

**Exploring women's experiences of**  
**diagnosis of ADHD in adulthood: A**  
**qualitative study**

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**Exploring women's experiences of diagnosis of ADHD in adulthood: A qualitative study**

**Abstract**

Objective

Women are more likely, than men, to be diagnosed late with ADHD but there is a paucity of research on their experiences. This paper reports on women's lived experiences of diagnosis of ADHD in adulthood.

Methods

Fifty-two qualitative interviews were undertaken, between March 2022 and March 2023, with women aged 19-56 years. The participants were primarily university students, and were diagnosed, as an adult, with ADHD by a psychiatrist in England, United Kingdom. Interviews were undertaken online, through Microsoft Teams, lasting on average 1 hour 15 minutes. Interviews were transcribed verbatim and thematic analysis generated six themes.

Results

Participants reported difficulties in being referred from primary care services to specialist ADHD services. Diagnosis was seen as empowering, but this was often tinged with sadness due to previous experiences which were painful and traumatic. Others struggled to cope with the diagnosis due to 'internalised ableism' and perceived stigma. There was minimal mental health and psychological support from professionals after diagnosis and inadequate follow-up and monitoring of medication. Participants identified numerous reasons for not having been diagnosed as a child including gender and racialised stereotypes, successful masking behaviour, lack of professional knowledge about ADHD, a perceived over-emphasis on diagnosing mental health issues, and women being invisible and not listened to.

## Discussion

Increased training and awareness are needed for professionals on how ADHD presents in girls to support earlier diagnosis. Specialised ADHD psychological therapies are required, in addition to medication. Support after diagnosis including monitoring of medication needs to be strengthened.

**Key words: ADHD, women, late diagnosis, lived experiences, qualitative, mental health**

## **Introduction**

Attention Deficient Hyperactivity Disorder (ADHD) is a neuro-developmental variation which is usually present throughout the life-course and is characterised by inattention, and/or hyperactivity-impulsivity (APA, 2013). Research has indicated that women are more likely than men to be diagnosed with ADHD later in life (Hinshaw et al., 2022; Da Silva et al., 2020). Numerous reasons for this have been identified including gender bias and the male oriented focus of many ADHD assessments which may not effectively take into account that ADHD often presents differently in girls (Bruchmuller et al., 2012; Nussbaum, 2012), with girls and women being more likely to display internalising behaviours, emotional dysregulation, and inattention (Klefsjö et al., 2021; Quinn & Madhoo, 2014; Young et al., 2020). In addition, girls are more likely to be socialised into normative feminine behaviours with an emphasis on pleasing others, which can result in high levels of masking of neuro-divergent behaviours to 'fit in' (Mowlem et al., 2019; Waite, 2010). Masking behaviour, in turn, has been shown to be associated with poor mental health (Bargiela et al., 2016). Furthermore, girls may be more likely, than males, to be misdiagnosed or have a late diagnosis because of the co-occurrence with mental health conditions such as depression and anxiety which are often treated first (Young et al., 2020; Attoe & Climie, 2023). Additionally, girls are less likely to be referred for ADHD diagnosis by teachers (Sciutto et al., 2004) and have their ADHD symptoms underestimated by parents (Mowlem et al., 2019).

There is limited research that explores the impact of late diagnosis of ADHD on women. What is available highlights that late diagnosis is associated with a detrimental impact on women's self-esteem, mental health, identity, and life chances including increases in psycho-social burden and adverse outcomes (Stenner et al., 2019; Young et al., 2008; Attoe & Climie, 2023; Gershon, 2002). Diagnosis can often lead to a reduction in self-blame and increased self-acceptance (Waite, 2010; Stenner et al., 2019) with treatments such as medication, in many

cases, reducing the symptoms of ADHD (Young et al, 2020). By listening to the voices of women, this qualitative research project fills an important gap in this area of research by documenting the lived experience of an ADHD diagnosis in adulthood.

## **Methods**

Participants were recruited through an email flyer which was sent to all student email accounts in one large university in an urban area of London, England. Students were told that they could share the email flyer with others who may be interested in the study. Participant information sheets and consent forms were then shared with women who contacted the researcher. Women were invited to spend some time thinking about the study and whether they would like to take part. Only those women who then contacted the researcher were included in the study.

Narrative qualitative interviews with 52 women, who met the inclusion criteria of an adult diagnosis of ADHD by a psychiatrist (as reported by the participant) and who consented to take part in the interview, took place online via Microsoft Teams during the months of March 2022 to March 2023. Microsoft Teams was utilised to facilitate each interview as some of the participants were not local. It also aimed to provide a safe space for neuro-divergent women who may prefer to be interviewed online. It was the women's decision whether to have their camera on during the interview and for those women who preferred not to have their camera on, cameras were turned off after the initial discussion around consent and introductions. The interviews started with a broad opening question "please tell me about your experience of being diagnosed with ADHD". The female researcher did not interrupt whilst the women were narrating their experiences and once the narrative was finished, she followed up with probing questions using incomplete sentences such as "tell me more about..." and "what happened before/after/then" (Bauer & Gaskell, 2000). This was an emotive subject for some of the participants and distress, for example crying, resulted for a few women. In these cases,

opportunities were frequently given to stop the interview if the participant wished. However, all women requested to continue, and no women withdrew from the interviews nor later requested the removal of their data. Compassion was a key element throughout the interviews as per Baldwin (2021, p.181) who highlighted the importance of 'an honourable mindfulness' and Quinlan et al. (2022, p.172) who stressed that an 'Ethic of Empathy' is key during interviews with potentially vulnerable women. At the end of the interviews, the recording was stopped, and time was spent discussing the interview with the women, who were explicitly asked how they felt about the interview. A list of support organisations was made available. Participants stated that the interview had been 'an opportunity to be heard' and that 'telling my story, is important if it helps other women'. The interviews lasted from 1-2.5 hours and the average length of interviews was 1 hour 15 minutes.

### Participant Characteristics

The ages of the participants ranged from 19 to 56 years with just under half of the sample being less than 25 years old. Over half of the participants identified as white (please see table 1). In relation to diagnosis more than half of the participants received their diagnosis through Right to Choose, an initiative which enables choice of health provider. To qualify for Right to Choose in England, a medical professional (normally a General Practitioner) needs to agree that although a specialist ADHD assessment is required, this cannot be provided locally on the National Health Service (NHS) because either no such service exists, or the waiting list is too long. As a result, the service user can choose their provider for ADHD assessment, including private provision from a list of recognised providers. Waiting times for Right to Choose private providers have increased substantially due to a lack of provision through the NHS. Thirty-five of the 52 participants were currently in higher education (15 of those from the researcher's university and 20 from fifteen other universities) whilst eight had completed their study (at other English universities) and were working. Seven women had not gone to

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university and were currently working, and two women had not been to university and were not working. All participants lived in England, United Kingdom. Table 1 below documents the ages of the participants involved in the study, their self-described ethnicity, the medication prescribed for ADHD, the type of ADHD diagnosis they received (inattentive, hyperactive/impulsive or combination) and the type of provider who undertook the diagnosis (private provider, NHS or Right to Choose).

**Table 1**

*Participant Information*

		Number of participants
Ages	<25 years	25
	26-30 years	12
	31-39 years	8
	40-49 years	5
	50+ years	2
Ethnicity (self-described)	White British	23
	Black British	7
	British Asian	6
	Black African	4
	White European	3
	White Irish	2
	White North American	2
	South American	2
	Romani Traveller	1
	Turkish	1
Moroccan	1	
ADHD medication prescribed*	Stimulants	32
	Non-stimulants	4
	Waiting for titration	10
	None	6
ADHD diagnosis	Predominately inattentive	25



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	Hyperactive-impulsive	0
	Combination	27
Provider who carried out diagnosis	NHS psychiatrist	12
	Private psychiatrist	10
	Right to Choose psychiatrist**	30

\* *Atomoxetine 40mg and 60mg capsules have been out of stock in the UK from July to September 2023.*

\*\* *Partnership between NHS and private providers*

Within the sample of 52 women a range of co-occurring conditions were reported with more than half of the participants being in contact with several safeguarding, educational support, and mental health providers prior to their referral for ADHD diagnosis. Please see table 2. All participants reported, during the interview, experiencing ADHD behaviours as children.

**Table 2**

*Co-existing Conditions and Previous Contact with Mental Health Providers, Education Support and Safeguarding Services*

<p><b><u>Co-existing conditions which were reported by women (both present day and historical)</u></b></p> <p>A number of co-existing conditions were reported including dyspraxia, anxiety, mutism, autism, obsessive compulsive disorder, anorexia, bulimia, binge eating, reliance on non-prescription drugs, tobacco, and alcohol, depression, self-harm and suicide attempts, borderline personality disorder, tics, post-traumatic stress disorder, sleep disorders, visual stress, bipolar disorder, panic disorder, dyslexia, adjustment disorders, polycystic ovary syndrome, irritable bowel syndrome, premenstrual syndromes, and fibromyalgia.</p>
<p><b><u>Previous contact with mental health, educational support, and safeguarding providers before ADHD diagnosis</u></b></p>

Participants reported long histories of previous contact with mental health and safeguarding providers before their ADHD diagnosis. This included Children and Adolescent Mental Health Services (CAMHS), private and NHS therapy including Cognitive Behavioural Therapy (CBT), Cognitive Hypnotherapy, counselling, psychologists (both NHS and private), psychiatric hospital inpatient treatment including being sectioned under the Mental Health Act 1983, school safeguarding referrals via Children's Social Services (Child Protection Services) and Pupil Referral Unit (after school exclusion for fighting and oppositional behaviours).

### Analysis and Ethics

Interviews were recorded and transcribed verbatim by the author. Written texts were read several times to get an overall feel for the narratives. Codes were generated inductively, by hand, through a process of iterative initial open-coding of each line of the interviews (Charmaz, 2014). Focused coding was then undertaken whereby initial codes were combined to make analytical sense and the texts were then reanalysed in relation to these new focused codes (Charmaz, 2014). This was a time-consuming endeavour given the large number of interviews undertaken but one that was worthwhile and enabled the researcher to explore the data, through an intersectional lens, from a wide range of participants of different ages, backgrounds and ethnicities. This is especially important when there is limited research on the topic (Thomson, 2011) to enable a wide range of voices and experiences to be heard. Ontologically the researcher was informed by Heidegger's (1962) work on 'being in the world' which puts emphasis on the importance of lived experience. As Johnson (2000, p. 140) stated, it is through 'the actual living of our own stories that individual events acquire significance'. Therefore, an interpretivist intersectional paradigm which focused on multiple ways of 'being in the world', multiple realities, and multiple interpretations was utilised (Crotty, 2005).

Ethical approval was given by the researcher's university (UREC/21.1.6.14) and a discussion about the research including informed consent took place at the start of each interview. Confidentiality was highlighted as was the right to withdraw.

All interviews were carried out by the female researcher who is a white university lecturer with an interest in women's health and wellbeing and who has post-graduate training in qualitative methods including phenomenology. None of the participants who were interviewed were students of the researcher. The thematic analysis was undertaken by one researcher, the same researcher who conducted the interviews. Thus, there is a risk that the themes reflect her perspective. To overcome potential bias as well as issues of power, a personal journal was used throughout the study to aid reflectivity on positionality, methodological decisions, and interpersonal dynamics (Walsh, 2003). The transcripts of the interviews were not shared with the participants but instead the researcher used techniques which are common in hermeneutical phenomenology, of restating and summarising what the participants had said and confirming this with participants throughout the interviews (Dibley et al., 2020). Moreover, at the end of each interview, the researcher asked women to summarise what they thought the main points of the interview were.

## **Results**

Six main themes were identified across the 52 interviews and are presented below with verbatim quotes. Pseudonyms are used.

### **ADHD as a possibility**

Even though more than half of the participants described long histories of engagement with mental health and counselling services, both as a child and as an adult, it was rare for these

providers to mention ADHD as a possible diagnosis. Instead, medical and mental health practitioners were more likely to have previously diagnosed the participants with depression and/or anxiety. For many participants, it was social media, such as TikTok, Facebook and Instagram, that made them aware of ADHD as a possible explanation for what they were experiencing and hearing other women talk, on social media, about their ADHD was “an epiphany”. For others, the transition to university and struggling to “fit in” or not passing modules led them to seek support from university wellbeing services. Rachel stated:

The things I used to do, like study last minute and panic cram, was no longer working in higher education, my grades started to drop, and I couldn't balance the deadlines anymore. I was always late, in a panic, and it became too overwhelming.

Other participants re-evaluated their lives and sought support after “dropping out” of their courses with some having previously left up to three programmes. Alternatively, for some participants it was seeing a friend, or their child being diagnosed with ADHD which raised the possibility. Ellie explained that it was her son's diagnosis that made her think that maybe “I have been misdiagnosed as there were so many similarities between what we do, and I never felt at home with the diagnosis of anxiety but when I read about ADHD, I just thought that is me”.

### **Seeking an ADHD Referral**

Receiving an official diagnosis of ADHD was not, for most of the participants, easy. Whilst a few had “great General Practitioners (GPs) who really listened,” this was not the case for the majority. Participants reported that some GPs blocked the diagnosis pathway, telling them “that you are too old to have ADHD”; “why should it matter now you are an adult”; “to look online”; “people would have noticed at school”; “it didn't matter now you were no longer at school”; and that “the waiting lists are long”. This resulted in many of the participants feeling

dismissed and that “nobody was listening”. Farah stated that she was repeatedly told that she could not have ADHD as she had done well at school with the mental health practitioner “expecting failure at school rather than I just hadn’t done as well as I should have done”. For others, referrals were lost. For one participant this occurred three times, which further lengthened her wait to be seen. Moreover, according to participants, many GPs did not know about Right to Choose and the National Institute for Clinical Excellence (NICE) guidelines on referral for ADHD which resulted in some seeking private provisions, which they had to pay for, to avoid long waiting lists. Those who did wait for NHS diagnosis waited over a year on average for first appointment with Adult Mental Health Services and in some cases over three years. This led to many participants highlighting that “seeking medical care as a person with ADHD is not ADHD friendly”.

### **Impact of ADHD Diagnosis**

For many participants, their diagnosis was a relief. They reported that it felt like a “curtain had been raised and my life makes sense now”. Sharon said:

Getting the diagnosis was a big thing for me. I understand my life now, I feel that I have got the power back; I have an opportunity to rebuild, unlearn a lot of things that I’ve thought about myself, try to get back some confidence.

Moreover, the diagnosis enabled many participants “to be kind to themselves” with some highlighting that they were not to blame and “it was beyond [their] control”. Mia said:

I have a disability; I didn’t ask to be this way and to be finally diagnosed brings me comfort as before I would criticise myself and compare; why am I not like them but now I know it is not my fault.

Whilst Jan said her diagnosis allowed her to see herself as “a human” as previously she had “hated herself, not being able to look in the mirror because I just didn’t want to see myself. I

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wanted to disappear and no longer be this useless thing always scared that things would not be okay”.

However, for others, diagnosis was not necessarily a positive experience and some participants, on hearing their diagnosis were in denial stating, “I don't have this”. For example, Maxine said that “it is my upbringing, I just have this irrational stigma in my head about it”. Charlotte explained that her diagnosis of autism and ADHD “crossed the line and I couldn't cope with it because of my own internalised ableism”. This meant that she still struggled to accept her diagnosis a year later.

Even though participants now had an official diagnosis, this was not always believed by others with Michaela stating, “my dad doesn't believe my ADHD diagnosis, I feel I can't talk about it because people won't believe me, or they'll think I'm making it up to make excuses”. However, for others the diagnosis had improved their relationships with friends and family with Miranda saying:

My mum knows better how to handle me now, we have less arguments and I have less emotional outbursts because she understands I am not doing it because I am being resistant but because I find it difficult to do. Before, it would just be awful and she would not back off, constantly telling me to do something and I would get so frustrated that I have punched the door, hit myself in the face even banged my head against the wall.

Another benefit of diagnosis for many participants was access to medication. Although for some, it took a while to find the right medication and dosage, most participants reported positively on the impact of medication stating that ‘I could finally focus’. Medication also impacted positively on some participants' mental health. Mollie stated:

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It had a massive impact on my depression, I stopped taking my anti-depressants which had not worked for me, and my ADHD medication just made me feel better, when I don't take them for a while, I start to feel sad again.

However, medication did not work for all participants or worked only partially and some reported side effects. Non-compliance with taking medication was also reported and some participants forgot to take it or made choices to only take it as and when they felt they needed to.

### **Trauma associated with late ADHD diagnosis**

Not having an earlier diagnosis was experienced as traumatic by many and some of their stories of childhood were painful. Esther stated that:

I look back on what I went through as a child and I am so angry and bitter about it, I was crying out for help. My life has been harder than it needed to be. My whole childhood was one of shame, of not being as good as other people, I hated myself for not being like other people. This has impacted my whole life and when I look back on my younger self I feel so sorry for myself and so sad.

Not knowing also impacted on the relationships between some of the participants and their parents with Priti stating:

My mum blamed me for being this way, for misbehaving, being lazy, being stupid. I just didn't understand why she didn't like me because I was trying so hard to behave. Now she says she understands [since diagnosis] why I was the way I was. I think she feels guilty now because she thought I was doing these things because I was bad rather than I couldn't help it.

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School, especially secondary school, and the onset of puberty, was difficult for almost all participants, and in many cases was “absolute hell”. Many detailed experiencing extreme distress during their teenage years with Rachael saying:

I was depressed and anxious during the whole of secondary school, I was self-harming, drinking, and starving myself, being out of control, my relationships with everyone were awful and I can see now I was really putting myself at risk. I never felt safe at school, I was constantly bullied, ignored, and belittled. I just felt like I was drowning, I went through my whole school time feeling that I was just wrong, but I didn't know why. I tried so hard to fit in and be, like an actual person, like everyone else, I had no friends, I was the gross kid, but I didn't know why I didn't fit in. I think if the school and CAMHS (Child and Adolescent Mental Health Services) had known about the ADHD then there would have been more support and I would not have crucified myself as a person, my mental health was at rock-bottom because I just didn't know why I was like this and so I blamed myself.

### **Medical, mental health and psychological support after ADHD diagnosis**

Psychological and mental health support after ADHD diagnosis was lacking for almost all participants unless they paid for this privately. This was problematic given the painful and traumatic previous experiences of many participants, which had impacted on a large proportion of their lives. Kate said:

It is so painful, I am finding it hard to cope with, there are 42 years of pain that I must deal with, and no support and I am fearful of people's reactions to it and their judgements. I was just offered medication and that was it, no support.



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Some identified the need for specialised ADHD therapy or counselling that would support them to “reauthor” their lives and deal with the trauma that they had experienced including therapy to support them to come to terms with their diagnosis. Sandy said:

Reauthoring is important, we been told at school, at home and at work we are terrible, lazy and stupid and have been given up on and we believed it. It's very difficult for someone to reauthor their story unless they are given a different perspective, one that is not negative.

Others stated that much of their support came from online forums, such as blogs, Instagram, and Facebook, and that there was a lack of follow-up from medical and mental health services. For example, once their medication for ADHD was stable, there was minimal to no contact, for many participants, from mental health professionals. Many participants had questions about whether they were on the correct medication or whether it should be changed and how they could possibly manage their ADHD without medication. Many were worried about taking medication for the rest of the lives and the impact this may have. Concerns were raised about getting pregnant and being on “this really strong medication”. Moreover, some participants reported not having had their blood pressure checked in the past year nor a medication review, which is recommended under NICE guidelines. Participants were unsure about who to turn to for many of their questions as their GP was ‘not a specialist’ and they had been discharged from Adult Mental Health Services or Right to Choose to the care of their GP. Jane said:

What is the point of going to the GP as they don't know, they didn't even know about Right to Choose and I had to take the NICE guidelines to the GP to be referred, so they will not know the answers to my questions, and I am not sure about how to get into contact with the psychiatrist or the mental health nurse.

### **“Why was it not picked up earlier”**

Participants identified numerous reasons why they felt that they had not been diagnosed earlier. For many, being a “good girl”, “being funny and having friends”, “being quiet”, “just appearing to get on with it”, “not being able to articulate what the issue was”, “being helpful” or “doing average at school” meant that they were “invisible”. Some reported that unless you were “a problem to others”, “were failing academically” or being really disruptive then you “fell through the cracks”. Slipping through the cracks was exacerbated by participants' concern about a lack of professional knowledge about how ADHD presents in women meaning that girls who did not exhibit established diagnostic traits such as “bouncing off the wall” were not identified or were potentially misdiagnosed.

Moreover, masking of behaviours to “fit in” were also reported and this, according to some participants, may have contributed to missed diagnosis. Jenny said:

Girls are always expected to be perfect and not a problem, and boys making mistakes is fine. Girls are better at hiding things to fit in with this idea. I spent so much time hiding my true self to not disappoint people or be judged or not get into trouble. It took all my effort to do this, I became an expert at it.

Participants described other strategies that they used to fit in, including “being quiet to not be noticed” as well as strategies to “suppress all of these hyperactive tendencies and find small ways to move”, including “tapping my foot or fiddling”, “constantly changing position in my seat”, and at school “asking to go to the toilet repeatedly”, and “running around and around at playtime to tire myself out”. These strategies were exhausting, and overwhelming for participants, and many “paid for it later [emotional outbursts] when they got home”.

However, while some participants may have masked their behaviours, many were having major issues at school (including in some cases fighting and exhibiting disruptive behaviour)

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as well as issues at home showing evidence of significant and acute distress. For some, no support was forthcoming from GPs and schools with how they were feeling being ignored, or attributed to hormones that they would grow out of, "to being a perfectionist", "to stuff going on at home", "to being a challenging girl", "to being a chatterbox who doesn't listen", "to the death of my grandfather", "to having English as my second language" or being put down to just "being an emotional girl".

Those who received psychological or mental health support were more likely to be diagnosed with an emotional condition such as emotional borderline personality disorder, depression and/or anxiety as the emotional aspects of their ADHD was often what was focused upon. Amelia said, "I learnt not to tell them (CAMHS) about my emotions first, if I started off on that route, I would get an emotional borderline personality diagnosis; yes, the emotion was a big thing but so was the inattention". Moreover, some participants queried, during the interviews, the initial diagnosis that they had received as an adolescent, for example, depression, anxiety, bi-polar. Some reported that they had been misdiagnosed with gender-based assumptions made by mental health practitioners who believed "you are female so it must be emotional". Molly stated that:

Girls are always thought to be emotional so immediately it was put down to that as opposed to digging any deeper, if they had just dug a bit deeper, they would have seen that what they thought was anxiety was me trying to control my ADHD, trying to deal with the stress that having ADHD causes. So yes, I was anxious, but it was because of my ADHD and because they focused only on the anxiety, they missed the ADHD.

Moreover, according to participants, CAMHS and other mental health support including counsellors, psychologists, and therapists, often focused on their childhoods and attributed

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many of the issues that they were facing to childhood issues. Tracey stated about CAMHS that:

They would pick on one thing, like my dad leaving when I was 18 months old, and it makes their life easier. It explains it. So, this happened to you, and this is the reason why you are like that. I kept on saying to them, but I don't think it is...it is my brain...it doesn't work like other peoples.

All of this, however, was complicated further as some participants experienced significant co-occurring mental health issues which required immediate intervention. Sandi said:

I can understand why they focused on my self-harm because it was serious but now, I can look back and see that it was a symptom, it was a symptom of me feeling different to everyone else and not being able to verbalise why I felt different, why I felt so alone and so deeply unhappy with myself. I think that was why my ADHD got missed as the focus was always on my binge-eating, my alcohol use, and my self-harm and I suppose, for me, that was the right thing to do, maybe, as the interventions that I had probably saved my life... but who knows maybe if I had been diagnosed with ADHD then I wouldn't have been self-harming in the first place.

Some participants highlighted that because of parental mental and physical health issues or a sibling with ADHD or autism they did not want to cause any further problems at home with Samantha saying, "so I just tried to be as good as possible". Likewise, Hilary stated that:

The focus was always on my brother who has ADHD/autism, and I was just ignored and left to get on with it, even my own therapist seemed more concerned about my brother and would attribute any difficulties I had with living with him, I would be thinking what about me, I can have issues that have nothing to do with my brother.

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Gender stereotypes intersected with ethnicity, and many indicated that they had not been diagnosed because of racialised stereotypes. Almost all participants of colour felt that they were not seen as a priority because of their ethnicity or that mental health and education professionals felt that it was part of their “culture” to be “quiet” or “loud and boisterous”. Pooja said that there were lots of assumptions made by her psychiatrist about her being Asian including speaking multiple languages and being born abroad and that this was the reason why she was finding life hard. Marcia said, “they just thought I was defiant; like the stereotype of the typical angry black woman”. Chidinma highlighted that in her family there was a focus on perfection and that she needed to be “strong and successful because of the discrimination black people face. I had to hide things because in my community being seen as less able is not good”.

### **Discussion**

This qualitative study adds to the limited previous research on women's lived experiences of late diagnosis of ADHD in adulthood. Understanding women's perspectives is an area which has been identified as key to improving outcomes for women with ADHD (Chronis-Tuscano, 2022). This study has shown that although for many participants diagnosis was a relief which helped them make sense of their life, it was often bitter-sweet. This was because, whilst diagnosis explained previous experiences and behaviours, it often resulted in participants feeling immense pain, anger, and sadness for their younger selves including reflections on lost opportunities and what it would have been like if they had been diagnosed earlier. The lateness of the diagnosis, rather than the diagnosis itself, led to many participants feeling misunderstood, being bullied, hating and blaming themselves, feeling weird or different. Late diagnosis increased mental health difficulties and resulted in poor relationships and difficulties at school, home, and work, all of which had a cumulative psycho-social effect on women across their life-course and was experienced, by many, as deeply traumatic, impacting on self-

esteem and mental health. Without a diagnosis for their experiences, many tended to internalise the 'shame of being different' or 'not good enough' and blame themselves.

Psychological and mental health support for participants after diagnosis was minimal to non-existent and participants had to deal with painful emotions and come to terms with their diagnosis without adequate mental health support as medication, in almost all cases, was often the first and only intervention offered. Many expressed a need for psychological therapies from practitioners who had specialisms in ADHD. Support in 'reauthoring' and 'reclaiming' life biographies through narrative therapy which promotes agency, self-determination and focuses on strengths and positives of difference (Monteiro, 2021) was considered by some to be helpful as they had internalised deficit models and negative narratives about themselves which had "been written by others" (Denborough, 2014, p. 8). Moreover, some participants would potentially benefit from trauma informed therapies due to cumulative experiences of victimisation, internalised shame, and stigma (Harris & Falot, 2001; Dolezal & Gibson, 2022). Thus, it is important, that a range of ADHD focused psychological and mental health therapies should be offered, post diagnosis, to women alongside medication.

Waiting times for referral for ADHD are also problematic with many participants in this study, waiting over one year to be seen by Adult Mental Health Services. More data on waiting times for ADHD assessments needs to be available and this needs to be routinely collected. Moreover, GPs need to be aware of NICE guidelines and initiatives such as Right to Choose as many reported that GPs were not aware of this initiative nor NICE guidelines. A lack of contact and follow-up from GPs and Adult Mental Health Services, post diagnosis, was also mentioned. Once the optimal dose of medication was achieved participants were discharged from specialist mental health care, back to their GP, with follow-ups and monitoring of medication often being inadequate, leading to feelings of invisibility, a lack of support, questions left unanswered, and frustration, all findings which align with those from Matheson

et al.( 2013). These experiences often led to participants having to seek advice from social media as opposed to Adult Mental Health Services. Moreover, support post diagnosis in relation to monitoring of blood pressure and medication including non-compliance as well as advice around medication and life events such as pregnancy needs to be strengthened.

As indicated by the findings, mental health, and medical practitioners require more training on how ADHD in girls may present differently to boys and assessments need to reflect the reality of ADHD for women and girls to ensure a reduction in diagnosis bias. This training should include an awareness of the role of gender and racialised stereotypes as well as the role of masking behaviours. Moreover, more awareness is needed amongst professionals about how the symptomatology of mental health conditions such as Bipolar Disorder, anxiety and depression often overlap with the presentation of ADHD, complicating the diagnosis of the latter (Barkley & Brown, 2008; Ginsberg et al., 2014). This can result in practitioners diagnosing a mental health condition but not ADHD or misdiagnosing ADHD as a mental health condition. The latter may be especially the case for girls with ADHD, who are more likely to present with emotional dysregulation and internalising behaviours leading to potential misdiagnosis of ADHD as anxiety or depression (Young et al., 2020; Attoe, & Climie, 2023). Moreover, while treating co-occurring mental health conditions such as anxiety, Bipolar Disorder and depression is important, untreated ADHD has potentially problematic outcomes, as shown in this paper, in relation to self-esteem, relationships, impact on life chances, and increases in mental health burden. Furthermore, untreated ADHD has been found to lead to non-compliance with mental health medication and poorer outcomes exacerbating existing mental health conditions (Barkley & Browne, 2008). The early diagnosis and treatment of ADHD is thus key to improved outcomes and can have both a positive impact on ADHD and in many cases co-occurring mental health conditions (Barkley & Browne, 2008), with

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research also showing that the treatment of ADHD with stimulants decreased the risk of later mental health issues such as depression and anxiety (Biederman et al., 2009).

More research is needed to understand the intersection of ethnicity and an ADHD diagnosis as there is currently minimal research which focuses on ADHD and the lived experiences of women of colour. This is important as research in the US context has shown the underdiagnosis and undertreatment of African American and Latino children in comparison to their white counterparts (Coker et al., 2016; Rowland et al., 2002). Moreover, quantitative research, which has taken an intersectional approach, has shown that the likelihood of diagnosis for ADHD varied 'by combinations of gender, race, and ethnicity' (Bergey et al., 2022 p.615) with black children being less likely to be diagnosed with ADHD if they are female and from a higher income background. This evidence points, therefore, to the importance of an awareness of how intersectionality can impact on the diagnosis of ADHD as well as the need for diversity in sampling in research studies which focus upon ADHD (Chronis-Tuscano, 2022).

There were some limitations to the study. The participants in the study were primarily university students and thus the results may not be reflective of women who did not attend university. One hundred and ten women initially contacted the researcher, but some did not meet the inclusion criteria as they were not yet fully diagnosed (n=28). Others consented to an interview but did not turn up at the designated time (n =20) or contacted the researcher just before the interview to say that they felt anxious about the interview and were not ready to take part (n=10). These latter women may have differed from the women who took part in the interviews. All the women had a recent ADHD diagnosis, within two years of the research interview. Thus, the findings of this research focus on the short-term. As time passes there may be additional mental health issues that arise around coming to terms with late diagnosis



of ADHD. Recall bias may also be evident in that women were asked to remember events from several years ago.

### **Conclusion**

Late diagnosis of ADHD can have significant psycho-social impacts on women. To support earlier diagnosis, increased training and awareness are needed for professionals on how ADHD presents in girls and women. This should include an understanding of the impact of gender and racialised stereotypes on diagnosis and potential misdiagnosis. A focus on increasing professional knowledge about masking behaviours is also needed. This would include the potential masking of ADHD in cases of co-occurring mental health conditions. Routes to diagnosis need to be improved to ensure that timely diagnosis is achieved. Specialised ADHD psychological therapies are required, in addition to medication. Finally, support after diagnosis including monitoring of medication and health status plus opportunities to ask questions about treatment needs to be strengthened.

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