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SOCIAL-PRAGMATIC COMMUNICATION IN WOMEN WITH AUTISM SPECTRUM DISORDER: A MULTIPLE CASE STUDY

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Abstract

Autism spectrum disorder (ASD) is identified much later and less often in females than in males. Some researchers suspect that a different set of characteristics of ASD in females may not be consistent with the more established and widely recognized characteristics of ASD, leading to under-identification in women. In the present study, four women and one non-binary feminine-presenting person with ASD were interviewed. The five participants conveyed their experiences with social-pragmatic communication, and their views on gender, ASD, and gender differences in ASD. The results are discussed in relationship to the limited amount of past research on women with ASD.

Keywords

autism, gender, pragmatics

Subject Categories

Speech Pathology and Audiology

SOCIAL-PRAGMATIC COMMUNICATION IN WOMEN WITH AUTISM
SPECTRUM DISORDER: A MULTIPLE CASE STUDY

by

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Abstract

Autism spectrum disorder (ASD) is identified much later and less often in females than in males. Some researchers suspect that a different set of characteristics of ASD in females may not be consistent with the more established and widely recognized characteristics of ASD, leading to under-identification in women. In the present study, four women and one non-binary feminine-presenting person with ASD were interviewed. The five participants conveyed their experiences with social-pragmatic communication, and their views on gender, ASD, and gender differences in ASD. The results are discussed in relationship to the limited amount of past research on women with ASD.

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Introduction

Characteristics of ASD

ASD is a developmental disability characterized by varying degrees of social and communicative impairments along with the presence of ritualistic and repetitive patterns of behavior (Hiller, Young, & Weber, 2015). ASD is diagnosed using standardized criteria from the American Psychiatric Association's Diagnostic and Statistics Manual, Fifth Edition (DSM-5). To meet criteria for an ASD diagnosis, individuals must have persistent deficits in social communication and social interaction across multiple contexts, manifested by deficits in social-emotional reciprocity; nonverbal communicative behaviors; and developing, maintaining, and understanding relationships. Individuals must also display restricted, repetitive patterns of behavior, interests, or activities. These symptoms must be present in the early developmental period, but may not fully manifest until social demands exceed the individual's capacities. Symptoms may also be masked by learned strategies later in life. Symptoms must cause significant impairment in social, occupational, or other areas of current functioning, and cannot be better explained by an intellectual disability or global developmental delay (American Psychiatric Association, 2013).

It is important to remain aware of differences between ASD and social (pragmatic) communication disorder. Social (pragmatic) communication disorder is characterized by difficulty with pragmatics, with deficits that result in limitations in effective communication, social participation, academic achievement, occupational performance, or the development of social relationships. While all individuals with ASD show impairments in social communication and social interactions, it is the additional

appearance of restricted and repetitive behavior or interests that allows the criteria for ASD, rather than social (pragmatic) communication disorder, to be met (American Psychiatric Association, 2013).

Under the DSM-IV, which was released in 1994 and used to diagnose individuals with intellectual disabilities until the DSM-5 was published in 2013, individuals were assigned a diagnosis of autistic disorder, Asperger's disorder, or pervasive developmental disorder not otherwise specified (PDD-NOS). The central features of autistic disorder were the presence of markedly abnormal or impaired development and social interaction and communication, and a markedly restricted repertoire of activity and interest. Asperger's disorder was characterized by severe and sustained impairment in social interaction and the development of restricted, repetitive patterns of behavior, interest, and activity, and differentiated from autistic disorder by a lack of clinically significant delays in language. The essential features of PDD-NOS were severe and pervasive impairments in the development of reciprocal social interaction or verbal and nonverbal communication skills; and stereotyped behaviors, interests, and activities. The criteria for autistic disorder would not be met with individuals diagnosed with PDD-NOS due to late age of onset, atypical symptomology, or sub-threshold symptomology (DSM-IV Diagnostic Classifications, n.d.). With the release of the DSM-5, individuals with a well-established diagnosis of autistic disorder, Asperger's disorder, or PDD-NOS were given the diagnosis of ASD (American Psychiatric Association, 2013).

Prevalence

In recent years the prevalence rate for ASD across both the U.S. and other countries has approached 1% of the population, with similar rates in child and adult

samples (American Psychiatric Association, 2013). However, there is a long history of an identified gender disparity in ASD, with Hans Asperger writing in 1944 that the children with autism he had seen were almost exclusively boys (River & Matson, 2011). Currently ASD is diagnosed four times more often in males than in females, with females in clinic samples tending to show accompanying intellectual disabilities (American Psychiatric Association, 2013).

Gender Differences in ASD

According to the DSM-5, skewed prevalence rates suggest that girls without accompanying intellectual impairments or language delays might go unrecognized due to a more subtle manifestation of social and communication difficulties (American Psychiatric Association, 2013). Most research has indicated that the core symptoms of ASD do not differ by sex (Begeer et al., 2012). Hiller, Young, and Weber (2014) found that there was no evidence of sex differences in the broad social criteria presented in the DSM-IV or DSM-5. However, based on the study of clinician and teacher reports for 69 girls and 69 boys with high-functioning autism, there are numerous sex differences in how those criteria are met.

One area in which there is evidence of a sex difference is that of restricted and repetitive behavior. Frazier, Georgiades, Bishop, and Hardan (2014) reviewed 2,418 probands with ASD in the Simons Simplex Collection, a core project of the Simons Foundation Autism Research Initiative. After analyzing the data from these probands, of which 304 were female and 2,114 were male, the researchers concluded that females showed lower levels of restricted interests. This was supported by Mandy et al. (2011), whose UK study using parent reports and direct observation of 52 girls and 273 boys with

ASD found that females had less repetitive stereotyped behavior. Additionally, there is evidence that girls present with different types of restricted interests than boys, which may be more difficult to identify as atypical (Hiller et al., 2015; Zaks, 2006).

In regard to social skills and friendships, research has led to varying results. In a survey distributed to members of the Dutch Autism Society, questioning 2,084 children and adults with ASD (81% of whom were male and 19% of whom were female), Begeer et al. (2012) found lower social, communicative, and cognitive functioning in females with ASD than in males with ASD. Frazier et al. (2014) also found that females had greater social communication impairment compared with males, in addition to weaker adaptive skills. However, not all studies have confirmed findings that females have lower levels of social functioning. Mandy et al. (2011) asserted that males and females had equal levels of social and communication impairment, and a number of other researchers have observed that females with ASD may in fact have more advanced social skills than their male counterparts. In a study using clinician and teacher reports on 69 boys and 69 girls with high-functioning ASD, Hiller et al. found that girls were more likely to be able to maintain a reciprocal conversation and be able to initiate, but not maintain, friendships. Additionally, girls were more likely to show an ability to integrate nonverbal and verbal behaviors; 34.5% of girls were rated as having no impairment in their ability to integrate nonverbal and verbal communication behaviors as compared to 9% of boys (2014). After performing another study collecting data from a 40-question online survey completed by the caregivers of 92 boys and 60 girls with a diagnosis of ASD and no intellectual disabilities, Hiller et al. found that cognitively able girls are better able to engage in

social strategies that add to the difficulty of identifying potential signs of the disorder (2015).

One such social strategy that has been reported to be high in females is mimicking. Imitation is a skill that children with ASD often struggle with, but according to Simone (2010), females are “better at mirroring than males and so may mirror many different types of personalities.” This statement is confirmed by Hiller et al. (2015), who found that, based on caregiver reports, girls were more likely than boys to use mimicking to engage in the social environment. It was found that social compensatory strategies significantly predicted sex, and if a preference for mimicking as a social strategy was reported, the child was over sixteen times more likely to be a girl. Additionally, it was found that children who engaged in complex imitation during pre-school years were over five times more likely to be girls.

Furthermore, there has been conflicting data in terms of sex differences in externalizing and internalizing behaviors. Frazier et al. (2014) found that females showed greater externalizing problems, while teacher reports demonstrated substantially fewer concerns for girls than boys, including for externalizing behaviors (Hiller et al., 2014). Similarly, teacher reports from the study done by Mandy et al. (2011) stated that males with ASD had greater externalizing and interpersonal problems than females, while females were reported as having worse emotional difficulties. Zaks, a woman with ASD, claimed that a girl with ASD is more likely to withdraw and take her frustrations out on herself or become depressed when faced with challenges. Conversely, a boy with ASD is more likely to act out, cry, or otherwise externally display his frustration (Zaks, 2006).

Hypotheses behind gender differences. While findings in regard to the relationship between gender and ASD are variable, one of the most consistent findings in ASD research is the higher rate of ASD diagnosis in males than females, leading numerous researchers to question the reasons behind this disparity (Halladay et al., 2015). Solomon et al. (2011) proposed two theories in regard to the gender disparity in ASD prevalence between males and females. After comparing autism and internalizing symptoms in forty children with ASD (twenty male and twenty female) and thirty-six children without ASD (seventeen male and nineteen female), Solomon et al. (2011) argued that ASD is less prevalent in girls, and those who do have the disorder are more severely impaired than boys with ASD. This would be in line with the “gender paradox” hypothesis, which states that the least frequently affected sex is more severely impaired. Another argument is that females have fewer protections against ASD traits. Higher levels of oxytocin could protect girls against the development of autistic traits, while high levels of fetal testosterone may predispose boys to have “extreme male brains” characterized by systematizing, or focusing on inanimate systems and details, rather than empathizing, which is to focus on interpersonal orientation. These theories lead to the conclusion that despite skill deficits compared to typically developing girls, girls with ASD symptoms may not be diagnosed due to a milder symptom presentation and referral biases (Solomon et al., 2011).

Additionally, gender differences in the general population could add to the difficulty of identifying women and girls with ASD. Research shows a “potential female advantage in decoding facial expressions and nonverbal cues, empathizing, and theory of mind” (Rivet & Matson, 2011, p. 959). Typically developing girls also tend to build

relationships by sharing thoughts and emotions, which requires more social communication skills than boys' tendency to form relationships based on object and activity themes. Furthermore, behaviors such as tantrums and aggression that are often focal in ASD diagnoses are less common in girls in the general population, indicating a potential difference not related specifically to ASD (Ernsperger & Wendel, 2007). These global gender differences might lead to women with ASD appearing less impaired than men with ASD, but ultimately more impaired than women without ASD.

According to several researchers, the basis of ASD diagnoses on male behaviors and traits has resulted in females being less likely to receive early and correct diagnoses (Simone, 2010). The standardization for ASD instrumentation has consisted primarily of males, with an approximate sex ratio of 3:1. This raises the question of whether there ought to be separate criteria and cutoff scores for an ASD diagnosis based on gender. Author and ASD expert Ernsperger says, "There is an immense need to examine the gender differences and the implications they may have on the diagnosis of ASD. For example, girls exhibit potential subtleties that are not detected by traditional assessment instruments and direct observation. Therefore, we need to consider whether our diagnostic criteria are too rigid or too narrow to include the symptoms of ASD in girls, which often appear 'milder'" (2007, p. 10). The so-called "one-size-fits-all" male-based diagnosis model may not accurately reflect the characteristics of ASD in girls (Hiller et al., 2015).

Social-Pragmatic Language

Pragmatics refers to the ability to use language for different purposes, change language according to the needs of the listener and situations, and follow rules for

conversations and storytelling; in other words, social language use. The use of language for different purposes could refer to greeting, informing, demanding, promising, or requesting, while changing language usage based on a situation or the needs of a listener could include providing background information to an unfamiliar listener, or using more formal language in a work setting as compared to a home environment. Conversational rules could include taking turns in a conversation, staying on topic, rephrasing when misunderstood, or appropriate use of verbal and nonverbal signals (American Speech-Language-Hearing Association, n.d.). Pragmatic impairments are a defining feature of ASD, and are universal across all ages and ability levels (Charman & Stone, 2008). Children with ASD find it difficult to understand pragmatics, often interpreting language literally and focusing on what the words mean rather than the speaker's intention. Many individuals with ASD "possess well-developed spoken language, with good vocabulary and perfect grammar. However, they still have difficulties with pragmatics and non-verbal communication" (Bogdašina, 2006, p. 189).

Research conducted with typically developing children shows that the development of pragmatics depends heavily on language socialization, such as parental, peer, and classroom socialization. Additionally, there is evidence that gender plays a factor in how children are socialized to communicate. According to Matthews, "Different patterns of language use depending on the gender of the parent and child have also been reported, illustrating how language socialization also provides boys and girls with models of how women and men talk. Through such patterns of language usage, parents socialize their children in specific cultural and gender-based ways" (2014, p. 329).

While little research has been done on social-pragmatic communication in women or girls with ASD, as previously mentioned some studies have found that women with ASD have stronger social communication and are better able to engage in social strategies that mask ASD traits (Hiller et al., 2014; Hiller et al., 2015). Additionally, there is a great deal of anecdotal evidence to suggest that gender socialization could lead to girls with ASD becoming adept at hiding social-pragmatic difficulties. Zaks (2006) shared that as a child she was told, “nice girls wait their turn,” and was often encouraged to use her “polite voice.” This led to Zaks developing strategies to better “fit in” socially, such as keeping quiet and asking an adult if it was alright to speak, although in reality she did not gain an increased understanding of turn-taking signals or socially appropriate voice volume (2006).

Current Study

The purpose of this research study is to gain a closer look at how ASD presents in women. Interviews will focus on participants’ experiences in regard to social-pragmatic communication, and potential gender differences in social-pragmatic communication. Additionally, interviews will examine what kind of relationship, if any, women with ASD see between gender and ASD.

Method

Participants

This study involved five people with a diagnosis of ASD.

<i>Participant</i>	<i>Diagnosis Age</i>	<i>Current Age</i>	<i>Gender Identity</i>	<i>Location</i>
Rowan	3	19	Non-binary ¹	Colorado, U.S.
Diane	7	18	Woman	Wisconsin, U.S.
Carol	29	30	Woman	Manitoba, Canada
Anna	30	41	Woman	New Hampshire, U.S.
Mary	44	48	Woman	New Hampshire, U.S.

In order to conduct a study using human participants, it was necessary to receive approval from the University of New Hampshire's Institutional Review Board. After the proposed research paradigm was approved, women with ASD were recruited for participation in the study. Participants were recruited by emailing a variety of individuals and organizations.

Procedure

General interview topics were developed based on a review of literature and previous studies examining the relationship between gender and ASD, and the manifestation of ASD symptoms in women. For a list of these topics and questions, see the appendix. Although similar guiding questions were used when interviewing each participant, interviews were open-ended so that participants could expand upon their answers and experiences, and to make it possible for follow-up questions to be asked if relevant. The goal was to conduct as many interviews as possible in person in a space that was comfortable and convenient for participants. However, due to participation from

¹ Non-binary is a term that denotes a gender identity that is not male or female.

individuals from a variety of locations, two interviews were conducted over FaceTime and one over email, with the other two conducted in person. The time each interview lasted ranged from twenty minutes to one hour. Prior to beginning the interviews, each participant was provided a consent form, which they read thoroughly and signed to indicate agreement to participate in the study. One in-person interview had notes taken to record the participant's responses. The other in-person interview and both of the FaceTime interviews were recorded, and later transcribed. All data from the interviews was stored on UNH Box to protect participant confidentiality, with confidentiality being further confirmed through the use of pseudonyms.

Results

Diagnosis

Some participants reported that gender may have played a role in their diagnosis, while others did not. Rowan's diagnosis was prompted by teaching herself² to read at age two and a half, in addition to being temperamental as a baby. Their parents felt these symptoms lined up with Asperger's, now known as ASD, and they were diagnosed at age three. Diane's diagnosis was first suggested by her school psychologist. Although her parents knew prior to the age of seven that she had sensory processing issues and was not neurotypical³, she only received a diagnosis when her ASD began to impact her day-to-day functioning in a school setting. At first Diane's symptoms were not recognized by her parents or school psychologist as ASD, leading her to believe that gender played a role in her later diagnosis. Carol also found that gender affected her ASD diagnosis, although hers occurred later in life. She began seeking help and assessment for two of her children, and came across a list describing ASD traits in females. She suggested the possibility of being a woman with ASD to pediatricians, child psychologists, a counselor, and a social worker, and every time she was questioned about the likelihood of such a diagnosis. Each professional assured Carol that she made eye contact too well, was too relational, not uncooperative enough, too intelligent, and would not have progressed through school and university without obvious behavioral disturbances. Eventually, Carol paid out-of-pocket for a thorough assessment and confirmed an ASD diagnosis at the age of twenty-nine. Similarly, Mary's ASD symptoms did not manifest fully until later in life.

² Rowan uses the pronouns *they* and *their*.

³ Neurotypical is an abbreviation of "neurologically typical" and is a term widely used in the autistic community as a label for people who are not on the autism spectrum.

At the time of her diagnosis, she was working for a company that wanted to reduce its working population. The company created a hostile environment that began causing Mary a great deal of stress. Around that time, her husband – who follows TED Talks, which are online talks that range from scientific to cultural to academic topics – viewed a talk from Temple Grandin, a prominent woman with ASD. He suggested that Mary might fall on the spectrum, leading her to attend counseling where a mild case of Asperger's was confirmed. Although Mary reflected that she had shown symptoms of ASD throughout her life, she was always at the top of her class in school and in her work was labeled as a great employee who was just socially challenged. If she had not been so stressed at her job (from which she was ultimately fired in order to prevent her diagnosis from going in her work file), she suspected that she likely would never have gotten diagnosed. Anna's struggles also began later; she started to have a lot of trouble once she went off to college. While there had been other "red flags" prior, her social problems were easily brushed off. She reflected that gender might have affected her late diagnosis, as she was not diagnosed until age thirty, and prior to that had received several incorrect diagnoses, including attention deficit disorder. However, she pointed out that far more is known about ASD than in the early 1980s. Additionally, there is more support for parents of children with ASD, and medication is different than it used to be.

Social-Pragmatic Communication

All five participants stated that they found it difficult to engage in social chit-chat, gossip, or conversation that lacks a "function" at least occasionally. Anna said that she does not gossip, dislikes rumors, and finds small talk hard. Both Mary and Rowan said that they sometimes have difficulty engaging in this type of communication, with Mary

stating that she is not good with subtleties, and prefers for people to take a more direct approach when interacting with her. Diane explained that while she does not often have difficulty engaging in gossip or social chatter, she strongly dislikes doing so. Likewise, Carol said that she “absolutely cannot stand small talk,” and when engaging in it spends most of her time worrying about appearing interested, displaying the correct facial expressions, and determining what to say next.

Restrictive and Repetitive Interests

In regard to restrictive and repetitive interests, Rowan, and Diane both said that they would prefer to engage in conversation related to their special interests, but it is not something they actively seek out in everyday life. Anna said that she does not always prefer to engage in conversation related to her interests, noting that it is good to talk with people and learn about other things, and there is a need to have good turn-taking skills. Some of Anna’s current special interests are dogs and dog breeds, dog training, cooking and baking, the trumpet and music, and hiking. She suggested that girls’ interests might be seen as less peculiar and more acceptable than the special interests of boys. Rowan agreed and said that their interests, which include colorguard, cosmetology, dogs, and specific historical events, are viewed by their friends and family as mundane, saying “[they] mostly just look like a hobby I’m really passionate about.” Diane, who has an interest in origami and can spend hours on it with incredible focus, also found the reactions of friends and family to her special interests to be overwhelmingly positive. In contrast Carol said that her interests are viewed negatively by friends and family, and are often seen as “obsessive” or “too much.” Carol’s interests include nutritional sciences and related physics, economics, psychology, dieting, obesity, body composition, and

specific medical conditions, and she said that she spends around ninety percent of her spare time doing something that is either related to her children or her special interests.

Use of Mimicking

As an adult, Anna never felt the need to copy or mimic someone else's behavior, saying, "This day and age, I do my own thing." She also has never felt like she is faking or performing in social situations. Instead, she stated that because ASD is a developmental delay, "I am the way I am because I work at [learning how to socially behave]." Similarly, Mary reported never feeling the need to mimic other's behavior to fit in. She simply just did not fit in, and while she became involved in different clubs throughout her time in school, she never had much of a social life and did not know how to make friends. However, Rowan, Diane, and Carol all stated that they use mimicking as a technique, and often feel like they are faking and performing in social situations. Rowan said that they feel the need to copy or mimic others' behavior all the time, saying, "I basically rely on scripts to get through the day." Diane agreed, and provided the example of her friends meeting up in the morning before school and acting very loud and outgoing, leading Diane to feel a need to match that behavior. In regard to feelings of performing in social situations, Diane said that around friends she feels more comfortable but that she often feels a need to fake or perform around her parents, who have high standards for behavior and do not want signs of her ASD showing outwardly. Likewise, Carol said that seeing the word "chameleon" to describe women with ASD was a light-bulb moment, as she often absorbs and integrates the traits of people she deeply admires and uses scripts to get through daily situations. She also spoke about feeling as though

she is performing as soon as she walks out of her house every day, and constantly struggles with “some vague fear of being caught as a ‘fraud.’”

Gender Expectations

Finally, participants were asked if they felt pressured to be more social due to their gender. Anna and Mary did not see gender as greatly influencing their experiences as people with ASD. Mary acknowledged that research indicates potential gender differences in ASD, suggesting that symptom presentation is more subtle in women. However, she views ASD as more of a spectrum, on which she would consider herself highly functional. She said that if she were further on the spectrum (i.e. low-functioning), then her diagnosis might have been made sooner. According to Anna, everyone has a different life story with unique experience, and a great deal of individual variability. Nevertheless, she acknowledged that girls with ASD do tend to face unique challenges and have certain experiences that boys may not. For example, girls with ASD tend to stay away from cliques, rumors, and gossip, whereas many typically developing girls engage in those activities. This is a trend that Diane noticed as well. She said that women are expected to engage in gossip and conversation, whereas it is generally more acceptable for men to be less social.

In contrast with Anna and Mary’s views, the remaining three participants felt that gender played a significant role in their lives. Carol stated that she did not have a great deal of experience with men with ASD, and therefore could not compare her experiences to say whether she has felt higher expectations to perform socially due to her gender. However, she noted that the lack of research, documentation, and basic education on ASD in females is hugely lacking, which leads to females being overlooked. Carol

thought that gender stereotypes and cultural influences likely play a large role in gender differences in ASD, in addition with hormonal biochemistry involvement. Aligning with the description of females as presenting very internally, Carol has seen this form of ASD presentation in herself as well as her oldest son. She said that this results in women with ASD being driven to lay low and blend in while having difficulty getting a diagnosis, making it, “a truly double-edged sword for females and, I suspect, a portion of males.”

Similarly, both Rowan and Diane saw gender having a strong influence on their experiences with ASD. Rowan drew attention to the gap in ASD diagnoses in boys as opposed to girls, with doctors having difficulty recognizing the signs in girls with ASD. They felt that ASD has always been very stigmatized, which has resulted in them having a difficult time telling people that they are autistic. This stigma is worsened by the expectation that if one is autistic they must be male, and they must present their ASD a certain way. According to Rowan, there is little room for falling outside of that rigid box. Diane also spoke of a hesitancy to tell people that she has ASD, because there is such a great deal of stigma and many stereotypes surrounding how people with ASD are supposed to appear and act. Diane said,

“A lot of the stereotypes about what kids with autism should be able to do don’t necessarily apply on a broad spectrum to girls with autism... All of the kids with autism that I know are boys, and so being lumped in with them is kind of a hard experience, because I’m very passing [as neurotypical] and a lot of them aren’t. So if people are lumping me in with that group, then it’s like I’m expected to be more like them.”

Diane found that following her diagnosis, her parents were insistent that she not display any outward signs and keep the information of her ASD diagnosis private. This was in large part because her parents did not want Diane to be bullied for having ASD, but Diane felt that the desire to hide her diagnosis also came from a place of shame. She acknowledged that misinformation surrounds women with ASD and her parents, like many others, had very rigid ideas of what a person with ASD was supposed to be like. Through having a younger brother who is also diagnosed with ASD, Diane has seen some differences in how she was treated by her parents as opposed to her brother. Her parents are willing to be more lenient with him and with some of his behaviors because they feel that he “can’t help it,” whereas Diane did not receive that same benefit of the doubt.

Discussion

The diagnosis of ASD depends on an individual displaying both social communication impairment, and restrictive and repetitive behavior. Although there is evidence of a number of potential gender differences in ASD, including a more subtle presentation of these deficits, research indicates that the core symptoms of ASD do not differ by gender. Data from the current study supports this, as all of the participants spoke of having some type of difficulty in engaging in small talk and gossip.

While women with ASD also demonstrate restrictive and repetitive behavior, it is oftentimes behavior that is more difficult to identify as atypical. As Anna acknowledged in her interview, the interests of girls and women tend to be seen as more palatable than those of boys and men with ASD. As an example, she pointed to her interests in dogs and dog training. Because many individuals appreciate and enjoy pets, it may not be viewed as unusual for one to have a strong interest in this area, particularly if one is a pet owner like Anna. Some of Anna's other interests, such as cooking and baking, are activities that are stereotypically seen as feminine or "women's work." This could lead to greater acceptance of these special interests. Diane, too, held interest in an activity which may be more acceptable for women to perform. Girls are often stereotyped as being more artistic and creative than boys, and a woman with ASD with an interest in origami could appear less out-of-place than a man with the same interest (Pomerleau, Bolduc, Malcuit, & Cossette, 1990). Likewise, while not a woman, Rowan is feminine-presenting, which could lead people in their life to view their interests, such as cosmetology or dogs, as stereotypically feminine passions and therefore find them less atypical. In contrast with Anna, Diane, and Rowan, Carol's special interests mainly revolve around science and

specific medical conditions. These are often viewed as more masculine interests, as seen by gender disparities in science, technology, engineering, and mathematics (STEM) fields (Su & Rounds, 2015). Women tend to be less engaged in STEM fields, and therefore interests in these areas are more frequently attributed to men and masculine individuals. This could explain why Carol's interests tend to be viewed negatively by friends, family, and other people in her life, as compared with the more positive or neutral reactions garnered by Anna, Diane, and Rowan's interests. These results indicate a need to look beyond social norms when diagnosing ASD, because restricted and repetitive interests that may appear to be "acceptable for any young girl" could in fact be indicative of ASD.

Although the research on gender differences in regard to social strategies is conflicting, a significant portion of research indicates that women with ASD may develop social strategies that better mask behaviors associated with ASD. Whereas boys with ASD were more likely than girls to use isolation as a strategy to manage social settings, girls were far more likely to engage in mimicking and complex imitation (Hiller et al., 2015). The current study somewhat supports this previous research. Of the five participants in this study, three stated that they used mimicking often in order to engage in their social environment. The use of various social strategies to mask ASD symptoms not only complicates diagnoses, but leads to less tolerance of ASD symptoms for women with ASD. In fact, women with ASD "tend to receive less tolerance and more expectation from others, because [they] appear more adept" (Simone, 2010 p. 234). As Diane reported in her interview, her parents had a propensity to accept her younger brother's

ASD traits over those that Diane displayed. As a girl, more expectation was placed upon her to present as neurotypical and socially adept.

ASD has always been envisioned as a male disorder, due to the gender disparity first acknowledged by Hans Asperger in 1944 that remains present today. Traits that are often associated with ASD, such as aggression, tantrums, isolation, poor social skills, and atypical obsessions, are not necessarily reflective of ASD presentation in women. In fact, women with ASD who display some or all of these traits are far more likely to be diagnosed with ASD than women who display more subtle signs of the disorder. This notion that women do not have ASD is also influenced by the understanding of women in the general population. Social skills have often been perceived as feminine, leading to an expectation for women with ASD, both prior to and following diagnosis, to be more socially competent (Eagly & Koenig, 2014). Carol, Diane, and Rowan all noticed that as women or feminine-presenting individuals there were greater expectations for them to conform to stereotypically feminine behavior; in other words, stereotype that having ASD is not compatible with.

Contributions of the Study

Few research studies have examined the relationship between gender and ASD, and the vast majority that exist have utilized parent, teacher, or clinician reporting. While this provides valuable information about the relationship between gender and ASD, women and non-binary individuals with ASD can share insights about their experiences that may not be clear or visible to outsiders. This project provides unique contributions in that four women and one non-binary person were interviewed directly, with interview

questions specially focusing on views of ASD, social-pragmatic communication, and gender differences in ASD.

Limitations

The open-ended questions used in this study at times made it difficult to find specific themes across participant responses. Additionally, factors such as participant educational background, socioeconomic status, and racial or ethnic identity were not taken into account. In the United States, research has shown an increased prevalence of ASD among households with a higher socioeconomic status, as measured by parent educational level or household income. It has been suggested that this higher prevalence is reflective of a detection bias, while children who come from families with a lower socioeconomic status may be less likely to have their ASD detected (Delobel-Ayoub, Ehlinger, Klapouszczak, Maffre, Raynaud, Delpierre, & Arnaud, 2015). Furthermore, significant racial and ethnic disparities exist in ASD recognition (Mandell et al., 2009). This suggests that girls and women with ASD who come from other marginalized backgrounds may face difficulties in accessing services due not only to their gender, but supplementary factors as well. The lack of this data, in addition to the small sample size used in the research project, does not allow these results to be generalized to the larger national or global population. However, the varied results from different participants support the idea that more research in regard to the complex relationship between gender and ASD is needed.

Future Research

The current study provides a small sample of results regarding the experiences that women and non-binary individuals have had with social-pragmatic communication,

and their views on gender and ASD. A study of a larger sample size could be helpful in collecting quantitative data with results that could be more generalized. A web-based survey would likely be less difficult to distribute, and participation rates may be higher as compared with a face-to-face or telephone interview format. In addition to collecting more demographic data, surveys could ask specific questions about the use of different social strategies, restrictive and repetitive behavior, and potential influences of gender on being an individual with ASD.

Additionally, it is important to realize that due to factors potentially complicating the identification of women with ASD, such as more successful social strategies and interests that fall within stereotypical expectations, there may be many women with ASD who fall outside of clinical identification. These individuals could be very socially adept and have socially appropriate routines and interests that go unnoticed, leading to a lack of identification or the possibility of misidentification as a disorder other than ASD. As many researchers have acknowledged, the standardization of ASD diagnostic criteria largely on the basis of male presentation could influence the low rate of female diagnosis (Simone, 2010; Hiller et al., 2015). Therefore, it may be beneficial for future researchers to examine the current population of women and non-binary individuals with ASD and, based on observed gender differences, develop diagnostic criteria that would more accurately identify them with ASD.

Conclusion

The current study utilized interviews with four women and one non-binary person with ASD, wherein participants conveyed their experiences with social-pragmatic communication, and their views on gender, ASD, and gender differences. These results

were discussed and analyzed in relationship to previous research on ASD and gender, which suggests that the consistent gender disparities in diagnosis rates stem from a more subtle ASD presentation in women. All participants reported difficulty engaging in social conversation. While other results varied, some participants reported having restricted and repetitive interests that were viewed as acceptable, using mimicking as a social strategy to better blend in, and facing pressure from people around them to act in more socially acceptable manners. These experiences align with research indicating that girls and women with ASD present with interests that are considered less atypical, use mimicking to engage in the social environment, and are better able to engage in social strategies adding to the difficulty of identifying signs of ASD.

The case studies conducted for this project could provide some insight on how the experiences of women and non-binary individuals with ASD differ from those of men. A deeper understanding of the ways in which ASD presents in women and non-binary individuals can greatly enhance the services provided by speech-language pathologists, teachers, counselors, social workers, and other professionals who often interact with this population. Increased awareness and education in this area is vital in order to best support women and non-binary individuals with ASD.

References

- American Psychiatric Association. (2013). *Diagnostic and Statistical Manual of Mental Disorders* (5th ed). Arlington, VA: American Psychiatric Publishing.
- American Speech-Language-Hearing Association. (n.d.). Social Language Use (Pragmatics). Retrieved April 07, 2017, from <http://www.asha.org/public/speech/development/Pramatics>
- Begeer, S., Mandell, D., Wijnker-Homes, B., Venderbosch, S., Rem, D., Stekelenburg, F., & Koot, H. M. (2012). Sex Differences in the Timing of Identification Among Children and Adults with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders*, 43(5), 1151-1156.
- Bogdašina, O. (2006). *Communication Issues in Autism and Asperger Syndrome: Do We Speak the Same Language?* London: Jessica Kingsley.
- Charman, T., & Stone, W. L. (2008). *Social and Communication Development in Autism Spectrum Disorders: Early Identification, Diagnosis, and Intervention*. New York: Guilford.
- DSM-IV Diagnostic Classifications. (n.d.). Retrieved April 01, 2017, from <http://www.autism-society.org/dsm-iv-diagnostic-classifications>
- Delobel-Ayoub, M., Ehlinger, V., Klapouszczak, D., Maffre, T., Raynaud, J., Delpierre, C., & Arnaud, C. (2015). Socioeconomic Disparities and Prevalence of Autism Spectrum Disorders and Intellectual Disability. *PLoS One* 10(11).
- Eagly, A., & Koenig, A. (2014). Research Reveals How Stereotypes About Leadership Hold Women Back. Retrieved April 20, 2017 from <http://www.footnote1.com/research-reveals-how-stereotypes-about-leadership->

- hold-women-back
- Ernsperger, L., & Wendel, D. (2007). *Girls Under the Umbrella of Autism Spectrum Disorders: Practical Solutions for Addressing Everyday Challenges*. Shawnee Mission, KS: Autism Asperger Publishing Company.
- Frazier, T. W., Georgiades, S., Bishop, S. L., & Hardan, A. Y. (2014). Behavioral and Cognitive Characteristics of Females and Males with Autism in the Simons Simplex Collection. *Journal of the American Academy of Child & Adolescent Psychiatry, 53*(3).
- Halladay, A. K., Bishop, S., Constantino, J. N., Daniels, A. M., Koenig, K., Palmer, K., . . . Szatmari, P. (2015). Sex and Gender Differences in Autism Spectrum Disorder: Summarizing Evidence Gaps and Identifying Emerging Areas of Priority. *Molecular Autism, 6*(1).
- Hiller, R. M., Young, R. L., & Weber, N. (2014). Sex Differences in Autism Spectrum Disorder Based on DSM-5 Criteria: Evidence from Clinician and Teacher Reporting. *Journal of Abnormal Child Psychology, 42*(8), 1381-1393.
- Hiller, R. M., Young, R. L., & Weber, N. (2015). Sex Differences in Pre-Diagnosis Concerns for Children Later Diagnosed with Autism Spectrum Disorder. *Autism, 20*(1), 75-84.
- Mandell, D., Wiggins, L., Carpenter, L., Daniels, J., DiGuseppi, C., Durkin, M., . . . Kirby, R. (2009). Racial/Ethnic Disparities in the Identification of Children with Autism Spectrum Disorders. *American Journal of Public Health 99*(3), 493-498.
- Mandy, W., Chilvers, R., Chowdhury, U., Salter, G., Seigal, A., & Skuse, D. (2011). Sex Differences in Autism Spectrum Disorder: Evidence from a Large Sample of

- Children and Adolescents. *Journal of Autism and Developmental Disorders*, 42(7), 1304-1313.
- Matthews, D. (2014). *Pragmatic Development in First Language Acquisition*. Amsterdam: John Benjamins Publishing.
- Pomerleau, A., Bolduc, D., Malcuit, G., & Cossette, L. (1990). Pink or Blue: Environmental Gender Stereotypes in the First Two Years of Life. *Sex Roles*, 22(5), 359-367.
- Rivet, T. T., & Matson, J. L. (2011). Review of Gender Differences in Core Symptomatology in Autism Spectrum Disorders. *Research in Autism Spectrum Disorders*, 5(3), 957-976.
- Simone, R. (2010). *Aspergirls: Empowering Females with Asperger Syndrome*. London: Jessica Kingsley.
- Solomon, M., Miller, M., Taylor, S. L., Hinshaw, S. P., & Carter, C. S. (2011). Autism Symptoms and Internalizing Psychopathology in Girls and Boys with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders*, 42(1), 48-59.
- Su, R., & Rounds, J. (2015). All STEM Fields Are Not Created Equal: People and Things Interests Explain Gender Disparities Across STEM Fields. *Frontiers in Psychology*.
- Zaks, Z. & Grandin, T. (2006). *Life and Love: Positive Strategies for Autistic Adults*. Autism Asperger Pub. Co.: Shawnee Mission, KS.

Appendix

Guiding questions and general areas of discussion in interviews:

1. Age at ASD diagnosis
2. Current age
3. How ASD diagnosis came about
4. Have you ever experienced difficulty engaging in social chit-chat, gossip, or other conversation that lacks a “function”?
5. Have you ever felt the need to copy or mimic other peoples’ speech or behavior in order to fit in?
6. Do you prefer to engage in conversation related to your special interests?
7. Do you ever feel like, as a [woman or feminine-presenting person], there was more pressure for you to blend in socially?