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Autism Spectrum Disorder: Difficulty in Adult Diagnosis

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Abstract

Adults have a significantly harder time being diagnosed with autism, and this is due to many reasons, such as the paucity of information about adults with autism, their diagnosis being missed as a child, lack of providers who feel confident in their knowledge to diagnose autism in adults, and an autistic adult's ability to mask and cope in a neurotypical world since childhood, among others. Few tests are available and specifically target adult diagnosis. Most tests are created for children or youth and may not account for the difference in the presentation of autism in adults and the coping skills and masking they have required to develop throughout their lives. This paper talks about the need for adequate knowledge and testing for autism in the adult population.

Resumé

Il est beaucoup plus difficile de diagnostiquer l'autisme chez les adultes, et ce, pour de nombreuses raisons, notamment le manque d'informations sur les adultes autistes, le fait que le diagnostic n'ait pas été posé pendant l'enfance, le manque de prestataires qui ont confiance en leur capacité à diagnostiquer l'autisme chez les adultes, et la capacité de nombreux adultes autistes à faire preuve de camouflage social et à se débrouiller dans un monde neurotypique depuis l'enfance, entre autres. Il existe peu de tests ciblant spécifiquement le diagnostic chez l'adulte. En effet, la plupart des tests sont conçus pour les enfants ou les adolescents et peuvent ne pas tenir compte de la différence de présentation de l'autisme chez les adultes et des capacités d'adaptation et de camouflage qu'ils ont dû développer tout au long de leur vie. Cet article traite de la nécessité d'une connaissance et d'un dépistage adéquats de l'autisme dans la population adulte.

Keywords

Autism, adult diagnosis, masking, assessment, ASD, autism spectrum disorder, diagnosis

Mots-clés

Autisme, diagnostic chez l'adulte, masquage, évaluation, TSA, troubles du spectre autistique, diagnostic

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Introduction

Autism Spectrum Disorder, hereafter referred to as ASD, is a lifelong neurodevelopmental condition that was only recognized in children for many years. Recently, there has been a notable increase in the availability of ASD-focused services for children and an improvement in the early diagnosis and intervention for young people with autism — to the extent that doctors can correctly diagnose ASD as young as infancy (Adams, 2016[CW1]). The issue in clinical psychology is the paucity of screening and diagnostic testing designed for adults, even though research shows similar rates of the disorder reported in this population as in children (Magiati, 2016). Another issue is the limited number of professionals who treat and are trained in diagnosing ASD in the adult population (McKenzie, 2015).

This paper defines ASD according to multiple diagnostic publications. It discusses some reasons ASD may be overlooked in children and the effect growing up undiagnosed can have. The paper also compares some of the available screening and testing methods developed for children and examines whether these measures are helpful for adults. Furthermore, it indicates the need to develop more accurate screening, diagnostic, and treatment options for those over 18.

History

The diagnostic criteria for ASD are continuously being adapted. Before Kanner described *the infantile autistic disorder* in his 1943 paper, the syndrome was viewed not as a neurodevelopmental disorder but as a result of poor parenting. This is noted in his paper; according to the Freudian viewpoint, children whose mothers were cold and un-nurturing (refrigerator mothers) were more likely to develop the syndrome. It was also viewed as something children outgrew (Kanner, 1943; Sponheim, 1996). Moreover, Kanner differentiated autism from schizophrenia, yet until the 1970's, they were still mistaken for each other (Kanner, 1943; Green et al., 1984).

Diagnostic Criteria

With the DSM-5 and the IDC-10, there is a consensus on a diagnosis. The DSM-5 has two symptom categories: social communication/interaction and restricted/repetitive interests (Adams, 2016; American Psychological Association, 2013). Deficits in social communication are broken down into groups: problems with social initiation and response, problems with non-verbal communication, and problems with social awareness and insight, as well as general concepts of social relationships. Restricted/repetitive patterns of behaviour, interests, or activities are broken down into four categories; Atypical speech, movement or play, rituals and resistance to change, preoccupations with objects or topics, and atypical sensory behaviours (APA, 2013).

To receive a diagnosis, the symptoms must be present in early childhood [but may not manifest fully until social demands become more than the individual can cope with]. The combined symptoms must also impair the individual's everyday functioning. Furthermore, according to the DSM-5, ASD has three severities. Level 1 [sometimes referred to as "high functioning" autism] requiring support, level 2 requiring substantial support, and level 3 requiring very substantial support (APA, 2013).

The DSM-5 views Autism as a spectrum and has included Asperger's syndrome within this

spectrum (APA, 2013), whereas the IDC-10 differentiates between Asperger's and what it terms "Childhood Autism" (APA, 2013; WHO, 2003). In the DSM-5, the previous diagnosis of Asperger's is lumped in with ASD. This is a better indication of autism being a spectrum because every person with autism struggles in different ways and with different aspects of their lives. Furthermore, Asperger's is named after the Nazi, Hans Asperger, and the DSM moved away from using this term which is an improvement on the original name of ASD-1. ASD as a spectrum allows for a complete picture when diagnosing because it includes many different factors degrees of the disorder while still including a number (1-3) for the "severity" of the disorder. In the IDC-10, 'communication' and 'social' impairments are separated into two categories (WHO, 2003). These are not the only two areas in which autism affects an individual, and thus is less inclusive than the DSM-5 for this particular disorder. It is important to understand how the disorder is classified to understand what measures are necessary to diagnose it accurately.

Factors Contributing to Underdiagnosed ASD

The reason ASD is so frequently overlooked is multifaceted. Gender can play a role (Murray, 2016). There is a distinct difference in how symptoms of ASD are presented between sexes. Wilson studied adults who were being diagnosed with ASD for the first time, trying to assess why their diagnosis had been delayed (Wilson, 2016). He explains that women are more likely to find the ability to mask their symptoms as they age and do not always act on symptoms in the same way as males, which leads to females being left untreated or misdiagnosed at a higher volume than their male cohorts (Wilson, 2016). For instance, girls may have different types of obsessive or repetitive behaviour, and their 'special interests' tend to be more socially acceptable — thus, even though they display symptoms of autism, they are not recognized until later in life (Wilson, 2016). There is also an unconscious bias, where a doctor may have a template for what autism looks like and base their diagnosis on this instead of on the actual diagnostic criteria. This happens in all areas of healthcare but is very prevalent when it comes to a diagnosis of Autism Spectrum Disorder.

A family's income may also play a role; there is a significant out-of-pocket expense for these assessments, which many families cannot afford. In addition to the initial assessment, the responsibility of paying for subsequent treatment and support is also placed on the caregiver or family. Race is another factor. A study which looked at children being screened and diagnosed with ASD. Although there is no known difference in the prevalence or presentation of ASD between different races, Mandell found that African American children were diagnosed approximately 1.4 years later than white children, and the diagnosis time was prolonged for these individuals as well (Mandell, 2007). The availability of screening methods for ASD sensitive to social-cultural differences needs to increase, as well as intervention programs for these children once ASD has been identified. Some evidence also shows that cultural factors may also affect a parent's ability to recognize or interpret the signs of ASD in their children (Mandell, 2007). Parents who view a child's actions as negative are more likely to seek help for the child, compared to parents who view the child's behavior as part of the child's personality and do not see the need to seek help (Barahona-Corrêa, 2017). The severity of symptoms also plays a role in the age of diagnosis as well. The traits of having an IQ lower than 70, being male, and having developmental regression are all associated with the individual receiving an earlier diagnosis (Adams, 2016).

Another reason that children often are not diagnosed until they go to school is that there are very few pediatricians who will diagnose ASD (Campbell & Sceil, 2016); this can be due to a lack of knowledge of the disorder itself, or lack of confidence in their ability to screen/test for it. However, even though the number of doctors has increased from 8% to 50% in the past few years (Campbell & Sceil, 2016), it still leads to a problem. With increased awareness of ASD and the characteristics of the disorder, more people seek a diagnosis. There is then an increase in people both seeking an ASD diagnosis and an increase in specialist referrals due to physicians' inability to diagnose this disorder, and patients are then sent to specialists. The waiting list for these doctors becomes longer, and because of this, the wait time for patients also increases significantly. Subsequently, there ends up being a bottleneck in the service flow. Not only does this ensure that individuals who need prompt assessment are unable to receive it, but it also extends the diagnostic process for everyone seeking a diagnosis. A system that can handle the large increase in ASD referrals is vital to ensuring children are accurately screened and diagnosed with ASD.

Adults With ASD

A study looked at adults being assessed for ASD for the first time. The differences between the individuals who received a diagnosis of ASD at their assessment and those who did not receive a diagnosis of ASD at their assessment were examined (Geurts, 2011). One difference was that adults who received the diagnosis reached out to the clinic much earlier (Geurts, 2011), which may suggest that their symptoms became more noticeable or an increased issue at an earlier age. Furthermore, despite both groups having similar exposure to mental health services in the past, those who received an ASD diagnosis had fewer previous diagnoses than those who did not receive an ASD diagnosis (Geurts, 2011).

It is recommended that adults seek assessment for ASD when they experience difficulties in social interaction and social communication or experience rigid and inflexible behaviours; resistance to change, and restricted interests, and if symptoms are affecting major areas of their life (i.e., work, school, relationships) (NICE, 2012). Nevertheless, adults have difficulty being diagnosed; for instance, clinicians find it more difficult to diagnose ASD in adults because they may present with less obvious impairments (Eriksson, 2013). Additionally, as individuals get older, they are sometimes misdiagnosed with another disorder, like OCD or ADHD which can have overlapping symptoms with ASD (McKenzie, 2015).

Little research has looked at ASD in the elderly population (Campbell & Sceil, 2016). Elderly patients presenting with ASD likely did not receive a diagnosis because the strong awareness of the disorder did not exist as it does now. Just a few decades ago, an individual presenting with symptoms of ASD may have been institutionalized (Hirota, 2018; Nierkerk, 2011). The lack of awareness, coupled with the fact that Asperger's syndrome and higher functioning forms of ASD were not acknowledged in the DSM until the 1990s, has led to many individuals being missed as children and seeking a diagnosis as an adult (APA, 1994[CW2]).

Available Screening and Diagnostic Tools

The lack of diagnostic tools for adults remains a serious methodological challenge for researchers and clinicians. A study done in 1989 is evidence that psychologists have been looking into testing adults for ASD for more than three decades (Mesibov, et al., 1989) and that this has

been an issue for an extended period of time. There were doctors showing concern and awareness around the disorder even before the heightened awareness around it, not just in the population it was increasingly being diagnosed in but also thinking ahead to adults[CW3] . The Childhood Autism Rating Scale (CARS) has been found to have higher validity than other childhood rating scales (Morgan, 1988); however, studies point to CARS being unreliable and having unsatisfactory measurement values (Baghdadli, et al., 2017). Researchers compared scores on the Childhood Autism Rating Scale (CARS) obtained by patients before age ten with results collected from the same children again after age thirteen (Mesibov et al., 1989). They found an improvement in the children's overall scores in almost every category. They concluded that if the measure were to be used in adolescents or adulthood, it would be more accurate to use a cut-off score lower than that used with children (suggested cut of scores: children: 30; adults: 27) (Mesibov, et. al., 1989). The improvement in scores shows a difference in the overall presentation of the disorder as one ages, and tests need to be adapted to fit this change. Mesibov points out the irony in the fact that the one score that did significantly increase was the "general impressions" category which translates to 'how autistic a person seems.' (Mesibov, et. al., 1989). This score goes up because many behaviours that may be acceptable as children seem increasingly unnatural as the individual ages. Thus, as these children age, their behaviour is more likely to stick out and to be noticed more by others – and possibly by the individual (Mesibov, et al., 1989[CW4]). The individual becoming more aware of their symptoms, or having symptoms become an increased issue as they grow older, may lead to the individual seeking a diagnosis (Lewis, 2016a).

Screening Measures

The author of an article reviewing nine different ASD screening methods found that most yielded unsatisfactory results, stating that "only the AQ-50, AQ-s, RAADS-R, and RAADS-14 had satisfactory or intermediate values for their psychometric properties" (Baghdadli, et al. 2017). The original Ritvo Autism Asperger's Diagnostic scale (RAADS) was developed to address the need for more ASD screening services for adults. Before the RAADS, the only peer-reviewed measure for adults was the Autism Spectrum Quotient (AQ) (Ritvo, 2010). The AQ is another screening test for adults, which is mailed and sent back by post (Magiati, 2016). People often use it as a self-diagnosis tool, although it is not intended to diagnose independently, regardless of who administers it (Magiati, 2016). The RAADS-R is a revised version of the RAADS scale that includes a self-report section for clients to complete. This version contains 80 questions and is completed in a clinical setting (Ritvo, 2010). The self-rating questionnaire in the RAADS-R has proven helpful when working with individuals with suspected comorbidities that may otherwise lead to a prolonged, unclear diagnosis (Eriksson et al., 2013). The RAADS-14 is a shortened version of the Ritvo Autism Asperger's Diagnostic scale, which may be helpful in clinical outpatient settings. This measure should be used in individuals without suspected comorbidity due to its shortened length and less ability to screen for differential diagnoses (Ritvo, 2010).

Diagnostic Measures

Although both the Autism Diagnostic Observation Scale (ADOS) and Autism Diagnostic Interview (ADI) were developed for children, they both can be used in adults (Baghdadli et al., 2017). A revised version of the Autism diagnostic interview, ADI-R, which took out many

unnecessary or misleading questions, requires the interviewer to have specialized training to perform the test. The ADI-R takes 2 hours, can be used on children or adults with a mental age above 2, and is usually done in a clinical setting (Hirota, 2018). The test is best used on those without suspected comorbidity. While this is a well-respected diagnostic test, some disadvantages are that it is very long to conduct, is costly to administer, and requires the interviewer to be trained in administering it (Russel, 2016). Some clinicians may be hesitant to use it because of this (Joshi et al., 2011). There is also a shorter 40-question true or false informant survey, which corresponds with the ADI-R and signals a need for conducting the entire test. The ADOS-2 is an instrument created by the same authors and requires only 40-60 minutes to complete. It is a list of observations a licensed examiner should look for as different scenarios are conducted (Joshi et al., 2011). The ADOS is sometimes considered a gold standard, as is the ADI-R; however, they both tend to be more costly, labour intensive, and require the examiner to have extensive training, which limits who can administer them (Joshi et al., 2011; Magiati, 2016; Russel, 2016).

The Adult Asperger's assessment (AAA) is an emerging diagnostic tool for adults. However, it is relatively new, so few professionals are trained in administering and scoring this test (Kuenssberg & McKenzie, 2011). Additionally, it takes a long time to administer. The AAA includes two components; the empathy quotient (EQ) and the autism quotient (AQ). It includes two self-report questionnaires and a clinical interview with the client and possibly an informant (Kuenssberg & McKenzie, 2011). The AAA is administered via computer, not mailed to the client, and sent back (Ritvo, 2010). The test has been reported as having good content validity (Baron-Cohen et al., 2011). The authors of one of the few studies which looked at the AAA found that the test tends to overweight social and communication factors (Baron-Cohen et al., 2006). Because social and communication are measured separately, some symptoms may be counted twice, leading to overdiagnosis. The findings from this study correspond to the DMS-5 more so than the IDC-10 because it shows that separating these two categories, can lead to overdiagnosis of the disorder.

One researcher created a DSM-based structured diagnostic interview comprising 16 questions with a sensitivity of 94% (Frazier et al., 2012). The author suggests it could be a quick, cost-effective assessment tool. Although there was a change to the DSM during the study, they retained the diagnostic criteria of DSM-III-R and then, after the study was complete, checked the results with the DSM-IV criteria, and there was a high correspondence (Frazier et al., 2012).

The AMSE (Autism Mental Status Exam) was created for clinicians who were knowledgeable about the disorder but were not trained to give standardized assessments (Grodberg, 2014). Administering this test requires little training; the training can be done online, and itis to be done in a clinical setting (Grodberg, 2014). The AMSE is also shown to compare well to a diagnosis of ASD when looking at DSM-5 (Magiati, 2016). However, it should not be a substitute for a more comprehensive examination. No single measure should be used alone during the diagnostic process (Mazefsky et al., 2010). Results can be misleading for many reasons; underestimation (Frazier et al., 2012) and overestimation (Gładysz et al., 2018).

Why Addressing ASD in Adults is Important

Delayed and underdiagnosis of ASD is common and can impact the individual's quality of life. A common symptom of ASD is alexithymia, which is difficulty coming up with words to

express oneself (Lewis, 2016b). This leads to an increased issue with assessment as an adult, where the diagnosis is based more on the patients' descriptions of childhood. Individuals with undiagnosed ASD or whose diagnosis has been delayed until adulthood are at a higher risk of depression, anxiety, and suicide (Lewis, 2016b). Reports have stated that two-thirds of adults with newly diagnosed Asperger's reported having considered suicide, and half of those individuals had made a plan or attempted it (Lewis, 2016b). Sadly, the number could be even larger. There have been findings that alexithymia can also lead to underdiagnosis and untreated depression in individuals with ASD (Lewis, 2016b). This can be due to the individual's inability to accurately describe the severity and impact of the symptoms they're experiencing on their life (Lewis, 2016b).

Adults with ASD also tend to be more anxious and have a higher rate of depression than the public (Russel, 2016). Sensory over-responsivity has been shown to lead to anxiety (Tavossoli, 2014). This increased sensory response and anxiety can further compromise someone's ability to function daily. Individuals can present as being more irritable, aggressive, violent, or suicidal (Tavossoli, 2014). Self-harm is also a dangerous symptom of ASD. These symptoms can produce problems with the patient and their family and occasionally result in hospitalization (Russel, 2016). Notwithstanding high rates of comorbid anxiety disorders, psychological intervention treatment for adults with ASD has been shown to be effective (Russel, 2016; Howlin, 2015). It is so important for physicians to look into the possibility of ASD when treating individuals for other suspected ailments.

Conclusion

Remaining undiagnosed, if an individual has ASD, can be detrimental, and it is always best to try for early intervention. Some tools developed for adults, like the AAA and AMSE, though more research needs to be done into their validity. More testing methods inclusive of sex, race, culture, and socio-economic status are vital in individuals receiving proper diagnosis and care. However, it will not be perfect regardless of what is done in an attempt at early intervention. The fact that children continue to be missed being diagnosed further validates the need for more adult-focused treatment. Not every person with autism spectrum disorder will be diagnosed in early childhood, and the resources need to be there to help support those individuals seeking a diagnosis at a later age.

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