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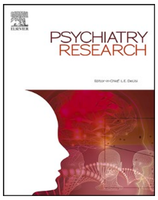

Original article

Perceptions of adults with ADHD on pharmacological treatment initiation and subsequent adherence: a thematic analysis

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ABSTRACT

Background: Following a diagnosis of attention deficit hyperactivity disorder (ADHD), many engage with pharmacological treatments to manage symptoms. However, despite efficacy in short-term ADHD symptom improvements, approximately half of adults discontinue pharmacological treatment within the first year, while others do not entirely adhere to treatment as prescribed. This study aimed to investigate experiences of adults with ADHD in the first year of pharmacological treatment, and how this impacted treatment engagement.

Method: Twenty-five adults with ADHD completed semi-structured interviews. The interviews investigated perspectives of pharmacological treatment including response to medication, experiences of titration, treatment adherence and decisions for (dis)continuation. Inductive thematic analysis was conducted to generate themes.

Results: Analysis generated four themes pertaining to pharmacological treatment engagement. (1) **Processing diagnosis** reflected the processing of one's diagnosis throughout treatment. (2) **Managing expectations** outlined how expectations at the outset of treatment can impact perceptions of treatment efficacy. (3) **Accessing support** highlighted areas of pharmacological treatment in which many felt support was lacking and the impact;

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(4) **Balancing costs and benefits** outlined the process that individuals undertook when balancing whether medication was worth continuing.

Conclusions: This study contextualised the high rates of treatment non-adherence and discontinuation for adults with ADHD, highlighting how ongoing processing of the diagnosis, high expectations of the medication's impact, available guidance from healthcare services and the ultimate balance of positives against negatives, contribute to an individual's treatment compliance and continuation. Ultimately, this study highlights the need for personalised treatment and the importance of the availability also of non-pharmacological treatment options.

1. Introduction

Approximately 2.5 % of adults globally have a diagnosis of ADHD (Faraone et al., 2021). As the receival of an ADHD diagnosis requires that symptoms be sufficiently impairing in an individual's daily life (APA, 2022), treatment will be offered to manage ADHD symptoms. The UK National Institute for Health and Care Excellence (NICE) guidelines (2018) recommend a holistic approach, incorporating adults' pharmacological treatment as a first-line treatment in conjunction with non-pharmacological treatment, where appropriate. Pharmacological treatment will typically involve a physical assessment and discussion between clinician and the individual to determine suitability of medication, followed by a titration period whereby type and dose of medication can be amended to achieve maximum benefit. The titration period duration varies but typically lasts two to three months (Clinical partners, 2025; Psychiatry UK, 2025). Network meta-analyses of randomised control trials indicate efficacy of several stimulants and atomoxetine in reducing ADHD symptom severity short-term (Cortese et al., 2018; Ostinelli et al., 2025). However, these are typically limited to only 12-week follow-ups post-initiation. A recent multi-national study of over one million individuals with ADHD indicated that only approximately half of adults who initiate pharmacological treatment remain on medication after one year, with around 30–40 % engaging with pharmacological treatment after 5 years (Brikell et al., 2024). The obvious yet crucial question that arises and to which we do not yet have a clear answer, is why do individuals discontinue pharmacological treatment for ADHD?

Qualitative research provides the opportunity to gain greater insight into experiences, whereby we can contextualise experiences of adults with ADHD during pharmacological treatment and further understand factors contributing to discontinuation (ceasing pharmacological treatment) and non-adherence (not taking medication as prescribed). Qualitative research on this topic is limited and mainly includes children and adolescents. Findings from these studies indicate side effects, social stigma, desire for self-expression without medication and the belief that ADHD is a childhood illness contributed to medication discontinuation (Meaux et al., 2006; Titheradge et al., 2022). Moreover, wanting to feel independent and disliking the feeling of medication were cited by young people as a reason for non-adherence (Barnard-Brak et al., 2023). Regarding adults with ADHD, severity of co-occurring clinical conditions, such as depression severity, has been significantly associated with poorer medication adherence (Nguyen et al., 2025); a crucial consideration given an estimated 75 % of individuals with ADHD have a co-occurring condition (Banaschewski et al. 2017). Qualitative research with adults with ADHD highlighted difficulties navigating healthcare systems and accessing treatment (Matheson et al., 2013). However, to our knowledge, no qualitative study has been conducted with adults with ADHD to specifically address reasons for pharmacological treatment discontinuation and non-adherence. Given the substantial increase in individuals seeking support from ADHD services, and the current strain on the system (Smith et al., 2024), understanding experiences of adults with ADHD of pharmacological treatment is imperative. The ADHD Remote Technology Study of cardiometabolic risk factors and medication adherence (ART-CARMA) (Denyer et al., 2022) provided the opportunity to gain adults' first-hand perspectives of changes in behaviours and symptoms; patterns of adherence; and reasons for (dis) continuation approximately one year after treatment pharmacological treatment commencement. The aim of this study was to gauge first-hand perspectives of adults with ADHD on pharmacological treatment and explore reasons for treatment continuation and compliance.

2. Methods

2.1. Study context

All individuals included in the sample had participated in the ART-CARMA study; a remote measurement technology study (Denyer et al., 2022). For the ART-CARMA study, individuals were recruited in both the United Kingdom (UK), through collaborating NHS clinics, and Spain, through clinicians at Vall d'Hebron University Hospital. For 12-months, participants engaged with active and passive monitoring via a wearable device and smartphone apps, to monitor aspects of physical and mental health, diet and lifestyle, and medication adherence, during their pharmacological treatment initiation, titration and subsequent medication use. Participants were enrolled into the ART-CARMA study approximately one month before commencing pharmacological treatment and thus their end-of-study interviews were conducted approximately one-year post-treatment initiation.

2.2. Participants

All participants who completed their 12-month ART-CARMA study period were invited to participate in end-of-study interviews. Twenty-five of these participants from the UK were included in these analyses, due to saturation being reached and the researchers agreeing that no new themes were emerging upon conducting further interviews.

Inclusion and exclusion criteria for the ART-CARMA study, and therefore the qualitative interviews, are outlined in Table 1.

2.3. Interviews

Interviews took place between November 2023 and November 2024 over Microsoft Teams and lasted from 24 min to 1 h (mean duration 44 min). Interviews were conducted and recordings were transcribed by ABa, HM or PR. Participants discussed their experience with participating in ART-CARMA, reflecting on challenges and benefits, as well as their journey to diagnosis and with medication. This paper focuses on the latter part of the interview, in which participants were asked to describe their treatment journey, from initiation to the time of the interview.

Topics included personal perspectives on the treatment initiation, the titration process, whether medication impacted ADHD symptoms, mood or behaviour, patterns of adherence and whether the individual continued medication and factors impacting these decisions. See supplementary material 1 for full interview schedule.

Participants were compensated £120 for completing the ART-CARMA study but were not additionally compensated for participating in the end-of-study interviews, which were optional.

2.4. Data analysis

The interviews were analysed using inductive thematic analysis. The

Table 1
Particpant inclusion and exclusion criteria for the present study.

Inclusion criteria[*]	Exclusion criteria
Diagnosis of DSM-V ADHD[**]	Symptoms of psychosis and/or drug dependence in past 6 months[****]
Aged between 18 and 60 years old	Currently experiencing a major depressive episode[****]
Able to give their informed consent for their participation	Currently experiencing mania[****]
Fluent in English[***]	Experiencing a major neurological disorder at baseline
Willing and able to complete self-reported assessments via smartphone	
Willing to use either own compatible smartphone or a study provided phone as their main phone	
Willing to wear the EmbracePlus wearable device during the data collection period	

[*] The only additional inclusion criterion for completion of the end-of-study interview was a willingness and availability to complete these interviews, as they were an optional element of the ART-CARMA study.

[**] To receive a diagnosis of ADHD, an individual must exhibit developmentally inappropriate symptoms of inattention and/or hyperactivity/impulsivity for 6 months or more. Symptoms must have been present before the age of 12 (i.e. there must be a pattern across the individual's lifespan) and must not be better explained by another psychiatric condition. Additionally, the individual will need to demonstrate sufficient impairment, in more than one setting (APA, 2013).

[***] Inclusion criterion at UK site only.

[****] These exclusions were based on the MINI International Psychiatric Interview 5.0.0 (Sheehan et al., 1998). When participants met threshold on exclusion criteria, the research team confidentially discussed their case with a collaborating psychiatrist to ascertain whether symptoms were sufficiently impairing, interfering with typical daily activity or a cause for the participant not commencing pharmacological treatment.

authors followed the protocol outlined by Braun and Clarke (2006, 2021): (1) familiarisation with the data; (2) systematic data coding; (3) generating initial themes; (4) developing and reviewing themes; (5) refining themes and (6) writing a report.

ABa, HD, both researchers, and ESN, a clinical psychologist and researcher, coded an initial subset of six interviews. ABa, HD and ESN then met to discuss and ensure consistency in coding. Agreement was high, with differences arising relating only to terminology used, and not themes. ABa and HD coded the remainder of the interview transcripts. NVIVO 14 (Lumivero, 2023) was used by all researchers to facilitate the coding of interview transcripts.

ABa and HD met to discuss themes, incorporating codes from ESN. Broader patterns were explored, based on the reported experiences relating to the research questions. Codes, interpretation, and overarching themes were discussed by ABa and HD over subsequent meetings, with the initial thematic structure being reviewed and refined, until both authors were confident that the themes identified adequately represented the experiences outlined. This process generated four themes and 15 subthemes.

2.5. Ethical considerations

The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national and institutional committees on human experimentation and with the Helsinki Declaration of 1975, as revised in 2013. All procedures involving patients were approved by Camberwell St Giles Research Ethics Committee (REC reference: 21/LO/0825). Privacy rights of participants were observed and written informed consent was obtained from all participants.

Please see supplementary material 2 for statement on reflexivity.

3. Results

Following the ART-CARMA study remote monitoring period, twenty-five participants completed optional audio-recorded interviews. Table 2 outlines the demographics of the participants.

Inductive thematic analysis generated four themes and 15 sub-themes. Table 3 includes a summary of generated themes and accompanying participant quotes. Supplementary material 3 includes a visual representation of themes and sub-themes.

3.1. Theme 1: Processing diagnosis

For many, the processing of the receival of an ADHD diagnosis is multi-faceted and ongoing throughout treatment; impacting quality of life and self-perception. The collective descriptions of this process roughly resemble the "five stages of grief" model (Kubler-Ross, 1969) with one participant labelling it as such. Much like the five stages of grief, this process is not linear, and not all participants reported feeling all five stages outlined below.

3.1.1. Subtheme 1a - Relief

Receiving the diagnosis provided participants with an explanation, validation and something to which their previous difficulties could be attributed. Many participants noted that they had previously believed that they were flawed, but receiving the diagnosis allowed them to view themselves more compassionately.

Similarly, several participants noted that reaching the end of the long diagnostic process and start of pharmacological treatment marked a sense of achievement for them, and they were relieved and proud to have initiated the process and actively sought support.

3.1.2. Subtheme 1b – Denial

Several participants noted that they had also experienced a form of denial following the receival of their diagnosis. Participants commonly reported questioning their diagnosis, and worrying that they were exaggerating, not struggling "enough", "just bad at stuff" or an "imposter".

One participant noted that this doubt was caused by a belief that they

Table 2
A summary of demographics and baseline assessments for participants in the present study.

Demographics of interview participants (n = 25)	
Gender, n women (%)	14 (56 %)
Age in years, range (mean)	23–57 (39)
Ethnicity, n (%)	
White	16 (64 %)
Black	4 (16 %)
Asian	1 (4 %)
Mixed/multiple ethnic background	4 (16 %)
Taking ADHD medication at the time of interview, n (%)	16 (64 %)
ADHD medications taken during 12-month study	18 (72 %)
Period, n (%)	6 (24 %)
Stimulants only	1 (4 %)
Stimulants and non-stimulants	4 (16 %)
Uncategorisable	6 (24 %)
Co-occurring clinical disorders[*], n (%)	4 (16 %)
Major depressive episode at baseline	11 (44 %)
Dysthymia	9 (36 %)
Past hypomanic episode	6 (24 %)
Lifetime prevalence of panic disorder	2 (8 %)
Generalised anxiety disorder	6 (24 %)
Obsessive-compulsive disorder	7 (28 %)
Alcohol dependence at baseline	1 (4 %)
Agoraphobia	
Social phobia	
Past manic episode	

[*] Based upon criteria from the MINI International Neuropsychiatric interview 5.0.0 (Sheehan, 1998), conducted at baseline.

Table 3
Summary of the four themes and 15 sub-themes, accompanied by quotes and demographics of participants who provided each quote.

Theme	Subtheme	Topic	Quote	Participant (age group, gender)
Processing diagnosis	Relief	Diagnosis provided an explanation	“Uh relief, I guess. Yeah, yeah. It was more like a relief [to receive the diagnosis] because it was, before I didn’t understand why I was the way I was. So, I just thought there was something wrong with me and when I got the diagnosis, it kind of all made sense after all. That it’s quite common then, for people to have this […] this wasn’t like an alien and not like oh you’re different. You’re just like people that have the same mind”	Participant 25, Female, 40′s
Processing diagnosis	Relief	Diagnosis provided validation	“I was kind of like oh I knew it and relieved because I just felt like I’ve been telling people I think I have ADHD for so long and, you know, […] you don’t know you have something until you’re diagnosed with it”	Participant 18, Female, 20′s
Processing diagnosis	Relief	Seeking a diagnosis itself providing relief	“Getting the diagnosis, I think I found it, myself, I found it quite rewarding because I felt like I was doing something about something […] so yeah, I found it quite rewarding that I was able to even begin to start a process of looking into what I was doing, what I was doing and speaking to the doctors and then finally get my diagnosis”	Participant 13, Male, 40′s
Processing diagnosis	Denial	Doubts about diagnosis	“There’s this weird kind of, I don’t know, I know it’s the wrong word to use but it’s almost like, going into it, I felt like I was so convinced, I was like, yes, you know, when you see all the symptoms online, I was thinking yes, yes, yes. And then when I got diagnosed, I had this weird like, it’s not imposter syndrome because it’s not a good thing to be diagnosed. But it was almost like I questioned it and I thought like, no, maybe it’s not true because someone said about, because obviously one thing is losing things. And I focused on that, I was like, well I don’t actually lose stuff because I have, there are places I’ve put my stuff around the house and I just know where they are. So I was like oh, okay, well that means I don’t have it. And maybe I’ve just, and then I just started over thinking the whole thing. And I was like oh maybe I’ve just wasted everyone’s time and I don’t have it”	Participant 7, Female, 20′s
Processing diagnosis	Denial	Doubts about diagnosis	“There was an element of it where, you know, still a small bit of me that’s thinking, you know, maybe it isn’t this, maybe you are just, you know, really bad at stuff”	Participant 16, Male, 40′s
Processing diagnosis	Denial	Using diagnosis to justify unhelpful habits	“I think ‘oh this is because I’ve got an executive dysfunction issue’, but other times, I guess, I’ll resist the, I guess thinking on, you know, do you really have ADHD? Sometimes I think, do you, like question myself and doubt myself and think actually it’s because maybe you can’t do this, period. That’s why and you’re using that as an excuse. So, […] I do sometimes really question my diagnosis and think do I really have this? Because I feel like I am using it as a way to kind of like justify unhelpful habits”	Participant 2, Female, 30′s
Processing diagnosis	Anger	Anger at the signs of ADHD being missed previously	“[There’s] this frustration and this sense of injustice as well. For all the years of struggle, particularly during school, just like ‘ugh that’s so unfair’. Like, why did no one notice? Like, why? You know, why can’t I’ve been better supported then, like there was no need for me to have to have gone through all that struggle like and you know, especially knowing at school like teachers would always go ‘oh there’s something not quite right. I don’t understand why she’s doing [this]’. But no one ever like bothered to investigate it. And I appreciate that, at the time, there was like less awareness and they probably didn’t have the training. But the fact that they kept saying there’s something not right and not wanting to figure out what it was and just sort of leaving me to struggle. And I yeah, I just yeah you know kind of think ‘oh why did I have to go through that”	Participant 10, Female, 30′s
Processing diagnosis	Anger	Anger at the signs of ADHD being missed previously	“It could have come sooner. And it should have come sooner. The amount of times I went to the doctor’s regarding my mental health”	Participant 23, Female, 50′s
Processing diagnosis	Depression	Lamentation about missed opportunities	“Even now [a little over a year after diagnosis], I’m still going for a really big grieving process of like grieving the person I feel I could have been, and that’s been really hard […] grieving the [participant’s name] that never was”	Participant 15, Female, 40′s
Processing diagnosis	Depression	Increased noticing of symptoms following diagnosis	“I started to reflect and notice and I think once you start seeing something, you start to notice it more. […] when I’ve kind of missed a deadline at work or I’ve kind of set a plan for the day and I’ve not just been able to focus, […] when I’m kind of like really emotionally overwhelmed and I react and I don’t like the way I react and kind of sitting with and thinking oh actually I know a lot of this related to ADHD and then think feeling quite defeated by it”	Participant 2, Female, 30′s
Processing diagnosis	Acceptance	Neutrality towards diagnosis	“I think you get to the point where you think well, that’s, what’s done is done. So that’s just life isn’t it? So yeah, so I think you get and then now it’s just like acceptance”	Participant 7, Female, 20′s
Processing diagnosis	Acceptance	Neutrality towards diagnosis	“I just accept that it’s part of, you know, who I am. [..] I don’t know if I have huge feelings about it”	Participant 1, Male, 30′s
Processing diagnosis	Acceptance	Increased confidence following diagnosis	“I’m happy. I’m proud to have a neurodivergent mind, and I embraced it rather than be the way, and I’ve liked to help other people that also have the same mindset”	Participant 25, Female, 40′s
Processing diagnosis	Acceptance	Increased confidence following diagnosis	“I’m definitely more me now and I don’t know if it’s like, I don’t know. Yeah I think that is a large part of it I think because I’ve changed a lot of bits of my life to make myself better and happier and more confident. But I	Participant 10, Female, 30′s

(*continued on next page*)

Table 3 (*continued*)

Theme	Subtheme	Topic	Quote	Participant (age group, gender)
			think knowing that I have this learning difference and I understand why I do certain things and that I'm not doing things wrong, I'm not being bad, it's made me a lot more confident in just being me, like an unfiltered version of me"	
Managing expectations	Initial optimism	Optimism when starting titration	"The guy who'd do the check ins with me, he was like oh this is going to be life changing. He really bigged it up for me"	Participant 20, Male, 20′s
Managing expectations	Initial optimism	Optimism when switching medication	"I think sometimes I was a bit […] optimistic because […] when they changed it from [one stimulant medication to another] I thought 'oh okay it's gonna get better now because it's new meds, we're gonna titrate up' and then as it was titrated up it interacted with my other medication. Then I stopped and we were like 'okay we're going to titrate up now because you're not on that other medication' and I thought 'okay I'm gonna see the full effects now, things are gonna get better'. But I guess it didn't work as well as I was hoping for it to work. So I guess each time I was kind of thinking okay this time it might be much better, but maybe I'll set some sort of expectation there"	Participant 2, Female, 30′s
Managing expectations	No panacea	Medication not a cure all	"I thought it would be more groundbreaking than it was"	Participant 20, Male, 20′s
Managing expectations	No panacea	Medication not a cure all	"If I can get some magic tablets, I'll be alright again but I've since realised that there are no magic tablets. There were tablets that can help with some things but yeah [not all things]"	Participant 24, Female, 50′s
Managing expectations	No panacea	Symptoms still requiring work	"One thing I still don't feel like I'm… [the clinician] said well this isn't a miracle cure [participant's name], you still got to work on yourself, it's just going to help in some areas"	Participant 8, Female, 50′s
Accessing support	Varied support	Positive guidance from clinician	"[The clinician] was really good. Like, really thorough. Like, talked through it all with me and like, listened to like, you know what my experience had been that month of it and you know and actioned it accordingly. […] I thought his care for me was really good. And it was really like, it really helps to have someone who's like, got a really nice, you know positive attitude or he's just like, he was like a big personality. He was always like, like sort of like a cheerleader. Like yeah you know, this is great. And even with the bits I was struggling, like 'don't worry, we'll sort that out, it's fine', you know. And I think that makes a huge difference when you know you're kind of going through a bit of a life changing thing and you're trying to find out something that's going to help your daily life and this person's going 'yeah, we can sort it out, it's all good', and just makes you feel a bit calmer and more relaxed about it all"	Participant 10, Female, 30′s
Accessing support	Varied support	Feelings of lack of support from clinic	"There's no support from the actual ADHD department with medications, like they're quick to give you medication but not quick to analyse how it's really going"	Participant 25, Female, 40′s
Accessing support	Varied support	Feelings of lack of support from clinic	"It's sort of like, okay, go off and do this and it's sort of like, and then you're left on your own and then I'll have to come back in and say, you know […] can I have more drugs […] especially because these are [medications] you, like, well you shouldn't abuse them, which I wasn't. But you know, the effects of things you could start to abuse or get to a point where you, you are starting to, you know, get up the dose then you would get like maybe potentially addictive problems or the fact that, you know. So, am I doing that properly or wrong? You know it's all very um, I didn't feel properly managed, you know, if I'm honest"	Participant 17, Male, 50′s
Accessing support	Varied support	Difficulty contacting clinic	"I found it quite tricky, because I could only get hold of the clinician through the email address that's linked to like the whole of [town]. So, every single person that's got ADHD in [town] all emails […] sometimes they wouldn't reply for like a week"	Participant 5, Female, 30′s
Accessing support	What now?		"When I tried the non-stimulant one, obviously I tried that. That didn't work, and then the doctor was kind of like 'ok bye' and discharged me. Is that it? Is there no other option? Like I don't know, like talking therapies or anything. And that was just, it, you were kind of just done"	Participant 7, Female, 20′s
Accessing support	Desire for non-pharmacological treatment		"The one thing […] I would like, that I don't know how I'd go about getting is like psychological support with things. I do want to maybe explore things like counselling, just to kind of help me get through some of the like more negative masking thing effects that I've kind of developed over the years and I don't know like at the moment all of my conversations with my psychiatrist are purely focused on the medication"	Participant 21, Male, 20′s
Accessing support	Linking parts of health system	Difficulty obtaining medication	"I've asked my doctor three or four times over the year that I came off it to get a review for medical change or medical checkup. Haven't heard anything. [The ADHD clinic] have done the same, still haven't had anything"	Participant 25, F 40′s
Accessing support	Linking parts of health system	Difficulty accessing medication	"The accessibility of getting the prescriptions is a problem for me. Communication between GP and mental health team, difficult again. For the GP to prescribe, and then if I want to change the dosage or I need a higher dosage, I have to go back to the mental health team to get it sorted out"	Participant 23, Female, 50′s
Accessing support	Linking parts of health system	Burden of advocating for self	"As I said, my organisation's not great and my memory isn't the greatest so I'm having to go against the feelings I've got and, like, constantly ring them	Participant 13, Male, 40′s

(*continued on next page*)

Table 3 (*continued*)

Theme	Subtheme	Topic	Quote	Participant (age group, gender)
			and say, can somebody get back to me? Can somebody get back to me? Can you do this? And I often find that quite draining"	
Balancing costs and benefits	Positives of medication	Improvement in ADHD symptoms	"Actually, I'm embarrassed about it, I think I actually cried because I just felt like I don't know, I just felt like a sense of peace when I took it so that one was great. That one really helped me and I felt calm, I felt like I could do stuff, I didn't want to procrastinate, I just got my task done"	Participant 7, Female, 20′s
Balancing costs and benefits	Positives of medication	Improvement in mood	"I find when I take my medication, my mood is better because I feel like I can concentrate better, which makes me feel happier because I'm not like, I guess I attribute a lot of my, I guess personal development and growth based off of like, how well I do at work and if I am running late on a project or I haven't finished the goals of the project, it gives me quite a lot of anxiety because it's like attributed to I'm slacking, I'm being lazy, I haven't work on this project, that's my fault and now I have anxiety about it. Whereas with the medication, because I'm able to concentrate better and kind of have better time management, I've found that I'm not pushing projects to the side. I'm not missing any of like my deadlines and I'm not having as much anxiety about work"	Participant 19, Female, 30′s
Balancing costs and benefits	Positives of medication	Improvements in mood	"It makes it [my mood] really good. Really good. I'm not really needing to take it [anti-depressants] when I'm on it [ADHD medication]. I don't really need to be on antidepressants anymore."	Participant 6, Male, 40′s
Balancing costs and benefits	Side effects	Physical side effects	"I've had times when, I sleep like a baby normally, but I've had times where I didn't sleep for three days because of [stimulant medication]"	Participant 4, Male, 20′s
Balancing costs and benefits	Side effects	Physical side effects	"I don't know what was going on with my body, but my heart […] rate was like messing around loads, so I had to come off that which is really frustrating. But, and that was also it was a tiny bit scary because it was going, even when I was resting, it was going to like 150–160 [bpm] and I was like this just doesn't feel right"	Participant 7, Female, 20′s
Balancing costs and benefits	Side effects	Psychological side effects	"I noticed that my moods were really low in the end, so I just had low moods. I and I generally tend to get, I can get low moods anyway, but there's nothing that necessarily triggers these low moods, it's just one day I just feel really flat. But I was noticing that this was happening on a regular, like a regular occurrence where I couldn't snap myself out of it. So, in the end, they ended up prescribing me [anti-depressant medication] as well to combat the low moods. So, now I'm on [anti-depressant medication] and [ADHD medication] at the same time"	Participant 13, Male, 40′s
Balancing costs and benefits	Side effects	Psychological side effects	"Basically, I spoke to the doctor again and I was just like because I have anxieties alongside, the stimulant medication wasn't always, like it gave me heart palpitations and stuff, it made me more anxious. So, in the end we just decided that medication is not for me right now"	Participant 5, Female, 30′s
Balancing costs and benefits	Balancing life and treatment	Uncertainty around effects of medication	"It's just like being on a roller coaster […] like trying out these new things and kind of not knowing what side effect they're going to have and trying to, and then some of them have crazy effects but also trying to maintain your daily life and your job. That's quite challenging"	Participant 7, Female, 20′s
Balancing costs and benefits	Balancing life and treatment	Concerns around duration of side effects	"Loads of people were saying it takes months [for side effects to reduce]. People were saying about the success stories were the ones that 'I made it through, the first two months were awful, the first 3 months was awful' and it was like hearing that, I was reading that everywhere. Like 'you gotta stick with it for two to three months'. I thought, 'I haven't got two to three months. I've got a job to do and I can't actually do my job"	Participant 24, Female, 50′s
Balancing costs and benefits	Balancing life and treatment	Flexi dosing around work	"I mostly do take them on days where I am working, so I find that they're mostly helpful for me to concentrate better at work"	Participant 19, Female, 30′s
Balancing costs and benefits	Balancing life and treatment	Flexi-dosing around types of tasks	"My ability to multitask [was negatively impacted], […] because I feel like day to day like, your brain kind of switching to loads of different things is really annoying, but when it came to my work, it was actually like actually quite a good thing that I can do that, especially because I switch between [two different creative tasks] as well. So, it's not like I just do one, I do both. So, what I found was that I didn't actually take my medication whilst I was working"	Participant 5, Female, 30′s
Balancing costs and benefits	Balancing life and treatment	Decision to flexi-dose	"What was good about the medication that way is like you can actually take it, like you don't have to take it on certain days if you don't want to"	Participant 5, Female, 30′s
Balancing costs and benefits	Medication wearing off	Daily rebound effect	"I noticed that I used to, where I first did the titration for it, I also noticed that when the medication wore off, there was a big rebound effect, so my mood would just tank"	Participant 22, Female, 20′s
Balancing costs and benefits	Medication wearing off	Daily rebound effect	"So, you're sitting on a beach, nice warm water comes over you, it's kind of enveloping your body. Next thing you know, that water starts getting a little bit colder, a little bit colder and it starts, instead of going up to your chest like a bath it starts slightly kind of going over your head, going over your head and actually, you know being covered in cold water. That's kind of what it felt like when [stimulant medication] started wearing off"	Participant 4, Male, 20′s
Balancing costs and benefits	Medication wearing off	Consequences of medication wearing off	"So I'll take them in the morning and then at around 4–5 o'clock, my head would be literally pounding. And I remember reading somewhere they said, 'cause I'm not really a huge drinker. I don't drink alcohol very much but I remember somebody saying alcohol gives you the same feeling as the medication. So, I started drinking like a little miniature bottle of brandy to get that same feeling which was happening"	Participant 13, Male, 40′s

were using their ADHD diagnosis to justify unhelpful habits.

3.1.3. Subtheme 1c - Anger

Several participants reported experiencing anger at their difficulties and behaviours not having been appropriately attributed to ADHD earlier in life and thus support not being available sooner. These participants noted that, upon reflection, the signs that they had ADHD were present from a young age, and they were frustrated that these had never been addressed in a meaningful way.

3.1.4. Subtheme 1d – Depression

A common feeling associated with the confirmation of an ADHD diagnosis was that of grief or lamentation, specifically regarding ruminating on a life that could have been, or opportunities missed. Unlike subtheme 1c, some participants noted that they did not feel anger at the diagnosis not having come sooner, but rather sadness.

Additionally, for some, receival of the diagnosis meant that they noticed their symptoms more frequently, now that it had been brought to their attention, and this sometimes led to the belief that it would always be a barrier.

3.1.5. Subtheme 1e – Acceptance

As interviews typically occurred over a year after diagnosis many participants described having reached a stage of acceptance, whether this be in the form of confidence, pride or neutrality.

Some participants described feeling limited or no feelings around their diagnosis now, explaining that they simply accept their diagnosis as a part of their life.

For those who had gained confidence, this resembled feeling as though they were only now living as their true, authentic selves, had more confidence and also support others with neurodevelopmental disorders.

3.2. Theme 2: Managing expectations

As pharmacological treatment commences, expectations of change can be high. However, this initial optimism was not always matched by reality.

3.2.1. Subtheme 2a – Initial optimism

Participants described feelings of optimism surrounding both treatment initiation and when switching medications during titration. Regarding treatment initiation, many described their hope that it would be life changing. Several participants noted that people in their lives, including clinicians, encouraged this expectation.

Similarly, during titration, of those whose trial of a previous medication had been unfavourable, many described their hope that “this time it might be much better” when switching to a new medication. This was reported to have sometimes led to disappointment when medication did not have the anticipated benefit or needed to be discontinued entirely.

3.2.2. Subtheme 2b – No panacea

Participants’ optimism was due, in part, to the expectation that medication would be a panacea – a cure all. Participants described the feeling that, while the medication could have a positive impact and could ameliorate certain ADHD symptoms, for many, it did not eradicate all difficulties, and did not always lead to a global shift in thought patterns or behaviours.

3.3. Theme 3 – Accessing support

Participants described commencing pharmacological treatment as a complicated and transitional time which involved a mixture of optimism, joy, disappointment and confusion. A common theme discussed by participants was the level of support that they felt they had during this period; where it was beneficial and where it was felt lacking.

3.3.1. Subtheme 3a – Varied support

Reported feelings of support during the titration period varied greatly across our sample. Several participants reported feeling well supported by clinicians, who guided them through their titration period, answered their questions and allayed their concerns.

Conversely, several participants noted that they had little clinician contact during their titration, and felt unguided, with a few participants reporting that they felt as though they were left to titrate themselves. Many in that situation reported feelings of anxiety and/or frustration.

Moreover, several participants noted that it was difficult to contact clinicians with questions, as the only available contact method was a shared email address, and it could take some time to receive a response to their queries. Our participants appreciated the capacity of the clinic and the limited resources available but advised that more guidance from clinicians during the titration period would have made the process less anxiety-inducing.

3.3.2. Subtheme 3b – What now?

Many participants explained that, once the clinician had exhausted all medication options, or they themselves had opted to discontinue medication, there was no follow up or alternative suggested and they were left feeling unsure about what to do next.

3.3.3. Subtheme 3c – Desire for non-pharmacological treatments

Many participants believed they would benefit from non-pharmacological treatments, and psychological support, either instead of or alongside pharmacological treatment. They felt as though psychological support would enable them to develop coping strategies and manage their symptoms in daily life, especially in the context of subtheme 2b

3.3.4. Subtheme 3d – Linking of parts of health system

Several participants experienced difficulties with linking their GP and clinic, due to the nature of the current administrative systems. This occurred during titration, in which participants needed to liaise with both sites regarding the changing of their medication prescription. This became particularly burdensome given the requirement to be physically present for a change in prescription for some clinics.

Similarly, several participants noted that towards the end of titration, when shared care agreements were being arranged, some participants felt as though they were somewhat lost in the system, whereby neither the clinic nor the GP took responsibility for their care. Consequently, they were required to be the intermediary, pushing the GP to respond to the clinic, or vice versa. This caused stress and uneasiness for participants, fearing that they would be lost in the system without substantial time and effort on their parts, as well as delaying access to medication. One participant noted that this was especially burdensome for individuals with ADHD.

3.4. Theme 4: Balancing costs and benefits

A process that commonly occurred during pharmacological treatment, and which ultimately contributed to participants’ decision on how to proceed with their medication journey, was balancing the positives of the treatment against the negatives. Although many reported that medication ameliorated certain ADHD symptoms and provided benefits, they also needed to consider whether these were overshadowed by the disadvantages and ultimately conclude whether the medication was worth continuing.

3.4.1. Subtheme 4a – Positives of medication

Many reported that medication positively impacted their ADHD symptoms. Outlined benefits included a general sense of clarity, increased focus and reduced procrastination or distractibility, reduced impulsivity, especially regarding financial decisions or diet, and improved organisation, specifically regarding management of space (e.

g. an improved ability to clean or tidy), and an improved perception and/or management of time.

In addition to the noted improvements in ADHD symptoms, several participants reported improvements in mood and anxiety. This was generally associated with the reduction of ADHD symptoms, less frustration and the joy that can come with completing tasks that had previously been difficult.

3.4.2. Subtheme 4b – Side effects

Reported side effects included both physical and psychological changes. Reported physical side effects included increased thirst, frequent urination, headaches, disrupted sleep, gastrointestinal complications, increased heart rate and/or heart palpitations, increased blood pressure, nausea or dizziness, hair loss and reduced appetite, though the last was not always noted unfavourably and severity of side effects varied.

In contrast to the improvements in mood and anxiety mentioned in subtheme 4a, several participants reported lower mood and/or increase anxiety. It was often noted that this was a deciding factor in switching medication during their titration period or discontinuing pharmacological treatment entirely.

3.4.3. Subtheme 4c – Balancing life and treatment

Many participants highlighted that pharmacological treatment can be difficult to maintain alongside daily life. Aforementioned side effects can lead to difficulty with maintaining work schedules and social obligations. Engaging with pharmacological treatment not being conducive to maintaining life was reported by several participants to be the reason that they discontinued medication use.

Difficulties with balancing life and treatment often occurred in the titration phase, with many participants noting that the uncertainty around the side effects of the new medication caused anxiety or stress: not knowing how the new medication would impact them, physically or psychologically, made it difficult to plan activities and workloads.

Similarly, concern about how long the side effects would persist led some participants to discontinue medication. Although they anticipated future benefits once their body adjusted and side effects reduced, the negative impact at that moment was so severe that they could not afford such a disruption to their lives.

Balancing life and pharmacological treatment was not exclusive to the titration period. Many participants noted that they engaged with ‘flexible dosing’ whereby they only took medication when they felt that the needs of the day required it, typically revolving around work schedules. For example, some participants took their medication only on days when they were working, so they were better able to concentrate. Conversely, one participant only took their medication on days that they were not working, as the reported calmer mind presented itself in a reduced ability to multitask or engage in creative activities.

Participants stated that this opportunity to decide on which days to take or not take medication was important for their journey, as it allowed for greater flexibility.

3.4.4. Subtheme 4d – Medication wearing off

It was also noted by many participants that there was a “rebound effect”, whereby they were left feeling tired or drained when the medication wore off. Several participants also noted that this led to a sharp decline in their mood and/or an increase in their anxiety.

One participant noted that they began consuming alcohol each afternoon to get the same effect that the medication had brought, as it had worn off.

4. Discussion

Participants in this study reported that experiences can be shaped even before treatment initiation, with the processing of the diagnosis and expectations of the impact of medication, as well as during the treatment process, with feelings of support and balancing effects, which coalesce to inform treatment continuation and compliance. Overall, our qualitative analyses highlight the array of experiences of adults with ADHD engaging with pharmacological treatment, both positive and negative, and contextualised pharmacological treatment (dis)continuation and non-adherence informed by these experiences.

4.1. Medication discontinuation

Many described the cost-benefit analysis in which they balanced improvements in ADHD symptoms and daily tasks against side effects and disruption to life and work, as outlined in theme 4. This finding is consistent with previous literature with young people (Meaux et al., 2006; Titheradge et al., 2022) and adults (Matheson et al., 2013) and further contextualises this balance as a contributing factor to treatment discontinuation for adults with ADHD, with adults ultimately needing to decide whether the positives justify enduring the negatives. This balancing act was also occurring through the lens of expectations of the medication’s benefits, as outlined in theme 2, with medication under-delivering when compared with its expected benefits. This seeming disappointment can contribute to discontinuation as medication, while not wholly ineffective, appears ineffective in comparison to the expected global change in ADHD symptoms.

Our results also highlight the desire and need for non-pharmacological treatments, instead of pharmacological treatments, for those who were unable to continue, and for others in conjunction with pharmacological treatments, to facilitate a greater improvement in symptoms. Theme 3 extended these concerns regarding feelings of support available and highlighted that, while some felt that they were adequately guided throughout the treatment process, others felt that they lacked support. This starkly highlights the concerns raised by Smith et al. (2024) regarding the current strain in ADHD services. In the context of medication discontinuation, a lack of support and confusion as to how to navigate the complicated journey of pharmacological treatment caused frustration, anxiety and, ultimately, disengagement amongst some participants. This clinical support also encapsulated the emotional response to the receival of the ADHD diagnosis, and the impact that this response can have on treatment engagement. As outlined in theme 1, the journey of processing the diagnosis continues throughout treatment and can impact mental wellbeing and willingness to engage with treatment. If an individual is experiencing low-mood and/or lack of confidence in the diagnosis itself, these feelings can impact engagement with the treatment process aligning with reports that co-occurring clinical symptoms can impact treatment engagement (Nguyen et al., 2025). Consequently, it is important that such feelings and concerns are addressed with clinicians throughout treatment.

4.2. Flexible dosing

Many described engaging in flexible dosing, in which they did not take medication every day but instead took medication only on days they deemed it beneficial. Participants expressed several reasons for this, including that they typically either preferred to take medication while working, or specifically preferred not to take medication when engaging in creative tasks, or tasks that required multitasking. This extends previous findings on reasons for non-adherence (Barnard-Brak et al., 2023) to an adult context, with the decision most commonly revolving around work demands. As such, the benefits of medication may be context-dependent and allowing individuals the option to choose when to take medication can improve general compliance and positivity towards the treatment itself. The option to engage with flexible dosing was often spontaneously mentioned as a positive, highlighting how such practice can be beneficial in treatment plans.

4.3. Variable experiences

The analyses also highlighted variability in the experiences of pharmacological treatment for adults with ADHD, with respect to both the response to the medication and clinic processes. Regarding the response to medication, while many participants experienced improvements in their ADHD symptoms, a wide range of both physical and psychological side effects were reported. The specifics of this balance appeared to be person-dependent: for example, while some noted that the medication reduced anxiety, others noted that it exacerbated it. Moreover, experiences with the treatment process differed greatly between participants, with some feeling appropriately supported, while others expressed that they lacked guidance and were unsure of how to navigate the process and/or seek help further help if required. This highlights both the need for a tailored, person-centred approach to pharmacological treatment and the inconsistencies in the current process.

4.4. Future recommendations

Based on the outlined results and themes, we make several recommendations for the treatment process going forward.

As outlined in theme 3, while positive sentiments were expressed by some towards the support provided by clinicians during pharmacological treatment, others expressed frustration at the lack of guidance and clinician contact they received during the process. These findings illustrate the present strain on adult ADHD services and negative consequences that such a strain can have on individuals' care; in many cases, sufficient time, support and follow-up may not be adequately provided and highlight the importance of increasing clinician contact time and resources available to adults undergoing pharmacological treatment.

Additionally, it is important for clinicians to acknowledge and support adults with ADHD as they navigate the emotions they may experience when processing a diagnosis. As outlined in theme 1, individuals may be questioning their diagnosis and may feel a sense of loss or anger, which can impact treatment engagement and quality of life. Consequently, incorporating a thorough discussion of reasons for an individual's diagnosis, their feelings towards the diagnosis and best ways to navigate any distress or confusion prior to treatment initiation may be beneficial to the individual's general mental wellbeing and treatment engagement.

As outlined in theme 2, many participants noted they had high initial expectations for the medication, which were subsequently not met. Consequently, clinicians should consider such expectation-setting and avoid a one-note message regarding the life-changing expectations of medication; instead offering a comprehensive view of what the medication may entail and guide individuals through the process as it is experienced.

Finally, non-pharmacological treatments were broadly desired by, but seldom available for, our participants. Though the capacity constraints are appreciated by the authors, our results suggest a gap between the holistic approach outlined in the NICE guidelines (2018), and the treatment options currently available for adults with ADHD.

4.5. Strengths and limitations

Participants in this study came from diverse backgrounds, including a roughly even split on gender, a diverse age-range, representative ethnic backgrounds and diverse occupational backgrounds, life experiences and reasons for seeking diagnosis, allowing us to represent and identify commonalities among a diverse group of adults with ADHD. However, we note that most of the participants lived in cities. Participants were also all individuals who had participated in the full 12-months of the ART-CARMA study. Consequently, participants who withdrew from the study and those who declined to take part altogether, were not represented.

4.6. Conclusions

Participants described a variety of experiences during their first year following treatment initiation. Ultimately, their engagement with treatment was informed by ongoing emotional response to receiving the diagnosis, performance of medication relative to expectations, feelings of support during the treatment process and balancing whether the positives of medication justified enduring the negatives. Together, these experiences highlight (i) the importance of tailored care, considering the emotional journey and daily requirements of the individual, (ii) a greater availability of non-pharmacological treatments and (iii) clear guidance on how to receive such treatment when available, to ensure that the needs of adults with ADHD are appropriately met.

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Ethical considerations

The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national and institutional committees on human experimentation and with the Helsinki Declaration of 1975, as revised in 2008. Ethical approval has been obtained in London from the Camberwell St Giles Research Ethics Committee (REC reference: 21/LO/0825) and in Spain from the Vall d'Hebron University Hospital Ethics Committee (CEIm code: EOM(AG) 004/2022(5944).

Data availability

Due to the nature of the content shared in the interviews and the risk of potential identification, transcripts will not be made publicly available.

CRediT authorship contribution statement

Alice Barnes: Writing – review & editing, Writing – original draft, Validation, Resources, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Hayley Denyer:** Writing – review & editing, Validation, Supervision, Investigation, Formal analysis, Conceptualization. **Sara Simblett:** Writing – review & editing, Supervision, Formal analysis. **Emilie S. Nordby:** Writing – review & editing, Formal analysis, Data curation. **Andrea Bilbow:** Writing – review & editing, Methodology, Investigation. **Wakaho Hayashi:** Writing – review & editing, Methodology, Investigation. **Nina Hoven:** Writing – review & editing, Methodology, Investigation. **Hannah Marriott:** Writing – review & editing, Methodology, Investigation, Data curation. **Ulrich Müller-Sedgwick:** Writing – review & editing, Funding acquisition. **Phoebe Rocks:** Writing – review & editing, Methodology, Investigation. **Susannah Whitwell:** Writing – review & editing, Funding acquisition. **Henrik Larsson:** Writing – review & editing, Funding acquisition. **Amos Folarin:** Writing – review & editing, Funding acquisition. **Josep Antoni Ramos-Quriога:** Writing – review & editing, Funding acquisition. **Richard JB Dobson:** Writing – review & editing, Funding acquisition. **Jonna Kuntsi:** Writing – review & editing, Writing – original draft, Supervision, Funding acquisition, Conceptualization.

Declaration of competing interest

JK has given talks at educational events sponsored by Medice; all funds are received by King's College London and used for studies of ADHD.

HL reported receiving grants from Shire/Takeda, personal fees from Shire/Takeda, Evolan, and Medici.

JARQ was on the speakers' bureau and/or acted as consultant for Biogen, Idorsia, Casen-Recordati, Janssen-Cilag, Novartis, Takeda, Bial, Sincrolab, Neuraxpharm, Novartis, BMS, Medice, Rubió, Uriach, Technofarma and Raffo in the last 3 years. He also received travel awards (air tickets + hotel) for taking part in psychiatric meetings from Idorsia, Janssen-Cilag, Rubió, Takeda, Bial and Medice. The Department of Psychiatry chaired by him received unrestricted educational and research support from the following companies in the last 3 years: Exeltis, Idorsia, Janssen- Cilag, Neuraxpharm, Oryzon, Roche, Probitas and Rubió.

AF and RJBD are co-founders of Onsentia. AF holds shares of Google.

The remaining authors declare no competing interests.

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Supplementary materials

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