

“A perfect storm”: Autistic experiences of menopause and midlife

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Abstract

Previous research indicates that menopause can be an extremely difficult transition for some autistic people. This study asks how autistic people experience menopause and how they can better access services, support and information; autistic Community Research Associates played an important role in each stage of the research. Online focus groups and interviews were conducted with 24 autistic participants who lived in Canada ($n = 13$) or the United Kingdom ($n = 11$) and had experience with the menopausal transition. Transcripts were coded and analysed by four team members using reflexive thematic analysis. Four themes and eight subthemes were identified: (1) Complexity, multiplicity and intensity of symptoms (0 subthemes); (2) Life experience and adversity converging at midlife (three subthemes); (3) The importance of knowledge and connection (two subthemes); and (4) Barriers to support and care (three subthemes). Limitations include a potential sample bias towards difficult experiences of menopause. The majority of our sample had a late diagnosis or discovery of autism, and their experiences might not generalize to wider autistic populations. This research may help autistic people prepare for menopause and recognize symptoms earlier. Hearing about the experiences of others may let autistic people who struggle with menopause know they are not alone.

Lay abstract

Previous studies report that menopause can be a very difficult transition for some autistic people. This study focuses on how autistic people experience menopause and what support and information might help them. Autistic Community Research Associates played an important role in the research and co-authored this article. We held four focus groups and eight interviews online with 24 autistic participants who lived in either Canada ($n = 13$) or the United Kingdom ($n = 11$). We analysed participant conversations using a method called reflexive thematic analysis. Participants described many intense challenges during menopause. Four themes and eight subthemes were identified across participant groups: (1) Complexity, multiplicity and intensity of symptoms (0 subthemes); (2) Life experience and adversity converging at midlife (three subthemes); (3) The importance of knowledge and connection (two subthemes); and (4) Barriers to support and care (three subthemes). The experiences of our participants may not be the same as other autistic people, and the study could have been more inclusive of diverse autistic groups. However, hearing about the experiences of others may provide reassurance to autistic people who struggle with menopause and let them know they are not alone.

Keywords

autism and ageing, autism in women, autistic research, autistic support, community participation in research, health services, menopause, mental health, neurodivergence

Introduction

Research on autistic people's experiences of menopause¹ is emerging, with early studies published in the United Kingdom (Karavidas & de Visser, 2022; Moseley et al., 2020, 2021) and the Netherlands (Groenman et al., 2021). These studies indicate that some autistic people find menopause tumultuous or even catastrophic (Groenman et al., 2021; Karavidas & de Visser, 2022; Moseley et al., 2020,

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2021).² Some menopausal autistic people report struggles like heightened sensory sensitivities, difficulty coping, reduced social contact, suicidality and challenges with adaptive functioning and cognitive changes (Moseley et al., 2020, 2021). Previous research has also indicated greater reporting of menopausal symptoms in autistic women living in the Netherlands³ which were associated with higher levels of psychological symptoms such as depression in comparison with non-autistic women (Groenman et al., 2021), the only study to date to have made this direct comparison.

While it is premature to conclude whether autistic people experience significant physiological and psychological differences in menopause in comparison to non-autistic individuals, it is clear that some autistic individuals experience an overwhelming and extreme confluence of symptoms and difficulties in menopause that can compound existing physical and mental health distress (Moseley et al., 2020, 2021). Adding to these challenges, autistic people may lack menopausal awareness (Moseley et al., 2020).

Although there is little research exploring the impacts of menopause specifically in autistic people, it is known that autistic women have challenges to their psychological wellbeing (Martini et al., 2022; Yau et al., 2023) and experience suicidality at 3 times the rate of non-autistic women (Hirvikoski et al., 2020; Kirby et al., 2019). Research points to greater rates of emotional dysregulation and anxiety for autistic women, which may be associated with the camouflaging of emotional difficulties and autistic characteristics (Cage & Troxell-Whitman, 2019; Kirby et al., 2019; Mandy, 2019). Autistic individuals, and especially women, are also more prone to central sensitivity syndromes (CSS) (Grant et al., 2022) which are affected by hormonal fluctuations.

Adding to these difficulties, research indicates that autistic people in general struggle to access healthcare and other support. These barriers include patient–provider communication, sensory sensitivity and executive functioning/planning issues (Mason et al., 2019). Knowledge gaps in the healthcare system may also deter patients who have had negative experiences; many healthcare professionals are unfamiliar with autism (Nicolaidis et al., 2013), particularly in adults (Corden et al., 2022; Lipinski et al., 2022; Zerbo et al., 2019) and older populations (Heijnen-Kohl et al., 2017), and have little training related to autistic patients (Unigwe et al., 2017). Barriers to healthcare, combined with social ignorance and taboos around menopause (Ussher et al., 2021), mean that autistic menopausal people are not likely to get the support they need. This may also be impacted by disparities in diagnosis for some autistic populations. Autistic people assigned female at birth (AFAB) are more likely to be unidentified or misdiagnosed, as the image of

and clinical criteria for autism tend to reflect the stereotypical presentation often seen in boys and men (Bargiela et al., 2016; Gould & Ashton-Smith, 2011; Lockwood Estrin et al., 2021).

The sociocultural sidelining of ageing autistic individuals is also reflected in autism research (Michael, 2016), the bulk of which centres on younger, White male populations (Mason et al., 2022). Although research related to autism has increased exponentially over the past decade, research about older autistic people still comprises only a very small percentage (Mason et al., 2022). Previous research indicates that autistic participants wish for more accessible, quality research related to ageing and menopause, and that community engagement is a central component to autistic accessibility (Autism Network Scotland, 2020). Better understandings of autistic menopause experiences can help autistic people recognize the signs of menopause earlier and provide reassurance that they are not alone; it can also prompt researchers, practitioners and policy makers to identify and address service gaps and barriers to healthcare and information.

This research aimed to explore how autistic people in Canada and the United Kingdom experience menopause and access services, support and information that might help them through the menopausal transition. Data collection from participants in both countries helped the researchers to draw conclusions which might move beyond one national context. It also helped the researchers gather information for a later stage of research, an international survey. The study is the first of its kind to include autistic Community Research Associates in every stage of research in the co-production of knowledge with academics (Fletcher-Watson et al., 2019). As with comparable research (Groenman et al., 2021; Moseley et al., 2020, 2021), this study included middle-aged autistic participants ($M_{\text{age}} = 50.34$ years) who had experience of the menopausal transition.

Methods

All participants ($n=24$) lived in Canada ($n=13$) or the United Kingdom ($n=11$), self-identified as autistic or were formally diagnosed with autism, and were either navigating the menopausal transition or believed themselves to have already transitioned through menopause.⁴ We held four semi-structured online focus groups in total: two with participants who lived in Canada and two with participants who lived in the United Kingdom. We included a total of 16 focus group participants across the 4 focus groups, 8 participants from each country. Due to scheduling conflicts and accommodations for those who were not comfortable in a group setting, we also allowed participation through separate online interviews with an additional eight individual participants, five from Canada and three from

Table 1. Participant demographic characteristics.

	Total		Canada		UK	
	M	SD	M	SD	M	SD
Age ^a [range 40–71 years]	50.34	6.48	49.8 ^a	7.89	50.9	4.62
Estimated age of menopause onset ^a [range 38–51 years]	44.5	9.19	44	8.48	45	8.48
	N	%	N	%	N	%
Race						
White	20	83.3	9	69.2	11	100
Latino/White	1	4.16	1	7.7		
South Asian	1	4.16	1	7.7		
Ashkenazi Jewish	1	4.16	1	7.7		
Chose not to respond	1	4.16	1	7.7		
Gender identity						
Female	18	75	9	69.2	9	81.8
Non-binary	2	8.3	1	7.69	1	7.69
Gender fluid	1	4.16	1	7.69		
Trans Male	1	4.16	1	7.69		
Chose not to respond	2	8.3	1	7.69	1	7.69
Sexuality						
Heterosexual	11	45.8	4	30.7	7	63.6
Bisexual	4	16.6	3	23	1	9.1
Gay	2	8.3	1	7.69	1	9.1
Queer	1	4.0			1	9.1
Other	3	12.5	3	23		
Chose not to respond	3	12.5	2	15.3	1	9.1

Note. N = 24 (Canada n = 13; United Kingdom n = 11).

^aInformation not provided for one participant.

the United Kingdom. All interviews and focus groups took place between April and May 2022.

Twenty-three participants completed a demographic questionnaire. The age range of participants was 40–71 years, with a reported estimated age of menopausal transition onset of 38–51 years. Two-thirds of the participants ($n = 16$) had a late discovery of their autism, as they were unaware or did not know with certainty that they were autistic at the time of menopause. Most UK participants were from England, one participant lived in Scotland and none were from Wales or Northern Ireland. Participants from Canada lived in British Columbia and Ontario, except one participant who lived in Manitoba. The majority of participants identified as White (20) and female (18), and just under half as heterosexual (11). Over half had caregiving responsibilities such as caring for an ageing parent or child(ren), and/or worked in part- or full-time employment. Tables 1 and 2 show further details of group and individual participant demographic characteristics.

Materials and procedure

Following institutional ethics approval, the Community Research Associates initiated online recruitment on Twitter

(now X) using project and personal accounts, and in Facebook support groups for autistic members. After the closing date for expressing interest in participation, volunteers were randomly sorted in Excel to select the list of participants. Randomization was used to avoid disadvantaging respondents based on the timing of their expression of interest. Participants provided written informed consent prior to completing a questionnaire, which asked them for demographic information and details about their experiences with menopause. Participants also indicated their preference for participation either in an online focus group or an individual online interview, both on Zoom; this choice of format allowed for greater accessibility, as did several features on Zoom such as the hand-up function, ability to turn off camera and mute microphone, change name, chat feature and live transcription. Participants were compensated \$200 CAD or £120 for their time and insights after participating in focus groups or interviews.

Our decision to offer fair compensation to participants follows an emerging body of literature on ethical, best practices for research with autistic participants (Cascio et al., 2021; Gowen et al., 2019). In a survey of autistic and academic participants about participatory approaches in autism research, den Houting et al. (2021) identified

Table 2. Individual participant demographics and characteristics.

Group	Nation/ ID	Age	Gender identity	Race	Geography	Sexual identity	Menopause onset approx. age (years)	Knew autistic before menopause
UK Focus Group 1	UKP1	46	Female	White	England/Urban	Queer	43	No
	UKP2	47	Female	White	Suburban	Hetero	44	Suspected
	UKP3	57	Female	White	England/Suburban	Hetero	49	No
UK Focus Group 2	UKP4	51	Female	White	England/Rural	Hetero	40	No
	UKP5	47	Female	White	Scotland/Rural/ Suburban	Hetero	44/45	No
	UKP6	55	Female	White	England/Rural	Hetero	48	99% certain
	UKP7	49	Female	White	England/Suburban	Gay	39	Yes
	UKP8	59	Female	White	England/Suburban	Hetero	51	No
UK Interview 1	UKP9	54	N/A	White	England/Rural	N/A	48	No
UK Interview 2	UKP10	51	Female	White	England/Urban	Hetero	40	No
UK Interview 3	UKP11	44	Non-binary	White	England/Suburban	Bisexual/queer	40	Yes
Canadian Focus Group 1	CP1	49	Female	White	BC/Urban	Hetero	N/A	No
	CP2	43	Non-binary	White	Ontario/Urban	N/A	41	Suspected
	CP3	44	Female	Latino/ White	BC/Urban	Bisexual	42	Yes
Canadian Focus Group 2	CP4	54	Female	White	Ontario/Urban	Hetero	50	No
	CP5	45	Fluid	White	Ontario/Urban	Bisexual	43	Suspected
	CP6	51	Female	White	Ontario/Suburban	Hetero	44	Suspected
	CP7	40	Female	White	BC/Urban	Bisexual	38	Yes
	CP8	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Canadian Interview 1	CP9	51	Female	White	Ontario/Suburban	Hetero	In 40s	No
Canadian Interview 2	CP10	52	Female	White	Manitoba/Urban	Panromantic/ Demisexual	46	Yes
Canadian Interview 3	CP11	51	She/Her	Ashkenazi Jewish	BC/Village	Not sure Not purely heterosexual	50	No
Canadian Interview 4	CP12	47	AFAB & not very stereotypical woman	South Asian	Ontario/Suburban	'Fairly straight'	45–46	Yes
Canadian Interview 5	CP13	71	Trans Male	White	Ontario/Urban	Gay	47–48	No

Note. UKP, United Kingdom Participant; CP, Canadian Participant.

funding as a systemic constraint. Contrary to the idea that compensation is necessarily coercive, it can mean that participation is more feasible for participants who may need to take time off paid work or other responsibilities (Cascio et al., 2021). It also helps to flatten the power dynamic between the researcher and participant by indicating the value of the time and expertise of participants.

We sent an information guide on participation in advance (Janse van Rensburg et al., 2022) which included

an agenda, interview or focus group questions and short profiles of each team member who would be present. We ensured that each focus group and interview included an autistic team member and limited the researcher-to-participant ratio. Each focus group had up to five participants and three researchers, and interviews included one participant and two researchers. During focus groups, two of the team acted as co-facilitators asking participants questions, while one supported the facilitators, providing feedback to

enhance participation and monitoring the chat feature. Interviews and focus groups were loosely structured and guided by questions; they were also conversational with informal comments from team members and participants. Focus groups lasted up to 1 h and 45 min, with an option for a 10 min break midway through. Individual interviews lasted approximately 45 min to an hour. Participants were invited to have their cameras on or off, use a pseudonym and contribute to the discussion by using the chat feature to communicate with the whole group or to send private messages to the researchers. They were asked to respect the confidentiality of others inside and outside the group. While some focus group participants contributed more to discussions, facilitators tried to ensure everyone had an opportunity to participate by encouraging turn-taking and inviting quieter participants to contribute. All focus groups and interviews were recorded, and participants had the option to debrief informally with researchers for 15 min after the session had ended and recording had stopped. Team members debriefed with one another after participants left. Audio recordings were transcribed using NVivo and edited for accuracy. Transcripts were de-identified prior to analysis.

Data analysis

Qualitative reflexive thematic analysis was employed to analyse focus group and interview data. We employed a flexible, interpretive and subjective/reflexive approach following recommendations by Braun and Clarke (2021). Given our different disciplinary backgrounds and relationships to the research, and our varying degrees of connection with autistic community members, we made a number of reflexive considerations in establishing the subset of our team assigned to code and analyse transcripts. For example, two out of four coders were autistic, one was a Community Research Associate and two had knowledge of thematic analysis from previous research. Following Braun and Clarke (2021), we opted to approach coding collaboratively and through a postpositivist approach that recognized our unique positioning in relation to this project, rather than employing coding reliability approaches such as inter-coder agreement.

After familiarizing themselves with one of the de-identified focus group transcripts, one team member established an initial set of codes and candidate themes from the transcript, and coding team members reviewed and met to discuss these initial codes and themes. Each of the remaining transcripts was then assigned a primary coder to establish candidate themes working from and building on the initial set; a second reader reviewed and discussed coding with the primary coder on each transcript. Codes were adjusted and added following the initial set of codes to get a complete overview of themes. After coding all transcripts, a final list of candidate themes which reflected

patterns of meaning across all transcripts was produced and interpreted collaboratively. A further reflexive review of 24 candidate themes by the whole coding team aided with identification of overlap and consolidation of final themes and subthemes, resulting in four final themes. In reporting our findings, we replaced participant pseudonyms with numbers and an initial representing the country (e.g. 'CP1' for Canadian Participant 1) to avoid implicit associations in name usage and to allow readers to distinguish participants by country.

Community involvement statement

Two autistic Community Research Associates (one from Canada and one from the United Kingdom) were involved in each stage of research, from design to data collection and analysis, to reporting our findings. Autistic Community Research Associates also co-authored this article.

Results

We identified four themes and eight subthemes across our focus groups and interviews displayed in Figure 1: (1) Complexity, multiplicity and intensity of symptoms; (2) Life experience and adversity converging at midlife; (3) The importance of knowledge and connection; and (4) Barriers to support and care. While some themes relate to more universal experiences of menopause and barriers in the healthcare system, for example, aspects of Themes 2 and 4, they introduced specific challenges for our participants which compounded with existing struggles.

Theme 1: complexity, multiplicity and intensity of symptoms

A major theme throughout focus groups and interviews was the interaction of menopausal symptoms with autistic characteristics and co-existing conditions like attention-deficit hyperactivity disorder (ADHD), as well as the difficulty in distinguishing them. For some, struggles with mental health, emotions and suicidality heightened these challenges. Their negative, intense emotions led to a spiral of distress and difficulty, emotional volatility and heightened sensory sensitivities. As a result, some identified a feeling of 'autistic overwhelm' (CP3) or 'autistic stress' (CP8). They also suggested that over time, this stress compounded, taking a toll on their health and well-being, and sometimes led to burnout:

I had so much going on with heading to autistic burnout without even knowing it. I've got multiple chronic health conditions that were you know manifesting left, right and centre and the perimenopause really kicked those into play . . . I often don't realize what's happening until something's quite severe . . . (UKP3)

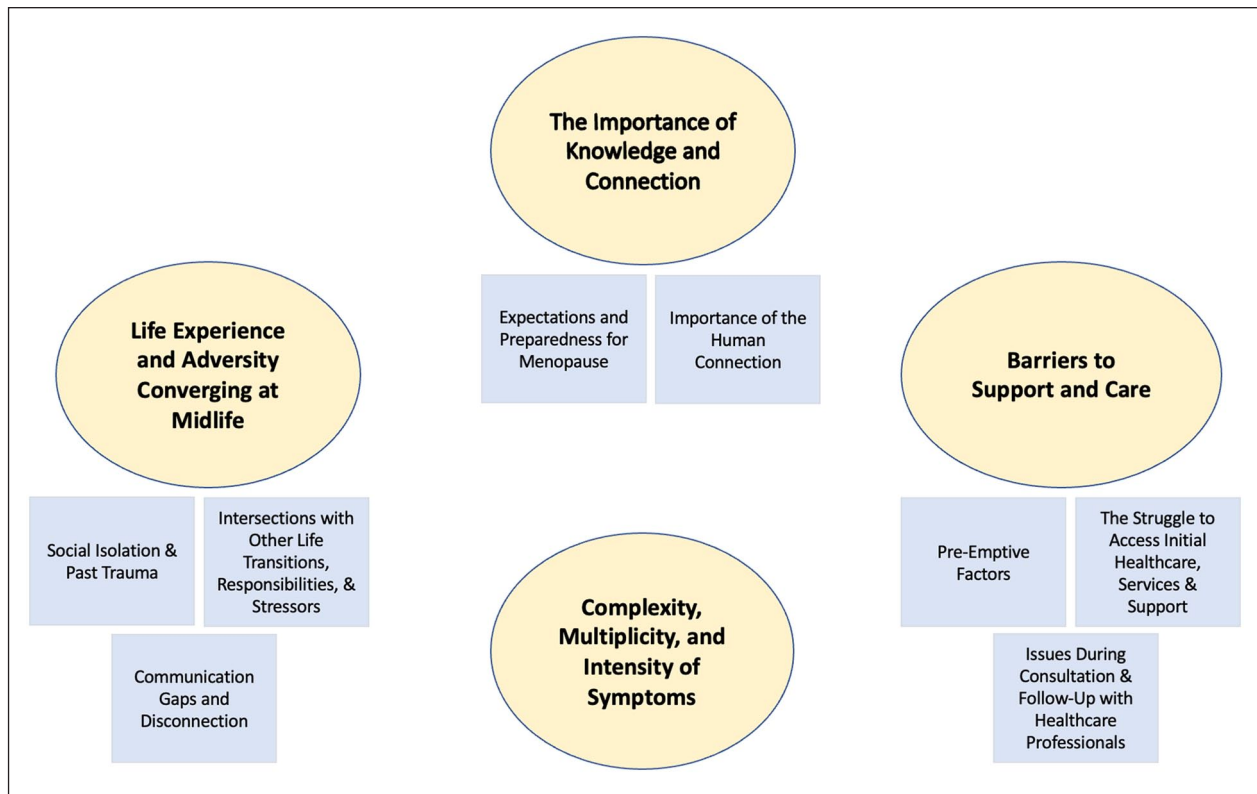


Figure 1. Thematic map showing identified themes and subthemes.

One large barrier for many participants in understanding the culmination of symptoms they experienced during menopause was that they did not know they were autistic at the time. Late discovery of autism often followed a lifetime of struggle, and was only triggered by reaching a breaking point:

I was only diagnosed with autism about two and a half years ago, so I've spent like 50 years not knowing . . . but then my sensitivities were so bad that I was in a real, real state and I couldn't cope anymore. (UKP9)

Several participants wished they had known they were autistic sooner, as they believed this would have helped them better understand themselves and their complex experiences of menopause. If participants had known, it might have also allowed them to identify sources of help earlier, and anticipate menopause symptoms before they got worse and compounded with autistic challenges, such as sensory sensitivities.

Theme 2: life experience and adversity converging at midlife

Social isolation and past trauma. Prior social experiences and traumas had a profound effect on the behaviours and

expectations of participants. These experiences had led to self-consciousness, self-criticism and self-censorship in various social contexts. For many participants, decades of being misunderstood, episodes of burnout and overwhelm, social isolation and bullying and victimization culminated in menopause when they had become so stressed and traumatized that they were no longer able to cope. Several participants also described a lifelong effort to camouflage their autistic characteristics to fit in better socially or professionally; they experienced this as exhausting, and some described it as a contributing factor to their ill-health. Camouflaging also became increasingly difficult or impossible for several participants in menopause, which may have added to the likelihood of being misunderstood: 'But yeah, just general sense of myself as not fitting in and not, not being able to cope socially . . . that's always been an issue for me, but it became much worse around that time' (UKP11).

For some, trauma had additional intersectional dimensions, as with an autistic trans male abuse survivor who felt very alone grappling with past traumas while transitioning through menopause and a late diagnosis of autism. As he stated, 'I've gone through a huge amount in my life and almost every time I was alone. No help. Zero help. And that's very difficult . . . don't wish that on anybody. You know?' (CP13).

Communication gaps and disconnection. Among a number of communication challenges, participants noted a difficulty in breaching the divide in understanding between self and others in general. This led to a sense of isolation and the feeling of going through the struggles of autistic menopause alone. One participant felt like an ‘outsider’ (CP3) interacting with neurotypical people transitioning through menopause because she believed her experiences were different.

In addition to general communication challenges including sensory issues, auditory processing difficulties and situational mutism, some participants noted intersectional barriers such as race and gender that added further layers of bias when they tried to communicate their needs. Many participants described interpersonal difficulties, especially in interactions with non-autistic people and feeling misunderstood as they struggled against assumptions and stereotypes.

Intersections with other life transitions, responsibilities and stressors. Often inherent in midlife is the co-occurrence of major life events and stressful life changes which can be difficult. While some participants grappled with care for ageing parents and children, many others tried to balance work stress and their own health challenges, relationships and financial stability. One participant explained how she became overwhelmed with a variety of issues and symptoms during menopausal onset, when her mother was also diagnosed with Alzheimer’s disease; added together, these stressors were too much:

... it was also just an experience of more stuff ... whereas previously, you know, I could handle the house, the job, the husband ... And then there’s another thing. And that other thing that happened at the same time as menopause with the increased symptoms was just what pushed me over the edge ... (CP4)

Similarly, for others, the care responsibilities they had while transitioning through menopause left little room for self-care: ‘by the time I’ve taken care of everybody else, there’s no energy left for me’ (CP1). A large proportion of participants also worked either full-time or part-time, and several described the impacts of menopause on work and vice versa, which led some to career changes: ‘my ability to ... function in the workplace, which is where I predominantly masked, was severely impacted to, to the point where I often just couldn’t ... it was quite catastrophic’ (UKP10). Several other participants similarly described no longer being able to camouflage their autistic characteristics at work once they started menopause.

Some participants also noted that brain fog and other cognitive changes made work tasks much more difficult or impossible. As one participant commented, ‘It’s like my mind’s different now’ (CP6). Another described an ‘abrupt’

transition from being capable and reliable at work to being ‘unrecognizable as that person’ (UKP6). Several participants recounted leaving paid employment, switching careers or changing the nature of their jobs. Another struggled with diagnosis and family concerns as well as graduate school, eventually dropping out:

So I had a perfect storm. I had so many different balls to juggle in the air that, you know, on top of the menopause and not knowing whether I was autistic. I had a lot, a lot to deal with. (CP13)

Theme 3: the importance of knowledge and connection

Expectations and preparedness for menopause. Participants described the power of information and, conversely, the disempowerment experienced through lack of access to knowledge about both autism and menopause. They widely perceived autistic menopause to be a distinct phenomenon accompanied by its own challenges. As such, they emphasized the importance of autistic-informed knowledge for those with similar experiences.

Many described struggling with the onset of unexpected symptoms and unpredictable menstrual cycles. The physical fluctuations in symptoms made it difficult to anticipate how they might be affected from one moment to the next. A lack of knowledge about menopause or uncertainty about whether menopause had begun, which stage they were in, or how long it would last was also upsetting. Some experienced perimenopausal symptoms that are not commonly discussed (e.g. heavier menstruation rather than cessation), so they did not initially make the connection between their symptoms and menopause.

Some participants attributed the deficiency of social awareness about the ‘double whammy’ (CP5) of being autistic and experiencing menopause to taboos:

I think our society doesn’t talk about, address, understand women our age in general very well. And so when you have the added dimension of autism ... There’s no resource, there’s no font of wisdom to tell me how to handle that. And there’s no room in society for it either ... Because we don’t talk about menopause, let alone autistic menopause. (CP8)

Several participants emphasized the importance of early education for young people about autism and biopsychosocial transition points, including menopause, suggesting that this might help offset social taboos and promote preparedness. Some explained that previous hormonal and social transition periods, such as adolescence and childbirth, had also been tumultuous for them. A number of participants agreed that menopause was like ‘going through puberty all over again’ (UKP10).

However, participants noted that self-advocacy and self-education could be empowering. For example, one

participant tracked her menstrual cycle and a variety of symptoms, which greatly helped her understand why she was feeling anguished at particular points. Several participants noted that they had done extensive research on menopause (which was clear from the technical terminology they used). This was partly because they were interested in doing research related to their experiences, and partly because they were not able to obtain the information they needed from practitioners.

Importance of human connection. Many participants noted benefits in sharing stories with neurodivergent allies and autistic support networks. Several had found common ground, community and connectedness around autism and menopause. Participants emphasized the importance of learning from others with similar experiences, highlighting the need for autistic-produced knowledge, and group support: ‘. . . but just being able to talk with each other and share symptoms and how they’re coping. So you don’t feel so much that you were alone’ (CP13). A common refrain within focus groups was that participants were happy to talk to others who understood their experiences: ‘Oh, it’s such a relief to hear this, this is great. Just having that sense of community, having that sense of common cause, that sense of I’m not alone in this. I’m not weird. I’m not isolated . . .’ (CP8).

Theme 4: barriers to support and care

Participants noted barriers to support and healthcare at all stages, from pre-emptive factors, which impact early in the patient journey such as perceptions of medical care prior to seeking help or support, to the first and second stages when they contact and consult a healthcare professional, through to post-care.

Pre-emptive factors: anxiety from prior experience, help-seeking fatigue and fear of repercussion. Overall, most participants had negative perceptions or past experiences with healthcare professionals which pre-empted their decisions around whether to seek help for menopause. Many felt there were barriers affecting access to public health services and saw a lack of awareness about menopause generally, and autistic menopause more specifically. Others feared contact with medical institutions. One participant described the threat of institutionalization as a child; fear of repercussions for her career made her reluctant to trust doctors and disclose information about her autism. Another participant expressed similar mistrust of the medical system: ‘the medical gaslighting that I’ve experienced just anywhere, I only really go [to the doctor] if I’m in an acute situation’ (CP2). Similarly, another participant stated, ‘NHS [National Health Service] is just absolute, just trauma, I can’t even go near it’ (UKP1). This reticence was generalized more broadly to other services. One Canadian

participant expressed concern that her own autism diagnosis might be used against her by the social workers meant to support her as the parent of autistic children.

Relating the lack of education and social awareness to their experiences with healthcare, several participants believed that their general practitioners (GPs), and even specialists, were ill-equipped to deal with menopause, and that autism was even further out of their realm of expertise. Participants indicated this treatment was particularly difficult for older patients and those not cisgender, White and presenting as male; as they believed many healthcare practitioners espoused a White male bias around autism and seemed to subscribe to the stereotype that autism is just diagnosed in childhood. Participants understood that bias is reflected in medical and healthcare research: ‘. . . there has to be an intersectional lens and there has to be better research, more data about gender and race and neurotypes and all the other factors that might influence menopause’. (CP12)

The struggle to access initial healthcare services and support. If participants did decide to seek out support, they faced many difficulties. Some were put off with gatekeepers, or the first level of attempting to make an appointment. At this stage, participants sometimes felt overwhelmed explaining why they needed the appointment, and feared judgement if they had to interact with someone to schedule it. Having to book appointments via phone was mentioned as a significant barrier. Compounding this initial reluctance was what participants identified as a gap in services and resources: ‘. . . in the UK . . . the access point for everything is our GP, time is very limited. Gaining an appointment is . . . a Herculean feat’ (UKP10). Overall, participants found trying to access services and support effortful and exhausting, especially given the struggles they were already experiencing.

Several participants also noted the long waiting times for assessment and services in public healthcare, and some had paid out-of-pocket for private care despite the high cost. As one participant stated, ‘I’m on a really low income. You know, I spent money that I could not afford on that because it was the only way to get any help’ (UKP11).

Medical issues during consultation and follow-up with healthcare professionals. Once participants had eventually made their way to being seen by a doctor or professional, many felt they had been ignored, misunderstood or had not been listened to or believed: ‘I don’t know if that’s different for other people who are neurotypical, but I get dismissed a lot. They don’t listen to me’ (CP10). One participant, whose long-standing communication challenges and health conditions had worsened, struggled to convince her doctor that she had started menopause. Another participant expressed a very similar experience in which two GPs disregarded their queries about being in perimenopause

because of their relatively young age, despite the participant's severe symptoms. Several participants had learned from experience that they needed to go to healthcare appointments equipped with information, noting the burden of having to educate medical professionals: 'I know if I don't start directing things, it's hopeless. And it shouldn't be like that because not everyone is going to be able to advocate for themselves like that'. (UKP3). Self-advocacy was not always welcomed by clinicians: 'There's so many ways in which patients need to be advocates for themselves . . . But then doctors get really frustrated when anybody has consulted or done their own research'. (CP12).

In extreme cases, participants had received inappropriate care or medication as well as misdiagnosis or conflicting diagnoses, leading them to believe that medical care is unreliable, insufficient or actively harmful. Other participants expressed anxieties at not being able to describe their emotions or what was happening with them physically (e.g. pain), particularly mentioning interoception and alexithymia. Participants described feeling that it was not always possible for them to get clinicians to understand just how close to the edge they were as they struggled with mental and physical health: 'I was told it's menopause, it's not life-threatening, but it bloody is, it's life threatening' (UKP6).

Perceived time pressures with doctors also contributed to communication challenges. One participant described the medical system as a 'mill' with implications for those who are multiply marginalized: '. . . They [doctors] just want to get rid of people. So especially with women or minorities or whatever, you get dismissed more as well' (CP12). Another participant stated of her GP that 'You get your seven minutes and you're out' (UKP6). Others treated visits to their GP instrumentally, using them only to obtain referrals or refill prescriptions. Some described power dynamics, diagnostic overshadowing and perceived bias with their doctors or clinicians. For example, when seeking autism assessment, one participant described being told by the clinician that there was nothing 'wrong' with her; she perceived this deficit-oriented language and the clinician's attitude as 'very dismissive' (UKP5).

Finally, several participants felt that they wanted to learn more or pursue particular treatments like hormone replacement therapy (HRT), but their doctors were not well-informed. One participant, who was experiencing extreme symptoms during menopause, reported being told by the doctor, 'well, you're not getting HRT because we don't give that out to people here' (UKP9). While past controversies related to HRT may mean some physicians avoid prescribing it, contrary to NHS clinical guidance (National Health Service, 2017), some participants insisted it was necessary for them to survive menopause.

Participants were equally frustrated after they received care. Many found a sense of powerlessness at being on long waitlists once they had finally been referred to

specialists by their GPs. Participants with chronic health struggles expressed their sense of helplessness as their symptoms compounded with no real support or follow-through.

Discussion

Our study on autistic experiences of menopause was the first to follow an inclusive approach where autistic Community Research Associates and academics worked together to design and conduct the research (Fletcher-Watson et al., 2019). We believe our approach benefitted the research process. In particular, participants seemed at ease to discuss their experiences in focus groups and interviews where autistic researchers were also present. This resulted in rich conversations and data that were reflected in final themes. Moreover, while previous related research has been focused in the United Kingdom (Karavidas & de Visser, 2022; Moseley et al., 2020) and the Netherlands (Groenman et al., 2021), this research is the first of its kind to indicate similar experiences across the cultural and healthcare contexts of Canada and the United Kingdom. Although previous work has not concluded definitively that there is a significant difference between autistic and non-autistic menopause, autistic participants in this study widely believed that their experiences of menopause were unique or amplified compared with non-autistic people. Unexpected physiological, psychological and social changes had a profound effect on participants; several described having inadequate information and support, or no support at all, and entering into a spiral of difficulty and distress in which they felt they could no longer cope. Several faced anguish, suicidality, loneliness and isolation compounding in menopause after experiencing a lifetime of struggles. These results corroborate previous research conducted with similar samples of middle-aged autistic participants who had experiences of the menopause transition (Groenman et al., 2021; Karavidas & de Visser, 2022; Moseley et al., 2020, 2021). For example, Groenman et al. found higher levels of menopausal complaints in autistic women aged 40 years and older and Moseley et al. (2020, 2021) reported similar struggles with participants reaching a breaking point in menopause. This study also corroborates research related to late-diagnosed autistic females, which indicated a lifetime of struggles in 'fitting in' with neurotypical society, followed by discovery of a new autistic identity that allowed for better self-acceptance and understanding (Gellini & Marczak, 2023; Leedham et al., 2020).

As with previous research (Botha & Cage, 2022; Lam et al., 2021; Michael, 2016), our participants powerfully emphasized the importance of autistic-informed knowledge and information about menopause to help support other autistic people and shape healthcare, public policy and early education with autistic perspectives. In line with

previous studies about autistic pregnancy and childbirth (Samuel et al., 2022) and menstrual periods (Steward et al., 2018), participants likened menopause to menarche and other biopsychosocial transitions during which they had experienced profound struggles as with Groenman et al. (2021). They indicated that being better informed earlier would have helped them to prepare and cope. More than half of the participants in our study did not know they were autistic, or did not know with certainty prior to menopause, and this knowledge and understanding of what to expect might have also benefitted them. In speaking with other participants, they expressed relief at finally finding others who related to their struggles. Therefore, we stress the importance of peer support and autistic-produced knowledge (Crompton et al., 2022; Lilley et al., 2023) to help autistic individuals feel informed and supported as they transition through menopause.

Our findings were also consistent with reports about problems of accessibility for autistic people with healthcare (Doherty et al., 2022; Mason et al., 2019; Nicolaidis et al., 2013; Unigwe et al., 2017; Zerbo et al., 2019). As participants noted, these problems are often systemic (Maddox & Gaus, 2019; Mason et al., 2021) as public healthcare systems in both Canada and the United Kingdom are bureaucratic and severely limited by time and resources. Participants languished on long waiting lists for unreasonable amounts of time (Camm-Crosbie et al., 2019), prompting some to seek private services they could not afford. Many pointed out the lack of knowledge in the medical system about the ‘double whammy’ (CP5) of autistic menopause and identified medical biases as major barriers to service and support. They believed taboos and ignorance around autism and menstruation extended into medical contexts. They described the broader problem of healthcare staff not being able to identify or accommodate autistic characteristics and communication styles (Doherty et al., 2022) and feeling dismissed in medical contexts, partly as a result of being autistic, and partly due to other biases (Camm-Crosbie et al., 2019). Shaw et al. (2023) described a triple empathy problem where autistic people struggle to make themselves understood and understand those of other neurotypes in the context of medical settings. We found an added dimension where communication challenges were even more profound for some autistic participants transitioning through menopause, combined with what we would characterize as medical misogyny; this could be seen as creating a quadruple empathy problem. Some participants indicated that menopause was reminiscent of former experiences of hormonal transition like puberty and menarche, transitions in which they had also struggled with communication. The adaptability of some participants (e.g. accessing private healthcare, self-identifying autism and menopause and educating medical professionals) was often the result of desperation rather than adequate systemic support. A key takeaway is the importance of person-centred, autism-informed healthcare that considers intersectionality and accessibility needs. We

encourage healthcare professionals to recognize autistic communication styles and the various symptoms of menopause, including those that are less widely discussed, and to be receptive to the fact that menopause may start earlier than is commonly expected. The reported range of estimated menopause onset was 38–51 years, and some participants reported that doctors had not recognized or believed their symptoms of perimenopause as they perceived the participants to be too young to be in perimenopause.

Limitations and future directions

This study had several limitations. As recognized by participants, a confluence of autism-related factors, trauma and life circumstances made it difficult to ascertain the source or origin of struggles; we cannot ascribe a causal role for menopause in the difficulties described. There was also no control group of non-autistic participants with which to compare our results, which is in keeping with a qualitative approach that centres the experiences of one group of participants and does not claim generalizability. Other limitations might have affected our findings including recall (Taffe & Dennerstein, 2000) and selection (Rubenstein & Furnier, 2021) bias.

The lack of measures to operationalize autistic features means that we cannot clearly and exclusively link certain menopausal experiences or difficulties to autism rather than other characteristics common but not unique to autistic people. The authors recognize the barriers to adult autism diagnosis (de Broize et al., 2022; Harmens et al., 2022; Huang et al., 2022; Murphy et al., 2023), which was the reason we did not require a formal autism diagnosis for participation in the study. A large number of older autistic adults are undiagnosed, and many of them are women/AFAB (O’Nions et al., 2023). Harrop et al. (2023) indicate a marked increase in autism diagnosis for those who were AFAB from 2000 to 2021, highlighting lower rates for those born in earlier years. As our study on menopause in autistic people was conducted in 2022, it naturally included participants who were born considerably earlier than 2000 and who are hence more likely to have been undiagnosed as children. There can be a number of benefits for autistic self-identification for those who do not have access to formal diagnosis, and especially those who were missed as children (Au-Yeung et al., 2019; Cassidy et al., 2021; Lewis, 2016a, 2016b; Maitland et al., 2021). In this study, the lack of requirement around formal diagnosis provided the benefit of including important perspectives from participants whose voices may have otherwise been excluded from the research. Nevertheless, we recognize that this posed a challenge to creating clearly defined cohorts of research participants in relation to diagnosis in our research. The lack of formal diagnosis may have added to the risk that some participants recognized traits in themselves that appeared to be autism related, but they may not have actually have been autistic.

Moreover, it is possible that taking part in the study may have seemed more urgent to those individuals who had difficult experiences of menopause. That the majority of our participants were unaware of their autism or did not know with certainty before menopause *could* reflect that menopause is particularly challenging to navigate as an undiagnosed autistic person (and hence bias our sample towards late-diagnosed individuals). However, the absence of direct comparisons between late- and early-diagnosed autistic people precludes any firm conclusions. While age at diagnosis may indeed influence menopausal experience and hinder the generalizability of our findings to autistic people diagnosed in childhood, it is also important to recognize that due to historically poor recognition of autism in female-presenting children (Lai & Baron-Cohen, 2015), autistic people who are currently at midlife are considerably more likely to be late-diagnosed as they grew up in this era. The impact of autism awareness on menopausal experience is a crucial research question, and one which will necessarily become easier to address as time goes on, and as more diverse populations are diagnosed in early life. Moreover, individuals who applied may have already been active in particular online autistic communities where recruiting took place. Research advertised in autistic social media communities may be more attractive to those with late diagnoses (Rødgaard et al., 2022). Therefore, it is possible that the experiences of our participant group may not be as generalizable to the wider autistic population as we intended. Moreover, those with intellectual disabilities, non-speaking people, those who do not communicate in English and people in remote communities and other individuals without Internet access were not represented in the sample.

Other limitations on generalizability relate to participant diversity. While we saw considerable diversity in sexual identity in demographic characteristics, our participant group could have reflected a broader range of racial diversity. We made efforts to encourage people from diverse autistic populations to participate, but more specific, deliberate steps at all stages of the research process could have been taken (e.g. more racial diversity within the research team itself, and targeted rather than randomized selection of research participants) (Malone et al., 2022; Maye et al., 2022; Williams et al., 2021). Collecting more data on other demographic characteristics influential for health and wellbeing, such as socioeconomic status, might have also helped explain experiences reported by participants, especially around access to healthcare. In addition, while our approach allowed participants to take part from home in relative anonymity, an approach which may benefit marginalized and autistic individuals (Crane et al., 2021), the physical distance from the researchers and other focus group members can affect rapport (Reisner et al., 2018). Dynamics may also differ between individuals interviewed one-on-one and those in focus groups, which may have influenced our results.

Further research is needed to better compare autistic and non-autistic experiences of menopause and to contextualize

particular socio-demographic impacts on experiences. For example, while participants from England, Ontario and British Columbia made up the majority in this study, additional participants from other UK member countries and Canadian provinces and territories would provide a more representative account. We focused on similarities across these contexts, but further research could focus on cultural nuances and differences between them. Finally, as reinforced by diverse sexual and gender identities in our participant pool and in previous studies (Hillier et al., 2020; Moore et al., 2022), more research is needed to explore gender identity factors.

Regardless of its limitations, this study draws attention to the similarities in menopausal experience across international contexts and adds to the growing evidence that menopause may present particular difficulties for autistic people, suggesting the need for greater attention to health-care, knowledge, connection and support.

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Supplemental material

Supplemental material for this article is available online.

Notes

1. Following guidelines from the National Institute for Health and Care Excellence (2015), we define menopause as a transition that occurs as ovaries stop maturing eggs and secreting oestrogen and progesterone. A person is considered having reached menopause or being post-menopausal after 12 consecutive months without having a menstrual period. Perimenopause is the symptomatic stage before a person has reached menopause. The entire process from

perimenopause to post-menopause can be described as the menopausal transition.

2. Autism can be understood as 'a lifelong neurodevelopmental condition' (Moseley et al., 2021, p. 710) as well as a social identity category (Pellicano & Heyworth, 2023).
3. We recognize the difference between sex assigned at birth and gender identity. When referencing previous research, we attempt to use original language used in reporting. For example, we use 'autistic women' following reporting in previous research, or pronouns that reflect the gender identity reported by our participants.
4. Given the prohibitive nature of clinical autism diagnoses due to high costs, long waiting lists and other barriers, we included participants who self-identified as autistic, though several participants noted having a formal diagnosis. For the same reasons, we did not require participants to have medical confirmation around being in the menopausal transition but asked them to explain how they knew they were in menopause.

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