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Stigma and the Hispanic Stuttering Experience: A Qualitative Study

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FLORIDA INTERNATIONAL UNIVERSITY

Miami, Florida

STIGMA AND THE HISPANIC STUTTERING EXPERIENCE:

A QUALITATIVE STUDY

A thesis submitted in partial fulfillment of

the requirements for the degree of

MASTER OF SCIENCE

in

SPEECH LANGUAGE PATHOLOGY

by

Leslee Dean

2020

To: Dean Ora Strickland
College of Nursing and Health Sciences

This thesis, written by Leslee Dean, and entitled Stigma and the Hispanic Stuttering Experience: A Qualitative Study, having been approved in respect to style and intellectual content, is referred to you for judgment.

We have read this thesis and recommend that it be approved.

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Date of Defense: June 24, 2020

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ABSTRACT OF THE THESIS
STIGMA AND THE HISPANIC STUTTERING EXPERIENCE:
A QUALITATIVE STUDY

by

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Florida International University, 2020

Miami, Florida

Professor Angela Medina, Major Professor

The stigmatization of stuttering has profound effects on the education, employment, and mental health of people who stutter. While there is a large body of research into the impact of stuttering stigma, few studies have considered the effects of cultural differences. The purpose of this study is to provide an in-depth analysis of how Hispanic adults who stutter experience stigma. To do so, seven Hispanic/Latino adults who stutter were interviewed using ethnographic interviewing techniques. A thematic analysis of participants' narrative responses gave rise to four major themes: Family, Stigma in Society, Stuttering Experiences in Cultural and Linguistic Contexts, and Stigma's Impact on Identity. Findings indicate that Hispanic adults who stutter experience stigma in unique ways that affect their language use, cultural participation, and identity. An understanding of these cultural and linguistic factors will allow clinicians to develop a more nuanced and effective approach when treating Hispanic adults who stutter.

TABLE OF CONTENTS

CHAPTER	PAGE
CHAPTER I. REVIEW OF THE LITERATURE	1
Introduction.....	1
Stigmatization of PWS.....	2
Cultural Differences.....	5
CHAPTER II. METHODS	8
Research Design.....	8
Research Team.....	9
Recruitment.....	9
Participants.....	10
Data Collection	11
Data Analysis	12
Reliability.....	13
CHAPTER III. RESULTS	14
Theme I: Family.....	14
Theme II: Stigma in Society	16
Theme III: Stuttering Experiences in Cultural and Linguistic Contexts.....	18
Theme IV: Stigma’s Impact on Identity	21
CHAPTER IV. DISCUSSION.....	23
Key Findings	32
CHAPTER V. CONCLUSION.....	32
Clinical Implications	33
Conclusion	34
REFERENCES	36
APPENDICES.....	40

LIST OF TABLES

TABLE	PAGE
1. Participant Demographics.....	11
2. Theme I: Family.....	14
3. Theme II: Stigma in Society.....	16
4. Theme III: Culture and Language.....	19
5. Theme IV: Stigma's Impact on Identity.....	21

CHAPTER I. REVIEW OF THE LITERATURE

Introduction

The stigmatization of stuttering is a significant issue that has profound effects on people who stutter (PWS). Many studies have documented how children and adults who stutter (AWS) are negatively perceived by students, teachers, clinicians, and the public (Boyle, 2018; Cooper & Cooper, 1996; Craig et al., 2003; Dorsey & Guenther, 2000).

The nature of stuttering leaves PWS particularly vulnerable to the effects of stigmatization. While stuttering is diagnosed based on specific speech behaviors and physical concomitants, it includes affective and cognitive components that impact PWS' feelings and attitudes about themselves and their ability to communicate (Bennett, 2006). Experiences with stigma can exacerbate these negative emotions and further impact the mental health, social and professional lives of people who stutter (Boyle, 2018; Bricker-Katz et al., 2013; Corcoran & Stewart, 1998). Therefore, an understanding of the stigma experienced by PWS is critical to an understanding of fluency disorders.

While there is a large body of research into stuttering stigma and its impact, very few studies have considered the effects of cultural differences. In their review of multicultural issues within stuttering, Finn and Cordes (1997) highlight the importance of clinician sensitivity to cultural differences and emphasize the lack of data related to stuttering in specific cultures. Within the Hispanic population, several studies have found connections between culture and the stigmatization of stuttering (Crutchfield & Wang, 2016; Erickson et al., 2002; Medina, 2018; Tellis, 2008). However, a deeper understanding of the way Hispanic AWS experience stigma is necessary to more effectively assess and treat members of this population.

Stigmatization of PWS

As classically defined by Goffman (1963), stigma occurs when an individual possesses an attribute that causes their social identity to diverge from what others expect it to be. The stigmatized person is therefore considered less than human, leading to discrimination and reduced life opportunities (Goffman, 1963). Elaborating on Goffman's premise, Link and Phelan (2006) describe stigma as a process containing five interrelated steps. In their conceptualization, the individual is first labeled, or stereotyped, through a process of social selection. They are then separated by the labelling group into "them" versus "us". The excluded individual in turn experiences discrimination and loss of status, leading to a loss of power (Link & Phelan, 2006). Naturally, the process of stigmatization can have a large effect on the life of the stigmatized individual, affecting their stress levels and overall health (Link & Phelan, 2006).

The processes of stigmatization detailed by Link and Phelan (2006) are reflected in the existing research on perceptions of PWS. It is well documented that children and AWS experience stereotyping and negative labeling from students, teachers, healthcare professionals, and the general public. This stereotyping begins in childhood, with school-age and middle school students holding negative views of peers or AWS (David et al., 2008; Franck et al., 2003). Research has shown that university students attribute more negative personality traits to a hypothetical adult who stutters than one who doesn't (Crutchfield & Wang, 2016; Dorsey & Guenther, 2000; Hall, 2007). Using self-reporting measures and the Implicit Association Test, Lesner and Walden (2018) found bias in both explicit and implicit attitudes toward PWS. These negative attitudes extend to young

children, with one study finding children who stutter were more likely to be stereotyped as shy, nervous, and insecure at as young as 3 years old (Blood & Betz, 2008).

Negative stereotypes of PWS have also been found among teachers and even speech-language pathologists. In one study in which college students and professors rated the personality of a hypothetical student who stuttered, professor respondents were found to have more negative perceptions of the hypothetical PWS than the student participants (Dorsey & Guenther, 2000). Research shows that classroom teachers hold negative opinions of students who stutter, and that teachers' beliefs about PWS do not differ from those in non-teaching professions (Arnold et al., 2015; Woods, 1978). Similar opinions have been found in past surveys of speech-language pathologists, where a significant number agreed there were personality traits common to those who stutter and many held unsubstantiated beliefs about early intervention (Cooper & Cooper, 1996). A more recent survey of school-based SLPs found that their willingness to help and sympathize with PWS was linked to their beliefs about whether stuttering is under PWS' control (Boyle, 2014). These results indicate that a lack of accurate information about stuttering can contribute to the stigma experienced by PWS, even among clinicians.

In the general public, opinion surveys demonstrate that adults hold stereotypes of PWS, presuming they are nervous, shy, or lacking self-confidence (Armson et al., 1993; Boyle, 2017; Craig et al., 2003). Some survey respondents have expressed the belief that there are certain occupations, such as teachers and lawyers, that PWS should not hold (Boyle, 2017). Boyle (2016) found that people who believed stuttering was caused by psychobehavioral factors under PWS' control were more likely to blame and stereotype PWS. Research involving the family, friends and colleagues of PWS found their

perceptions of PWS to be more positive, demonstrating that increased contact with PWS could serve to reduce stigma (Klassen, 2001). However, existing literature makes clear that the generally negative perceptions of stuttering held by students, teachers, clinicians and the public result in the stereotyping and subsequent stigmatization of PWS.

According to Link and Phelan's (2006) conceptualization of stigma, the labelling or stereotyping of those who stutter will lead to an "us" versus "them" mentality and discrimination against people who stutter. Starting in childhood and adolescence, PWS experience negative social consequences and feel the desire to conceal their stuttering (Blood et al., 2003; Hunsaker, 2011). Among adults, research has demonstrated that beliefs about stuttering and opinions of PWS can predict how people who stutter are treated (Arnold & Li, 2016). In a 2016 survey, respondents who held accurate beliefs about the cause of stuttering and who felt that PWS could lead successful lives were more likely to try to help and accommodate PWS, as opposed to interrupting or making fun of them (Arnold & Li, 2016).

In his 2018 survey, Boyle explored the impact of stigmatization on the lives of PWS, distinguishing between enacted and felt stigma. Enacted stigma included social devaluation, negative treatment, and discrimination, while felt stigma entailed PWS anticipating and expecting future negative experiences. Most respondents had experienced social devaluation and negative treatment at some point in their lives, and thus anticipated future stigmatizing experiences (Boyle, 2018). These findings align with those described by Bricker-Katz et al. (2013), who found that PWS' expectations of negative evaluations from others significantly affected their self-perceptions and professional lives.

Negative treatment towards PWS can ultimately lead to feelings of shame and helplessness, or the loss of power that reflects the final element in the process of stigmatization (Link & Phelan, 2006). Corcoran and Stewart's (1998) interviews with AWS found suffering to be the most common theme in their participants' descriptions of stuttering. Within that suffering, they found that discriminating treatment such as being made fun of, imitated and ignored caused participants to feel deep shame and resulted in feelings of helplessness (Corcoran & Stewart, 1998). As its ultimate consequence, this loss of power and anticipation of negative treatment results in increased stress and reduced physical and mental health for the stigmatized group (Boyle, 2018; Link & Phelan, 2006).

Cultural Differences

It is well-established that the stigmatization of stuttering has significant effects on the perceptions, life opportunities, and mental health of PWS. However, within this research very few studies have considered the effects of cultural or linguistic differences. The United States' population is increasingly diverse, and as of July 2019, the U.S. Census Bureau estimated it to be approximately 18% Hispanic (U.S. Census Bureau, 2019). It is estimated that approximately half a million bilinguals in the United States stutter, and most bilinguals in the United States report Spanish as their additional language (Shenker, n.d.; U.S. Census Bureau, 2015).

Despite the United States' increasing Hispanic population, there is little research into the experiences of Hispanic AWS. When mentioned, the demographic information in existing research demonstrates culturally homogenous samples with few ethnic minorities included. Studies of the perceptions of PWS completed with middle school students

(David et al., 2008), university students (Hall, 2007), and the general public (Boyle, 2007) all state that over 80% of their participants identified as Caucasian, with 5% or less identifying as Hispanic. Boyle's 2018 survey of 324 AWS provided critical information on the stigma experienced by participants and its effect on their mental health. However, 74% of its respondents identified as Caucasian non-Hispanic, and only 7% identified as Hispanic (Boyle, 2018).

In their review of multicultural issues within stuttering, Finn and Cordes (1997) stressed the need for clinician sensitivity to cultural differences and highlighted the lack of data on stuttering within specific cultures. When evaluating the personal impact of stuttering, a clinician must suspend their own cultural framework and seek to understand their client's perspective (Finn & Cordes, 1997). To do so, clinicians need data related to stuttering within different cultures, such as Daniels et al.'s (2006) analysis of the experiences of African American men who stutter. As African American AWS, Daniels et al. found their participants were uniquely affected by both their racial identity and communication difficulties.

With regard to Hispanic populations, there is limited research indicating that stigma exists and may be influenced by cultural factors. Crutchfield and Wang (2016) surveyed Hispanic university students to assess their perceptions of PWS. They found that similar to non-Hispanic cultures, Hispanic students viewed PWS as having lower personality and sociability characteristics (Crutchfield & Wang, 2016). Tellis (2008) developed a Stuttering Inventory for Hispanic Americans to assess the Hispanic population's opinions on social stigma, causes and cures, and perceptions of PWS. The inventory accounted for acculturation, or the degree to which participants had taken on

characteristics of mainstream non-Hispanic culture. It was administered to Hispanic American college students and found that in general, the students held mostly positive beliefs about stuttering (Tellis, 2008). However, the results also demonstrated that as students' acculturation increased, they were more likely to disagree that stuttering is socially stigmatizing. This suggests that among less "acculturated" Hispanic populations, stuttering may be perceived as more socially stigmatizing (Tellis, 2008).

Erickson et al.'s (2002) research with forty members of a Hispanic family further supports the influence of culture on the Hispanic experience of stuttering. Through open and close-ended questions, researchers interviewed family members spanning four generations about the causes and treatment of speech, language and hearing problems. Causes and cures were separated between medical beliefs and "folk beliefs," defined as beliefs with a cultural basis such as religion and home remedies (Erickson et al. 2002).

Erickson et al.'s (2002) interviews with Hispanic family members found that the majority of participants agreed with the five folk beliefs listed for prevention or cure of disabilities, with the most common being prayers to a specific saint for favors. For treatment of stuttering, most participants reported that they would turn to a speech-language pathologist for help, with 80% reporting they would also use prayer, and 75% indicating they would tell the person to slow down (Erickson et al. 2002). Among participants with a high school education, 27% agreed with folk beliefs related to cures for stuttering (Erickson et al., 2002). These findings align with those found in an interview with a Hispanic mother of a PWS, who felt that difficulties during pregnancy may have caused her child to stutter and referenced cures for stuttering rooted in cultural practices (Medina, 2018).

In summary, research has found that both children and adults who stutter experience stigma and negative stereotyping from peers, teachers, healthcare professionals, and the general public. This stigma includes overt acts of discrimination and the anticipation of negative experiences, and adversely affects the social and professional lives of AWS. As the ultimate consequence of stigma, AWS experience a loss of power that can affect their mental health. While research shows that cultural factors affect how AWS experience stigma, existing research among the Hispanic population is limited to university students and individual Hispanic families. Therefore, this study seeks to provide a deeper understanding of Hispanic AWS' experiences with stigma that could lead to more nuanced and effective treatment for members of this population.

To provide a detailed description of the ways Hispanic AWS experience stigma, this study will utilize traditional qualitative methods in which narrative data from a small number of participants is analyzed in-depth. Data collection and analysis procedures were designed to answer the following research questions: 1) How do Hispanic AWS experience stigma? 2) Do Hispanics who stutter experience stigma differently in different cultural or linguistic environments? 3) How do these cultural factors affect Hispanics' feelings about their stuttering?

CHAPTER II. METHODS

Research Design

This study utilized traditional qualitative research methods to provide a detailed description of the ways in which Hispanic adults who stutter experience stigma. As opposed to searching for one right answer, a qualitative approach generates data from the

experiences of a small number of participants to provide an in-depth understanding of the subject matter (Armstrong et al., 1999; Braun & Clarke, 2006; Daniels et al., 2006). Data was collected through semi-structured interviews consisting of seven open-ended questions and eleven guided prompts. Data saturation was determined to have been reached when initial themes contained a significant amount of detailed data, and no further themes were emerging (Fusch & Ness, 2015). Participants' interview transcripts were analyzed using thematic analysis, in which information rich quotes were highlighted and categorized into emergent themes and subthemes (Braun & Clarke, 2006).

Research Team

The research team was comprised of one graduate student in their second year of a master's in science in speech-language pathology (SLP) program and a senior researcher. The graduate student has extensive experience in Spanish/English translation and narrative data collection. The senior researcher has PhD training, CCC-SLP credentials, experience as a National Stuttering Association chapter leader and research expertise in stuttering. Prior to the start of the current study, the graduate student researcher was trained to use thematic analysis procedures using data from the senior researcher's lab.

Recruitment

Participants were recruited using purposeful sampling, in which a small number of individuals are selected based on their knowledge of the topic of interest, willingness to participate, and ability to communicate their thoughts and experiences (Palinkas et al., 2015; Spradley, 1979). Following approval by FIU's institutional review board (see Appendix A) and the National Stuttering Association's Research Committee, a

recruitment email was sent to the National Stuttering Association's listserv. Interested participants responded to the researcher by email and were screened according to the following inclusion criteria: self-identifies as a PWS; self-identifies as Hispanic or Latino; 18 years of age or older; and began stuttering in childhood. Participants were required to be proficient in English for purposes of informed consent, but data collection could occur in the language the participant was most comfortable with (English or Spanish). All participants chose to be interviewed in English.

Once established that interested participants met the inclusion criteria, interview dates via Skype were arranged on a first come first served basis. Upon scheduling an interview through an online scheduling system (Calendly), participants were assigned individual study identification numbers (P1, P2...). Recruitment ended after transcription of the seven participants' interviews determined they had provided a large quantity of detailed data with no additional themes arising, resulting in data saturation (Fusch & Ness, 2015). This process yielded seven total participants who signed up for and completed an interview. One prospective participant scheduled an interview, but did not respond when contacted to complete it.

Participants

Before participating in the interview, participants gave their informed consent and completed two questionnaires providing information on their demographic and cultural background as well as their history of stuttering (see Appendices B and C). Participants consisted of four adult females and three adult males. Of the seven participants, four were 2nd generation American (at least one parent born outside the United States) and three were born in Latin America. Participants and their parents represented different places of

origin including Guatemala, Mexico, Cuba, Peru, Honduras, and Puerto Rico. In close-ended data collection of race/ethnicity, all participants identified as “Hispanic/Latino,” with some selecting both “Hispanic/Latino” and “White.” Participants also had the opportunity to culturally identify through an open-ended statement (see Table 1). The majority of participants (5/7) rated their own stuttering severity as moderate.

Table 1. Participant Demographics

Participant	Age Range (years)	Gender	“I culturally identify as...”	Country of Origin	Level of Education	Age of Onset (years)	Perception of Own Stuttering Severity
1	46-61	M	Latino	2 nd gen. American [Puerto Rico and Mexico]	Doctorate	6	Moderate
2	18-24	F	White Hispanic	Honduras	Some college	8	Moderate
3	31-45	F	No response	Peru	No response	4-5	No response
4	31-45	F	Mexican American	2 nd gen. American [Mexico]	Associate degree	5-6	Moderate-Severe
5	31-45	M	Hispanic	2 nd gen. American [Cuba]	Master’s degree	3	Moderate
6	18-24	F	Latina	2 nd gen. American [Mexico]	High school degree	4	Moderate
7	46-61	F	Guatemalan	Guatemala	Some college	3	Moderate

Data Collection

Data was collected through semi-structured interviews via Skype in which participants were asked a series of open-ended questions and planned prompts (see Appendix D). The interviews were audio recorded and lasted from 30 to 60 minutes. The study utilized ethnographic interviewing techniques, in which initial open-ended

questions were designed to elicit comprehensive responses and prompts were used to further elaborate on participants' experiences of stigma (Westby, 1990).

Interview questions explored four main topics intended to draw out detailed descriptions of participants' experiences with stigma and its effect on their lives. These topics were developed from existing literature regarding the processes of stigmatization and cultural conceptions of stuttering. They included: a) participants' cultural identity and language use (e.g. Finn & Cordes, 1997), b) cultural attributions as to causes or cures for their stuttering (e.g. Boyle, 2016; Erickson et al., 2002), c) how they feel they've been treated as a person who stutters (e.g. Corcoran & Stewart, 1998) and d) their attitudes toward their stuttering (e.g. Boyle, 2018; Daniels et al., 2006). Open-ended questions in these areas of interest generated narrative data on participants' experiences with stigma and allowed them to elaborate on the topics most salient to them. Following each interview, the audio recordings were transcribed by the researcher.

Data Analysis

Following transcription of all data, participants' narrative responses were analyzed using thematic analysis, in which themes emerge through the coding and categorization of narrative data (Anderson & Felsenfeld, 2003; Braun & Clarke, 2006). The researcher first read each transcript several times, becoming familiar with the data and taking notes on initial patterns (Braun & Clarke, 2006). They then highlighted relevant quotations, or those that provided the most detailed and nuanced information pertaining to the research questions (Fusch & Ness, 2015). The quotations were then placed into a separate document, color coded, and sorted into preliminary groups based on the similarity of their content. The initial groups and relevant quotations were

discussed by the research team to account for potential bias (Armstrong et al., 1997). These preliminary groups were then refined and collapsed, creating distinct themes with mutually exclusive data (Braun & Clarke, 2006). The resulting themes include a large quantity of nuanced, detailed quotations, meeting the “rich” and “thick” standards for data saturation (Fusch & Ness, 2015, p. 1409). The thematic analysis process resulted in four major themes and eleven subthemes.

Reliability

Throughout the analysis process, researchers ensured reliability and controlled for bias through the processes of data triangulation and member checking (Armstrong et al., 1997; Corcoran & Stewart, 1998; Damico & Simmons-Mackie, 2003). Data was triangulated by the senior researcher, who independently coded groups of salient quotations at 93% inter-rater reliability. Discrepancies in coding were then discussed by the research team, creating clear and comprehensive definitions of the data encapsulated in each theme (Braun & Clarke, 2006; Miles et al., 2014). After agreeing on each theme’s central idea, researchers determined a name for each theme based on its core meaning (Braun & Clarke, 2018). The research team’s interpretations were further confirmed through member checking (Damico & Simmons-Mackie, 2003). To ensure that results reflected participants’ intended meanings and to rectify any misinterpretations, each participant was contacted and shown their quotations and corresponding themes. Six of the seven participants reviewed their individual quotations relative to the research team’s themes and confirmed their intended meaning. One participant did not respond to the research team’s request for review.

CHAPTER III. RESULTS

Four major themes emerged from participants’ responses to open-ended interview questions. They include: Family, Stigma in Society, Stuttering Experiences in Cultural and Linguistic Contexts, and Stigma’s Impact on Identity.

Theme I: Family

All seven participants discussed their experiences with family as children as a primary source of stigmatization. Participants described this stigma primarily through family members’ proposed causes and cures for their stuttering, resulting in the subthemes “Beliefs about cause” and “Beliefs about cures.” Most participants also recounted their family’s general reactions to their stuttering, as described in the subtheme “Reactions.” These reactions were generally negative and included low expectations for people who stutter, being made fun of by family members, and stuttering as something the family did not talk about.

Table 2. Theme I: Family

Theme	Subthemes	Exemplar Quotes and Participant Codes
I. Family	i. Beliefs about cause	<p>“My mom and dad would say well, you know he’s little, he’s having a hard time with the English, and the Spanish both, and he’s going back and forth with the languages...” [P1]</p> <p>“When we were like at house functions or with relatives I would always hear that... ‘it happened because he got really sick, and then he got really nervous, and then it affected him psychologically’...” [P1]</p> <p>“And my parents just thought it was a phase type of thing, or they thought it was a reaction, because I had been bullied at school before.” [P2]</p> <p>“I didn’t know what a stutter was back then. But they used to send me to ESL. So I don’t know if they thought that I was just having trouble with English, or confused. Because my family just speaks Spanish, I don’t.” [P4]</p> <p>“...my dad too, he’s just like ‘oh, you stutter because I made fun of so and so,’ like [someone] deep in his family who stutters.” [P4]</p> <p>“They definitely thought it had to do with us [my twin and I] being nervous and excited to talk and stuff like that. And, they thought it was because there was some sort of competition between the two of us, like to tell a story that had</p>

		<p>happened in school...and so because of that we would just stutter, because we were excited.” [P6]</p>
	<p>ii. Beliefs about cures</p>	<p>“I always had that well-meaning aunt or uncle that would give me like articles about getting therapy, and then there were the people who would give me the old, ‘just slow down and breathe’ things and that really doesn’t work.” [P1]</p> <p>“My mother and my grandmother are very religious. And they attended an evangelical church. So, laying of the hands, and you anoint with oil... And for many years they would put me through these services and the heads of the church would grab the oil and anoint me with oil, and they would put it on my tongue, and ‘we rebuke these evil spirits’...so then you think you have this evil spirit in you...in the Bible you read about all these miracles, and I was waiting for that miracle.” [P1]</p> <p>“My parents thought it was a phase, so they would try to tell me to breathe before I said a sentence, or my dad would have me read out loud and tell me when to breathe.” [P2]</p> <p>“They [family] would always say ‘breathe,’ I’m like, but I’m breathing. They were like ‘don’t talk too fast,’ but I’m like I can’t stop it that’s the way I talk, I just talk fast. And then they’re like ‘oh, she’ll be ok, something temporary.’” [P3]</p> <p>“...they [family] would tell me to just slow down and breathe, not be so anxious...like all these things and I’m like, I’m not anxious, I’m fine. But they just think that it was like a breathing problem.” [P4]</p> <p>“...my sister also, she doesn’t have a stutter, but when she was little she had a problem where she couldn’t pronounce her ‘c’s...so then they would stick Cheerios in the bottom of her tongue, to correct her. Because that’s what someone in our family said to do...So she would have all these Cheerios underneath her tongue because they were afraid she was gonna end up stuttering like me.” [P4]</p> <p>“...in hindsight reading some of the research of sort of what we know now of like how you’re supposed to treat kids who stutter, and not you know, be constantly correcting them, or completing their sentences for them, or telling them to slow down, or to calm down, or do things like that. There was a lot of that.” [P5]</p>
	<p>iii. Reactions</p>	<p>“When I was younger, they [family] did say things like well, ‘he’s not gonna do too much,’ or ‘he’s gonna work in a warehouse, he’s gonna be you know just lifting boxes his whole life’.” [P1]</p> <p>“I mean, obviously like they’re super embarrassed they still are now. I mean, they [family] don’t tell me that but you can see it in their faces. And then the worst thing that you can do to someone, I feel like when I stutter and stuff, is to speak for me, or to finish my sentences no matter how long I take. And like, they do that all the time where they’ll just like cut me off, or they don’t like to have conversations with me, and they don’t really have a lot of patience for it.” [P4]</p> <p>“My family used to laugh, and give me a hard time about it, and like about how I need to keep this job, because I’ll never be able to get another job with my</p>

		<p>disfluencies. And like, ‘oh you’re so lucky you got this job with your stutter’...” [P4]</p> <p>“I think if anything like with my Hispanic relatives I think just because they were more old fashioned, like you know, it’s like, if anyone has anything wrong in the family it’s more like we don’t talk about it.” [P5]</p> <p>“I do remember, you know, I have recollections of them making fun of my stuttering. And, like I said that was early in life. And I remember comments made by my mother, that were not very nice. You know, like things like, ‘may God give you your speech’ but like laughing, saying it like that. So that was not nice of course.” [P7]</p> <p>“It was like, something that no one talked about. Even though later...I realized it, my second brother stutters also. But as a child, growing up, I didn’t know that. To the extent that I knew about stuttering is about like jokes people tell about a stutterer, or later watching TV. But, not really ever really knowing that stuttering as a condition, or as a problem with your speech.” [P7]</p>
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Theme II: Stigma in Society

When describing their experiences with stuttering, all participants described experiencing stigma from society as a whole. These descriptions fell into three subthemes: “Negative experiences in school,” “Not fitting into gender stereotypes,” and “Public misconceptions of stuttering.” Most participants, particularly those who grew up outside of the United States, reported how they were treated in school as formative to their experience with stuttering. Four participants, both male and female, described reactions to their stuttering that fell in line with traditional gender expectations. Apart from school and gender-based experiences, participants reported experiences reflecting the perception of stuttering in the general public. These experiences included laughter, being considered “*mentally slow*” (P4), and negative portrayals of people who stutter in the media.

Table 3. Theme II: Stigma in Society

Theme	Subthemes	Exemplar Quotes and Participant Codes
II. Stigma in Society	i. Negative experiences in school	<p>“...as I started getting older maybe 6th grade... I started getting into fights, because people would tease me... I think that’s when I started to really become very introverted, and just hated speaking in class, hated speaking in front of people.” [P1]</p> <p>“I recall being made fun of by kids. I went to an international school, so it was kids from many places but people did not understand it too well, so I got made fun of a lot for how I talked. So that really affected me. Because teachers didn’t seem to do much about it I guess.” [P2]</p> <p>“So in school, in Peru when I was there...they didn’t see it as a problem. They saw it more like ‘Aw, it will just happen. She’ll get over it.’ And, I was the only person that I knew that stuttered, no one else stuttered in school. [P3]</p> <p>“Well, back then it wasn’t called bullying, but they would mimic what I used to say. And then, yeah, even in high school, like high school here [U.S.] they would be like, mimicking what I said, or laughed at what I say.” [P3]</p> <p>“... you know kids are mean and they will, you know, call you names and make fun of you. I think especially in the middle school, high school years...you know, I remember having teachers telling me I didn’t have to speak in class, or trying to give me sort of like exceptional treatment. And, even kind of as a young kid I always thought that was weird, and I was like, I don’t want you to treat me special, I just wanna, you know, I just wanna be normal.” [P5]</p> <p>“...when I started 3rd grade, one of the things that we had to do is that we had to memorize our lessons...then we had to recite the lesson the next day from our seats, but standing. And I remember the first time, I was a mess. You know, I got started, and of course I got stuck, and I was nervous, and I could hear kids, some were laughing maybe. Which made it worse cause then I was dealing being nervous too. So and the teacher said well, ‘Did you learn your lesson?’ And I said yes, you know, yes. And then I tried to continue, but it was hard. So she told me to sit down....So, that was embarrassing, you know, cause I couldn’t finish. So, then came the next time...she told me to just sit down, just sit down. So, I did. But it really hurt.” [P7]</p>
	ii. Not fitting into gender stereotypes	<p>“If I got into a fight...as a young man because of it...somebody would make a comment, or they would tease me or things like that, and then I’d have to say something back.” [P1]</p> <p>“I guess people perceive me [a female] as like, not being confident or being unsure of myself. That’s how I feel sometimes, but I’m like, like if I want something, so like in a restaurant, if I want that thing, then I’ll still order it in spite of my stuttering.” [P2]</p> <p>“Like they [family] think, oh well no one’s gonna want someone who can’t speak type of a thing. But I feel like if I was a boy it would be different, because I would know like a trade, that was a labor trade or something like that. Which wouldn’t really matter to them cause I could take care of myself. You know, I would have a wife who would stay home and take care of all my needs and stuff.” [P4]</p> <p>“...through the traditional patriarchal structures on which our society is constructed, you know men who stutter are you know, perceived as weaker, they’re perceived as not as intelligent or not as, in charge or forceful, or you know less masculine, I guess. I think it does carry that stigma to it as well. Because you can’t you know, act like a man in the way that other men who don’t have speech impediments do.” [P5]</p>

		<p>“I’m not gay, but...kids call each other you know, slurs for homosexuals a lot when they’re younger as like an insult, especially between boys. But I mean I think like I also experienced that too. I think maybe because I was quieter, I was meeker, and that is definitely I think connected to my stuttering.” [P5]</p>
	<p>iii. Public misconceptions of stuttering</p>	<p>“...sometimes when I have bad periods of fluency people would be like ‘ahhh’ they would look over like that. And just like be shocked, or people whenever I stutter they always ask me if I’m cold, so I have to explain to them that no, it’s just how I talk.” [P2]</p> <p>“And I’ve had some bad reactions [in U.S.], like I’ve had people ask me if I forgot my name, or they’ve made a comment about me being slow. But that’s just been a couple people, but I think people are just fine with it. I’ve had the most issues with food service, because they think that I can’t hear them, so they repeat the question and then it can be hard for me to say it.” [P2]</p> <p>“I’ll tell you something funny so, whenever I stutter here [New York] they think I’m getting a cold, or if I’m cold.” [P3]</p> <p>“One thing I do remember, about stuttering at least in Peru...some of the TV shows that they had, there always was a character that had to stutter. And they always, the stutterer would be dumb. And I don’t think that connection is relevant or true.” [P3]</p> <p>“Well in general everybody laughs, that I’ve met. Like it’s very rare that people don’t laugh, but I don’t know if they think it’s cause I’m joking, or what, and then they realize that I stutter.” [P4]</p> <p>“...they think because I stutter...like oh, she’s mentally slow. So we can rack up her prices, or we’re gonna take advantage in some way, and I’m just like, no. That’s not gonna happen. Don’t confuse the speech with my mental state.” [P4]</p> <p>“Most times, most people don’t really understand what stuttering is, so they just think it’s because I’m nervous, or that it should go away soon...But recently, I just started college, so when I introduce myself and I often stutter on my name, and the state that I’m from. So recently people laugh a little, or they’ll be like ‘I can’t believe you forgot your name, that’s so funny, are you sure that’s your name?’” [P6]</p> <p>“Now I’ve had other situations where people just laugh. And like start to imitate it. You know, think it’s funny. I guess cause when, most of the time they don’t hear me stutter, so when it happens, I don’t think they’re doing it because they know that I stutter. Just cause, they think it just happened and it’s funny.” [P7]</p>

Theme III: Stuttering Experiences in Cultural and Linguistic Contexts

The effects of culture and/or language were discussed by all seven participants when describing their experiences with stuttering. Within this main theme two subthemes emerged: “Perceptions of stuttering within cultural communities” and “Role of linguistic

environment in language selection.” The significance of participants’ cultural communities arose through their explicit comparisons of reactions to stuttering in different cultural environments. In addition, six out of seven participants reported that the language they spoke or were expected to speak (English or Spanish) affected their stuttering and choice of language. Within this subtheme, three participants (P2, P5, P6) reported feeling more rushed or anxious when speaking Spanish, which exacerbated their stuttering. Two participants (P1, P7) reported switching between languages as a method used to avoid stuttering.

Table 4. Theme III: Culture and Language

Theme	Subthemes	Exemplar Quotes and Participant Codes
III. Stuttering Experiences in Cultural and Linguistic Contexts	i. Perceptions of stuttering within cultural communities	<p>“...in Honduras I didn’t have support groups. There was no such thing there, so I didn’t really know anybody else who stuttered. So it was hard for me to relate to people. But here, because I have some support groups I can somewhat relate to them...so us moving here has been easier because I have found more people that understand.” [P2]</p> <p>“And I think the culture there [Honduras] is not really too understanding of stuttering. So it has been kinda hard, well I’ve been fortunate that my family has been understanding. But other people have not been too understanding in the culture there, because it’s not something that’s too common.” [P2]</p> <p>“...people in Peru would just laugh. People here [in U.S.] they would just wait and see what was going on, and they would stare at me. And some people were anxious, like ‘speak up,’ and some of them, they actually let me take my time.” [P3]</p> <p>“I do think that if I would have stayed in Peru, with my stutter it would have been a challenge to graduate, to find a job. Because they would have thought because I stutter I was like, not up to the level of what they need.” [P3]</p> <p>“...and it’s not just my family but my Mexican friends...they say things, like, ‘you can’t give babies hot sauce’ and things like that, because they’ll develop a stutter...or they’ll put that little bug in your mouth, to try and correct the stutter and things like that.” [P4]</p> <p>“My white friends...whenever I finally started going over to my friends’ homes and stuff like that, they were very patient with me. They didn’t laugh and stuff, they would just engage me, like hold eye contact and wait until I was done. Which I had never experienced before.” [P4]</p>

		<p>“I don’t know if it’s just like culturally, people feel like they can tell you how you need to solve your problems. Like you don’t live with them every single day of your life. Like they always have to offer some type of advice.” [P4]</p> <p>“...there is a stigma about it. Just, anecdotally in Latin American culture, you know. I think because the language is so fast, and people are always talking very very quickly in Spanish. Like, I think if you have a stutter, and you quote ‘can’t keep up’ it’s, it’s kind of looked down upon and it’s frowned upon...and it seems to carry a certain stigma. And I mean like there’s a stigma too in English and in English-speaking cultures, but just for whatever reason, I don’t know Spanish or Hispanic people seem to be way meaner about it.” [P5]</p> <p>“...I think that may be part of why I feel like Hispanic men are like meaner, about people who have a stutter. Or they look down upon it more, because it seen as this, as like a sign of weakness. And to be weak is not, is out of conformity with the sort of traditional Latin American strong man, you know that is at the center of, sort of the way that life is organized.” [P5]</p>
	<p>ii. Role of linguistic environment in language selection</p>	<p>“...it can be hard for me to talk in Spanish, because it’s just really rushed as well. And it’s really...like they speak really fast too so it’s harder. But I’ve always felt like I’ve had a problem more in Spanish than with English, probably because I get more nervous talking to people in Spanish, because it’s not really understood about stuttering.” [P2]</p> <p>“...I started going into English and Spanish, because if there was a word I didn’t wanna say in Spanish, then I would say it in English it was much easier.” [P1]</p> <p>“To me, stuttering doesn’t involve language, it’s just the way I speak.” [P3]</p> <p>“...personally when I speak Spanish I stutter a lot more. And I think that’s just because I grew up not speaking Spanish. So, it’s new sounds, it’s new words, it’s new syntax stuff. And I’ve worked really hard, with being able to speak fluently in English. And trying to speak Spanish, it’s just like all of the sort of disfluency that I’ve been able to kind of smooth out over the years just comes right back up to the surface when I try to speak Spanish. So, when I speak Spanish I think people say like ‘oh, this is a guy who looks white, he’s like a white guy trying to speak Spanish’ and that’s where I get sort of negative feedback. Or people kind of like, rolling their eyes at me. Or trying to complete sentences for me, or you know, showing visible frustration that I can’t speak fluently.” [P5]</p> <p>“...I haven’t spent that much time in Latin America. And frankly it’s like a thing that makes me nervous...just like, you know, the physiological barrier that I come up against trying to speak Spanish you know makes me nervous that if I need to get directions somewhere...me being a clearly stuttering foreign person who speaks Spanish, like is that gonna make me somehow more vulnerable, or something like that.” [P5]</p> <p>“So then certain vowels, that you only say in Spanish, like with the ‘r’ and stuff like that, it’s really difficult for me to do. But</p>

		<p>when I'm completely relaxed, and just talking with anyone, then it's fine. And, so I pretty much stutter the same in Spanish, except for when I get really anxious." [P6]</p> <p>"...a lot of times, when you're in a bilingual area, so people start speaking Spanish to me, and if I stutter, I think they often think that it's because I can't speak Spanish. So then they'll immediately switch to English. But that's not the case, like I would have probably stuttered just the same in English." [P6]</p> <p>"And, another thing that I guess was more of a crutch than anything else was like, because I learned English when I came here [to U.S.]. And, so a lot of times when I would pretend that I didn't know something, so people assumed that it was because I didn't know English...So that became kind of an excuse, like not knowing how to say something...I was not afraid of stuttering but, just afraid of using the English language, would make me nervous. Which did not help my stuttering either." [P7]</p>
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Theme IV: Stigma's Impact on Identity

The final theme emerged from participants' feelings about their stuttering and the impact of stigma on their identity. Participants' expressions of identity separated into three subthemes: "I always thought there was something wrong with me," "Navigating connections to Hispanic culture as PWS," and "Journey toward overcoming stigma." The first subtheme encompasses the negative feelings related to self-identity expressed by five out of seven participants. One participant, P2, expressed feeling like there was always something wrong with her. This sentiment was echoed by most participants, as they described feeling shame and embarrassment related to their stuttering.

The second subtheme, "Navigating connections to Hispanic culture as PWS," includes the complicated relationships with cultural identity expressed by four participants. As described by these participants, the act of stuttering combined with their Hispanic/Latino identity has forced them to navigate their sense of connection to Hispanic culture. The final subtheme emerged from participants' descriptions of their

journey toward overcoming stigma. Most participants expressed this journey as a struggle for self-acceptance, often facilitated by exposure to other people who stutter.

Table 5. Theme IV: Stigma’s Impact on Identity

Theme	Subthemes	Exemplar Quotes and Participant Codes
IV. Stigma’s Impact on Identity	i. “I always thought there was something wrong with me”	<p>“It was just a lot of pain...a lot of loathing, a lot of self-hate about who I was. I was ashamed, I was embarrassed. Asking the questions of ‘why me?’” [P1]</p> <p>“I always thought there was something wrong with me because I stutter...cause I was always made to feel like something was wrong with me.” [P2]</p> <p>“...they used to make me feel so bad it stopped me from going to school. It stopped me from doing a lot of things, because I thought like, well if my own family laughs then everybody around me’s gonna laugh too.” [P4]</p> <p>“...still whenever I talk, I want to be as fluent as possible. And, I know that along with the mode of thinking that I’ve learned from the NSA...that should not be your goal. Like, you should be ok with the way you talk. So I think I’m aware of the fact that I need to change my mode of thinking, but I still want to talk, like be as fluent as possible, and I still don’t like the fact that I stutter...” [P6]</p> <p>“...even though I knew my lessons and everything, the teacher would just skip me and not have me do it. And it was like, each and every time that happened it was like failure. Like shameful feelings of why I couldn’t be like other kids. And that really well, I guess hurt me throughout my life. It created this feeling where I wanted to hide it. I didn’t want people to know. Cause I was ashamed of it.” [P7]</p>
	ii. Navigating connections to Hispanic culture as PWS	<p>“You don’t have a lot of Latinos in academic affairs, so I’ve felt that I’ve had to be, like a harder worker...more than others...I think it’s affected me in the sense that, I don’t want anybody to think that I’m just there only because I’m a minority and a number. And then also, I was hired only because I stutter, because they wanted to hire somebody who had a disability and who is Latino as well.” [P1]</p> <p>“I already had the problem in Honduras, about I always felt different because I’m half, so I didn’t really feel like I belonged with the Honduran kids or the American kids because I was half and half. And the stuttering was another barrier. So I always felt really different. So I would have still felt different if I wasn’t Hispanic, but...I wouldn’t feel the cultural difference.” [P2]</p> <p>“That’s something that has been hard...trying to speak more Spanish in my 20’s and 30’s. And trying to sort of reconnect with that part of my identity, is that, you know being kind of looked down upon, or being kind of mistreated, or having people complete my sentences for me or immediately switch into English when I’m trying to speak Spanish. But it’s that much harder because I look white. And, because I have a stutter. And that’s just, that’s been a big challenge.” [P5]</p> <p>“Because I stutter more when I speak Spanish, I experience stuttering more. So, yeah that inherently kind of changes my relationship both to the language, to be Hispanic and to the act of stuttering itself.” [P5]</p> <p>“I’d probably just be like a lot more confident about my Hispanic heritage, and speaking Spanish with my family, and stuff like that. And, now it’s ok, but several years ago I was definitely really anxious about speaking Spanish, and I wouldn’t want to. And I think a lot of my family members just assumed that was because I</p>

	<p>couldn't, speak Spanish, I just didn't know how. But it really was just because of like the stutter, and being afraid of stuttering." [P6]</p>
<p>iii. Journey toward overcoming stigma</p>	<p>"When you're stuttering and your mom and dad are going to these churches, and they're laying hands on people, and you see some miracles...you're always hoping it's you like gosh, I stutter, God please, I don't want to stutter anymore...and I just got to a point where, it was ok. Because I feel that He made me how I am, and that's ok how He made me." [P1]</p> <p>"I've been receiving speech therapy here for about a year, and I've definitely learned to like, advocate for myself, and talk more about stuttering and also stuttering comfortably, like with family I can feel okay...I still sometimes feel embarrassed, but most of the time I don't feel too bad. It's part of who I am. It's not the only part of me, but it's something that I can't change, so I've learned to accept it." [P2]</p> <p>"So my technique was like you know what, if I can't be friends let me be smart, so I got all A's and B's. I'm not gonna let them judge me for my stutter, I'm gonna let them know for what I do." [P3]</p> <p>"I saw online there was like a monthly group session for people who stutter. I was like oh, let me just go to one. And then I met like doctors, and writers, and nurses. I was like blown, like 'oh my God, I'm not the only one!'" [P3]</p> <p>"I speak more fluently now, where before, growing up, or when I realized that I stuttered, it would be like every word would be a block, like a hard block...my whole face would hurt after the day was done because I would just block so hard all the time...And I was like that for a long time, but then I just worked on it. And I got out of my comfort zone and started to talk to people more." [P4]</p> <p>"Because I was the only person I knew who stuttered, around me. So I just really felt alone for a long time, but then I got on the NSA website, and I found a group, and I went to that for a while." [P4]</p> <p>"And then I think as I've gotten older, and I've sort of become more comfortable with it, and I've become more fluent, you know, it's just sort of something that I can be more open about...like it's not a big deal...sort of allowing it to sit in me, and just be a part of who I am, has been both a big help in becoming more fluent and also just kind of like existing with it as a social human." [P5]</p> <p>"...after talking to my grandson and telling my grandson how he should be honest with himself, and strong and all this talk. Then I one day just looked at myself and said, I'm not honest with myself. I wanna hide something. I don't engage with me. And that's what made me finally start going to the support meetings, once a month." [P7]</p> <p>"...it [support group] was the first time in my entire life that I had other people surround me, that stuttered. And actually people, and that for me too was very difficult to think that other people knew that I stuttered. Cause I always hid it from others. It was a very weird feeling, but it was one of the best choices that I have ever done. In my life." [P7]</p>

CHAPTER IV. DISCUSSION

This study's data collection methods were designed to collect narrative data providing a detailed description of the way Hispanic AWS experience stigma. To that

end, seven participants responded to open-ended questions related to their cultural identity and language use, proposed causes and cures for their stuttering, how they've been treated as a PWS, and their feelings about their stuttering. Participant interviews generated narrative data that was analyzed using thematic analysis procedures, which identified commonalities across participants' narratives and gave rise to themes. Each of the four major themes derived from the data is supported by responses from all seven participants and contains two to three subthemes. These themes answer the study's stated research questions by thoroughly describing: 1) The ways in which Hispanic AWS participants have experienced stigma; 2) Participants' different experiences with stigma according to their cultural and linguistic environments; and 3) How these cultural factors have influenced participants' feelings about their stuttering.

Family

The first major theme, "Family," includes the subthemes "Beliefs about cause," "Beliefs about cures," and "Reactions." All participants discussed interactions with family members as central to their experiences with stuttering. It should be noted that while not all participants grew up in a predominately Hispanic environment, all had at least one parent born in Latin America and connections with Hispanic family members. When they began stuttering as children, most participants were told causes or cures for their stuttering that Erickson et al. (2002) referred to as "folk beliefs," or beliefs with a cultural basis. These proposed causes included learning two languages simultaneously, getting sick, being nervous or excited to talk, and previous bullying. In addition, most participants' family members suggested ways to fix or cure them of their stuttering that went beyond speech therapy. Cures based on cultural beliefs included an Evangelical

laying of the hands to rid one participant of “*evil spirits*” (P1) and placing Cheerios underneath the tongue to prevent stuttering (P4). Methods to fix stuttering also included common misconceptions about stuttering that occur across cultures (e.g. Boyle, Dioguardi, et al., 2016). These methods included techniques such as slowing down and breathing, as described by P3: “*They [family] would always say ‘breathe,’ I’m like, but I’m breathing. They were like ‘don’t talk too fast,’ but I’m like I can’t stop it that’s the way I talk, I just talk fast. And then they’re like ‘oh, she’ll be ok, something temporary.’*” The implication that a PWS can fix their stuttering implies that it is under their control, and that their behavior may have caused it. As described by Boyle (2016), this causal attribution for stuttering that may contribute to increased stigmatization of PWS.

In addition to proposed causes and cures, most participants described how family members reacted to their stuttering. These reactions were generally negative and ranged from low career expectations to being overtly made fun of or cut-off by family members. For two participants, stuttering was something that was not discussed, as expressed by P5: “*...if anyone has anything wrong in the family it’s more like we don’t talk about it*” and P7: “*It was like, something that no one talked about. Even though later...I realized it, my second brother stutters also.*” Through negative reactions, hypothetical causes and suggested cures, participants were labeled by family members as having a difference that needed to be fixed. This labeling and subsequent separation of PWS into “us” versus “them” reflects the early processes of stigmatization (Boyle, 2018; Link & Phelan, 2006).

Stigma in Society

The second major theme, “Stigma in Society,” involves participants’ experiences with stigma outside of their family, in society as a whole. These experiences branched

into three different subthemes: “Negative experiences in school,” “Not fitting into gender stereotypes,” and “Public misconceptions of stuttering.” For participants born outside of the United States (P2, P3, P7), stigmatizing experiences in school emerged as their most salient, in that they were brought up by these participants almost immediately after being asked the second open-ended question: “Tell me about when you started stuttering.” Both in and outside of the U.S., participants expressed their experiences in school as “enacted stigma,” or stigma involving negative treatment and discrimination (Boyle, 2018).

Descriptions of enacted stigma included being made fun of by other kids as well as being treated differently by teachers. One participant, P7, recalled being silenced by her teacher after stuttering during an oral recitation: “...*she told me to just sit down, just sit down. So, I did. But it really hurt.*” These stigmatizing experiences had lasting implications, evolving into what Boyle (2018) called “felt stigma,” or the anticipation of negative experiences. As reported by P7, her experience in school caused her to hide her stuttering well into her adult life. Another participant, P1, “...*started to really become very introverted, and just hated speaking in class, hated speaking in front of people.*”

In addition to experiences at school, participants described societal stigma in terms of gender stereotypes and public misconceptions of stuttering. These two subthemes align with Goffman’s (1963) classic definition of stigma, or the idea that as PWS, participants’ social identity diverges from what others expect it to be. When asked how stuttering affected their gender identity, most participants reported not meeting others’ expectations of how a male or female should speak. These gender stereotypes affected the way they experienced stigma: “*I guess people perceive me [a female] as like, not being confident or being unsure of myself*” (P2) as well as their status in society as a

person of that gender: “...men who stutter are you know, perceived as weaker, they’re perceived as not as intelligent or not as, in charge or forceful...” (P5). Participants also experienced public misconceptions of stuttering when their social identity differed from what was expected of them. These misconceptions included mistaken beliefs about the cause of stuttering, “...whenever I stutter they always ask me if I’m cold...” (P2); being laughed at and/or imitated, “...people just laugh. And like start to imitate it” (P4); and negative portrayals of PWS in the media, “...there always was a character that had to stutter. And they always, the stutterer would be dumb” (P3).

Stuttering Experiences in Cultural and Linguistic Contexts

The effects of culture and language on participants’ experiences with stigma form the third major theme, “Stuttering Experiences in Cultural and Linguistic Contexts.” Within this theme, the subtheme “Perceptions of stuttering within cultural communities” includes participants’ culture-based experiences, while “Role of linguistic environment in language selection” explores how language affects their stuttering. During their interviews, most participants described experiences stuttering within specific cultural communities. For example, P4 expressed: “...and it’s not just my family but my Mexican friends...they say things, like, ‘you can’t give babies hot sauce’ and things like that, because they’ll develop a stutter.” These experiences occurred both in the U.S. and in other countries, as articulated by P3: “...people in Peru would just laugh. People here [in U.S.] they would just wait and see what was going on, and they would stare at me...” Another participant cited support groups as a key factor in her experiences in Honduras and the United States: “...in Honduras I didn’t have support groups. There was no such

thing there, so I didn't really know anybody else who stuttered. So it was hard for me to relate to people" (P2).

Participants' descriptions of cultural experiences with stigma align with existing research and provide new data suggesting that stuttering may carry more social stigma in Latin American countries or Hispanic communities. In his research with Hispanic American college students, Tellis (2008) found that students who had adopted more characteristics of mainstream U.S. culture were more likely to disagree that stuttering is socially stigmatizing. This suggests that among those with closer ties to Hispanic culture, stuttering may be viewed as more socially stigmatizing (Tellis, 2008). In the current study, participants who directly compared their experiences in non-Hispanic versus Hispanic environments described increased stigma in Hispanic communities. They attributed this stigma to several factors: a lack of awareness of stuttering, "*it's not something that's too common [in Honduras]*" (P2); low expectations of PWS, "*...if I would have stayed in Peru, with my stutter it would have been a challenge to graduate, to find a job*" (P3); and the nature of communication, "*...people are always talking very very quickly in Spanish. Like, I think if you have a stutter, and you quote 'can't keep up' it's, it's kind of looked down upon and it's frowned upon*" (P5). These cultural differences imply that within Hispanic communities, the loss of status and power that accompanies stigmatization may take a higher toll on PWS.

In addition to citing cultural contexts, six out of seven participants described different experiences with stuttering when speaking English versus Spanish. These experiences comprise the subtheme "Role of linguistic environment in language selection." One participant (P3) noted no difference between languages, but most

participants described how their stuttering made it more difficult to communicate in Spanish. They attributed their communication difficulties to the nature of the language itself “*it can be hard for me to talk in Spanish, because it’s just really rushed as well...*” (P2); the attitudes of their communication partners, “*...so people start speaking Spanish to me, and if I stutter, I think they often think that it’s because I can’t speak Spanish...*” (P6); or the exacerbation of stuttering in another language, “*...it’s just like all of the sort of disfluency that I’ve been able to kind of smooth out over the years just comes right back up to the surface when I try to speak Spanish*” (P5). These experiences with stuttering in different linguistic environments were a determining factor in what language participants chose to speak, and when. One reported feeling hesitant to travel to Latin America, while others, like P1, expressed switching languages as a technique used to avoid stuttering: “*...I started going into English and Spanish, because if there was a word I didn’t wanna say in Spanish, then I would say it in English it was much easier.*” As described by Kim (2003), language is a key component of culture and its use reflects one’s identity and power in society. Participants’ experiences being bilingual but unable to effectively communicate in one of the languages they speak affects their ability to participate in Hispanic culture, and represents a loss of power. This loss of communicative power aligns with what Link and Phelan (2006) describe as one of the final stages of stigmatization.

Stigma’s Impact on Identity

The final major theme, “Stigma’s Impact on Identity,” includes three subthemes: “I always thought there was something wrong with me,” “Navigating connections to Hispanic culture as PWS,” and “Journey toward overcoming stigma.” This theme reflects

the final step of stigmatization, in which negative treatment towards PWS leads to feelings of shame, embarrassment and helplessness that can affect their quality of life (Boyle, 2018; Corcoran & Stewart, 1998; Link & Phelan, 2006). The first subtheme, named after a quotation from P2, encompasses participants' negative feelings about their stuttering, or the feeling they had "*something wrong*"(P2) with them. As described by Boyle (2018), the anticipation of stigmatizing experiences leads PWS to avoid situations in which they may experience stigma, and can significantly affect their mental health. Participants described their negative feelings as preventing participation in daily activities, "*...they used to make me feel so bad it stopped me from going to school*" (P4) and leading to "*...a lot of self-hate...*" (P1).

In addition to negative feelings surrounding stuttering, most participants described difficulties navigating their identity as both a PWS and Hispanic/Latino. Two participants described feeling like a double minority, both in the workplace: "*...I don't want anybody to think that I'm just there only because I'm a minority and a number ...because they wanted to hire somebody who had a disability and who is Latino as well*" (P1), and in society: "*I always felt different because I'm half, so I didn't really feel like I belonged with the Honduran kids or the American kids because I was half and half. And the stuttering was another barrier*" (P2). Others expressed how their experience of stigma and stuttering created a sense of disconnect from their Hispanic culture: "*Because I stutter more when I speak Spanish, I experience stuttering more. So, yeah that inherently kind of changes my relationship both to the language, to be Hispanic and to the act of stuttering itself*" (P5). Another stated that if she didn't stutter, she would "*probably just be like a lot more confident about my Hispanic heritage, and speaking Spanish with my*

family...” (P6). As indicated in Daniels et al.’s (2006) research with African American men who stutter, these findings support the idea that culture and ethnic identity affect AWS and their relationship to their stuttering in unique and individual ways.

The final subtheme includes the ways participants sought to overcome the helplessness and mental health difficulties represented in the final stage of stigmatization (Link & Phelan, 2006). Most participants described this process as a journey toward accepting themselves and their stuttering: *“It’s part of who I am. It’s not the only part of me, but it’s something that I can’t change, so I’ve learned to accept it”* (P2). Others expressed the steps they took to overcome dysfluencies, *“...I would just block so hard all the time...And I was like that for a long time, but then I just worked on it. And I got out of my comfort zone and started to talk to people more”* (P4), or to be recognized for something other than stuttering, *“So my technique was like you know what, if I can’t be friends let me be smart, so I got all A’s and B’s...”* (P3). For many participants, attending support groups was a critical step on their path to self-acceptance. It should be noted that participants were recruited through the National Stuttering Association (NSA)’s listserv, and were therefore potentially more likely to attend NSA support groups. These support groups were often described as life-changing: *“...it was the first time in my entire life that I had other people surround me, that stuttered....It was a very weird feeling, but it was one of the best choices that I have ever done. In my life”* (P7). The importance of community for PWS speaks to what Boyle, Buhr, et. al. (2016) described as a “culture of stuttering,” or a history of shared experiences among PWS. By drawing on shared experiences of discrimination, community members can assist PWS in accepting their stutter and adopting advocacy techniques as they work toward overcoming stigma

(Boyle, Buhr, et al., 2016). For Hispanic PWS, this journey involves navigating two identities: one as an AWS, and one as a Hispanic/Latino.

Key Findings

As demonstrated by the four major themes, Hispanic AWS experience stigma in unique ways that are influenced by their cultural and linguistic environments. Participants faced stigma that came from home, school, and society, affecting their cultural participation and forcing them to navigate their identities Hispanic/Latino AWS. Findings provide new data suggesting that stuttering may be more stigmatizing in Latin American countries or Hispanic communities, and that difficulties communicating in Spanish may impact Hispanic AWS' linguistic selection. Overall, these cultural factors affect Hispanic AWS' connection to their Hispanic heritage and influence their personal journeys toward overcoming stigma.

CHAPTER V. CONCLUSION

Limitations and Future Research

This study utilized qualitative methods to generate data from seven participants recruited from the National Stuttering Association (NSA)'s listserv. Given the small sample size and recruitment based on NSA affiliation, it may be difficult to generalize the results. Members of NSA support groups are more likely to have processed their experiences with stigma and more willing to share them. Therefore, future research should focus on larger samples of Hispanic AWS and those without NSA affiliation. The finding that stuttering may be viewed as more stigmatizing in Latin American countries or Hispanic communities in the U.S. is significant and warrants further investigation.

This research should extend to AWS who identify with other ethnic or cultural communities and speak languages other than Spanish.

The results of this study also provide a foundation for future research related to reducing the stigma experienced by Hispanic AWS. Existing research shows that methods such as contact with PWS, exposure to personal stories, public awareness and education may reduce the stigma associated with stuttering (Boyle, Dioguardi, et al., 2016). Given the connection between culture, language and stigma, future research should investigate the efficacy of these stigma-reduction methods within the Hispanic community.

Clinical Implications

An understanding of the way stigma affects Hispanic AWS is critical to the effective assessment and treatment of fluency disorders for members of this population. While stuttering is diagnosed based on specific speech behaviors, it includes underlying emotions that affect PWS' overall communication abilities (Bennett, 2006). As described by Finn and Cordes (1997), to evaluate the personal impact of stuttering a clinician must look beyond their own cultural framework and seek to understand each client's needs. The current study's findings support the need for an individual and nuanced approach when assessing and treating Hispanic AWS. The knowledge that Hispanic AWS' experiences with stigma are uniquely affected by cultural and linguistic factors will enable clinicians to address the affective and cognitive components that go hand in hand with speech dysfluencies. An understanding of these influences will assist clinicians as they help Hispanic AWS overcome negative feelings, reduce the stress involved in speaking and improve their quality of life.

In addition to culturally sensitive evaluation and treatment, this study's findings highlight the necessity of culturally appropriate education regarding the causes of and cures for stuttering. Providing correct and culturally sensitive information for parents of Hispanic children who stutter will allow them to access the resources available to them and seek the assistance of a speech-language pathologist or support group network.

Conclusion

It is well-established that PWS experience stereotyping and negative treatment from students, teachers, clinicians and the general public (Boyle, 2017; Cooper & Cooper, 1996; Craig, et al., 2003; Dorsey & Guenther, 2000). Research shows that the stigmatization of stuttering has significant effects on PWS, influencing their life experiences, professional opportunities, and mental health (Boyle, 2018; Bricker-Katz et al., 2013; Corcoran & Stewart, 1998). However, few studies have investigated the effects of culture and language on AWS' experiences with stigma.

Using qualitative research methods, this study allowed a small number of participants identifying as Hispanic/Latino AWS to thoroughly describe their experiences with stigma. A thematic analysis of their narrative responses resulted in four major themes: Family, Stigma in Society, Stuttering Experiences in Cultural and Linguistic Contexts, and Stigma's Impact on Identity. These themes provide a detailed picture of how Hispanic AWS experience stigma: through proposed causes and cures for their stuttering, negative reactions from family members and at school, and societal stigma in the form of gender stereotypes, misconceptions about stuttering, and negative treatment.

Findings indicate that Hispanics who stutter experience stigma differently when speaking Spanish versus English, which influences their language selection and cultural

participation. In addition, Hispanic AWS experience stigma differently in predominately Hispanic environments, suggesting that stuttering may be viewed as more socially stigmatizing in Latin American countries or within Hispanic communities in the United States. These experiences with stigma impact Hispanic AWS' feelings about their stuttering, causing negative emotions and forcing them to navigate their connection to Hispanic culture. As a result, Hispanic AWS' journeys towards self-acceptance involve coming to terms with their language use, participation in Hispanic culture, and identity as both a PWS and Hispanic/Latino.

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Appendix A



Office of Research Integrity
Research Compliance, MARC 414

MEMORANDUM

To: Dr. Angela Medina
CC: File
From: Elizabeth Juhasz, Ph.D., IRB Coordinator EJ
Date: June 4, 2019
Protocol Title: "Stigma and the Hispanic Stuttering Experience: A Qualitative Study"

The Florida International University Office of Research Integrity has reviewed your research study for the use of human subjects and deemed it Exempt via the Exempt Review process.

IRB Protocol Exemption #: IRB-19-0197 **IRB Exemption Date:** 06/01/19
TOPAZ Reference #: 107969

As a requirement of IRB Exemption you are required to:

- 1) Submit an IRB Exempt Amendment Form for all proposed additions or changes in the procedures involving human subjects. All additions and changes must be reviewed and approved prior to implementation.
- 2) Promptly submit an IRB Exempt Event Report Form for every serious or unusual or unanticipated adverse event, problems with the rights or welfare of the human subjects, and/or deviations from the approved protocol.
- 3) Submit an IRB Exempt Project Completion Report Form when the study is finished or discontinued.

Special Conditions: N/A

For further information, you may visit the IRB website at <http://research.fiu.edu/irb>.

EJ

Appendix B

Demographic Questionnaire

Instructions: Please complete this questionnaire to the best of your ability. If you are uncomfortable answering particular questions, you are not obligated to provide a response. All information provided in this questionnaire will be kept confidential.

BACKGROUND INFORMATION

Age: 18-24 years old

Gender: **M** **F** Other:

_____ 25-30 years old

31-45 years old

46-61 years old

61+ years old

Where were you born?

United States, city/state: _____

Outside of the US: Country? _____

Age you came to U.S. (if applicable) _____

Race/ethnicity:

White

Hispanic/Latino → Origin(s): _____

Black/African American

Asian

American Indian/Alaska Native

Middle Eastern/North African

Native Hawaiian/Pacific Islander

Other: _____

I culturally identify as _____.

Marital status

Single (never married)

Married, or in a domestic partnership

Widowed

Divorced

Separated

What is the highest degree or level of education you have completed? (If you are currently enrolled in school, please indicate the highest degree you have already received.)

- Less than a high school diploma
- Bachelor's degree (e.g. BA, BS)
- High school degree or equivalent (e.g. GED)
- Master's degree (e.g. MA, MS, MEd)
- Some college, no degree
- Professional degree (e.g. MD, DDS, DVM)
- Associate degree (e.g. AA, AS)
- Doctorate (e.g. PhD, EdD)

What is your current employment status?

- Employed full time (40 + hours per week)
- Employed part time (up to 39 hours per week)
- Unemployed and currently looking for work
- Unemployed and not currently looking for work
- Student
- Retired
- Homemaker
- Unable to work
- Self-employed

If currently employed, what is your profession?

LANGUAGE HISTORY

What is your native language? (If you grew up with more than one language, please specify.)

Do you speak a second language?

- Yes, my second language is _____.
- No. (If you answered 'no', then you do not need to continue this form.)

When did you start learning your second language?

Estimate, in terms of percentages, how often you currently use your native language and other languages per day (in all daily activities combined):

- Native language _____%
 - Second language _____%
 - Other languages _____% (Specify languages: _____)
- (Total should equal 100%)

Please share any other information you'd like us to know about your language use.

Appendix C

Stuttering History Form

Instructions: Please fill out this form in as much detail as possible. Any information provided will remain confidential.

HISTORY OF STUTTERING

- 1. Give the approximate age at which you first started stuttering: _____

- 2. Currently, I stutter when I: (**Circle** all that apply)
 - A. Ask questions
 - B. Talk to family members
 - C. Say my name
 - D. Speak in a second language
 - E. Talk to authority figures
 - F. Speak when tired
 - G. Speak in my native language
 - H. Use the phone
 - I. Give presentations
 - J. Recite memorized material
 - K. Talk to strangers
 - L. Talk to friends

3. Please describe your stuttering:

- 4. How severe is your stuttering?
 - Mild
 - Moderate
 - Severe
 - Profound

- 5. Did you ever attend speech-language therapy?
 - Yes
For how long? _____
 - No
Why not?

6. Do you use any strategies or techniques during stuttering moments? If so, what are they?

STUTTERING EXPERIENCES

Please select the extent to which you agree with the following statements.

- 1. I have been discriminated against by the general public because of my stuttering.
 - Strongly Agree
 - Agree
 - Neutral
 - Disagree
 - Strongly Disagree

2. I have been discriminated against by other Hispanics because of my stuttering.
- Strongly Agree
 - Disagree
 - Agree
 - Strongly Disagree
 - Neutral
3. People's reactions to my stuttering make me keep it to myself.
- Strongly Agree
 - Disagree
 - Agree
 - Strongly Disagree
 - Neutral
4. Sometimes I feel that other Hispanics talk down to me because of my stuttering.
- Strongly Agree
 - Disagree
 - Agree
 - Strongly Disagree
 - Neutral
5. Other Hispanics have been understanding of my stuttering.
- Strongly Agree
 - Disagree
 - Agree
 - Strongly Disagree
 - Neutral
6. The general public has been understanding of my stuttering.
- Strongly Agree
 - Disagree
 - Agree
 - Strongly Disagree
 - Neutral
7. My stutter is the defining characteristic of my identity.
- Strongly Agree
 - Disagree
 - Agree
 - Strongly Disagree
 - Neutral
8. People react differently to my stutter depending on what culture they are from.
- Strongly Agree
 - Disagree
 - Agree
 - Strongly Disagree
 - Neutral

Please share any other information that you think is important or that you would like us to know about your stuttering.

Appendix D

Semi-structured Interview Script

Researcher: First I want to remind you that the interview will be audio recorded. What language do you prefer to use for the interview? Thank you for being willing to share your experiences with stuttering. I'm going to ask you a few questions about your culture, how you've been treated as someone who stutters and how you feel about it. Since I'll be asking questions about stuttering, some questions may make you feel uncomfortable and/or remind you of unpleasant past experiences. The study is voluntary and you have the right to not respond to any question that makes you uncomfortable or end the interview at any time. Do you have any questions?

Open-Ended Questions

1. Tell me about the culture you grew up in.
2. Tell me about when you started stuttering.
 - a. How did your family react when you started stuttering?
3. Tell me about how you've been treated as a person who stutters.
 - a. By family
 - b. By friends
 - c. By co-workers
 - d. By other Hispanics
 - e. By the general public
4. How do you feel about your stuttering?
 - a. If bilingual:
 - i. How do you feel when you stutter in English?
 - ii. How do you feel when you stutter in Spanish?
5. How has your stuttering affected your identity as a man/woman?
6. If you weren't Hispanic, how would your experience with stuttering be different?
7. Have you attended a support group for people who stutter?
 - a. If yes- How did you feel about it?
 - b. If no- Why not?

Planned Prompts

8. When you started stuttering, what did you think caused it?
9. In your culture, how are people treated who aren't considered "normal"?
10. Does your culture view men who stutter differently than women who stutter? How so?