IMPLICATIONS OF CAMOUFLAGE ON THE DELAYED DIAGNOSIS OF AUTISM SPECTRUM DISORDER (ASD) IN WOMEN

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Introduction

Camouflaging is a trait that many Autism Spectrum Disorder (ASD) individuals, regardless of sex or gender, utilize to adapt to social situations and mask their autistic traits to fit in better with others.[1] Learned skills such as copying others' behaviors, masking, or hiding personality[2] and ignoring discomfort engaging in these behaviors to convey 'normalcy'[3] make up some of the different processes that occur as a part of camouflaging. Research indicates camouflage plays a significant role in delayed diagnosis of ASD in girls, aged 0 to 17 years, and women, aged 18 years and older. Of those diagnosed with ASD, women are much more likely than men to be misdiagnosed or receive a delayed diagnosis.[4-10] In fact, there is an estimated 3:1 ratio in boys diagnosed with ASD to girls diagnosed with ASD[4,5,8] and lessening gaps with increased age.[5,8] Most ASD research focuses on participant populations that are younger than 18 years of age.[4] For women who do receive a diagnosis, it occurs, on average, 10 years in age later than for boys and men.[6] The gender gap in ASD diagnosis creates the problem of women going longer without a proper diagnosis and the corresponding support and treatment. Many possible reasons for this gender discrepancy are explored within the literature; consensus suggests a misunderstanding of the female presentation of Autism and the prevalence of camouflage in ASD women. The current diagnostic process utilizes the male phenotype of ASD, indicating that a comprehensive female phenotype is needed to better assess ASD in girls and women. This review investigates how camouflage works to delay ASD diagnosis in girls and women via its appearance in the female experience of ASD and the implications for quality of life and in treatment.

The Female Experience of Autism Spectrum Disorder

Literature on ASD attempts to understand how the female experience of autism relates to the gender gap of ASD prevalence. Research suggests that girls undergo different socialization processes than men, causing gender differences in ASD presentation.[2,3,6,7,9] The spectrum nature of autism does create difficulty in understanding specific differences of presentation between men and women; however, there have been some established trends that aim to explain gender differences and their origins.

One such explanation involves the pressures of societal gender roles. Gender expectations of women are incredibly varied; however, some include friendliness and sociability, empathy, non-disruptive behaviors, helpfulness, etc. In many instances, expectations of the role of women in society do not coincide with the ASD experience.[2,3] For instance, the role of the nurturing caretaker may be difficult for women with ASD who have trouble with social communication or relating with others. Compared to boys, girls with ASD seem to place a greater importance on friendships and social communication, even if it is difficult for them to do so.[2,3,6-10] Evans et al[1] performed an analysis of current ASD assessment tools and found that, with regards to social communication and interaction (SCI), girls had higher SCI deficits than boys, which is seemingly counterintuitive to other findings that girls are more interested in social communication. However, Evans et al[1] utilize

passive case ascertainment methods, which involve recruiting participants who have already received an ASD diagnosis. Thus, Evans et al[1] only account for children already diagnosed with ASD and do not attempt to study SCI deficits in undiagnosed boys and girls. In contrast, active case ascertainment methods involve participants who may not necessarily have an ASD diagnosis, which is more useful for studying undiagnosed children.[9]

Evans et al's[1] findings also reflect consensus within ASD literature that girls must exhibit stronger deficits to obtain the same diagnosis of ASD as boys.[1,2,4-6,10] Further reinforcing this point, Evans et al[1] also state that physicians should not place judgement on a female patient's perceived SCI strengths; rather, they should trust assessment tools and evaluate from there.[9,10] ASD women also have stronger non-verbal communication skills[1-3,6,7] and better emotional intelligence[7] than ASD men, traits which typically align with societal expectations of women. The participants of Geelhand et al's study[10] were adults who were told to pretend they had a child and observe their child's social interactions. Geelhand et al[10] found that participants believed that girls would grow out of concerning symptoms or abnormal behaviors in their adolescence, while boys would continue these behaviors and be perceived as atypical in adolescence. This suggests the adult participants believed in certain gender roles and gendered behaviors of girls, while boys were allowed atypicality.

Camouflaging is exhibited both in men and women; however, it is more common in ASD women[2,3,5,7] and serves as a possible explanation for the gender gap in ASD prevalence.[2-4,6,7] For women, camouflaging appears as mimicking or copying behaviors of celebrities, peers, movies, shows, etc., to appear more 'normal'.[2] Specific camouflage behaviors include attempting eye contact despite any possible discomfort, memorizing phrases or jokes to use in conversations, adjusting speaking volume, and mimicking others.[7,8] Hiding autistic traits used in diagnosis contributes to delayed diagnosis and misdiagnosis in girls and women.[2,3,5,7] Because camouflaging is more prevalent in women, it is reasonable to suggest that gender roles play a part in how girls are socialized and thus influence the behaviors autistic girls begin to mimic and adopt. Most notably, camouflaging hides autistic traits that are an important diagnostic tool for ASD and contribute to more time without proper support.

Delayed Diagnosis and Misdiagnosis of Autism Spectrum Disorder

The estimated 3:1 gender gap cited by most ASD research most clearly reflects the experience of children and adolescents,[4] not the experience of all ages. Research does show that the gender gap decreases with increasing age.[5] In fact, Rutherford et al[5] found that while children and adolescents had a ratio of about 3.5:1, adults had a much smaller ratio of around 1.8:1. This statistic does not provide much insight into the corresponding experience of ASD and could be attributed to a range of factors. From the perspective of camouflage, women may grow tired of hiding their traits with increasing age[2] and therefore seek understanding or help for what they are going through. While Rutherford et al's study[5] does have reduced generalizability to other populations due to data being drawn from Scottish patients of a smaller sample size than ideal, the study corroborates Loomes et al's findings.[4] Most recent Autism Spectrum Disorder research cites the gender ratio found in Loomes et al,[4] indicating that while there are limitations in Rutherford et al's study,[5] it does have validity.

Gesi et al[6] performed an investigation on the specific gender differences in misdiagnosis and delayed diagnosis of adults with no intellectual disability. The most notable finding of this study was that women, on average, received a first clinical referral and ASD diagnosis at ages 21 and 29, respectively. This alone represents the nature of delayed ASD diagnosis; however, the difference is

most shocking when compared to the age of boys and men at first clinical referral and ASD diagnosis, ages 11 and 19, respectively. Women, on average, received an ASD diagnosis 10 years in age after men. Women also were much more likely to be misdiagnosed than men. With regards to gender similarities, both men and women had the same time frame between first clinical referral and ASD diagnosis and similar rates of missing a diagnosis altogether. Gesi et al[6] had a very small sample size (n=61), and participants were not evenly split by gender: there were 39 men and 22 women. However, inclusion criteria required a previous ASD diagnosis. The significant gender gap within ASD prevalence, as noted by many studies,[4-6] is reflected by a gender gap in the results of passive case ascertainment studies where ASD diagnosis is required. Using active case ascertainment would likely provide a more balanced gender ratio. In any case, the results of this study are not statistically significant, but the Gesi et al's findings are consistent with other statistically significant research.

Despite patterns reported within recent studies regarding ASD, the causes of the gender gap are still largely unfounded. One explanation for delayed diagnosis is the role of camouflage. The decline in gender gap with age, as noted by Rutherford et al,[5] most likely reflects the nature of long-term camouflage of autistic traits. Research indicates that ASD women camouflage at higher rates than ASD men,[2,3,5,7] suggesting that consequences relating to camouflage disproportionately affect women. Hiding autistic traits makes them undetectable by parents, teachers, diagnosticians, etc., and prevents individuals from receiving a diagnosis and following treatments. Another explanation is professional misunderstanding of the female presentation of autism. Diagnosis of autism is based on the male phenotype. While male and female ASD traits are often similar, there can be differences that affect overall presentation of ASD. A female phenotype is therefore needed for improved ASD assessment of women.[2-5] The harmful implications of the delayed diagnosis of ASD largely target girls and women.

Implications for Quality of Life

Autism Spectrum Disorder research overwhelmingly shows that girls need to exhibit greater deficits than boys to receive the same ASD diagnosis.[1,2,4-6,8-10] Intellectual disability plays a large role within ASD detection. Loomes et al[4] found that at lower-than-average IQs, the gender gap of ASD prevalence was smaller than when examining boys and girls with average IQs, indicating that girls with 'normal' abilities have more difficulty than girls with intellectual disability, and especially more difficulty than boys. When examining ASD screening processes, Evans et al[1] found that while current screening questionnaires, particularly the Social Communication Questionnaire (SCQ), are successful, danger lies within clinician interpretation of the scores and ASD symptoms of an individual. Researchers also emphasize that perceived strengths of an individual should not override scores on ASD screening questionnaires.[1,9] Findings related to participant scores on the SCQ indicated that, of participants who already were diagnosed with ASD, girls displayed greater social communication deficits than boys did. Girls generally need to show greater impairment than boys for a similar diagnosis, especially at younger ages.

Women with ASD also tend to have poor mental health. Research indicates that long-term camouflaging is associated with negative self-perception and exhaustion[2] and higher rates of mental health issues, such as anxiety,[3,7,8] depression, and disordered eating.[7] Camouflaging is often unintentional and is capable of hiding negative emotions and feelings, causing greater immediate danger regarding mental illness[2] or social conflicts.[3,7] The closing of the gender gap with increasing age could likely be related to women growing tired of camouflaging, or more troublesome, facing serious mental health issues that required them to get support they otherwise may not have received.[5]

Another concerning implication of camouflage is the relation to sexual abuse. Bargiela et al[3] discussed the female experience of ASD with fourteen women who had received a late ASD diagnosis. Nine out of the fourteen women reported experiencing sexual abuse, with half of these accounts occurring within their relationships. Women reported that as they camouflaged and mimicked others, typically without conscious effort, they began to copy flirtatious behaviors that led them into unsafe and unwanted sexual actions. Furthermore, the expectations of being a 'good girlfriend' pressured some women into sex in order to please their partner and receive affection in return. Other reported reasons for passivity were difficulties reading others' intentions, feeling isolated from others as adolescents, feeling desperate for acceptance due to past peer rejection, and uncertainty about social rules.[3] Fortunately, after diagnosis, women had more confidence in asserting their opinions and asking for clarification when needed. This study's small sample size and qualitative data collection do make it difficult to draw scientifically valid conclusions, but the findings warrant future quantitative research into the participants' reported experiences. Difficulties associated with the late diagnosis of ASD are highlighted from individuals who received a late diagnosis themselves and provide invaluable insight into the female experience of ASD.

Late diagnosis of ASD has multiple impacts on quality of life. Unfortunately, a large barrier to ASD diagnosis is a lack of childhood history regarding 'abnormal' behaviors.[7] The later that ASD diagnosis occurs, the more likely that an individual will face poorer quality of life, whether it be feelings of isolation from peers, mental health issues like depression and anxiety, sexual abuse, difficulty communicating and relating to others, or simply longer time without ASD therapies and treatments. An ASD diagnosis can also provide individuals with empowerment in certain behaviors, like asking for clarification when confused, and with a sense of community that they may not have felt before.[3]

Conclusion

Autism Spectrum Disorder is an unequal playing field for boys and girls. There are gender differences in ASD presentation, and more notably, there are differences in the diagnostic process for boys and girls. Girls are much more likely to be misdiagnosed or receive a late diagnosis compared to boys.[4-10] The girls who are diagnosed in a timely manner are likely to have greater deficits than boys, but women who are diagnosed later face an abundance of difficulties. At either time of diagnosis, more work needs to be done to provide women with more timely ASD diagnosis and care.[1-7,9,10]

Researchers agree that camouflage is significant in the female experience of ASD. Camouflage works to hide abnormal traits and serves as a method for ASD individuals to socially integrate successfully.[1-3,8,9] Subduing signs of autism due to gender pressures reduces the chance that girls will get to a professional diagnosis until much later in their lives. Lacking a comprehensive developmental history of certain behaviors and traits also reduces the possibility of receiving a diagnosis, especially later in life.[7] Camouflage also has lasting unintended consequences. In some cases, camouflage results in mental health issues such as disordered eating, anxiety, and depression.[3,7,8] In other cases, women are confused about their true identities after suppressing traits for extended periods of time.[2] Camouflage may also lead those with ASD into dangerous situations, such as sexual abuse and manipulation by others.[7] Camouflage is insidious in that it hides traits for more immediate benefits but creates greater issues the longer it continues. Research explains the role of camouflage in the female experience of ASD but not how to diagnose ASD in spite of camouflage.

A common finding within ASD research is that girls must show greater deficits than boys for the exact same diagnosis.[1,2,4-6,8,9] When assessing boys and girls of similar ages with average IQs, the gender ratio was much larger than when assessing boys and girls with lower-than-average IQs.[4] It is difficult to draw conclusions for the entire population of those with ASD due to the wide spectrum of symptoms and presentation. Most research within this review did not assess those with intellectual disabilities. This is potentially problematic for other ASD research; however, this review focuses on ASD diagnosis in those with seemingly 'normal' abilities. Furthermore, those who do have intellectual disability, lower IQs, or more severe symptoms, such as being non-verbal, have a greater chance of being diagnosed, especially at younger ages.[1,2,4-6] Higher rates of social communication deficits in girls already diagnosed with autism[1] combined with greater prevalence of mental disorders[2,3,7] indicate that women generally have a more difficult experience with ASD than men do.

Perhaps the most important conclusion of ASD research is that there needs to be a better understanding of the female phenotype to be used in assessment and diagnosis.[2,4] The creation of a female phenotype of ASD would allow women to be assessed according to the female experience, not be misunderstood according to the experience of a man. Research does not provide a consensus on how this should be done or what should be included. Nevertheless, multiple patterns have emerged creating at least a preliminary understanding of the female experience of ASD and how it differs from the male experience.

Limitations

Autism Spectrum Disorder research so far fails to prove a direct relationship between gender roles and camouflage. In addition, there is a lack of primary research investigating how specific gender roles affect ASD. At this time, most research identifies the possibility of a connection, but no study provides a scientifically valid conclusion. Primary research tends to be fairly limited in terms of participant population, with Gesi et al[6] and Bargiela et al[3] having smaller participant samples than ideal. Some primary research has reduced generalizability regarding country of origin, which is problematic for investigating how specific gender expectations may affect ASD, as expectations can differ from country to country. However, of the studies involving participants from a single country, consequences of perceived expectations, rather than specific gender expectations, were investigated, indicating that the above limitation does not have a strong effect on this review.

Confusion arises in case ascertainment within ASD research. Passive case ascertainment involves reviewing existing databases to find individuals who have already received a diagnosis. Active case ascertainment methods screen all available samples regardless of diagnosis.[4] This can create misunderstanding when reporting on research results. For instance, Evans et al[1] utilized passive case ascertainment which may contribute to the continued misinformation on ASD struggles with SCI.[9] Participants had to have already received an ASD diagnosis to be included in the study, indicating that the struggles with social communication in those with undiagnosed ASD are going undetected. Results in other research regarding greater social motivation in girls with ASD seems to contradict Evans et al's[1] finding due to the differences in case ascertainment.

Most studies in this review call for more research on creating a female phenotype of ASD to provide women with more timely detection and treatment.[1-7,9,10] None provide statistically significant recommendations for how this should be done, but many studies reach similar conclusions that, with specific research, can help inform this process.

Recommendations

A female phenotype is needed for improved and more timely assessment of ASD in girls.[1-7,9,10] Unfortunately, there is no consensus on what should be included in this description. Nonetheless, research does seem to report on differences in female ASD presentation, allowing for a basic construction of the female phenotype.

The most prevalent finding is that girls with ASD show greater motivation for social communication[2,3,6-9] even if they have struggles. When considering ASD assessment, this creates a problem for certain diagnostic tools like the Social Communication Questionnaire (SCQ) studied by Evans et al.[1] Most importantly, the SCQ is most effective for ASD assessment from ages 4-5, an issue for girls who are older than ideal and especially problematic for women diagnosed in adolescence or adulthood. Girls with ASD also seem to have better non-verbal communication skills than boys.[1-3,6,7] Girls tend to utilize more hand gestures and interjections while speaking[2] and tend to behave in ways that are more acceptable to gender stereotypes.[3,9] Other differences of the female phenotype of autism include behaviors that show greater emotional intelligence and understanding of social rules, increased imaginative play pretend as a child, and perfectionist tendencies.[7,9] By camouflaging autistic traits that are not in line with stereotypical gender roles, ASD girls can better fit in with peers and in different social environments. Camouflaged behaviors and traits can make the ASD diagnostic process more difficult; however, it is important to understand how visible behaviors contribute to the larger picture of a possible autism diagnosis in order to provide women with more timely support.

Work also needs to be done to mitigate professional bias in ASD assessment. To reduce this bias, professionals should undergo gender sensitivity training if not already required. It could also be recommended that, when applicable, parents complete diagnostic tools without informing gender and diagnosticians begin the assessment process in this manner.

It is crucial to provide female patients with a clinical model that more accurately represents their own strengths and difficulties instead of forcing them into a box that represents a male-centered experience. Camouflage plays a significant role in the female experience of ASD, and more research needs to be done to understand how it affects not only the diagnostic process, but overall quality of life.

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