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THE FEMALE AUTISM EXPERIENCE: A LITERATURE REVIEW

A MASTER'S THESIS

SUBMITTED TO THE FACULTY
OF BETHEL UNIVERSITY

BY

MEGAN E. MAAS

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THE FEMALE AUTISM EXPERIENCE: A LITERATURE REVIEW

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APPROVED

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Abstract

Autism Spectrum Disorder (ASD) is characterized by communication challenges, difficulties in socialization, and the occurrence of restrictive, repetitive behaviors. Current data in the United States indicates that 1 in 44 children are diagnosed with autism. Males are diagnosed at a ratio of four to one compared to females. Evidence suggests that females with autism present differently than males. Current diagnostic criteria based on typical male presentation of autism may account for underidentification in females with ASD. This literature review explores the experience of females with autism, including diagnosis, differences in behavior, communication, social and emotional skills, and the lived experiences of females who have received an autism diagnosis.

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Chapter 1: Introduction

The Centers for Disease Control and Prevention (CDC) reports that about 1 in 44 children have a diagnosis of autism spectrum disorder (ASD). The CDC also reports that males are four times more likely to receive an ASD diagnosis than females. The CDC defines Autism Spectrum Disorder as a “developmental disability that can cause a wide range of challenges in social interaction, communication, and behavior” (Maenner et al., 2018) The *Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5)* defines ASD as “the occurrence of persistent impairments in social interaction and the presence of restricted, repetitive patterns of behaviors, interests, or activities” (5th ed.; DSM–5; American Psychiatric Association, 2013).

Hull, L., Petrides, K. V., & Mandy, W. (2020) noted that in recent years, there has been a rise in adults, particularly females, diagnosed with autism, a disorder commonly diagnosed in childhood. Loomes et al. (2017) stated that one possibility is that in 2013, the DSM was updated with new criteria for diagnosis that may not have accounted for females in the past. Some researchers stated that professionals suggest that there could be a genetic component within the female brain that “protects” them. Another suggestion is that there may be a diagnostic bias and a variation in presentation for females that results in not receiving a diagnosis (p. 306).

Teachers who work in primarily center-based autism classrooms typically report classrooms are comprised of a majority of male students. Some classrooms may see one female student here and there, but for the most part, the classrooms have male students. Even when females with autism are present, their symptoms are expressed differently than their male counterparts. Why is this so? Does autism really affect males more than females? In most of the classrooms where I have worked, I have had a relatively small female population. Most self-

contained ASD classrooms that I have encountered have only one or two females, while some have no females. Why do female autism symptoms look so different than male characteristics?

Autism is typically diagnosed more in males than it is in females. The most widely considered gender ratio is 4:1, which is stated in the DSM-5 (5th ed.; DSM-5; American Psychiatric Association, 2013). However, other epidemiological studies suggest that the ratio may range from 8:1 to 2:1. It is also important to note that the ratio is lower in individuals with an intellectual disability. Loomes, R., Hull, L., Polmear, W., & Mandy, L, (2017) sought to determine the most accurate ratio was. Until their 2017 study, little research had been done on determining the most accurate ratio. Current research suggests that there is a diagnostic bias against females with ASD. Females are likely to camouflage, or mask, autism symptoms. Girls are also less likely to exhibit restrictive and repetitive behaviors which decreases the likelihood that they will receive an autism diagnosis. Another factor that contributes to a diagnostic bias is the fact that professionals in the field, including teachers, doctors, psychologist, and psychiatrists, hold the belief in the stereotype that autism is generally a disorder found in males which leads to decreased sensitivity to noticing autism symptoms occur in females, even in females who show more severe symptoms. Loomes et al.(2017) determined that the more true ratio was 3:1 (p. 466-472).

This topic was brought to my attention a few years ago by a family with whom I worked as a personal care attendant for their 3-year-old son, Blake, who has autism. For the purpose of this literature review, names have been changed to protect the confidentiality of the family. Blake presented with the typical symptoms of autism: limited verbal communication skills, lack of eye-contact, low social interaction with peers and adults, arm flapping, sensitivity to loud noises, easily overwhelmed by sensory stimuli, and restrictive and repetitive behaviors. I only

worked with this family for two years but kept in close contact afterwards. A year later, the oldest daughter, Amanda, who was 13 at the time, was also diagnosed with autism. Amanda was moody, withdrawn, easily overwhelmed in crowds of people, and had quirky interests that bordered on obsessions at times. At the time, she was also going through a period of being too overwhelmed to leave her house, which resulted in her mother homeschooling her for a short time and then enrolling her in a day treatment program. A few years later, Blake's other sister, Kate, was diagnosed with ASD as an 8-year old. Kate was outgoing and friendly with adults, but often struggled to make and maintain peer friendships. Kate also had extreme anxiety when encountering novel situations. Kate had previously been diagnosed with dyslexia at age six. I originally thought both girls were just quirky and eccentric in their own ways, but when they received an ASD diagnosis, it made sense. I understood why the girls had such a difficult time making and keeping friends and why they were both overwhelmed so easily. After the last child was diagnosed with autism, the mother, Jamie, started to reflect on herself and her life experiences. She reflected on her children's experience receiving an autism diagnosis and had learned a great deal about autism through it. She was diagnosed with Attention-Deficit/Hyperactivity Disorder, but she always felt like there was something more that made her different from others. Finally, at the age of 40, Jamie received an autism diagnosis for herself. Knowing this family and following them through this experience made me question a lot about the differences in diagnosing autism for different sexes. Why was Blake diagnosed when he was two, but the females in his family were diagnosed when they were 8, 13, and 40-years-old? What more could have been done to recognize autism in these females when they were younger, so they would not have had to struggle through life until they received a diagnosis? Even though autism is a spectrum disorder, the three individuals, all from the same family, showed vastly

different autism symptoms and made me question what was so different about females with autism compared to males.

Throughout my years in education, both as a paraprofessional and now a special education teacher, working in self-contained elementary and middle school classrooms for students with autism, I experienced a variety of autism characteristics from both males and females. One theme that I noticed in many of the female students was they needed a sense of control or exhibited an urge to gain control and stifle strong feelings, whereas I did not observe this in a majority of my male students. I also noticed female students were more willing to reach out to others and in friendship or to seek connection with others, even if they did not have the skills to make or maintain age-appropriate relationships. Many of the male students seemed fine playing by themselves and did not often reach out to build relationships with others.

I also experienced female students outside of my classroom who may not have a diagnosis of autism, but definitely have some signs or symptoms of autism. Last year, I worked with a girl during extended school year who was very sweet and friendly, yet painfully shy. A paraprofessional mentioned to me that if she could just open up to the peers around her she would have more friends. While in the midst of research for this literature review, I thought that maybe she didn't know how. Maybe she isn't just shy, maybe she has autism. A colleague mentioned earlier this school year that she felt as if a girl in her class did not have autism, despite other colleagues suggesting that maybe she did. My colleague said that she doesn't flap her arms or get stuck on topics like the other kids she knew with ASD. She described the student as talking about her anxiety all the time. I thought to that maybe it wasn't just anxiety, maybe it truly was autism. Maybe she was stuck on talking about anxiety, but we did not view it as we would if a male student were stuck on something.

When choosing the topic for this literature review, I reflected on the family that I worked with so many years ago and also other autistic females that I have taught in the school setting. Throughout many of my undergraduate courses, I learned a lot about autism. In most of my classes, the topic of how autism manifests differently in females came up, but there was not a lot of in-depth information provided around this topic. I had heard that many of the original studies done surrounding autism that lead to developing the criteria for an autism diagnosis were completed on a majority of male participants (Mandy, 2018). Because of this, many females are at risk for receiving a late diagnosis of autism, typically sometime in adulthood, compared to males with autism which is typically diagnosed in childhood. Some females were at risk and would never receive a diagnosis. Undiagnosed autism can lead to females struggling through the first few decades of their life feeling like an outcast, wondering if something is wrong with them. The individuals are at risk to suffer from more serious feelings of anxiety or depression, until they receive an appropriate diagnosis.

My research was led by wondering what makes females with autism different from males with autism. The guiding question for this literature review is: What differences in autism are noted between males and females? I also wanted to explore how autism is diagnosed and how and when symptoms typically present in males compared to females. I also hoped to explore the experiences of females diagnosed with autism later in life. With the knowledge collected and gained from my research, I hope to apply it to the female students that I teach. The goal is to help them get needed special education services, rather than watching them struggle through life until they receive a diagnosis as an adult.

Chapter II: Literature Review

Literature Search Procedures

Information for this literature review was obtained from LibSearch with Bethel University and partner libraries and EBSCO MegaFILE with publications dating from 2015-2022. Keywords searched included “females with autism,” “autism,” “autism diagnosis,” “autism diagnosis female,” “female autism phenotype,” “female autism puberty,” and “female autism experience.” This chapter will review the literature on the experience of females with autism, including their diagnosis, the neurological and biological indicators of autism in females, sex and gender differences in autism, behavior, communication, social emotional experiences, comorbidities, the act of camouflaging symptoms, reviews of studies on the lived experiences of females with autism, and information on late diagnosis.

Diagnosis

Elsa K. Suckle (2020) published a letter in the Journal of Autism and Developmental Disorders related to how utilizing the DSM-5 criteria for autism diagnosis may not apply equally to males and females resulting in misdiagnosis or late diagnosis for females. In her letter, Suckle questioned if current diagnostic autism criteria accurately reflected behavioral data exhibited in the autistic female population. Suckle argued that females with autism showed a wide array of behaviors that did not resemble typical autism symptoms observed in males. Females often compensate for social emotional shortcomings and appeared neurotypical. This phenomenon means diagnosticians must decipher the complex ways autism presents in females (p.754).

Suckle (2020) stated that the DSM-5 definition of autism and diagnostic criteria should be considered a more fluid tool, rather than a checklist. This could lead to inconsistent diagnoses if practitioners and diagnosticians are trained differently. Suckle stated that the DSM-5

evaluated a range of symptoms, but did not include an exhaustive list of every possible autistic symptom. The letter also stated that the DSM-5 looked for underlying issues, rather than relying on actual behavioral evidence. Restrictive and repetitive behaviors are one area that the DSM-5 considers in the diagnosis of autism. Many studies documented that females display fewer of these behaviors, but some studies also noted that these behaviors may be more subtle and therefore, more difficult for practitioners to identify (p.755).

Symptoms in females with autism are often compared to behaviors that same-aged neurotypical females may experience, such as shyness, introversion, or anxiety. However, autistic symptoms can change as an individual gets older and emerges into different phases of life where autistic females may display more observable symptoms. Increased social demands as people age is a leading theory as to why many females are not diagnosed with ASD. The DSM-5 recognizes that autistic symptoms may change throughout the lifespan, especially regarding changes in social demands. The article also stated that symptoms must be present across multiple settings. The statements are contradictory pertaining to the lived experience for females with autism symptoms. Many autistic females reported that this stipulation caused significant delays in their diagnostic process. The issue should be considered a rationale to allow self or parental reporting measures during the diagnostic process (Suckle, 2020, p.756-757).

While the DSM-5 acknowledges masking or camouflaging, the behaviors also interfere with receiving an early autism diagnosis in females. Masking can lead to individuals hiding their autism symptoms until they explode and exhibit severe symptoms, such as aggression, self-harm, anger, yelling, depression, sadness. Oftentimes these are the observable behaviors or symptoms, rather than the underlying symptoms that lead to the occurrences (Suckle, 2020, p.756)

Individuals with autism also suffer from comorbid mental illnesses such as anxiety, depression, bipolar disorder, obsessive compulsive disorder, post-traumatic stress disorder, or eating disorders. Comorbidities are frequently related to a delayed diagnosis. The DSM-5 does not distinguish females with autism who have additional mental illnesses which may result from a trickle down effect from a delayed autism diagnosis. Suckle concluded her letter by acknowledging that the DSM-5 had a broad enough window to include females in the diagnostic criteria (Suckle, 2020, p.757).

Kavanaugh, B. C., Schrepf, C. A., Jones, R. N., Best, C. R., Sheinkopf, S. J., & Morrow, E. M. (2021) sought to determine specific clinical moderators to observe when diagnosing females with autism who are older than typical male diagnosis. Delayed autism diagnosis can have harmful, long-term effects since many evidence-based treatments rely on early intervention. Similar studies have been done with smaller sample sizes. Kavanaugh et al. (2021), incorporated a large sample size of more than 20,000 females by gathering data from two separate studies, using databases from the Rhode Island Consortium for Autism Research and Treatment (RI-CART) and the Simons Foundation Powering Autism Research for Knowledge (SPARK) database. Participants from both databases were diagnosed with autism during childhood or young adulthood.

Results from this statistical analysis showed a large age gap for females compared to males with fewer restrictive, repetitive behaviors. Data suggested that females were more likely to receive a delayed diagnosis if they exhibited a milder or atypical clinical phenotype that may have resulted in a missed diagnosis in early childhood. Researchers were unsure as to why females were more at risk for a late diagnosis. One factor could be ineffective screening methods that need to be updated to reflect current data (Kavanaugh et al., 2021).

This study had many strengths, including the largest sample size to date. The study utilized the RI-CART and SPARK databases which are two strong, phenotyping databases representing females with autism who are greatly underrepresented in many studies of similar nature. The participant age of diagnosis was based on parent ability to remember and limited the accuracy of information in this study. Within the RI-CART database, 90% of diagnoses were validated by a community ASD diagnosis (Kavanaugh et al., 2021).

Loomes, R., Hull, L., Polmear, W., & Mandy, L, (2017) used meta-analysis to calculate the proportion of males to females with autism since the introduction of the DSM-IV. The DSM-IV stated that ASD was diagnosed four times more often in males than in females; other studies have shown different statistics (Loomes et al., 2017, p. 466).

This meta-analysis evaluated 54 studies that included a total of 13,784,284 participants, with 53,712 participants diagnosed with autism, 43,972 males and 9,740 females. All participants were between the ages of 0-18 years. The authors considered a study eligible for this review if the sample size required at least 1,500 participants. Studies that included the *DSM-5* or *International Classification of Diseases, Tenth Revision* autism criteria were included. Loomer et al. (2017) considered studies that provided information about the numbers of males and females with autism, the year the data was collected, and an age range of 0-18-years (p.467). The authors analyzed subgroups such as those with low versus higher IQs and young versus older participants. The odds of being male in a group with ASD was compared to the odds of being male in a non-ASD group (Loomes et al., 2017, p.466).

Of the 54 studies, 14 were conducted in North America, 24 in Europe, 11 in Asia, two in South America, and two in Australia. The studies occurred over a span of 19 years (1992-2011). The average number of ASD cases was 61.9 per 10,000. The resulting data correlated with the

4:1 autism ratio of males to females published in the *DSM-IV*. Throughout the analysis, the authors found studies with no significant variable, such as IQ or age, or studies with low male to female ASD ratios. This suggested that perhaps the ratio was 5:1 (Loomes et al., 2017, p.470).

The authors concluded that the predictions about male to female ratios in ASD were lower than stated in the *DSM-IV*. It was worth noting that throughout the analysis, males were more susceptible to ASD than females. Loomes et. al. (2017) emphasized the value of research in this field that would seek to explain why this occurs. Researchers noted that studies should focus on better ways to detect autism in females (Loomes et al., 2017, p.472).

Researchers suggested one issue with the study was the possibility of skewed results because females were often either misdiagnosed or diagnosed later than males with autism. Perhaps this was the reason for the low prevalence rate of females to males with autism (p.471). The authors also noted that there was criticism around this study because the findings were based on the *DSM-IV* and not the *DSM-5* ASD criteria. The *DSM-5* introduced diagnostic criteria changes for ASD. The *DSM-5* criteria was more friendly to the female ASD population. Another caveat was that data was collected only for children and not adults. Since a significant number of females were diagnosed with ASD in late adolescence or early adulthood, current numbers could differ from information found in this analysis (Loomes et al., 2017, p.472).

A main strength of this study was the data driven process for selecting appropriate research based on stringent eligibility criteria. Researchers explained the process used to extract data and monitor for bias (p. 467). This study was the first of its kind to systematically calculate the proportion of males to females with autism (Loomes et al., 2017, p.466).

Gender is not typically considered when diagnosing autism, even though vast differences in autism characteristics and symptomology exist between males and females. Lundström, S.,

Mårland, C., Kuja-Halkola, R., Anckarsäter, H., Lichtenstein, P., Gillberg, C., & Nilsson, T. (2019) compared autism characteristics with comorbid conditions in males and females who had been clinically diagnosed with autism.

Lundström, S. et al. (2019) used two different sources to collect data, the Child and Adolescent Twin Study in Sweden (CATSS) and the Swedish National Patient Register (NPR). The CATSS was a study of all twins born in Sweden from July 1992 and beyond. Around the 9th birthday, the parents of the twins were contacted via phone interview to complete the Autism-Tics, ADHD, and other comorbidities inventory (A-TAC). The A-TAC involved answering 96 questions related to child psychiatric problems. Within the 96 questions, 17 of them are related to ASD, ADHD, LD, and ODD. The NPR helped researchers retrieve information related to autism diagnoses and other comorbidities of Swedish citizens. Through the NPR, researchers found 308 males and 122 females with a clinical autism diagnosis from among 30,392 individuals who were part of the CATSS sample. This data indicated a prevalence of 1.4% of that population diagnosed with ASD with the male-female ratio of 2.5:1 (Lundström et al., 2019, p.2).

Results from the A-TAC showed that males scored higher on each module than females. Male children with autism, who had no comorbidities, scored higher than females within the same category. Through this study, the researchers found that males with autism had higher A-TAC scores in the areas of ASD and ADHD than the female participants. They also found that female scores deviated further from the male scores in ADHD, LD, and ODD. Females with ASD may face a greater degree of dysfunction and suffering due to their autism compared to males. Another result suggested that it may be beneficial to omit sex-specific criteria when evaluating females because ASD may be dismissed (Lundström et al., 2019, p. 3).

Strengths of this study included a large sample size, high response rate, and the ability to access data from the NPR. A limitation was that no age parameters for participant ASD diagnosis were included or whether the diagnosis occurred before or after the A-TAC interview, which may have affected the scores in this study. Another limitation was that the data was based on twins and could suggest that twins have a greater likelihood of autism diagnoses (Lundström et al., 2019, p. 3).

One of the diagnostic symptoms of ASD is difficulty understanding nonverbal communication, including eye gaze which is often present in young children before the initial ASD diagnosis. However, this diagnostic criteria has been found to be an inaccurate prediction of autism for females as opposed to males. In their study, Whyte, E.M. & Scherf, K. S. (2018) explored potential gender differences between autism traits and eye gaze behavior. The goal was to determine whether eye gaze behaviors were related to gender and how gaze related to the severity and presence of autistic-like symptoms. Whyte and Scherf (2018) hypothesized that males with more autistic-like traits would do worse on eye gaze tasks than males with fewer autistic-like symptoms. They also wondered how autistic-like traits impacted female eye gaze. If eye gaze behaviors were not observed in females with autism, there would be cause to reconsider whether impaired eye gaze was part of the female autism phenotype (Whyte & Scherf, 2018, p.280-281).

The study included 120 undergraduate students; 60 male and 60 female. Participants could not have a diagnosis of ASD, ADHD, anxiety, depression, developmental delay, intellectual delay, or seizures. Participants completed an Autism Quotient (AQ) which asked 50 questions to measure autistic-like traits. They also completed the Broad Autism Phenotype Questionnaire (BAPQ), a 36 item questionnaire that measured autistic traits related to rigidity

and language issues. Eye gaze was measured through a procedure that presented participants with 165 photographs of actors directing their gaze toward an object. Each photograph contained the target object, a plausible non-target object, and several implausible objects. Participants were asked to name the object the actor gazed at in the image based on a list of four included objects (Whyte & Scherf, 2018, p. 281-282).

This study found that males who scored as having more autistic-like traits, performed subsequently worse on the eye gaze portion of this trial compared to males with fewer autistic-like traits and females with similar levels of autistic-like traits. The level of autistic-like traits did not impact how females performed on the eye gaze trial. Whyte and Scherf (2018) stated that a possible explanation for this was that the autism phenotypes were different in males and females. Other studies found that females were more likely to develop deep friendships and exhibit fewer restricted and repetitive behaviors. The results of this study indicated that eye gaze was probably not a reliable diagnostic trait in females and should be studied further in other high-risk populations and in the global autism population (Whyte & Scherf, 2018, p. 284-285).

Neurological/Biological Indicators of ASD

Studying sex-differences in brain structure related to social cognition for individuals with autism may help researchers discover more information about the neurobiology of autism, specifically in females. Cauvet, É., van't Westeinde, A., Toro, R., Kuja-Halkola, R., Neufeld, J., Mevel, K., & Bölte, S. (2020) examined qualitative and quantitative brain structure data in relation to social cognition within sets of twins who participated in the study that included 154 individuals, 77 sets of twins. Participants were identical twins with previously completed MRI scans, able to complete the MASC, and older than 12 years. Within this group, 28 individuals were diagnosed with autism (Cauvet et al., 2020, p.424).

This study used the Movie for the Assessment of Social Cognition (MASC) as an evaluation tool. The MASC was developed to understand the complexities of social situations including both the implicit and explicit social cognitive mental processes. Using the MASC, participants were shown a 15-minute movie clip of four individuals, two males and 2 females, having dinner together on a Saturday night. The movie was paused at 43 different points. The participants were then asked a total of 44 multiple-choice questions about the characters' emotions, thoughts, or intentions. The participants' parents filled out the Social Responsiveness Scale-2 (SRS-2) to measure autistic traits, such as difficulties with social communication, social motivation, social behavior, and social awareness. Researchers also looked at participant MRI results and examined the cortical thickness, volume, and surface area from each hemisphere of the brain, focusing on 20 specific areas of interest related to social cognition (Cauvet et al., 2020, p.424-426).

The study results found that participants with an autism diagnosis along with more autistic traits were linked with lower social cognition. This result was more significant for males than in females. Researchers also found that within the sets of twins, those with lower social cognition had an increased thickness in parts of the brain related to social cognition. Although the relationship between brain structure and brain function has not been always easily understood, the structural differences might lead to an underlying causative factor in the brain. The MASC results showed that few males scored poorly, while female participants had a narrower range of scores, meaning that even though females with autism had problems with social cognition, it was less likely that their scores were on the more severe end of the social cognition scale. The data suggested that gender differences seen between autistic males and

females was comparable to those seen in the subjects' typically developing peers (Cauvet et al., 2020, p.429-433).

This study was the first of its kind to examine the links between social cognition and social brain structure. The use of twins within this study was another parameter that set it apart from others. The twins acted as the control group because they shared 50-100% of genetics, age, and socio-economic status as one another. One caveat in this study was the large age and IQ range amongst participants. Participants were typically grouped within a study based on one of these factors, or the window of age or IQ would be narrowed to only include a specific range (Cauvet et al., 2020, p.434).

In their study, Kirkovski, M., Enticott, P. G., Hughes, M. E., Rossell, S. L., & Fitzgerald, P. B. (2015) aimed to use functional magnetic resonance imaging (fMRI) to understand the neurological sex differences related to social understanding in high-functioning adults with ASD, specifically related to blood oxygen level dependent (BOLD) activity. They expected that the participants with ASD would be less likely to accurately describe and identify social interactions and would show reduced BOLD activity compared to the neurotypical participants (Kirkovski et al, 2015, p.954-955).

There were a total of 50 ASD participants in this study. 27 participants, with 13 being male and 14 being female, had been previously diagnosed with high-functioning autism without an intellectual disability. Twenty-three neurotypical participants were also included in this study. All neurotypical participants were right handed. Of ASD participants, 17 were right handed, five were left handed, and five were ambidextrous (Kirkovski et al, 2015, p.956).

To measure symptoms and severity of autistic traits, the Autism Quotient (AQ), Empathy Quotient, and the Ritvo Autism and Asperger's Diagnostic Scale-Revised (RAADS-R) were

used. During the procedures, stimuli was displayed on MRI compatible screens. The stimulus presented was a block design. Block figures were used to prevent gender bias in facial processing. Participants were shown 12 silent animations illustrating social interactions between two characters, a large red triangle, and a small blue triangle. The trials depicted random movements, goal-directed interactions, such as chasing, fighting, or dancing, and theory of mind (ToM) interactions, such as mocking, coaxing, or surprising each other. After participants were shown a 40-second clip, they were asked to answer a multiple-choice question as to what type of interaction the clip depicted (Kirkovski et al, 2015, p.956)

Results of the procedures showed no difference in the ability to identify different types of interactions between the groups. The BOLD activity results also did not differ between the groups. One difference observed in the whole-brain analysis was in the right post superior temporal sulcus (pSTS) during the ToM clips for the male ASD participants. The STS is a part of the brain responsible for recognizing meaningful motion. Impairment in the STS could lead to impaired social cognition. One potential explanation of the results was that females tended to exhibit an interest in interacting with others. Predictably, because of the interest, females with ASD would be more likely to develop an understanding of social interactions which would strengthen neural pathways related to information processing in this area (Kirkovski et al, 2015, p.959-961).

A limitation of this study was the minimal number of trials that were conducted which could have altered the statistical results. Another limitation was that because the sample consisted of high functioning young adults with ASD, the results of the study may represent only those within similar age and symptom severity categories limiting generalization of results to younger participants or those with more severe symptomatology (Kirkovski et al, 2015, p.961).

Sex and Gender Differences

In their study, Bitsika and Sharpley (2019), sought to find a more accurate measure of diagnosing autism and developing a profile for both male and females than the Autism Diagnostic Observation Schedule-Second Edition (ADOS-2) that only considers children in clinical environments. The ADOS-2 also only compares ASD related behaviors. Bitsika, V & Sharpley, C. F. hypothesized that by using age, IQ, and ASD severity, experts could compare males and females with autism at greater detail. This study sought to use a detailed ASD-related parent-reported behavioral profile of school-age male and female participants who were matched by ASD severity and another group who was also matched on age and IQ (Bitsika & Sharpley, 2019, p.4429-4430).

There were 102 participants, including 51 male participants with a median age of 10.2 years and 51 female participants with a median age of 10.1 years. Each participant had one parent involved in this study. Pairs were formed based on age and IQ matching with one male and one female in each pairing. The subsample pairings, including 32 of the original sample group, were matched based on age, IQ, and ADOS-2 scores. The parents of all participants were given written instructions on how to complete the Social Responsive Scale-Second Edition (SRS-2). Data was collected in the homes of all participants in hope to ease potential stress while testing. Evaluators conducted the ADOS-2 and The Wechsler Abbreviated Scale for Intelligence (WASI-II) (Bitsika & Sharpley, 2019, p.4431-4432).

Results of this study identified specific ASD-related behaviors that could be significantly more severe in females with ASD, such as difficulty with social communication, as noted on the SRS-2. The most significant sex differences were the ability to interpret social cues, displaying reciprocal social behavior, motivation to engage in social interactions, noticing social cues, and

behaving in ways that may seem odd to neurotypical peers. Females consistently had higher scores than the male participants with no effect based on participant age, suggesting that camouflaging behaviors were developed prior to starting school leading to females exhibiting a wider array of ASD symptoms in order to meet diagnostic criteria. While there are many limitations to this study, including age, geographic and cultural representation, and the sole use of the SRS-2, at a single point, rather than utilizing another ASD behavior-related scale, the limitations did not render this study invalid. However the study results should not be generalized across populations (Bitsika & Sharpley, 2019, p.4435-4439).

Howe, Y. J., O'Rourke, J. A., Yatchmink, Y., Viscidi, E. W., Jones, R. N., & Morrow, E. M. (2015) examined differences in communication, daily living and social skills, adaptive behavior, and internalizing and externalizing problems between males and females with ASD. Data was collected from four separate datasets: the Autism Genetic Resource Exchange (AGRE), the Autism Consortium (AC), the Autism Speaks Autism Treatment Network (ATN), and the Simons Simplex Collection (SSC). The AGRE is a national DNA and family registry that tracks genotypic and phenotypic information for families who have more than one member with autism. The AC is a dataset with genotypic and phenotypic information collected from parents, siblings, and the affected individual in the Boston area. The ATN is a registry of patients who have sought clinical treatment for their autism symptoms. The SSC is a dataset that contains data from 12 clinical sites within Canada and the US. This dataset looks at genotypic and phenotypic information for families with one member who has autism (Howe et al., 2015, p.3538).

All data sets included the Autism Diagnostic Observation Schedule (ADOS), a semi-structured, standardized assessment in the areas of play, social interaction, communication, and restrictive, repetitive behaviors, as part of the battery of instruments used to verify an autism

diagnosis. The ADOS presents a number of subtests that procured behaviors needed to diagnose autism. Using the ADOS, participants were grouped based on verbal abilities. ADOS Module 1 was administered for participants with limited verbal abilities or who were completely nonverbal. ADOS Module 2 was used for participants who produced phrase speech. ADOS Modules 3 and 4 were for participants with fluent speech. Module 3 was for children and adolescents and Module 4 for adolescents and adults. All datasets also included IQ measures. IQ measures varied amongst the datasets, including the Stanford-Binet Intelligence Scales-5th edition (SB-V), the Differential Abilities Scale Early Years and School Years (DAS), the Wechsler Abbreviated Scale of intelligence (WASI), the Wechsler Preschool and Primary Scale of intelligence Third Edition, 4.0–7.3 (WPPSI-4.0–7.3), and the Wechsler intelligence Scale for Children-Fourth Edition (WISC-IV). Other measures included the Vineland Adaptive Behavior Scale (VABS), a standardized assessment tool for adaptive functioning, the Social Responsiveness Scale (SRS), a questionnaire that measured the severity of autistic symptoms, and the Child Behavior Checklist (CBC), a standardized questionnaire that measured emotional functioning (Howe et al., 2015, p. 3538-3539).

The authors of this study compared only participants who were greater than five-years old and met ADOS criteria for ASD. Within each independent study, sex differences were compared and analyzed. In total, there were 5723 participants (872 females and 4851 males) with a median age per data set ranging from 8.6 years to 9.7 years. The authors analyzed the data using hierarchical loglinear analysis (Howe et al., 2015, p.3539).

No cognitive, adaptive, or social differences were found between nonverbal male and female ASD participants (ADOS Module 1). Female participants who used phrase speech (ADOS Module 2) in the ATN and SSC datasets were found to be more adversely affected by

autism, showing symptoms of lower IQ, lower social functioning, and more externalizing behaviors. Female participants with fluid speech (ADOS Module 3) in the AGRE and AC datasets had better social skills compared to the male participants. The findings suggested a correlation between verbal abilities and the severity of autistic symptoms. Differing results were found within some of the datasets related to emotional and behavioral categories. The ATN and SCC found that female participants showed worse externalizing behaviors compared to males while female participants in the AC dataset showed less severe internalizing problems compared to males (p.3540). In conclusion, Howe Y. J. et al. (2015) found that sex differences could be found across the autism spectrum (p.3547).

This study highlighted possible bias toward those who have been diagnosed using a male phenotypic diagnostic method or criteria. This bias leads to the higher male-to-female ratio. Another limitation was grouping participants based on verbal abilities, using the ADOS module, which has not been widely used in other studies (Howe et al., 2015, p.3546).

In 2020, James and Grech published a paper to chronicle, explain, and support Simon Baron-Cohen's theory of Extreme Male Brain (EMB) theory of autism. Baron-Cohen identified four symptoms of autism: repetitive movements, increased systematizing, a lack of empathy related to appreciating the mind of others, and reading facial expressions. The symptoms did not intercorrelate. James, W. & Grech, V. sought to summarize the sex similarities and differences in those with ASD and to support the findings of Baron-Cohen and EMB with two well-substantiated hypotheses. The first hypothesis was that autism was caused by both environment and genetics. This multifactorial approach said that when certain thresholds were reached, autism would occur. The thresholds could be a sibling with autism or intrauterine exposure to high levels of testosterone. The second hypothesis discussed the relationship between pre and

postnatal testosterone levels in healthy males and females. High levels of testosterone could cause demasculinization in males and masculinization in females. The authors noted that prenatal *T* could slow the growth of the left side of the brain while simultaneously enhancing the right side of the brain, responsible for visual-spatial and mathematical functioning. Because of this, they hypothesized that some autistic behaviors were developed during the prenatal programming of the brain (James & Grech, 2020, p. 1-2).

James and Grech (2020) explained eight similarities and differences in males and females with autism. The first one was mental rotation performances. After finding mixed results from research in this area, the authors reiterated the two hypotheses and stated that they felt autistic males were no better than autistic females regarding mental rotation. The second anomaly was androgynous facial features. Females with autism were reported to have less feminine facial features while males with autism tended to have less masculine facial features. The authors related this to postnatal *T* levels. It should also be noted that this could be an evolutionary trait. The third anomaly was attention to gender-related images. It was reported that females with ASD tended to show more attention to images of toys, objects, and faces than their male ASD peers. High uterine levels of *T* in females with ASD may have led to the more typical attention to gender-related images. The fourth anomaly included findings from the Cambridge Sympathy Test. The test which measured sympathy and distress found that autistic males and females did not significantly differ. This was explained by comparable intrauterine *T* levels (James & Grech, 2020, p.2-3)

The fifth anomaly was Reading-the-Mind-in-the-Eyes Test. There was also no difference between autistic males and females on this assessment, however a significant difference between the results of autistic and neurotypical women was noted. Testosterone reduces functional

connectivity, leading to these results. The sixth anomaly observed finger length ratios between the second and fourth digit. This may be an indicator for intrauterine exposure to *T*. Healthy males typically have smaller finger length ratios than healthy women. The findings were similar in autistic subjects, suggesting that high levels of intrauterine *T* may have caused this anomaly. The seventh anomaly was behavioral differences, such as fewer restrictive, repetitive and externalizing behaviors for females with ASD. The differences could be explained by differing levels of pre- and post-natal testosterone. The eighth and final anomaly found functional via magnetic resonance imaging (fMRI). Studies of functional imaging show that healthy males and females have higher levels of activity during rest in certain regions of the brain. In individuals with autism, female subjects showed a shift towards the neurotypical male, while males with ASD shifted towards the neurotypical female. The authors of this paper suggested that this was due to different brain connectedness between males and females with ASD and was related to higher exposure to intrauterine *T* during brain programming. James, W., & Gerch, V. concluded by stating that the eight anomalies evaluated may be related to high levels of pre- and post-natal testosterone. They stated that this was in agreement with Baron-Cohen's theory of EMB (James & Grech, 2020, p.3-4).

Behavior

Previous studies of restrictive interests proposed that connections in the sulcus and gyrus regions of the brain connected the restrictive interests symptoms for females with ASD, but not for males. The findings led researchers to question how restrictive interests were expressed for females with ASD. McFayden, T.C., Albright, J., Muskett, A. E., & Scarpa, A. (2018) wanted to address gaps in research related to restrictive interests by creating a descriptive profile of males and females with ASD. They also wished to provide experts with findings about how females

with autism presented. McFayden et al. (2018) hypothesized female participants would have less severe restrictive, repetitive behaviors and restrictive interests than males. They also hypothesized that the nature of restrictive interests would differ amongst the two genders (McFayden et al., 2018, p.1693-1694).

The study took place in southwest Virginia using 125 participants with and without ASD from ages two to 83 years. Following an ASD assessment based on the DSM-5 criteria, 40 female participants were selected for a mixed method study. Participants completed self-reported measures before the in-clinic visit where they were assessed for three hours. The measures included: Autism Diagnostic Interview-Revised (ADI-R), the Autism Diagnostic Observation Schedule, 2nd Edition (ADOS-2), the Repetitive Behavior Scale-Revised (RBS-R), and the Social Responsiveness Scale-Second Edition (SRS-2). Seventy-five participants were diagnosed with ASD (McFayden et al., 2018, p.1694-1695).

The findings from this study showed similar male and female restrictive, repetitive severity ratings, however male participants scored higher than female participants on the RBS-R Restricted Behavior subscale. Another finding was that females had a narrower range of interests that were considered more socially oriented, like living objects, vs. male interests which were mostly object-related (McFayden et al., 2018, p. 1698).

Many limitations were found in this study including the small female sample size. A larger sample size would have provided more data related to restrictive interests. Another limitation was that age-specific analysis could not be completed given the broad participant age range. This was a self-referred study, meaning that participants could sign up with the Autism Research Center if they were interested or needed assessment and diagnostic services. This may have led to more males than females seeking to join the study due to having greater, or more

visible impairments (McFayden et al., 2018, p. 1698). Many variables in this study made it unique compared to others of its kind. The sample included participants from mostly rural areas. The wide age-range could assist in developing assessment tools for individuals across the lifespan. Participants included a wide variety of ages. Many other studies drew participants from urban areas.

Communication

Parish-Morris, J., Liverman, M. Y., Cieri, C., Herrington, J. D., Yerys, B., Bateman, L., Donahar, J., Ferguson, E., Pandey, J., & Schultz, R. T. (2017) used granular language-based analysis to examine how females with autism utilized social camouflaging behaviors by producing natural, gender-typical pauses in conversations with typical peers. During normal conversations, participants pause, rework, and revise what they say. This process is called disfluency. Pauses during speech can either remain unfilled or are filled with words like *uh*, *um*, *like*, and *you know*. Interjections UH and UM often signal to the listener that the speaker needs more time to finish delivering a current thought. Current evidence shows that there may be a difference in the use of UH and UM. UH communicates a short delay, while UM communicates a more significant delay. Several studies have been done considering the UH/UM ratio in children and adolescents with ASD, a population that displays high rates of disfluencies. Studies suggested that children with autism use UH and UM differently than peers and that the UH/UM ratio was associated with symptoms of autism. However, specific studies have not been done to examine sex-differences and the use of the UH/UM ratio. The implication that males and females with autism use different patterns of speaking, such as the UH/UM ratio could change how symptoms of autism are evaluated in males and females. Researchers hypothesized that girls with

ASD would produce more UM sounds and boys with ASD would produce more UH sounds (Parish-Morris et al., 2017, p.2-3).

The study used language samples to evaluate 65 children, aged 6-17 years with ASD. Participants could not have been born prematurely (<32 weeks) or have low birth weight. They could not have uncorrected auditory or visual impairments, significant psychiatric conditions, or any genetic or medical history that explained their ASD symptoms. All participants needed to use phrase speech, since all data would be obtained through conversations. Participants were given the ADOS-2, the Social Communication Questionnaire (SCQ), and the Vineland Adaptive Behavior Scales-2nd edition (VABS), which measured adaptive behavior from a parental perspective. Subjects were also given the Differential Abilities Scales-II (DAS II) designed to obtain the general intelligence of children 2-18 years old (Parish-Morris et al., 2017, p. 3-4).

The results of this study showed that girls with ASD used the UM interjection and had a higher UH/UM ratio than boys with ASD. The greater likelihood for females with ASD who used UM as opposed to UH may allow them to camouflage linguistically and blend in with peers. The greater likelihood for males who used the UH interjection could lead them to appear more atypical. It is important to note that girls in this study did not fill more conversational pauses than boys, but they filled them differently. Girls used UM less than 70% of the time to fill pauses while boys used UM around 55% of the time. It was hypothesized that a female with ASD might produce more UM interjections during conversational pauses to appear more normal. Results of this study suggested that subtle sex behavioral differences could contribute to female misdiagnosis or being diagnosed later in life. The authors concluded by stating that the linguistic camouflage in females with ASD shown in this study emphasized the continued need to study

biological and environmental factors that may impact how ASD presents (Parish-Morris et al., 2017, p. 5-10).

This study had several limitations. The first limitation was unequal numbers of boys and girls which skewed some of the results when examining other variables. Another limitation was that due to the nature and flexibility of administering the ADOS, some participants may not have answered the same questions or prompts in the same order which may have altered speech production leading to skewed results. The study also did not consider whether any participants had comorbid disorders, such as anxiety, depression, or ADHD (Parish-Morris et al., 2017, p. 10).

In their 2016 study, Rynkiewicz, A., Schuller, B., Marchi, I., Piana, S., Camurri, A., Lassalle, A., & Baron-Cohen, S. sought to create a new technique to objectively evaluate non-verbal communication during two Autism Diagnostic Observation Schedule, Second Edition (ADOS-2) tasks. Male and female participants' results were compared. The authors hypothesized that female participants would use more non-verbal gestures than males (Rynkiewicz et al., 2016, p. 2-3).

The participants included 33 Polish males and females diagnosed with Asperger's syndrome. Participants were between the ages of 5-10 years, fluent in Polish with average to above average intelligence. Participants were evaluated during the Demonstration and the Cartoons Tasks of the ADOS-2. Computer software measured gestures which recorded the number of gestures without distinguishing the type of gesture (Rynkiewicz et al., 2016, p.3).

Researchers focused on specific aspects of the two tasks evaluated, such as motor activity when retelling a story and when brushing teeth. Researchers noted the length that participants moved their respective body parts, the time they spent gesturing and the gesture Index (GI), a

ratio of the first two measurements. GI results showed that female participants used gestures more poignantly than the male participants. The gestures occurred with increased frequency and performed more rapidly making them easily observed. A human examiner may notice the poignant gesture more easily in females leading to the belief that participants performed more typically, contributing to under-diagnosis for females with autism (Rynkiewicz et al., 2016, p. 4-7).

Limitations of this study included that the technology was only performed during two testing components of the ADOS-2. The authors recommended another study to use the technology throughout an entire ADOS-2 assessment and with participants with comorbidities (Rynkiewicz et al., 2016, p. 7).

Camouflaging

Females with high-functioning autism are often better able to camouflage their symptoms than their male counterparts, but not much is known about how camouflaging works. In their study, Lehnhardt F. G. , Falter, C. M., Gawronski, A., Pfeiffer, K., Tepest, R., Franklin, J., & Vogeley, K. (2015) investigated the executive functioning and mentalizing abilities behind camouflaging in females with high-functioning autism diagnosed later in life. They hypothesized that females with ASD exhibited different cognitive strategies that put socio-communicatives above intellectual functioning as opposed to male counterparts (Lehnhardt et al., 2015, p.140-141).

The participant sample consisted of 71 females and 144 males recently diagnosed with autism as adults. Participants completed three self-reporting instruments, including the Autism Questionnaire (AQ), the Empathy Quotient (EQ), and the Systemizing Quotient (SQ).

Participants also completed the Reading-the-Mind-in-the-Eyes Test to assess mentalizing

abilities. Intelligence was assessed using the Wechsler-Adult-Intelligence-Scale (WAIS)-III. Executive functioning was measured using the Trail Making Test (TMT), the Wisconsin Card Sorting Test (WCST), and Verbal Fluency Task, adapted from the Controlled Word Association Test (COWAT). A record review was also conducted for all participants to note mental health consultation, frequency of romantic or intimate relationships, living arrangements, educational level, and vocational status (Lehnhardt et al., 2015, p. 141-142).

Results from this study revealed differences for females and males with ASD. Male participants displayed higher verbal abilities, while female participants exhibited higher processing speeds and better executive functioning. Both male and female participants showed high general intelligence and understanding of social norms and contexts. The results suggested that females with high-functioning ASD possessed abilities to camouflage or hide autistic symptoms (Lehnhardt et al., 2015, p.150)

Tubío-Fungueiriño, M., Cruz, S., Sampaio, A., Carracedo, A., & Fernández-Prieto, M. (2021) systematically reviewed evidence on camouflaging effects for females with ASD and ways to inform parents and health professionals about how autism manifests in females. Tubio-Fungueirino et al. (2021) defined camouflaging as a "complex copying behaviors and/or masking some personality traits with an adaptive function that promotes adjustments into specific environmental demands" (Tubío-Fungueiriño et al., 2021, p. 2191).

Data was obtained from electronic databases PubMed, Web of Science, PsychInfo and Scopus. The databases met the necessary criteria for the study, such as being published between January 1st, 2009 and September 30th, 2019 with English as the language of publication. The thirteen studies included in the databases focused on camouflaging autistic symptoms in females

and included both males and females with autism or Asperger's (Tubío-Fungueiriño et al., 2021, p.2192).

Camouflaging is a coping mechanism often used to meet social expectations. Compared to males, females with and without autism seem to experience more social pressure. This leads to increased camouflaging behaviors as a way to cope with feelings of social expectations and stress or anxiety related to possible rejection or misunderstanding by peers. Females with ASD often reported being bullied by peers which resulted in loneliness and isolation. Camouflaging may lead to late-diagnosis, anxiety, depression, loss of self-identity, self-esteem issues, self-harm, or suicidal ideations. Because individuals learned to camouflage autism symptoms, they also camouflaged the emotional symptoms (Tubío-Fungueiriño et al., 2021, p.2192-2193).

Tubío-Fungueiriño et al. (2021) found an increased number of studies related to the effects of camouflaging over the last decade. The studies also suggested that females with autism may be more aware of the necessity of friendships, despite having difficulties navigating friendships. Many studies reported that females with ASD have difficulties understanding the rules of social relationships, complying with social gender expectations, and displaying inabilities with socio-communication. As females camouflaged their symptoms, they were expected to become more social and establish deeper friendships and connections with others, which could be hard to do when they lacked understanding of social expectations. The number of studies and evidence related to camouflaging suggested a need for sex-specific diagnostic criteria for ASD. It was also found that females with ASD were better at incorporating non-verbal communication signals, such as gestures. Researchers also discovered a study that considered how individuals with autism used the interjections "um" and "uh" as a strategy to fill empty spaces in conversations. The study found that females with ASD tended to use the interjection

"um." The use of "um" as opposed to "uh" was often related to more sophisticated language skills. The study suggested that the interjections were learned as part of camouflaging. Tubío-Fungueiriño et al. (2021) concluded by stating that camouflaging could be a useful tool for females with autism but included negative side effects, such as late diagnosis and underdiagnosis (p.2197).

In a narrative review, Hull, L., Petrides, K. V., & Mandy, W. (2020) explored the female protective effect, female autism phenotype, and camouflaging behaviors. Current statistics state that for every female diagnosed with autism, three males also receive a diagnosis. Some may believe that something within females “protects” them from developing autism. Hull et al. (2020) argued that females were just as likely to develop autism as males, but due to diagnostic biases and the manner autism manifests in females, female autism was more likely to go unnoticed (Hull et al., 2020, p.306-307).

Hull et al. (2020) defined the Female Protective Effect Theory (FPE theory) as “females require greater environmental and/or genetic risk than males to express the same degree of autistic characteristics, and, hence, that females are ‘protected’ from autistic characteristics relative to males with a comparable level of risk factors” (p.307). It was suggested that females required a greater severity of autism symptoms, or a greater genetic load, to meet the diagnostic threshold compared to males. If true, close genetic relatives would also carry the same genetic load, meaning that more autistic females would have relatives who also have autism compared to autistic males (Hull et al., 2020, p.307).

Females must exhibit more symptoms that more significantly impact their life than males to receive an autism diagnosis. Females are typically diagnosed at a later age than males. Current diagnostic criteria for autism is based on pre-existing ideas of autism based on the male autism

phenotype. The female autism phenotype represents autistic characteristics such as difficulties with social communication, restricted, repetitive behaviors and interests, and unusual sensory responses. However, these traits may present differently in females compared to traditional autism diagnostic criteria. Females may also exhibit other traits related to their autism that are not included in current diagnostic criteria (Hull et al., 2020, p. 308). The female autism phenotype suggested that females with autism had fewer social impairments than males, due to the desire to form friendships. However, they may struggle with conflict and maintaining long-term relationships or friendships. Restrictive, repetitive interests may also differ in females. Females typically have interests considered less atypical than males, even if their interest levels are the same, such as animals, fictional characters, or psychology. Interests are viewed as more functional and age-appropriate than autistic male interests, so they may not be reported as atypical by parents or clinicians (Hull et al., 2020, p.309).

Internalizing problems is another characteristic of the female autism phenotype. In females, this manifests as anxiety, depression, eating disorders, or self-harm. Males with autism clinically presented with externalizing problems through aggression and difficulty relating to others. Females were more likely to have co-occurring internalized disorders than males. More co-occurring internalized disorders may mask autism symptoms leading to mis- or undiagnosed autism. Females who are not diagnosed and continue to internalize problems may have more severe mental health issues thus the less likelihood of receiving a diagnosis (Hull et al., 2020, p.309).

Another characteristic of the female autism phenotype is camouflaging. Camouflaging occurs when autistic individuals try to minimize their symptoms during social situations. This occurs consciously or unconsciously and can be a learned behavior or implicitly developed.

Camouflaging includes mimicking others' facial expressions, forcing eye contact, staying close to other females to avoid standing out, or limiting the amount of talking about certain topics of interest. Some researchers said that females may develop learned social behaviors from reading books or watching television. Camouflaging negatively impacts individuals, resulting in missed autism diagnosis, emotional exhaustion, needing more alone time, or identity issues (Hull et al., 2020, p. 309-313)..

Camouflaging was initially hypothesized by Lorna Wing in 1981 when she stated that some autistic females, who did not have intellectual disabilities, may be undiagnosed via autism assessments due to better developed social and communication capabilities. Since 2015, a number of studies have investigated camouflaging behaviors in females using qualitative methods, such as interviews or observations in social settings (Hull et al., 2020, p. 309-313).

Hull et al. (2020) concluded a narrative review on the female autism phenotype and camouflaging by stating that one reason females were diagnosed with autism less frequently than males was due to discrepancies in the male and female presentation of autism symptoms. The review findings implied that camouflaging commonly occurred in females with autism. Clinicians who diagnose autism should be made aware of camouflaging behaviors when evaluating patients who nearly meet the criteria for an autism diagnosis (Hull et al., 2020, p. 313).

Social Emotional

Impairments in emotional recognition and processing can lead to a greater severity of autistic symptoms. In their study, Ketelaars, M. P., In't Velt, A., Mol, A., Swaab, H., & van Rijn, S. (2016) investigated emotional recognition in adult females with ASD. The hypothesis stated that women with ASD have mostly intact emotional recognition skills. It has been documented

that this is not true for males with ASD, supporting the female ASD phenotype. The study also looked at alexithymia as a factor in emotional recognition impairments, meaning that individuals have an inability to recognize or describe their own emotions (p. 51-52). Participants included 31 females with ASD and 30 neurotypical women, above the age of 18. Participants took various assessments meant to capture intellectual functioning, ASD symptom severity, vocal emotion recognition, visual emotion recognition, and alexithymia (Ketelaars et al., 2016, p. 53).

In the area of vocal emotion processing, participants accurately recognized emotions, however the speed at which emotions were recognized was slower than average. Visual emotional processing was found as similar to neurotypical peers. Visual and vocal emotional recognition were not related, suggesting that individuals may have alternative ways to recognize emotions. Females with ASD struggled to label and describe their own emotions, but recognized the intensity of their feelings. The authors noted that this may mean that recognizing emotions was not a priority. High rates of alexithymia were found within this group of participants. The results coincided with females being misdiagnosed or diagnosed later in life (Ketelaars et al., 2016, p.57-58). Vocal and visual recognition measurements did not consider processing and reaction times which limited the validity of this study. This additional data could have led to more significant conclusions regarding emotional recognition in females with ASD (Ketelaars et al., 2016, p.58-59).

Myles, O., Boyle, C., & Richards, A. (2019) explored the experiences of adolescent females who attended mainstream schools. Experiences considered in this study were related to social experiences and a sense of belonging. Researchers wanted to understand and identify the meaning and determine significance of a “sense of belonging” and sought to answer the following: “What do adolescent females with autism feel about their social experiences in

mainstream secondary school? In what ways do adolescent females with autism feel like they belong? In what ways do adolescent females with autism feel excluded?" (Myles et al., 2019, p. 8-11).

Ten female students, aged 12-17 years, from schools in southwest England were invited to participate in the study. Eight students agreed. Semi-structured interviews were conducted to understand participant views regarding belonging and exclusion within their school. Participants, prompted by researchers, led the discussion with topics or questions not formally addressed. Topics included belonging, fitting in, valued involvements, relationships, and support from school staff (Myles et al., 2019, p. 8-12).

Participants were interviewed for 30-45 minutes on two separate occasions with a one-week gap between interviews. Following the first interview, participants completed a "Feelings of Belonging" worksheet. Participants reflected on their sense of belonging throughout the school day. During the second interview they discussed responses from the worksheet (Myles et al., 2019, p. 12-13).

The data was analyzed thematically. Regarding the research question that asked how adolescent females with autism felt about social experiences in their mainstream secondary schools, researchers found the themes of reciprocal friendship, feeling safe or supported, encouragement, inclusion, and establishing social expectations. Participants also described times when they felt excluded from a group. Themes that emerged were feelings of being devalued and feelings of being on the periphery of social groups (Myles et al., 2019, p.13-17).

Key themes that emerged from this study were based around perceived peer acceptance, friendship, and social competence. The themes suggested that peers influenced a sense of belonging for adolescent females with autism who attended mainstream secondary schools. The

findings suggested that adolescent females with autism were willing to seek social contact and form friendships in the same way as their neurotypical peers. The results illustrated how social difficulties added to feelings of exclusion in adolescent females with autism (Myles et al., 2019, p.17).

This study only represented a small group of adolescent females with autism, so the findings could not be generalized to all adolescent females with autism. The researchers suggested that if they were to replicate the study, they would try to narrow the participant age range. It was also noted that the social experience account may not have been an accurate portrayal of participants' lived experiences. The participants may have given inaccurate information to appear as if they had more friends or that they misunderstood peer actions (Myles et al., 2019, p.17).

Even with the small sample size, a main strength of the study was the accuracy of obtaining real experiences from adolescent females with autism through semi-structured interviews. If a survey or questionnaire had been used, the researchers may not have discovered themes and would not have been able to analyze how the themes related to females with autism.

Individuals with autism often have difficulties with perspective taking. In their study, Stroth, S., Paye, L., Kamp-Becker, I., Wermter, A.-K., Krach, S., Paulus, F. M., & Müller-Pinzler, L. (2019) sought to understand more about the difficulties females with autism had with empathy-related processing. Based on findings in a previous study of a similar nature with males, Stroth et al.(2019) hypothesized that in response to various complex social situations related to the feelings of embarrassment and physical pain, females with ASD would show a hypoactiveness in areas of the brain related with empathy (Stroth et al., 2019, p.2-3).

The study evaluated 18 female participants: nine with autism and nine neurotypical. The mean age of the ASD group was 18.7 years and the mean age of the control group was 19.9 years. Using two functional magnetic resonance imagings (fMRI), researchers introduced stimuli to induce feelings of empathy. The stimuli included 28 colored, point-of-view images that portrayed painful and non-painful situations. Participants were shown each image for 4.5 seconds and asked to rate the pain strength the person experienced based on a five-point scale where 1=no pain at all and 5=very strong amount of pain. To measure empathy for social pain, the participants were shown 30 hand drawn sketches depicting a protagonist in socially undesirable and neutral situations (Stroth et al., 2019, p.3-4).

This study found that females correctly inferred physical pain of another, but struggled to accurately detect social pain. The participants with ASD attributed strong feelings of embarrassment to most of the depicted scenarios, even to the ones in which the protagonist was unaware of the possible threat to their social integrity. The fMRI showed less activity in the anterior insula, part of the brain responsible for social-emotional processing, when participants with autism were shown both images of social and physical pain. Because of this, the participants may have lacked the ability to empathize with others. This study did not assess alexithymia, the inability to assess one's own emotions, even though many individuals with ASD also suffer from it (Stroth et al., 2019, p. 8-10).

Jamison and Schlutter (2015) explored the similarities and differences in items such as social competence, self-perception, quality of life, and problematic behavior in adolescent females with autism. Four research questions were examined in this study: (1) What is the relationship among factors of social-emotional health for adolescent females with and without autism? (2) What differences are there between adolescent females with and without autism in

regards to social-emotional health? (3) The impact of problematic behaviors, like internalizing symptoms or camouflaging, on the social-emotional health of adolescent females with and without autism? and (4) Are social competence or problematic behaviors related to parental perception of autism symptom severity? Jamison and Schuttler (2015) hypothesized that there was a strong relationship among the indicators of social-emotional health, that adolescent females without autism would rate higher in terms of social competence than adolescent females with autism, that problematic behaviors would negatively impact social-emotional health, and that patients perceptions of social competence will also impact perceptions of symptom severity (Jamison & Schlutter, 2015, p.3-4).

In total, there were 75 participants in this study, 23 adolescent females with ASD, 29 adolescent females without, and 23 parents of a daughter with ASD. All adolescent female participants were part of six separate social skills groups that took place over the course of four years either as participants or peer mentors. Data to evaluate female adolescent social emotional health was collected through self and parent reports including the Social Skills Improvements System (SSIS), Harter's Self-Perception Profile for Adolescents (SPPA) , and Youth Quality of Life Instrument-Research Version (YQOL-R). The reports measured social competence (SSIS), self-worth (SPPA), and quality of life (YQOL-R) (Jamison & Schlutter, 2015, p.4-5).

Across both ASD and non-ASD groups, a significant relationship was found among all three aspects of social emotional health: social competence, self-worth, and quality of life. Participants in the ASD group rated themselves substantially lower than their non-ASD peers. Females with ASD also reported more internalizing and externalizing symptoms compared to their non-ASD peers. With results such as these, low scores in various areas of social-emotional health, females with ASD are considered a vulnerable population and prone to developing

additional mental health disorders. A relationship between ASD symptom severity and social emotional health was also considered. According to the parent reports, no notable relationship existed between symptom severity and internalizing or externalizing symptoms, however there was a significant relationship between symptom severity and social competence. Parents noted when symptoms were more intense, they perceived that their daughters had low social competence (p. 9-13). Parent reporting measures were not available for participants without ASD which limited comparisons (Jamison & Schlutter, 2015, p. 15).

In 2016, Jamison and Schuttler published a paper outlining a social skills and self-care program, Girls Night Out (GNO), specifically designed for adolescent females with ASD. Much of the current social skills research has been focused around group-based social skills training within the school setting with school-aged, male students with ASD. Social skills training typically targets conversational skills, nonverbal behaviors, and emotional regulation and understanding (Jamison & Schuttler, 2016, p.110-111).

The objective of GNO was to improve social-emotional health in adolescent females with ASD. GNO combined analytically-based strategies, gathered data on program objectives, and involved typically developing female peers as mediators and models of the skills presented. Skills practice was age-appropriate, meaningful, occurred in a community context, and based on social learning theory and cognitive behavioral principles. GNO was meant to empower young women, promote inclusion, and develop social competence (Jamison & Schuttler, 2016, p.112-113).

The three core areas of GNO included relating to others, self-care, and self-determination. For relating to others, students were taught conversational "entry" skills, or initiating conversations with others, and relationship building skills. GNO included self-care in

the curriculum because building independent self-care skills could lead to improved confidence, increasing confidence and competence in social relationships. GNO was designed to take place weekly for two hours, continuing for 12-16 weeks. Groups included 4-6 individuals with a disability (ASD/DD) and an equal number of trained, typically developing female peers. Sessions followed a similar outline, but introduced a new theme each week, such as exercise or eating dinner out at a restaurant. Sessions included a targeted skill, practice opportunities, visual supports, and opportunities for feedback or reinforcement. GNO used multiple methods to develop intrinsic and extrinsic motivation and reinforce desired behaviors for participants, including positive labeled praise, differential attention, and a token economy system (Jamison & Schuttler, 2016, p.113-115).

Preliminary findings were taken from a sample of five GNO groups that met over the course of four years. Jamison, T. R., & Schuttler, J. O. (2016) hypothesized that GNO participants would make significant improvements in the areas of social competence, self-perception, and overall quality of life. Results from the sample groups showed a significant increase in all areas via self-reported measures. However, parental-reported measures did not show any significant growth in these areas. It is important to note that the samples were small and parental reports are typically not as precise as self-reported measures. Fidelity data was kept on four of the groups in the sample with a mean fidelity score of 90%, suggesting good fidelity. Consumer reports collected from peers, parents, and participants from all five sample groups noted that almost all (95%) respondents were highly satisfied with the program and reported some improvements in self-care and conversational skills. The results suggested that GNO was a practical and socially valid curriculum for adolescent females with ASD (Jamison & Schuttler, 2016, p.118-122).

In a 2020 case study, Frasier, K. F., Collier, J., & Glade, R. sought to answer the following questions: (a) Can the social skills program, "Social Thinking," improve the social behaviors of adolescent females with ASD? and (b) Do techniques such as positive reinforcement and self-management assist in improving executive functioning in females with ASD? The aim of this case study was to consider the efficacy of joining multiple treatment strategies to help adolescent females with ASD develop executive functioning skills, self-management, and targeted social skills (Frasier et al., 2020, p. 316).

The study included one middle school female participant diagnosed with ASD at 11 years old. She attended school in a general education classroom and did not receive additional special education services or social skills training during the study. The participant had a history of aggression, tantrums, and noncompliant behaviors across multiple settings. She was described as having an outgoing personality and a desire to make friends. She also showed some signs of anxiety. Tests were given to the participant prior and following the social cognitive training, the Behavior Rating Inventory of Executive Function (BRIEF) and the Social Skills Improvement System (SSIS). To reach targeted social cognitive skills, the training used social mapping, discussions of "expected" and "unexpected" behaviors, cue cards, role-play, modeling, video modeling, schedules, checklists, and positive reinforcement. There were 24 training sessions over the course of four months including group and one-on-one sessions (Frasier et al., 2020, p. 316-318).

Post-test parent and teacher reports showed that the participant made significant gains in the areas of social behavior and executive functioning. However, there were also negative influences, such as participant anxiety and changes related to puberty, that may have hindered more significant growth. During the treatment, the participant maintained social skills that

allowed her to thrive and participate in a general education class, maintain As and Bs in most of her classes, and develop friendly peer relationships. Skills such as self-management, attention, on-task behavior, and compliance all increased over the course of treatment. There was also an improvement for social behaviors, such as conversation initiation, topic maintenance, and compromising abilities. The participant also began to show executive functioning improvements, such as discussing her anger and other strong feelings with clinicians, something she had previously never done. Findings from this case study led to providing support for the participant within the school setting such as being provided with self-management sheet, a clear list of classroom rules, and positive reinforcement (Frasier et al., 2020, p. 320-322).

Comorbidities

Individuals with autism report having social anxiety. Ludlow, A. K., Roberts, H., and Guitierrez, R. (2015) found a gap in the research literature addressing social anxiety and tactile sensation abnormalities, specifically the effect for females. The study aimed to understand autistic traits and the relationship to social anxiety and sensitivity to touch for the general population who had varied levels of autistic traits. Ludlow et al. (2015) hypothesized that the participants with a greater number of severe autistic traits would have both greater levels of social anxiety and sensitivity to touch (Ludlow et al., 2015, p. 1-2).

This study used 173 female undergraduate students from the University of Birmingham aged 18-38, with a median age of 20.31. Participants completed the Autism Quotient (AQ) questionnaire, a reliable and widely-used 50-question self-reported questionnaire, to assess autistic traits. Participants rated their behaviors in the areas of attention switching, attention to detail, imagination, communication, and social skills. The Touch Processing subscale of the Adult/Adolescent Sensory Profile (AASP) was also used in this study. This subscale measured

the severity and frequency of 13 stimuli. The third measurement, the Liebowitz Social Anxiety Scale–Self-Report (LSAS-SR), assessed the avoidance and anxiety components of social anxiety in 24 situations (Ludlow et al., 2015, p. 3).

This study found that individuals with greater social anxiety showed more adverse reactions to tactile stimuli, especially for those with a strong likelihood of avoiding social situations. This study pointed out that autistic traits may trigger the connection between social anxiety and adverse reactions to sensory stimuli. Participants who scored higher in both autistic traits and social anxiety showed more adverse responses to sensory stimuli (p. 5). Although this study found links between autism and social anxiety with abnormal reactions to tactile sensations, it did not prove that there were links to other sensory behaviors. One limitation of this study was that the authors defined "tactile sensation abnormalities" as having greater levels of sensations to sensory stimuli, including both under or over reactivity. This may not have provided a complete profile of all adverse reactions to sensory stimuli, but only subjects who demonstrated the most reactivity (Ludlow et al., 2015, p. 5).

Neurological symptom overlap exists between the eating disorder Anorexia Nervosa (AN) and Autism Spectrum Disorder (ASD), such as hyper-attention to detail; difficulties with Theory of Mind (ToM), empathy and emotional recognition; issues with anxiety, isolation, and bullying. Eating disorder symptoms are common amongst children with autism, related to food selectivity or restrictive eating patterns. Many researchers question whether ASD and AN are linked neurologically, or if starvation could lead to autistic-like symptoms: behavior rigidity, social withdrawal, and occurrence in females. In their study, Kerr-Gaffney, J., Hayward, H., Jones, E. J. H., Halls, D., Murphy, D., & Tchanturia, K. (2021) compared ASD symptoms in four

focus groups: females with acute AN, females with recovering AN, females with ASD, and a control group of typically developing peers (Kerr-Gaffney et al., 2021, p. 2)

To qualify for the study, participants were female, between the ages of 12-30, and had an average IQ greater than 85. Participants who were in the acute AN or recovering AN groups met or had met the requirements for AN according to the DSM-5. In total, there were 218 participants. Participants completed a 10-item self-reported Autism Quotient (AQ-10), and the Social Responsiveness Scale, 2nd edition (SRS-2). They also participated in an observational interview based on the Autism Diagnostic Observation Schedule-2nd edition (ADOS-2). To measure AN symptoms, participants completed the Eating Disorder Examination Questionnaire (EDE-Q) and assessed the severity of their disordered eating symptoms. They also completed the Hospital Anxiety and Depression Scale (HADS). IQ was assessed using the Wechsler Abbreviated Scales of Intelligence-Second Edition (WASI-II) [61] or the National Adult Reading Test (NART) (Kerr-Gaffney et al., 2021, p.3-4).

Generally, participants within the ASD group scored the highest in exhibiting ASD symptoms using the ADOS-2, while the typically developing group scored the lowest. The acute AN and recovery AN group were in the middle. However, in the category of restricted and repetitive behaviors, the two AN groups scored similarly to the ASD group. On the AQ-10, participants in the ASD group had the highest scores, with the acute AN and recovery AN group significantly below and the typically developing group significantly below the two AN groups. The scores from the SRS-2 were similar to the AQ-10, however the ASD group and the two AN groups showed much less differentiation specifically in the categories of social motivation and restricted interests and repetitive behaviors (Kerr-Gaffney et al., 2021, p.4-9).

Although all three clinical groups showed some similarities in autistic behaviors, it is important to note that the motivation, or function, behind the behaviors might be different. For example, one of the items in the SRS-2 asked if participants thought or talked about the same thing repeatedly. All three clinical groups may have answered yes to this question, but the subjects discussed were different. Someone with acute AN or recovering from AN may excessively talk about food, while someone with ASD may excessively talk about a special interest. Many differences were discovered through this study. More participants with ASD displayed speech abnormalities compared to the other groups. Another finding was that participants with acute AN scored higher in the category of unusual sensory interest, primarily sensory seeking behaviors, compared to participants with ASD. Another difference was social reciprocity. Participants with ASD appeared to have more difficulties with reciprocal social interactions, such as the quality of their social response, as measured by the ADOS-2 (Kerr-Gaffney et al., 2021, p.4-9).

This study had several limitations. One limitation was that only individuals with autism who had an average IQ were included. Symptoms and results of this study may have been different if the participants had an intellectual disability. Another limitation was that individuals with AN were not assessed for ASD prior to the study and vice versa. There may be some diagnostic overlap between those with ASD and those with AN. The age restriction also limited this study. AN also can occur in middle and late adulthood, but the study did not include data to reflect that. One final limitation was that participants may have used camouflaging to hide ASD symptoms during the interview or self-assessment questionnaires, which may have led to inaccurate results (Kerr-Gaffney et al., 2021, p.9-10).

Kerr-Gaffney, J. et al. (2021) concluded by stating that in clinical interviews and self-reported measures, females with autism showed characteristics similar to females with AN. Many of the same ASD symptoms were found in the acute and recovering AN groups based on the AQ-10, SRS-2, and ADOS-2 results. This could mean that starvation (acute AN) was not the only developmental disability that caused ASD symptomology (Kerr-Gaffney et al., 2021, p.10).

Lived Experiences

Milner, V., McIntosh, H., Colvert, E., & Happe, F. (2019) sought to collect various perspectives about females with autism to add to qualitative research previously published. Through their study, Milner et al. (2019) hoped to advance the current understanding of autism in females and reduce the solely male-dominated research (Milner et al., 2019, p.2389).

The U.K. study included 18 females with autism, both clinically and self-diagnosed, along with four mothers of autistic females. Participants were between the ages of 11-55 years. Data was collected from four group, seven individual, and four telephone discussions. A topic guide helped lead discussions and covered subjects such as diagnosis, the impact of autism, resilience, and coping (Milner et al., 2019, p.2390).

A thematic analysis revealed five themes from the data with multiple sub-themes. The first, fitting in with the norm, included the sub-themes friendship, motivation, conflict, and maintenance. All participants mentioned wanting friends or social contacts, but noted that making and keeping friends was difficult. Another sub theme was living in a neurotypical world. Many participants said that they found "normal" life exhausting and struggled to cope in the neurotypical world due to social communication difficulties and misunderstandings about autism by others. Gender also emerged as a sub-theme. Participants felt that as females, there was more

social pressure compared to their male peers. These social pressures appeared more significant due to autism. Females felt an increased need to mask or camouflage autistic symptoms to fit in with the norm. Some women mentioned that gender norms were foreign to them. Participants did not feel like they related well to their own gender. One mother felt that her daughter could not grasp certain concepts of femininity.

The final sub-theme under fitting in was coping strategies. Most participants needed time alone when they began feeling overwhelmed and required routines in their daily lives. Subjects shared that coping in a neurotypical world led them to mask or camouflage some of their autistic characteristics (Milner et al., 2019, p.2390-2396).

Obstacles for autistic women and girls was the second theme that included the struggle to obtain a diagnosis. Two participants had not yet received an ASD diagnosis. Many reported a negative experience with the diagnostic process. Some participants reported a sense of relief when they received a diagnosis. Another sub theme was lack of appropriate support. Multiple participants reported that they had little to no support from medical teams or their schools once they received a diagnosis (Milner et al., 2019, p.2396).

Negative aspects of autism emerged as the third sub-theme in this study. The sub-themes included: (a) *comorbid conditions*- 16 out of the 18 participants reported having comorbid conditions including anxiety, OCD, and depression. Two participants reported initially being diagnosed with a comorbid condition not autism. (b) *sensory sensitivities* were reported by many participants who mentioned feeling overwhelmed by sensory stimulation and considered it the most disabling part of life. (c) *meltdowns and shutdowns*. Many women expressed having "meltdowns," "shutdowns," or "overloads" when faced with overwhelming emotions or sensory stimulation. (d) *dependence/vulnerability*. Several women mentioned feeling vulnerable or

dependent on help from others and admitted that their feelings of vulnerability often occurred in terms of sexual relationships. (e) *feeling different*. Participants discussed that from a young age they noticed they were different from peers. They felt discouraged because of differences, but did not understand why. Many noted struggling to understand concepts like humor and small talk. (f) *additional problems*. Other issues not related to co-morbid conditions and sensory sensitivity arose from the discussions, such as poor memory, difficulty with experiencing puberty, and trouble in sexual relationships (Milner et al., 2019, p.2396-2398).

The fourth theme was The Perspective of Others. One sub theme within this was that girls could be autistic, too. Participants mentioned the need for more awareness of autism in females in our society. Misunderstandings about autism in females caused many complications for the families interviewed. Parental attitudes were noted in perspectives by mothers with autistic daughters with autism who shared personal feelings about having a child with autism. Some mentioned being concerned about what their child may achieve in life (Milner et al., 2019, p.2398-2399).

The fifth and final theme, Positive Aspects of Autism addressed the benefits of having autism. Participants felt they viewed the world from a perspective different from neurotypical peers. They benefited from having longer attention spans and good memory. Some possessed a stronger sense of empathy and were more creative. Accepting Autism and Understanding Differences was another topic participants identified where having autism did not define their life. A Strong Sense of Justice was the final sub-theme. Several participants mentioned that they felt a strong sense of justice or a strong moral compass. They recounted instances of feeling they could stand up for themselves and others (Milner et al., 2019, p.2399).

The authors noted that a better understanding of how autism presented in females could lead to improved awareness of autism in females, improvements in diagnosis, and support for girls and women. Strengths of this study included a range of topics that led to open and in-depth discussions from participant who recounted their lived experiences. The participant group represented a wide age range and varied stages of diagnosis, which led to gathering information that included multiple perspectives. The data collected was compatible with other studies completed on similar topics. Positively, females currently undiagnosed, or self-diagnosed with autism were invited to participate to make the study more inclusive (Milner et al., 2019, p.2399-2401).

While this study helped researchers gain a better understanding of the female autism experience, the sample size was small, which made it difficult to understand how race, ethnicity, or social-economic status may have affected experiences and outcomes. The findings may not represent autistic females as a whole. Two individuals self-diagnosed with autism were also included. The study was one step in the direction of inclusivity, but small compared to the number of females who received a clinical autism diagnosis. Another issue was that all participants volunteered to participate. An argument could be made that someone who volunteered for a study of this nature may cope better with their experiences and because of this, researchers may not have a representative sample of autistic females across the spectrum (Milner et al., 2019, p.2400-2401).

Mademtzi, M., Singh, P., Shic, F., & Koenig, K. (2018) acknowledged that many previous studies conducted around the experience of those with ASD were primarily male-focused. They wanted to study the perspectives and experiences of females living with ASD through the lens of their parents. Researchers aimed to understand the unique needs of females

with autism to determine what therapies, services, or activities may benefit them and their families (Mademtzi et al., 2018, p. 1301).

The parents of 40 females with ASD were interviewed. The daughters ranged in ages from four to 29 years with an average age of 15.9 years. Parents were interviewed during five separate two-hour long focus groups that included 7-10 members. Participants were asked to think about and discuss their daughters current or past struggles, such as daily living, recreation, socialization, and obtaining services and funds (Mademtzi et al., 2018, p. 1302).

Two of the authors, Singh, P., & Koenig, K, designed the questions and led the focus groups in a relaxed environment over coffee and snacks. Facilitators tried to interject as little as possible to allow a genuine conversational flow so participants shared original thoughts (Mademtzi et al., 2018, p. 1303).

Thematic analysis of field notes organized data collected from the focus groups. The focus groups led authors to see what challenges females with autism and their families encountered and the types of resources they desired. Many parents noted that their daughters had difficulty with social skills, specifically making and maintaining friendships. Parents noted occasions when their daughters were unable to continue or contribute to conversations and often found that monologuing was easier. Parents also mentioned that they often felt their daughters had no filter and difficulty recognizing emotions in others. Some parents reported that their daughters did not have any motivation to make and maintain friendships or even participate in many social interactions. Parents shared their worries related to romantic life, and said that it seemed like the daughters had a difficult time understanding men and boys. Some parents talked about their daughters being bullied, including cyber-bullying, as they got older when social and communication differences became more noticeable to peers. Parents commented on the

daughters' need for structure and routine and demonstrated rigidity and obsessions. Many were concerned with self-care and sexual life, feeling that their daughters did not care what they looked like, wore visibly dirty clothes, and had disheveled hair. Parents also shared about the girls difficulty taking care of menstrual cycles. Many noted a lack of education related to exercise, physical health, substance abuse, and sexual education. Some daughters were reported to be embarrassed by their physical appearance, the need for therapy, and having to go to a community college as they got older. Parents were greatly concerned about the lack of knowledge around concepts like menstruation, birth control, puberty, and safe sex, especially since the girls may be sexually active at some point. They worried about their daughters being exploited sexually or taken advantage of due to vulnerability, lack of social skills, and understanding (Mademtzi et al., 2018, p. 1304-1305).

It was difficult for the daughters to find or qualify for appropriate services. Parents wanted services such as driving lessons, life skills training, and vocational skills. Parents also wished there was education targeting the use of social media. They also wanted a program available to understand parental and student rights under IDEA. They shared financial concerns and barriers to receiving services such as not receiving an early diagnosis. Some felt that they had to threaten the schools with legal action to receive needed services. They noted that the most useful resources were ones related to life skills training, creative arts, technology, and physical education (Mademtzi et al., 2018, p. 1305-1306).

The findings of this study represent why it is important to understand sex difference within ASD. Some of the challenges mentioned in this study can be applicable to males as well, such as lack of social, academic, and vocational skills. The authors suggested that future research should be related to the autistic female need for education and services related to sexual

vulnerability, friendships, self-care, and difficulties receiving adequate and appropriate services (Mademtzi et al., 2018, p. 1308).

Strengths of this study included the vast information and perspectives obtained from the discussions. Study limitations included lack of demographic information and a broad age range. Another limitation was the possibility that conversations were dominated by a few individuals in the discussion groups, skewing an accurate picture of the group as a whole. Because of this, the authors used themes that had been noted across all focus groups (Mademtzi et al., 2018, p.1308).

Vine Foggo and Webster (2017) explored experiences with social interaction and friendship for females with autism. The study considered how this population comprehended expectations related to social interactions and friendships with neurotypical adolescent females (Vine Foggo & Webster, 2017, p.75)

The study participants were seven females on the autism spectrum between the ages 13-17 years. All females attended mainstream secondary schools and participated in general education classes over 90% of the school day. Information was collected through semi-structured interviews. Each interview contained 33 open-ended questions exploring topics related to friendship and social interactions, such as self-perceptions, definitions of friendships, activities with friends, conversation topics, conflicts, groups of friends, peer social expectations, and the emotional impact of social interactions. Interview results were compared with recurring themes and key words highlighted (Vine Foggo & Webster, 2017, p.76).

Two primary themes emerged: the importance and difficulty with social interactions. Six participants noted that it was important to have friends. They explained that having friends made them feel happy and supported. Many noted feeling a sense of belonging when they were around friends. Participants described a friend as someone who offered trust, support, and respect.

Additional friend definitions included someone who was nice, considerate, who offered emotional support, and someone who would stand beside you in times of trouble. Six of the seven participants stated that they had a best friend and the other was unsure if she had a best friend or not. When describing the difference between a friend and a best friend, participants used the phrase "each other" frequently (supporting each other, listening to each other) which suggested reciprocity within the friendship. Many participants noted that activities with friends were largely unstructured, such as shopping, watching a movie, or having a sleepover (Vine Foggo & Webster, 2017, p.78-80).

The second theme was that friendships and social interactions were difficult. Conflict and disagreements were specifically noted. Participants discussed themes such as not getting along with peers, not knowing how to maintain friendships, and not knowing how to react in certain social situations. All seven participants mentioned that a conflict had caused the ending of a friendship. All but one participant claimed that they felt lonely and had gone through periods where they felt like they had no friends. Four participants shared that they felt like peers perceived them negatively due to their sometimes abnormal behavior. While participants noted finding social interactions difficult, they said that spending time alone would help them de-stress (Vine Foggo & Webster, 2017, p. 80).

The findings suggested that participants had a realistic view of friendships, with friendship characteristics similar to those noted in neurotypical adolescent female friendships. Reciprocity in best friendships was a critical feature found in adolescent friendships. Overall, the participant reports were generally positive (Vine Foggo & Webster, 2017, p.81).

Limitations for this study included a small sample size. Authors noted that it was difficult to find participants who fit the necessary criteria of having ASD and being enrolled in inclusive

classes. This study also did not obtain data from the peer perspective, so there was no way to judge bias or information accuracy. The final limitation questioned the validity of information from participants. Since all but one participant wrote or typed answers from home, there was no way to guarantee that parental influence did not skew the data (Vine Foggo & Webster, 2017, p.83).

Little research has studied the impact of puberty in females with ASD and an intellectual disability or who have limited verbal capability. Cummins, C., Pellicano, E., & Crane, L. (2018) explored the experience of puberty for adolescent females with ASD who also had an intellectual disability and were minimally verbal through interviews with parents and teachers. The study also aimed to target concerns the individuals had prior to the onset of puberty and to create effective ways to assist the girls, their families, and educators (Cummins et al., 2018, p.2440).

Study participants in the study included 10 parents, nine mothers and one father, and 10 educators who worked with the targeted population. The parents had a minimally verbal autistic daughter with an intellectual disability currently experiencing puberty. Two separate interview schedules were created for each group. All interviews had a similar structure being semi-structured with four open-ended questions and a number of probing or prompt questions. The data collected from the interviews was analyzed using thematic analysis (Cummins et al., 2018, 2440-2441).

Three major themes arose throughout the interview process: individual experience and needs, the importance of dignity and respect, and ways to better support the girls through puberty. A clear emphasis on the variety of needs each girl had being able to cope and manage puberty was noted. Some families shared that their daughters were fairly independent in managing menstrual hygiene and some reported that their daughters were at an exploratory stage

and needed assistance putting on a pad and wiping. Some participants reported that the girls were not bothered by their periods, while some reported changes in behavior and menstrual pain. Educators and parents discussed varied degrees of difficulty teaching about puberty due to varying levels of understanding. Some parents noted positive puberty understanding, such as healthy development and the excitement of being a "big girl" now. Another parent reported that her daughter being a rigid learner and thinker, made it easy to teach exactly how to care for herself because she will do it the exact same way. Some parents showed concerns about being unable to properly communicate the intensity of possible menstrual pain (Cummins et al., 2018, p. 2441-2442).

Promoting dignity and respect was another item interviewees emphasized. Parents stated that some skills were important to have, like shaving, or putting on deodorant, but that they really wanted their daughters to become independent in more personal and intimate skills, like menstrual care. Parents and educators raised questions about the most appropriate ways to teach and speak about puberty. Educators felt that it was important to start teaching these skills as early as possible, because it may take this population a long time to learn new skills. Some interviewees expressed concerns about educators involved in discussions related to puberty with their daughters, specifically around the area of masturbation. Many parents emphasized that they wanted consent teaching at home and at school and were concerned that educators may teach the daughters something different. The girls vulnerability was also a significant concern. Parents worried about allowing people outside of the family, such as teachers, paraprofessionals, personal care workers, or extended family to provide one-on-one assistance with toileting and menstrual care. In response to the concerns, educators emphasized the need to teach these girls about consent and the right to say "no" (Cummins et al., 2018, p.2442-2443).

The final theme was to support girls during puberty. Parents and educators mentioned that they taught the skills slowly and gradually. One parent shared that the first skill she taught her daughter was to accept a sanitary pad when it was handed to her and built on the skill from there. Educators estimated that it takes teaching the skills on average 18 months. Parents estimated that it would take their daughters longer to learn. Interviewees mentioned helpful resources for teaching the girls about puberty included social stories, visual strips, life sized dolls, calendars, and vibrating watches. Parents spoke positively about the school and educators who worked with their daughters. They noted they had been helpful in teaching their daughters to care for themselves and provided additional resources, such as social stories and visuals (Cummins et al., 2018, 2443-2444).

A limitation was that the study did not capture the perspective or experience of the girls who were the focus. Cummins et al. (2018) had intended to interview the girls using pre-teaching around the interview along with visual cue cards, but only four parents consented to their daughters being interviewed. Interviewers still performed interviews with those for girls, but determined that the data was insufficient and was not included in the study. Researchers may try to conduct a similar study when they collect an adequate number of participants (Cummins et al., 2018, p.2446).

Late Diagnosis

Bargiela, S., Steward, R., & Mandy, W. (2016) explored the autism phenotype in females diagnosed with autism in late adolescence or early adulthood (p. 3281). The 14 female participants without intellectual disabilities were between 18 and 35 years and diagnosed with Autism Spectrum Condition (ASC) by a certified professional in the United Kingdom after age 15 (Bargiela et al., 2016, p.3283).

Several measures were used to collect data, including semi-structured interviews, the Autism Quotient-10 (AQ-10), the General Health Questionnaire-12 (GHQ-12), The Hospital Anxiety and Depression Scale (HADS), and the Wechsler Test for Adult Reading (WTAR) (p. 3284). Topics covered in the semi-structured interviews included having the participants share their diagnosis story or how they felt gender impacted an autism diagnosis, interests, social relationships, sensory experiences, and mental health. Participants were also asked about any gender differences they noticed in ASC. The AQ-10, a ten-item self-report, confirmed the clinical diagnosis and measured ASC severity. The GHQ-12, a 12-item screening device, assessed participants' mental state. The HADS, a 14-item self-assessment scale, detected depression and anxiety over a one-week period. The WTAR provided a valid and low intensity estimate of intelligence (Bargiela et al., 2016, p. 3284).

The average HADS-A (anxiety) score was 13.5, meaning that participants were clinically distressed in the area of anxiety. The average HADS-D (depression) score was 5.3, which signified participants not clinically depressed. The average GHQ-12 score was 15.4, below the cut-off that indicated a mental disorder. Three participants scored in the range of “distress” and two participants scored in the range of “severe” (Bargiela et al., 2016, p.3285).

Four themes arose from the semi-structured interviews including that participants informed that they were not autistic, participants who pretended to be normal, participants who moved from passivity to being assertiveness, and participants who tried to identify as a woman with ASC. Being told that she was not autistic related to a young woman whose results identified a mental health disorder, such as anxiety, depression, and eating disorders. The theme of pretending to be normal found that most of the women reported that their teachers had not noticed their differences, but their peers had, which led to attempts to try to fit in. Participant

changes from being passive to being assertive were related to multiple accounts of victimization. The victimization was related to passivity. Participants described how their passivity led to unhealthy relationships and trying to avoid conflict. Nine of the 14 participants reported incidences of sexual abuse. Four participants reported that after their ASC diagnosis, they felt more assertive, noting that the diagnosis gave them a sense of confidence. Finally, the theme of discovering an identity as a woman with ASC related to traditional gender stereotypes and navigating friendships (Bargiela et al., 2016, p. 3285-3289).

The authors felt that this study emphasized the need to understand why females with ASC were diagnosed later than males. A few considerations need to be made to improve female early identification. First, the female autism phenotype should include camouflaging so it can be understood and further studied. Second, ASC training about the female autism phenotype for health care workers and educators should be investigated. Lastly, the findings noted that females with ASC were more likely to be sexually abused, which should lead to immediate action (Bargiela et al., 2016, p.3292).

Though the sample size was small, the accuracy of obtaining real experiences from females with autism through semi-structured interviews was a strength in this study. If the evaluation had been completed through a survey or questionnaire, researchers may not have identified themes that appeared for each participant, nor would they have been analyzed. The researchers also stated that to their knowledge this was the first study to specifically address the experience of late-diagnosed ASC in females (Bargiela et al., 2016, p. 3291).

Little is known about the experience of women diagnosed with autism at a later age. In their study, Leedham, A., Thompson, A. R., Smith, R., & Freeth, M. (2020) examined the lived experiences of female adults diagnosed with autism in middle to late adulthood. Participants in

this study included 11 females who were diagnosed with autism over the age of 40 years. Semi-structured interviews were conducted with each interview lasting between 35 and 95 minutes.. The interviews were transcribed verbatim along with notes from the interviewers detailing the participants' personal thoughts, emotions, and non-verbal body language. Data was analyzed using Interpretative Phenomenological Analysis (IPA). IPA provided a subjective look at the lived experiences and personal interpretations of the experiences from participants (Leedham et al., 2020, p.136-137).

Four themes appeared through data analysis. The first theme, *a hidden condition*, alluded to the fact that autism was usually hidden in females through the use of masking as they learned to adjust to the norms of the world around them. Participants noted efforts to fit in, many failed social interactions, and feeling the need to hide their true selves. Many participants also mentioned struggles with mental health throughout their lives, including being mislabeled or misdiagnosed, struggling to be understood by doctors, and not receiving proper support. These factors lead the participants to continue feeling confused about their identity, as if they were defective, or having a devalued sense of self. The second theme was *the process of acceptance*. Many participants recalled the assessment process that led to their autism diagnosis. They remembered various feelings from sadness, confusion, and anxiety, to relief and elation and stated that after the autism diagnosis, they viewed life through a new lens. There was finally an explanation as to why they felt different from others all their lives. They stated a new and different self-understanding related to the social world around them. Participants also felt a sense of grief, anger, or sadness for their past selves who had not received an autism diagnosis and needed support. They felt they missed out on life by trying to change who they were to fit into

the world around them, instead of discovering their true identity (Leedham et al., 2020, p. 138-140).

The third theme, *the impact of others post diagnosis*, explored the impact of the ASD diagnosis on those around them. Some participants were eager to share their diagnosis with loved ones, while others waited to share until they felt more comfortable. Positive experiences about sharing the diagnosis included feeling accepted and understood. Some recounted feeling as if their loved ones dismissed the diagnosis which led to a fear of continuing to disclose with others. The fourth and final theme was *having a new identity-being on the autism spectrum*-which detailed how the participants felt that their lives had changed after diagnosis. Some reported ending relationships that no longer supported them including friendships and romantic relationships. Participants felt good about the decisions and credited the newfound confidence to the autism diagnosis. They felt more free to be themselves, rather than masking the symptoms to meet others' expectations of who they should be. Others had mental health issues, such as anxiety, and acknowledged that it would be a continuing part of their lives. However, many stated that they now felt like they had permission to cope in a way that met their needs, rather than conforming to what was expected of them (Leedham et al., 2020, p.140-142).

Overall, this study reinforced the continued misunderstandings of autism in females, leading to missed and late diagnoses. Participants felt powerless, anxious, and depressed before the diagnosis. Leedham, A. et al. (2020) stated that an earlier diagnosis could alleviate these feelings in females with autism. One problem with this study was that participants were diagnosed with autism at different times in their life, some within the last few months, and some nine years ago. This could have skewed the interview data due to varied acceptance levels of the ASD diagnosis (Leedham et al., 2020, p.144-145).

Chapter III Discussion and Conclusion

Summary

Autism spectrum disorder is proven to manifest differently in females compared to their male counterparts, yet many of the criteria for an autism diagnosis is still based on studies completed primarily on autistic males, leaving autistic females at risk for receiving a diagnosis later than their male counterparts. Many autistic females camouflage their symptoms in order to appear typical and blend in with their peers, which can also lead to not receiving a timely diagnosis.

Professional Application

Throughout my research I feel like I gained a nearly-full picture of how autism presents in females. This full view of autism will be beneficial as I move forward in my career as a teacher for students on the autism spectrum. One of the bigger takeaways from my research is the effects of camouflaging. So many females will receive a late diagnosis due to their camouflaging behaviors, which can lead to comorbid diagnoses, such as anxiety, depression, or eating disorders. As a special educator, it is vital to notice if a female may be hiding her symptoms in an attempt to fit in with peers. A female may seem shy but truly not know how to interact with those around her. A female who seems quirky or odd, may struggle to understand social norms. A female who struggles with anxiety could be overwhelmed by social interactions and scenarios or be overwhelmed by sensory stimuli. All these factors are a form of camouflaging and should be considered when evaluating a female student for special education services.

The study that impacted my sense as a special educator was Cummins et al. (2018) study that interviewed parents of females with autism who also had an intellectual disability and encompassed themes such as the onset of puberty. Many of the parents in this study recounted times when they were concerned about how their daughters would experience puberty. They felt like services or resources in this area did not exist or were inaccessible. Some noted that they felt it could take their daughters years to learn skills around self-care and personal hygiene management related to menstruation. Many were also concerned about their daughters' vulnerability since many of their daughters relied heavily on many different people, including parents, older siblings, extended family members, personal care attendants, and school staff, to provide or oversee some or all of these personal hygiene tasks. Mademtzi et al.(2018) also referenced in their study that many parents had concerns about their daughters' vulnerability in the area of taking care of their personal hygiene. This article touched me so much because this is the population I work with, and I share the same concerns as the parents. After reading this article, I was moved to be a part of the change in order to give my students a service they desperately need. I am currently working to create some video models around the topics of menstruation and am hoping to petition to create a health class targeted towards students with intellectual disabilities within the next few school years, which would include writing curriculum for this class, as I assume it does not currently exist or is not widely available.

In the realm of education, all special educators will encounter females with autism throughout their career. It is important to know how autism presents in females and how female autism differs from male autism. Autism can impact all areas of a female's life including behavior, emotions, communication, executive functioning, social skills, friendships and relationships, and mental health. Females with autism perceive the world differently than males

with autism. Behavior strategies, curriculum, and other supports that work for males with autism, may not benefit females with autism. The Girls Night Out (GNO) social skills curriculum presented by Jamison & Schuttler (2016) is specifically designed for adolescent females with ASD with the objective to improve social-emotional health in this population. GNO is designed to target areas such as self-care, relating to others, and self-determination. More curriculum like GNO, that is specifically designed for the targeted female population should exist and be widely used.

Limitations of the Research

One of the most noted limitations throughout the research included small participant groups. Many researchers noted that because of small sample sizes, the conclusions and findings within these studies could not be generalized to the entire female ASD population. Vine Foggo and Webster, 2017 noted in their study that it was difficult to find participants who fit all the necessary criteria for the study, which included having ASD and being in inclusive classes. McFayden et al. (2018) noted that a larger participant group would have been more beneficial in collecting additional data.

Another common limitation throughout the research was regarding the validity of the information or data obtained by researchers. Due to the nature of many of the studies found in this literature review, most of the data was qualitative, told from personal experiences, or collected from individuals with autism who may not have a clear perspective of the experiences as observed by others. Vine Foggo & Webster (2017) questioned the validity of information they received from participants. Since all but one participant in the study wrote or typed answers from home, there was no way to guarantee that parental influence did not skew the data. Kerr-Gaffney et al. (2021) was concerned that participants within the study may have been camouflaging ASD

symptoms during the interview or self-assessment questionnaires, which may have yielded inaccurate results. Myles et al. (2019) noted that the participants may have intentionally provided inaccurate information to appear as if they had more friends or that they misunderstood peer actions. Loomes et al (2017) suspected skewed results in their study because the female participants were either misdiagnosed or diagnosed later than males with autism and suggested that this could be a possible cause as to why there is a low prevalence rate of females to males with autism.

Another common limitation in the research was lack of data including females with an intellectual disability. The study conducted by Cummins et al. (2018) was one of the few that represented autistic females who also had an intellectual ability. A fault within this study though was that it did not capture the voices of those girls, but instead the experience of their parents related to the topic of puberty in the girls. Cummins et al. (2018) stated that they intended to interview the girls in this study, but did not receive enough parental support or consent to conduct these interviews and were hopeful that this would be a possibility in future studies (2446.)

Implications for Future Research

A common theme in much of the research in this area was the development of the female autism phenotype. Bargiela et al. (2016) noted that camouflaging should be included in the female autism phenotype. They also noted that there should be more training on the female autism phenotype for health care workers and educators. Loomes et al. (2017) stated that increased knowledge of the female autism phenotype would decrease the possibility of diagnostic bias (472).

Hull, L., Petrides, K. V., & Mandy, W. (2020) suggested that more research should be conducted around the area of camouflaging since it is so prevalent in females with autism. They noted that most current research on camouflaging has been completed with either adults or children, but it is believed that camouflaging occurs and develops over the lifespan and that researchers should consider this. Hull et al. (2020) also noted that most current research uses a binary approach to gender, comparing males to females. While this concept works for developing the female autism phenotype, it neglects the minority of the autistic population that identifies as non-binary or gender fluid. They also suggested that future research into camouflaging should consider that an autistic individual's reasoning or motivations behind camouflaging can vary across the lifespan and across various situations. They implored future researchers to not generalize camouflaging behaviors as a positive or negative behavioral trait, but instead, look at camouflaging at the individual level for each client to determine if it is a helpful or harmful behavior.

Other researchers insisted on data that would be beneficial and provide knowledge in areas that are currently lacking for the female ASD population. Mademetzi et al. (2018) contended that future research needs to be done in the areas of providing education and services related to sexual vulnerability, friendships, self-care, and difficulties receiving adequate and appropriate services (p. 1308).

Conclusion

The intent of my research was to gain a broader understanding of what it was like to be a female with autism. The findings throughout this literature review reflect the need to understand sex differences in ASD. While this literature review covers a broad range of topics related to the

female autism experience, it is important to note that much of the information in this literature review cannot be generalized to all females with autism.

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