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Menopause Representations as Predictors of Health and Well-being During Menopause: A Comparison Study of Autistic and Non-Autistic People

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Abstract

Background: Menopause can be a challenging time for health and well-being. Research suggests that autistic people may experience menopause differently than non-autistic people, although explanatory mechanisms for this are under-investigated. Using a short-term repeated measures approach over 5 consecutive weeks, we examined whether menopause representations (thoughts, beliefs, and feelings about menopause) are associated with perceived menopause symptom severity, mental health (depressive and anxiety symptoms), and quality of life in autistic and non-autistic people.

Methods: Over 5 weeks, we measured menopause representations, menopause symptom severity, quality of life, depression, and anxiety using self-report standardized scales in 476 autistic and 425 non-autistic participants aged 40–60 years. Using mediation analyses, we examined associations between menopause representations, and health and well-being outcomes (perceived menopause symptom severity, depression, anxiety, and quality of life) across all timepoints.

Results: Autistic participants reported more severe menopause symptoms, greater depression and anxiety, and poorer quality of life, across all timepoints. Sense of control and sense of coherence, two aspects of menopause representations, were significant predictors of health outcomes over time. Feeling less in control and having a less coherent understanding of menopause mediated relationships between being autistic and increased menopause symptoms, depressive and anxiety symptoms, and reduced quality of life, across all timepoints.

Conclusion: While requiring replication under more controlled conditions, our findings suggest that menopause representations may partially explain poorer health outcomes in autistic people who are peri- or postmenopausal. This partial mediation reflects that other mechanisms exist through which aspects of being autistic are associated with these poorer outcomes. Further investigation is needed to elucidate health inequalities during and after menopause, yet our findings suggest that feelings of control and coherence may be important for well-being during menopause, highlighting the importance of appropriate information and support to help autistic individuals confidently navigate this life stage.

Keywords: menopause, menopause representations, health and well-being, autism, short-term repeated measures

Community Brief

Why is this an important issue?

Menopause is a transition that the great majority of autistic people who menstruate will encounter, regardless of their gender. It often involves many symptoms and changes, though some people will experience more of these than others. Studies suggest that autistic people might experience menopause quite differently to non-autistic people, with some finding it particularly difficult. Understanding the reasons for these differences and potential difficulties is extremely valuable, as it points us toward areas we can help. Research in the general population suggests that the way people think and feel about menopause, known as menopause representations, may affect the way they experience menopause.

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What was the purpose of this study?

We examined whether perimenopausal and postmenopausal autistic individuals report poorer well-being than non-autistic comparison participants, looking at menopause symptoms, depression, anxiety, and quality of life (QoL) over 5 weeks. We then explored whether differences in menopause representations could explain possible differences in menopause symptom severity, and well-being, across autistic and non-autistic people.

What did the researchers do?

We used online questionnaires to collect data from participants across 5 weeks in a row. Participants were 476 autistic and 425 non-autistic people. We measured their menopause representations (i.e., their thoughts, beliefs, and feelings about menopause) and looked at whether these could predict menopause symptom severity, depressive and anxiety symptoms, and QoL in the weeks ahead.

What were the results of this study?

The autistic group consistently reported more severe menopause, depression and anxiety symptoms, and poorer QoL over the 5-week period. They also reported feeling less in control of their menopause and having a less coherent understanding about their menopause compared with the non-autistic group. These feelings partially explained our statistical findings of more severe menopause, depressive, and anxious symptoms in autistic than non-autistic participants, as well as poorer QoL in the former.

What is new or controversial about these findings?

There are no existing short-term repeated measures studies comparing menopause experiences in autistic and non-autistic people. Ours is also the first study to test this possible explanation for why autistic people may experience more severe menopause symptoms, as well as poorer well-being in midlife (ages 40–60).

What are potential weaknesses in this study?

Our autistic sample is not representative of all autistic people. We relied on self-reported data over a short time period and could not confirm the menopausal stage and autism diagnoses of participants. Our analyses did not include other factors that might explain more severe menopause symptoms and poorer well-being in autistic people.

How will these findings help autistic adults now or in the future?

We found that compared with non-autistic people, autistic participants consistently reported feeling less in control of their menopause and having a less clear understanding about their menopause. This contributed to their poorer health and well-being. While further research is needed, these findings highlight a need for tailored, autism-specific information, support, and resources in social and health care settings to help autistic people feel prepared and confident before and during menopause.

Background

Menopause[1] is the hormonal shift from a reproductive to nonreproductive state, which typically affects people assigned female at birth (AFAB), and some intersex individuals, in their mid to late forties.[1,2] Although menopause is, as a reproductive transition, characterized by the cessation of menses, its symptoms are by nature largely neurological, with far-reaching impacts on cognition, emotion and perception,[3] alongside physical manifestations, such as joint pain and musculoskeletal discomfort.[4,5] There is increasing evidence that autistic people experience menopause differently to non-autistic people. Qualitative studies suggest they might struggle with its unpredictable nature and can find that menopause amplifies sensory sensitivities, emotions, and challenges with executive function.[6–11] As a broad population, autistic people are already subject to inequalities in quality of life (QoL) and health, including reduced life expectancy and heightened suicide risk.[12–16] This is highly significant in a menopause context because menopause can exacerbate preexisting mental and physical health conditions,[17–19] and has significant consequences for health and even mortality in later years.[20] We do not know the extent to which menopause experiences contribute to heightened morbidity and mortality in AFAB autistic people,[16,21] but studies suggest that autistic people are inadequately supported during menopause, and many suffer significant deterioration in their health and well-being.

[1]Complying with typical British vernacular, we use 'menopause' or 'the menopausal transition' to refer to this entire transition stage. It encompasses *perimenopause* (the symptomatic time prior to the complete cessation of periods) as well as 'reaching' or 'passing through' menopause (having had 12 consecutive months without a period), after which individuals are considered *post-menopausal.*

There are presently few large-scale comparisons of menopause experiences between autistic and non-autistic people: research is largely qualitative,[7,8,22,23] with existing quantitative research limited by relatively small samples[24,25] or the absence of non-autistic comparison groups. While these studies have highlighted possible factors that might explain greater difficulties during menopause in autistic people, none have systematically examined predictive associations over time. Understanding the mechanistic pathways explaining differences between autistic and non-autistic people is essential for revealing pathways to support.

One such mechanism may be differences in the way autistic people think and feel about menopause and menopause symptoms. Menopause representations are mental models, i.e., thoughts and beliefs (such as the extent to which a person can control their symptoms), and emotions about menopause (such as anxiety about its repercussions), which affect the way people manage the experience and health issues related to menopause.[26] The concept originally derives from the Self-Regulation Model of illness,[27] which posits that people develop cognitive models of illness through first- and second-hand experience and information gleaned from external sources,[28,29] and that these affect coping and experience. These cognitive representations include individual's thoughts and beliefs about the identity or labeling of symptoms, causes, timeline, consequences, and controllability of a health condition[27]; subsequent literature added an emotional aspect of illness representations affecting a person's responses toward their condition, the coping procedures and subsequent health outcomes, such as anger and worry.[30] Applying this framework to menopause, previous research has demonstrated the relevance of cognitive and emotional representations of menopause to the way in which people experience and cope with menopause symptoms.[26,29,31] For instance, people who perceive themselves to have control over menopausal symptoms (a cognitive representation) are more likely to view menopause as a positive change, and are less likely to endorse symptoms of depression as well as negative emotional representations of menopause.[26,31] Vitally, this is not intended to delegitimize the experience of physical symptoms but to understand cognitive and emotional influences on health alongside other relevant factors. Similarly, the relevance of menopause representations to the experience of menopause symptoms in no way disputes the reality and well-established biological cause of said symptoms,[3] or suggests that individuals are responsible for how they experience and manage them. Rather, understanding bi-directional interactions between thoughts and experiences may open additional avenues to intervene. Indeed, on the strength of studies demonstrating associations between cognitive and emotional menopause representations, and perceived menopause symptom severity, alongside broader health and well-being,[26,31] academics highlight the importance of menopause knowledge, feelings of self-efficacy, and empowerment during this life stage.[32,33]

Autistic people form mental models, throughout their lives, on topics as diverse as how friendships work and gendered expectations. We would similarly expect them to have mental models of menopause, and research indicates that these might differ from those of non-autistic people. Autistic people surveyed and interviewed about menopause frequently expressed feeling unprepared, confused, frightened, and less in control.[6,22] Some linked this to lacking supportive relationships or trusted health care practitioners that they could speak to, others to the inaccessibility and unrelatability of publicly available menopause information.[8,22] These difficulties will be shared by many autistic people, given increasing isolation with age,[34,35] and the pervasiveness of accessibility and communication barriers in healthcare settings.[36–38] Autistic menopause may involve less common menopause symptoms (e.g., chronic illness flare-ups) and amplification of autistic/ADHD features,[8,22] which alongside potential difficulties identifying internal states and emotions, may make it difficult to identify that menopause is occurring. These and other common aspects and experiences of being autistic, from intolerance of uncertainty to reduced access to social support, may cast thoughts and feelings about menopause and the individual's own coping ability in a more negative light.

Menopause representations might be one mechanism, among others, through which such factors and experiences common to autistic people are associated with difficulties during the menopausal period. Associations between menopause representations, menopause symptom severity, health, and well-being have not been explored in autistic people, much less via short-term repeated measures designs, which allow more confident conclusions about the associations between variables. Toward identifying possible predictive associations between menopause representations, menopause symptom severity, and health and well-being outcomes, our study had three specific aims: firstly, to compare differences and fluctuations in self-reported menopause symptom severity, menopause representations, and well-being outcomes over 5 weeks in a large autistic and non-autistic sample. Secondly, to explore whether different aspects of menopause representations might influence the severity of menopause symptoms, as one explanation for the association between being autistic and experiencing more severe symptoms. Thirdly, to examine whether menopause representations and symptom severity consistently mediate well-being outcomes (depression, anxiety, and QoL) in autistic and non-autistic individuals using a short-term repeated measures approach. While predicting greater depressive and anxiety symptoms and poorer QoL across timepoints in autistic participants, our analysis was exploratory with regard to the profile of menopause representations in autistic people and which, if any, aspects of menopause representations might be especially associated with menopause symptoms and broader well-being.

Methods

Participants

We recruited 901 autistic (n = 476) and non-autistic (n = 425) participants via social media platforms of organizations related to menopause or autism, social media groups run by and for autistic people, and networks of Bournemouth University (see Supplementary Data S1 for data cleaning). Eligible participants were English speakers of any gender, aged between 40 and 60 years, who self-reported as being either perimenopausal or postmenopausal.

Because many older AFAB autistic people are undiagnosed,[21] we included both formally diagnosed ($n = 161$) and possibly autistic[2] participants ($n = 315$) in our autistic group. Diagnosed and possibly autistic participants did not differ significantly in menopause symptom severity, depression, anxiety, and QoL. By screening possibly autistic and non-autistic participants using the AQ-10,[39] we confirmed that possibly autistic participants reported a significantly higher level of autistic traits than non-autistic participants ($p < 0.001$). We did not ask self-reported diagnosed autistic participants to complete this measure in order to reduce participant burden (Supplementary Data S2).

Measures and procedure

Prior to data collection, an autistic advisory panel (now authors R.C.S. and D.D.W. and a third member who preferred to be anonymous) reviewed all materials for acceptability and appropriateness. We obtained ethical approval from Bournemouth University Research Ethics Committee (Ethics ID: 52659). Once they provided informed consent, we gave all participants the opportunity to complete an initial (T1) online self-report questionnaire and questionnaires at four follow-up timepoints (T2–T5) at weekly intervals. To complete the four follow-ups, we helped interested participants to create unique codes at T1, to enter and link their data across timepoints. We signposted relevant menopause, neurodiversity, and mental health support on each information and debrief sheet.

Figure 1 presents questions and measures completed for initial assessment and subsequent follow-ups in order of completion in schematic form. Internal consistencies for standardized scales were good to excellent ($\alpha > 0.8$) in both groups at all timepoints, unless otherwise stated (Supplementary Data S3). Additional measures of intrapersonal and interpersonal factors collected at T1 are reported elsewhere.

Initial assessment (T1). ***Sociodemographic and health-related information.*** Participants provided their age, ethnicity, gender identity, employment status, and highest educational attainment. We also asked participants to self-report information about their menopausal stage (perimenopausal/postmenopausal) and type (entered menopause naturally or through medical intervention), autism diagnostic status (formally diagnosed/self-identifying/awaiting assessment/not completely sure if autistic or not/not autistic to the best of their knowledge), and health behaviors (e.g., smoking frequency). From these questions, we operationalized menopausal stage as a moderator in our analyses and several covariates, which, affecting menopause experience, might give rise to differences between participant groups: age, BMI (body mass index), physical activity, smoking frequency, drinking behaviors, employment status, and education level (Supplementary Data S4).

[2]The possibly autistic group included participants who self-identified as autistic; those who were awaiting assessment; and those who said they were not completely sure if they were autistic or not. Participants could endorse all of these statements.

Menopause-related measures. There are presently no menopause-related measures validated in autistic people. We adopted the below measures, standardized in the general population, for comparability with previous literature.

Menopause symptom severity. Participants self-reported the severity of their menopause symptoms over the past week using 20 items from the Identity subscale of menopause representations questionnaire (MRQ)[26] and five additional symptoms (palpitations, concentration problems, bladder problems, irritability, muscle pains) from the Menopause Rating Scale (MRS).[40] Instead of the original scoring system of the MRQ, which asks about the presence of symptoms, we adapted the response scale from the Menopause-Specific Quality of Life[41] in order to measure how bothersome the menopause symptoms were in the past week. This 5-point Likert scale ranged from Not at all (1) to Almost always (5), with higher scores demonstrating greater symptom severity. In the majority of analyses, we used total symptom severity as calculated from these 25 items, but we also identified it in relation to four different types of symptoms: physical, psychological, genitourinary, and vasomotor symptoms (Supplementary Data S5).

Menopause representations. We used primarily the MRQ,[26] but added items from the revised Illness Representations Questionnaire (IPQ-R),[30] MenoSensations-Q,[42] and MRS to more comprehensively measure aspects of menopause representations not included in the MRQ, changing items to replace "illness" with "menopause" where necessary. The seven broad facets of menopause representations are listed below: they yielded scores for 12 subscales, where (except Identity) items were scored on a 5-point Likert scale from Strongly disagree (1) to Strongly agree (5).

i. Identity (25 items) measures the extent to which participants identify a number of symptoms as part of their menopause. We adopted the identical list of symptoms used for measuring menopause symptom severity, asking participants to indicate whether these symptoms were part of their menopause. We scored items from No (0), Uncertain (1), and Yes (2), with higher scores indicating a greater number of symptoms that participants experienced.
ii. Consequences (10 items) examines how participants perceived the consequences of menopause on their health, well-being, social functioning/relationships, and life more broadly. It comprises three subscales of the MRQ measuring the extent to which participants felt negatively impacted by menopause in the areas above (Impact), experienced menopause as a relief (Relief), and felt positive about moving into a "new phase of life" (New phase). In each, higher scores indicate greater endorsement of that sentiment. While internal consistency for Impact and New phase was acceptable, Relief showed relatively poor Cronbach's alpha ($\alpha = 0.51$ for autistic, 0.45 for non-autistic).
iii. Timeline (6 items) consists of two subscales measuring how long participants felt their menopause and its symptoms would last (acute/chronic) and how changeable the symptoms were (cyclical). Higher scores indicate that participants perceived their menopause as lasting longer and being more unpredictable. We adopted these subscales from the IPQ-R.

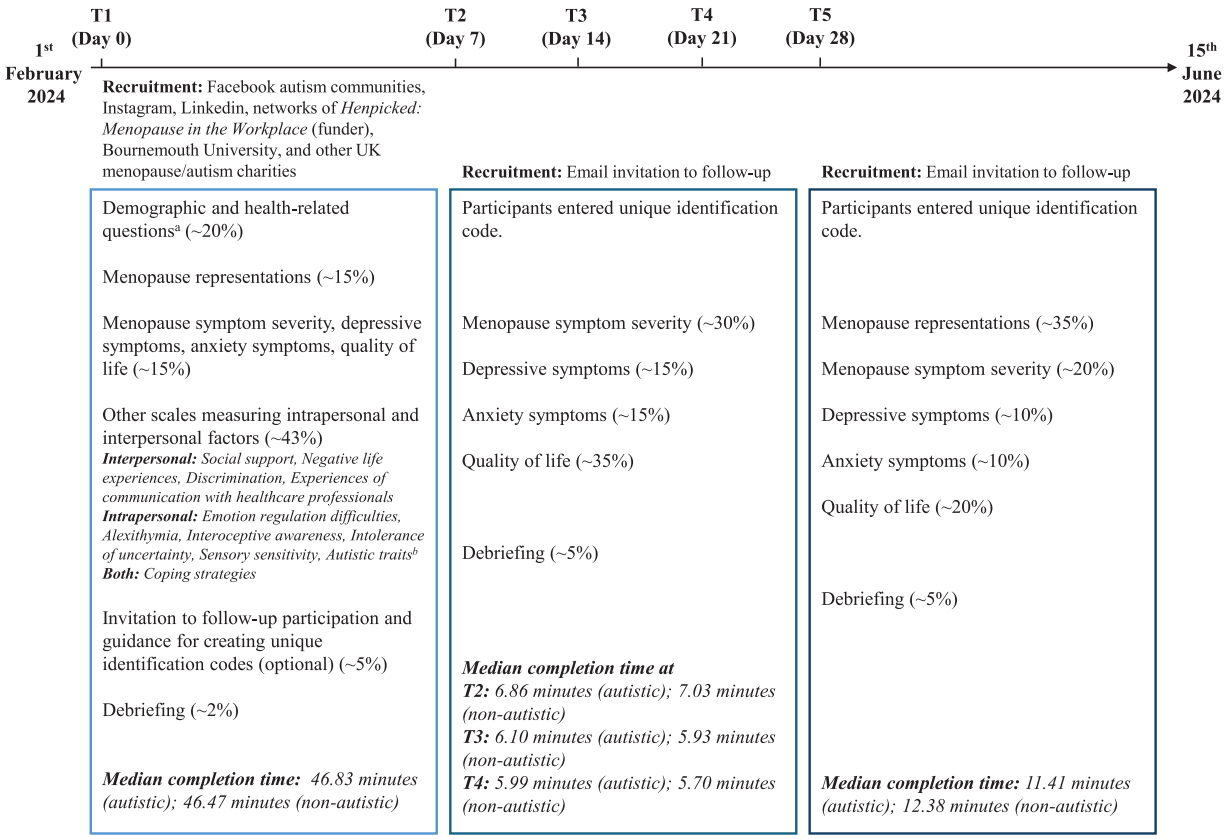


FIG. 1. Timeline of participation with scales used at each timepoint. Notes: [a]Information about health behaviors, autism diagnosis, physical/mental health conditions, and menopause-related questions (i.e., menopausal stage, natural vs medical menopause, last menstrual period); [b]Used AQ-10 for only possibly autistic and non-autistic participants to complete; both = factor that is intertwined with both intrapersonal and interpersonal aspects.

iv. Control (9 items) measures the extent to which participants believed or felt they could control their menopause symptoms personally or through professional intervention. Higher scores indicate that participants felt they had less personal capacity and fewer appropriate professional resources to manage their menopause.
v. Coherence (3 items) assesses participants' metacognitive understanding of their menopause, reflecting how clearly they perceive and comprehend it and its symptoms (e.g. "My menopause symptoms do not make any sense to me"). Higher scores indicate that participants had a less coherent understanding of their menopause. We added this subscale from the IPQ-R.
vi. Emotional representations (6 items) measures six emotional responses (upset, fearful, depressed, angry, afraid, worried) generated by their menopause. Higher scores indicate greater endorsement of those emotional responses toward menopause. We added this subscale from the IPQ-R.
vii. Causes (15 items) examines participant perceptions of factors that might influence their menopause symptom severity. It comprises three subscales measuring the extent to which participants: attributed symptom severity to their "mental attitude," including personality and work/life balance (Psychological attributions); attributed symptom severity to factors associated with health, like genetic vulnerability (Risk factors); and attributed symptom severity to other possible causes (e.g. chance or luck). Having these subscales derived from the IPQ-R, where items focus on the illness context, we excluded items less relevant to menopause such as "accident". Although the original IPQ-R did not comprise Other possible causes, we created it as a subscale that includes items that are not suitable for the other two subscales but still potentially relevant to menopause. Though internal consistency for Psychological attributions was very good ($\alpha = 0.86$) in both autistic and non-autistic groups, it was poor to acceptable ($\alpha = 0.34$–0.66) for Risk factors and Other possible causes.

Well-being outcomes. We used three scales demonstrated to have good psychometric properties in autistic as well as non-autistic people.[43–49]

Quality of life. A brief 26-item version of the World Health Organization Quality of Life (WHOQOL-BREF)[50] measures QoL over the past 2 weeks. We scored items on a 5-point Likert scale, scores ranging from 26 to 130. Higher scores indicate greater perceived QoL.

Depressive symptoms. The Patient Health Questionnaire-9 (PHQ-9)[51] measures depressive symptoms over the past 2 weeks. We scored the items on a 4-point Likert scale from Not at all (0) to Nearly every day (3). Scores of 10> are the clinical cut-off for moderate depressive symptoms.

Anxiety symptoms. The Generalized Anxiety Disorder-7 (GAD-7)[49] measures anxiety symptoms over the past 2 weeks. We scored items on a 4-point Likert scale from Not at all (0) to Nearly every day (3). Scores of 10> are the clinical cut-off for moderate anxiety symptoms.

Follow-up assessments (T2–T4). We sent the follow-up questionnaires to participants every 7 days after the completion of T1. These contained only measures of menopause symptom severity, depressive and anxiety symptoms, and QoL over the past week (i.e., a modification from the typical 2-week response period of the three latter scales). We requested that participants complete them within 2 days of receipt: on average, of participants who completed the follow-ups, 70% completed on the same day, and 18% finished within 2 days at each follow-up. The remaining 12% was completed within 7 days.

Final assessment (T5). We emailed participants 28 days after completion of T1 with the final assessment, containing measures of menopause symptom severity, depressive and anxiety symptoms, and QoL for the past week. We also asked participants to complete our adapted measure of menopause representations again in order to check their stability; we omitted this from earlier follow-ups to reduce participant burden, given that these were not expected to fluctuate rapidly over the 5-week period. On average, 70% of participants completed on the same day of receiving it, and 15% finished within 2 days. The remaining 15% completed within 7 days.

Data analysis

Prior to conducting inferential analyses, we removed responses with missing data for each timepoint on key variables relating to autistic status, menopause stage and type, menopause symptom severity, and menopause representations (Supplementary Data S1). We ensured independence of the predictor and parallel mediators to one another (all VIF [Variance Inflation Factor] < 3) and subsequently examined the distribution of scores and correlations between all variables.

To meet our three aims and test our hypotheses where relevant, we implemented a three-part analysis, using SPSS (version 28). In the analyses that follow, wherever feasible, we included in our analyses participants who only completed T1 or who missed one or more follow-up timepoints in analyses; we point out below where we used data from only certain timepoints (see Supplementary Data S6 for the characteristics of participants who stayed and withdrew).

Part 1: Comparisons of autistic and non-autistic participants over time. Our first analyses aimed to compare autistic and non-autistic participants in their total scores for menopause representations, menopause symptom severity, and well-being outcomes over the 5-week period and, moreover, to examine group differences in the extent that variables fluctuated over this period. We ran nine one-way ANOVA analyses (corrected alpha levels to $p = 0.006$) to examine differences in the nine menopause representations subscales between autistic and non-autistic participants at T1 and T5; we excluded three causes subscales as their internal consistency was relatively poor. Subsequently, we ran four analyses (corrected to $p = 0.013$) to compare scores related to menopause representations, menopause symptom severity, depressive and anxiety symptoms, and QoL between the groups across all five timepoints. We separately examined group differences in the four types of menopause symptoms at each timepoint to compare the overall severity of each symptom type between the two groups and observe fluctuations of symptom severity across timepoints.

In the second batch of analyses related to this aim, we examined if groups differed in the extent that variables fluctuated over time. We conducted four mixed ANOVAs (with levels Time [5] and Group [2]; corrected alpha levels to $p = 0.013$) to assess variability of menopause, depressive and anxiety symptoms, and QoL across three timepoints (T1, T3, and T5: timepoints chosen to maximize participant retention where analyses used listwise deletion). Since all outcome variables violated the assumption of sphericity, we reported Huynh-Feldt corrected values. Homoscedasticity identified on the menopause, depressive, and anxiety symptom variables indicated use of Pillai's Trace corrected values.

Part 2: Menopause representations as a mediator of menopause symptom severity. Toward our second aim of examining different aspects of menopause representations as one explanatory mechanism for menopause symptom severity, we used PROCESS for SPSS.[52] Using T1 data, we applied moderated mediation analysis (Model 59) to examine the effect of autistic status on menopause symptom severity via the 12 constructs of menopause representations as mediators. We modeled menopausal stage as a moderator on all pathways. As PROCESS is limited to six parallel mediators, with two analyses, we corrected alpha levels to $p = 0.025$. Where any menopause representations subscales showed significant indirect effects, we replicated these analyses controlling for the aforementioned covariates. Subsequently, we retained these subscales for the next part of our analyses.

Part 3: Menopause representations and symptom severity as mediators of broader well-being outcomes over time. Our third goal was to examine the relevance of menopause representations and menopause symptom severity to well-being outcomes, namely depressive and anxiety symptoms, and QoL. Initially, we used PROCESS Model 92, and T1 data, to conduct moderated serial mediation analyses with any subscales of menopause representations identified as significant in Part 2. We examined whether these subscales (Mediator 1) mediated the relationship between autistic status and each of our outcome variables, either directly or sequentially via their effect on menopause symptom severity (Mediator 2). In each analysis, we also examined the effect of menopausal stage as the moderator on these relationships. As these analyses were informed by Part 2, we applied statistical correction as appropriate when the number of analyses became clear, and replicated these analyses with the inclusion of covariates.

Finally, we repeated these analyses with menopause symptom severity and outcome variables from T3 and then from T5. Using the same moderated serial mediation model with menopausal stage as the moderator, we first used the subscales of menopause representations collected at T1 with menopause symptom severity and the three outcome variables collected at T3. We then repeated this analysis swapping T3 data for T5

data. As above, we applied statistical correction as appropriate and replicated analyses with the inclusion of covariates.

Results

Participant characteristics

The sociodemographic information of our majority White British sample, who had mostly gone through natural menopause (85%), is displayed in Table 1 (see Supplementary Data S7 for additional detail).

Part 1: Group comparisons of menopause representations, menopause symptoms, and well-being outcomes across autistic and non-autistic participants over time

Total scores in these variables are shown in Supplementary Data S8. The autistic group reported feeling significantly less in control and had a less coherent understanding about menopause, as well as more severe menopause symptoms, depressive and anxiety symptoms, and lower QoL than the non-autistic group across all five timepoints (Fig. 2). Out of four types of menopause symptoms, only psychological symptoms showed consistently significant group differences across timepoints (adjusted $p = 0.005$); breaking down this analysis by menopausal stage, autistic participants showed more severe psychological symptoms at both peri- and postmenopausal stages than did non-autistic participants. Vasomotor, physical, and genitourinary symptoms did not consistently show significant group differences across timepoints, albeit perimenopausal autistic participants showed significantly greater levels of physical and genitourinary symptoms at T1 and T2 (see Supplementary Data S8 for full details with more detailed breakdowns of participant groups by menopausal stage).

Our mixed ANOVA analyses indicated, with within-subjects effects, that menopause, depressive, and anxiety symptoms significantly fluctuated for all participants over time, but the absence of any Time*Autistic status interactions suggested autistic participants did not experience greater fluctuations over time than non-autistic people in any of the outcome variables. However, the between-subjects effects corroborated that, across all timepoints, autistic participants reported significantly more severe menopause, depressive and anxiety symptoms, and poorer QoL than non-autistic participants (Supplementary Data S9).

Part 2: Mediation effects of menopause representations on relationship between autistic status and menopause symptom severity

Only Control ($b = 3.29$, CI = 2.02, 4.73) and Coherence ($b = 1.51$, CI = 0.70, 2.54) partially mediated the relationship between being autistic and experiencing more severe menopause symptoms (Table 2; Supplementary Data S10, for full details) and were henceforth retained for subsequent analyses. Although identity, consequences (New phase), emotional representations, and causes (Psychological attributions) were associated with menopause symptom severity, they did not significantly mediate the association between autistic status and symptom severity. Partial mediation effects of control and coherence, however, remained once covariates were controlled for (Supplementary Data S11).

A significant main effect of menopausal stage on Control became nonsignificant after statistical correction. However, the model predicting menopause symptom severity ($F(3,834) = 13.14$, $p < 0.001$) indicated that being perimenopausal significantly strengthened the association between being autistic and more severe menopause symptoms via feeling less in control. Menopausal stage did not predict coherence or moderate its relationships with menopause symptom severity.

Part 3: Mediation effects of menopause representations and menopause symptom severity on relationships between autistic status, depressive, and anxiety symptoms, and QoL over time

Only Control and Coherence were taken forward into subsequent analyses; as such, with 6 analyses (for each of the

Table 1. Participant Characteristics and Scores on Menopause Representations by Autistic, Non-Autistic, and Total Groups

Participant characteristics	*Autistic* (n = *476*)	*Non-autistic* (n = *425*)	*Total* (N = *901*)
Age M (SD)	50.6 (4.9)*	51.8 (4.7)*	51.2 (4.82)
Age (years) at diagnosis (formally-diagnosed autistic participants)	46.5 (7.3)		
Gender identity *n (%)*			
Female	458 (96.2%)	423 (99.5%)	881 (97.8%)
Other	18 (3.8%)	2 (0.5%)	20 (2.2%)
Employment status *n (%)*			
Employed	368 (77.3%)	383 (90.1%)	751 (83.4%)
Unemployed	17 (3.6%)	5 (1.2%)	22 (2.4%)
Other [a]	89 (18.7%)	36 (8.5%)	125 (13.9%)
Education level *n (%)*			
Below undergraduate degree	121 (25.4%)	175 (41.2%)	296 (32.9%)
Undergraduate or above	350 (73.6%)	244 (57.4%)	594 (65.9%)
Menopausal stage *n (%)*			
Perimenopausal	269 (56.5%)	206 (48.5%)	475 (52.7%)
Postmenopausal	183 (38.4%)	183 (43.1%)	366 (40.6%)
Don't know/not sure	24 (5%)	36 (8.5%)	60 (6.7%)

Notes: * $p < 0.05$ in group difference.
[a]Includes "Student," "Retired," "Receiving benefits," "Voluntary roles," and "Engaged in one or more unpaid roles."

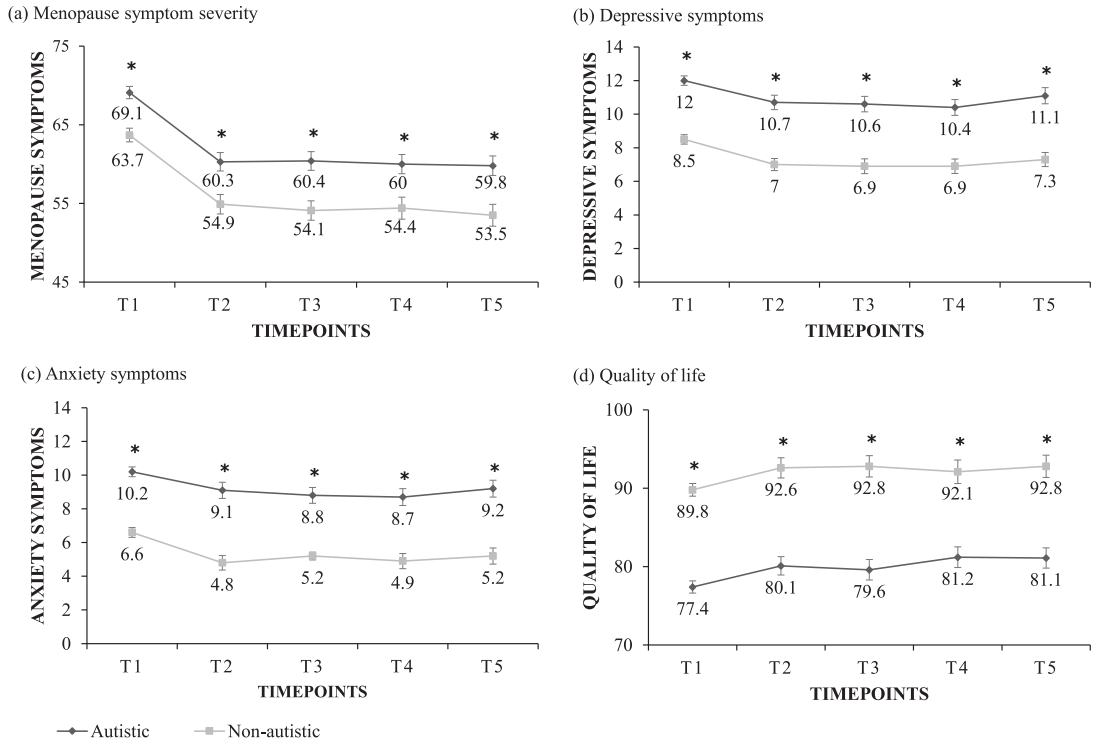


FIG. 2. Average scores for **(a)** menopause symptom severity, **(b)** depressive symptoms, **(c)** anxiety symptoms, and **(d)** quality of life in the autistic and non-autistic groups at five timepoints. Notes: $*p = 0.013$ in group difference at each timepoint. Higher scores in menopause, depressive, and anxiety symptoms indicate greater symptom severity, whereas higher QoL scores indicate better perceived QoL.

three outcome variables, for both Control and Coherence), alpha levels were corrected to $p = 0.008$. Indirect effects of the two mediators independently indicated that feeling less in control and less coherence about menopause each partially mediated relationships between being autistic and experiencing higher levels of depressive and anxiety symptoms and lower QoL at T1 (Supplementary Data S12). Statistical notations for the analysis with QoL are displayed in Figure 3. While both mediators predicted these outcome variables independently, they also exerted effects sequentially through the second mediator, menopause symptom severity, where more severe symptoms were associated with more severe depressive and anxiety symptoms and lower QoL. These effects remained after controlling for covariates (Supplementary Data S13). There were no significant moderating effects of menopausal stage on any of the relationships between variables, though perimenopausal status predicted greater depression (Supplementary Data S12).

With 12 analyses examining the consistency of serial mediation effects of control and coherence via menopause symptom severity on our three health and well-being outcomes at T3 and T5, we corrected alpha levels to $p = 0.004$. At this corrected threshold, as hypothesized, indirect effects of control and coherence significantly mediated the relationships between being autistic and having more severe depressive and anxiety symptoms and poorer QoL at T3 and T5 (Supplementary Data S14), essentially showing that the relationships depicted in Figure 3 were consistent at T3 and T5. That autistic people felt less in control and had a less coherent understanding of their menopause at T1, directly predicted their having greater depressive symptoms, anxiety symptoms, and lower QoL than non-autistic people at T3 and T5. These aspects of menopause representations also predicted scores in these outcomes sequentially via their association with menopause symptom severity, which was greater at lower levels of control and coherence. Menopausal stage did not consistently moderate the main relationships across timepoints; nor did replication with covariates affect these mediation effects (Supplementary Data S15).

Discussion

We compared the severity of menopause symptoms and other health and well-being variables in autistic and non-autistic people over time. As hypothesized, autistic individuals consistently reported more severe menopause, depressive and anxiety symptoms, and lower QoL, than non-autistic individuals. Aiming to understand the possible mechanisms of this disparity, we then examined varied menopause representation constructs as mediators of the relationship between being autistic and experiencing more severe menopause symptoms. We identified two facets that mediated this relationship: the extent to which participants felt in control of their menopause and the coherence of their meta-cognitive understanding of their menopause. Finally, we investigated whether these facets of menopause representations and menopause symptom severity consistently impacted other health and well-being outcomes in autistic and non-autistic people. As expected, feeling less in control and having a less coherent understanding of menopause mediated the association between autistic status and poorer health and well-being over time. We observed an additional indirect impact on these outcomes via menopause symptom severity as a sequential predictor.

Table 2. Simple Moderated Mediation Models Demonstrating Relations Between Menopause Representations (Control, Coherence), Autistic Status, and Menopause Symptom Severity

	Relationship to control (mediator)			*Relationship to coherence (mediator)*		
	b	*t*	*p*	*b*	*t*	*p*
Autistic status	**3.15**	**5.94**	**<0.001**	**1.10**	**3.99**	**<0.001**
Menopausal stage (moderator)	1.30	2.25	0.03	–0.03	–0.09	0.93
Interaction: status*stage	**–1.94**	**–2.44**	**0.02**	–0.66	–1.58	0.11
Model	**R^2 = 0.05, F(3,834) = 13.14,** $p < 0.001$			**R^2 = 0.16, F(3,837) = 7.59,** $p < 0.001$		

	Relationship to menopause symptom severity (outcome)		
	b	*t*	*p*
Autistic status (path c')	**3.87**	**2.89**	**0.004**
Control	**1.05**	**7.65**	**<0.001**
Coherence	**1.36**	**5.04**	**<0.001**
Menopausal stage (moderator)	–5.88	–0.83	0.41
Interaction: status*stage	–0.30	–0.15	0.88
Interaction: control*stage	–0.14	–0.71	0.48
Interaction: coherence*stage	0.05	0.11	0.91
Model	**R^2 = 0.42, F(17,820) = 34.91,** $p < 0.001$		

Conditional direct effects of autistic status on menopause symptom severity by menopausal stage

	b	*t*	*p*	*LLCI*	*ULCI*
Perimenopausal	**3.87**	**2.89**	**0.004**	**1.24**	**6.50**
Postmenopausal	**3.57**	**2.48**	**0.01**	**0.74**	**6.40**

Conditional indirect effects of autistic status on menopause symptom severity by menopausal stage

	b	*LL (95%) CI*	*UL (95%) CI*
Control			
Perimenopausal	**3.29**	**2.02**	**4.73**
Postmenopausal	1.09	–0.09	2.32
Coherence			
Perimenopausal	**1.51**	**0.70**	**2.54**
Postmenopausal	0.81	–0.31	2.02

Index of moderated mediation

	b	*LL (95%) CI*	*UL (95%) CI*
Menopausal stage	**–2.20**	**–4.06**	**–0.46**

Table displays mediation effects of Control and Coherence only. Significant main and mediation effects are displayed in bold at a corrected alpha level of $p = 0.025$. Lower limit confidence intervals (LLCI) and upper limit confidence intervals (ULCI) are displayed.

Poorer health and well-being among autistic people at midlife

While there are few sizeable quantitative comparison studies of autistic and non-autistic people at midlife, our findings corroborated previous observations of more severe menopause symptoms,[24,25] poorer mental health,[53,54] and lower QoL in autistic individuals,[14,55] all of which demonstrated persistence and stability over time. Notably, we also observed a preponderance of physical health conditions reported by autistic participants compared with non-autistic participants at baseline (Supplementary Data S7), corroborating findings that autistic people, including AFAB individuals, have poorer physical and mental health than non-autistic people in midlife.[13,56,57]

As pertains to specific types of menopause symptoms, we found that autistic people consistently reported more severe psychological symptoms, which aligned with previous research documenting that autistic people are likely to experience greater psychological symptom burden.[24,25] While significant differences in vasomotor symptoms (e.g., hot flushes) were consistently absent, as in other studies, differences in physical and genitourinary symptoms between autistic and non-autistic people were inconsistent, and where they appeared, they were driven by participants who were perimenopausal. These studies did report significant differences in physical and genitourinary symptoms between autistic and non-autistic people, but only at a single timepoint.

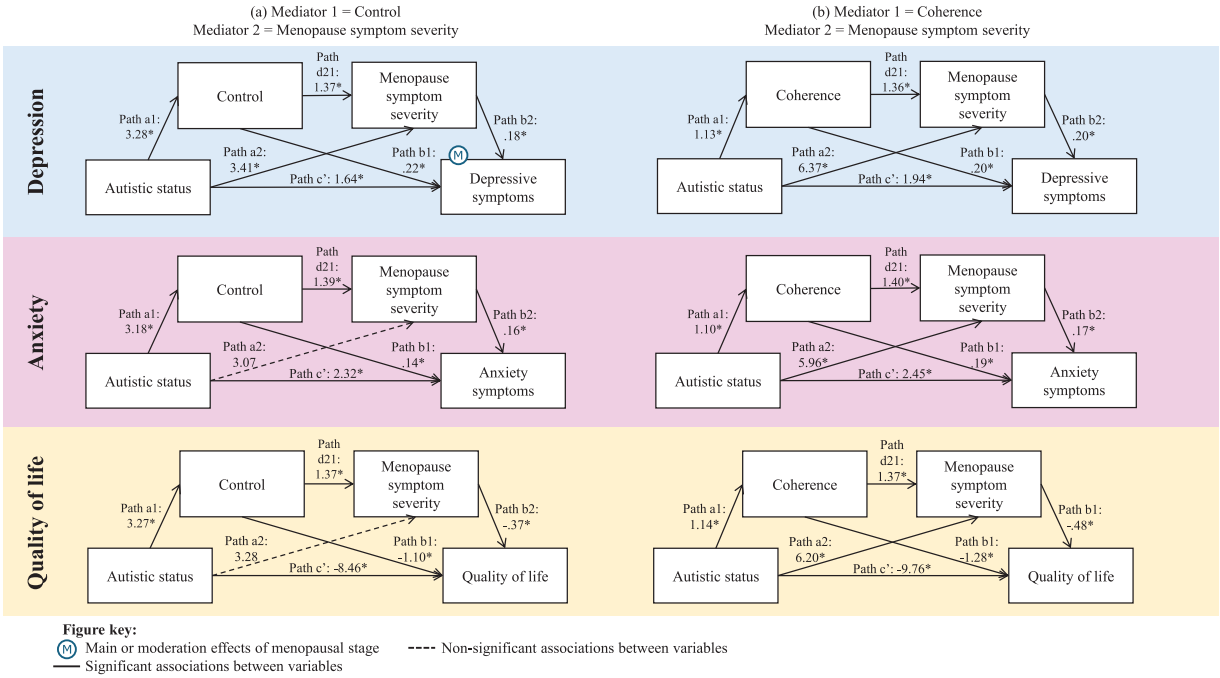


FIG. 3. Serial mediation effects of **(a)** control or **(b)** coherence and menopause symptom severity on relationships between autistic status and depressive symptoms, anxiety symptoms, and quality of life. Notes: Significant direct and indirect effects are marked with asterisks; main or moderation effects of menopausal stage were displayed with an "M" mark where significant at a corrected alpha level of $p = 0.008$.

Cross-study comparisons are complicated by variation in the operationalization of menopause symptoms. We included in our physical domain both somatic symptoms (e.g., joint pains) and broader physical symptoms (e.g., sleep problems), although studies that reported significant differences between autistic and non-autistic people focused specifically on somatic symptoms,[24,25] where differences might indeed be expected due to the prevalence of chronic pain and hypermobility spectrum conditions.[58,59] Another reason for inconsistent findings across studies may lie in imprecise identification and operationalization of menopausal stage (see Limitations section). While our findings support qualitative research and grey literature[8,22,23,60] with regard to intensity of psychological symptoms for neurodivergent people, it is still possible that other specific symptoms are more severe in autistic than non-autistic people and fluctuate more over longer timeframes.

Menopause representations mediate more severe menopause symptoms and poorer health and well-being in autistic people

While menopause is not an illness, the impact of menopause representations on expectations and experience of menopause symptoms[26,29,31,61] is conceptually consistent with a robust body of work demonstrating meaningful impacts of mental models of illness upon the ways that people experience and cope with symptoms.[27,28,30] While not disputing that menopause symptoms indubitably also affect people's thoughts and feelings about menopause (i.e., their menopause representations), the nature of a two-way relationship between menopause representations and symptoms enables possible interventions[37,62,63] helping people to feel a greater sense of control and understanding of their menopause.[32,33] Prior literature is suggestive of possible differences in the menopause representations of autistic people, who report feeling unprepared for varied, atypical, and unexpectedly intense symptoms, which they struggle to identify as menopause-related. They report feelings of "losing control" and finding their efforts at symptom management insufficient.[6,8,22,64] Autistic and non-autistic participants did significantly differ in sense of control and coherence of menopause. Moreover, our short-term repeated measures findings suggest consistent and predictive relationships between these facets of menopause representations and links to the more severe menopause symptoms that we and others observed in autistic people.[6,11,23–25] Sense of control and coherence also partially mediated more severe depressive and anxiety symptoms, and poorer QoL over time, both directly and via their effects on menopause symptom severity. While this mechanistic pathway and the longer-term interplay between menopause representations and symptoms require further investigation in more rigorously controlled longitudinal designs, these preliminary findings suggest the relevance of these two constructs, and indeed of menopause symptom severity, to a broader range of health and well-being inequities in autistic individuals at midlife.

To understand reduced sense of control and coherence in autistic as compared with non-autistic people, we might consider intrapersonal and interpersonal-environmental sources of vulnerability or inequity. Core characteristics of being autistic, such as preference for sameness, intolerance of uncertainty, and sensory sensitivities, might increase distress and feelings of powerlessness in relation to the sudden, unpredictable symptoms and bodily changes of menopause, especially if individuals are unaware of their autism.[6–8,31,65] Other common autistic characteristics, including alexithymia and interoceptive difficulties, may contribute to increasing

distress and difficulty with sense-making in relation to menopause. The fact that our autistic sample exhibited a considerable burden of mental and physical illnesses is relevant since menopause often exacerbates existing mental and physical health conditions.[19] This, alongside the fact that menopause may heighten neurodivergent features,[8,65] could make it difficult for autistic people to relate their experiences to available information about menopause designed for neurotypical people, or indeed for clinicians to recognize their descriptions as menopause-related. This potentially limits access to relevant information, professional, and social support[8,22,23,64,66] and might contribute to autistic people feeling less in control and having a less clear understanding around their menopausal experiences.

Menopause representations only partially mediated associations between being autistic, experiencing more severe menopause symptoms, and poorer health and well-being. A wider range of intrapersonal and interpersonal-environmental determinants of health and well-being are likely to differ between autistic and non-autistic people. These differences may affect menopause symptoms and broader health and well-being directly, rather than through their impact on menopause representations. These include autism-related intrapersonal factors, such as heightened sensory sensitivity[6,8] and alexithymia,[67–69] and interpersonal factors that autistic individuals often struggle with, including reduced social support[35,70] and negative life/healthcare experiences.[71,72] Identifying such factors is imperative to address excess morbidity and mortality in older autistic populations.[13,16,56]

In closing, it is imperative that our focus on menopause representations, as one intraindividual influence on the severity of menopause symptoms in autistic people, is not interpreted as placing responsibility for menopause symptoms and ill-health and their remediation on autistic people. This is particularly so given that societal inequalities mean autistic people may have less information, fewer resources, and fewer supports to manage menopause, and since our findings indicate other explanatory mechanisms for disparities in menopause experiences across autistic and non-autistic people. Rather, we suggest that the amenability of menopause representations to change[33] opens numerous avenues for intervention at individual (e.g., through providing psychological intervention) and population levels (e.g., through providing accessible and relevant information for both premenopausal people and those undergoing menopause). Given growing literature documenting autistic people's challenges related to limited access to healthcare services and appropriate sources of support,[37,62,63] interventions helping people to feel a greater sense of control and understanding of their menopause may support autistic people in managing their menopause experiences.[32,33]

Strengths, limitations, and implications for research, practice, and policy

Constituting the largest comparison study to date between autistic and non-autistic AFAB people, the present work corroborates previous quantitative findings of more severe menopause symptoms[24,25] and the implication of particularly debilitating symptoms in qualitative work on menopause,[6–8,22,64] as well as, more broadly, poorer mental and physical health in autistic AFAB people than non-autistic counterparts.[13,73,74] Our short-term repeated measures approach critically extends on previous literature[6,8,22,65] by demonstrating the consistency of this relationship over time and identifies one mechanism that partially explains greater symptom severity in autistic people. The involvement of an autistic advisory group as experts by experience enhanced the accessibility and appropriateness of study materials used across the data collection process. The group also helped us ensure that findings were interpreted through an autism-informed lens, identifying and mitigating potentially misleading interpretations that could negatively impact individuals with lived experience. Demonstrating predictive links between being autistic, feeling less in control, having a less coherent sense of one's menopause, and having more severe menopause symptoms, we also showed that this has relevance for poorer health and well-being in autistic people at midlife. Controlling for covariates, such as socioeconomic status, we were able to get closer to isolating the mechanistic roles of lower sense of control and coherence in making menopause a difficult time for some autistic people.

However, this study has a number of limitations. In our short-term repeated measures analyses, we did not control for baseline levels of menopause symptoms, depression, anxiety, and QoL variables, because we were not measuring change associated with an intervention or other manipulation. While to some degree suggesting directional relationships between variables measured at T1 and those at later time points, we cannot infer that relationships between menopause representations, menopause symptom severity, and other health and well-being outcomes were causal, particularly as we measured these across a relatively short time frame in order to reduce participant attrition. Given that symptom severity is highly likely to affect feelings of control and coherence, more severe menopause symptoms prior to our first measurement point might explain why autistic people had lower scores in Control and Coherence and why symptoms continued to be severe across time. It is also possible that menopause representations are more influential for some menopause symptoms than others. Importantly, all of our outcome measures depended on self-report; we make no speculations about relationships between menopause representations and physiological indices of menopause symptoms, health, and well-being. While the current findings indicate consistent associations between menopause representations and self-reported difficulties autistic people experience during menopause, future investigations using a longer measurement period are necessary to elucidate potential causal pathways between menopause representations and experiences in autistic people.

While historic underdiagnosis of autism in AFAB people supports the inclusion of self-identifying autistic people and those with high levels of autistic traits in studies of midlife and older age,[24,54] we were unable to validate autism diagnostic status in any of our participant groups. Nor could we validate menopausal stage and symptoms of our participants. Classification using 12 consecutive months without menstruation is well-supported in previous research,[24] but we did not certify this or other information, which may be a source of variance with other studies differentiating participants by menopausal stage. Postmenopause includes a number of

stages varying in symptom load and nature,[75] and different proportions of postmenopausal people at each stage may have masked distinctions between autistic and non-autistic participants, as well as confounding comparisons with other studies.

While we examined the moderating effects of menopausal stage and controlled for socioeconomic and lifestyle factors as confounders in our mediation analyses, we were unable to account for broader health-related variables such as history of medication use, co-occurring ADHD, and existing physical and mental health conditions, which could have affected our outcome variables. This reduces our ability to infer that greater perceived menopause symptom severity, poorer mental health, and QoL in our autistic participants were related to their autistic status per se, rather than, for instance, commonly occurring confounding factors associated with more severe difficulties during the menopausal transition. Relatedly, the absence of premenopausal autistic and non-autistic comparison groups meant that differences in outcome variables, including depression, anxiety, and QoL, might reflect well-established differences observed across autistic and non-autistic age cohorts. As such, future research is needed to identify the determinants of health and well-being outcomes in autistic and non-autistic people during midlife and to characterize these outcomes in relation to other age cohorts.

Our sample may have been affected by several biases relating to generalizability of findings. First, recruiting participants from menopause- and autism-related organizations and communities may introduce self-selection bias. In line with this, the study was most likely to appeal to individuals interested in the topic by virtue of experiencing more severe menopause symptoms, who might be most motivated to complete the follow-ups. Indeed, participants who maintained participation in our follow-ups tended to exhibit greater menopause symptom severity, lower feelings of control and coherence, and poorer QoL. In addition, given the higher education attainment of the autistic group compared with the non-autistic group, we acknowledge that our highly qualified sample is unlikely to represent all autistic people, most notably those with learning disabilities or higher support needs, those diagnosed in childhood who may show different developmental trajectories,[76,77] as well as those with minority ethnic and/or racial identities, and/or autistic people who are trans men, transmasculine, nonbinary, or with gender-divergent identities. The educational attainment of our autistic participants suggests that they might have had higher degrees of health literacy than community samples who tend to have lower educational attainment, and this could influence menopause representations and symptom reporting. That the menopause representations of our autistic sample still differed from those of non-autistic participants is perhaps the more striking, for their similar levels of qualification and employment, but future research should explore the development and profile of menopause representations across more diverse autistic samples, as well as their relevance for symptom severity and well-being.

Limitations to our measures included our use of several scales not validated in autistic people, chiefly those pertaining to menopause representations and symptoms. As a first approach to considering menopause representations as one possible explanatory mechanism for more severe menopause symptoms in autistic people, we combined relevant constructs, from several measures, for a comprehensive approach grounded in psychological theory.[26,27,78] Since emotional representations are a key aspect of illness representations,[30,31] we hypothesized that these would be similarly relevant to a menopause context. It is unclear whether the absence of associations between emotional representations and menopause symptoms is due to measurement weaknesses or invalid application of this construct to a menopause context: this is true of other facets of menopause representations. As none of the constituent measures making up our scale have been used in autistic people, we cannot confidently assert that the constructs we measured, such as "Control" and "Coherence," are identical in nature to those measured in non-autistic populations. This necessitates further detailed work to investigate their relevance in autistic people.

In light of this, there is an urgent need for further research to address the methodological inconsistencies and weaknesses which impede progress in this field, and to establish optimal practices for study comparability. Developing valid and specific measures for menopause representations and for different types of menopause symptoms requires fundamental work on scale-development. Clarity around the nature of menopause symptoms and experiences at different stages[24] also necessitates finding feasible means of more precisely operationalizing reproductive or post-reproductive stage. In these efforts, partnership with the autistic community is vital to ensure the relevance, acceptability, and accessibility of future approaches. These findings underline the necessity of understanding the needs and desires of autistic people for autism-informed support, and developing and evaluating ways of providing this.

For policy and practice, our findings indicate the importance of a sense of control and coherence during menopause for well-being. This highlights the necessity of autism-appropriate information and support to aid feelings of confidence and self-efficacy related to menopause in this group.[25,32,33] Recognizing differences in menopause experiences across autistic and non-autistic people and providing information relevant to "autistic menopause,"[65] targeted at premenopausal autistic people and those approaching and entering the transition, may help individuals feel less confused and alone and enable them to identify and manage their experiences and access support more confidently. Healthcare professionals play a vital role in helping people feel supported and empowered during menopause, but menopausal individuals often find menopause-related knowledge and empathy lacking in practitioners.[79,80] With emerging evidence that healthcare professionals are equally, if not more, ill-equipped to support neurodivergent people through menopause,[22,66] there is an urgent need, beyond the general upskilling of healthcare practitioners in relation to menopause, to increase their knowledge and capacity to empower autistic people as they approach and go through menopause.

Conclusion

In the largest comparative study of menopause experiences in autistic and non-autistic people to date, we corroborated previous findings of more severe menopause symptoms and poorer health and well-being in autistic individuals and demonstrated the stability of these inequities over time. We

identified sense of control and coherence as mechanisms partially explaining greater menopause symptom severity and poorer health and well-being in autistic people. Given the relevance of these mental states to wider health and well-being, our findings highlight the urgency of empowering autistic people with sufficient information and support, including from professionals, to navigate menopause with greater ease and confidence.

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Authorship Confirmation Statement

All five authors reviewed and edited this paper. E.K., R.L.M., and J.G.T. conceptualized and designed the study and developed the methodology. E.K. conducted statistical analyses, investigated and visualized results, and wrote the original draft. R.C.S., D.D.W., and the third anonymous advisor reviewed all study materials, including online questionnaire, to ensure the appropriateness and accessibility for autistic participants. R.L.M. and J.G.T. were responsible for funding acquisition, project supervision, and administration. All authors read and approved the final article. The article has been submitted solely to Autism in Adulthood.

Availability of Data and Materials

The anonymized data used in this study are available from the corresponding author upon reasonable request.

Author Disclosure Statement

R.L.M. is a deputy editor at Autism in Adulthood. Otherwise, the authors have no financial or nonfinancial competing interests.

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Supplementary Material

Supplementary Data

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