THE EXPERIENCE OF JAPANESE AMERICANS WHO STUTTER

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A THESIS

Submitted to
Michigan State University
in partial fulfillment of the requirements
for the degree of

Communicative Sciences and Disorders – Master of Arts

2023

ABSTRACT

Some experiences of people who stutter are universal. However, the intersection of being a person who stutters and being Japanese American is likely to yield unique perspectives that can be used to better inform speech-language pathologist's on culturally competent practices. There is an absence of research on the experiences of Japanese Americans who stutter within the communication sciences and disorders field. In the current, exploratory study, Japanese and Japanese Americans who stutter and Japanese speech-language pathologists participated in semi-structured interview that gathered perspectives of Japanese American who stutter and the cultural and clinical expertise of Japanese speech language pathologists. Qualitative analysis revealed six potential themes: communication challenges, stuttering in the context of Japanese communication, reluctance to seek support, acceptance in people who stutter, understanding of stuttering, and cultural change in Japan. The results indicate that there are unique challenges that Japanese Americans who stutter face, and there is a large cultural influence on the concept of disability among Japanese Americans in general. The overarching goal of this study was to inform and to encourage future research within the intersecting areas of Japanese culture, American culture, communication disorders, and stuttering.

ACKNOWLEDGEMENTS

I would like to thank my advisor, Dr. J. Scott Yaruss for his endless support, hours and hours of revisions and feedback, and for being someone that I greatly look up to not only as a SLP and researcher, but as a person. I would also like to thank my committee members Dr. Jeff Searl, Dr. Bridget Walsh, and Dr. Keiko Ishikawa for sharing their time and effort to assist me by sharing their wealth of knowledge and expertise. I hope to one day conduct research at the expert level that you all have, that makes a tangible difference in people's lives like yours do.

I would like to thank my parents, Yuko and Yuzuru Ito, for answering my constant calls at all hours of the day to help me translate a word or answer a very complex question about Japanese culture. I hope this project served as a small token of my appreciation for your constant support. Also, thank you to Ken for being the best brother a person could have. I'm grateful for the perspectives you give and am constantly inspired by you. いつも応援してくれてありがとう。これからも頑張ります。

I would also like to thank my friends who have endlessly supported me during my graduate study whether it be rooting for me, listening to me stressing out, spending time with me, sending me quick texts, and being understanding when I inevitably cancel plans because I need to work on my thesis. A special shoutout to Molly S., Isabel V., Emilia M., Nessy B., Sarina Z., Kendra P., Alaina S., Nicole H., Casey F., and Randall S. You have all enriched my life in ways that I thought wasn't possible and demonstrated to me what true love is. Thank you for being the best friends in the world.

I want to express my deepest gratitude to all of the participants in this study who shared their experiences and expertise with me. I have learned so much from all of you, and meeting fellow Japanese people like you in general has been a privilege for me.

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Introduction

The United States is a country where communication and language is direct, the landscape is culturally and linguistically diverse, leniency and flexibility are often valued, and individualism is important (Markus & Kitayama, 1991). Japan is a country where diversity is generally not present, true feelings are often not revealed, indirect communication is the norm, and collectivism is valued (Markus & Kitayama, 1991; Western Washington University, 2022). Not only are these two cultures different, but there is great historical context between the two nations stemming from events such as the Pearl Harbor attack and the Japanese American incarceration camps. The resulting Japanese American identity is one that involves many layers and is generally less represented compared to other ethnic minority groups in the United States (U.S. Census Bureau, 2020).

Stuttering is a communication issue that is present across cultures (E. B. Cooper & Cooper, 1996). This cultural history of stuttering includes myths and misunderstandings about people who stutter and the cause(s) of stuttering, as well as beliefs about various treatment methods that may or may not be effective (Finn & Cordes, 1997; Flynn, 2009; MacKinnon et al., 2007; Ogundare, 2012). When people who stutter seek speech therapy, they should receive care that is individualized, comprehensive, and effective. Despite the cultural competence training necessary for Speech-Language Pathology (SLP) certification, the majority-white composition of the field of SLP can pose as a barrier for people seeking therapy due to the lack of cultural and linguistic relatability (Finn & Cordes, 1997; Mahendra et al., 2009). The search for effective and culturally appropriate speech therapy for people who stutter can be further complicated by the fact that many SLPs do not feel comfortable or competent in treating stuttering (Beita-Ell & Boyle, 2020; Tellis et al., 2008).

The experience of some minority groups in the United States has been the subject of some research (D. E. Daniels et al., 2006; Dean & Medina, 2021; Ellis & Hartlep, 2017), and this work has revealed different personal experiences for people from different cultural backgrounds. This demonstrates the impact that culture has on one’s experience as a person who stutters. When a Japanese American person stutters, three distinct identities come together to shape an intersectional person who must balance different cultures in one: being Japanese, being American, and being a person who stutters. The uniqueness of the Japanese American experience of people who stutter highlights the need for research and consideration by SLPs about how to create effective and inclusive practices for this population. The goal of this paper is to gather and share information about the experience of Japanese and Japanese Americans who stutter and the experiences and expertise of Japanese and Japanese American SLPs. The aim is to give a voice to Japanese Americans who stutter, learn from their experience through an intersectional lens, and serve as a resource for SLPs who treat Japanese and Japanese Americans who stutter. By investigating the Japanese American perspectives and attitudes of people who stutter, this project will improve the understanding of Japanese American people who stutter, not only by SLPs but also by the public.

Literature Review

The Role of SLPs in Stuttering Treatment

Stuttering is a communication issue that, to a listener, can be perceived as disruptions in the flow of speech, such as repetitions, prolongations, and blocks (ASHA, 2022). To the speaker, however, stuttering involves much more than just these speech disfluencies (Tichenor & Yaruss, 2019). Tichenor and Yaruss (2019) used the World Health Organization's (WHO), International Classification of Functioning, Disability, and Health (ICF; World Health Organization, 2001) to describe stuttering as a multi-faceted condition that not only includes disfluent speech but also the speaker's reactions to these disfluencies (personal context), the environment's reactions to stuttering (internal and external), and the negative impact it has on a speaker's quality of life, including shame, embarrassment, and limitations in the speaker's ability to participate in society (Tichenor & Yaruss, 2019).

Some people who stutter may seek help from a professional to address their stuttering. In the United States, SLPs are the professionals who are trained to evaluate, diagnose, and treat various speech, language, cognitive communication, and swallowing disorders including stuttering (ASHA, 2022). Stuttering treatment by an SLP is a comprehensive process that can involve indirect and direct interventions for children, and stuttering management for adults (Yaruss, 2010). Although the diagnoses and treatment of stuttering is within the scope of practice for the field of SLPs, research suggests that many clinicians do not feel prepared for or feel comfortable treating stuttering (Byrd et al., 2020; Tellis et al., 2008; Yaruss et al., 2017). For example, compared to other communication disorders, SLPs are significantly less comfortable directly using the diagnostic term "stuttering" (Byrd et al., 2020). Furthermore, a study conducted by Gabel (2013), which surveyed SLPs in Ohio, found that only 1% of respondents agreed that they have had sufficient experience in stuttering treatment. This lack of confidence with stuttering could be due to multiple factors. A study surveying SLP undergraduate and graduate programs in the United States revealed that 59% of programs could graduate students who had no clinical experience with fluency disorders (Yaruss et al., 2017). Another study found that clinicians' comfort with evaluating and treating stuttering was not associated with whether they held the ASHA Certificate of Clinical Competence (CCC), had attended continuing education seminars in fluency, or took a graduate level course in fluency (Tellis et al., 2008). According to Yaruss et al. (2002), there is a positive correlation between client satisfaction levels and the clinicians' competence, suggesting that improving SLPs clinical competence in stuttering could yield improved treatment outcomes. The disparity between the supply of SLPs who are comfortable working with people who stutter and the demand of individuals who stutter seeking therapy leads to limits to the ability of people who stutter to receive effective therapy (Tellis et al., 2008).

The relationship between the clinician and client, which is ideally built on understanding, trust, and collaboration, is the foundation of effective therapy (Bordin, 1979), and the development of this relationship should be a priority in treatment (Plexico et al., 2010). This relationship is often referred to as the therapeutic alliance (Bordin, 1979). The presence of a strong therapeutic alliance is a predictor of successful therapeutic outcomes (Horvath et al., 2011). Unfortunately, low confidence from the clinician can affect the trust and foundational clinician-client relationship. An effective therapeutic alliance involves more than the skills of the clinician; the perspectives and considerations of people who stutter who seek SLP services are also important considerations for developing a strong therapeutic alliance. Plexico et al. (2010), identified several characteristics that speakers might consider when seeking SLP services, such as professionalism, confidence in clinical skills, active listening, and encouragement. The main point of consideration among all of these factors was the clinician's ability to develop a therapeutic alliance. Plexico et al.'s respondents defined the therapeutic alliance to mean that the SLP would conduct therapy following a holistic approach and get to know them on a personal level. This included learning about their home life, hobbies, and individual history (L. W. Plexico et al., 2010). According to Constantine (2002), the satisfaction levels of the client are mostly predicted by the clients' perceptions of the therapist's cultural competence and the therapists' overall competence. These factors are all inter-related in stuttering treatment (and the field of speech-language pathology as a whole) because the discomfort of clinicians treating stuttering can affect the therapeutic alliance. The therapeutic alliance can especially be in a vulnerable position when there are other factors, such as race or cultural background, that might lead to separation between a client and clinician (Howgego et al., 2003; Manning, 2010; L. W. Plexico et al., 2010; Rafael & Peluso, 2018; Wintersteen et al., 2005).

SLPs working with culturally diverse populations

According to the American Speech-Language Hearing Association (ASHA), 92% of SLP's are white, and 96% identify as women (American Speech-Language-Hearing Association, 2019). The SLP population is not representative of the client population which is comprised of people from all cultures and backgrounds. Some of the challenges facing the white-dominated, SLP field includes the impact that a racial-gap has on the therapeutic alliance, implicit bias, linguistic bias, and cultural differences. The discussion of the therapeutic alliance is relevant for SLPs due to the impact that a person's culture and cultural background have on the individual's life experiences and perspectives (Park & Huang, 2010; L. W. Plexico et al., 2010). There is conflicting evidence on whether a racial gap between client and clinician correlates with client outcomes and the therapeutic alliance. Wintersteen et al. (2005) reported that there was no significant difference in the therapeutic alliance for a white therapist – minority client relationships compared to same-race relationships. However, they found that trust was often compromised in a mixed-race therapeutic relationship, and that this could lead to high drop-out rates and low expectations from the client (Wintersteen et al., 2005). Walling et a. (2012) found that in a white clinician - white client relationship, clients reported an increasing therapeutic alliance over time, but clients in a mixed client - clinician relationship reported no difference. Inherent in the concept of the therapeutic alliance is the assumption that clients prefer a clinician who can empathize and align with them on some level; for some clients, this alignment may involve factors such as race (Howgego et al., 2003). Conversations about race may be especially challenging in a mixed-race therapeutic relationship, and this is more likely to happen in the field of speech-language pathology given that the overwhelming majority of clinicians are white (Knox et al., 2003).

With the racial disparity between clients and providers in the field, numerous opportunities for implicit bias based on race, ethnicity, language, and culture can arise. Ebert (2013) found that roughly 30% of white undergraduate students in communication sciences and disorders expressed that they pay no attention to racial differences with their clients. This presumed “colorblindness” can be dangerous because it dismisses the racial identity of the patient and ignores the implications that race can have on a client’s individual experiences. Among the fields of education and healthcare, both fields relevant to the work of SLPs, there is evidence of implicit bias. According to Yull (2015), implicit bias from educational professionals is greater for children who are autistic and black or Latino. They further found that black and Latino children are less likely to receive support services even though they are more likely to be diagnosed with autism. Despite the fact that majority of healthcare fields require implicit bias training across several states, research has also shown that healthcare workers have the same levels of implicit bias as the general population (Cooper et al., 2022; Fitzgerald & Hurst, 2017).

When SLPs work with a non-native English speaker, the assessment, diagnosis, and treatment process should all be conducted with the client's linguistic profile in mind (Hook et al., 2013). Research has shown, however, that linguistic bias is a notable problem in the field. For example, Paradis (2005) showed that SLPs may misdiagnose non-native English speakers experiencing second language acquisition as having a language impairment or delay. Linguistic bias also contributes to the further alienation and prejudice towards marginalized communities (de Costa, 2020). Even without the linguistic and implicit biases, cultural differences should be explicitly considered by the SLP. Examples include differences in communication styles, beliefs about the most appropriate provider for speech-language services, knowledge about the US health system, knowledge about available SLP services, and lack of familial support living in close proximity (Mahendra, 2012).

Mahendra (2012) concluded with some best practice implications for all SLPs serving culturally diverse patients: 1. Speak with a cultural informant. 2. Ask the client what their understanding of SLP services are. 3. Gather information about linguistic acquisition. 4. Encourage parents of clients to provide feedback regarding services. Furthermore, Daniels et al. (2006) found that while there are special resources offered to people who stutter and to people who come from marginalized communities, resources can become limited for people with both identities. One way for SLPs to support people who identify both as minority and as a person who stutters is to obtain and maintain appropriate cultural competence (Blood et al., 2009; Mahendra, 2012).

Cultural Competence

Cultural competence is described as “a dynamic and complex process requiring ongoing self-assessment, continuous cultural education, openness to others’ values and beliefs, and willingness to share one’s own values and beliefs” (ASHA, 2022, para. 1). ASHA states that the two elements that make up cultural competence are: (a) self-awareness and identification of the SLPs own racial identity and associated privileges and (b) active consideration of race. Cultural competence variables, including age, gender, religion, and race, are often overlooked and forgotten (ASHA, 2022). SLPs are required to conduct comprehensive evaluations of clients seeking treatment. For an assessment of stuttering to be comprehensive, information such as the patient’s language, cultural environment, support system, and socioeconomic markers should be included, in addition to measures of speech behavior, personal reactions, and impact (Brundage et al., 2021).

Another way for clinicians to develop cultural competence is to strive for cultural humility. Cultural humility is the active decision to put the client first and for the clinician to strip themselves of racial and cultural superiority biases (Edwards-Gaither, 2018). A clinician’s cultural humility and the client’s perceived success in therapy is believed to be positively associated through the working alliance between patient and clinician (Hook et al., 2013). Cultural humility is not only important for clinicians to be unbiased and self-aware; it is also helpful for strengthening the relationship between the SLP and client, and this is particularly true for clients from diverse backgrounds (Hook et al., 2013).

According to ASHA (2019), “the newest SLPs—those joining ASHA within the last five to 10 years—are more likely to belong to a racial or ethnic minority group than those joining more than 10 years ago.” Although the purpose of cultural competence is for comprehensive training of all SLPs (regardless of clinician's cultural or linguistic background) so that they can treat people from all backgrounds, this increase in diversity creates a field that is more representative of the clients being treated. Drawing parallels from similarly homogenous fields such as education, research shows that minority educators are more likely to choose to work in high-minority school and stay at these schools long-term compared to white educators. The representation in that field helps to maintain professionals in these settings that are otherwise seen as less desirable by their white colleagues (Villegas & Irvine, 2010). Research also shows that in the educational sector, teachers of color are linked to greater minority student performance and outcomes (Villegas & Irvine, 2010). When diversity is not prevalent in a field, the great benefits of having minority representation such as these in a field are decreased. For people who stutter that are also people of color, the combined effect of limited access to SLPs who are comfortable with treating stuttering and the high likelihood of a cultural or linguistic gap between clinician and client can bring challenges. These challenges can be further discussed when considering how stuttering is clinically defined, personally experienced, and experienced differently across cultures.

Experience of people who stutter

Humans carry many identities, including race, occupation, societal role, gender identity, sexual orientation, health condition, and more. If a person identifies as a person who stutters and a person of color, the experiences of both identities should be explored and sought to be understood by SLPs. First, the experiences of people who stutter includes both the external perceptions about stuttering, as well as their own internal perceptions. External perceptions may include public opinions and media representation of people who stutter. Internal experiences are the first-hand experiences of people who stutter and how they perceive their world. The culture that a person who stutters resides in and their culture of origin can both greatly influence these external and internal factors (Finn & Cordes, 1997).

Being a person who stutters

In the context of stuttering, external experiences are the collective, public, non-stuttering population's perceptions about people who stutter. Many people who stutter can experience stigma, which is an unwanted, undesirable trait that is assigned to a certain group (Boyle, 2013a). Through the lens of stigma, external experiences can also be described as *enacted stigma*. Enacted stigma is the external stigma that is placed on people with a stigmatized condition or characteristic (Boyle, 2018; Molina et al., 2013). In the United States, there have been numerous studies of the perceptions about stuttering of people who do not stutter. Often, these negative perceptions are usually present in children who do not stutter from early childhood, indicating the role that family life and generational beliefs have on culture and stereotypes (Guitar, 2013). The negative perceptions of people who stutter have been well-documented on a global scale (Klassen, 2001; Lass et al., 1989; van Borsel et al., 2011). People who stutter are often subject to a "stuttering stereotype" which categorizes them as shy, introverted, passive, and self-conscious (Boyle et al., 2009; Mckinnon et al., 2007). St. Louis & Lass (1981) found that speech-language pathology and audiology students believed that stuttering was more psychologically damaging to a person than other communication disorders, and very difficult to treat clinically. Negative perceptions of people who stutter have also been held by SLPs, either by using negative or undesirable adjectives to describe people who stutter or holding implicit biases about them (Lass et al., 1989; Walden et al., 2020).

The internal experiences of people who stutter are the actual, lived experiences and how they perceive their world. *Felt* stigma, also referred to as anticipated stigma, is the belief that a person with a stigmatized characteristic may encounter a negative interaction from others and the internal experience that comes from that (Quinn & Earnshaw, 2013). Just as external perceptions of people who stutter can vary, the internal experiences of people who stutter can also differ greatly. There has been a large number of research on documenting the experiences of people who stutter through the lens of people who stutter (Boyle, 2018; Carter et al., 2017; Perez et al., 2015; Tichenor & Yaruss, 2019; Tichenor & Yaruss, 2018). People who stutter are often aware of the negative societal perceptions about stuttering. These internalizations shape how people who stutter view themselves and their experiences (Boyle, 2017). Documenting the experiences of people who stutter is an important method to create effective treatment and destigmatize marginalized communities.

Tichenor & Yaruss (2019), asked people who stutter to define what stuttering is to them. Six categories were identified amongst the responses. The first category was the sensation of losing control. This was described as the disconnect between intention and execution and the feeling of being “stuck.” The second category was affective and emotional reactions, commonly including shame, guilt, worry, anxiety, embarrassment, and pain. The third category was behavioral reactions which was further split into three categories: overt behaviors, covert behaviors, and physical tension. Covert behaviors and overt behaviors lie along a spectrum, with covert behaviors being those used by a speaker to “pass” as fluent and overt behaviors being behaviors that do not attempt to hide or mask stuttering. Example of covert behaviors included removing themselves from situations, choosing to not speak, and utilizing strategies to avoid detection of their stutter. Examples of overt behaviors included prolongations, repetitions, and blocks. Speakers also reported experiencing physical tension which meant the physical manifestations of the stutter including struggle and bodily movements that were closely related to the feeling of being stuck. The fourth category was cognitive reactions which split into two categories: identity and anticipation. Identity reflected the relationship between the sense of self and the impact of stuttering. Anticipation was described as the thought that stuttering might occur soon, and how that reaction often lead to other reactions. The fifth category was limitations, which described how being a person who stutters lead them to negatively impact their real-world encounters including conversations, social relationships, or educational and employment opportunities. The last category was the perceived influence of listeners and conversation partners which meant the impact that a listener has on the conversational dynamic. Further research on this topic shows that people’s experiences of stuttering is affected by their own perception and the perceptions of others (Boyle, 2017). One common theme amongst many of the categories was the sense that these behaviors and beliefs are all deeply ingrained in the person who stutter. The limitations of being a person who stutters varied from not being able to say what they wanted to say to not engaging in opportunities such as making friends and employment. Lastly, the perception of people who do not stutter about people who stutter makes a large influence on the actual experience of the person who stutters and creates for the fear of being judged by others. The research done on the experiences of people who stutter contain some universal experiences as well as some that differ between cultures. Establishing an understanding of how people have experienced stuttering provides a baseline for exploring the multiple identities and unique lives of all people who stutter and their other identities.

Stuttering research in the context of culture

How a person’s culture views disability and differences in general, as well as the communication style of that culture, can greatly shape the public perception of people who stutter (Üstün-Yavuz et al., 2021). The external perceptions about people who stutter in the cultural context is often captured using the *Public Opinion of Human Attributes- Stuttering* (POSHA-S) (St. Louis, 2011). Although different countries can have different cultural views and practices, there are some human traits that are universal no matter the culture (Brown, 2004). This is also evident in relation to people who stutter; public opinions regarding people who stutter reflect many stigmas and are largely negative. Still, there are variations depending on the culture. For example, research has shown that, in some countries, including Egypt, Kuwait, South Africa, and China, many people believe that stuttering is a form of a punishment (Abdalla & St. Louis, 2014; Al-Khaledi et al., 2009; Arafa et al., 2021; Ip et al., 2012). In China and Hong Kong, people who do not stutter have reported their beliefs that stuttering is a learned habit or that it has a non-genetic, unknown cause (Ip et al., 2012; Ming et al., 2001). In the United States, many people report their belief that stuttering originate due to a nervous system or brain disorder, but the most reported cause is stress and pressure (Boyle, 2017). The United States and Australia generally hold more positive attitudes towards people who stutter compared to other countries; however, attitudes in these countries still reflects some stuttering stereotypes (Boyle, 2017; Lefort et al., 2021; Węsierska & St Louis, 2014). In general, European countries also hold relatively less negative views on stuttering than non-European countries, but this can vary, depending on the specific country and cultural related to national identity (St. Louis et al., 2016; St Louis et al., 2014; Węsierska & St Louis, 2014).

The internal experiences and perspectives of people who stutter are often captured using the *Overall Assessment of the Speaker's Experience of Stuttering* (OASES), an assessment tool used to measure the impact of stuttering through various perspectives of the experience of stuttering (Yaruss & Quesal, 2016). The OASES has been translated to more than 30 countries and normative data has been collected globally in Arabic, Brazilian Portuguese, Dutch, German, Hebrew, Japanese, Korean, Norwegian, Spanish, Swedish, Polish, and Portugal Portuguese (Yaruss & Quesal, 2016). Blumgart et al. (2012), compared OASES results from people who stutter in Australia, Holland, and the United States, and found that people who stutter in all countries ranked their stuttering to be in the moderate impact category overall. Polish children ranked themselves significantly higher than those in the United States regarding their perceptions of their speech, knowledge of stuttering, and their internal feelings about being a person who stutters (Kowalczyk et al., 2022). A study conducted in Sweden showed that the emotional and cognitive impact scores from Swedish people who stutter were significantly lower compared to those from Australia, Japan, and the United States (Lindström et al., 2020). Lindström et al. (2020) argued that the reason why the United States and Australia compared higher than Sweden could be related to how each country adheres to traditional family values and respect for authoritative figures.

Compared to people in the United States, people in Japan reported that being a person who stutters had high adverse impact on their knowledge of stuttering, treatment options, self-help groups, anxiety, and nervousness (Sakai et al., 2017). Sakai et al. (2017) further discussed that the higher behavioral and cognitive reactions could be the result of a national characteristic of Japanese people in which the fear of feeling shame is very significant (Zhang et al., 2001). One study found little difference between the United States and Japan in terms of the adverse impact of stuttering on daily communication for those with whom the participants were “close” with. This could be explained by how countries view someone as “close”. People in the United States may only consider family members to be close, whereas people in Japan may consider friends to be close (Hofstede et al., 2005). Sakai at al. (2017) noted that this cultural difference is related to Japan being a collectivist society that focuses more on community; in contrast, the

United States is a more individualistic society that focuses more on personal identity (Hofstede et al., 2005). The largest theme that emerges when comparing the experience of people who stutter across countries is the significant differences in culture, thus demonstrating the impact that culture and environment may have on the internal experience of people who stutter. These data assessing the experience and quality of life of people who stutter helps to inform culturally relevant and applicable research questions. Such data are also useful for expanding information regarding different perspectives of people who stutter globally.

Stuttering research on different communities in the United States

There is currently no research on the differential impact of stuttering in different ethnic groups living in the United States (Yairi & Ambrose, 2013). In 2020, 43% of people identified as non-white in the United States, an increase from the 34% reported in 2010 (U.S. Census Bureau, 2020). There are many cultural groups in the US, and differences between each of these communities exist that must be considered. Each culture that merges into American society (African-American, Hispanic-American, Asian-American, European-American etc.) has different perspectives and cultural views that can manifest through food, language, communication, and community, etc. The research and discussion regarding multicultural American communities equips SLPs with an informed perspective of the lived experience of these people. Some research has been done on the experiences of individuals who stutter who come from different cultural groups within the United States.

The Hispanic American experience

The Hispanic population is the largest non-white ethnic group in the US, accounting for 19% of the entire US population (U.S. Census Bureau, 2020). Dean & Medina (2021) examined the experiences of Hispanic Americans who stutter through a qualitative study. Interviews revealed four themes that described how Hispanic Americans who stutter experience stuttering in ways that might be unique from how other individuals experience stuttering. These themes included family, stigma in society, stuttering experiences in cultural and linguistic contexts, and stigma's impact on identity. In the theme of family, family members would often express inaccurate beliefs and stereotypes regarding treatment for stuttering included a religious laying on of hands to rid evil spirits, placing cereal under the tongue, and slowing down and breathing. Family members also expressed negative attitudes and low career expectations for people who stutter. These beliefs from family members were described as being central to the experiences of the person who stutters. The results for the theme of stigma in society revealed that teachers would shush children who stutter during an oral presentation. Additionally, within this theme, people from both genders felt that their stuttering prevented them from reaching the gender norms expected of them. Participants expressed that they felt that stigma specifically in the Hispanic community was strong compared to North American culture. Reasons for this included a lack of awareness of stuttering, low expectations for people who stutter, and the socially expected rate of speaking in Spanish. The theme regarding the impact of stigma on identity reflected the intersectional identities of the participants. Participants cited that they felt twice as disadvantaged because they were both a minority in the US as well as a person who stuttered. Multiple participants also shared the beneficial role that support groups had played in their experience of being a person who stuttered and their journey to self-acceptance.

The benefits that support groups provide have been well-documented including high self-esteem, good quality relationships, addressing negative opinions, greater well-being, and psychological support (Boyle, 2013b; Medina et al., 2020; Raj et al., 2023; Yaruss et al., 2002). A prevalent theme of support groups is the idea of a "community" meaning that people who stutter make up a “culture” of stuttering (Boyle et al., 2016). There are currently no official stuttering support groups that are specifically for members of a certain ethnic group. One participant in the Dean and Medina (2021, p. 7) study stated that “…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.” This suggests that while stuttering support groups have many benefits for any person who stutters, there is a possibility that a stuttering support group designed for a specific cultural or linguistic group could connect people who identify as a person who stutters and an ethnic identity.

The African American experience

Black or African American people make up 13% of the US population (U.S. Census Bureau, 2020). As a historically disadvantaged community in the United States, African American people who stutter have to balance both identities carefully as an African American person and as a person who stutters (Daniels et al., 2006; Ellis & Hartlep, 2017). Daniels et al. (2006) interviewed six African American men about their experiences with stuttering. Five of the six believed that stuttering affected their self-identity, and three of the six participants stated that their identities as both an African American individual and as a person who stutters shaped their experiences in a unique way. One participant stated that stuttering has prevented him from interacting with other African Americans due to the feeling of not living up to the “black male stereotype.” This highlights the idea of humans existing with intersectional identities, and with each identity comes a societal expectation. For this participant, being a person who stutters and a person who is African American comes with certain expectations, and the presence of one identity can make it difficult to embrace the other.

The LGBTQ+ experience

Another aspect of the experiences of people who stutter involves gender and sexual orientation. There are parallels among members of the LGBTQIA+ community and people who stutter because both groups often must navigate concealing these identities until they feel comfortable or ready to go against oppressive, societal beliefs. When a person who stutters is also a member of the LGBTQIA+ community, a common theme was the need for affirmation and visibility of both identities (D. E. Daniels et al., 2022). Furthermore, the intersection of race, sexual orientation, and being a person who stutters means the need to manage external expectations on all three identities (Daniels et al., 2022).

The impact of culture on being a person who stutters

Individuals who stutter from different cultural groups within the United States experience being a multicultural American and a person who stutters in different ways. Despite the differences in ways that prejudice and negative encounters are experiences among these groups, negative stereotypes and stigmas continue to be a highly consistent factor in the United States, as well as around the world. Considering public perceptions of stuttering in different regions in the world can provide additional insights in the cultural basis for variations in the experience of stuttering.

Disability in Japan

Japan, an island nation in the eastern coast of Asia in the Pacific Ocean, is a country with an extensive history independently and with the United States. Until 1868, Japan was entirely secluded from all other nations in the world. No foreign influences were allowed, and no foreign people were allowed in the country. During the Meiji era (1868 to 1912), the borders of Japan opened for the first time, and modernization and western influences began to make an impact on the Japanese culture known today (Saito, 2021). This history going from being completely exclusive to being heavily integrated and modernized has shaped Japan to be a country where modern practices and extreme isolation are both present. The effects of remaining isolated for thousands of years can still be seen in Japanese culture today.

One example that highlights this is the homogeneity of Japan. Japan is one of the most ethnically homogenous countries in the world with a Japanese population of 97.9% (Central Intelligence Agency, 2022). The country is not only ethnically homogenous; cultural homogeneity is also prevalent. The idea of diversity or embracing differences is not always tolerated and people generally value being able to all live together peacefully in sameness. Dr. Hideki Shirakawa, a Japanese chemist and Nobel peace prize recipient, described Japanese culture by saying "Fundamentally, Japanese culture is based on rice farming. Rice cultivation requires a lot of water, and water must be shared evenly by everyone. Planting rice also required teams of people walking from row to row, at the same speed. And all of this has meant that uniqueness had to be suppressed" (French, 2001, p. 1). This idea of sameness has created a culture where shame is placed on anyone who deviates from the societally accepted norm including culturally and for people with disabilities. Most notably, Japan's Eugenic Protection Law from 1948-1996 was created to allow voluntary and involuntary sterilization of people with intellectual and mental illness, regardless of whether the condition was hereditary or not. It was only in 2019 that the Japanese government passed a law to compensate the victims and families of sterilizations (Hovhannisyan, 2021). The recency of the formal apology and reparations for the victims of the sterilizations sheds light on the lack of priority placed on creating an inclusive and safe space for all people, including those with disabilities.

This desire for Japanese people to maintain *wa*, or harmony, within the collective community is evident by the cultural practice of saying “yes” to indicate that they agree even if that is not how they truly feel. Japanese people consider it highly rude to openly disagree with other people and go against the “collective” grain, especially with respect to authority figures (Hofstede et al., 2005). Culturally, this contrasts the culture in the United States where honesty is welcomed. In western countries, the idea of “self” is self-explanatory—the individual. For Japanese people, the idea of “self” can be described as the relationship between the individual and others (Miyanaga, 1993). This interdependence is evident through the practice of many Japanese people being highly sensitive to the perceptions and opinions of other people and prioritize “fitting in” to society (Kim et al., 2001). Furthermore, talking positively about oneself is encouraged in western countries, while in Japan, negative self-talk is commonly used because it is a sign of humbleness and aims to uplift the other communication partner (Kim et al., 2001).

One challenge relating to Japanese communication and disability is the fact that Japanese people may outwardly claim to not discriminate or hold prejudice against people with disabilities even though their comments are designed to “save face” rather than to express their true feelings. These challenges are important to consider for SLPs with Japanese clients because their communication style, needs, and priorities may differ from western ideas. Researching Japanese people can give insight to Japanese Americans, a related yet vastly different group of people.

Japanese Americans

Despite having an extensive history with the United States, Japanese Americans are an underrepresented community in the United States compared to other immigrant groups (U.S. Census Bureau, 2022). The most widely known Japanese American historical event is the Japanese incarceration camps during WW2. These incarceration camps stripped people with

Japanese heritage of all belongings and assets and then forced them to cease speaking Japanese to prove their loyalty to the United States. Japanese Americans are the only ethnic group in the United States to endure incarceration on the grounds of ethnicity (Saito, 2021). While not all Japanese Americans currently living in the US are direct descendants of those who were in the incarceration camps or impacted by the camps, there are several values that have developed in the community that have remained relevant amongst many Japanese Americans.

In a study interviewing elderly Japanese Americans to explore common themes on the definition of success, one specific cultural value that arose was the idea of *gaman (我慢)*, meaning enduring and tolerating a particularly uncomfortable event or feeling while practicing patience (Iwamasa & Iwasaki, 2011). This idea emphasizes that there is a level of dignity, honor, and maturity that comes with submitting and accepting the reality for what it is without complaints. The practice of *gaman* was especially prevalent during the incarceration camps to help the prisoners in coping with the circumstances, and this has now passed down through many generations in the Japanese American community today. Another value that is prevalent and documented among the Japanese American community is the avoidance of the idea of *haji (恥)*, meaning a deep feeling of shame that extends past self but also to family and community (Tamura, 1994). Because haji is a negative feeling that extends to people's communities, efforts to prevent haji are taken very seriously among Japanese Americans. Especially after the incarceration camps, which created a great sense of haji within the community, the avoidance of this feeling is even greater and people will go great lengths to avoid this shame for the sake of the community. Due to this, many Japanese Americans have residual trauma where individuals keep feelings of shame to themselves, leaving them to suffer alone for the greater good and reputation of the community (Saito, 2021).

Even the term “Japanese American” is viewed as ambiguous because it includes every generation of Japanese Americans, starting with the first wave of Japanese immigrants to the US in 1800’s (also known as *issei)* to the current fifth generation (*gosei*) with each generation having different experiences and values (Daniels, 1977). The term Japanese American also applies to people who have immigrated to the United States during the Immigration Act of 1990 which allowed companies to sponsor highly skilled workers. Many of these immigrants do not have generational ties to the United States or to the incarceration camps, and this can lead to a completely different perception of what it means to be Japanese American (Ransom & Winters, 2021). Multiracial Japanese American people are also classified as Japanese American; one-third of Japanese Americans are multiracial, the highest percentage among Asian groups in the United States (U.S. Census Bureau, 2022). This means that the culture of Japanese Americans is susceptible to change as more intercultural influences become present.

Stuttering in Japanese People

Few studies have examined the experiences of Japanese individuals who stutter. Ujihara (2011) explored the linguistic and phonemic differences between stuttering in Japanese and American English; the author discussed how the structure of language affects the patterns of stuttering and linguistic theory of stuttering. Another study (Iimura et al., 2018) examined the public perceptions about stuttering by people in Japan regarding their knowledge and awareness of stuttering. Results showed that there were various beliefs about the cause of stuttering. The two most common responses were psychogenic (28%) and genetic (25%); fewer respondents indicated their belief that the cause of stuttering was neurologic, environmental, or the result of faulty learning. In addition, 77% of respondents believed that stuttering can be cured, 74% believed that intelligence is no different in people who stutter than people who do not stutter, and

47% believed that stuttering was a greater burden and handicap than eye or hearing deficits. When asked about parental action, 46% claimed that they would consult a family medicine doctor and 42% would consult a SLP. Perception about Japanese people who stutter in the workplace also showed that the biggest indicator of whether a person had a positive attitude towards people who stutter was if they had been in contact with people who stutter, either in the workplace or outside (Iimura & Miyamoto, 2021). The correlation between having contact with a person who stutters and having increased positive attitudes towards people who stutter has also been found in other cultures. Boyle et al. (2017) found that contact with a person who stutters was correlated with better public attitudes. There is also a positive correlation between people who stutter that self-disclose their stuttering, which is a form of "contact" that involves explicitly exposing the public to stuttering, and perceived positive public attitudes (Byrd et al., 2017). Self-disclosure also benefits the person who stutters, and this also is directly correlated with improved quality of life for people who stutter (Boyle, Milewski, et al., 2018). These findings all together indicate that self-disclosure and contact can have many positive outcomes. The stuttering research conducted in Japan reveal certain similarities and differences that can be found across Japan and other cultures. The treatment of stuttering in Japan can also give insight as to how stuttering is viewed in Japan and what factors influence stuttering treatment.

Stuttering treatment in Japan

Speech-Language-Hearing-Therapists (SLHT), the Japanese equivalent of Speech-Language Pathologists in the US, are trained to work with speech and language, voice, feeding and swallowing, hearing loss, and cognitive disorders. Although the field has been in existence for roughly 50 years, SLHTs in Japan are not allowed to diagnose stuttering (Chu et al., 2014). People who stutter must first receive a diagnosis from a physician who then refers to a SLHT if services are deemed necessary. However, most physicians often dismiss stuttering as a developmental behavior that will be outgrown, a practice that is partly influenced by Wendell Johnson's diagnosogenic theory of stuttering (Chu et al., 2014; Johnson, 1942).

There is a limited number of SLHT's in Japan who provide services for stuttering treatment, and SLHT's are rarely employed in Japanese schools. As a result, stuttering intervention is not required to be performed by a SLHT; it can be provided by general education and special education teachers (Iimura et al., 2022). The combination of the limited number of people who are competent in stuttering treatment and the confusing process of diagnosis and treatment being provided by different providers leads to parents that are left unaware or confused about stuttering therapy outside of the school system from a SLHT (Chu et al., 2014).

Treatment of stuttering for adults includes a mix of psychotherapy, self-help groups, and western techniques (Chu et al., 2014). One clinically unproven treatment method that is unique to Japan is the mental rehearsal program. This program is rooted in psychotherapy and claims to reduce negative reactions from previous negative experiences relating to stuttering (Tsuzuki, 2012). The psychotherapeutic method of stuttering treatment has been slowly losing traction. Now, a more technique-based approach is gaining popularity which includes fluency shaping, delayed auditory feedback, and easy onsets (Sakai et al., 2008; Sakata, 2012; Yasuda et al., 2012). Group therapy sessions are not considered due to the inability for people who stutter to feel comfortable enough to be open and vulnerable in front of peers (Chu et al., 2014). The Japan Stuttering Genyukai Association (JSGA) hosts self-help groups that started to gain in popularity in the late 20th century, where the acceptance (not curing) of stuttering is promoted and embraced (Kobayashi, 2004; Sakata, 2012). According to Dr. Kenjo Masamutsu, a SLHT from the Fukuoka University of Education, the most common treatment method for people who stutter is the practice of self-acceptance, rather than any direct therapy or fluency techniques (personal communication, 2022). This is because many Japanese SLHTs are not familiar with the fluency-enhancing techniques, which are commonly promoted in western countries.

The limited research that has been conducted with Japanese people who stutter opens the opportunity to extract clinical practices and treatment ideas specifically for this population and draw research questions for Japanese Americans who stutter. Research involving Japanese people who stutter is only partly relevant to the study of Japanese Americans, because it addresses just one part of the overall experience of Japanese Americans who stutter. Further consideration of how being Japanese American impacts the experience of being a person who stutters is therefore necessary.

The Japanese American experience

As noted above, stuttering research on people who stutter in various ethnic groups in the United States has been increasing over time, including studies of African Americans (Daniels et al., 2006; Ellis & Hartlep, 2017; Robinson & Crowe, 1998), Hispanic-Americans (Dean & Medina, 2021), Native Indian-Americans (Meeks, 2022), and Indian Americans (Ganesh, 2022). To date, there has been no research on the experiences of Japanese American people who stutter. While stuttering research in other Asian countries can provide some insight into the experiences of people within the same continent, there are many differences between Japanese American people and those from other Asian American communities. For example, Japanese Americans participate less in Asian American panethnic beliefs and do not necessarily culturally identify as “Asian American” (Tsuda, 2022). This poses an interesting position, in which Japanese Americans who stutter may have difficulty identifying with monocultural Americans who stutter, monocultural Japanese people who stutter, and even Asian Americans who stutter. Given the already small community of people who are Asian Americans who stutter in the United States, Japanese Americans who stutter may particularly have a challenging time feeling a sense of community or likeness.

Japanese Americans also participate in interracial marriage more than any other Asian ethnic group in the United States (U.S. Census Bureau, 2022). This means that the number of people who identify as Japanese American will also increase over time. Stuttering research on this population will become increasingly relevant as the number of people who identify as mixed-race Japanese American increase. Therefore, research on this population regarding people who stutter will provide SLPs with the cultural knowledge and implications needed for proper treatment of Japanese Americans who stutter, while also amplifying the experiences of Japanese Americans who stutter.

Purpose

The experiences of people who stutter are directly shaped by their cultural background and identities. Seeking to understand the person’s cultural background and experiences is the foundation to conducting effective clinical services. Even within the United States, there are many intersectional identities that involve people who stutter, and many nuances that come with these characteristics that clinicians must be aware of. If a person living in the United States is a racial minority (non-white) and a person who stutters, these two identities can often clash with each other in a way that further complicates the experience of living in the United States.

Without research on the experiences of Japanese Americans who stutter, SLPs will have limited resources on how to work with the population and offer culturally competent and effective care. The purpose of this study is to address this gap in the literature by documenting the lived experiences of Japanese and Japanese Americans who stutter. Data will be collected by interviewing Japanese and Japanese American people who stutter and Japanese and Japanese American SLPs. The OASES will also be administered to participants who are people who stutter, to gain insight on the impact that stuttering has on the individual level. The goal is to provide information that will help SLPs treating Japanese Americans who stutter to have more insight into their clients' cultural background and foster a more welcoming, effective therapy environment that is informed by cultural humility.

Methods

Participants

Participants were seven people total, each selected to provide unique insights about Japanese Americans and Japanese American people who stutter. Group 1 (PWS) consisted of three people who stutter with Japanese heritage to gain insight about their personal experiences. Group 2 (SLP) consisted of four Japanese and Japanese American SLPs to learn about differences in working with Japanese American clients and non-Japanese Americans.

Participants were recruited through personal contact with the author and postings in social media groups, professional societies, and flyers (Appendix A). Once the consent form was reviewed and consent was given, interviews were conducted over video-call (Appendix B). The number of participants for each group was determined based on the preliminary nature of this thesis and the broad goal of seeking to identify ideas for future research. Inclusion criteria for group 1 was to be over the age of 18, self-report as having at least half Japanese ancestry, and self-identify as a person who stutters. Inclusion criteria for group 2 was to be over the age of 18, self-report as having at least half Japanese ancestry, and be a speech-language pathologist. Demographic data was collected from all participants including age at the time of the interview, ethnicity, country of residence, gender, education level, and occupation (Table 1). Given the exploratory nature of the study and the relevance of participant characteristics to findings, information about participants will be listed in results.

This study was determined to be exempt by Michigan State University's Institutional Review Board (IRB) under 45 CFR 46.104(d) 2ii given the qualitative nature of the study being exploratory and data collection being open-ended interviews and surveys.

Data Collection & Analysis

Data was collected though semi-structured interviews consisting of a combination of closed- and open-ended questions in both Japanese and English (see Appendix C). Questions were chosen based on similar qualitative research studies on communication disorders (Dean & Medina, 2021; Luu, 2015) and the author's personal experience. Interviews, which were audio and video recorded to facilitate transcription, lasted between 50 to 75 min. Interviews were conducted in either Japanese or English depending on the language preference of the participant. Responses from interviews conducted in Japanese were translated to English. After the interviews, people who stutter were asked to complete the OASES which was offered in both English and Japanese.

Interviews revealed personal experiences and stories as a person who stutters, the cultural influence of being Japanese American, and information regarding stuttering in Japanese and American communities. This information will shed light on the personal experiences of people who stutter, explore the cultural nuances of Japanese Americans, and the SLP culture in Japanese and American communities, thus resulting in insightful information for SLPs treating Japanese Americans who stutter.

Data analysis followed a phenomenological approach, a qualitative research design that interprets individual experiences and compounds common features of the experiences (Creswell & Poth, 2015; Fourie & Murphy, 2011). This approach analyzes the lived experiences of participants through a subjective and objective lens. The subjective being that it is a personal experience, while objective relates to how multiple people experience the same phenomenon. Due to the exploratory nature of this study, a phenomenological approach was appropriate to understand the first-hand experiences of the intersection between being a person who stutters and being Japanese American. All transcripts were deidentified. Data was only accessible by the primary researcher, faculty supervisor, and Michigan State University International Review Board (IRB).

Deidentified and finalized transcripts were uploaded into Dedoose 9.0.107, a qualitative research analysis software program that allows media files to be shared, coded, and analyzed. Thematic analysis is an analysis method in which patterns and emerging themes are identified to describe the experience of the participants (Braun & Clarke, 2006). Once transcripts were entered into Dedoose, misspellings and coding errors were manually adjusted as needed. Phrases and sentences that highlight the participant’s experiences were collected and analyzed through an inductive analysis process which is a data-driven model that does not have any preexisting coding frames. Codes were generated in a consistent manner using tables and templates. Initial codes then developed into potential themes as the thematic analysis progressed. Codes that did not initially fit any general theme were placed in a miscellaneous theme to table them temporarily. During the theme refinement phase, themes that did not have enough data to support them with several codes were re-evaluated and discarded. Themes in this study are considered potential themes, due to the low number of participants. In a heterogenous sample, data saturation is thought to be achieved once 12 interviews have been conducted (Guest et al., 2006a). According to Braun & Clarke (2006), themes should have numerous texts to support them. Once the final list of themes was established, themes were defined and named to accurately portray the story behind each theme (Braun & Clarke, 2006). The goal of using thematic analysis in this way was to emphasize prominent meanings and features found among the data (Braun & Clarke, 2006).

Credibility and Reliability

Data saturation is reached when new, additional data adds no new information or insight that are relevant to the research questions (Guest et al., 2006b, 2020). Due to the small sample size, data saturation was not achieved in this study. Instead, this study sought to identify potential themes that may be useful for follow-up and further examination in future research.

Throughout the data analysis process, credibility and bias were controlled through the process of data triangulation, that is, intentionally posing the same interview questions to different participant groups and cross-checking responses for consistency or divergence. To establish inter-rater reliability, a second reviewer with experience in qualitative research and thematic analysis analyzed the themes identified by the first author. First, the second reviewer and author independently prepared transcripts of the interviews and identified an initial set of potential themes. Second, the second reviewer and author met on several occasions to discuss the list of potential themes and reach consensus on which were most likely to reflect the participants' responses. All potential themes were found to be met with a consensus from both the author and second reviewer.

Results

Participant demographic information can be found in Table 1. Demographic information includes occupation and/or clinical setting, ethnicity, age, gender, and location.

Table 1: Participant Characteristics

Participant	Occupation	Ethnicity	Age	Gender	Location
SLP1	SLP/ University professor in CSD (Voice)	Japanese	51	F	KY, USA
SLP2	SLP/ University Professor in Special Education & Fluency	Japanese	51	M	Hiroshima, JP
SLP3	SLP/Inpatient acute & private practice	Japanese	49	F	HI, USA
SLP4	SLP/ Pediatric Outpatient	Japanese	35	M	CA, USA Tokyo, JP
PWS1	University Student	Japanese & American	24	F	TX, USA
PWS2	University Student	Japanese	21	F	GA, USA
PWS3	MD/ Stuttering Researcher	Japanese	45	M	Fukuoka, JP

OASES results of PWS1 and PWS3 were gathered including the mean scores of each category and the impact rating (See Table 2). OASES results for PWS2 are not included, as the participant did not finish the questionnaire. Participant results can be compared to the normative data from Japan and the USA. Scores show that there was variation between participants; however, their total scores all yielded “moderate” impact ratings. This is an interesting preliminary finding due to the very different characteristics of the people who stutter. For example, PWS1 is a half-Japanese & half-American person who identifies with Japanese culture but has never visited Japan. Contrarily, PWS3 is a native Japanese person who has lived and worked in Japan for the majority of his life.

Table 2: OASES Results for Participants compared to normative data for Japan and USA

	PWS1		**PWS3**		**Japan**		**USA**	
	Mean score	Impact rating	Mean score	Impact rating	Mean score	Impact rating	Mean score	Impact rating
1: General Information	2.15	Mild-mod	2.30	mod	2.86	mod	2.67	mod
2: Reaction to stuttering	2.73	mod	3.30	Mod-severe	2.97	mod	2.75	mod
3: Communication in daily situation	2.38	Mild-mod	2.48	mod	2.57	mod	2.66	mod
4: Quality of Life	1.86	mod	3.00	Mod-severe	2.74	mod	2.37	mod
Total	2.28	mod	2.77	mod	2.79	mod	2.60	mod

Analysis of the interview transcripts revealed six potential themes highlighting the Japanese American experience of stuttering and the cultural implications: (a) Communication challenges, (b) Stuttering in the context of Japanese communication, (c) Reluctance to seek support, (d) Understanding of stuttering, (e) Cultural change in Japan, and (f) Acceptance in people who stutter. The following section includes quotes from the participants to illustrate the potential themes. Some quotes applied to more than one theme. Relevant portions of quotes are italicized to highlight the corresponding theme that it represents, as many themes were represented in one quote.

Communication Challenges

Frustration

Participants expressed the general frustration they experienced as a result of their stuttering. This was demonstrated in the following quotes from people who stutter who described how stuttering affects their ease of communication:

> PWS3: I can't say what I want to say smoothly, so *it can be frustrating*. I get annoyed at it sometimes. Being unable to express myself smoothly and taking so much time to speak still makes me frustrated.
>
> PWS1: *I would get so frustrated* because when you're young, you want to just go, go, go, but it was hard to get everything out of me so I would get really really angry with myself a lot.
>
> PWS3: In elementary school, I couldn't speak fluently *which left me feeling frustrated*. In front of most people, I was prone to anxiety and fear and avoided speaking in most situations.

Impact on Communication

Participants also discussed the effects of being a person who stutters that go beyond observable fluency or stuttering behavior, such as the effect it has on conversations and discourse. As demonstrated in the following quotes, this was observed by SLPs and described PWS.

> SLP2: There are some people who stutter that are so fixed on what they're saying themselves that *they're unable to pay attention* to what others are saying during the conversation.
>
> PWS2: In the middle of me talking, *I would blank out* on what I want to say.

Stuttering in the context of Japanese communication

Some participants reported that being a person who stutters in the context of communicating in Japan also yields specific challenges. Participants specifically mentioned the cultural practice in Japan of not speaking up in order to avoid disrupting the *wa*, or harmony. Two unique categories were revealed when considering challenges for people who stutter in Japan. First, the overall custom in Japanese culture that discourages speaking up and openly sharing further prevented people who stutter from expressing their feelings and participating socially.

> SLP2: I have a client that stutters that I have been seeing in therapy for 6 years. In the beginning of the 6 years, his parents had told me that he had been getting bullied at school which led him to stop attending school. *However, the client himself never talked to me about it*. But very recently, he himself finally told me about how he had been getting bullied… I know it took a lot of courage for him to open up and tell me about that… *There might be a lot of people in Japan who have a hard time actually saying "I'm struggling."*
>
> PWS3: My family accepted me as a person who stutters. However, *we never openly discussed my stuttering in general for several years* during elementary and middle school, so that was very challenging for me.

Second, this culture of not speaking up in order to maintain peace may in turn encourage people who stutter to stutter more covertly, because assertively expressing one's thoughts is not expected in general.

> PWS3: In Japan, *it's not as troublesome to just keep quiet*… if you're quiet and don't talk, people don't really care and just think that you're just a quiet person… There's less pressure in Japan to participate in conversations compared to the US.

> SLP2: Because *a lot [of people who stutter], try to hide it*, it's easier to blend in. For example, even if a person who stutters may know the answer to a question in class, they won't raise their hand because they don't want to speak. They really live trying to make sure that no one finds out.

Reluctance to seek support

Participants also noted specific challenges for Japanese people regarding reluctance to access services and the awareness of services available. This was demonstrated in the following quotes made by SLPs.

> SLP4: *Japan has a history of hiding disability and conformity*. It's a lot harder to access services because of it. Receiving services are not a legal mandate in Japan [compared to the USA].
>
> SLP2: That's why it would be good if people who stutter raised their voices and demanded services more proactively, but because *they don't want to speak up*, it can be challenging for Japan to feel the urgency to make good change.
>
> SLP3: Culturally speaking, seeking help or therapy if somebody who is crazy. The therapy itself has a negative undertone. *They feel that it's a sign of weakness, a sign of not being mainstream so many people do not seek help*.

Acceptance within people who stutter

Throughout the course of the interview, several people who stutter expressed that they had felt an increased sense of personal acceptance as a person who stutters that occurred over time.

> PWS1: I used to do this, I used to [be] like extremely covert in front of other Japanese American people because I was afraid because I didn't want them to think "oh you're not understanding because so and so" so sometimes I did hide it [my stutter] but *as I've*

> *grown older, I've been more like putting it into the conversation and including it into the conversation and frame it as "this is just a slight difference that I have."*
>
> PWS1: I think when I was a lot younger, and still learning how to accept myself, it was really hard on my self-esteem. I had like severe social anxiety, I never wanted to go out to talk to people. But *as I've gotten older and more confident, it's gotten a lot easier I suppose like my confidence has gone up for sure.*
>
> PWS3: I used to be worried or scared about it [speaking fluently], *but recently I would say that I have acknowledged myself as a person who stutters.*

Participants also noted the role that stuttering support groups made on their journey to acceptance and the impact that community made on them.

> PWS3: When I was in college, *I joined a self-help group for people who stutter [Genyukai]. I realized that I wasn't alone. That was a major point in my acceptance journey.* Also, it helped me to actively learn more about the science of stuttering and all of the knowledge that comes with it, including the mechanisms of stuttering, causes and treatment.
>
> PWS1: Well, people know me [at NSA conference] and I am a person who stutters so it's like I prioritize that more…. *I literally never met someone with a stutter until 5 years ago, so it's more like I'm so happy and focused on that when I'm at a conference.*

Understanding of Stuttering

Participants reflected on the notion that different groups of people may have a different understanding (or a lack of understanding) about stuttering. Specific groups that were highlighted include the general public, people who stutter, SLPs, and family members of people who stutter.

By the Public

Participants reported that the general public holds many misconceptions about stuttering relating to the cause of stuttering and what communication disorders are in general..

> PWS3: People here don't view stuttering as a disability. Not many people do. For example, Tanaka Kakuei [former prime minister of Japan] had a stutter as a child, but they believed that he cured his stutter when he was a kid. *They think that stuttering is something that can and should be cured* more than Americans.
>
> PWS3: *People in Japan often think that people who stutter are just nervous so if they work hard enough, they won't stutter anymore*. People who don't understand may commonly tell a person who stutter to just stop stuttering.
>
> SLP1: Generally, *people in Japan view communication sciences and disorders more as special education.*

Participants also indicated that the general public has specific expectations about the careers that would be most appropriate for people who stutter. Beliefs about work performance for people who stutter also intersected with beliefs about work performance related to gender.

> PWS3: For people who stutter pretty severely, *they may work in a factory so they don't have to talk as much.*
>
> SLP3: I'm sure that *people who stutter and seek jobs won't be working in jobs, for example, that require a lot of talking over the phone*.
>
> PWS1: It's kind of is unfortunate because I work in the science field so a lot of men will be like "oh, *well you're a woman, you seem like you don't know what you're saying' [because of stuttering]*

> PWS1: I was having a harder day with my speech, and I was trying to explain something at work and *he [a male coworker] said "oh my god are you on your period or something?"*

By Speech-Language Pathologists

The lack of specialization of stuttering by SLPs was mentioned in Japan and in the United States. The culture of staying quiet rather than speaking up in Japan also intersected with the beliefs of SLPs.

> SLP2: The symptoms of stuttering can be hard to treat, so they [SLPs] often *don't know what to do or they think that there's no point in specializing because it's hard*, or they think that it's better to just not talk about it, almost like an unspoken rule.
>
> PWS1: I hated it [stuttering] and I was getting mad at myself because *my previous speech therapist, she never had a student who stutter before so she really didn't know how to help me.*

By Family Members of People Who Stutter

The participants also reported on the reactions and perspectives of family members. These perspectives ranged from feelings of shock, shame, and ability.

> PWS3: My father is a person who stutters. When my stutter began, *my family was shocked* that my father's stuttering was inherited.
>
> PWS1: I definitely felt more shame because I couldn't *cure myself like my family had wanted me to.*
>
> PWS1: I was never really taught to speak [Japanese] because.. my grandma was like *"oh, I don't think you'll be able to handle [learning Japanese] because you have a stutter.*

By People who Stutter

Similar to the general public having varying degrees of understanding of stuttering, people who stutter also have varying levels of understanding of stuttering ranging from not knowing what stuttering is to having misconceptions about it.

> SLP2: In Japan, it's gotten a little better, but *a lot of people don't attend therapy until they're adults because they say things like "I didn't know that this was even called stuttering," "I thought I was the only one that talked like this*." I still see people like this very frequently.
>
> SLP2: *There are some that don't know what stuttering is, they don't understand that it's an actual condition.*
>
> PWS2: I was born and raised here in America, I speak [English] all the time. *So I was constantly questioning why I keep stuttering when I know what I want to say.*

One participant's conceptions about their stutter demonstrate the interplay between personal beliefs about stuttering as a person who stutters and the individual experiences as a Japanese American.

> PWS2: It does make me a little, sad? I don't know if that the right word. But as I said before, I was born and raised in America, I spend most of my time speaking in English. But when I think about getting to know people, I think about the fact that I stutter, and that *they may not think that I'm not as "American".*

Interviews reflected varying levels of misconception and understanding of stuttering by people who stutter themselves, common members of support such as family and SLPs, and the public. These perceptions can depend on the individual and culture, and how those two factors evolve over time.

Cultural Change in Japan

Participants reported that the Japanese culture historically viewed disability in an out-of-sight-out-of-mind lens. While participant interviews did not directly address inclusivity for people who stutter, several participants did note changes occurring in terms of accepting people with disabilities and being more inclusive in general.

> SLP2: *Those values might be changing a little bit recently*. Back then, the culture was that we need to hide kids with disabilities or not ever acknowledge that they have a disability in the first place. But young parents nowadays, often can understand and accept the disability more. Of course, some people still think the opposite of that. But generally, *there isn't a big stigma against people with disability compared to before*….I think there's a general consensus that we need to do something to support people with disabilities."
>
> SLP2: So the idea that we need to do something perhaps to assist those people has increased a little slowly in our society.
>
> SLP2: We also have the Japanese version of the ADA here as well. I think the idea of DEI has also picked up in Japan recently, even towards people who are LGBTQ, or foreigners. Society's recognition of the need has increased, and we need to be more inclusive to include all different groups of people.
>
> PWS1: I think like recently, it's become more acceptable to seek help no matter what. But growing up it was harder because it's something that wasn't widely researched. We're still learning something new everyday, it's so much. It's insane.
>
> SLP1: I think the culture has changed a little bit in the past 20 years. The importance of communication has been promoted recently in workplaces and schools…. The younger

generation is a lot different I think compared to the older generation. They've been educated through a different curriculum to express how they feel directly instead of holding back while still being polite.

Discussion

The current study aimed to describe the intersection of people who stutter and those that identify as being Japanese (either native Japanese or Japanese American). This was achieved by interviewing Japanese American and Japanese people who stutter, as well as Japanese speech-language pathologists (SLPs). The original goal was to learn about the Japanese American experience; however, this goal was broadened due to the small target population. While the Japanese experience is different from the Japanese American experience, gaining a deeper understanding of the contextual factors surrounding Japanese society can shed light on the Japanese American experience as well. Further, it should be noted that the Japanese American experience can differ depending on the individual. The results of this study reflect the arguments made by Ohnishi & Ibrahim (1999) who found that the Japanese American experience is influenced by several factors including level of acculturation, age of arrival to United States, socioeconomic status, region of residence, and purpose of migration. Therefore, these individual differences between and within groups should be considered when addressing cultural competency and to viewing culture as a tool to inform, but not to generalize.

The OASES responses were collected with the intent to see the varying levels of impact that stuttering had on the person, and compare that to normative data in the United States and Japan. Results showed that both participants that filled out the OASES fell in the moderate impact range. Some future analysis might allow comparison between people’s opinions and perceptions about the stuttering experience in Japan to their own individual experience as reflected in the OASES. However, more data will be needed in order to complete that analysis.

This discussion attempts to dissect some of the cultural practices and attitudes of Japanese people that could explain these unique experiences of Japanese and Japanese Americans who stutter. This was based on the potential themes identified through the interviews.

Communication challenges: Participants highlighted their feelings of frustration when experiencing stuttering. These feelings are often found to be universal for people who stutter (Klompas & Ross, 2004; S. E. Tichenor & Yaruss, 2019b, 2021). Furthermore, the impact that stuttering has on pragmatic communication, more than just observable fluency, was mentioned by participants. For example, participants stated that people who stutter often have challenges listening to a conversation partner due to their own focus on their fluency. These internal frustrations and challenges have also been found to affect the self-esteem of people who stutter, which in turn affects their social and professional lives (Blood et al., 2003; Boyle, Beita-Ell, et al., 2018).

Stuttering in the context of Japanese communication: A notable communication challenge that particularly impacts Japanese people who stutter is the cultural practice of *wa*,or harmony. The general collectivist society of Japan, contrary to the individualistic society of the United States, creates an environment that prioritizes harmony of a collective group rather than the satisfaction or comfort of an individual. Instead of considering what might be viewed as inherently good or bad, people view maintaining a harmonious group dynamic as being most important (Lebra, 1976). De Mente (1997) described the collectivism of Japan saying, "Generally speaking, conforming to proper etiquette was the Japanese equivalent to being religious" (p.112). However, collective society alone cannot be attributed to all practices. One study showed that when comparing communication practices between Japan and Thailand (both collectivist societies with Buddhist influences), the social communication of each group were found to be completely different. For example, Japanese people viewed Thais to communicate in a disordered and self-centered manner while Thai people viewed Japanese as being too formal and guarded about personal feelings (Aoki, 2010). Therefore, there are aspects of Japanese communication that extends further than the collectivist culture.

Maintaining this harmony can be explained by other Japanese expressions, including *honne* and *tatemae*. *Honne* and *tatemae* operate like yin and yang: *honne* represents the true feelings of a person and *tatemae* represents the actual public action and display (De Mente, 1997). In an individualistic society, one's actions may often represent how they truly feel. However, in a collectivist society, the harmony of the group is so important that people are expected to publicly say or act in a certain way even though it may not be genuine, for the sake of not disrupting the peace. Most participants brought up the concept of Japanese people being very passive and not speaking directly. They also highlighted the importance and prominence of the "group" and doing anything to maintain that group dynamic even if it means to adjust your own characteristics.

The need for *wa* specifically affects people who stutter in two ways. First, because the Japanese culture often discourages speaking up, people who stutter in Japan may have particular difficulty participating socially and having open conversations, even with family members. This is illustrated in the quote from PWS3 who stated that his stuttering was not talked about in the family for several years. Second, the general cultural practice in Japan of not speaking up or expressing true feelings parallels covert stuttering behaviors. Covert stuttering behaviors, which are found in people who stutter globally, include remaining silent, choosing not to speak, and removing themselves from a situation (Tichenor & Yaruss, 2019a). Participants in the present study noted that Japanese culture in particular, may encourage people who stutter to be more covert, because passiveness is the standard for all people.

Wa is also maintained through the cultural practice of *haji,* or shame. Haji describes the fear of what others will think, how that effects their reputation, and whether shame will arise as a result of other people's judgements (Farese, 2016). De Mente (1997) describes haji as follows: "while Christian, Muslims, and others relied more on the threat of damnation and punishment by a vengeful god and powerful clergy, … the Japanese resorted to shame as their primary psychological sanction to keep people in line" (p. 112). Haji is described as a behavioral restraint for Japanese people, but it can specifically influence people who stutter by encouraging covert behaviors. Participants also reflected this notion by saying that they hid their stuttering in front of other Japanese Americans because of the fear of judgement.

Reluctance to seek support: Haji was also prominently represented in several participants' comments regarding their reluctance to seek help and the stigma about attending therapy and being vulnerable. Seeking therapy for people in Japan was described as being a sign of weakness, as captured by SLP2's statement, "there are a lot of people in Japan who have a hard time actually saying 'I'm struggling.'" Research confirms that Japanese people are less likely to seek support in the context of psychological support (Mojaverian et al., 2013). Several cultural practices could potentially explain the reluctance of actively participating in the therapeutic relationship including the respect for authority, haji, and the culture of not speaking up.

Japanese culture has historically operated on a vertically hierarchical society that emphasizes the importance of the social roles of an individual and staying in the group that an individual is a part of (Lebra, 1976). A large effect of this construct is the prominence of the respect for authority (Roger & Davies, 2019). While this strict structure has evolved over time to be less rigid, elements of Japanese culture such as the linguistic usage of honorifics to denote status and respect is still the standard today (Lebra, 1976; Ogihara, 2017). Respect for authority among Japanese people creates challenges relating to the therapeutic relationship and building rapport. Literature on therapeutic relationships in Japan and Japanese Americans states that many Japanese people will indicate that they are encountering challenges but have a hard time disclosing what exactly it is (Nagayama Hall et al., 2019). The fear of shame also influences the therapeutic relationship. Tsushima et al., (2011) stated that within therapy, Japanese people are likely to feel more vulnerable to shame the more they reveal about themselves. Japanese people view a therapeutic relationship socially, meaning that keeping their concerns to themselves is better for the sake of the relationship (Mojaverian et al., 2013). The act of sharing too much personal information is concerning to the patient because they feel that disclosing struggles may burden the therapist and disrespect the relationship, especially because they view the therapist as a person in power that has authority (Nippoda, 2012). Participant excerpts support this idea, as demonstrated by one participant SLP3 who stated, "you have to prepare to take a long time to establish a connection [with Japanese clients] to get things done." and participant SLP2's comment stating, "building rapport is important [so that] the truth will come out eventually". This engrained hierarchical structure in Japan leads to challenges when members of different "groups" with different levels of power interact. However, one established benefit of this structure is the bond that builds within members of the same group.

Acceptance in people who stutter: Self-help groups are a common resource that can enhance acceptance of stuttering and improved self-image for many people who stutter (Boyle, 2013b; Yaruss et al., 2002b). Participants mentioned the large role that stuttering self-help groups played in their journey to self-acceptance, notably the National Stuttering Association (NSA) for American people who stutter and Genyukai, the Japanese Stuttering Association.

The National Stuttering Association (NSA) is the largest stuttering self-help support group in the United States which began in 1977 (National Stuttering Association, 2023). Members of the NSA have reported that joining the self-help group has made a positive impact on their self-image and acceptance (Yaruss et al., 2002b). Japan has a history as early as 1909 of creating self-help support groups for marginalized people such as those with disabilities, mental health issues, and alcoholism (Oka, 1994). Genyukai, the stuttering self-help support group, began in 1966 and has grown to be the largest stuttering self-help group in Japan (Kenjo et al., 2015). Similar to native Japanese people, Japanese Americans have also reported that leaning on family and friends, socializing with others, and self-help support groups as significantly more helpful that white Americans (Narikiyo & Kameoka, 1992). The success of the community-based approach of stuttering self-help groups in Japan could be explained by several reasons. First, associating and colleting in groups is a practice that many Japanese people feel comfortable with. Also, the group creates an environment where people are surrounded by peers without the pressure of authority and the personal freedom within the group. Lastly, the risk of haji, or shame, could be minimized because people are gathered on the shared, stigmatized experience of being a person who stutters. Despite the geographical and cultural differences in which the stuttering support group were in, the participants in this study recounted that joining a stuttering self-help support groups served as a significant factor in their journey to self-acceptance.

Understanding of Stuttering: Participants shared the perspectives from the public regarding people who stutter. Notably, the misconceptions surrounding the causes of stuttering and the intersection of being a person who stutters and gender. These perspectives can be found across many cultures. Literature shows that people who stutter globally endure public misconceptions especially surrounding the causes, however the level of public misconception depends on the country (Abasi, 2022; Boyle et al., 2009; Valente et al., 2017). However, Bebout & Arthur (1997) reported that Japanese adults tend to think that people who stutter are stuttering because of not trying hard enough, more than North or South American people. These misconceptions in Japan are not limited to stuttering, as communication disorder in general are seen as psychogenic (Matsuda, 1989). Participants also discussed this idea that people in Japan may not understand the nature of communication disorders in general.

In addition to participants discussing general beliefs surrounding stuttering, participants commented on the intersectionality of being a person who stutters and gender. In the United States, men and women have different socially prescribed expectations regarding their language use. Women are commonly stereotyped as speaking with more euphemisms, unfinished sentences, and being nonassertive (Haas, 1979). In Japan, gender roles and expectations for speech have long been determined by men, with women serving a more ancillary role (Belarmino & Roberts, 2019). Japanese women are often expected to speak softly and in a feminine manner (Abe, 1995). In both the United States and Japan, there are expectations set on the basis of speech and gender. For PWS1, this manifested through her receiving inappropriate comments by male coworkers due to her stutter. While people who stutter face misconceptions from the public in general, the intersections of culture, gender, and race can certainly influence these perceptions.

People who stutter can also have their own understandings, or lack of understandings of what stuttering is. People who stutter often may not know that they are a person who stutters. Participants shared several examples of people who stutter not knowing what a stutter is, or realizing that they are not the only person who stutters as an adult for the first time. Some participants stated that Japanese people may be more likely to not identify as a person who stutters. However, there is currently no literature to support or refute these claims.

The understanding of stuttering by SLPs was also a point of discussion by participants. Participant excerpts shared perspectives from both sides of the therapeutic alliance for stuttering intervention: the person who stutters and the SLP. PWS1 discussed her experience working with a SLP in the United States who had never worked with a person who stutters before, therefore leading to a less productive therapeutic outcome. Literature shows that SLPs in the United States do not feel confident treating stuttering, and Communication Sciences and Disorders graduate programs in the United States may not be prioritizing specialization in stuttering as evidenced by their clinical requirements (Byrd et al., 2020; Yaruss et al., 2017). Furthermore, SLP2, who is a clinician who specializes in stuttering, mentioned that many SLPs in Japan do not specialize in stuttering due to the nature of stuttering symptoms being difficult to treat. Sakata (2012) confirms this lack in her research, which found that there are very little SLPs that treat stuttering in Japan today. The lack of SLPs who specialize in stuttering appears to be a problem in both the United States and Japan (Byrd et al., 2020; Sakata, 2012; Tellis et al., 2008). SLPs can often play a large role in the journey to acceptance for people who stutter, and these encounters by both SLPs and people who stutter show that there is a lack that should be addressed.

In addition to SLPs and their level of understanding of stuttering, varying levels of support and understanding were found amongst family members of people who stutter. The reactions of the family members of people who stutter often paralleled the personal reactions of people who stutter. For example, several people who stutter shared how their family’s initial reactions to stuttering may have been misinformed about the causes of stuttering, but now serve are an active source of support. Literature states that the presence of familial support can positively influence stuttering management, while conversely, the lack of familial support can cause negative implications (Plexico et al., 2005; Yaruss & Quesal, 2004). Furthermore, people who stutter have often acknowledged that family members often have good intentions despite having incorrect assumptions about stuttering (Hughes et al., 2011). Familial support may often differ depending on culture, but remains an important aspect of support for people who stutter (Medina et al., 2023).

Cultural change over time: Lastly, participants overwhelmingly noted the topic of change, acceptance, and inclusion of disability occurring in Japan despite some cultural practices being very deeply rooted. SLP2 mentioned the notable increase of the elderly population in Japan may have forced the country to re-evaluate the accessibility of the country. Others stated that western ideas of communication, specifically assertively speaking and openly debating, have been incorporated in academic curriculums more. While people who stutter face stigma and stereotypes globally, the challenges that Japanese people who stutter endure could partially be attributed to the collective society and intolerance for differences. However, small characteristics of individualism have been emerging in Japanese society such as the low birth rate and the concept of "uniqueness" being thought of more positively (Ogihara, 2017; Roger & Davies, 2019). While cultural changes happen over time on small and large levels every day, the influences of foreign practices continue to shape Japan to be a country with deeply rooted sociological structures but with growing opportunities for change.

In conclusion, the discussion of these potential themes indicate that Japanese American people who stutter hold some experiences that are specific to Japanese culture, but also highlight the highs and lows of being a person who stutter in general. The cultural concepts mentioned in this discussion are only potential ideas that could explain the experiences shared by participants, and are used to attempt to dissect what it means to be a Japanese person who stutters. Each person’s experiences are different, and could be explained by several factors including race, culture, and ability.

Limitations and Future Directions

Although this preliminary study identified a number of potential themes that can be further explored in future research, the study itself has some limitations that should be considered. First, the small sample size of participants limits the perspectives shared and the generalizability of results. The author made efforts to mitigate the impact of the small N by being cautious in interpreting the findings, for example, by discussing “potential” themes and by interpreting the respondents’ answers broadly. Additionally, as with most qualitative research, implicit researcher bias is a risk that could rise due to the researcher’s knowledge and personal experiences (Nowell et al., 2017). Despite efforts to limit the presence of leading questions by using neutral language and asking all questions to all participants, the possibility of leading questions arose given the need for follow-up questions in some interviews.

Several topics of discussion that would benefit from further investigation arose from this research. First, the experiences of Japanese American people with communication disorders in general could produce more specific challenges that both clients and SLPs face when working with each other. Furthermore, the discussion of the lack of SLPs specializing in stuttering should continue to be investigated for the purpose of being more readily available to people who stutter and to increase the general competence of SLPs. Future directions also include following up with a larger N to get a larger sample size. Furthermore, considering questionnaires or surveys that can target specific potential themes may be appropriate.

Final Conclusions

The purpose of this study was to give voice to Japanese Americans who stutter, learn from their experiences through an intersectional lens, and inform SLPs on the cultural context of Japanese and Japanese American people who stutter. Results indicated that there are some universally shared experiences of people who stutter, such as feelings of frustration and challenges communicating. Furthermore, culturally specific experiences of Japanese people who stutter revealed a very different culture from the United States specifically in terms of communication styles and sociological relationships. The potential themes and experiences shared here should not be conflated to be the experience for all Japanese and Japanese American people who stutter. Having an informed idea of a person's culture is one aspect of practicing with cultural competency. However, all therapy should be curated to the client's goals, no matter their cultural identity. In summary, the intersection of being Japanese and being a person who stutters does lead to unique experiences but also parallels experiences of both identities independently.

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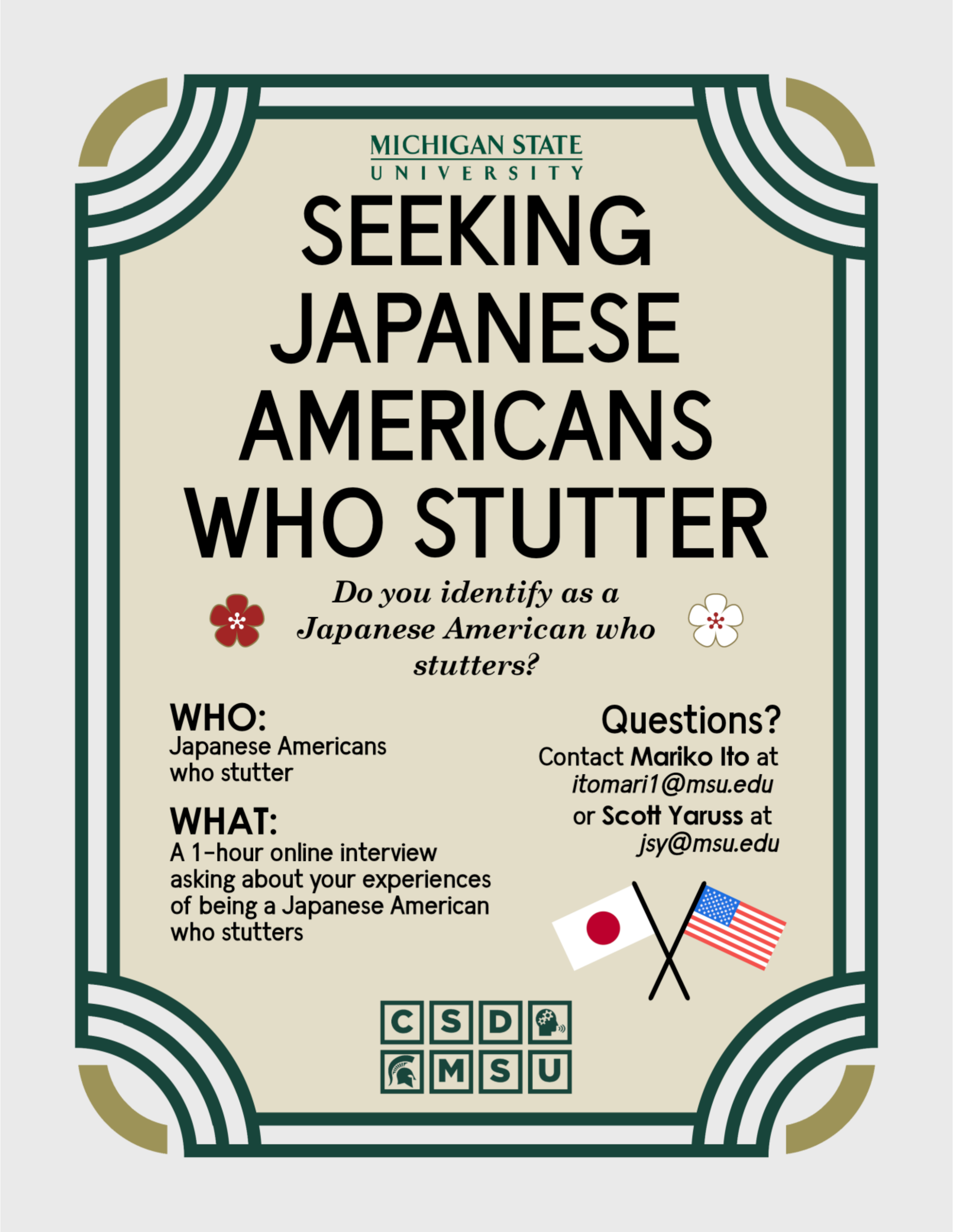
APPENDIX A: RECRUITMENT FLYER

Figure 1: Recruitment Flyer



MICHIGAN STATE UNIVERSITY

SEEKING JAPANESE AMERICANS WHO STUTTER

Do you identify as a Japanese American who stutters?

WHO:
Japanese Americans who stutter

WHAT:
A 1-hour online interview asking about your experiences of being a Japanese American who stutters

Questions?
Contact **Mariko Ito** at *itomari1@msu.edu* or **Scott Yaruss** at *jsy@msu.edu*

CSD MSU

APPENDIX B: CONSENT FORM

Consent Form

Study Title: The Experience of Japanese Americans who Stutter

Background and Purpose of the Study

The purpose of this study is to learn about the experiences of Japanese Americans who stutter. Research in this area has not been conducted. Our goal is to know about the intersection of being a Japanese American who Stutters to better inform the SLP community and the general public.

WHAT YOU WILL DO

You will be asked to provide answers to survey and interview questions about your experiences as a Japanese American and as a person who stutters. Your participation in this study will require about 60 minutes.

POTENTIAL BENEFITS

Though you will not directly benefit from your participation in this study, your response will help clinicians, researchers, and other people who stutter better understand your experiences of stuttering.

POTENTIAL RISKS

There are minimal foreseeable risks associated with participation in this interview. The primary risk is a breach of confidentiality. We will take every precaution to guide your privacy by ensuring that your personal information will not be released publicly or shared with anyone. The other possible risk is that some of the questions may cause you to feel uncomfortable. You will not be required to answer any question that you do not wish to answer.

PRIVACY AND CONFIDENTIALITY

Information about you (including name and demographic information) will be kept confidential to the maximum extent allowable by law. Data (including recorded interviews for transcription) will be stored on a secure, password-protected server at MSU. The only people who will have access to this server will be people directly involved with the research study and the University's Institutional Review Board (IRB).

All survey item responses will be de-identified for analysis, and no personally identifiable information will be included in any presentations or publications resulting from this study.

All data will be collected via interview and responses will be anonymized. Results of this study will be made available to you and anyone who is interviewed. A link will be sent via email when the study is completed.

With participant permission, all interviews will be audio and video recorded to facilitate transcription.

Your rights to participate, say no, or withdraw

Participation is voluntary.
You have the right to say no.
You may change your mind, discontinue, and withdraw from the study at any time.
You may choose not to answer specific questions or to stop participating at any time.
You may choose to not have the interview video-recorded.

COSTS AND COMPENSATION FOR BEING IN THE STUDY

There is no cost to you or compensation provided for this interview. We appreciate your time and your responses so that we can learn more about the experiences of Japanese Americans who stutter.

Contact Information

If you have concerns or questions about this study, such as scientific issues, or to report an injury, please contact the researcher or the faculty supervisor:

- Mariko Ito; itomari1@msu.edu; 248-719-5430
- Prof. J. Scott Yaruss, PhD, CCC-SLP BCS-F, F-ASHA (Lab Director) jsy@msu.edu
  Michigan State University Spartan Stuttering Laboratory
  1026 Red Cedar Road, Oyer Building, MSU, East Lansing, MI 48824

If you have questions or concerns about your role and rights as a research participant, would like to obtain information or offer input, or would like to register a complaint about this study, you may contact, anonymously if you wish, the Michigan State University's Human Research Protection Program at 517-355-2180, Fax 517-432-4503, or e-mail irb@msu.edu or regular mail at 4000 Collins Rd, Suite 136, Lansing, MI, 48910

DOCUMENTAION OF INFORMED CONSENT

Please select your choice below. You may print a copy of this consent form for your records.

You indicate your voluntary agreement to participate by beginning the interview and to the following:

- You have read the above information
  You are 18 years of age or older

APPENDIX C: INTERVIEW QUESTIONS

Background/ Japanese American Culture

1. What is your ethnic and cultural background?
2. Please share about your upbringing:
    a. Where were you raised?
    b. What language(s) do you speak?
    c. What ethnic community/ies do you identify with?
        i. Has your ethnic or cultural identity changed over time?
    d. What are your experiences as a Japanese American?
        i. Do you have positive memories or experiences growing up as a Japanese American?
        ii. Do you have negative memories or experiences growing up as a Japanese American?
        iii. What do you think are some factors that have led to your identity as a Japanese American?
3. What would you rate your Japanese and English language proficiency level? For example, on a scale of 1-100, 1 being zero proficiency and 100 being native speaker.
4. Are you a member of a Japanese-related cultural group?
    a. If yes—why did you choose to become a member of the group?

Stuttering

5. At what age did you begin to stutter?
6. How did you react to your stuttering as a child?
7. How do you react to your stuttering now?

8. How did your family react when you started stuttering?
9. How does your family react to your stuttering now?
10. What are your beliefs about the causes of stuttering?
11. I'd like to know more about your stuttering overall. Can you share with me your feelings and thoughts about stuttering?
12. How has stuttering affected your identity as a man/woman/other?
13. Are you a member of a stuttering support group?
    a. If yes—do you find it helpful?
14. Have you sought treatment for stuttering?
    a. If yes, where did you go and who did you see?
        i. What was your experience with the therapeutic experience?
    b. If not, what factors led to your decision to not seek treatment?
15. How has stuttering affected your self-esteem i.e., the way you have valued yourself over the course of your life?

Japanese American & Stuttering

16. How would you describe the impact of being Japanese American who stutters on your well-being?
    a. Personal well-being (thoughts, emotions, shame, acceptance)
    b. Social well-being (coping strategies, interaction strategies, passing/blending)
17. What are your thoughts on how you are treated as a person who stutters who is Japanese American?
    a. How has that affected you?

18. What would you say is your greatest source of support as a Japanese American who stutters?
19. In an environment in which stuttering is accepted (e.g. at a stuttering support group conference), what adjustments might you make, if any, as a person who is Japanese American?
20. In a predominantly Japanese American environment, what adjustments might you make, if any, as a person who stutters?
21. Do you feel that being Japanese American and a person who stutters affects your identity in a different way?
22. If you weren’t Japanese American, do you believe your experience with stuttering would be different?
23. Is your identity as a Japanese American affected by your stuttering?
24. How do you think Japanese Americans view people who have physical or mental conditions?
25. What assumptions, if any, do people make about you as a Japanese American who stutters?
    a. How do those assumptions affect you?
26. How do you think Japanese Americans react to seeking treatment for stuttering?
27. What do you think speech-language pathologists need to know about working with Japanese Americans who stutter?