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Women are significantly less likely to be diagnosed AuHD, meaning they could be struggling without receiving support or knowing why. This can be detrimental to their mental health and well-being, which is why this topic is so important to Amanda. Making diagnosis more accessible doesn't erase the gender bias or solve all of these women's struggles, but a diagnosis does grant access to the few accommodations available as well as a better understanding of oneself, which will, in turn, improve these women's overall quality of life.

Late Diagnosis of Autism and ADHD in Adult Women: A Literature Review

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Abstract

Gender bias in research and clinical practice prevents many women from receiving a joint diagnosis of autism and ADHD (AuDHD) until later in adulthood. This literature review provides insight into the process of late diagnosis of AuDHD in women and the impact diagnosis has on their life. Research was obtained from the PsycINFO database. Thirteen journal articles published between 2021-2024 met the criteria to be included and were subjected to in-depth narrative analysis. Results indicated common themes in the experiences of late diagnosed adult women including frustration with lack of support pre- and post-diagnosis, skewed understandings and reinforcement of autism/ADHD stereotypes, and gender-biased diagnostic criteria. Implications for future research are discussed and include expanding sample diversity and incorporating AuDHD voices into all stages of research.

Introduction

According to the DSM-5-TR, autism spectrum disorder (ASD) is characterized by "deficits in social communication" and "restricted, repetitive patterns of behavior, interests, or activities" (American Psychiatric Association [APA], 2022). The condition is most often diagnosed in white male children, although it can appear in people of all genders and races (APA, 2022). Meanwhile, attention-deficit/hyperactivity disorder (ADHD) is characterized by patterns of inattentiveness, hyperactivity, and impulsivity with three main subtypes including inattentive, hyperactive-impulsive, and combined, which features symptoms from both of the previous subtypes (APA, 2022). Similar to autism, ADHD is most commonly diagnosed in young white males. Interestingly, there is a high co-occurrence of autism and ADHD, which led to the creation of a joint diagnosis of the two conditions in 2013; many people in the neurodivergent community now refer to this as 'AuDHD' (Craddock, 2024).

However, there is currently a massive gender bias in research and clinical practice that prevents many women from receiving this joint diagnosis of AuDHD (Craddock, 2024; French et al., 2024). As a result, many women aren't diagnosed until later in adulthood, which can have a huge impact on their overall well-being. Thus, in this narrative review, I wanted to explore the process of late diagnosis of AuDHD in women and analyze gender differences in symptom presentation, potential barriers to diagnosis, and the effect late diagnosis has on their life and well-being.

Methods

I conducted my research using the PsycINFO database with access provided by Michigan State University. In my key search terms, I needed to include three main topic areas: some terms to

represent autism and ADHD, some terms to represent women/the gender bias, and some terms to represent the process of late diagnosis. The key terms went through many revisions including removing terms such as "Asperger's" and "adult diagnosis" due to irrelevant or no change in results. The asterisk was included in terms such as "autis*" to account for different variations of the term (e.g. autistic, autism) and to search for both the plural and singular versions of terms such as with "female*". Terms were revised to the following:

> ("autis*" OR "ADHD" OR "attention deficit hyperactivity disorder" OR "AuDHD" OR "neurodiver*") AND ("women" OR "gender bias" OR "female*") AND ("diagnos* process" OR "late diagnos*")

These terms were entered into the PsycINFO database. Using the advanced search features, I specified to search for the terms in the abstracts of journal articles, and I refined the search to the last five years to include only recent data. Sources were excluded if they examined only caregiver or professional opinions of AuDHD women without including AuDHD voices, if the topic was not about late diagnosis or the diagnostic process for adult women, if autism or ADHD was not the main focus, and if the study explored autism/ADHD in young children as opposed to adult women (no hard age cutoff, but general age requirement of 18+). Due to a lack of research on the joint diagnosis of AuDHD, studies were not excluded for focusing solely on autism or on ADHD as long as they met the rest of the inclusion criteria.

Results

Results are split up into three groups of studies with a focus on a joint diagnosis of AuDHD, a sole focus on autism, and a sole focus on ADHD. Many similar themes were found throughout all three sections, which are later discussed in the conclusion section.

Experiences of AuDHD Women: A Joint Diagnosis of Autism and ADHD

Craddock (2024) conducted an analysis of email interviews with six late diagnosed AuDHD women exploring their experience with late diagnosis and how their identity as a woman related to their neurodivergent identity of AuDHD. In terms of symptom presentation, women generally presented with more internalized symptoms than most men and were significantly more likely to mask (hide) their AuADHD traits in an effort to appear neurotypical or non-AuDHD (Craddock, 2024). This may be one of the reasons why AuDHD is often unnoticed in women as the official diagnostic criteria places a stronger emphasis on externalized symptoms that are more common in men. Interestingly, some women also noted that their symptoms of autism and ADHD tend to "cancel each other out" (Craddock, 2024). For example, autism is characterized by repetitive behaviors that may help one maintain a sense of organization and routine, but given the inattentive nature of ADHD, women may struggle to maintain said routine. As symptoms cancel out, they become less noticeable, which creates a barrier leading to later recognition and diagnosis in life.

When speaking of their experiences with the results of late diagnosis, the women in the Craddock (2024) study shared many common themes, with the stand out being a lack of post-diagnosis support. Many women shared that they were given medication to treat their ADHD symptoms and were then shoved to the side with few options for therapy or other social support. While medication may improve symptom severity for some women, others may not benefit from medication at all. Therapy and workplace accommodations would likely also be helpful, however these weren't available for many women (Craddock, 2024). Additionally, getting post-diagnosis support relies on receiving an official diagnosis in the first place. It's common knowledge among researchers that diagnosis isn't accessible for everyone due to cost of diagnosis, poor insurance coverage, length of waitlists, biased clinicians, etc. (Craddock, 2024; Cook et al., 2024; Morgan et al., 2023). While self-diagnosis is becoming more common and valid in the neurodivergent

community, it has yet to be widely accepted (Cook et al., 2024), posing challenges in ensuring all AuDHD women receive equal support.

Holding semi-structured interviews with late diagnosed AuDHD adults, French et al., (2024) shared similar themes to that of Craddock (2024) with an additional emphasis on timing of diagnosis. While an AuDHD diagnosis comes as a relief to many in helping them better understand themselves or providing them access to accommodations, some may view an AuDHD diagnosis as a burden with a large focus on "what could have been" if they were diagnosed earlier in life (French et al., 2024). This suggests a need for pre-diagnosis support to help prepare AuDHD women for the emotional transition of receiving a diagnosis. If the timing is wrong and a woman isn't mentally prepared, it's possible that a late diagnosis may do more harm than benefit, which is important to note given that a lot of research only focuses on the ways an AuDHD diagnosis can improve one's life.

Experiences of Autistic Women

Conducting a post-hoc analysis of 20+ years of diagnostic data in the state of North Carolina, Harrop et al. (2024) highlighted some of the biggest disparities in autism diagnosis between men and women. As established, women are 38% more likely to be late diagnosed in adulthood, receiving their diagnosis an average of two years later than men (Harrop et al., 2024). Interestingly, the ratio of men to women who are diagnosed has decreased over time, likely due to the larger sum of research on autistic women that is available today. Even with this decrease, however, there remains a significant gap between rates of diagnosis for men and women (Harrop et al., 2024).

While clinicians' understanding of autism in women may have increased, in a qualitative study using photovoice methodology, Cage et al. (2024) noted that the "incongruence between diagnostic tools and female presentation" is still a major barrier to adult women receiving an autism diagnosis. Many women cited struggles with finishing the Autism Questionnaire (AQ), in particular being stuck on the wording of "significant impairment" (Cage et al., 2024). After being overlooked their whole life, women diagnosed autistic in adulthood may be used to coping with their symptoms and not view them as an 'impairment.' While it's true that many women seek diagnosis after some sort of breaking point in their life when the demands of life exceed their capacity (Cage et al., 2024), this isn't the case for everyone: some women may simply want to better understand themselves. Thus, the wording of 'impairment' may cause women to self-report lower AQ scores which could cloud a clinician's judgement of whether their patient is autistic. Given that both the diagnostic criteria and the AQ were created in response to research done on white males, it's natural that women's presentation of autism may not align with these measures. These findings indicate a need to redesign diagnostic criteria and diagnostic tools with the female phenotype of autism in mind.

Masking is another common barrier to the diagnostic process as explored by Seers et al. (2022) using a feminist disability lens in qualitative interviews with late diagnosed autistic women. A natural and subconscious action for most women, masking is often used as a way to avoid rejection or stigmatization in society (Seers et al., 2022). Given that this makes autistic traits less noticeable, masking makes it harder for clinicians to assess for autism. For example, making eye contact is one way many women mask, and since avoidance of eye contact is listed in the DSM as an example of a social deficit (APA, 2022), this may cause a clinician to believe the woman isn't autistic. Females often mask significantly more than males, and since the diagnostic criteria was created based on male presentation, many clinicians don't naturally look for signs of masking during assessment, preventing many women from being diagnosed (Seers et al., 2022). Murphy et al. (2022) reinforced many of these struggles with masking through qualitative interviews with women seeking an autism diagnosis. Another theme that emerged from this study was the importance of women understanding and being prepared for the actual process of a diagnostic evaluation. This may include researching different clinicians to find ones that specialize in late

diagnosis or writing out a list of all the reasons that they believe they're autistic for self- and provider-validation (Murphy et al., 2022). Given that women often self-report more autistic traits than clinicians do (Murphy et al., 2022), this list could be extremely helpful in describing some autistic tendencies that may be masked during the assessment period.

Another option, as Cook et al. (2024) pointed out, would be for clinicians to have more awareness of and assess for masking; their narrative review of the autism diagnostic process highlights many areas clinicians could improve. For example, using the Camouflaging for Autistic Traits Questionnaire (CAT-Q) would be one option to test for masking in adult women and should thus be regularly administered during autism assessments (Cook et al., 2024). While clinician knowledge has improved some over time, many clinicians still lack knowledge of the gender bias and differences in symptom presentation of autistic females. Clinicians are also more likely to focus on external presentations of autism that are over-represented in most autistic questionnaires––which as previously stated, often excludes women whose symptoms tend to be more internalized (Cook et al., 2024).

These struggles make the diagnostic process stressful for women, as Harmens et al. (2021) discovered when exploring autistic women's blogs. Women who are familiar with the autism gender bias may fear being misdiagnosed, which can cause great worry about the assessment being a waste of time and money. Upon diagnosis, immense relief is a common theme for women as they finally have an explanation for why they have felt so different their entire life (Harmens et al., 2021). However, many women also go through some form of identity crisis, either fixating on why they weren't diagnosed earlier or feeling imposter syndrome over the fact that they don't perfectly align with the male-based diagnostic criteria (Harmens et al., 2021). Some women may even feel a combination of both, which would be extremely confusing for them to process. This highlights the importance of autistic online communities, where these women can share their experiences with other autistic women who understand their struggles.

Experiences of ADHD Women

With an observational study exploring timing of ADHD diagnosis in relation to co-occurring mental health diagnoses, Siddiqui et al. (2024) noted many gender disparities in ADHD presenta- tion and diagnosis. Similar to autism, the average age of ADHD diagnosis is significantly higher in women, who are often diagnosed between ages 16-28, with the average age at diagnosis being 11-22 in men (Siddiqui et al., 2024). As with autism, this may be due to the emphasis placed on externalizing symptoms. Given that women are more likely to present with the inattentive subtype, they are often ignored due to the lack of external hyperactivity they display (Siddiqui et al., 2023). Since 'hyperactive' is in the name of ADHD, it's a common stereotype that all ADHDers are the constant energy, scatter-brained, 'bouncing off the wall' type. Many people only notice external behaviors of ADHD when they cause significant problems in a workplace or school setting (Siddiqui et al., 2024), so clinicians' ignorance of the internalization of ADHD may be one of the barriers to women receiving a diagnosis.

Examining these biases in the diagnostic criteria, Morgan et al. (2023) discovered in qualitative interviews that many ADHD women are often diagnosed with anxiety, depression, or bipolar disorder before viewing ADHD as a possible diagnosis. This is likely very confusing for women as it may seem obvious to them that they have symptoms that don't align with the diagnosis they were given. After ADHD diagnosis, many women felt immense relief, but others still struggled with internalized ableism––holding themselves up to a neurotypical standard (Morgan et al., 2023). While co-occurring diagnoses such as anxiety and depression are common in ADHD, these don't explain the whole picture and certainly don't replace the need for an ADHD diagnosis.

Women in academia also receive significant pushback in the process of receiving an ADHD diagnosis (Cripe et al., 2024). As ADHD scholars Cripe et al. (2024) explained about their diagnostic experience, clinicians were hesitant to diagnose them because they all had PhDs and

thus must have been able to cope with their symptoms. In reality, some aspects of ADHD may be helpful in an academia career such as the ability to hyperfixate on information for an extended period of time. But, that does not take away from the struggles ADHD scholars face as they do their work; the women in this paper noted particular difficulties with procrastinating and feeling frustration with small changes that ended up causing significant overwhelm in their ability to work (Cripe et al., 2024). It's important to look at the whole picture of a person instead of just focusing on their achievements, which may cause clinicians to overlook the possibility of women in higher status careers having ADHD.

Similarly, ADHD scholars Bertilsdotter et al. (2023) expressed their struggles with trying to re-story ADHD in a narrative of their shared experiences. There are many harmful viewpoints that aim to pathologize ADHD such as that of a social construct or a neurodevelopmental deficit; instead, ADHD should be re-storied as a neurodivergence (Bertilsdotter et al., 2023). This implies that ADHD is merely a different way of cognitive processing as opposed to a problem that needs to be fixed. Given that many women struggle with accepting their ADHD identity, it's important to normalize differences. In any population, it's highly unlikely that everyone is going to think and process information in the same way, regardless of whether they have ADHD. This is why some people have an issue with ADHD medications as they tend to medicalize ADHD as a disease that needs to be cured with medication (Bertilsdotter et al., 2023). Interestingly, a lot of popular media does the opposite and tends to downplay ADHD as simply being scatter-brained or having a lot of energy, but as Bertilsdotter et al. (2023) describe, ADHDers face many struggles but are still human and deserve to be treated as more than just their condition.

Conclusion

This literature review was conducted with the goal of developing a better understanding of what the process of late diagnosis looks like for AuDHD women. Several common themes emerged including frustrations with the lack of support available, limited knowledge of clinicians, and male-biased diagnostic criteria.

Lack of support pre- and post-diagnosis was one of the most important themes to emerge. Many women expressed struggles with being mentally ready to accept a diagnosis and struggled with an identity crisis after receiving their diagnosis. Pondering thoughts of 'what if I was diagnosed earlier' was common, and some struggled to shed their ableist views and comparisons to neurotypical standards. That being said, diagnosis was also an immense relief for the majority of women as they finally had an explanation for why they felt ostracized in life. This suggests that while diagnosis is important in and of itself, the process could be greatly improved by offering more support to the AuDHD women. For example, clinicians could meet with women before an AuDHD assessment to explain what it means to be AuDHD and how a diagnosis might impact their life. During this, it might also be helpful to explain what the evaluation process will look like so that women can be fully prepared. Since many women noted significant levels of stress during evaluation, knowing what to expect may help ease some of their concerns. After receiving an AuDHD diagnosis, clinicians need to provide more guidance in helping AuDHD women accept their new identity. Being given an information pamphlet isn't enough. While medication may be helpful for some ADHD symptoms, most women would largely benefit from one-on-one neurodivergent affirming therapy and/or AuDHD support groups, specifically those within the AuDHD community. In areas with limited in-person support available, clinicians should also be more aware of AuDHD online communities as an alternative.

In addition to providing more support, many studies discussed the importance of clinicians developing a better understanding of the female phenotype of AuDHD. Most research supports the idea that women are more likely to present with internalizing symptoms, but many clinicians still focus on external behaviors that cause some sort of 'problem' in social settings. This means that many women aren't able to receive their diagnosis until they reach some sort of breaking point in their life when they are no longer able to cope with their symptoms, which is problematic.

Clinicians should be focusing on providing women with enough support so that they don't have to reach a breaking point in order to be heard. Masking may make it harder for clinicians to notice some of these signs, but awareness of masking is vital since the female phenotype portrays that women are significantly more likely to mask their symptoms than men and do so frequently. Given how difficult it is for many women to get a diagnostic appointment in the first place, they shouldn't have to worry about clinician ignorance once there. Increasing clinicians' knowledge of female symptom presentation and masking will likely increase the chance that women are able to be diagnosed earlier in life.

Finally, gender bias in diagnostic criteria and questionnaires was another major theme to emerge from research, which may be counteracted by increased clinician understanding. Since the diagnostic criteria and many other diagnostic tools were created based on research done on white male children, many AuDHD women don't fit well within traditional measures. The fact that most women present with internalized symptoms whereas many of these measures place a strong emphasis on externalized symptoms that cause a 'problem' for others is a massive barrier to diagnosis. While it may be difficult to completely change the diagnostic criteria, clinicians can enter an assessment with the female phenotype in mind. Simply knowing to look for more internalized symptom presentations may help more women get diagnosed. Additionally, clinicians can be selective about which questionnaires they choose to use and how much emphasis they place on questionnaire results. Incorporating a combination of self-report questionnaires, clinical interviews, familial/friend observations, etc. is important to get a full picture of the person and increase diagnostic accuracy.

Limitations and Suggestions for Future Research

While this literature review spoke in great depth about the gender bias against AuDHD women, there are other gender identities outside of the binary who are still excluded from current research. For example, only a couple studies included non-binary people in their samples, and none of the studies included transgender people. Since all gender identities can potentially be autistic/ADHDers, and given the fact that different gender identities often show different symptom presentations (as proven with the female phenotype that differs from the traditional male presentation of AuDHD), it's vital that future research explores a wider variety of gender identities outside the binary.

Similar to the gender bias in AuDHD, there is also a massive racial bias present in research. The majority of current research examines the presentation and experiences of a predominantly white sample when exploring AuDHD. People of other races and ethnicities are just as likely to be AuDHDers, even if they're significantly less likely to be diagnosed and studied (like women). This is a major limitation of most existing research, so in the future, research needs to be done on how autism/ADHD presents in people who aren't white. Forming a general phenotype of symptom presentation––similar to that of women––would be beneficial for increasing clinicians' understanding and ability to provide support.

Another limitation of current research is that most researchers look at autism or ADHD individually as opposed to a combined diagnosis. While it's true that not everyone who is autistic is also going to have ADHD, there is a high rate of co-occurring diagnosis between autism and ADHD, so much so that the neurodivergent community coined the combined term 'AuDHD' to refer to a joint diagnosis––but this term has yet to become popularized in the field of academia (Craddock, 2024). Future research needs to do a better job of taking a joint AuDHD diagnosis into consideration to establish any differences in symptom presentation and the resulting implications for diagnosis and support/treatment.

Finally, future research needs to include neurodivergent voices in all stages of research, not just as participants. While there are many neurodivergent researchers starting to emerge, this usually only includes a small population of upper-middle class white people and is not representative of the neurodivergent community as a whole. In many ways, the neurodivergent community is ahead of researchers when it comes to knowledge of autism and ADHD, so it

would be beneficial to include them in the planning process. For example, as previously stated, the neurodivergent community created the term 'AuDHD' to refer to a joint autism/ADHD diagnosis, and the community also had a better understanding of different gendered symptom presentations before the female phenotypes of autism/ADHD were widely accepted in research. Furthermore, there is still a significant sum of research that aims to find the cause and cure for autism/ADHD, despite the majority of the neurodivergent community stating that they don't want a cure (Craddock, 2024). Since research is aiming to help neurodivergent people, it's crucial that researchers take neurodivergent opinions into account.

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