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An interpretative phenomenological analysis

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Experiences of and treatment preferences for insomnia in autistic adults: An Interpretative Phenomenological Analysis

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ABSTRACT

Insomnia and insomnia symptoms are frequent experiences of autistic people resulting in pronounced daytime effects and poor quality of life. This study employed an Interpretive Phenomenological Analysis approach to explore lived experiences of autistic adults with insomnia, perspectives on current available interventions and future treatment preferences. Twelve participants (aged 21–48 years old) were interviewed following screening for insomnia, using the Sleep Condition Indicator (scores ranged from 1 to 12; cut off >16). Each interview was analysed individually developing Personal Experiential Themes for each case, which were then mapped across cases based on identified patterns and connections. Results yielded rich personal accounts and identified two Group Experiential Themes: “The Night is Friendlier” and “It Doesn’t Really Work for Me”. Participants described experiences with sleeplessness throughout their adult lives and often since childhood. They discussed how the night time offers them a more relaxed and safe space to freely behave as they wish. Advice and interventions were viewed by participants via the prism of underlying social issues, such as autism acceptance and trust, and how these structures can affect participants’ experiences with insomnia, help seeking and effectiveness of current interventions. Our results highlight the need for inclusion of autistic people in insomnia research through co-production and co-creation as well as clinical practice and delivery. This is the first study to integrate perspectives and experiences of autistic people towards insomnia and sleep-related advice by health care professionals. Findings are discussed in relation to theoretical and practical implications, as well as directions for future research.

1. Introduction

Autism is a lifelong neurodevelopmental condition currently defined by the presence of differences across a range of domains including sensory processing [1], social communication style [2] and attentional allocation [3]. In addition to higher instances of physical [4,5] and mental health concerns [6,7] many autistic^{*1} people experience significant challenges with sleep [8]. Sleep disturbances frequently emerge in early life of autistic children [9] and remain a common symptom

throughout their development and adulthood and are more pronounced in autistic adults compared to non-autistic groups [10]. Insomnia is characterised by experiences of initiating, maintaining or (upon early awakening) returning to sleep for at least three months despite adequate opportunity to sleep and absence of other conditions or substances explaining the difficulties, according to DSM-5 [11]. Findings indicate the high prevalence of insomnia symptoms in autistic individuals, evidenced by increased sleep latency, poor sleep efficiency and shorter night sleep [12–14].

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¹ Throughout this paper we use identity-first language or neutral terms (‘autistic people’ or ‘people on the autism spectrum’) rather than person-first language as a result of the article by Kenny et al. [49] highlighting the preference for identity-first language by the majority of autistic people and their families in the UK, where the study was conducted. It is also the preferred language of the autistic researchers in this paper.

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There is a large body of work surrounding the bidirectional relationship between sleep and mood [15], emotion regulation [16], reactivity [17], employment [18], and social activity (21) in the general population. In relation to autism, the direction of these associations remains unclear [19–21] with some evidence suggesting that sleep disturbances are an exacerbation if not a symptom of mental health difficulties, primarily anxiety and depression, in autistic adults [22,23] that may also exacerbate core autistic symptoms [20,22,24].

Despite the evidence of the high prevalence of sleep disturbances in autistic adults and their resulting accumulating burden in daytime functioning, research on sleep interventions for this group is limited. Cognitive Behaviour Therapy for insomnia (CBT-I; [25] is the most promising intervention for insomnia in adults even in the presence of co-occurring mental health disorders [26]. However, currently there is no evidence for a CBT-I tailored intervention for autistic adults, with limited evidence demonstrating promising results of CBT-I in improving sleep in autistic children and their parents [27] and an internet-based CBT-I intervention in autistic adolescents that were also interviewed on their experiences with the intervention [28]. For autistic adults there is emerging pilot evidence of the efficacy of ACT for insomnia [29], however, without larger, controlled studies a pronounced lack of evidence of non-pharmacological or other interventions exists. Behavioural interventions [30,31] or melatonin [32] remain the main treatment choices for insomnia in younger autistic individuals and across the lifespan. Meaningful participatory research in autism, as has been advocated by the autistic community over the past decades [33,34] is important in order to understand autistic experiences with insomnia and what they wish future interventions to include or ways to be delivered.

The current study is the first in-depth exploration of autistic adults' experiences with insomnia disorder and their perspectives on current and future interventions. We employ qualitative design methodology, specifically Interpretive Phenomenological Analysis [35], as it is the most suitable design to explore complex perspectives of lived experiences without pre-existing theoretical assumptions in order to inform current practice and future research directions.

2. Method

2.1. Community participation

This study was conducted in consultation with the charity Scottish Autism. Their experts by experience worked with our research team, confirmed the importance of a qualitative exploration of the topic as currently a gap of first-hand accounts from autistic people is apparent in sleep medicine research and clinical practice. They also offered feedback on the study resources and methods, such as Participant Information, Consent and interview questions offering valuable pre-study considerations. In later parts of this paper, we recognise the need for in-depth co-participation and establish co-creation pathways by future studies.

Our interactions on a consultancy level with experts by experience supported us to examine our biases and assumptions around the conception, ethical application, recruitment and interview stages of the study. We held useful exchanges with our internal team of neurodiverse researchers around autism on a personal and professional level in relation to the many identities we are also holding related to our gender, career level, clinical, research as well as personal or family neurodivergent experiences.

Ethical approval

Ethics approval was awarded by the Ethics Committee of the College of Science and Engineering, University of Glasgow [Ref: 300180036]. The study is aligned to the British Psychological Society's Code of Ethics and Conduct.

3. Procedure

The study adapted a purposive sampling design as the best approach to recruitment for an IPA analysis as it allows the engagement with the most suitable participants for the topic under consideration, whilst the clear inclusion and exclusion criteria reduced the risk of sampling bias [36]. Participants were recruited via social media, such as Facebook and Twitter (current X), and subsequently were asked to complete a short online screening form regarding their age, diagnosis, and preferred medium and format of interview as well as the Sleep Condition Indicator (SCI; 37) scale to assess the presence of insomnia disorder and symptoms. The SCI is an eight-item rating scale designed as a screening psychometric tool for insomnia based on DSM-5 criteria with a cut off of ≥ 16 in which higher scores indicate better sleep [37].

4. Inclusion and exclusion criteria

Using a cut-off score of ≥ 16 (SCI), participants were invited to participate in the study. Eligible age range was set to 18–50 years old to account for sleep difficulties due to older age or menopause related sleep disturbances in women. All participants had to have an autism diagnosis at the time of the interviews based on self-report. Informed written consent was obtained prior to the interviews.

Eligible participants were invited to take part in the interviews and were sent thorough instructions on what the format of the interview will be and introductions to the research team and surroundings. These included short videos introducing all the researchers, the surroundings of the department and the actual room where interviews were to take place (if the interview was scheduled in-person). Additionally, a short video of the walking route to the building itself from various local stations and bus stops was shared with consented participants. The participants were not known to the members of the research team and no compensation was offered for their time taking part in the study.

5. Participants

In total, 36 participants responded to the study recruitment advertisements of which 12 (5 men and 7 women) that met the inclusion criteria were invited to take part in the study. Participants ranged in age from 21 to 48 years of age ($M = 35.6$, $SD = 9.2$) with SCI scores ranged from 1 to 12 ($M = 6.3$, $SD = 3.34$). Only 4 participants had been diagnosed with autism in childhood whereas the remaining participants had received their diagnosis in their late 20s or later on in life ($M = 25.5$, $SD = 14.1$). Presence of a clinical diagnosis of autism was reported directly by the individual participants. More information on the demographic characteristics of the sample and the individual SCI scores is available in Table 1.

6. Data collection

The study employed a flexible, multimodal approach to interviews to allow autistic adults to express their communication preferences. Of the twelve interviews, five were conducted face-to-face, four took place over the phone, two were via an online platform (Skype) and one interview was done through written responses sent by the participant via email. All interviews were recorded and transcribed with the exception of the written one. Interviews averaged 82 min in duration (range 53–115 min). Interviews were conducted by AB and MY, who opted out of authorship on this paper, whilst feedback was provided by MG following the first two interviews. The research team kept reflective jotting notes about participants' comments and researcher's thoughts during the interviews.

7. Data analysis

Interpretive Phenomenological Analysis (IPA) was conducted

Table 1
Information on age, autism diagnosis and individual Sleep Condition Indicator (SCI) scores of participants.

Unique identifier	Age at interview	Age at autism diagnosis	SCI score	SCI01	SCI02	SCI03	SCI04	SCI05	SCI06	SCI07	SCI08
			Total score	How long does it take you to fall asleep?	If you wake up during the night, how long are you awake for in total? (add all the awake time together)	How many nights a week do you have a problem with your sleep?	How would you rate your sleep quality?	To what extent has poor sleep affected your mood, energy, or relationships?	To what extent has poor sleep affected your concentration, productivity, or ability to stay awake?	To what extent has poor sleep troubled you in general?	Now thinking about your whole life, how long have you had a problem with your sleep?
P1	18–24	12	8	>60min	46–60min	4	Very good	Much	Much	Very much	>1year
P2	45–54	35	1	46–60min	>61min	5–7	Very poor	Very much	Very much	Very much	>1year
P3	35–44	43	3	46–60min	46–60min	5–7	Poor	Very much	Very much	Very much	>1year
P4	35–44	29	7	16–30min	46–60min	5–7	Poor	Very much	Much	Much	>1year
P5	18–24	9	9	46–60min	31–45min	4	Average	Much	Much	Much	>1year
P6	35–44	29	5	>60min	>61min	5–7	Poor	Much	Much	Somewhat	>1year
P7	45–54	46	6	>60min	31–45min	5–7	Poor	Much	Much	Much	>1year
P8	25–34	31	4	46–60min	>61min	5–7	Poor	Much	Much	Very Much	>1year
P9	25–34	3	12	16–30min	0–15min	4	Average	Much	Much	Very Much	>1year
P10	25–34	5	3	46–60min	31–45min	5–7	Very poor	Very Much	Very Much	Very Much	>1year
P11	35–44	36	11	31–45min	46–60min	5–7	Average	A little	Much	Somewhat	>1year
P12	45–54	28	7	>60min	>61min	3	Average	Much	Very much	Somewhat	>1 year

following closely the methodology outlined in Smith, Larkin and Flowers 2nd Edition [35]. Consisting of seven steps, the first entails reading and re-reading the transcripts to immerse oneself in the data. This step was accompanied by listening and re-listening to audio recordings of the interviews to get a sense of emotions, tone and emphasis used by the participants throughout the interviews. Following this, exploratory notes and codes were recorded both in paper (during the reading) and online using NVivo (v.12). The third step was to construct experiential statements, looking for the most important features of the previous steps and developing conceptual meanings based on the transcripts and researchers’ interpretations. Fourth, connections and patterns across experiential statements by the participants were collated and examined in light of the research aims of the study. In step five, these connections were mapped and named as reflected in the coding. Step six repeats the abovementioned processes for each of the interviews. Finally, step seven involved reflecting on the personal experiential themes to develop group experiential themes. Primary analysis of all transcripts was conducted by DN. To enhance the credibility of the findings, MG and ER independently coded a different transcript each, after which codes and comments for all transcripts were discussed amongst the entire research team. Steps three, four and seven were conducted by MG and DN working collectively.

8. Positionality

Within IPA, reflexivity is a necessary process in interpreting and developing an understanding of participants’ experiences [38] exploring their positionality in reference to a phenomenon and the people experiencing it. The subjective nature of qualitative research is recognized by establishing how one’s identity (i.e., gender identity, gender presentation, class, education, sexual orientation, race, ethnicity, age, language, culture, etc.) and contextual (i.e., immigration status, etc.) positionality contribute to the construction of the research process and findings. This positionality can be explored through the use of reflexivity [39]. Smith et al. [35] set out seven steps for the completion of IPA analysis, embedding a reflexive process within the steps which were followed by all members of the research team that were included at various stages of the analysis (DN, MG, ER, GP).

Researchers commented on their different interpretations of the

same quotes from the interviews and related these to their own experiences drawn from research and clinical practice. In the final stage of analysis and writing, LM was asked to review the study, results, and interpretations of the findings via the prism of their personal experiences. This shed light on differences in the emphasis of concepts and meaning within the themes and the addition of concepts, such as trust.

9. Results

Using IPA two Group Experiential Themes (GET) were identified with both containing two Experiential Themes (ET; Table 2).

10. The night time is friendlier

10.1. Normalising sleeplessness [that’s the way life is]

All participants talk about experiencing some form of sleeping issue since their early childhood or at the very least their teenage years, with differing degrees of severity. They discuss not being aware of the extent of their sleeping issues ‘because I just felt, like, well that’s the way life is’ (P7), accepting it as part and parcel of life and their autism.

‘Um so I-I personally couldn’t say, for sure that it’s the autism that does it but I [sigh] I-I mean I speak to other autistic people who say they have trouble sleeping and think “Yeah, yeah that sounds like me” you know?’ (P7).

External sounds are undesired and keep them awake because ‘it feels

Table 2
Experiential and group experiential themes (ET, GET) generated using IPA.

Themes and Codes		
	Group Experiential Theme (A)	Group Experiential Theme (B)
Personal Experiential Themes	The Night Time is Friendlier	It Doesn’t Really Work for Me
	1. Normalising Sleeplessness [that’s the way life is] 2. The Night Time is Friendlier	1. Advice for Better Sleep 2. Interventions and Preferences

like everyone else is intruding' (P6). They describe an importance for creating a comfortable (head) space for themselves in order to fall asleep.

'I go through about four different positions before I go to sleep, you know, I have to do this and then I have to do that and so on [...] I have trouble figuring out where, where my body ends and the rest of the world begins, as it were. So what I've always done ever since I was a child is hold myself in quite rigid positions so that I can feel my limbs, um, and I think that's part of it as well, is that, um, I'm never truly relaxed. I'm always tense in some way or in an uncomfortable position in some way because that's the only way I feel like I'm, me and the rest of the world is out there' (P7).

Despite their otherwise acceptance of a life with sleeping difficulties they do notice that their autistic symptoms do benefit from a good night's sleep. When they do not sleep well, their ability to engage with an otherwise manageable environment diminishes. Still, this was not enough to make them aware of the extent of their sleeping problems.

'I don't really have too many hearing problems when it comes to my autism, but if I'm tired it's like a hundred, like a hundred times worse. Small noises seem really loud. Big crowds seem really overwhelming and places that I can handle when I've had enough sleep are a nightmare' (P1).

Consequently, participants describe their mood plummeting: *'I get really low, um, and I feel, um, I feel things are getting on top of me. Like things are more stressful [...] I get more introverted than usual and I find it harder to tolerate being around other people or speaking to people' (P6).*

10.2. The night time is friendlier

Participants talk about the night-time as a period undisturbed by the presence of others that *'energizes me and sometimes I feel it has the opposite effect, because it's, um, it's quiet and it's nice' (P6)*. During the day they *'try really hard to sort of hold everything together' (P3)*, but at night they can explore their own interests, catch up on tasks or reflect. One participant describes how the night period is a *friendlier* space for them when they feel *naturally* more relaxed.

'There are more interesting things to, to look at or there's always things that need done [...] Then I kind of resent having to go to sleep, because I'd rather be doing something else [...] I don't know if it's the same for all autistic people but, night time is friendlier to me than daytime and I enjoy it being night time so, it's kind of rum, it's feel like, it's feels like my natural daytime when I'm more relaxed and happy and, kind of 'me time'.' (P6).

For some it appears that they engage in active sleep procrastination activities as they *'definitely fight sleep' (P1)* and the lack of an inherent desire to sleep. Several participants describe sleep as boring and disliked; having no need or wish to sleep. They do understand they need (to) sleep and they describe this need as not unlike to the recommendation to exercise, and thus they do try to sleep.

'Sleep's like exercise. Like, you need it, but it's, it's really boring. Like, what's more boring than lying in the bed doing what feels like nothing' (P1).

One participant notes their surprise at discovering that other people *like* to sleep and don't consider sleep as chore.

'I had nothing to compare it to, really. You know, it's um, [sigh] [pause]. Yeah, so I never really felt motivated to do much about it, um, to be honest. Because I just felt, like, well that's the way life is. And it took me a long time, I think, to realise that other people didn't sleep like I did, and you know, that other people actually like sleeping' (P7).

The night-time is in stark contrast to their daytime that is loaded with the pressure to mask who they are during their interactions with non-

autistic people. At night, there is no need to engage in such behaviours and they can be themselves without any self-imposed pressures to act differently.

'And I put, um, I put too much pressure on myself to be perfect and to be great at things so I can prove that I'm normal [laughs] when I'm not. Um, I don't really want to be normal anyway, it's- it's so I can prove that I'm coping by doing these silly things, like having, um, a perfect house that's clean and shine and smells nice and the kids are nicely dressed [...]' (P6).

The pressure adds up for them and is described as contributing to feelings of tiredness that is accumulating via exhausting interactions with others that affects their mental health and sleep as the participant below describes poignantly.

'Tiredness gathers up over the days and weeks after a meeting of social "performance"/interaction [...] [P12] becomes overwhelmed by feelings I dread and paranoia, self-worth, and sense of who [P12] is disintegrates and sleep is very bad' (P12).

11. It doesn't really work for me

11.1. Advice for better sleep

There is a clear distinction between the forms of sleeping advice that participants have implemented or simply tried out and the ones they are to be hesitant to try. All participants describe having tried a wide variety of low effort sleeping advice, such as essential oils, mindfulness apps and/or using their own form of (highly familiar or curated) media. In particular, the use of devices at night and different forms of media are the main part of most of the participant's sleeping routines.

'I've started using an app on my phone which plays like noises, you know like the crackling bonfires and the rain and things that helps it-it's almost like a Pavlov's dog thing now I, I switch on the little thing that makes rain noises and I know that's sleep time and that seems to help a bit. I have tried giving up screens it doesn't really work for me, uhm. [...] it is hard to get away from screens but I do try [...]' (P7)

'I've tried, uhm, meditation, which doesn't work for me anyway. Uhm, I've tried not having anything sort of electronic around so no TV, no audiobooks, uhm, just a room and darkness, that doesn't really work either, uhm.' (P6).

Sleeping advice that involves more consistent effort and requires more time, such as engaging with CBT or establishing a consistent sleeping routine, have been more difficult to adhere or implement.

'I feel like if I did [establish a routine], it would make things a bit easier for me. But I just find it difficult to get it set' (P9).

'[Regarding CBT] My default would be, I would just prefer to read about it myself, but I know that I have read about it, and I've not really been able to work in a lot of it. Stick to it, that's the issue, I've not been able to stick to it, um' (P8).

Those that have a partner who participates in the routines or supports the sleeping advice in another way report it being helpful. On the other hand, others within the household also play a role in disrupting routines.

'So if my husband is with [daughter] trying to get her to fall asleep, then it takes, it has a knock-on effect of my sleep schedule, and when I can go to sleep.' (P3).

Most participants described a dependency on external commitments and influences when it comes to their ability to form or stick with a routine, despite overwhelmingly indicating a desire and preference for one. These influences, such as work and school, provide a sort of anchor to inform what their rough timelines should be. Having a responsibility

towards someone else creates the essential need, which is not there for the participant's themselves because *'I will break a plan with myself [...] I will forgive myself for [breaking] that plan, but I just assume the other person won't'* (P1).

11.2. Interventions and preferences

All participants report that in healthcare settings being autistic is often the endpoint of any investigation with no solutions provided or in some cases resulting in contradicting responses among professionals. One participant characteristically says: *'So one GP says CBT, one GP said Propranolol, and one GP said you're autistic'* (P1).

Almost all participants noted that the standard duration of CBT and other forms of talking therapies was not sufficient for them to implement long-lasting changes. Note that participants in our study have only experienced these forms of therapy for issues other than sleeping difficulties or insomnia. This is especially important for forms of sleep treatments that require significant and consistent daily and inter-daily effort, such as keeping a sleep diary and doing mindfulness exercises. They note it helps if someone else is checking in regularly, both to keep them accountable and to help them if any challenges arise.

'Uh, my thoughts on it [sigh] You're not supported when you get put on these things' (P2).

When it is simply information or a module to complete by themselves, there is a tendency to forget about it.

'I know that sometimes if I come up against a challenge or something that's maybe, I can just get a bit stuck and I can just, I probably just avoid it. I'd probably just, I would probably just get to a point where I had, say something if it was something challenging, I would just not go back to it.' (P8).

Another example of the need for individualised treatment was the use of mindfulness and sleep aiding apps. While these worked really well for some participants, others remarked on their potential counter-productiveness noting *'if I become engrossed in something like that I find it very hard to then get away from my phone'* (P11). Some of these apps rely on different forms of breathing and muscle relaxation. Several participants note having trouble engaging in these activities as it has the opposite effect of the intended for them. They relate this to their autistic features, such as not being able to feel where their own body begins and ends, like P7 below and having difficulty adjusting to different breathing patterns (P12). Others note not having the concentration or focus to do these types of techniques.

'But actually, just you know sort of going through that thing of "Oh you're sinking through the floor, and first your toes are going soft" and all those kind of things, I-I've never been able to do that. It makes me feel really quite self-conscious and em, like I say m-my-my touch perception is very, is not very good, so I can't, I can't feel where I end and other things begin, and so the only way I can feel that is through being tense in some way, um finding it hard to explain, yeah' (P7).

'Breathing has always caused [P12] anxiety when she tries the breathing exercises. It often ironically triggers a panic attack' (P12).

In particular, talking therapies or interventions focusing on cognitions and emotions highlighted by participants as being particularly challenging for autistic people due to the common feature of alexithymia (inability to recognise or describe one's emotions).

'[...] obviously we have um, obviously spectrum wise, um, people have different issues, with, um, talking about emotions. Uh, understanding emotions, link-linking emotions, and behaviours' (P2).

This corresponds with participants previously noting difficulty in *'sticking with'* interventions such as CBT.

'Challenging unhelpful thoughts for instance, um, if you're a neurotypical person that might be relatively simple, well not simple, cognitive behaviour therapy might be helpful in, helping you to challenge unhelpful thoughts but because of the way autistic people sort of persevere on things and things and think about things over and over again it might need more tailoring, um, towards them' (P7).

Online therapies were noted to be useful for people that had difficulty traveling or fitting it into their schedules and had the added bonus of being able to choose their own comfortable environment away from external distractions. However, not everyone preferred online therapy as *'if I'm reading it on a screen I don't feel as though I'm actually [sigh] it doesn't feel as though I'm uh I'm not expressing anything?'* (P11).

Regarding the mode of delivery participants expressed opposing opinions on the effectiveness of group versus individual therapies and in-person versus online therapies, highlighting issues with travel or sharing experiences with others.

'I feel like the, the stress of traveling somewhere, and being somewhere would maybe outweigh the benefit of getting the help' (P3).

'I think email is good because you have the ability to, not t- you know like do it when you can do it. Um, but then I also do like, like I do like going to my therapist now because it's like a regular thing that I go, and it's a nice experience' (P3).

'I think when you're actually relating to people and sharing things I think it, it wouldn't, my, my, I know the way my brain works and I would tend to see that more as a, almost like a-a-a course that I was pa-passing through, working through rather than something that was em designed to be a therapeutic em change to my lifestyle' (P4).

For some, it was difficult to deal with multiple different people, voices and opinions when talking about something so intimate. Others noted the comfort, validation and helpful advice they could get from group therapies, especially if the groups were with other autistic people.

'Speaking to one person at a time is good, but trying to speak to different people at one time I don't know who to hear and I struggle a lot with that' (P3).

While seemingly contradicting each other on what works for autistic people or not, underlying these feelings is the desire to be treated as an individual person and to be listened to seriously.

'There's so much that can help, different people, um, sleeping. But it's got to be individualised [pause] you know? One thing is not going to work for everybody' (P2).

Moreover, participants highlighted that they valued information being disseminated by other autistic people, as they would be able to put it into an autistic perspective. This also helps to build trust, as participants previously expressed negative interactions with care professionals when asking for help.

'I think the thing I find most useful is an autistic person or a group of autistic people having a discussion about what works for them and em stuff like that. I think em. [sigh] The idea of it being peer-led is a very important thing, and I think you'll find is a very important thing to lots of autistic adults, who would like to see, you know, themselves involved more in, in initiatives and things' (P7).

Several participants note that they would find it helpful to have a group for autistic adults to come together. This could be structured and related to a specific problem or treatment it could be drop-in and talk about how you've been. This would also be helpful alongside standard sleep treatments. Overall, participants are clear that they want to be heard and involved in interventions.

'So for instance you might have a CBT programme like this but also have a once a week um group of autistic adults who, who go to a drop-in centre and talk about this and how it's going for them or

something like that [...] I think the thing I find most useful is an autistic person or a group of autistic people having a discussion about what works for them and, um, stuff like that. I think, um [sigh]. The idea of it being peer-led is a very important thing[...]. So I-I think a YouTube video that was like three or four people, you know talking about their sleep problems and what's helped them [um] as autistic people would-would be good, I'd like to see something like that. I think you would be slightly less likely to pay attention if it was like a researcher or an academic who wasn't autistic, talking to you about it' (P7).

Participants talk about being autistic when they discuss what would help with their sleep. Specifically, they are unsure whether there a prominent solution for their sleeping problems exists or whether a combination would be more effective. However, they all agreed that any interventions would be more effective if they were adapted to autistic people rather than being based on the general population.

'For me, the way, the way that I can think of is probably a very unfair assessment but the way that I can conceptualise general talking therapies such as psychotherapy and counselling, would not be particularly relevant to me and the issues that I have with sleep um, because my anxiety, even though I call it anxiety, whether it's anxiety or whether it's just a part of the way my brain works and whether that's kind of attached to being autistic or not regardless of that, that kind of anxiety isn't really tied to a specific trigger or um, it isn't really tied to something that I think could be spoken away or helped through talking therapies, um, for me personally.' (P5).

A key to a successful intervention for autistic people lies in the involvement of autistic people across all stages of a sleep intervention including the service provision and delivery.

'The most important thing for research of autistic adults in general um, in my view, is um to get autistic people involved, in the development of the service, in figuring out how, you know not just asking them at the end what they think of it, but to get them involved in developing from the beginning, what's going on. So um I think that involvement is very important um. That I think is the key to, hopefully a more successful intervention' (P7).

13. Discussion

Our study explored the experiences of autistic adults with sleep disturbances and specifically insomnia. More specifically, their personal experiences with advice and treatment preferences for insomnia and how they make sense of their experiences within the context of the UK healthcare support system. Following extensive analysis based on the IPA guidelines [35] two Group Experiential Themes were identified: "*The Night is Friendlier*" and "*It Doesn't Really Work for Me*". These themes demonstrate the unique experiences of autistic adults with sleep difficulties and insomnia and their distinct approach to advice and currently available interventions.

Although overall, participants' experiences and perceptions of their insomnia symptoms did not differ in quality from narratives of non-autistic people with insomnia [40], the underlying and maintaining reasons expressed by autistic participants seem to relate to specific pressures and striving to navigate life as an autistic person living in a neurotypical environment. The first theme (*The Night is Friendlier*) mainly refers to participants' experiential statements of using late-night hours as a respite from the world and from the obligation to conform. Experiences of masking during the day and striving for perfection to avoid stigma related to being autistic build up during the day, leaving the night-time as a window to engage in activities that align with their passions and interests without judgement. This is often at the expense of sleep and evidence suggests a mediating role of self-control [41], emotion regulation [42] and more general emotions, such as anxiety

[41,43]. Participants describe nights where their daily interactions and practices are mentally repeated and self-analysed in order to improve the social scripts they have created or to create safety in predictability by rehearsing them. These appear to be internally driven motivations to promote connection, and secondly assimilation to cope with external behavioural demands by society [44]. Masking adds to the post-event processing, generating a unique additional load to their experiences. Post-event processing, having an active/alert brain at night, and using media such as familiar TV shows or music to help them fall asleep are not unique to autistic people and are reported widely by those with insomnia. However, it is important to acknowledge that for autistic people, these experiences are considered part of being autistic, deeply personal, and should be taken into account for any intervention. Research suggests that masking is used for short-term goals but can have long-term effects on mental health and wellbeing [44]. Included in the detriments are feelings of defeat [45], isolation and exhaustion [44]. Our results indicate to the possibility that day time masking may play an important role in participants' night time sleeping behaviours, thus it is important to recognise the potential for compounding long-term consequences of masking and sleeping problems in autistic adults.

The second GET (*It Doesn't Really Work for Me*) brings to light the intricacies of identity within the realm of autism, with participants discussing how the subtle interplay of autistic traits and mental health co-occurring conditions, can create uncertainty in discerning one from the other. This confusion is often compounded by well-meaning but perhaps misguided healthcare professionals, who at times dismiss concerns as simply 'part of being autistic'. Often 'being autistic' was enough to be the endpoint of any investigation. This dismissal reinforces insecurity surrounding the distinction, leaving autistic individuals uncertain about the legitimacy of their experiences and eroding trust in support and care systems. The aspect of trust featured heavily in participants' suggestions for improvement of insomnia treatments for autistic people, albeit implicitly. Further, lack of trust and lack of feeling in control can affect participants' attitudes towards their perception of being capable of changing their sleeping behaviours and towards the effectiveness of sleeping advice.

14. Strengths and limitations

The involvement of autistic people at every step of the process, from inception to data collection and interpretation of the findings is a strength of the current study. Direct perspectives and experiences of autistic people with insomnia are scarce in the literature. This study was able to amplify autistic people's voices regarding their experiences with insomnia and its treatment in the current clinical and research framework. Our results echo the calls for patient and participant involvement in design of non-pharmacological sleep interventions in order to understand the barriers to seek support and develop acceptable treatment options [46,47].

Although the present phenomenological inquiry provided insights about nuances and experiences that could inform clinical adaptations to support sleep difficulties, we were not able to identify specific tailored adaptations for CBT-I or other non-pharmacological interventions for autistic adults. However, Lawson et al. (2023) reported on a tailored Acceptance and Commitment Therapy programme for Insomnia (ACT-I). In their study, all participants commented on the suitability, language use, and presentation of materials in the ACT-I programme, which was piloted with eight autistic adults with insomnia [29]. This can be attributed to the methodology of IPA interviewing that did not allow guiding participants to specific questions and can be accomplished by future research. Our study, however, highlighted the difficulty of finding a one-size-fits-all solution due to the heterogeneity across the autism spectrum.

We also did not collect any information on co-occurring health conditions experienced by the participants so we are unable to draw any conclusions on whether these conditions and any medications or other

forms of treatment prescribed to manage them may have impact on the experiences with insomnia described by the sample. Additionally, we did not collect data on any further demographic characteristics of the participants beyond the information reported in Table 1 in the results section.

15. Clinical and research recommendations

While there was no consensus agreement on how current interventions and advice for insomnia needs to be adapted to autistic people, participants' voiced their desire to be included and listened, with participants suggesting sleep advice to be disseminated by autistic people and participation of autistic people in research and clinical practice development. Our findings corroborate previous research showing that 21% of autistic adults report not wanting to participate in CBT-based interventions, with CBT ranking sixth amongst the approaches they would use unless these were adapted and evaluated by autistic people [48]. Future non-pharmacological interventions for insomnia should look holistically at the presentations including day time factors and ease any pressures that may lead to masking, adopting an approach sensitive to autistic experiences. The role of underlying daily stress, and mental health co-occurring conditions need to be better understood by researchers and healthcare professionals.

16. Conclusions

This is the first comprehensive study to explore the perspectives and experiences of autistic people with insomnia and their preferences for sleep-related advice and non-pharmacological interventions. Our results highlight the imperative to include autistic individuals in research design and clinical practice in order to gain a more nuanced and accurate understanding of their unique challenges and preferences, paving the way for more empathetic and relevant recommendations. Further research is needed to uncover gaps in healthcare professional's attitudes, skills and knowledge about insomnia in autism. By meaningful participatory research we can ensure that interventions and advice are tailored to their specific needs, enhancing the effectiveness of support strategies and contributing to building trust between autistic people and researchers.

CRedit authorship contribution statement

Dewy Nijhof: Writing – review & editing, Writing – original draft, Formal analysis, Data curation. **Craig Melville:** Writing – review & editing, Supervision, Conceptualization. **Ewelina Rydzewska:** Writing – review & editing, Formal analysis. **Georgia Pavlopoulou:** Writing – review & editing, Formal analysis. **Lily Meehan:** Validation. **Maria Gardani:** Writing – review & editing, Writing – original draft, Supervision, Methodology, Formal analysis, Conceptualization.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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