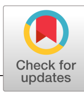

CLINICAL REFLECTION

Adult attention-deficit hyperactivity disorder: time for a rethink?[†]

Shevonne Matheiken, Meriç Erden, Rajeev Krishnadas & Mariana Pinto da Costa

SUMMARY

Recent years have seen a rise in media coverage as well as demand for specialist attention-deficit hyperactivity disorder (ADHD) assessments in adults and children. This article explores the challenges in the diagnostic process for adult ADHD, amidst much misinformation and controversy. In doing so, we look at the social model of ADHD; a glossary of terms to better understand lived experience; underdiagnosis and misdiagnosis; and the fallacy of the 'high functioning' label. We propose the use of co-production to bridge the gap between the medical and social models. We conclude with suggestions for future research. The article includes anonymous contributions from doctors with ADHD.

LEARNING OBJECTIVES

After reading this article you will be able to:

- describe the social model of ADHD
- outline challenges in reaching an accurate diagnosis or exclusion of ADHD, particularly in certain groups of adults
- propose research ideas for the future on this topic.

KEYWORDS

Attention-deficit hyperactivity disorder; co-production; pandemic; neurodevelopmental disorders; stigma and discrimination.

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[†]This article is based on an oral presentation by S.M. that won first prize in the World Psychiatric Association's 3 Minute Presentations Competition at the 22nd World Congress of Psychiatry in Bangkok, Thailand, 2022. The presentation was titled 'Racing thoughts and racing cars – adult ADHD, a golden opportunity for meaningful co-production'. The theme of WCP 2022 was 'Psychiatry 2022: the need for empathy and action'. *BJPsych Advances* offered first-prize winners the opportunity to write an associated article for the journal, subject to the usual academic peer review.

What do you think of when a patient tells you about 'racing thoughts' or a mind that is 'never quiet'? Do you think about anxiety or hypomania? Do you also consider screening for adult attention-deficit hyperactivity disorder (ADHD)?

A rise in the demand for adult ADHD assessments

The past few years have seen a significant increase in demand for ADHD assessments in the UK. A recent meta-analysis that collated data from 18 studies across 10 countries concluded that children experienced a significant increase in ADHD symptoms during the COVID-19 pandemic (Rogers 2023). A recent paper (Smith et al 2023) explores the various factors contributing to the crisis facing UK adult ADHD services, and estimates a waiting time of 5–10 years in many services for a newly referred patient. Some doctors believe that social media influencers and celebrity bloggers have contributed to perceptions that ADHD is a fashionable diagnosis to have and that this is driving the increase in demand for assessments. However, individuals with ADHD report that their coping mechanisms failed during the stress of pandemic life, owing to loss of day-to-day structure, lack of certainty and information overload. This triggered burnout or led to 'unmasking' of undiagnosed ADHD, prompting them to seek an assessment (Box 1). However, getting assessed is not easy owing to long waiting lists in the National Health Service (NHS) or an absence of affordable access to trained specialists in other healthcare systems.

The medical and social models of ADHD

The medical model of ADHD is largely deficit- and pathology-based, whereas the social model recognises the 'differently wired' brain and its many strengths. This 'difference' results in disability only because of difficulties in accessing the right tools to fulfil the person's true potential, living in a world built for the neurotypical majority. Adjustments in the environment and special strategies are needed, just like the additional skills and maintenance needed to drive a racing car without crashing.

The medical model uses the core symptoms of inattention, hyperactivity and impulsivity to understand the experience of adults with ADHD. But adults with ADHD often describe several other issues, which may be unfamiliar to many general practitioners (GPs) and psychiatrists who are primarily trained to detect ADHD in children. An understanding of these issues is valuable to adults with ADHD because it provides an understanding of how their minds work and why they struggle with certain things. It also provides a language to explain their invisible disability to family, friends, employers or educational institutions.

We describe some of the terms and concepts used in the medical and social models of ADHD in Box 2. Other terms, such as rejection sensitive dysphoria, have been critiqued by some medics as being non-specific to ADHD, but this does not mean that their relevance in understanding the condition can

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be ignored, as well as their potential role in targeting treatment.

Underdiagnosis and misdiagnosis in women

Good practice guidelines for adult ADHD published by the Royal College of Psychiatrists (RCPsych) report evidence that women with ADHD are often undiagnosed or misdiagnosed, as they tend to show less externalised ADHD behaviours, more affective features and more sleep disorders compared with men (Royal College of Psychiatrists 2023). Impulsivity, a core symptom of ADHD, may contribute to misdiagnosis when seen through a lens of inadequate training. There is a theoretical possibility that many women diagnosed with emotionally unstable personality disorder (EUPD, a highly stigmatised diagnosis, in comparison with other diagnoses in psychiatry) may have undiagnosed ADHD, if we consider the overlap of clinical presentation in relation to impulsivity and emotion dysregulation (Box 3). Past trauma is also common in both these conditions, making it even more necessary to obtain a thorough clinical and neurodevelopmental history (ideally, informed by nuanced co-produced training) to reach an accurate diagnosis. We take this hypothesis further and opine that there is an ethical argument for the accurate identification of patients who have ADHD misdiagnosed as EUPD, particularly because more effective pharmacological treatment options are available for the former than for the latter.

Perinatal mental health services are likely to see undiagnosed or misdiagnosed women in their caseloads because additional stresses during pregnancy and early motherhood can trigger burnout or unmasking of undiagnosed ADHD. There may be atypical presentations related to the effects of hormonal changes.

BOX 1 Accounts from NHS doctors diagnosed with attention-deficit hyperactivity disorder (ADHD) during the COVID-19 pandemic

'The pandemic made me decompensate in the work environment, which was why I ended up seeking an [ADHD] assessment. Remote online working (despite its many benefits) took away the in-person secretarial support which was vital for me to function. That daily check-in with another person helped me to keep on track and stopped me from falling behind on my administrative work.' (Consultant oncologist, female)

'I have had episodes of burnout every 1–2 years since my GPST2 [Year 2 General Practice Speciality Training]. I was going through an ADHD referral questionnaire in 2020 (for a patient) and had a lightbulb moment when I realised that I scored high on it. Having to juggle work while home-schooling children (one with significant special educational needs) was extremely challenging. My executive functioning got worse. Two and a half years on a waiting list and I now have a diagnosis, and treatment. I am no longer overwhelmed by everything. I feel functional again and it has made a huge difference in every aspect of my life.' (GP, female)

Are we being too quick to judge and stigmatise?

Controversy surrounding ADHD is global and clinicians are not immune to this. Psychiatry as a specialty is, to some degree, influenced by subjectivity, and so the approach of GPs and psychiatrists to adults seeking an assessment may be influenced by factors such as long waiting lists and concerns about the risk of misuse of first-line ADHD medications (i.e. stimulant drugs). If a doctor can confidently assess that a patient's suspicion that they have ADHD is not clinically plausible, they should then be willing to explore what else would explain the individual's difficulties and signpost them to

BOX 2 Terminology in the medical and social models of attention-deficit hyperactivity disorder (ADHD)

Masking: conscious (and sometimes subconscious) efforts to hide traits in order to seem 'normal' or 'neurotypical'.

Hyperfocus: a prolonged period of intense focus on a topic or activity of interest that may either give immense satisfaction and/or interfere with other tasks that need prioritising. Hyperfocus could also be the result of difficulty in task shifting (executive dysfunction).

Time-blindness: a different experience of the passage of time, especially during hyperfocus.

Out of sight, out of mind: the experience of forgetting that a person or thing exists if they have not seen it for a while, until reminded again by contact with the person or seeing the object.

ADHD tax: a term that encompasses the many ways in which core difficulties due to ADHD can lead to financial loss or long-term debt (e.g. late fines in libraries, forgetting to cancel free trial subscriptions). This is usually a result of task initiation difficulties, poor working memory, difficulties with complex organisational tasks or impulsivity (e.g. impulsive shopping).

Stimming: Repetitive movements, gestures or other self-soothing coping mechanisms, better known in the context of autism. This may extend to less visibly hyperactive acts such as listening to the same song on repeat or watching a video on repeat.

Executive dysfunction: Difficulty in working memory, task initiation, task shifting, impulse control, planning, organisation and prioritisation. Task initiation difficulties can present to the observer as chronic procrastination. This can then be perceived as the person being lazy and leads to common misconceptions such as 'Everyone is a little bit ADHD'. But the inability to overcome such problems even when wanting to do a task is very different for someone with ADHD. Among those familiar with the social model, this phenomenon is quite well-known as 'ADHD paralysis'.

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BOX 3 Quotations from NHS doctors about their lived and professional experience of the challenge of distinguishing emotionally unstable personality disorder (EUPD) from attention-deficit hyperactivity disorder (ADHD)

'I thought of this about many of my female patients during my psychiatry rotation as a GP [general practice] trainee.'

'I have 2 patients who have had a diagnosis of EUPD removed from their record and replaced with ASD [autism spectrum disorder] and ADHD after (specialist) assessment. The "EUPD behaviours" all went away with ADHD medication.'

'I was misdiagnosed with EUPD/BPD [borderline personality disorder] in the 1990s. It has come back to haunt me in my 40s despite having had no contact with mental health services since late adolescence. I never fulfilled the diagnosis of EUPD, and am now diagnosed with ADHD and treatment resistant depression.'

find answers, as they would do in other conditions in medicine.

The above-mentioned RCPsych good practice guidelines note that many psychiatrists lack confidence in assessing neurodevelopmental conditions, with 67% of respondents in one survey wanting further training in this subject area (Royal College of Psychiatrists 2023). When there is evidence that our training is inadequate, how can we invalidate the lived experience of our patients based on a seemingly outdated understanding of the condition? Blaming social media hype alone risks dismissing the positive effect of social media in raising awareness and reducing stigma surrounding ADHD (two outcomes that would be welcomed in relation to most other conditions we diagnose and/or treat in psychiatry). One could rather take the stance that social media can have both positive and negative consequences, and that with reasonable quality control, it can be a powerful vehicle for disseminating awareness.

The fallacy of 'high functioning'

The concept of 'high functioning' can be a fallacy when it comes to ADHD diagnosis.

There are many aspects of language usage in the context of neurodevelopmental conditions that are divisive when considering the medical and social models of ADHD. Although autism is generally more widely accepted as a condition that presents as a 'spectrum', this is less talked about in relation to ADHD.

BOX 4 Quotations from doctors with attention-deficit hyperactivity disorder (ADHD) regarding use of the term 'high functioning'

'"High functioning" feels like an excuse to not help. My daughter has inattentive ADHD but because she is academically able, the additional support needed for her schoolwork is not acknowledged by her teachers. As an NHS consultant, I am "high functioning" and so no one acknowledged the struggle to keep up with my work. This made it hard for me to seek an [ADHD] assessment and I was told things such as "we all struggle with admin". ADHD medication has literally changed my life, not only at work but also at home. I'm able to be really present for my children for the first time. As an undiagnosed "high functioning" woman, I've had multiple episodes of depression because, among other things, I cannot keep my house tidy. The lack of an explanation for my difficulties destroyed my self-esteem.'

'I spent my whole life telling teachers, family and employers that I found things difficult. But because my output was acceptable, I was told that I just needed to lower my expectations and work on switching off. I never understood how to relax or switch off and I found more things to do to drown out the noise in my brain until I eventually formed a progressive burnout spiral. After diagnosis I was earmarked as "high functioning" and I felt it completely negated all my struggles, as if I was not ADHD enough to be recognised and not neurotypical enough to cope without spiralling into the burnout cycle. This may as well equate to high masking ability or seeing you as "almost neurotypical" or "almost normal", which I think leads to implications that being neurotypical is better or that the goals of ADHD treatment are to make someone more neurotypical, which is not the case.'

'I might be high functioning, i.e. I am a successful professional woman. But it comes at a cost to my mental health. Working so hard to function has caused years of anxiety due to being on high alert all the time (not to forget things, to remember to plan things, to do basic tasks that neurotypical people do not have to think about). It causes me to be exhausted when I get home and I spend my weekends sleeping rather than being with my family.'

'People who know me only on a superficial level would probably say I am "high functioning" because I managed to get through medical school and I work. If they saw my house, or how tired I am and how I often just crash with exhaustion when I'm not at work, their opinion would change. My work impacts other people and so it gets prioritised over everything else, leaving little energy for me.'

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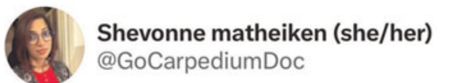

FIG 1 The need for co-production to bridge the gap between medical and social models of attention-deficit hyperactivity disorder (ADHD). Tweet shown is by the author. RSD, rejection sensitive dysphoria.

We are of the opinion that 'level of functioning' should be based on the individual's baseline functioning, not on comparisons with others who have the same condition. Research data showing that higher IQ may lead to masking symptoms of ADHD for longer suggest that timely diagnosis can be a challenge in particular groups of adults (Milioni 2017). Many of these individuals may be high functioning in some aspects of their life but struggling significantly in other aspects (Box 4). As NHS psychiatrists assessing adults for ADHD, there is barely enough time to complete a thorough clinical history, rule out other differential diagnoses and comorbid psychiatric conditions, and gather adequate collateral neurodevelopmental history. Often, it is not possible to explore the multiple aspects of adult functioning.

Therefore, we are of the opinion that labels based on functioning can be inaccurate, worsen stigma and minimise the very real costs of being so-called 'high functioning'. These labels may also become barriers for many adults seeking an assessment to be able to convince their general practitioners (GPs) of the necessity of a specialist referral, especially if they are perceived as being 'high-functioning' by clinicians. The 'spoon theory' (first described by Christine Miserandino, explaining that a particular disorder confers finite options, abilities or energy), the 'spiky profile' concept (the presence of significant disparities in an individual's ability in different areas of cognitive function) and rating scales such as the Weiss Functional Impairment Rating Scale can help to understand the day-to-day difficulties and dilemmas facing individuals living with invisible and chronic disabilities, including ADHD.

The case for a radical rethink

Research data from over 15 years ago suggest that between 2.5 and 4% of adults in Britain have ADHD (Faraone & Biederman, 2005, cited in Smith 2023: p. 10). Failing to detect and treat ADHD can have significant implications in relation to education, family life, employment, crime, healthcare burden and avoidable trauma. ADHD treatment appears to decrease the risk of accidents and injuries in all ages, with medication resulting in more than a 50% reduction in road traffic accidents in men with ADHD (Chang 2014). Scientifically, there is no doubt that ADHD is worth diagnosing and treating (Chen 2022). Despite this, many doctors believe that there is little value in referring screened patients to 'sit on a long waiting list' for assessment, especially the seemingly 'high functioning'. As the quotations in Boxes 1 and Box 4 illustrate, even getting answers (i.e. a diagnosis) can have a huge positive effect on mental health, besides the additional possibility that treatment could be 'life changing' for many.

Co-production as a bridge between the medical and social models of ADHD

There is a golden opportunity to make change by meaningful co-production (Fig. 1). Now is the time to co-design services, diagnostic pathways,

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education and training, as well as research, in collaboration with the people that we are trying to help. We must move away from being adamant that the understanding of conditions we treat only comes from textbooks. We need empathy and action.

Ideas for the future

There is so much that we do not yet have clear answers for and so we list some questions that clinicians and researchers working in primary care or mental health can explore.

- What are the attitudes of primary care clinicians towards people seeking ADHD diagnosis as an adult?
- What can we learn from the experiences of doctors with ADHD who work across different specialties?
- Are joint assessments for ADHD and autism in adults (who are screened for any neurodevelopmental condition) feasible, beneficial and cost-effective?
- What are the occupational health experiences of NHS staff in accessing reasonable adjustments for ADHD in accordance with the Equality Act 2010?
- What is the prevalence of ADHD in patients being treated for anxiety or depression in general adult community mental health teams or perinatal mental health teams?
- In peri-menopausal women, do decompensation or unmasking of undiagnosed ADHD clinically present as a worsening of cognitive or executive functioning?
- What proportion of (particularly female) patients with a diagnosis of EUPD would also meet criteria for ADHD? And in these cases, is the EUPD a comorbidity or a misdiagnosis?
- What is the prevalence of rejection sensitive dysphoria in adults who have a diagnosis of ADHD?

Conclusions

We highlight in this article that there is much value in using both the medical and social models of ADHD to understand lived experience better. Co-production has the potential to play a vital role in addressing the current challenges of adult ADHD assessment, including underdiagnosis and misdiagnosis in women. The 'high functioning' label may not be helpful and risks minimising the costs of being high-functioning in certain groups of adults with ADHD.

We conclude with the opinion that better training for clinicians in primary care and psychiatry is needed as a priority, as is tackling the long waiting lists (of several years on average) for ADHD assessments in the NHS. Creating fit-for-purpose specialist ADHD teams would be impossible without innovative ideas and ring-fenced funding, in the light of ever-increasing demands on a dwindling workforce.

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Author contributions

S.M. initiated the plan for publication. S.M., M.E. and R.K. were involved in writing the content, including literature review. All authors were involved in editing and final review of the article, with M.P.d.C. providing overall supervision.

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