

THESIS

IMPLICATIONS OF LATE AUTISM SPECTRUM DISORDER DIAGNOSIS FOR FEMALES

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## ABSTRACT

### IMPLICATIONS OF LATE AUTISM SPECTRUM DISORDER DIAGNOSIS FOR FEMALES

The purpose of this qualitative case study is to examine the implications of the timing of an Autism Spectrum Disorder (ASD) diagnosis for females, specifically its impact on psychological well-being. While it is well-known that females are less likely to be identified at young ages than their male counterparts, we know relatively little about the experiences or service needs of women with Autism Spectrum Disorder (ASD) who are identified later in life. Five women, ages 22 to 46 years who received a formal diagnosis after the age of 12 years, participated in an in-depth interview with a clinician focused on the impacts of a late Autism Spectrum Disorder diagnosis and the participants' overall well-being. Participants also completed a standardized self-report measure of psychological well-being. Participants then partook in a semi-structured interview to share their experiences of being a female with ASD. Responses from the questionnaires were summarized to provide a baseline understanding of participants' well-being while the semi-structured interview was analyzed to find themes in participant experiences. This qualitative case study includes a small number of participants, but we learned about the potential impacts of late diagnosis for females and their self-report of overall well-being. Both of which has implications for both research and practice.

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## Introduction

### Overview of ASD

Autism Spectrum Disorder (ASD) is a complex neurodevelopmental disorder that is characterized by impairments in social reciprocity and social communication, accompanied by restricted and/or repetitive behaviors and interest (American Psychiatric Association, 2022). See Table 1 for a brief summary of the diagnostic criteria.

*Table 1: DSM Diagnostic Criteria for ASD (APA, 2022)*

**TABLE 1:**

<b>DEFICITS IN SOCIAL COMMUNICATION AND INTERACTIONS:</b>	Limited interest in communication	Difficulties in back-and-forth communications	Deficits in understanding nonverbal communication and lack of eye contact	Difficulties in navigating and establishing relationships
<b>RESTRICTED, REPETITIVE PATTERNS OF BEHAVIOR, INTEREST, OR ACTIVITIES:</b>	Stereotype or repetitive motor movements	Insistence on sameness or routine	Restricted and fixated interests	Hyper- or hypoactivity to sensory input

Autism Spectrum Disorder has been actively researched since the first individual, Donald Triplet, was diagnosed in 1938 by Leo Kanner. Donald exhibited repetitive interests and limited social interests. His parents' extensive recordings of his behaviors gave researchers a strong launching point into conceptualizing key features of ASD (Mason et al., 2019). Autism Spectrum Disorder has been associated with other names throughout history, such as Kanner's

syndrome and Asperger's syndrome (Wolff, 2004). Despite the difference in names, researchers began to observe and record children with characteristics such as being extremely intelligent, socially impaired, and exhibiting repetitive behaviors and interests. Kanner described children with significant communication delays and intellectual disabilities. Asperger described children who were intellectually very bright, but clumsy and less competent in daily life than would be expected from their IQs. Because these physicians recorded their observations during World War II, they didn't share their descriptions with each other – Asperger was in Nazi Germany and Kanner was in United States. Due to this separation of information, the European and American models did not converge until the 1990s. Prior to the 1990's, two thirds of children with ASD in the United States also had intellectual disabilities. After broadening the criteria to include children without a history of language delay and an IQ in average range in 1994, now less than 30% of children on spectrum have cooccurring intellectual disability (Wolff, 2004).

### **Under Identification of Females**

Historically, males have been identified more often than females and current ratios are estimated to be four males to one female (Beeger et al., 2014). Early researchers focused so much on males that they believed that ASD may not even be a disorder that affected females (Haney, 2016). This misconception about the epidemiology of this neurodevelopmental disorder has greatly underserved females who present with this pattern of impaired social reciprocity, social communication and behavioral flexibility that is now recognized as ASD.

There are several contributing factors in current research that may explain why males have been diagnosed more readily. The initial factor is that research has been primarily conducted on males (Tillman et al., 2018). Early research focused so much on males there is no early record of a differing presentation in females. A second potential factor is that diagnostic

instruments and screening tools used to detect ASD have been developed primarily from predominately male samples (Navarro-Pardo et al., 2021). Third, and perhaps most clinically relevant, females may actually show different symptoms or experience a different onset or developmental course of symptoms (Mandy et al., 2018).

How the presentation of ASD varies between males and females remains a relevant research question. There are shared characteristics in the presentation of the disorder between males and females, but there are also some notable differences. Shared features are reported for females and males with co-occurring intellectual disability, while differences in symptoms are more often reported in verbally fluent and intellectual competent females (Carter et al., 2007). For example, females with ASD with intact intellectual functioning often appear to have better social relating skills than males with ASD who are matched by intellectual potential (Haney, 2016). Due to this relative strength, females are more likely to receive other diagnoses (such as attention deficit disorder or social anxiety disorder) instead of ASD, even if they present with other characteristics of ASD. Females often exhibit fewer repetitive behaviors and restricted interests than males and show a greater interest in social interactions (Mandy et al., 2018). Even with this enhanced social interest, females with ASD show limited social reciprocity and less understanding of social and emotional concepts than typically developing individuals. Males' externalizing symptoms are often greater than females' externalizing symptoms, and due to this males are more likely to receive a diagnosis (Werling & Geschwind, 2013). This is important to consider because if an individual's symptoms don't appear extreme outwardly, that does not mean that the individual is not feeling distress internally.

The combination of fewer repetitive behaviors and greater motivation for social interactions is often considered "camouflaging" and can be a clear indicator of ASD in females

(Young et al., 2018). The camouflage makes the ASD less obvious but does not mean that the difficulties are not still present. Due to females' greater interest in social interactions, they may develop skills, knowingly or not, that allow them to mask their autism. Examples of camouflaging include copying facial expressions, maintaining eye contact, and repressing the desire to talk about specific interests (Hull et al., 2020). While this adaptation may allow females to present as more socially responsive and engaging than many of their male counterparts, it does not diminish the extra effort that an individual is expending to fit into a neurotypical world. ASD is a spectrum disorder, which means that every individual will have different strengths and weaknesses, while sharing a common set of general characteristics. However, for many females their considered strengths have been used against them as exclusionary criteria for a diagnosis, thus invalidating real challenges in spontaneous social interactions, emotion regulation, and cognitive flexibility.

### **Implications of Under Identification**

There are many implications of under-identification of ASD. Females are less likely to be referred to services for diagnosis, treatment, or support, possibly because they are less likely to be identified prior to entering elementary school (Haney, 2016). Autism spectrum disorder is usually diagnosed in childhood and there is an emphasis on early interventions to promote development in social interactions, communications, play and flexibility. Research has found that the mean age of diagnosis of ASD is between 38 and 120 months (van 't Hof et. al., 2020). There is a recognized understanding that early intervention/treatment can support individuals more in areas such as language and cognitive abilities (van 't Hof et al., 2020). The meta-analysis conducted by van 't Hof and researchers indicated that globally, ASD is diagnosed and recognized at an early age. Furthermore, they showed that early diagnosis is recognized as

important for supporting individuals globally. Other significant findings of this meta-analysis showed that individuals who are “high functioning” (i.e., intellectually capable) tend to be identified at a later age than those with co-occurring intellectual disabilities. Majority of the studies reviewed showed there was not a significant age difference between boys and girls, however; five of the studies reviewed did show that girls were diagnosed at a later age than boys (van ‘t Hof et al., 2020). The later age of diagnosis is likely due to girls not presenting their autistic symptomology in the same way as boys. Females are often not timely diagnosed and suffer direct consequences, including impacts to their psychological well-being. Due to a lack of identification, individuals may not receive as much support as they could with a diagnosis. These interventions often focus on positive supports that decrease distress related to anxiety or depression. In addition, without the social supports such as interventions that teach individuals how to be social, females may be at higher risk for unsafe relationships. Lack of identification has strong negative implications because it decreases individual’s access to crucial interventions at time points in which they are the most helpful.

### **Psychological Well-Being**

A potential consequence of under-identification is an adverse impact on the overall well-being of individuals with ASD. The construct of “well-being” is often contextualized as psychological well-being. This is defined as overall life satisfaction and mental health (An & Cooney, 2016). Neurodivergent individuals that have developed in a society that has been largely constructed for neurotypical individuals can experience higher levels of distress that can be contributed to difficulties understanding nonverbal behaviors, social conventions and a lack of intuition in social settings. It is possible that well-being can be further impacted for females who have delayed access to evaluations for ASD symptoms and have had little support or awareness

of how a diagnosis can support well-being. There is extensive research around psychological well-being for the general population following the development of Carol Ryff's Psychological Well-Being scale (Ryff et al., 2007). However, the research is limited in understanding how a diagnosis can impact impacted perceived well-being, nonetheless the timing of a diagnosis.

Additionally, there is an abundance of research on mental health and well-being for parents of children with ASD. Many studies have found that parents of children with ASD experience higher levels of stress and report more depressive and anxious symptoms than parents of typically developing children (Lai et al., 2015). Studies have indicated that when raising a child with a disability, parental well-being may be decreased (Lai et al., 2015). The research conducted has focused on parent's wellbeing, not the child with the disability. Furthermore, there is an emphasis on providing mental health support for caregivers because it directly impacts and supports their children (Lai et al., 2015). This study is helpful in highlighting a need for mental health support but distinguishes a clear gap of care for the individuals with the diagnosis. Caregivers certainly deserve mental health supports, but so do they children that are directly impacted by their disability. A direct intervention of proper mental health should be granted to the individuals carrying the diagnosis, not just their caregivers. Moreover, if a diagnosis has never been made, caregivers may not know seek out these resources in the first place.

There is a clear gap in research regarding how researchers and care providers should specifically support the individual with a diagnosis of ASD. Understanding how ASD impacts a specific individual across all areas of well-being (autonomy, environmental mastery, personal growth, positive relations with others, purpose in life and self-satisfaction) can provide clearer directions for interventions and support for individuals with a diagnosis of ASD. It highly

decreases the guesswork in creating positive change by directly targeting what care individuals need.

This study adds to the literature by precisely identifying the potential consequences of untimely diagnosis of ASD for females. Due to the minimal amount of research that exists for females with ASD it is unknown which areas of study would be most impactful. This qualitative case study informs researchers on the most prevalent themes and experiences women with late diagnosed ASD have reported.

## **Methods**

### **Participants**

Five adult women (i.e., over the age of 20 years) who received a formal diagnosis of ASD after the age of 12 years were recruited from the Participant Database of the Neurodiversity Lab at Colorado State University and completed this interview study. All participants previously provided informed consent to be contacted for future studies to the Neurodiversity Lab PI. All participants previously completed an IRB-approved battery of developmental and behavioral measures that were administered by a licensed clinical psychologist or under her supervision. ASD diagnoses were confirmed via the Autism Diagnostic Observation Schedule-2 and the Social Responsiveness Scale and through inter-observer reliability on a DSM-V symptom checklist (Lord et al., 2012; Constantino et al., 2012).

In order to partake in the study, participants had to identify as a female and be over the age of 20 years of age. Participants must have received an official diagnosis of Autism Spectrum Disorder from a licensed clinical psychologist or physician. Participants of all ages above 20 years, and of all races, ethnicity, economic circumstances, and functioning levels were invited to participate. Collecting data from the demographic questionnaire, the age range of the five participants was between 22 and 46 years of age. Four of the participants reported their ethnicity to be white, non-Hispanic with one participant reporting their ethnicity as Asian.

## Procedure

The PI of the Neurodiversity Lab at CSU (Hepburn) sent an email to potential participants to tell them about the study and invite them to participate. The email included a consent form, a psychological well-being measure, and information on potential risks and rewards of the study. The Lead Author (Tomasula Martin) then requested times the participants were able to meet and scheduled a Team's meeting for the participant and Lead Author. In addition, an undergraduate research assistant watched the interviews via videotape to assist with consensus coding. All study information was included in the initial email to avoid attrition.

Participation required no more than 3 hours total, including providing informed consent, completing one self-report questionnaire (psychological well-being), and then participating in a 1:1 interview for approximately 90 minutes with the Lead Author via videoconferencing. Participants completed the *Psychological Well Being Questionnaire* individually within a week of the interview portion of the study (Ryff et al., 2007). This measure supported the research team in understanding the baseline psychological well-being of the participants. The interview consisted of a set of questions designed by the research team to understand the impact of diagnosis on psychological well-being. However, there was room within the interview to allow the participants to elaborate or further divulge information that felt important to them. The interview was recorded and transcribed on Microsoft Teams for future data analysis. The Undergraduate Research Assistant corrected errors in the transcription manually to ensure that the transcript that was being analyzed was correct.

## Measures

Demographic Questionnaire: Participants completed a web-based demographic questionnaire during their initial involvement with the Neurodiversity Lab at Colorado State

University. This information was maintained in the lab with participant permission.

Demographics that were used for this study were age, race, and ethnicity.

The Psychological Wellbeing Scale (PWB) (Ryff et al., 2007): The PWB measured six different areas of well-being and happiness in a self-report survey. Psychological well-being was important to conceptualize because individuals who have a diagnosis of ASD may have a decrease in well-being compared to those without ASD. The six different aspects measured were autonomy, environmental mastery, personal growth, positive relations with others, purpose in life, and self-acceptance. There is a shortened format of the questionnaire, which is 18 questions, as well as the full-length questionnaire which is a 42-item questionnaire. Participants answered the full-length questionnaire. Participants answered each question using a Likert scale that ranges from one to seven. Responses were indicated following the format of 1 = strongly agree; 2 = somewhat agree; 3 = a little agree; 4 = neither agree or disagree; 5 = a little disagree; 6 = somewhat disagree; 7 = strongly disagree. There is an even split of positively worded questions and negatively worded questions with the negatively worded questions reverse scored (Abbot et. al, 2006).

The psychological wellbeing scale developed by Ryff, has a test-retest reliability coefficient of 0.82 (Baynai et. al., 2008). Within the subscales of autonomy, environmental mastery, personal growth, positive relations with others, purpose in life, and self-acceptance there were statistically significant test-retest reliability coefficients that ranged between 0.78 and 0.96 (Akin, 2008). The full 42-item measure of PWB is found to be more statistically significant than the shortened version. The PWB scale is found to have an acceptable internal consistency ranging from .93 to .86 (Ryff et al., 1989). This measure is a valid and reliable metric to assess psychological well-being when using the full-length scale.

## **Data Analysis**

The responses collected from the demographic questionnaire were summarized to describe the participants involved. No identifiable information was included, only general demographics that the participants shared including ages and ethnicity.

The psychological well-being scale was scored following the original creator's direction. Primarily, Q1, Q2, Q3, Q4, Q6, Q7, Q11, Q13, Q17, Q20, Q21, Q22, Q23, Q27, Q29, Q31, Q35, Q36, Q37, Q38, and Q40 are negatively worded items and will be reverse scored. The provided formula for reverse scoring is  $((\text{Number of scale points}) + 1) - (\text{Respondent's answer})$ . Each subscale item was totaled, and a higher score was an indicator of poorer overall well-being. The subscales with correlation items are; autonomy: Q1, Q13, Q24, Q35, Q41, Q10, and Q21, environmental mastery: Q3, Q15, Q26, Q36, Q42, Q12, and Q23, personal growth: Q5, Q17, Q28, Q37, Q2, Q14, and Q25, positive relations with others: Q7, Q18, Q30, Q38, Q4, Q16, and Q27, purpose in life: Q9, Q20, Q32, Q39, Q6, Q29, and Q33, and self-acceptance: Q11, Q22, Q34, Q40, Q8, Q19, and Q31.

The interview titled "Female Experience Interview" portion of the study was analyzed using thematic analysis and inductive coding by hand. Rather than establishing determined codes (deductive coding), inductive coding was used due to the importance of allowing participants to share what has been impactful to them. Members of the research team met after each interview was completed. The research team coded each interview to completion before moving onto the next interview. The research team found themes in the interviews and coded them as they arose.

In addition, researchers used their clinical discretion to pick out themes or similarities from participants. Consensus coding was achieved by having an additional member of the research team that was not present at the initial coding, review the themes. This supported the study in having inter-rater reliability. Interviews were done until saturation was found at five participants. On the fifth participant interview no new themes arose and the research team concluded they had met saturation.

## **Results**

### **Overview of Themes**

Throughout all five interviews similar themes were discovered as well as themes that only apply to some participants. Participants expressed several themes that they felt directly related to their late diagnosis of Autism Spectrum Disorder. These participants all have different lived experiences and backgrounds but there was a sense of commonality in what they went through or what they had a lack of due to a late diagnosis. Universal themes that were discovered included a lack of awareness of what autism spectrum disorder could look like in women, unsupported self-diagnosis, comorbidity, and misdiagnosis, feeling different than their peers, stigma of diagnosis, desiring supports earlier on (specifically social supports and support in school), and difficulty navigating boundaries and vulnerability in unhealthy relationships. Themes that were not universal but are still significant included differing opinions on timing of diagnosis, a sense of community due to diagnosis, difficulties in executive functioning, and identified strengths.

### **The Psychological Well-Being Scale**

The Psychological Well-Being (PWB) scale developed by Ryff (2007) provided a baseline number for the participants general well-being. The PWB was scored out of 294 total points with the higher scores related to higher overall well-being. Four participants completed the measure and scored 190, 216, 203, and 161. There is no global cut-off score published for the PWB by the creators, instead they recommend establishing quartiles based on the sample size

(Ryff, 2007). Due to the relatively small sample size, it does not make sense to establish higher and lower quartiles based on responses. However, some guesses can be made about the participant's well-being based on what the highest possible score could be. On average, self-acceptance and environmental mastery were rated the lowest amongst the subscales measured. Each participant had a different category that they scored the highest in which included: personal growth, positive relations with other, purpose in life, and autonomy. This questionnaire was only administered once to participants and cannot be used to compare their well-being at different points in their lives. Yet, it is beneficial to begin to contextualize well-being and how participants viewed their overall wellness at the time of the study.

### **Universal Themes**

There were four themes that arose during the interviews that each participant reported during the interviews and appeared to be a shared experience.

#### ***Lack of Awareness, Isolation, and Comorbidity/Misdiagnosis:***

The first persistent theme shared by all of the participants was a lack of awareness or understanding of autism spectrum disorder in women. None of the participants had heard of women or girls having autism spectrum disorder in their childhood. When participants were asked if they knew any women with ASD, most women could only identify Temple Grandin as a woman they knew that had autism. Participants did not know ASD could exist in women and often learned they may have ASD by themselves. Instead of having concerned adults or professionals address concerns of ASD for them, the participants in this study had to that for themselves. They learned about a diagnosis and how to get support for it in isolation. This is not unheard of or surprising, especially due to the delay in recognition or research of how ASD may be present in women. However, that does not diminish the distress the participants felt due to

lack of recognition and lack of a sense of belonging. Whether it was through teaching students with ASD or reading textbooks that depicted ASD, these women discovered the ASD diagnosis may fit their experiences completely by themselves. Participants parents and health care providers were also inflicted by this lack of understanding. Participants reported that adults in their life also did not understand that ASD could exist in women and because of this were not able to support the participants in contextualizing their symptomology as ASD.

In addition, many women were either misdiagnosed or diagnosed with additional disorders alongside ASD. ASD is known to have comorbidity with depression, anxiety, and attention deficit hyper-active disorder (ADHD) (Findon et al., 2016). Many women interviewed were diagnosed with something other than ASD primarily. Having a proper diagnosis of ASD would have supported the participants in understanding the root of their comorbid diagnosis or how to implement more helpful coping strategies that would have worked with their autism (Tint & Weiss, 2017). It is possible that if they had been diagnosed with ASD first it would not have been necessary to carry an additional diagnosis. Several participants felt that the diagnosis of anxiety or depression made sense but did not explain all of their challenges. Misdiagnosis is unfortunately not uncommon, especially for women on the spectrum. Having a diagnosis or label is not a cure or fix-all solution, but it can be an extremely helpful tool to name and contextualize impairments individuals are feeling.

### ***Feeling Different than their Peers***

A second theme that most of the participants reported was feeling different than their peers. One participant poignantly described her experience as “watching everyone through a window”. Participants wanted to be accepted by peers but never felt like they fit in with the group. Furthermore, they felt as though they couldn’t quite figure out why they felt different,

they just did. While this feeling can be normal for developing children and adolescents, for the participants of this study, this feeling did not alleviate as they got older. Participants yearned for social connections yet were unable to feel as though others wanted that connection with them. As hard as they may have tried, they had an overwhelming feeling of not belonging and not knowing what to do to feel accepted by others. This sense of disconnectedness and loneliness had a profound impact on the participants' self-identity and self-acceptance.

### ***Stigma of Diagnosis***

Many participants either heard messaging or felt that a diagnosis of ASD carried a harmful stigma. Several participants' parents did not want their adult children to have a diagnosis of ASD because they worried that people would not accept them or think differently of them. Several participants shared experiences of making lists of the ways ASD did not fit for them due to their worry of feeling different or judged by people. Stigma is a common weight that individuals with ASD carry throughout their lives. Participants heard messaging that if they had a diagnosis of ASD people would never accept them or would believe something was wrong with them. This is not accurate, but people often make rash judgments based on misconceptions they have. Fear of judgment is an extremely valid concern and can make seeking out a diagnosis hard. Which then can impact individual's access to support or care. Regardless of how the diagnosis may have supported the participants in getting more resources, participants shared that a lot of their life was spent feeling different or worried about what others may think of them.

### ***Desiring Interventions, Supports and Connection***

Participants had varying feelings about their diagnosis, yet every participant wished they had more supports than they did. ASD is a diagnosis that includes a heavy emphasis on early interventions, especially in terms of social skills. A common theme among participants was

wishing for more support in developing their social skills and their understanding of social interactions. Many women wanted to be social and have fulfilling relationships, but they felt like they had little awareness of how to be socially adept and did not have anyone to teach them. Participants also shared remarks about feeling as though school would not have been as much of a challenge if they had received supports. Participants reported often feeling that they couldn't see the big picture of what they were learning or why it mattered. When this was the case, they struggled immensely to do their schoolwork. Furthermore, they felt like their questioning to understand was seen as being defiant by teachers. Participants felt like if they had more flexibility in their learning style or understanding from teachers, they would have been able to navigate their education in a way that did not feel as overwhelming or confusing.

Participants felt that as soon as they got their diagnosis of ASD many more doors opened to them in terms of positive supports. Without their diagnosis, there was no built-in understanding or support in navigating situations that appeared to be easier for neurotypical individuals. Though the supports are perceived as helpful to the participants now, most participants remarked just how much of a difference it would have made for them to have these supports in crucial developmental periods, such as their adolescence.

***Difficulty navigating boundaries and vulnerability in risky relationships:***

A crucial theme that emerged in this study that should not be understated is the difficulties in navigating relationships and ultimately ending up in risky, unhealthy relationships. Participants reported not understanding boundaries they could have for themselves. Participants wanted to be liked and desired friendships and romantic relationships and likely had more social desire than males with ASD. Due to not feeling accepted by majority of people, participants felt like they were often taken advantage of by others. Every participant that was interviewed

reported being in at least one or more toxic relationships. These toxic relationships arose in friendships, romantic relationships, and employee/employer dynamics. Participants attributed this to not understanding when someone was taking advantage of them and not knowing that they could have firm boundaries for themselves. Personal boundaries are often nuanced and vary person to person based on individual needs. Ambiguity is not something that feels comfortable for individuals with ASD. Participants felt that they have benefitted greatly if they would had someone that could help them with developing their understanding of what appropriate treatment feels like in relationships in addition to how to recognize and respond when they are treated improperly.

### **Relevant but Nonuniversal Themes**

Throughout the interview important themes arose that applied to some of the participants but not all. Due to the importance of the themes, it is still essential to elaborate on them.

#### ***Opinion on timing of diagnosis***

All participants had differing/diverse opinions on their ASD diagnosis. Many of the participants wished they would have had an earlier diagnosis. Many of the participants wished they had an earlier diagnosis, while others felt like an early diagnosis could have been used against them. Several participants did not have safe adults in their life and reported that their diagnosis would have been used to belittle or diminish their value as individuals. These participants reported that had they received a diagnosis in childhood, it likely would have contributed to more abuse from their caregivers. Those who desired an earlier diagnosis expressed an acceptance that they could not go back in time, and an acknowledgement that their challenges earlier in life allowed them to build strength and resilience. One participant felt resoundingly that an earlier the diagnosis would have dramatically changed her life. The totality

of the participants could see the benefits of having an earlier diagnosis but many recognized that they also couldn't go back in time.

### ***Executive Functioning***

Another theme participants differed on was difficulties in executive functioning. Several participants remarked that executive function was a deficit they had felt their whole lives and felt like they had not received proper support. Executive functioning is cognitive abilities to plan ahead, complete goals and have control of one's own behaviors (Van Eylen et. al., 2015). Difficulties in executive functioning is a marker that many providers will look for in a diagnosis for ADHD and ASD. Women with ASD are often misdiagnosed or have a comorbidity of ADHD (Findon et al., 2016). When a female seeks support due to executive functioning difficulties it is not uncommon for a clinician to assume ADHD. However, executive functioning is known to be a root cause of restricted interests and repetitive behaviors, which are central components of ASD (Van Eylen et. al., 2015). A clinician should not rule out a diagnosis of ASD when a female is presenting with difficulties in executive functioning just because they are female and assume that ADHD is a more likely diagnosis. Regardless of what diagnosis the participant did or did not carry, they still felt the difficulties of executive functioning. Multiple participants remarked how helpful it would have been in having support in staying organized, accomplishing schoolwork, and planning. Knowing that these struggles are not uncommon, supports researchers in applying interventions that focus on alleviating discomfort related to executive functioning.

### ***Sense of Community***

Though difficulties in relationships and friendships was a consistent experience for the study participants, many participants remarked that once they had found a positive community that felt safe and supportive, they felt extremely connected to them. Several participants found

connections with other people with ASD or shared lived experiences after their diagnosis. They were able to find support groups or community resources for exactly what they needed or had experienced. This sense of community was not something they had felt prior to diagnosis. In addition, many participants felt that even though they had had some difficult experiences with negative relationships, they had gotten to a place where they felt very positively about the people in their lives. Some credited this to being able to communicate their needs due to ASD and have people in their life understand them. This feeling of belonging did not occur for all participants, especially for those with a newer diagnosis. In addition, some participants felt like they had found supportive people before their diagnosis was present.

### ***Identified Strengths***

The last nonuniversal theme that emerged for participants was their self-identified strengths. Even through the felt stigma and hardships the participants reported, they were able to recognize their true strengths and abilities. All of the women interviewed are extraordinary, capable people and while their diagnosis may impact them in diverse ways it also empowers them. Many see their abilities to connect with people, advocate for others, and diverse perspective taking as skills they would not have without ASD.

## **Discussion**

This qualitative case study successfully identified themes in the experiences of females with late diagnosed Autism Spectrum Disorder. While the timing of diagnosis was important, it was important in different ways than expected. It was expected that needing a diagnosis in a timely manner would be more central to the study. It is not surprising that many participants had never heard of ASD in their childhoods. Nor is it unexpected that this lack of awareness or knowledge, to no fault of their own, impacted their lives. It is difficult to know how to cope or work with a diagnosis that an individual does not know exists. A majority of the participants would have wanted an early diagnosis to qualify for supports/interventions and to have reasoning behind why they felt different than their peers. Retrospectively though, participants reported a gratitude to their late diagnosis by identifying resilience in themselves and recognizing that stigma might have negatively impacted them in their early life if they had been diagnosed sooner. Participants reported greater mental health challenges and greater comorbidity due to not knowing what ASD was and how it may be impacting them. In addition, participants also reported unhealthy relationships and experiences with manipulation. Due to ASD being characterized by social difficulties and these participants never receiving interventions for social support, it makes sense these individuals felt like they did not have the tools to keep themselves safe or to build relationships with safe individuals across their lives (American Psychiatric Association, 2022).

While this study did provide evidence of a potentially adverse consequences of late diagnosis, it was also informative about providing specific ideas about which services should be developed. The overlap in experiences, despite participants being from different backgrounds emphasized the need for specific attention in areas such as relationships, interventions, acceptance, and understanding. An initial area where services should be developed is in relationships. Risk in relationships and prevention skills is not a groundbreaking idea and is applied in a multitude of relationship dynamics. There is no reason for this gap in knowledge to continue and because of the severity of implications it could cause, for example, risk for interpersonal violence and abuse. Secondly, this case study found that all participants had wished they had more support for social skills and school-based interventions during adolescences. Participants indicated that have a social skills group would have made a large difference in learning techniques to interact with peers as well as having social support built into the group setting. Likely due to lack of a diagnosis at all, many participants didn't have accommodations like an individualized education plan.

### **Limitations**

The participant sample of the present qualitative case study was diverse in terms of age and lived experience; however, a limitation of this study was a lack of diversity in ethnicity due to the geographic location. A majority of the participants identified as Caucasian. In addition, all the participants are currently living in northern Colorado area. The study did accomplish saturation in themes, but it was a small sample size, nonetheless. Participants were all recruited from the same diagnostic service. Due to this, participants were easily accessible and motivated to be a part of the study. To achieve greater generalizability more participants from a wider geographic region would need to participate in the study.

A crucial element of this study was learning from participants of their own experiences. Self-reported data and responses were what made this study what it is. Yet, it is still important to recognize that self-report only allowed for one perspective on any given situation. There is potential for bias or inaccurate perspectives, but it likely does not outweigh the valuable information that was learned from the participants being able to share their own experiences freely. In addition, all participants were verbally fluent, and eighty percent of the sample had average or above average intellectual quotients. There are many individuals who may not fit these parameters but whose experiences are just as important but not represented.

### **Future Research**

As stated previously, ASD in females is an extremely under researched and underserved group of individuals. There is a great need for more awareness of how autism spectrum disorder presents in females and how to accurately diagnosis and support girls and women. This study solidified important themes for women with ASD that serve as launching point for future research. There needs to be more research explaining and supporting differences in symptom onset, timing and lived experiences of females and males with ASD. Females should not have to continue to learn about their diagnosis unsupported and in isolation. This requires more research and education that health care providers can use to provide more informed diagnosis and care. Women should not be misdiagnosed based on outdated and limited understanding. An additional impactful area for research to be continued in is supports specifically for girls and women and the implication of vulnerability in their relationships due to autism spectrum disorder. Lastly, future research should focus on how supports can be better implemented and catered towards females with ASD. Similar interventions as their male peers may be sufficient, however, research should be conducted to be sure.

## **Conclusion**

This qualitative case study explored salient themes for late diagnosis for females with Autism Spectrum Disorder. Themes that were clearly identified included lack of awareness of what autism spectrum disorder could look like in women, unsupported self-diagnosis, comorbidity, misdiagnosis, feeling different than their peers, stigma of diagnosis, desiring supports earlier on, difficulty navigating boundaries and vulnerability in risky relationships, opinions on timing of diagnosis, a sense of community due to diagnosis, difficulties in executive functioning, and identified strengths. These themes indicated important areas for future research and practice. Lack of awareness or understanding is no longer a viable excuse for females with ASD to be neglected in terms of research or care. This case study allowed the people it is about to educate researchers on what they can be understanding better, particularly as they work to improve diagnostic and intervention services for people who live with this challenging and complex neurodevelopmental disorder. This qualitative case study is unlike any other in the current literature and greatly adds to perspective on Autism Spectrum Disorder for females.

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