality of life, etc. between the PWS and the network.

The AoS: The largest variation between PWS and the inner circle was found in the Acceptance of Stuttering as a Disability Scale (AoS). The average PWS scored 1.64 while the average rating of the inner circle was 2.10. This indicates that people within the networks of PWS perceive stuttering to be more debilitating than PWS do. Participant 3 scored 1.53 less than the average of their inner circle, the highest difference among all participants. Interestingly, this same participant did not differ from the inner circle on the 4S. This suggests that although this network agrees on the level of stigma and the severity of the PWS's experiences of stuttering, the inner circles as a whole perceive stuttering to be much more debilitating than PWS do. This could be due to lack of communication throughout the network. This possibility will be discussed further in the Discussion section.

The IOS: On the IOS scale, the average score of the inner circle was 5.33. No clear relation was detected between the IOS ratings and any other survey, but a few trends were noted. First, the two participants who each had the highest IOS score of 7 were very similar to their inner circles. The only notable difference was a higher OASES score for the inner circle, showing that they perceived the PWS's overall experience of stuttering to be slightly more negative than the PWS did. Overall, Participant 2 had the least variation between their scores and those of their inner circle, indicating similar perceptions about the stigma of stuttering, experiences of stuttering and stuttering as a disability. A similar trend was noted for Participant

4, whose score on the OASES was 1.11 higher than the inner circle, despite having the third highest IOS score of 6.67.

Participants 1, 6, and 7 did not show the same trend. These participants received average reported IOS scores between 5.50 and 6.00. However, Participant 1 had a nearly identical OASES score to their inner circle, but received a higher 4S and a lower AoS. This suggests that inner circle similarly perceives impact of stuttering on quality of life but does not agree on level of stigma and debilitating aspects of stuttering. Conversely, Participants 6 and 7 scored lower compared to the inner circle, indicating more negative perceptions of stuttering compared. Once again, these discrepancies may be due to a lack of communication within the social networks.

Participants 3 and 5 received the lowest IOS scores, each below 4.30, indicating an inner circle with the lowest perceived closeness. The 4S and OASES scores for Participant 3 were very similar to the inner circle, in contrast to a difference of 1.53 points on the AoS. Participant 5 had similar scores to their inner circle 4S and the AoS, but the OASES was higher by 0.69. If his social network is not as close, it is unlikely they discuss aspects of stuttering such as speaker's reactions and quality of life.

In summary, the high 4S scores suggest a stigma that exists within social networks of participants in this study. The 4S was also associated with the least variability between PWS and their inner circles, revealing a consistency of perceived stigma. Scores on the OASES showed that PWS often report a lower overall impact of stuttering on quality of life compared to what those closest in their networks perceived. This suggests that people who do not stutter believe that stuttering has a stronger impact on daily life than PWS perceive. Finally, the Acceptance of Stuttering as a Disability Scale showed the most variation between PWS and their inner circles, revealing a disconnect about the debilitating aspects of stuttering.

DISCUSSION

The purpose of this study was to evaluate the attitudes about stuttering within the social networks of PWS. For this study, only people close to PWS were evaluated. A maximum of five individuals identified as being close to a PWS were used for the inner circle of each PWS. It was predicted that knowing a PWS would impact how members of that network think about or perceive stuttering. It was also predicted that people close to PWS would have more positive attitudes about people who stutter.

Main findings

The main finding from this study is that the presence of a PWS within a social network did not appear to strongly influence how members of the network thought about or perceived stuttering. Boyle (2013) found that these negative attitudes negatively correlate with a PWS's quality of life, which may be the case in these social networks. One reason for this finding may be lack of communication among individuals in the social network about stuttering, including the PWS and members of their inner circle.

The prediction that knowing a PWS would have a positive impact on attitudes about stuttering within the social network was not addressed because of the lack of data from the second and third circles. This prediction could have been evaluated by comparing attitudes in the inner versus the outer circle. We did find that those in the inner circle of a PWS rated the overall experiences of stuttering as being more negative than the PWS rated them. These more negative ratings by the inner circle could be associated with the negative characteristics, such as helplessness, loss of control, and low self-esteem, mentioned earlier (De Nardo et al., 2016;

Wright, 1983). If those closest to a PWS notice these characteristics, it may lead them to believe that that they are having a more negative experience than they do.

Ancillary findings

Having members of the inner circle complete the OASES as if they were a PWS was elucidating. The first is the lack of consistency across participants. This would suggest that each network is unique, and this might depend on many different and independent factors. Likewise, finding that those in the inner circle rated the overall experiences of a PWS to be more negative and for stuttering to be more debilitating than actual PWS report it to be shows a disconnect between PWS and those close to them.

In one participate, the spouse of the PWS rated the overall experiences on the OASES to be severe while the PWS rated their experiences to be in the mild-moderate range. It is possible that due to their high perceived closeness, the spouse is more aware of the negative characteristics associated with stuttering such as anxiety, shame, etc. (Boyle, 2015). These observations combined with a lack of communication about stuttering may be contributing the heightened OASES score leading to a disconnect about stuttering. This false stigma of stuttering could lead to a poorer quality of life according to Boyle (2013).

Another observation made from the study was the different stereotypes attributed to PWS on the 4S. There were trends that suggested people believe that the general population find PWS to possess several negative stereotypes such as shy, embarrassed, and insecure. However, it was also reported that PWS are believed to possess positive characteristics such as outgoing, mentally healthy, intelligent, and confident. The most reoccurring trait reported was “nervous”, which is consistent with several studies linking stuttering to heightened anxiety (DiLollo, Manning, & Neimeyer, 2003).

Another finding from this study was that most individuals within the social networks of PWS are aware of a stigma of stuttering which would support the ideas of hyperdyadic spread (Christakis & Fowler, 2009). Although most people may not notice the idiosyncrasies of stuttering behaviors, most people do seem to be aware of the stigma about PWS. Many people, even professionals, may be misinformed about stuttering due to negative stereotypes that persist in society, possibly due to misinformation about stuttering and/or lack of open communication about stuttering between PWS and members of their social networks (Dorsey & Guenther, 2000).

Likewise, people can have positive attitudes about stuttering that cause them to feel biased as well. During the recruitment process, two individuals chosen as “strangers” of a person who stutters reported feeling the need to reveal information before completing the study. Both reported knowing someone else who stutters and having positive feelings about them. They questioned whether this would affect data collection. This also would suggest that not only do PWS sometimes perceive stuttering as part of their self-identity, but others may perceive it as a defining characteristic as well (DiLollo, Manning, Neimeyer, 2003). Although this was not an issue to the study as we cannot control for how others may affect the perceptions of others, we found it interesting that there were cases of a positive stigma that seemed to impact how a person felt about stuttering as a whole

When observing the differences between males and females in this study, we found no differences in the results. It was interesting to find that the two female participants in the study had the fewest members of their inner circle complete the survey. Likewise, 50% of mothers asked to participate in the study completed the survey while 100% of fathers completed the survey. It is possible that both of these findings are due to higher taboo associated with communication in females.

Finally, an important finding from this study concerns how to conduct research to investigate stigma in stuttering. Many clinicians are starting to treat disfluency by observing the attitudes and feelings that the PWS has about stuttering, and it makes sense that we would also study the attitudes within their social networks.

Limitations of study

A primary limitation of the study is that the stigma of stuttering presents a major obstacle when studying the stigma of stuttering. During the initial recruitment, two PWS reported that they felt uncomfortable to be in the study. Likewise, two PWS who agreed to participate reported only being comfortable giving four names in their inner circle to take the survey. One reported that they had never talked about stuttering outside of those few people. Likewise, there were several more cases of people in the inner circle who reported being uncomfortable completing the survey. Several of these refusals were colleagues which could be due to the stigma in the workplace discussed previously (Klein & Hood, 2004). Several inner circle members were unwilling to share the names of acquaintances and strangers that could participate in the study. This may be because they feel it's a private topic, that they felt the PWS would not want them to extend this information, or that they themselves would rather it not be revealed.

There was a clear hesitation and carefulness when naming others that would be taking the survey, revealing a stigma that is present even when researching the stigma of stuttering. PWS and those close to them shared that stuttering was something that was not talked about with many others. The largest struggle was found with the refusal of those in the first circle to name two acquaintances and strangers that would be willing to take the survey. Along with the ones that were uninterested in the study, they were some who reported being unable to imagine their self as a PWS or that felt uncomfortable doing so. The responses were interesting because they

revealed attitudes and stigmas surrounding stuttering through the active refusals. This opened an interesting discussion in the taboo nature of stuttering.

In the future, it would be beneficial to meet with the inner circle of people face to face to discuss the nature of the study before asking them to consent. Likewise, it would also be beneficial to offer compensation to the participants in order to motivate them to complete the survey. It may be more beneficial to continue this study on a younger population due to an inner circle that would be more willing to complete surveys that examine the participant's speech.

Future research

Further research on this topic could lead to a better understanding on the stigma of stuttering within a social network. Larger sample sizes would lead statistically significant results that would better represent the population as a whole. It would also be beneficial if further research included the severity of a person's disfluencies and how this affects their social network's results on these subtests. Further investigation of the differences in male and female circles should also be studied to see whether males that stutter are more likely to have family and friends respond to a study about their speech. Finally, it would be beneficial to include the two outer circles, as the study intended, to better understand how stigma changes within different levels of a network.

Research on the stigma that exists within a social network of children should also be explored so Speech-Language Pathologists can better understand how to aid younger clients. By identifying when a stigma begins to exist, we can better address these topics in therapy and encourage them to be discussed within the social networks of children who stutter as well.

Using younger participants may also aid in the participation limitation as well. If done in a school setting, this may lead to a better response rate. If parents, general education teachers,

specialty teachers, SLPs and the child all are encouraged to take the survey, it may lead to more responses due to the educational environment. Using teachers would provide interesting data to contrast the study with PWS and college professors (Dorsey & Guenther, 2000).

A study with children would also be beneficial to explore whether this stigma exists when the PWS is a child instead of an adult. We know that school-age children see stuttering as a defining characteristic, making it a large part of their life (Lau, et al., 2012). Therefore, seeing how they rate their attitudes about stuttering vs. adults close to them could lead to interesting data. This could expand to studies examining the stigma surrounding preschoolers that stutter vs. adolescents who stutter, which would be easily adjusted using the OASES-S (for school age kids) and the OASES-T (for teenagers). It would be interesting to compare age groups to examine if and when a stigma forms within a network.

Clinical implications

The knowledge from this study can be used in therapy sessions in order to create a more dynamic approach to therapy. Research has been conducted about the importance of assessing and managing emotionality with people who stutter, so we know that there is more to treatment than trying to decrease disfluencies (Choi, Contune, Walden, Jones, & Kim, 2016). By opening up channels of communication in treatment with those in a PWS's social network, we can allow the PWS to see what people in his life think about his stutter as well as clear up and misconceptions. This could be helpful at all ages, especially with the younger population. We believe that the younger we implement open lines of communication within the social network, the more likely a person's self-acceptance will increase as a whole. If friends of young PWS believe it to be more negative, as our study found, this could lead to more negative feelings about

the PWS as a whole. By teaching young people who stutter how to navigate obstacles to communication, they can help change the perception of stuttering as a whole.

Clinically, many SLPs are approaching stuttering with open communication techniques. Many organizations such as the National Stuttering Association promote support groups in order to address confidence and community with PWS (National, 2019). With research on how there is a stigma that spreads past the PWS and within the social groups, it can be possible to support opening these lines of communication for therapy purposes as well. This could also extend to children in the school systems, with reducing stigma being on the Individualized Education Plans at school. The stigma of stuttering is something that should continue to be addressed to help best serve PWS's treatment.

Conclusions

In conclusion, this study found that stigma does exist within the social networks of people who stutter. This stigma of stuttering also seemed to negatively affect data collection due to a variety of feelings including discomfort and unwillingness to openly acknowledge stuttering. I was also found that those close to a PWS may feel that the experiences a PWS is more negative than what is perceived by PWS. Those close to PWS were also more likely to report stuttering as more debilitating than PWS. Stigma is a topic that requires more research, but due to the taboo nature, may come with several obstacles. By opening communication within the social network of a PWS, it may be possible to reduce some of this stigma and increase the overall quality of a PWS's experiences.

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