



Autism research is ‘all about the blokes and the kids’: Autistic women breaking the silence on menopause

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Objectives. The menopause is a major transition marked by considerable challenges to health and well-being. Its impact on autistic women has been almost largely ignored but is of significant concern, given the poorer physical and mental health, emotion regulation and coping skills, and the common social isolation of this group. We aimed to explore awareness and perception of the menopause; menopausal experiences and their impact across each individual’s life; ways that menopause with autism might differ from a non-autistic menopause; and what optimal support might look like.

Design. A qualitative interview study.

Methods. Comprehensive interviews were conducted with 17 autistic participants (16 of whom identified as cisgender women). Inductive thematic analysis was used, guided by IPA principles and literature.

Results. Four major themes were identified: (1) covering the long journey of our participants to recognizing autism in adulthood; (2) menopausal awareness and perceptions; (3) symptoms and their impact; and (4) ways that a neurodiverse menopause might differ from the norm. Menopausal experiences varied greatly and some participants experienced marked deterioration in daily function and coping skills, mental health, and social engagement. Menopausal awareness was often low, so too was confidence in help from health care professionals.

Conclusions. These findings implicate the potential for menopause to severely compromise health and well-being of autistic people and indicate an area of underserved support needs.

Statement of contribution

What is already known about this subject?

- Menopause is recognized as a biopsychosocial transition point where women are particularly vulnerable to mental and physical ill-health and the deleterious effects of stress, unhealthy behaviours, and environments.
- Autistic people are known to have a reduced lifespan, with elevated suicidality, higher stress levels, and greater incidence of chronic illness.

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- Difficulty coping with change is characteristic of individuals with this condition, which also tends to be associated with having poorer coping skills and being socially isolated.
- At present, only a single focus group has explored whether menopause is an issue of concern for autistic people and suggested that many find this time of the lifespan extremely difficult.

What does this study add?

- With difficulties heightened, some autistic women are identified at menopause.
- Mental illness and suicide risk may be higher for autistic women during menopause.
- There are health care access problems and unmet needs for autistic women at midlife.

Background

From its origins in the 1940s, conceptualization of autism has changed conspicuously (Volkmar & McPartland, 2014). Two highly notable developments include growing awareness of the manifestation of autism in girls and women (Loomes, Hull, & Mandy, 2017), and recognition of autism as a lifelong neurodevelopmental condition, increasingly diagnosed in adulthood (Bargiela, Steward, & Mandy, 2016; Leedham, Thompson, Smith, & Freeth, 2019; Lehnhardt *et al.*, 2016). Growing up alongside the diagnostic category, those individuals diagnosed in the infancy of autism are now reaching or have reached midlife and older age. Worryingly, a dearth of research concerning these life stages means the health and support needs of autistic adults are poorly understood and underserved as they progress into middle age and beyond (Murphy *et al.*, 2016), despite the fact that with higher rates of suicide and physical illnesses (including those related to chronic stress), life expectancy for autistic people is markedly lower than that in the general public (Cassidy, Bradley, Shaw, & Baron-Cohen, 2018; Hirvikoski *et al.*, 2016; Lai *et al.*, 2019).

From an epidemiological perspective, certain biopsychosocial transition points are associated with elevated health risks (Hoyt & Falconi, 2015). One challenge particular to women is the menopausal transition, which in the Western world typically begins at around 40 years of age (National Health Service, 2018; North American Menopause Society, 2019). The menopausal transition spans the period where dwindling hormones induce symptoms (the ‘perimenopause’) to the point where women are post-menopausal, having experienced at least twelve months without menstruating (National Institute for Health and Care Excellence [NICE], 2015). The transition can last several years, most women reaching complete cessation of menses by between 50 and 53 years of age (Palacios, Henderson, Siseles, Tan, & Villaseca, 2010). This epoch is suggested to be a ‘sensitive period’ where the biological wear-and-tear caused by stress, unhealthy behaviours, and environments is intensified (Falconi, 2017; Hoyt & Falconi, 2015). Underpinning this sensitivity is major reorganization of neuroendocrine systems, which gives rise to a host of psychological and physiological symptoms, including those associated with mental health (e.g., depression, anxiety) and physical illness (e.g., cardiovascular and autoimmune diseases). With impacts on mood and cognition, it is common for women to report significant disruption to their well-being, relationships, and daily life (Newhart, 2013). Since the hormonal imbalance continues post-menopause, symptoms too may persist.

Surprisingly, very little is known about the ways that autistic women experience and cope with the menopause. The likelihood of poorer outcomes may be greater in autistic compared to non-autistic women, given the likelihood of pre-existing health difficulties combined with their difficulty accessing health care (Mason *et al.*, 2019a). The key features of autism, including sociocommunicative difficulties, cognitive, and behavioural

rigidity, render everyday life extraordinarily stressful (Bishop-Fitzpatrick, Minshew, Mazefsky, & Eack, 2017; Hirvikoski & Blomqvist, 2015). Autistic people often lack the buffers that might be offered by effective coping skills (Mazefsky & White, 2014), good executive function (Zimmerman, Ownsworth, O'Donovan, Roberts, & Gullo, 2017), and social support (Happé & Charlton, 2011). One pilot participatory study explored the state of current knowledge around menopause and whether this was an area of concern for autistic people (Anonymous, 2020). This investigation suggested a lack of professional knowledge, support, and interest in autistic experiences of menopause which was juxtaposed with the dramatic decline that some participants experienced across adaptive function, daily coping, communicative abilities, and cognitive abilities. Psychiatric issues emerged or worsened; self-injury and suicidality increased. Participants discussed future research which might serve to improve health and well-being, one important goal being the creation of a knowledge base in this area.

In contrast to the aforementioned participatory approach, which focused on extent knowledge and future research, the present study undertook an in-depth exploration of lived experiences through individual interviews with autistic people. Since attitudes to menopause are important predictors of symptom impact (Avis & McKinlay, 1991; Duffy, Iversen, Aucott, & Hannaford, 2013) and research in autism has similarly linked negative self-perceptions with mental health outcomes (Gotham, Bishop, Brunwasser, & Lord, 2014), we sought to understand not only the menopausal changes which occurred and their impact on our participants, but also the emotional experience and attitudes of our autistic sample.

Method

Participants and recruitment

Following approval by the Science and Technology Faculty Ethics Panel at the authors' institution, participants were sought in two purposive approaches to two Facebook support groups run by and for autistic people (see Supporting Information). The first approach was for the purpose of interview development, with a small participatory group of eight individuals (Moseley, Druce, & Turner-Cobb, 2020). The second approach, approximately two months later in May 2019, was made to recruit participants for individual interviews. Six of the eight participatory participants returned to take part in the study, and another ten individuals volunteered to take part. One more participant (P16) volunteered after hearing a talk given locally by the first author, bringing the group to 17 in total.

Our advertisements invited autistic individuals of any gender identity to take part, if they believed themselves to be currently navigating the menopausal transition (experiencing perimenopausal symptoms) or to have been through the menopause. We subscribe to convincing arguments to welcome self-identifying participants (Au-Yeung *et al.*, 2019; Lewis, 2016; Milner *et al.*, 2019): many older autistic women may not have been diagnosed as children due to historical unawareness of female autism and face barriers to diagnosis in adulthood, including sex-biased diagnostic tools (Gould, 2017; Lewis, 2017). Self-diagnosed individuals constituted seven of our sample (P1, P8, P9, P11, P12, P16, and P17). Participants completed two brief screening measures (the Autism-Spectrum Quotient 10 (AQ-10: Allison, Auyeung, & Baron-Cohen, 2012) and the Ritvo Autism and Asperger Diagnostic Scale 14 (RAADS-14: Eriksson, Andersen, & Bejerot, 2013)). The group had an average AQ-10 score of 7.8 (SD: 1.5) and a RAADS-14 score of

29.5 (SD: 9.4); every participant scored above the typical cut-off for autistic people in the AQ-10 (cut-off: 6), the RAADS-14 (cut-off: 30), or both.

The average age of the sample was 53.5 years (median = 53, SD = 5.8, age range: 41–66 years). Nearly all participants identified as female (the one exception, P13, suspected they were agender). Thus, the cohort was comprised of a total of 17 autistic participants (16 of whom identified as cisgender women). Menopausal status can only be confirmed by invasive yet highly fallible tests (North American Menopause Society, 2019), so in Britain the menopause is normally identified through self-reporting symptoms (National Institute for Health and Care Excellence [NICE], 2015). In terms of a person having ‘reached’ or passed through the menopause after 12 consecutive months without a period (Palacios *et al.*, 2010; North American Menopause Society, 2019), 11 participants were post-menopausal (P1–P8, P11, P13, and P15). From their estimates based on symptom-reporting, they had last experienced a period between 2–21 years ago (average 10.7 years [SD: 6.5, range: 19] since last period). Four were currently transitioning through menopause (P9, P10, P14, and P17). Two participants (P12 and P16) were experiencing menopausal symptoms but due to medical interventions, periods could not be used as a marker of menopausal transition. Additional information, including nationality and diagnostic status, can be seen in Supporting Information.

Materials and procedure

A semi-structured interview was devised following a participatory online discussion with our advisory group of autistic people and our perusal of existent literature from non-autistic menopause (see Supporting Information). Initially, questions aimed to obtain a brief overview of the participant’s autism diagnosis; any pre-menopausal neurodevelopmental, mental, or physical health conditions, formally diagnosed or suspected; and any pre-menopausal gynaecological issues, including difficult periods and fertility problems. Having ascertained the signs and the participant’s awareness of their menopause, the interview covered the following symptom domains with factual and open-ended questions: physiological symptoms, effects on executive function, communication and relationships, sensory symptoms, and quality of life; perception of and feelings around the menopause; how the menopause might differ for autistic people; and what optimal support might look like.

After having been sent the information sheet and conversing with the researchers over email, participants received an online form to indicate their fully informed consent. Their comfort being paramount, participants were asked their preference for the format of the interview. Choices included (1) interview via telephone or Skype (audio only (P10, P13, P14, P15, P17) or audiovisual (P1, P5)), (2) asynchronous online data collection via a survey platform (Qualtrics: P2, P4, P6, P7, P8), or (3) synchronous (P9, P11, P12) or asynchronous (P3) online interview via instant messenger. One participant (P16) asked to be interviewed in-person. All participants, except those filling in the online survey, were sent the interview questions beforehand to avoid anticipatory anxiety. The interviews took place over approximately a three-month period (June–August 2019) and lasted between 60 and 150 min each (the majority, 72%, lasted between 90 and 120 min). Interviews were conducted by one interviewer, either the first or second author. Whilst the interviewer engaged in member checking during the interviews, the first author returned to individuals during transcription and analysis, where needed, in order to clarify uncertainties in the text (for instance, related to sound distortions) and their

interpretation of it (for instance, to ask follow-up questions where meaning was unclear, or clarify any inconsistencies).

Data analysis

The researchers approached the analysis with an aim of understanding personal menopausal experiences and perceptions of autistic participants. Interpretative phenomenological analysis (IPA) was initially chosen as a fundamentally idiographic and individual approach which has recently gained popularity in autism research for its efficacy in revealing divergent autistic experiences (Howard et al, 2019; MacLeod et al, 2017) and flexible use in verbal or textual contexts (e.g., Rodham, McCabe, & Blake, 2009; Sutherland, Dawczyk, De Leon, Cripps, & Lewis, 2014). However, given the size of the participant sample recruited and finding a substantial heterogeneity in the group, the decision was made to eschew the more abstracted and idiographic analysis in order to capture more descriptively the experiences which are at present unrepresented in autism literature. Consequently, though analysis was guided by IPA principles and literature, the inductive thematic analysis presented here focuses on patterns of menopausal experiences, attitudes, and emotions across our autistic sample.

Analysis was guided by Smith and Osborn (2003) and completed without digital assistance. Initial note-taking for a single interview was followed by interpretation of themes that 'move[d] the response to a slightly higher level of abstraction' (Smith & Osborn, 2003, p.68). Identifying relationships between themes, these were 'sculpted' into a meaningful order which was checked back against the transcript to ensure fidelity with the participant's account, and an individual thematic table produced. The same pathway was followed in a bottom-up fashion for all interviews up to P10, at which point clear patterns were beginning to be apparent and orientated the researcher to the likely emergence of these themes in the remaining interviews. Finally, the researcher created a master table of themes common across participants. This recursive process involved frequent review of individual interviews and tables to check the fit of superordinate themes. Analysis was conducted predominantly by the first author, who recoded two interviews one month later to ensure consistency with previous coding. The second and third authors independently analysed a random sample of 11 interviews between them (65% of participant sample) before meeting for discussion. Finding themes whose nature resonated across the authors, titles, and theme summaries were finalized. Reflexive considerations can be seen in Supporting Information (item 3).

Results

The authors reached consensus on four overarching themes (see Figure 1): (1) Journey to self-awareness (with five subthemes); (2) Menopausal attitudes and understanding (five subthemes); (3) Signs, symptoms and multiple impacts of menopause (eight subthemes); and (4) Navigating a neurodiverse menopause (three subthemes).

Journey to self-awareness

This theme reflected the transition of participants, none of whom recognized their diagnosis until adulthood, to a place of self-awareness and greater self-acceptance. It was composed of five subthemes.

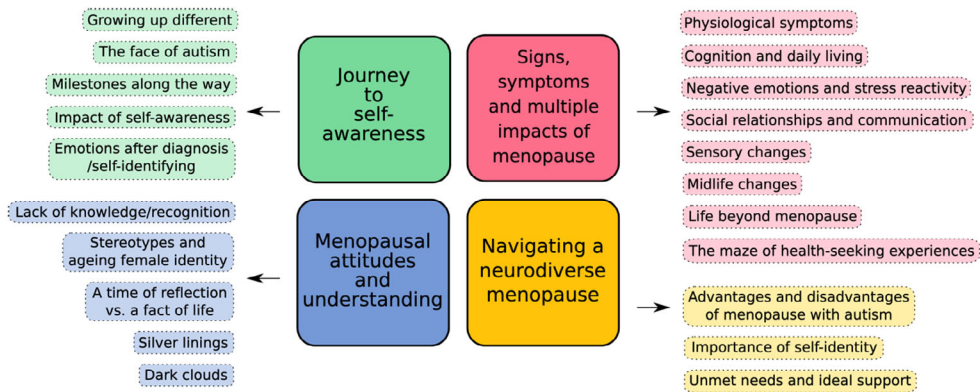


Figure 1. Visual overview of the themes and subthemes from thematic analysis.

Growing up different

Participants commonly described a history of mental and physical illnesses from childhood onwards. Depression and anxiety were almost universal, but other conditions included eating disorders, digestive issues, allergies, menstrual pain, and chronic illnesses such as myalgic encephalomyelitis (ME). For several participants (P1, P3, P8, P11, P13, P14), their autism was compounded by diagnosed or suspected ADHD/ADD. A ‘lifelong feeling of not fitting in and being out of sync with things’ (P1) was inherent in accounts. Participants borrowed colourful metaphors to illuminate the impact of ill-health on otherwise considerable intellect (‘a Jaguar car going at 0 miles per hour because it had four punctures’ [P16]) and their imperfect attempts at camouflage. Several participants recognized that their social naivety had resulted in rape and abuse (‘... stuff’s done to you, you don’t, you can be quite passive’ [P5]). Tragically, many internalized their problems and blamed themselves.

The face of autism

Our participants did not recognize themselves in the male stereotypes that permeate public perception of autism, in media representations like *Rain Man*, or in the diagnostic descriptions and screening tests available online. Female representations of autism were apparently scarce (‘I’ve seen the [autistic women] who are dependent, if you know what I mean, but not ... any functioning autistic woman’ [P10]). For some, diagnosed male autistic relatives, colleagues, or partners informed their ideas of autism and of what it meant to be ‘very’ or ‘deeply’ autistic (P10, P16). To others, autism initially meant ‘handicapped’, ‘disabled’, or ‘special needs’ (P13, P14, P16), which was difficult to adapt to once diagnosed.

Milestones along the way

For most participants, their self-identifying/diagnosis was preceded by a neurodevelopmental diagnosis in their own or a close child. Others stumbled upon online resources which linked what they experienced to autism or had their autism recognized by health care professionals during treatment for psychiatric illnesses. Interestingly, P3, P4, P9, P14, and P16 ascribed the menopause a role in their road to diagnosis/self-identifying:

I believe it was menopause that led me to my ASD diagnosis, as my ASD traits become so much more exaggerated during menopause. (P9)

I would say that I found out that I am autistic because I'm perimenopausal, because I've stopped being able to cope with my life, the life I was able to cope with before. (P14)

Impact of self-awareness

On recognizing themselves to be autistic, participants described that they were able to be more self-compassionate and less self-critical. Participants reduced their efforts to maintain a neurotypical front ('stopped trying to be something I'm not' [P6]), including allowing stims and reducing the social demands they had previously made for themselves. Self-awareness allowed participants to find understanding communities; strengthen relationships with new understanding; seek professional support; protect themselves from things that would previously have exhausted or upset them; to reframe past difficulties in a kinder light and to develop strategies for the future ('instead of blaming it on my terrible personality' [P13]). Importantly, they were able to adjust their self-image; in P16, for instance, from a 'broken horse' to a 'beautifully functioning zebra'.

Emotions after diagnosis/ self-identifying

Diagnosis or self-identification also evoked difficult emotions. These included anger and resentment for unnecessary suffering and injustices which could have been prevented by an earlier diagnosis, and sadness and regret:

I wish . . . I could've been a bit more objective with my thinking and then accepted myself the way I was (P10).

Having grown up at a time where neurodevelopmental conditions were heavily stigmatized, some participants felt shock and impact to their self-esteem at diagnosis. One participant who had self-identified also explained her anxiety that others would question her identity (P16).

Menopausal attitudes and understanding

This theme was centred around participant expectations and prior knowledge about menopause; their ideas around ageing female identity; their current perception of the menopause (whether wholly negative, positive, or having aspects of both) and the gravity they afforded it (viewing it matter-of-factly, or as a significant life event). Accordingly, these five subthemes were as follows.

Lack of knowledge/recognition

Menopausal awareness and knowledge differed among participants, but the prevailing feeling was that menopause was a taboo topic with friends and family. Some participants had a fair factual understanding of the menopause but admitted they lacked understanding of 'what it would feel like' (P1). Others were fearful of the health risks associated with menopause. Hot flushes were the stereotypical symptom associated with menopause, which confused participants who based their expectations on the experiences of women close to them. There was also confusion around the concept of perimenopause, the transitional nature of menopause, and whether action was needed (P17). Social support

was crucial to some participants in helping them to mentally prepare (P10). Others, socially isolated, felt 'on my own with my body and feelings' (P2); P6 reflected 'I thought I was going mad'.

Stereotypes and ageing female identity

In entering midlife, participants felt themselves affected by ageist stereotypes at work, job interviews, and even in the form of emotional abuse from partners. Inherent in their comments were beliefs that female worth is based on fertility:

Once your body has realised it is no longer going to reproduce, it starts killing itself slowly, because it says 'okay, you're no longer relevant'. (P3)

And/or sexual desirability:

Women in menopause are women who are losing value completely because since they're no longer sexual objects, they don't have value. They become either nanas, or they become cougars, or they become silly old bats with 20 cats (P13).

It was recognized that stereotypes are strongly culture-dependent and further fail to recognize moderation of experience by values, personality, and even hobbies.

A time of reflection vs. a fact of life

The divergence in this subtheme reflected the difference in perceptions of the menopause. Some participants spoke of the menopause in an accepting manner ('Natural part of ageing. Don't have to worry about it. Tick' [P1]). Others found that menopause induced pensive reflection on their pasts, and a sense that 'the clock switches to countdown' (P13) the future; a time to make changes in lifestyle and relationships, to reflect on 'what I would like to be and where I would like to go' (P10).

Silver linings

Participants recognized several benefits to menopause, with cessation of periods being a unanimous pleasure. Several participants credited the menopause with their increasing self-awareness; some appreciated the 'invisibility' it brought (P13) and that it 'reduced the "female" pressures to look good and be sexy etc.' (P6). Some participants, as above, found the menopause had prompted them to make healthy lifestyle choices, including being 'more selfish' (P16), pursuing self-care and activities they enjoy ('This has been an absolute springboard for me, to... do amazing things' [P5]); letting go of toxic relationships and improving close ones. P3 explained that menopause, for her a period of 'incredible mental discombobulation', had forced her to develop new and effective strategies for cognition and communication, new empathy and connection with others in distress. For her, menopause was a 'maturing period', where she discovered unexpected strength and resilience.

Dark clouds

Negative aspects to the menopause included the impact of symptoms on sex life, appearance and self-esteem. P5 pointed out that the menopause 'can make you feel very,

very out of control'. For some, there was nothing good at all about it (P4); others perceived it as a 'countdown to death' (P12), or a 'sub-optimal' state of illness (P3). The same participant found she no longer benefited from certain aspects of ADHD:

My ADHD is broken, it's got lots of D's in it, the deficit and the disorder. Before that I didn't feel it to be that way . . . you could have these wonderful gifts (P3).

Signs, symptoms, and multiple impacts of menopause

This theme, split into eight subthemes, covered the wide-ranging effects of menopause and their impact on physical and mental health, cognition and daily living, social function, and sensory symptoms. It also covered the situation of the menopause more broadly within midlife; life beyond menopause; and the experiences of participants in seeking help. The subthemes were as follows:

Physiological symptoms

Women endorsed a range of physical symptoms in the realm of neurotypical experiences (including night sweats, hot flushes, irregular periods, fatigue, insomnia) and a few unusual ones (such as increased libido and flare-ups in chronic illnesses). P5, who compared menopausal symptoms to her experience of ME, described it being 'like walking through like with a head full of cotton wool and a body which just isn't going to behave'. Recognition of these symptoms was often confounded by medication, life circumstances, and even long-term autistic or mental health difficulties. The severity and impact of symptoms was greatly varied and mitigated by individual circumstances, but some participants described a substantial impact on self-care and daily functioning. P3 explained that through desperation, she disregarded medical advice around breaks from hormonal medication ('Within a day I feel like I can't live like this . . . without it I can't do anything really . . . I don't have the energy'. [P3]). Mental health was naturally impacted by these difficulties, by the impact of physical changes on self-esteem, and by palpitations, which exacerbated existing anxiety. For some, social engagement was restricted by symptoms like hot flushes, which caused anxiety and embarrassment in public.

Cognition and daily living

Participants frequently mentioned 'brain fog', a state of 'crushing tiredness and executive function of a 12-year-old' (P14). Memory, organization, and attention deteriorated for some participants, and ADHD/ADD was exacerbated if present. Work performance deteriorated, with some losing income, falling into debt or requiring long-term sick leave; others were protected somewhat by lifestyle changes made, perhaps through necessity (P14), around the time of the menopause. P13 attributed a spontaneous, abusive, and ill-judged marriage to 'menopausal madness'. Self-care was also affected ('My self-care and cleaning of my clothes/flat etc has reduced practically to zero' [P9]), with some participants highly dependent on spouses or relatives, even elderly parents, and others dependent on developing new strategies in order to function. This loss of functionality, skills, and independence, for some, shook their self-esteem:

I used to think, whatever anyone thought about me, they thought I was hardcore because I could get done loads of stuff and they were like, 'I don't know how you do it' and I was like, 'it's easy' . . . then suddenly it wasn't easy anymore. (P14)

Negative emotions and stress reactivity

Many participants had a history of anxiety and depression, and some reported that these worsened or manifested in new ways during menopause. Emotional lability was common ('Whereas previously I'd be a little bit grumpy maybe - I was psychotic, like . . . my emotions have been turned up a notch' [P14]), participants were more reactive to uncontrollable environmental events, and previous coping mechanisms 'just completely failed' (P5). For some, meltdowns became extreme ('sitting in a corner naked, rocking and bashing my head against a wall . . . it was like visible autism to the max' [P3]), sparked by sensory sensitivities, communication difficulties, and executive dysfunction. Increased depression and anxiety was, for some, accompanied by increased self-injury and suicide ideation or attempts. After five overdoses in this time, P15 was diagnosed with emotionally unstable personality disorder. She doubts the diagnosis and retrospectively wondered if menopause played a role in her new emotional lability. Some participants, however, welcomed the 'emotional flatline' [P16] which came with the cessation of periods.

Social relationships and communication

Several participants commented that during the menopausal transition, they became far less capable and/or tolerant of social interaction. Sadly, increased loneliness and social disconnection could occur alongside 'not being able to bear' interaction (P4). Most participants reported masking less, being 'less able to bear the effort (not enough available energy) and less motivated' (P6). Some reported greater difficulties with non-verbal and verbal communication: problems with eye-contact, body language, prosody and tone, non-literal language, small talk, finding words, and reading cues from others. Some reported periods where they couldn't speak at all. Some participants found their ability to recognize and communicate their emotions deteriorated and affected their ability to seek support:

I suspect that GPs etc thought that the symptoms weren't that bad because I wasn't breaking down and crying or giving any emotional detail. . . . When you can't describe what's going on, you can't really ask for help. (P6)

Close friendships and familial relationships were affected by these and other changes related to menopause, such as increased anxiety, emotional lability, and fatigue. Marital/romantic relationships were additionally affected by heightened sensory sensitivity, reduced libido and inclination/enjoyment of sex, and by inability to communicate this ('if I was touched in a sexual way . . . it was a terrible feeling. . . I couldn't talk to him about it because I just didn't have words for these things' [P3]).

Sensory changes

Many of the participants reported some degree of heightened sensitivity to lights, smells, touch, and sounds (including heightened misophonia). For some of these, this was entirely new. This had multiple impacts on mental health, relationships, social engagement, and daily function. 'A major dominating, incredible, awful, debilitating thing', P3's heightened sensitivity dramatically curtailed her natural extroversion; affected relationships and sex; left her unable to manage self-care or shop for food.

Midlife changes

Menopause occurs in an epoch marked by great lifestyle changes. Participants experienced the breakdown of marriages, ill partners, caring for children with neurodevelopmental conditions, older children leaving home, new medical conditions, family arguments, and ageing and dying parents. Many of these changes were stressful, worrying, or upsetting, as was the awareness of mortality in others ('my husband IS going to die before me probably, and I'm going to be on my own' [P14]). Alternatively, self-conscious P10 felt the distance between herself and non-autistic peers widening, having not had many of the same life experiences.

Life beyond menopause

Some post-menopausal participants suggested that they experienced a degree of improvement in physiological symptoms, executive function, sensory sensitivity, mood, social communication, and/or relationships – but improvements were often costly, involving new efforts and strategies that might only be partly effective ('it takes so much stuff to keep me functioning... okay.' [P3]). Improvements were recognized to be multifactorial (for instance, related to medication or self-awareness) – so too was further cognitive deterioration (for instance, after illness [P2]).

The maze of help-seeking experiences

Not all participants sought medical assistance during menopause. Some had positive encounters, but several were distrusting of medical professionals, perceiving them as highly fallible, naive or keen to 'medicate me up to the eyeballs' (P14). Others found it difficult to communicate their difficulties or obtain the information they wanted. With a lack of understanding and trust around HRT, few were receiving it.

Navigating a neurodiverse menopause

This theme attempted to elucidate how neurodiversity might affect experience of menopause. It was divided into three subthemes.

Advantages and disadvantages of menopause with autism

Participants suggested that menopause might be made more difficult by pre-existent difficulties with communication, executive function, 'the ability to understand what's happening inside' (P1), unpredictability, social relationships, mental health, sleep, sensory issues, and health care access – overall, 'this extra overload of trying to be a normal when they're NOT normal' (P17). These issues might be shared by other neurodiverse groups and exacerbated by intellectual disability. One participant suggested that autistic people might be more affected emotionally by the loss of fertility (P13). In a positive light, others suggested that autistic people might be more 'analytical' (P5) and matter-of-fact; more used to feeling out of place; less 'trapped by categorisation' (P6) and so less concerned about age and appearance; and less fearful of death if they have experienced suicidality (P6). It was recognized that great variation would exist between autistic people and that non-autism-specific factors, like mental ill-health, might complicate menopause for some non-autistic people, too.

Importance of self-identity

Asked about the importance of knowing about your autism when navigating menopause, participants recognized this was very individual. A few felt that it wouldn't have made a difference, but others felt that the knowledge could help people 'harness' strengths and support (P5), have coping strategies in place, be more self-compassionate, and understand why their experience of menopause might be a bit different to non-autistic accounts. Some felt that the menopause might be much harder and more 'overwhelming' (P11) without self-awareness and 'disliking what was happening to my body... would have heightened the intensity of being different' (P10).

Unmet needs and ideal support

Finding general descriptions unhelpful or irrelevant, participants adamantly requested the development of autism-specific resources (e.g., symptom lists, video messages) and enthused research attention to autistic people other than 'the blokes and the kids' (P5). They emphasized the importance of social support, especially from autistic peers and people who had 'walked the path back from Mad Land' (P3), and also the importance of education for health professionals on issues concerning autistic women. Ideal care was conceptualized as holistic, involving realistic goals and perhaps a therapeutic component, and delivered by time-generous physicians who 'also pick[s] up my feelings' (P16). Assistance to develop plans beforehand was highlighted, as was practical help to carry them through, and the importance of reassurance: 'it doesn't have to be forever' (P10).

Discussion

The menopausal experiences of our autistic participants were heterogeneous in symptom profiles and severity. Some reported minor symptoms with little disruption, whilst others reported experiencing menopausal symptoms quite dramatically, with substantial impact on functioning, health, and well-being. As implied previously (Anonymous, 2019), these interviews confirmed that some autistic individuals experience severe mood dysfunction and co-occurring self-injury and suicidality; furthermore, that self-care and health behaviours could be severely compromised. The interviews also showed our participants navigating major midlife changes and living within multiple circles of marginalization: female, ageing, and autistic. The extent of this perceived and/or actual marginalization was moderated by individual, situational, and cultural differences, but participants were sensitive to deeply embedded attitudes which affected their self-perceptions. This kind of marginalization, embedded not only in attitudes towards ageing women but in those around autism, is known to affect health (Botha & Frost, 2018) and might further contribute to high mortality and morbidity in autism (Cashin, Buckley, Trollor, & Lennox, 2018; Lai *et al.*, 2019).

Our findings were consistent with known barriers to health care access in autistic people (Mason *et al.*, 2019a), including difficulties communicating and more fundamentally recognizing and labelling differences from the norm. Negative experiences with health care providers, based on perceived inaccuracies or gaps in practitioner knowledge, were also barriers to access, as was lack of knowledge and distrust around medical interventions, which some participants feared would be imposed upon them. Interviews suggested that autistic people might lack the knowledge needed to make empowered health decisions during menopause and that many struggle alone. As well as highlighting unmet support

needs around menopause (particularly for accessible information), our data corroborate the importance of helping people process the shame, shock, depression, and anger that might accompany a new, often highly stigmatized diagnosis (Kock, Strydom, O'Brady, & Tantam, 2019; Leedham *et al.*, 2019). The new awareness of their 'normality' within an autistic identity could, however, transform self-criticism into self-compassion, resonant of previous studies around late diagnosis (Bargiela *et al.*, 2016; Kanfisz, Davies, & Collins, 2017; Kock *et al.*, 2019; Leedham *et al.*, 2019; Milner *et al.*, 2019; Tan, 2018).

Our findings extend this previous literature with a fascinating observation around the role of menopause in late diagnosis of autistic women. Five of the seventeen participants suggested that the elevated difficulty and distress associated with menopause, the loss of coping skills, the exacerbation of autistic features, and their inability or lack of energy to hide these had precipitated self-identifying or seeking formal assessment. Thus far, factors *precipitating* self-identifying or diagnosis-seeking have been merely a side-note in studies on late diagnosis. Researchers in the autism literature have commented on a trend where autistic girls are often diagnosed at adolescence (Cridland, Jones, Caputi, & Magee, 2014; Gould & Ashton-Smith, 2011; Jamison, Bishop, Huerta, & Halladay, 2017). This increased visibility of autistic difficulties is generally attributed to interpersonal factors (e.g., an increasingly complex social world) rather than to intrapersonal psychoneuroendocrinological changes, which are known to elevate the risk of psychiatric symptomatology (Hoyt & Falconi, 2015). An integrated, systematic, and longitudinal examination of autistic symptom presentation and diagnostic rates, with consideration and disentangling of biopsychosocial factors, would be a valuable goal for future research and should elucidate whether menopause, too, increases visibility of autism.

The deteriorating quality of life that some participants experienced during menopause accentuates the scant literature on autism and middle age. Older autistic people are less likely than non-autistic peers to maintain optimal physical and cognitive fitness, and more prone to reclusiveness (Hwang, Foley, & Trollor, 2018). Within this demographic, quality of life declines most in those with poor mental health (Mason *et al.*, 2019b), consistent with the greater impact of menopausal symptoms on non-autistic women with mental illnesses (Bauld & Brown, 2009). Whilst the present data did not directly examine mental ill-health as an outcome, this qualitative foundation in autism menopause research may provide a springboard for further investigations. Worthy avenues to inform future interventions would be to isolate the impact of particular menopausal symptom domains, to clarify the direction of interactions between symptoms, and to examine any potential mediation/moderation by physical and psychosocial factors which affect menopausal experience for non-autistic women, including life stress, aspects of physical fitness, and socioeconomic status (Chedraui, Aguirre, Hidalgo, & Fayad, 2007; Dennerstein, Lehert, Guthrie, & Burger, 2007; Pérez-López *et al.*, 2014). It would also be crucial to disentangle the distinct effects and impacts of menopause, potentially rooted in hormone depletion, from those of ageing more generally. Other approaches might examine aspects of the autistic profile that might buffer menopausal challenges, and the impact of self-awareness and self-compassion. This might be supplemented by other qualitative approaches to this topic, which might employ the more in-depth phenomenological approach originally intended. In the current work, there is no way of identifying if the experiences reported are specific to autism, shared with neurodevelopmental conditions like ADHD or psychiatric populations without autism, but this presents an intriguing research goal.

The present investigation was subject to a number of limitations. Participants were included based on self-report, with no confirmation of menopausal status. The variation observed between participants might, in part, reflect symptomatic development across

the menopausal transition (Woods & Mitchell, 2016), but this cannot be confirmed without physiological indices. Studies in non-autistic women have attempted to combine symptom-report with physiological measures (e.g., Woods, Cray, Mitchell, & Herting, 2014) and this highlights the importance of developing longitudinal, mixed-methodological research on female autistic ageing to document changes experienced in comparison with younger autistic and transition-matched neurotypical peers.

In pursuit of credibility and dependability in our analysis (Anney, 2014), we recoded the data after one month to notice any changes in interpretation; employed triangulation across researchers; and performed member checking for narrative accuracy and interpretation during and after interviews. Regardless, these findings cannot aspire to generalizability among the autistic population. Our recruitment strategy excluded individuals with literacy difficulties and those without technological access, and those with severe anxiety may have been less likely to volunteer. The menopausal experiences of those with severe communication impairments and intellectual disability require specifically targeted investigation. Our advertising may have been most salient to those who experienced a particularly challenging menopause, although some participants reported only minor issues. Given the suggested lack of menopausal awareness in our participants, it is also likely that some autistic people did not recognize their eligibility for the study. We avoided screening by common non-autistic menopausal symptoms, but no 'symptom-checker' (as requested by P15) is yet available for autistic people.

Additional methodological limitations exist in the possibility of recall bias (Taffe & Dennerstein, 2000) in some participants who had experienced their last period up to 21 years ago. Although previous research has found data quality comparable across in-person and online interviews (Abrams, Wang, Song, & Galindo-Gonzalez, 2015), it is possible that differences in the type and depth of responses were introduced through varying interview modes. Our methods were designed with participant comfort as first priority, so future research may corroborate our findings with stricter methodological control.

Conclusions

Menopausal experiences reported by participants varied greatly, but suggest that some autistic people will experience major deterioration in everyday function, communicative ability, extant relationships, emotion regulation, and mental health. Menopausal awareness was similarly variable but often poor, and inadequate support was apparent in the lived experiences of many participants. Whilst many of the themes and issues discussed may also be seen in the non-autistic population, there appears to be a particular impact of menopause on autistic people, and additional menopausal difficulties specifically related to autism. As menopause may be a crisis point for some autistic people, it is vital that future research works with the autistic community to understand, ameliorate, and increase visibility of the threat it may pose to health and well-being.

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Author contributions

Rachel Moseley: Conceptualization; Data curation; Formal analysis; Investigation; Methodology; Project administration; Supervision; Writing – original draft; Writing – review & editing. Tanya Druce: Conceptualization; Data curation; Formal analysis; Methodology; Writing – original draft. Julie Marie Turner-Cobb, Ph.D.: Conceptualization; Data curation; Formal analysis; Investigation; Methodology; Supervision; Writing – original draft; Writing – review & editing.

Conflicts of interest

All authors declare no conflict of interest.

Data availability statement

The terms of our ethical agreement with participants prevent us sharing the full interviews. However, participant approach, demographic information, interview script and reflexive considerations are provided in Supporting Information online.

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Supporting Information

The following supporting information may be found in the online edition of the article:

Supporting information item1: Participant approach and demographic information

Supporting information item2: Interview script

Supporting information item3: Reflexive considerations