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# Managing conversations about attention deficit hyperactivity disorder: Perspectives from females living with a late diagnosis

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### **ABSTRACT**

Background: Attention Deficit Hyperactivity Disorder (ADHD) remains underidentified, under-diagnosed, and under-treated in females, possibly due to differences in the way ADHD is experienced and the ways in which healthcare professionals communicate and interact with females with ADHD. Aim: This study aimed to explore the diagnostic process and the emotional experience of living with a late diagnosis of ADHD. Methods: Semi-structured interviews of nine females, aged between 23 and 55, were analysed using a reflexive thematic analysis. Results: Analysis revealed four themes: earlier effects of undiagnosed ADHD; emotional toll of living with ADHD; navigating diagnostic processes and its aftermath; hope and support post-diagnosis. These encapsulated the prediagnosis communication difficulties and emotional toll of managing ADHD. With diagnostic criteria not always encompassing the female experience of ADHD, participants experienced difficulties initially identifying and communicating ADHD-related symptoms, alongside deficits in post-diagnostic support. Conclusions: To improve outcomes and better meet the needs of females with ADHD, consideration must be given to early markers of ADHD which encompass internal experiences of symptoms and how these might be communicated to health professionals. Conversely, professionals offering ADHD-specific postdiagnostic support and signposting ADHD female-specific support groups could enhance wellbeing for females with ADHD.

#### **KEYWORDS**

ADHD, adult, communication, emotional expression, females

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# Introduction

Despite the use of evidence-based national guidelines in the United Kingdom (UK) for attention deficit hyperactivity disorder (ADHD), it remains under-identified, under-diagnosed, and under-treated (Kooij et al., 2019; Young et al., 2020). For females, the situation is particularly troubling; with many females being missed or misdiagnosed (Babinski & Libsack, 2025). Even though it is acknowledged that females with ADHD may present a modified set of behaviours, symptoms and co-occurrences compared to males with ADHD (Simon et al., 2009), this has yet to be fully addressed amongst clinical professionals and within the diagnostic criteria (American Psychiatric Association, 2022). Hence, despite ADHD being a neurodevelopmental condition with markers in early childhood, females with ADHD are less likely to effectively recognise and communicate ADHD-related symptoms potentially impacting their ability to access referrals for a diagnosis; and/or to gain access to the support and services they require (Quinn & Madhoo, 2014).

As ADHD often co-occurs with other neurodevelopmental disorders (Dewey, 2018), physical (Pan & Bölte, 2020) and mental health conditions (Becker & Fogleman, 2020), it can have a diverse impact on many aspects of life from childhood into adulthood (Young et al., 2020), resulting in significant discrepancies between potential and achievement (Biederman et al., 2008). For example, evidence suggests children with ADHD struggle academically, resulting in lower levels of academic attainment (Barry et al., 2002); an impact which can extend throughout their lifetime (Birchwood & Daley, 2012). Consequently, people with ADHD have lower admission rates to higher education facilities compared with neurotypical controls (Kuriyan et al., 2013); lower occupational status than neurotypical peers even when possessing the same degree of education (Biederman et al., 2008); and, when employed, often have higher rates of dismissal compared to neurotypical peers (Mannuzza et al., 1993). Therefore, undiagnosed and untreated ADHD in adulthood results in poorer prognosis, a higher risk of co-occurring conditions and overall lower functionality (Ginsberg, 2014); with financial distress increasing suicide risk for those with ADHD (Beauchaine et al., 2020).

The less overt presentation of ADHD in females may mask their underlying condition, due to females not meeting stereotypical expectations of ADHD behaviour (Simon et al., 2009). Thus, females generally present with higher levels of inattention than hyperactivity (American Psychiatric Association, 2022; Levy et al., 2005), and hyperactivity symptoms are often less conventional, generally manifesting as increased emotional reactivity and hyper-talkativeness (Quinn, 2005). Furthermore, females with ADHD are often less likely to have a learning disability, and are less likely to engage in antisocial behaviour, exhibiting lower levels of aggression (Abikoff et al., 2002). Indeed, whilst teachers were able to competently identify ADHD symptoms, many attributed difficulties to emotional problems or attentional difficulties for females. Moreover, when females presented with combined ADHD subtypes, they were less likely to be referred to specialist services to receive assessments or support (Groenewald et al., 2009).

Females may be more likely to attract a primary diagnosis of internalising disorders (Sciutto et al., 2004), often being misdiagnosed with other psychiatric disorders (Young et al., 2003) and/or gaining a later diagnosis of ADHD (Garcia-Argibay et al., 2021). For example, a high

proportion of woman with early onset recurrent depression were found to have undetected ADHD (Powell et al., 2021), and many females with undiagnosed ADHD are often forced to develop compensatory strategies to mask their difficulties and manage everyday life, resulting in feelings of shame and significantly lower levels of self-esteem. This suggests that depression may mask some of the underlying symptoms of ADHD in clinical practice, particularly for females (McIntosh et al., 2009). Yet, particularly for adult females, it has been argued that being both missed and dismissed as neurodivergent represents an epistemic injustice preventing the gaining of knowledge to better understand themselves (Cilia Vincenti et al., 2023; Craddock, 2024).

It is still unravelling as to why and/or how ADHD in females present itself differently from males (Redshaw, & McCormack, (2022). ADHD symptoms in females may appear later due to symptoms becoming particularly salient in puberty. Biologically, this could be due to gender differences in brain maturation. Genes are assumed to explain up to 76% of the variability of ADHD-related symptoms in the population (Rietveld et al., 2003). However, ADHD can also be shaped by social and cultural environments, and the social norms which set out societal expectations of the rules to follow to minimise judgement from others. For example, females are encouraged to show a mix of qualities, such as being good listeners and empathic, along with downplaying qualities, such as being competitive and academically driven. This may lead females to spend more energy masking ADHD behaviours deemed to be less socially acceptable (Quinn, 2005), which become more challenging during adolescence and early adulthood when there are increasing demands for independence.

It is acknowledged that many adults want their ADHD to be recognised medically, acknowledging that their brain works in certain ways resulting in certain behaviours: "You are not ADHD – you have ADHD"; consequently, medical treatment could alleviate the unwanted symptoms (Nielsen, 2017, p. 36). With diagnostic anomalies, perhaps females with ADHD place importance on the understanding and aligning of their behaviours to be compatible with ADHD, as this clinical diagnosis manifests as an identity marker for which they can relate and express themselves through (Brinkmann, 2014; Jutel, 2011). In this instance, having an ADHD diagnosis can bring relief, leading to actions and an increased sense of responsibility (Hansson Halleröd et al., 2015). Therefore, in the current study, we take the standpoint that having a medically recognised health condition can be experienced both negatively and positively. However, the prospect of understanding one's challenges and gaining access to appropriate support can be lost when ADHD remains unidentified (Quinn, 2005). This can also impact the ability to articulate underlying experiences more generally, yet also specifically with health professionals.

Indeed, in the autism literature, research has found that misinformation and stereotypes about autism, can result in some autistic people being cautious or avoidant in disclosing their diagnosis to healthcare providers, employees and friends (Bradshaw et al., 2021). It is anticipated that the stereotypical male presentation of ADHD symptoms presented in the media, may lead to females being less confident in seeking out a diagnosis of ADHD until later life (Kessler, 2006). Therefore, through qualitative interviews, the current study explored firstly, the underlying reasons females with ADHD believed they had received a diagnosis later in life, secondly, their understanding of their ability to communicate their symptoms, and finally, the emotional impact of living with a late diagnosis of ADHD.

# Method

# **Participants**

Adult females with a formal diagnosis of ADHD obtained in adulthood were recruited through advertisements on Facebook, support groups specifically for females with ADHD and snowballing. Eleven participants initially made contact, with nine responding to follow-up emails, all of whom were interviewed. Out of the 9 participants, 8 were from the United Kingdom and 1 was from Canada. Participants were aged between 23 to 55 (M=43.67; SD=9.95), with an age of diagnoses ranging from 19 to 53 (M=40; SD=10.09). All except one of the participants reported to have additional current physical health and/or mental health conditions; most notably highlighted as being either a co-occurring anxiety and/or depressive disorder. All participants were diagnosed by a health care professional; length of time between diagnosis and participation in the study varied from <one year to 13 years. A summary of participant demographics is shown in Table 1.

Participant	Age	Ethnicity	Occupation	Country of residence	Marital status	Age of ADHD <sup>1</sup> diagnosis	Other neurodevelop- mental/mental health diagnoses	Other physical health conditions
Рорру	48	White	Specialist coach and psychologist	UK	Married	44		
Megan	37	White	Family support worker	UK	Co- habiting	36	Depression; Anxiety	
Amalie	51	White	Stay-at- home parent	UK	Married	51	Post-natal depression; Anxiety	
Clarabella	45	White	Stay-at- home parent	ИК	Married	41	Sensory and auditory processing difficulty; Depression; Anxiety	Arthritis; Migraines
Eliza	36	White	NHS	UK	Single	35	Anxiety	Hypermobility
Piper	55	White	Deputy head teacher	UK	Married	53	Generalised Anxiety Disorder	Coeliac disease; Underactive thyroid
Rina	50	White	Pharmacy technician	Canada	Married	37	Depression	Migraines
Ripley	48	White	Unemployed	UK	Married	44	Autism; Obsessive Compulsive Disorder; <sup>2</sup> C- PTSD Bipolar disorder (misdiagnosis); 3EUPD (queried)	Epilepsy; High blood pressure

Lauren	23	White	Student /	UK	Single	19	Eating	
			part time				Disorder,	
			support				3EUPD, mixed	
			worker				anxiety and	
							depression	

Table 1: Participant information. <sup>1</sup>Diagnosed by healthcare professional, <sup>2</sup>Complex post-traumatic stress disorder, <sup>3</sup>Emotionally unstable personality disorder.

#### **Procedure**

A semi-structured interview schedule was created by the research team based upon available literature. This was given to an adult female with lived experiences of ADHD, who did not take part in the actual interviews, to check for relevance and appropriateness. Questions included:

- 1. How does living with ADHD impact on your wellbeing?
- 2. What was your experience like undertaking and receiving your ADHD diagnosis and accessing support?
- 3. What strategies do you use to help you manage your symptoms and live well with ADHD?
- 4. How has your experience of ADHD and your ability to manage your symptoms progressed over your life?
- 5. What is the best advice you could give to other females about managing symptoms of ADHD, accessing a diagnosis/support and living a fulfilling life? Roberts et al., 2021; Sy et al., 2020).

Each participant received a participant information sheet detailing the study, how information would be stored, their right to withdraw, and anonymised quotes being used in a publication. Explicit informed consent was obtained, and online interviews were arranged at a time convenient to the participant. All participants were interviewed via Zoom with interviews lasting between 50-110 minutes (M= 71.3; SD= 19.41). The first author carried out all interviews, with the other authors part of their supervisory team. Online interviews were chosen due to the potential geographical, financial and social restrictions of in-person interviewing (Keen et al, 2022). To address concerns related to data confidentiality with online interviews, password-entry features were used (Yuan, 2020). All interview recordings were downloaded directly to researchers' passworded computers and stored in folders disconnected from the internet. Recordings were deleted following transcription, with all identifiable features removed and pseudonyms applied. A debrief sheet was given at the end of the study with information regarding further help and support, and opportunities given to raise concerns. Ethical approval was given by the institution's ethics committee (Protocol Number: aLMS/PGT/UH/05025(1).

#### Data analysis

A qualitative reflexive thematic analysis (TA) was used, enabling both recurring ideas as well as the diverse impact of ADHD to be identified and explored (Braun & Clarke, 2006; 2019).

Each interview was transcribed verbatim and read multiple times by the first author enabling familiarisation with the data prior to the development of initial codes. A line-by-line process was used to initially generate codes and collated into potential themes and subthemes. Reflexive thematic analysis was undertaken, with all analysis, coding and themes being discussed and explored within the research team; this also ensured themes were representative of the data and coding (Braun & Clarke, 2006, 2019); and personal lived experiences of ADHD within the research team were acknowledged and reflected on. Akin to the principles of reflexive thematic analysis, codes represented the research teams interpretations of patterns of meaning across the dataset (Byrne, 2021). Once themes were consolidated, member checking was carried out, with themes presented to all participants (Varpio et al., 2017). Member checking of the final themes enabled participants to express whether they felt the analysis was representative of their experiences; no changes were requested (O'Brien et al., 2014). However, weaknesses of this approach meant that minimal information was gained from participants given concerns that checking transcripts may be stressful for some participants reliving unpleasant experiences (McKim, 2023).

It was also noted that the members of the research team had clinical and research experience, yet also personal experience of caring for neurodivergent individuals; therefore we acknowledge we came from a more inside position. While this may offer advantages, including the ability to ask more meaningful or insightful questions (due to possession of a previous knowledge), there are distinct biases which may arise, including the inability to bring an external perspective to the process (Holmes et al., 2020). Therefore, individual and collective reflexive conversations ensured the team remained aware of their individual interpretations, and possible influences from personal backgrounds.

# **Results**

Four main themes were identified, comprising of eleven sub-themes, which are shown in Table 2.

Main Theme	Subtheme			
Earlier effects of undiagnosed ADHD	Struggles navigating interpersonal relationships			
	Self-image: falling short of expectations			
Emotional toll of living with ADHD	Compensations to make life work			
	Constant exhaustion of everyday life			
	Heightened levels of anxiety and depression			
Navigating diagnostic processes and	Missing ADHD: Alternative explanations			
its aftermath	Role of self-advocacy in diagnostic processes			
	Identification and understanding of ADHD symptoms			
Hope and support post-diagnosis	Mourning the life that could have been			
	The journey towards support			
	A different perspective of ADHD: making allowances and recognising			
	strengths			

Table 2: Main and subthemes.

# **Earlier effects of undiagnosed ADHD**

This theme outlines the diverse effects of undiagnosed ADHD, prior to participants obtaining an ADHD diagnosis in adulthood.

# Struggles of navigating interpersonal relationships

All participants described how ADHD impacted their ability to navigate interpersonal relationships:

So always felt different. Never quite fitted in, was always on the outside of the group. Mum and Dad, you say to me, don't worry, we're both loners, as well. You're just meant to be a loner. But I was like, no, I want to have friends. I just don't know how to do it. (Clarabella)

Whilst not expressly stated, Clarabella's relational difficulties implicitly suggested loneliness and frustration given she was unable to make friends despite clearly craving connection. The use of poignant phrases usually perceived negatively "loner"; "always on the outside", indicating how Clarabella felt "different", potentially negatively impacting her self-image.

These difficulties were echoed by all participants; Ripley expressed the torment and severe impact from difficult relationships with peers.

I just left school; I just refuse to go back. Because it was, it was torture, going in there. You know, I was just ostracised except by a few people that were like me, you know?

Ripley's use of evocative language ("torture" and "ostracised") embodied a sense of pain and anguish at school where the only solution was to leave and emphatically "refuse" to go back.

Interpersonal difficulties extended further, with participants discussing family-based struggles: "The family were in the circle, while I was sitting on the outside looking in" (Piper). Piper illustrated a sense of exclusion and distance, highlighting awareness and identification of differences between herself and others, a prominent narrative within all accounts.

### Self-image: falling short of expectations

Significant attentional difficulties framed participants' earlier academic lives:

...like the words "tête dans les nuages" like saying my head is in the clouds, came up every year, like I was always daydreaming in class...but I was smart enough that I could still get by without paying too much attention but that didn't hold up once the...load got too heavy. (Rina)

Over time, Rina offered a contrast between "natural ability" and being "smart enough", finding herself unable to cope as demands increased. Repetition of "head in the clouds" in French and English seemed to emphasise the inattentiveness characteristic of ADHD, at this point undiagnosed. For participants, such difficulties intensified over time meaning they struggled to find education which suited their needs impacting on their self-image:

I was not able to find...post-secondary education programme that worked for me, that I could complete, that I could stick with...I've a trail of failures behind you when people had very high expectations for me, because I was kind of considered a gifted kid and stuff and I got very good grades in high school, and then that changed. (Rina)

Whilst guilt was not directly stated, Rina was clearly impacted, implicating this indirectly when concluding: "So I feel like I've let a lot of people down and that weighs heavily on me".

A negative self-image related to falling short of expectations was a prominent narrative for all participants. Clarabella outlined how childhood experiences moulded and provided a blueprint for her now adulthood experiences:

...it just makes you feel a bit shit isn't it, makes you feel a bit shit about yourself. So, then you don't really have a great picture of yourself, and you can beat yourself up. So sometimes, you know, certainly as a child...it's the name calling or the, you know, "you're so bossy" or "you're such a know it all, and such a drama queen", and all those things. It's "why can't you just sit still, why can't you be more ladylike?" And yes, I guess all those things, they just really impact your mental health...it's your view of yourself. And then your confidence.

Clarabella recounted a profound impact laced with self-attack where "you can beat yourself up" when unable to conform to expectations; perhaps this was driven by communication by others being laced with critique for characteristic elements of ADHD hyperactivity, such as the inability to sit still, so intrinsically central to how she physically expressed herself. Clarabella's recollection of name-calling was suggestive of the weight this carried; the potential internalisation of this narrative seemed observable when she stated: "it makes you feel a bit shit about yourself".

Similarly, Ripley discussed how her confidence was lost with the depth of feeling like a failure: "...you just believe is something fundamentally wrong with you, and you lose your confidence as a person, and you just feel like a failure, you know". Indeed, all participants highlighted feelings of inadequacy that impacted self-esteem, especially when minimising their personal struggles comparative to others:

...there was a lot of self being self-critical...why am I finding this so hard...It should be easy enough to do. So, yeah. I think I just was trying so hard to be that perfect mum...it was just so exhausting and so challenging. Yeah, I did have periods of depression after my second child. (Amalie)

The extremity of the impact of attempts to be "perfect" were emphasised with the repetitive use of "so" when noting how exhausting and challenging it was, Amalie seemed to suggest that "depression" was a natural outcome from this by raising this immediately after.

#### **Emotional toll of living with ADHD**

This theme highlights the adaptions needed to live with ADHD and its consequential emotional impact on wellbeing.

### Compensations to make life work

All participants expressed extreme difficulty managing everyday life: "For me. I'd managed all of my life. I've managed clinging on by my fingernails" (Piper). The struggle of managing daily life was echoed by Megan, repeatedly outlining her compensations in her desperate attempt to achieve:

I was already trying twice as hard in the first place without realising it, and then I'm putting more pressure on myself, and try...doubly as hard. I liken it to...pedalling with a bike without gears, the other person's bike has gears when they go up a hill, and I didn't, but I didn't know that.

Megan was clear that greater struggle compared to others was initially beyond her awareness, and likely difficult to articulate in words, consequently embodying a sense of frustration at the additional pressures she experienced. This was evident across participants' accounts with difficulties intensifying over time, driving overwhelming feelings and difficulties coping: "...you would say, like the wheels fell off...I just couldn't deal, couldn't cope anymore" (Megan).

# Constant exhaustion of everyday life

The intensity of their unspoken struggles meant that all participants discussed dealing with constant exhaustion:

...exhausting having a lot going on in your brain all the time, and you know it's something that we don't talk about, and then also managing all the pain, and the ticker tape, constant internal dialogue, and perhaps all the tabs that are open. (Clarabella)

Clarabella's long sentence structure illustrated the external hyperactivity of ADHD, providing a representation of the fast-paced internal dialogue which represented her internalised hyperactivity; her difficulty outwardly talking about it contrasted with a draining "constant internal dialogue."

Exhaustion and fatigue often preceded burnout highlighted by Piper: "...exhaustion. I'm constantly... I go from being tired to fatigue, fatigued, to exhausted, to feeling like burnout". Piper discussed ramifications of constant exhaustion and burnout on mental health, "I'd...wish myself ill a lot so I'd be able to have some time to just rest". Whilst guilt was not directly affirmed, it seemed evident that her self-image was being impacted when she berated herself with: "And that's horrible. I wish myself ill."

#### Heightened levels of anxiety and depression

Feelings of anxiety resulting from the effort needed to manage ADHD symptoms were a key feature of participant recounts:

Because you always think something bad is gonna happen, or you worry about what's going to happen. Your enjoyment of everything you do, really, things that should be nice, you're always worrying and just things that you should be looking forward to, you can't because you just have such bad anxiety over. (Ripley).

It seemed "anxiety" robbed Ripley of enjoyment, perhaps evoking frustration and sadness. Ripley outlined the potential role ADHD played: "...because my brain was going so fast all the time, it was running fast. So, all the time that it caused problems. And that's what caused my anxiety." This seemed to represent a kinder understanding towards her heightened emotional distress. Similarly, Megan noted the intense impact this eventually had on even simple tasks:

I just got so anxious. So, it was to the point where I'd wake up anxious and...it got so bad that my brain basically just stopped working. So, I couldn't even do simple administrative tasks.

Similarly, all participants reported heightened levels of depression, with many attempting to end their lives:

...yeah, I got really depressed in secondary school... I tried to commit suicide twice in my A level years, which was quite hard... And I was trying to do that, because I was depressed, didn't fit in, hated life. (Clarabella)

Phrasing like "hating life" embodied a sense of extensive hopelessness and futility around her alienation from others. Such experiences seemed too hard to communicate at the time, for example, when discussing relationships between ADHD and depression, Piper similarly stated:

...when my little boy, so he was three, and my nephew was a baby, and I was looking after him, I almost took an overdose...if it wasn't for my dad ringing on the door... And then I only told my parents recently that happened because I just...kept everything inside. I didn't talk about anything; and internally, it was just really difficult.

Piper's vivid recollection and ability to recall intricate setting details implied this was a significant memory potentially indicating an intense emotional association, which also remained unexpressed to others at the time.

## Navigating diagnostic processes and its aftermath

This theme highlights diagnostic processes, implicating earlier misdiagnoses and its aftermath, before ADHD was finally diagnosed.

# Missing ADHD: Alternative explanations

Most participants were given alternative diagnoses to explain symptoms, and given the emotional impact ADHD had, depression and anxiety were common:

I've had these diagnoses of depression and anxiety, but looking back I think it was a reaction to being overwhelmed. I think it was just, not knowing I had ADHD, being really hard on myself because I couldn't cope, like, I felt, like, I should be able to. (Amalie)

Amalie seemingly implicated the commonality of misdiagnosis instead of ADHD when concluding "I think those were missed diagnoses, because that's kind of what you get". This was echoed by Megan who expressed being "kind of led to believe it was depression and anxiety", phrasing which suggested a sense of being misinformed during consultations. Participants also felt a lack of curiosity was indicative of a lack of understanding more broadly around their struggles:

No one has ever thought this woman's had anxiety, depression; now she's got these things, she's in the menopause. There's something else going on? I don't feel...anyone else did that; and it was, I felt like I had to be a detective for myself; and I've prompted everything. None of this has been looked at in a holistic way. (Poppy)

# Role of self-advocacy in diagnostic processes

With a lack of professional knowledge and curiosity, all participants highlighted the importance of becoming more aware and vocal by self-advocating through the diagnostic process, with many feeling that accessing a referral was "a lot of work, a huge amount of

work" (Eliza). Not only were the symptoms and emotional toll of ADHD exhausting, the diagnostic process navigating the system also highlighted this when Eliza concluded: "Yeah. I'm quite exhausted having to do that on my... feeling I have to do that on my own"; and Megan stated: "assessment process and pathway isn't very ADHD-friendly". Piper recounted experiencing extreme distress, hiding this from others, yet also desperately pleading for help:

And I remember just hiding in my office, on the floor crying on the phone to someone in the department saying, please, I just, you've got to help me I can't. I can't live like this anymore. I can't go on.

Piper's repetition exemplified the emotional toll of symptoms, suggesting a sense of hopelessness and desperation. Despite taking charge and clearly communicating their relevant symptoms participants felt dismissed by the response:

I got a referral to an adult mental health. Met a mental health professional, whoever they are. I'm not sure what their qualifications are. I had colour coded my symptoms. I'd done the job for them. And they decided that since I was still married, and I was a teacher, and I'm not addicted to anything, that I didn't have ADHD, so I could jog on. Right. So, what you're saying is basically, come back when you're broken. (Poppy)

# Identification and understanding of ADHD symptoms

Most participants identified more with internal, rather than external, representations of hyperactivity symptoms:

...when I got diagnosed, I got diagnosed with inattentive type. I do now recognise the hyperactivity within myself is...within my brain. It never stops. I didn't see that. Because I've always been like this. I don't know any different. Yeah. And I didn't see the similarities between myself and the...primary age boys that I work with that do have diagnoses or will have diagnoses of ADHD and it's, you know, blatantly obvious to anybody. (Eliza)

Such distinctions seemed to highlight disparity between the commonality of ADHD symptoms in females yet, diagnostic criteria not matching this, suggestive of confusion around ADHD in females: "I didn't identify with the phrasing and the wording of the questions where it's, it's made sense when I've been talking to other women with ADHD and the female experience of you know, those descriptors" (Eliza). Participants highlighted how gendered presentations impacted their view of ADHD:

I hadn't thought of myself, particularly as hyperactive or inattentive, I knew I was a bit impulsive, but anyway, I don't really see myself like that. But in those first few months, reading about the condition more in terms of how women and girls are experiencing it, and understanding that, basically, those three core symptoms are the tip of the iceberg, and it's the executive functioning, it's the emotional regulation; and so that was a big change. (Poppy)

Poppy indicated distance between herself and labels, indicating that communication with others, alongside self-education provided her with the answers she needed to understand her symptoms were "core symptoms" in females.

#### Hope and support post-diagnosis

This theme focusses on the post-diagnostic journey to access positive experiences encapsulating the ways which helped them re-capture often overlooked qualities.

# Mourning the life that could have been

The emotional impact of receiving an ADHD diagnosis later in life reoccurred across accounts with participants likening the process to grieving:

So, it's, it's almost like the stages of grief. I was just almost walking around in trance at first thinking, "Hmm, how has this happened? How... I got this far in my life without knowing this?" And then it's sort of anger, and "why didn't anybody see it? Why did I have to go through all those years of my life struggling so much?" (Piper)

The evolution of "grief" to "anger" indicated the emotional processing required to come to terms with the diagnosis. Fast paced rhetorical questioning and strong evocative references seemed to accentuate her frustration, embodying a sense of emotional pain. Feelings of loss seemed to be another pertinent feeling experienced by participants, as described by Rina:

Regret like, not regret, it's like a loss like a death almost like it's a grief. I grieve for what could have been. Yeah...I grieve for what I could have accomplished, not necessarily what other people expected of me, but what I would have wanted for myself. I grieved for being able to handle my relationships better.

By using such poignant death-associated phrasing, the emotional impact of late diagnosis was illustrated, embodying a profound sense of sadness around how her life and relationships had been, yet could have been made better with an earlier diagnosis and effective communication with professionals about her symptoms. Ripley's account outlined trauma resulting from late diagnosis and living with symptoms:

I have C-PTSD from everything, my life and everything, and it's left me with that; and I think that is something that plays on your mind... I've never stopped feeling sorry that I didn't. I wish that my life had been different.

Ripley's account embodied a sense of sadness and longing for a "different" life, exhibiting the severe emotional impact living with undiagnosed ADHD had — where perhaps an earlier diagnosis of ADHD may have better accounted for her heightened emotional distress. Nevertheless, in acknowledging the impact from the past, such grieving seemed an important process to access a more hopeful present and future.

#### The journey towards support

On their initial journey, all participants expressed concerns around accessing support, and difficulties they had in dialogues with clinicians:

...one of the ladies that I saw for my medications, positively hostile, off the bat. She didn't let me answer a question fully before she was interrupting me and telling me my answer to my question. Like, it's almost like with the NHS experience, you have to prove, you know what I mean, like, prove that you're ADHD. (Megan)

Clearly this had been a difficult, almost disempowering interaction, the repetition of 'prove' emphasised just how hard it was to be taken seriously, and access a diagnosis, posing questions around the limitations preconceived ideas might have on clinicians. Indeed, all participants reported receiving no support for their ADHD: "None. But what support should I expect? No, they're so bloody massively overstretched. Aren't they? No money anywhere" (Clarabella). Participants also revealed that co-occurring mental health conditions also

remained unacknowledged, implicating limitations in knowledge, for example, Lauren reported receiving no support when beginning stimulant medication despite having a prior history of anorexia: "No. No, no. okay. Not at all. But then to be fair, like. Yeah, no, not at all". Lauren's statement seemed both uncertain, yet emphatic as signified through her use of fragmented sentences contrasted by the ardent repetition of "no".

With seemingly nowhere to turn post-ADHD diagnosis, participants found solace in eventually finding and communicating with others like themselves who could understand and help them find alternative more hopeful perspectives: "The thing that would make the biggest difference would be to keep company with other women with ADHD...that would bring the biggest fast change, change to your feelings about yourself" (Poppy). The importance of positive relationships with others contrasted with the sense of being an outsider in earlier relationships at school. This narrative was perpetuated by Amalie; "...for me, just being able to talk to other people, like, definitely helps a lot. People who are in the same situation who have that understanding". Further, it seemed that having a diagnosis allowed participants to connect and communicate with others increasing self-acceptance: "...diagnosis has kind of given me that permission to be me, and then to find people like me" (Clarabella).

## A different perspective on ADHD: making allowances and recognising strengths

Changing perspectives on symptoms post-diagnosis was a repeating narrative for many participants, for example, Amalie stated: "I can see now that I just hyperfocus if I if I'm really determined to do something, I will just go for it. If I will do it." (Amalie). Repetition of this sentiment seemed to positively exemplify intensity and drive. Of particular importance was a better understanding around emotional expression with their internal dialogue and emotional responses:

So, I can tell myself when I burst into tears "It's okay, you are an emotional sensitive person, and then for you this is your response to whatever it is"; and understanding that...having big emotional responses is part of ADHD, is very useful as well. So, I know it's nothing I did. Or nothing that's happened to me to make me that way, [it's] that I was made that way.

Poppy reflected on how her diagnosis enabled understanding towards emotional responses enabling acceptance and self-validation. The development of self-compassion and understanding was implicitly evident, and further exemplified by Amalie: "I feel like for me, it's been a real revelation, it's actually really helped explain a lot of why I've had so many challenges. Now I can have a lot more self-compassion, which is wonderful". Amalie's testimony highlighted the profound effect having a diagnosis had, her ability to practise self-compassion, self-tolerance and empathy, seemed to illustrate the powerful change to her internal monologue, evidenced when she concluded; "But since my diagnosis, I feel like I've become a lot softer in that respect, like more empathic towards myself". Whilst some ADHD symptoms had detrimental effects, participants identified how ADHD enriched their lives:

I have an understanding and tolerance for other people...with similar needs, or especially in terms of emotions and stuff. Yeah. It's probably not being the best at other times, but then it's kind of made you more of an understanding person. (Lauren)

Choosing to conclude with a more positive perspective represented a change in her internal monologue and recognition of the strengths associated with ADHD, particularly with

emotions, an area where ADHD may better account for emotional dysregulation. Similarly, Clarabella stated:

I think I'm very empathetic to other people's emotional states. And I'm really good at reading their emotional states...I don't really know how that ties into ADHD, but somehow, it makes me feel better about being less scattered in other ways...I am good at connecting to people

The consistent balance of attempting to perceive both positives and negatives of her ADHD, appeared to represent her renewed internal monologue around recognising her strengths communicating with, relating to, and ultimately positively connecting with others regardless of her difficulties.

# **Discussion**

Participants highlighted the emotional toll of difficulties from undiagnosed ADHD, difficulties around communication dynamics related to this, and the subsequent impact this had on their self-image. These accounts mirror previous ADHD research highlighting difficulties achieving academically (Barry et al., 2002); increased social rejection in earlier life (Hoza et al., 2005), and struggles managing employment demands (Shifrin et al., 2010). Moreover, the management of these effects alongside managing everyday life impacted participants wellbeing, detailing severe levels of anxiety (Schatz & Rostain, 2006), and depression (Spencer, 2006).

Pre-ADHD diagnosis, participants placed themselves under high levels of pressure, often without respite, to perfectly meet perceived and expected life and work demands. High levels of guilt and frustration were reported when unable to meet expectations throughout their life, alongside a higher likelihood of experiencing perceived failures, which had a profound impact on their self-image. Participants expressed intense distress and desperation for rest, to the extent some wished for physical ailments to justify a break.

Fatigue due to constant internal hyperactivity (Targum & Adler, 2014; Holthe et al., 2017) and attempts to meet demands, often left them in a permanent state of exhaustion (Rogers et al., 2017), for some akin to burnout seen with adults with autism (Raymaker et al., 2020). It seemed participants were unable to allow themselves to stop; for many the intensity meant they were barely able to cope, often experiencing hopelessness. All this was laced with a constant internal dialogue, experiences of negative critiques from others, difficulties expressing symptoms to others and when they did, misunderstanding or dismissiveness from professionals. To counter difficulties from keeping up with demands and managing their undiagnosed ADHD, all participants implemented compensatory strategies (Canela et al., 2017), yet they also described the emotional struggles of engaging in these. For some participants, the emotional impact and isolation were so profound they attempted to end their own life. That said, the emotional impact was described as secondary to the impact ADHD symptoms had, yet participants felt pre-diagnosis clinicians instead centralised depression and anxiety as the issue (Quinn & Madhoo, 2014). This suggests that the language used to communicate symptoms can have profound impacts on participants' ability to identify symptoms within themselves, to communicate this to others and for this then to be accurately conceptualised.

Underpinning much of participants' struggles were professional misunderstandings around their hyperactivity and inattentiveness symptoms. For participants, hyperactivity symptoms involved rapid thoughts, and in line with literature, they resonated with symptoms manifesting internally through inattentiveness (Levy et al., 2005) and emotional dysregulation (Retz et al., 2012). Since the diagnostic criteria are written in ways that does not always capture the female experience of ADHD, participants seemed unable to recognise or communicate the difficulties related to ADHD with many preferring to distance themselves from perceived stereotypical external presentations of hyperactive males.

Further barriers for diagnoses arose through clinicians perceiving participants to be too high functioning and/or too successful to have ADHD for a diagnostic process to be considered, often regardless of symptom presentation. Indeed, research has noted significant questions regarding the predetermined ideas clinicians possess, creating barriers for people accessing support (Young et al., 2020). A possible explanation for this could be the way ADHD symptoms are communicated within diagnostic manuals. For example, inattentiveness and hyperactivity tend to focus on outward observable symptoms and emotional dysregulation is only noted as an associated feature in ADHD (American Psychiatric Association, 2022). Without the recognition of internal hyperactivity and emotional dysregulation as explicit criteria within diagnostic frameworks clinicians are less likely to consider ADHD as a diagnosis. This can make it difficult for clinicians to identify levels of impairment in females with ADHD (Mowlem et al., 2019), alongside appropriately understanding ADHD-based conceptualisations of emotional dysregulation. Early diagnosis can increase levels of psychological wellbeing (Goksøyr et al., 2008), and significantly poorer quality of life is associated with untreated ADHD (Agarwal et al., 2012). Thus, earlier access to diagnostic processes is crucial, yet participants highlighted the essential need for self-advocation to identify and diagnose ADHD in adulthood; they also expressed frustration with the process being so self-driven, as it did not account for ADHDrelated difficulties and its longstanding impacts when left undiagnosed. For participants in this study, a late diagnosis triggered a bereavement process (Young et al., 2008), having to adjust to the pervasive losses they had experienced through misdiagnoses, mismanagement and misunderstandings. Indeed, one participant stated that the longstanding impact from ADHD alongside the late diagnosis, resulted in significant trauma (Morgan, 2023).

Upon diagnosis of ADHD, participants revealed that they became better equipped to understand their difficulties, providing an almost transformative effect (Grønneberg et al., 2024). Many reported that their strengths post-diagnosis often ameliorated some of the difficulties, reframing their perspectives of ADHD (Fleischmann & Fleischmann, 2012). For example, many discussed how hyperfocus and hyperactivity enabled them to achieve goals when appropriately channelled. Indeed, when optimised, ADHD can be an asset (Sedgwick et al., 2019), with disabilities, when understood, facilitating an environment enabling individuals to flourish (Garland-Thomson, 2012).

Further, an ADHD-based explanation enabled participants to become more empathic, compassionate and understanding towards themselves (Henry & Jones, 2011). It also fostered meaningful connections with people and facilitated the identification of their emotional states. Other women with ADHD became predominant within participants support systems, in formal (support groups) and informal capacities (new friendships). Participants discussed how interacting with females with ADHD positively influenced well-being and self-image providing them a space to discuss commonalities. Through this, participants reported feeling

understood, a stark contrast to the social isolation and difficulties often described (Hoza et al., 2005) in earlier life, particularly at school. Indeed, notably through dialogues with other females with ADHD, this seemed to enable a more compassionate understanding towards emotional dysregulation rather than diagnoses of, for example, emotionally unstable personality disorder (EUPD) which some participants had previously stated they had been (mis)diagnosed with pre-ADHD diagnosis.

Thus, a systemic change is required to re-dress these imbalances involving specific tailored support for females with ADHD, regardless of their age. Firstly, since communication with other females diagnosed with ADHD had such benefits, attempts should be made to develop and integrate support groups into standard practice, for all ages. Secondly, given the emotional impact of life pre- and post-diagnosis, this study implicates the need for post-diagnostic psychological support to aid adjustment and to facilitate the grieving process. Given participants often felt like outsiders at school, experiencing critique for ADHD symptomatology, schools should provide workshops which normalise emotional expression, and educate around the positivity associated with ADHD to facilitate compassionate dialogues which foster a more positive self-image. In line with the participants in this study, dialogues earlier in life, would support females who may be struggling internally, but are not yet aware of why. It would also enable a strength-based approach towards the way their brain works.

Finally, given misunderstandings surrounding participants' hyperactivity symptoms and potential for depression and burnout (Fleischmann & Fleischmann, 2012), ways of managing these difficulties might involve energy accounting, as suggested with burnout in autism (National Autistic Society, 2021), and greater acceptance of adaptive avoidance. This form of demand avoidance is a valuable and important strategy to empower individuals to take charge of their energy levels and should be understood and validated as such, rather than pathologized. With greater likelihood of success, this might potentially protect self-image, despite the natural vulnerability and fragility humans experience within life.

A core strength of this study was consultation throughout of people with lived experience when developing the interview guide and when verifying themes. Nevertheless, whilst the sample is appropriately sized for qualitative research, it still inhibits generalisability. Further, we recruited through two main channels, including social media and ADHD research groups and charities. Our use of social media also meant that our sample may be biased (Rødgaard et al., 2022), such that there may be a systematic difference between those who choose to participate or not (Andrade, 2020; Rubenstein & Furnier, 2021). Importantly, some demographic groups may be more likely to respond to the advert than others (Cheung et al., 2017) and be motivated to take part based on their interest in or position on the topic (Groves et al., 2004). One limitation potentially related to this was all participants were white, this requires further exploration in future studies to ensure the cultural contexts of females with ADHD are better understood.

To conclude, the present study outlined the emotional effects for females who gained a late ADHD diagnosis in adulthood, often due to misunderstanding from health professionals and/or their own confusion over meeting the symptomology for an ADHD diagnosis. Findings highlighted difficulties accessing referrals and support resulting in the need to self-advocate. Furthermore, participants did not fully identify with the diagnostic criteria for ADHD and terminology used, maintaining it did not reflect their experience of ADHD impacting the attainment of an earlier diagnosis. To address this, both diagnostic terminology and clinician

preconceptions of female presentations of ADHD require consideration. For example, explicitly incorporating emotional dysregulation in diagnostic criteria, and by providing frontline services with training into alternative presentations of ADHD in females. Healthcare professionals also need to move away from deficit-based language that can perpetuate stereotypes and contribute to feelings of helplessness and low self-worth. These results potentially indicate the value of reframing narratives and communication surrounding ADHD symptoms, potentially improving detection and diagnosis in females. Furthermore, deficits in formal post-diagnostic support meant participants contacted ADHD support groups to compensate; given the benefits therein, it seems signposting or integrating these into standard practice should be prioritised.

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