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Diagnosis of autism in older women: reflections of a psychologist and a client

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Editorial comment:

Tamara May works in autism research and is a psychologist in private practice in Melbourne, Australia. Carol Adams is a Professor at Durham University working in the field of sustainable development accounting and accountability, including accountability for social justice issues. In this paper, they explore the issues in diagnosing autism in women and make recommendations for diagnostic assessment. The process of Carol's diagnosis from first suspicions to the confirmation of autism is presented. Carol talks about the process of completing the assessment tools and the response to getting her autism diagnosis. Tamara identifies some of the current issues in the diagnostic assessment of autism in adulthood, and both make suggestions for how the process can be enhanced.

Introduction

A generation of adults who meet today's diagnostic criteria for autism would not have been identified as having autism earlier in their lives. These older adults are seeking autism assessment services to explain a lifelong feeling of being different and sometimes significant challenges. In this case study, we explore the challenges in recognising autism in women.

The diagnostic criteria for autism have undergone considerable change over the last 40 years becoming much broader in the most recent version of the DSM-5 (American Psychiatric Association, 2000; 2013). There is now also greater public awareness of autism and less associated stigma, as more and more people identify as neurodivergent (May, Brignell, & Williams, 2020). Adults who now meet the diagnostic criteria have been referred to as a 'lost generation' who were not recognised or supported (Lai & Baron-Cohen, 2015).

There are challenges for clinicians and individuals undergoing assessment despite the diagnostic guidelines for adults (NICE, 2016; Whitehouse, Evans, Eapen, & Wray, 2018). These include: a lack of well validated tools that can differentiate autism from other psychiatric conditions; and issues in recalling and gaining a good history of the adult's childhood and early developmental period.

Undiagnosed adults can be very self-critical and feel a sense of failure and struggle to understand why they are different or why certain activities are challenging, but appear easy to others of similar age and intelligence. An autism diagnosis can help to explain a strong sense of social isolation, not fitting in, and feeling like their brain works differently.

In the case study presented below, we examine the diagnostic process for Carol, from first suspicion through to a diagnostic decision.

Case study: Carol's experience

What prompted you to seek a diagnostic assessment for autism in adulthood?

In 2019, I read a review of a novel by an autistic author, Helen Hoang, and felt compelled to buy it, seeking to gain a better understanding of someone who has a vivid and detailed visual memory of early childhood, a preference for being alone and yet a keen intuition about people. I had not read a novel for decades. My reading was vast, but limited to material related to my field of expertise. I devoured Hoang's novel (2018), its sequel (2019) and then all the novels by Graeme Simsion depicting the autistic academic, Don Tillman and Rosie (Simsion, 2013; 2014; 2019). I found the diverse autistic characters intriguing and there was something, perhaps a way of seeing the world and being seen by the world, that I could relate to. I did not see the characters as being like me, other than being a little different and somewhat intense.

Some weeks later, a Clinical Psychologist noted that I needed be direct and to say what I mean when conversing with this autistic person I know. My reply, without thinking, was that I am always direct and that (drawing on the novels I'd read and TV shows such as *The Good Doctor* and *Atypical*), I thought I had other stereotypical autistic traits. Some days later, I was shocked as I realised what I had said and I researched widely about the characteristics of being an autistic woman (male characters dominated the novels and TV shows).

I watched YouTube videos of people recounting their experiences. I listened to Sarah Hendrickx (2019) talk about the lives of autistic women. Many are tom boys, wear comfortable clothes and, as teenagers, when socialising starts to take a more complex form, suffer from depression and anorexia. Autistic people tend to be fair-minded and don't discriminate on the basis of status, wealth, race, etc: to do so is illogical. I saw myself in *all* of this.

The characteristics I related to most were those I also like in other people: logical, evidence-based decision making; tenacity, integrity, being direct, honesty, persistence, focus, bringing a different perspective. I am able to assimilate and make connections between different ideas, bits of information and see the bigger picture. When I do socialise, I am aware I am not a natural at it, but I don't feel I am 'masking'. I do however find it tiring.

I had been on a long-time quest to understand why an adult I spent time with as a child did not warm to me and why my teenage struggles seemingly went unnoticed by those around me. At three significant adult experiences - a funeral, being raped and a period of working in a toxic cloud of confusing office politics, I was thrown back to the trauma of adolescence, and feelings of not knowing who I was or how I felt resurfaced. I did not think I was a bad person, yet I seemed to be judged as one. The response of others to my differences increased the feelings of isolation.

As a child I spent hours studying alone in my room and, before and after a period of controlling what I ate (not much), I ran long distances. Later, as an adult, I found pleasure in the company of people from diverse backgrounds and the joy of being a mother. But at 60, I still needed answers to questions that troubled me.

Tamara's perspective as a psychologist

Carol's experience is now a common way that prompts an individual to consider whether they have autism. The sheer volume of adults seeking an autism assessment results in long waiting times for many assessment services (Jones, Goddard, Hill, Henry, & Crane, 2014). In some countries, recommendations for multi-disciplinary team-based diagnostic assessments for adults (NICE, 2016) are not practical due to shortages of clinicians. Individuals may need to privately fund the assessment.

Women with autism may be misdiagnosed with other conditions such as eating disorders or personality disorders (Gillberg, 1983; Rydén, Rydén, & Hetta, 2008). They may also be more vulnerable to experiencing trauma, including bullying (Bargiela, Steward, & Mandy, 2016). Carol reported having previously seen a number of different counsellors over the years to help with situations that triggered psychological distress. None had suggested that she might have autism, which illustrates the need to enhance awareness of autism amongst mental health professions.

The diagnostic assessment experience

Carol's perspective

In preparation for my first appointment, I wrote down everything I could think of that might be relevant to a diagnosis of autism, in chronological order. Reliving my adolescent experiences was disturbing but I felt this account was relevant to the process. I was surprised at how many of the points that I had taken as unconnected characteristics of self, when put together, looked like autism. But the idea of having 'deficits' when I have significant strengths and some rewarding relationships seemed ridiculous. Whilst I was

aware I communicated directly, I saw that too as a strength because I prefer to be on the receiving end of clear communication. I find indirect communication confusing and hence inefficient. I now realise that simply being different to others has presented difficulties for me.

I wear earplugs on trains, sometimes at work and always to sleep. I could not bear the nylon sheets we had when I was young, I wear comfortable clothes, I prefer to watch TV in darkness, and I do not like sitting facing the TV with its flashing lights if I am not watching it. But I don't have heightened sensory issues the way some autistic people do, and noise doesn't cause the pain referred to in the Ritvo Autism Asperger Diagnostic Scale – Revised (RAADS-R) questionnaire. Completing the RAADS-R questionnaire was troublesome. For many questions none of the answers fitted fully.

The experience of trying to tell a story and making objects something they were not, was excruciating. I prefer the spoken word and give it more weight in interpreting the communication. Where words are out of kilter with a person's body language, I would likely still assume it was honest. Similarly, in a meeting, I might not accept a head nod as an acknowledgement of a contribution, instead requiring a verbal response to properly understand.

I imagine some people thinking but '*a lot of people experience that*'. That may be true, but it's also true that I struggled with adolescence more than my contemporaries. I now live a happy, fulfilled life and workwise have delivered what my employers want (perhaps at times with an honesty they didn't).

Tamara's perspective

Autism was not mentioned in the DSM-III that existed during Carol's childhood and only childhood type schizophrenia mentioned autistic behaviour, a diagnosis that was inappropriate for Carol. The diagnosis of autism now requires evidence of autistic symptoms being present in the early developmental period. DSM-5 removed the requirement that symptoms need to be present before the age of 36 months as stated in earlier versions. Symptoms may not be obvious until social demands become greater (as in adolescence) (American Psychiatric Association, 2013).

Carol's detailed written history provided highly relevant diagnostic information highlighting patterns and life stressors relevant to autism. Three people who knew Carol as a child provided some information via the Childhood Autism Spectrum Test (CAST) (Scott, Baron-Cohen, Bolton, & Brayne, 2002). They were asked to recall Carol's behaviour between the ages of 5 and 12 years to complete this report. Only one person could complete all the CAST questions. Their answers were scored above the cut-off point for the test, indicating clinically significant levels of autistic symptoms.

The current tools to assist with an autism diagnosis for adults include several self-report questionnaires. The adult Autism Quotient (AQ 10 and 50) is widely used, due in part perhaps to public exposure (Greenberg, Warrier, Allison, & Baron-Cohen, 2018), and its recommendation for use in NICE guidelines (NICE, 2016). However, it performs poorly in being able to differentiate adults with autism from other psychiatric conditions (Ketelaars et al., 2008) or even to predict a diagnosis of autism (Ashwood et al., 2016). The RAADS-R (Ritvo et al., 2011) is another commonly used self-report questionnaire and also recommended in NICE guidelines (NICE, 2016). Independent verification of these tools

often reports poor sensitivity and specificity (Conner, Cramer, & McGonigle, 2019; Sizoo, 2015). For example, 55% of adults with other psychiatric disorders who completed the RAADS-R French version scored over the cut-off but did not have autism (Picot et al., 2020). Psychiatric disorders that can have similar symptoms include ADHD (Attention Deficit Hyperactivity Disorder), generalised anxiety disorder, social anxiety, personality disorders including Borderline, Schizoid, Schizotypal and Avoidant, eating disorders, complex PTSD or complex developmental trauma. These may result in false negatives using the AQ (Ashwood et al., 2016). Thus, differential diagnostic decisions are not always aided by the AQ or RAADS-R (Picot et al., 2020).

The clinician-administered Autism Diagnostic Observation Schedule (ADOS) is considered the reference standard in childhood autism diagnostic assessment, however, the psychometric properties of this tool in adults can be poor (Conner et al., 2019). For example, while the sensitivity of the ADOS was 92% in a study of adults presenting for autism assessments, the specificity was only 57% (Adamou, Jones, & Wetherhill, 2021). The clinician needs to carefully assess potential differential or comorbid diagnoses and use other tools to screen for the most common psychiatric problems that may mirror autism symptoms. For Carol, her self-report on the RAADS-R was above the indicated clinical cut-off for autism.

Carol also scored in the autism spectrum range on the ADOS 2nd Edition, Module 4. This tool elicited some autistic behaviours relating to social communication that were not evident in clinical interview. This included unusual eye contact when she was engaged in activities and challenges with activities which involved pretending. Notably, she scored zero on the stereotyped behaviours and restricted interests during this observation

assessment, but these were indicated from her self-report. For example, Carol reported eating a narrow range of food, repetitive thoughts, or 'thinking in a loop', and sensitivities to sounds.

Carol completed other broad screens for psychiatric problems as part of the assessment. Minimal symptoms were indicated on the Depression, Anxiety and Stress Scale (Lovibond & Lovibond, 1996), similarly for the Adult ADHD Self-Report Questionnaire (Kessler et al., 2005). Carol reported via clinical interview that she experienced a mismatch between her childhood needs and her environment growing up. However, she was not experiencing the symptoms of complex trauma at the time of her assessment. As such, no other adult psychopathology was indicated which assisted in overcoming the challenges with poor specificity of the RAADS-R and ADOS Module 4 and having confidence in their results.

Having the autism diagnosis confirmed

Carol's perspective

Despite all the information gathering, the diagnosis was a shock. Everything I'd been working towards and everything I judged myself by was based on being neurotypical and, at 60, I found out I was not. It seemed surreal. In her book, *Odd Girl Out*, Laura James (2018) likened this to thinking she was a dog and finding out she was a cat. There was a period of disbelief, of grief, followed by days of acceptance and days of not.

I try to work out emotional problems by thinking and with logic and my thoughts (on big emotional issues) get stuck in a never-ending loop. I am sometimes uncomfortable joining in conversations in groups. When plans change it unsettles me. Now I know why.

But I don't see it as my disability, disorder or deficit. I also see why I have a unique bundle of strengths.

As a child I was judged because I walked out on group conversations that didn't interest me and I didn't express a need for social interaction. I worked hard and excelled at school hoping it would bring approval. Nothing ever seemed like enough, but I kept trying. Now I know who I am. Many of the problems that autistic people face stem from a lack of understanding of their difference, rather than what diagnostic manuals refer to as deficits or disorders.

Tamara's perspective

For some clients, a diagnosis of autism is a relief but various emotions, including no emotional response, may be experienced (Huang, Arnold, Foley, & Trollor, 2020). Diagnosis can prompt some individuals to review their life with this new knowledge, to re-analyse challenging social situations and relationships. Some also lament missed opportunities from a lack of accommodations they needed in social, education and occupational settings resulting in underachievement and interpersonal challenges. A process of grief including periods of anger, denial, depression and eventual acceptance can occur. Carol's diagnosis ultimately strengthened her sense of self.

Suggestions for improving autism diagnostic assessment in adulthood

Carol's perspective

The assessments for adults need an overhaul in four key ways. Firstly, they need to **focus on autistic strengths**. We should not accept that difference means we are inferior. Secondly, **consider our common experiences**. Many of us can't remember or don't

know what we were like as children and perhaps there is no one else who does. Autistic adults have many common experiences. These common experiences as described by Sarah Hendrickx (2019), Drew (2017) James (2018) could be incorporated into diagnostic tools. Thirdly, **allow for the different presentations between genders.** Numerous researchers, clinicians and autistic women have identified differences between women and girls on the spectrum and men and boys. These need to be reflected in the diagnostic process and the tools used. Finally, **involve autistic people in the design of tests.** This applies not only with respect to content, but also in allowing designs so that autistic people can answer honestly, rather than pick the closest answer.

Tamara's perspective

A UK survey suggested only 47% of those who had received an autism diagnosis in adulthood were satisfied with the process (Jones et al., 2014). Dissatisfaction related to delays, having to see numerous clinicians, and poor post-diagnosis support (Jones et al., 2014). Assessment of autism in adults requires clinicians with a broad knowledge and experience of adult psychopathology, child development and autism and related diagnoses. There is a lack of such experienced clinicians in many countries.

There is currently no adult specific autism criteria in DSM-5 or ICD-10/11. This is unlike ADHD, for example, where a reduced symptom count is provided for those over 18 years with examples of adult specific symptoms (American Psychiatric Association, 2013). Having clear adult specific symptom examples and corresponding thresholds for severity would be helpful for clinicians to make reliable and valid adult autism diagnoses. Improved tools to assist with the diagnosis of adult autism that can differentiate other psychiatric conditions is also needed.

There is a growing awareness of autistic women and much public information from personal accounts. There is a notion of different symptoms or a female presentation of autism. The research in this area has not yet been able to reliably define or identify unique female symptoms, that would warrant changes or a different symptom criteria for women and girls. Autism symptoms based on the existing diagnostic criteria have been found to be fairly similar in males and females, with the exception of fewer repetitive and restricted behaviours in females (Van Wijngaarden-Cremers et al., 2014). Having fewer obvious restricted and repetitive behaviours can result in autism not being considered and women may remain unnoticed. Some reported symptoms of autistic women overlap with other disorders, involving emotion regulation issues that exist in other psychiatric conditions. The notion of camouflaging is also poorly defined and can be challenging for researchers and clinicians to operationalise (Fombonne, 2020). Going beyond the current conceptualisation of autism symptoms to a finer grained approach, such as through the use of research domain criteria (RDoC), will assist with better understanding and identifying women with autism and any unique symptoms or specific profiles.

Many adults who seek an autism assessment have been able to function in multiple areas of their life, succeed at very high levels, have families, run households and navigate life. They may report finding these tasks psychologically harder and may have some functional areas of deficit, such as repeated workplace issues or may have few friendships and consequently experience some psychological distress. They may have also been able to organise their environments so they thrive in supportive relationships, employment and in their day to day lives. The threshold of functional impairment required by the DSM may not be clearly met in these cases. The broader autism phenotype (Piven,

Palmer, Jacobi, Childress, & Arndt, 1997) may accurately describe these individuals with subclinical impairment. Having clearer definitions of the functional impairment required for clinical significance is needed.

Concluding comments

Carol's perspective

Some people know they are autistic, accept it and don't feel the need to get assessed. If you have got to the point where you think you might be, but aren't sure, you probably don't have anything to lose by finding out. Critically, my diagnoses helped me to understand that my difference is not a character defect.

Collectively, autistic people bring significant benefits to business and society (Adams, 2020). Singer (1999), who is credited with first coining the term neurodiversity, from neurological diversity, notes (p 64):

“The neurologically different represent a new addition to the familiar political categories of class/gender/race...”

Much is yet to be done to recognise the neurodiverse and their contributions and Singer offers a way of thinking about neurodiversity as another strand of diversity which leads to better decision making and understanding difference that is fundamental to achieving equal opportunities.

Tamara's perspective

Adult autism assessment can be a challenging but rewarding process for clinicians and clients alike. Finally receiving diagnostic clarity can be extremely helpful for individuals to better understand themselves and seek and access support via autism communities or

other support services. Improvement in the assessment process to enable timely, rapid assessments is needed, especially with the growing awareness of autism resulting in an increase in requests for assessment. Making the process of autism assessment simpler, faster, and more accurate should be a goal for researchers and clinicians alike.

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