Autism: Girls Are Under-diagnosed

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According to the Centers for Disease Control and Prevention (CDC), an estimated 3 million people in the US have autism, translating to 1 in every 68 children. There is a wide gender disparity; however, 2.3 percent of the general male population is autistic versus .59 percent of the female population. These rates yield a gender ratio of about five boys for every girl (Bargiela et al., 2016). Nevertheless, it remains a question whether autism is less prevalent in females or simply under-diagnosed (2016). If autism is being under-diagnosed in females, it could lead to some potentially devastating effects for those individuals' lives because we know in males that the earlier the diagnosis occurs, the better the outcome for the autistic individual. This is in part due to early interventions that may take place if autism is identified earlier. Parents, teachers, and friends may be able to help the child develop healthy coping strategies ("Autism Statistics." 2020). Many women diagnosed as adults suffer years of unstable and sometimes abusive relationships, employment, and financial problems (Beck, et al., 2020).

This literature review will analyze the existing studies on autism in females and examine the possible effects of under-diagnosis and misdiagnosis in females. First, I will examine the barriers to diagnosis for females in terms of outdated diagnostic tools and prevailing biases in the medical establishment. Then I will discuss camouflaging, the principle way autistic females try to cope in the world and pass as neuro-typical. Finally, I will investigate various co-morbidities common in autistic females and how many psychiatric illnesses may be directly related to trying to mask autistic traits.

The current gender gap in autistic diagnoses exists in part because the diagnostic tools that are used by medical professionals are based on 1940's and 1950's data that primarily used boys as research subjects ("The Evolution of 'Autism' as a Diagnosis, Explained," 2018). There is also a lack of understanding of the causes of autism. In the 1940's through 1970's, it was thought that the cause was so-called 'refrigerator mothers' who were cold and un-emotional. Researchers also thought that autism was a kind of detached childhood schizophrenia ("The Evolution of 'Autism' as a Diagnosis,

Explained," 2018). More recently, some compelling research has linked autism to heavy metal exposure (Exposure to Heavy Metals May Increase Risk of Autism, 2017 and Mohamed et al., 2015. Carter & Blizard, 2016). There are also some indications that autism may be the result of multiple environmental and genetic factors (Szatmari, 2003). Since a definitive consensus of the cause(s) of autism may be decades away, I believe the best course of action is to educate the medical establishment and public on the true prevalence of autism in females and the effects of under-diagnosis and misdiagnosis. There also needs to be more education to break down the various stigmas autistic people may face. If teachers, friends, and bosses know the unique talents and gifts that autistic people bring, they can foster a culture that is inclusive of neuro-diverse individuals.

Review of Literature

Barriers to Diagnosis:

Because there is a prevailing assumption that autism is more common in boys, parents of girls who suspect their child may be autistic face an uphill battle that often involves convincing incredulous doctors that their child is autistic. Many women are not so fortunate to receive a diagnosis in their youth but stumble upon autism after their own child is diagnosed or hearing another autistic woman speak about their experiences. One autistic female puts it thus, "I had always felt 'different' and excluded by others, and wanted to know why…I read a personal account of having Asperger's by a woman on the Internet, and it made me cry with recognition" (Hendrickx, 2015, 43).

One barrier to diagnosis in females is that all of the models and clinical diagnostic tools were developed by researchers' observations of autistic boys to the exclusion of autistic girls (Szalavitz, 2016). One mom of two autistic children, one boy and one girl, recalls the difference between diagnosing them,

Lowell [male] received an autism diagnosis at 16 months…it was easy. With Frances [female], they went from doctor to doctor and were told to simply watch and wait—or that there were various physical reasons for her delays, such as not being able to see well because of an eye condition. 'We got a lot of different random little diagnoses,' she recalls. "They kept saying, 'Oh, you have a girl. It's not autism'" (Hendrickx, 2015, 135).

Traditional diagnostic tools may leave out many girls on the spectrum because their symptoms look different. One reason for this may be that there are neurological differences in how male and female brains process(McCarthy et al., 2012). However, it is essential to note that autistic females may display less outward signs of traditional autistic behaviors such as stimming or lack of eye contact, but may not feel any less autistic than their male counterparts. Some autistic traits may look 'weird' or eccentric to a person not familiar with autism. A person with autism may not have any interest in fashionable clothing; they may obsessively research niche subjects like medieval manuscripts or even public figures like Jimi Hendrix or Regis Philbin. They may have obsessive interests in the arts or sciences, and they may have an incredible memory; their friends might call them a 'human encyclopedia' or 'Google' (Hendrickx, 2015, p. 125). Having one or two of the diverse symptoms of autism does not make a person autistic. It is possible to be a neuro-typical individual with autistic traits; what makes a person autistic is an aggregation of symptoms that may interfere with everyday life to a greater or lesser degree (Johnson, 2007).

Camouflaging:

Female autistics tend to use a technique called camouflaging to disguise their autistic traits and pass as neurotypical (Beck et al., 2020. Invisible Diversity, n.d.). This may include studying social interactions between individuals like someone might study physics or biology to "get it right." Autistic females, particularly individuals with high intelligence quotients (IQ), report having "an encyclopedia of data" in their brains of all of the data they have compiled regarding social interactions (Autism Research News, 2016). They attempt to call upon this data at the right moments to "act

properly." The data they have observed may include: appropriate amounts of eye contact, speech speed, vocabulary usage, hand gestures and positioning, personal-space distance, appropriate displays of affection, memorized idiomatic expressions and jokes, and smiling and nodding (Hendrickx, 2015, p. 161). These are all things that a neurotypical person learns in childhood and growing up, but to an autistic person, something as simple as the word "envy" may be downright mystifying.

It is important to understand that although girls may appear less symptomatic than boys on the surface, both genders share similar internal profiles. Females hide their distress much more than boys, which leaves them feeling empty, exhausted, and unfulfilled in life (Wilkinson, 2008). The instinct to hide autistic traits in females may be due to the fact that females are more community-oriented; they tend to feel more distressed than males when ostracized from groups. Therefore, camouflaging can allow autistic females to be accepted into the larger society. However, camouflaging comes with high emotional costs, with the majority (97 percent) of autistic females reporting feeling exhausted by the effort, physically, mentally, and emotionally (Beck et al., 2020). Autistic males may not feel the need to camouflage as much because they tend to do better than females when ostracized. Additionally, autistic females tend to display different traits than autistic males, making the old criterion for a diagnosis of autism faulty at best and obsolete at worst. This creates a double-blind for researchers and diagnosticians. Autistic females have high reward receptors for hiding their autism, and most of the tools in use today leave out most autistic traits in females.

Prevalence of Co-morbidity:

Some studies have indicated that autistic females have higher instances than males of co-morbidity. An estimated 64 percent of women with autism have received one or more psychiatric diagnoses before being diagnosed with autism. Additionally, 71 percent of autistic females reported suicidal ideation (2020. "The Costs of Camouflaging Autism," 2018). Common co-morbidities in autistic females include:

- Anorexia nervosa.

- Obsessive-compulsive disorder (OCD).

- Attention deficit hyperactivity disorder (ADHD).

- Bipolar disorder

- Anxiety disorders.

- Major depressive disorder.

Additionally, these other diagnoses may, in fact, cover up the underlying issue: autism. Some girls receive non-specific diagnoses such as "learning disabilities" when a diagnosis of autism may be more appropriate. "A recent survey of women with Asperger syndrome indicated that most received a diagnosis of anxiety or mood disorder prior to being identified with an autism spectrum disorder" (Wilkinson, 2008). Unfortunately, a misdiagnosis can delay or prevent the implementation of the appropriate interventions and treatment. As a result, many girls may not receive the assistance and understanding that could make an important difference in their lives.

More research needs to be done on instances of co-morbidity. Still, it may be that a diagnosis of autism is more appropriate in some cases where the individual's masking or camouflaging techniques engender the appearance of anxiety or bipolar. It is also interesting to note that males are more likely to receive an autism diagnosis despite both sexes displaying symptoms clinically associated with autism (Hendrickx, 2015, p. 35). It may also be that the stress of having to mask symptoms and appear neuro-typical causes co-morbidity. Many autistic females diagnosed later in life report high amounts of relief after receiving their diagnosis because they no longer feel like they have to mask as many autistic traits around close family and friends. Much research still needs to be done in this area; we do not know if these co-morbidities stem from the underlying cause of autism, which is still unknown, or if they are misdiagnoses.

Autism research in the last decade has uncovered that autism may be under-diagnosed in females (Volkers, 2018). There are potentially millions of individuals in great distress, not knowing

why they feel different and why something simple like going to the store or a meeting with a co worker is hard for them. As one woman with autism relates,

> "I get physical feelings of anxiety. I have learned to hold it in when in the workplace, although not always successfully, and have spent many a lunch hour hiding in the work toilets hyperventilating and sobbing uncontrollably. I used to feel pathetic when this happened; I now realize since diagnosis how incredibly brave I was, actually pulling myself together and going back to work in the afternoon" (Hendrickx, 2016, p. 135).

In several studies, almost all participants revealed clinical levels of mental health symptoms, with anxiety, depression, and eating disorders being the most commonly reported (Bargiela et al. 2016. Szalavitz, n.d.). Anxiety, depression, and feelings of loneliness and alienation are simply part of most autistic women's experience trying to fit in. All too often, these professionals instead misinterpret the considerable difficulties of these girls as simply 'shyness,' and when these feelings become overwhelming, women may be diagnosed with a psychiatric disorder ("Women with Autism Hide Complex Struggles behind Masks," 2016).

One study uncovered high instances of sexual assault and abuse among participants. Researchers said, "this shocked the two neuro-typical members of the research team, but not Steward. As an autism consultant working in education, social services, and theater, Steward had heard a number of stories in which men had manipulated girls and women with autism. The reasons for the abuse varied, but they all appeared to relate to the social difficulties of autism in the context of being female" (2016). One woman in the study for example, linked an experience of sexual abuse to "not reading people to be able to tell if they're being creepy." Another related that her uneasiness about social cues meant that she was not sure whether she could say "no" to an abusive partner's demands. Still, others felt that isolation and lack of friends and relationships in their teenage years resulted in a lack of opportunities to develop skills to stay safe in relationships and to discuss healthy relationships with female friends (2016).

Conclusion

First, I looked at the barriers to diagnosis for autistic females. The diagnostic tools currently in use were developed exclusively for males, and there may be biases against autistic females in medical professionals. There needs to be more research into the areas where autistic females may appear differently from their male counterparts and new diagnostic tools developed to diagnose females. Additionally, since autism may appear differently in children than adults, there needs to be two sets of diagnostic tools; one for younger females and one for adults.

I also looked at how autistic females may mask or camouflage their autistic traits to appear neuro-typical. Most participants autistic women report the effort of camouflaging as exhausting, disorienting, and many believed it contributed to their delayed diagnosis. A significant gap in understanding is the complete lack of tests for camouflaging; this is a major obstruction to medical professionals diagnosing, helping, and understanding women with autism. There needs to be the development of tests and measurements of camouflaging. Researchers postulate that it is much more common with women than men on the spectrum, but it is impossible to run clinical trials without tests and measurements. This will also help us determine the prevalence and extent of a missed or erroneous diagnosis's negative consequences.

Finally, we looked at the effects of under-diagnosis and misdiagnosis in females. The fact that one study concluded 64 percent of women with autism have a co-morbid psychiatric diagnosis, and 71 percent reported suicidal ideation means that we are missing a percentage of autistic women whose feelings of overwhelm have resulted in suicidal ideation but are not yet diagnosed or receiving treatment for their suicidal thoughts. These individuals who are slipping through the cracks are at the greatest risk for self-harm. Because of the high prevalence of suicidal thoughts amongst women with autism, I am proposing that all individuals treated for psychiatric conditions also be screened for autism.

These proposals will immediately begin improving the quality of life for women with autism, allowing them to lead full and healthy lives. With the right coping mechanisms, social and profes-

sional support, most autistic individuals find ways of living in the world that allow them to use their unique talents and abilities while maintaining their own sense of self. As we see with autistic individuals like Temple Grandin, who invested humane ways of meat processing; and Jerry Seinfeld, who revolutionized comedy, when people's talents and abilities are used and fostered, they help us see the world differently. By misdiagnosing and under-diagnosing females, the world is potentially missing out on all of their respective gifts.

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