

‘When my autism broke’: A qualitative study spotlighting autistic voices on menopause

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Abstract

Autistic women often struggle with the onset of menstruation, a key transition point in the female reproductive lifespan. Presently, there is no research investigating how autistic people navigate the menopausal transition, and whether it poses additional challenges in addition to those already faced by neurotypical women. As a preliminary participatory study in this area, we conducted an online focus group with seven autistic individuals, aged 49–63 years (median = 64.5 years) and assigned female at birth, to explore the state of knowledge about the menopause in autism, difficulties the menopause might bring, support that might be needed, and what questions require scientific investigation. Thematic analysis of the discussion generated three themes: (a) lack of knowledge and understanding; (b) cracking the mask and adaptive functioning; and (c) finding support. Themes suggested a lack of professional knowledge, understanding and communication about menopause for autistic people, and an absence of support. Menopause was discussed as heightening pre-existing and generating new cognitive, social, emotional and sensory difficulties. This study illustrates the need for greater focus of attention towards how autistic people cope with the major life transition of menopause.

Lay abstract

Autistic girls are known to struggle with the onset of menstruation, reporting that during their period, sensory sensitivities are heightened, it becomes more difficult to think clearly and control their emotions and they struggle more with everyday life and self-care. Yet surprisingly, nothing is known about how autistic women handle the menopausal transition in midlife. In non-autistic women, the menopause brings many physical changes and challenging symptoms from hot flushes to feeling more anxious and depressed. Because autistic women are *already* vulnerable to suicide, poor physical and mental health, and because they may *already* struggle with planning, controlling their emotions and coping with change, the menopause may be an especially challenging time. Yet, not one single study exists on the menopause in autism, so we conducted an online discussion (focus group) with seven autistic women. They confirmed that very little is known about menopause in autistic people, very little support is available and that menopause might be especially difficult for autistic people. Autism-related difficulties (including sensory sensitivity, socializing with others and communicating needs) were reported to worsen during the menopause, often so dramatically that some participants suggested they found it impossible to continue to mask their struggles. Participants also reported having extreme meltdowns, experiencing anxiety and depression, and feeling suicidal. This study highlights how important it is that professionals pay attention to menopause in autism, and discusses future research directions.

Keywords

autistic people, autistic women, climacteric syndrome, knowledge, menopause, perimenopause, reproductive lifespan, sensory sensitivity, support

Autistic women are historically under-researched and their experiences under-represented. The lack of lifespan research specific to autistic women is striking, considering the particular health and mortality risks that are inherent to being biologically female (Hoyt & Falconi, 2015). Many

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of these female-specific risks are associated with reproductive transition points: times where major reorganization of neuroendocrine systems gives rise to physiological and psychological changes, and where exposure to stress and other environmental factors has a heightened impact on health and well-being (Ben-Shlomo et al., 2016; Halfon et al., 2014; Hoyt & Falconi, 2015; Viner et al., 2015). The first of these is female puberty, which is associated, among other changes, with a surge in anxious and depressive symptoms, increased baseline cortisol and heightened stress reactivity, and with increased prevalence of autoimmune diseases and cancer (Hoyt & Falconi, 2015; Viner et al., 2015). Major shifts in the neuroendocrine system also occur when women enter perimenopause and the subsequent menopausal period,¹ when rates of morbidity surge again (Hoyt & Falconi, 2015). However, very little is known about how autistic people² manage these endocrine changes associated with physical, cognitive and emotional symptoms. Furthermore, it is unknown whether such changes in the endocrine milieu of autistic people engender difficulties and risks that are the same or different to those observed in the neurotypical population.

Admirable efforts have been made to address concerns relating to issues of puberty, menarche and menstruation. Caregiver reports suggest that dysmenorrhoea (painful periods) and premenstrual dysphoria are common, and self-injury, repetitive behaviour and sensory sensitivity increase around menstruation (Burke et al., 2010; Hamilton et al., 2011; Obaydi & Puri, 2008). Autistic individuals themselves corroborate experiencing a ‘dramatic’ worsening of their communicative abilities, emotion dysregulation and sensory sensitivities (Steward et al., 2018). Minimally verbal autistic individuals may be dependent on their supporters recognizing signs of pain, distress and discomfort during or preceding menstruation (Cummins et al., 2018).

The growth of research in this area is encouraging, but very little attention has been paid to major endocrine changes occurring later in life. Women in the Western world may begin to experience menopausal symptoms from approximately 40 years of age (National Health Service, 2018; North American Menopause Society, 2019), signifying the oncoming end of their reproductive lifespan. Most have reached the menopause, the point at which periods have been absent for 12 months, between 50 and 53 years of age (Palacios et al., 2010). Within the menopausal transition and after menopause, women can experience a host of symptoms, known as climacteric syndrome, which can last between 4 and 8 years. These are rooted in hormonal changes which affect multiple neurotransmitter systems, including serotonin, acetylcholine and gamma-aminobutyric acid (GABA). Cognitive repercussions are felt in reported difficulties with memory and executive functioning (Karlman et al., 2017; Koebele & Bimonte-Nelson, 2017; Weber et al., 2014). Rates of depression, anxiety and suicidal feelings surge (Pinkerton

& Stovall, 2010; Soares & Maki, 2010; Usall et al., 2009), perhaps partly underpinned by the effects of the menopause on the hypothalamic–pituitary–adrenal (HPA) axis, which controls the stress response (Gordon et al., 2016; Reed et al., 2016). Perimenopause and menopause are also associated with a raft of physiological symptoms and long-term health risks which, alongside the mood and cognitive changes, affect relationships, daily living, work performance and general well-being (Newhart, 2013). Accordingly, many women fear the menopause (Hoga et al., 2015) and these attitudes are important, as is the social environment. Resilience to menopausal symptoms is associated with strong social support, optimism, non-avoidant coping strategies and a lack of historical psychiatric illness (Deeks, 2003; Duffy et al., 2013; Pérez-López et al., 2014), with studies also finding protective effects conferred by greater physical fitness and activity levels.

This literature pertains only to the experiences of non-autistic people – the voices of autistic people are nowhere to be heard. We suggest that menopausal changes and associated physical and psychological morbidity, *if also relevant* to autistic people, raise serious concerns when we consider that autistic people are already at greater risk of mental ill-health and suicidality (Cassidy et al., 2018; Lai et al., 2019); experience life events as more stressful and have poorer coping and emotion regulation skills (Hirvikoski & Blomqvist, 2015; Mazefsky & White, 2014); and tend to lack social support, which further reduces with age (Happé & Charlton, 2012; Povey et al., 2011). Quite regards from the menopause, a wealth of literature has documented that autistic people already face significant difficulties with executive function, and that this affects mental health (Wallace et al., 2016; Zimmerman et al., 2017). Furthermore, we query how menopausal changes might affect this group who, tending towards poorer physical health, diet and fitness, are *already* at elevated risk of morbidity and mortality (Cashin et al., 2018; Hirvikoski et al., 2016). This is especially worrying when we consider that ironically, despite their poorer health, autistic people face major accessibility barriers to medical support (Crane et al., 2019; Mason et al., 2019).

Despite this striking backdrop, we are unaware of a single study to date that has explored how autistic people cope with the menopausal transition. This paucity reflects the general lack of understanding around ageing in autism and highlights the vital need for research in this area (Happé & Charlton, 2012; Michael, 2016; Roestorf & Bowler, 2016; Wright et al., 2019). What little work exists suggests that autistic people may exhibit a different and sometimes less extreme trajectory of cognitive ageing than that seen in non-autistic people (Geurts & Vissers, 2012; Koch et al., 2015; Raznahan et al., 2010; Roestorf & Bowler, 2016). Alongside reduced social support, they also experience high rates of psychological distress, depression, anxiety and psychosocial difficulty as they get

older (Magiati et al., 2014; Mukaetova-Ladinska & Stuart-Hamilton, 2016; Patra, 2016; Stuart-Hamilton & Morgan, 2011; Uljarević et al., 2019). Since there is no documentation of menopausal experiences, it is possible that autistic people may show a less exaggerated change during the menopausal transition. Alternatively, it may be that as with menstruation, the challenges of menopause exacerbate autistic difficulties, and that autistic people are especially vulnerable to menopausal symptoms. Their vulnerability could likely be heightened by a general lack of appropriate psychoeducation around sexual and reproductive health (Tullis & Zangrillo, 2013), and, in some, an inability to communicate confusion, discomfort, pain or distress associated with menopausal symptoms.

Through means of an online focus group with autistic participants, we aimed in this pilot investigation to explore how autistic individuals perceive the extant state of knowledge around menopause in autism; whether they believe the menopause might pose particular challenges for autistic people above non-autistic experiences; what kind of support might be needed; and, given the importance of participatory research (Fletcher-Watson et al., 2018), what kind of questions should guide future research.

Method

Participants and recruitment

Following recommendations (Bloor et al., 2012; Wilkerson et al., 2014), the online focus group was kept small. It included seven participants obtained using a purposive sampling approach, and two moderators to facilitate the group. Permission to advertise the study was sought from the moderators of two Facebook support groups run by and for autistic adults. The call for participants specified that participants should be self-diagnosed or formally diagnosed with autism, currently navigating the menopausal transition (experiencing perimenopausal or menopausal symptoms) or believe themselves to have been through the menopause. It was expected that midlife individuals who likely identified as female would respond, but there were no exclusion criteria regarding age range or gender identity. As a relatively 'young' diagnostic category which has undergone substantial nosological changes, a problematic bias exists in research: if ageing studies recruit only females with formal autism diagnoses, these individuals will likely be those who met criteria in the period where the diagnostic category *excluded* people with more subtle presentations and without intellectual disability (ID) – a time when female autism was scarcely recognized (Happé & Charlton, 2012). An increasing number of autistic individuals, especially women, are diagnosed in adulthood (Bargiela et al., 2016), but as this path is inaccessible for many, there is a growing trend of self-diagnosis or self-identifying as autistic (Lewis, 2017). Given that many of the autistic people in this study would have been children

in a time with restricted diagnostic criteria and/or little recognition of autism in girls, we accepted self-diagnosed *and* formally diagnosed individuals. We did however conduct two brief, well-validated screening tests (the Autism Spectrum Quotient (AQ-10) (Allison et al., 2012) and Ritvo Autism Asperger Diagnostic Scale-14 (RAADS-14) (Eriksson et al., 2013)) to partially corroborate diagnoses.

Relevant demographics of the sample are displayed in Table 1, along with their scores on the screening questionnaires. Full data, including socioeconomic status, ethnicity and educational attainment, were not collected, but the average age of the sample was 54.8 years (median = 54.5 years). We were unable to acquire full information for one of the participants who was only present during the first 20 min of the discussion, but their partial data were included.

As can be seen in Table 1, both diagnosed and self-identifying participants scored highly on the AQ-10, the RAADS-14 or both (P2 did not complete either). The mean and median scores for autistic adults on the RAADS-14, in the original publication, were 30 (standard deviation (*SD*): 8.6) and 32, respectively (Eriksson et al., 2013), as compared to markedly lower scores in other clinical populations (e.g. attention deficit hyperactivity disorder (ADHD) participants having a mean score of 15.4, *SD*: 9.3). Autistic adults in the original investigation of the AQ-10 scored an average of 7.9 of 10 (standard deviation: 1.9) as compared to a normative score of 2.7 (*SD*: 2) (Allison et al., 2012); a cut-off score of 6 was identified as best balancing specificity and sensitivity, and scores of 6 and above have since been ratified as the point at which full assessment is advisable, at least for autistic men without ID (Booth et al., 2013; Lundin et al., 2019). On the RAADS-14, three of the five participants who completed it scored above cut-off (P4 having experienced frustration with the inflexibility of the test). On the AQ-10, five of the six participants who completed it scored above cut-off. Scores below the cut-offs are not concerning, as the suitability of both measures for autistic women has been queried (Lundin et al., 2019; Moseley et al., 2018; Murray et al., 2017, 2019).

The menopause is notoriously difficult to identify without invasive procedures, and even blood and hormone tests are highly fallible (North American Menopause Society, 2019). In Britain, the menopause is normally identified through self-reported symptoms alone (National Institute of Health and Care Excellence (NICE), 2015). With the understanding that the menopause has been reached when a woman has not experienced a period for 12 consecutive months (North American Menopause Society, 2019; Palacios et al., 2010), all of our participants reported that they were post-menopausal.

Materials

A list of questions for the focus group discussion was devised by the three researchers following extensive discussion. The format was informed by recommendations

Table 1. Participant demographics and characteristics.

Participant number	Age	Gender identity	Nationality	Diagnostic status	Self-reported menopausal status during the study	AQ-10 score	RAADS-R score
1	63	Female	Australian	Self-identified (aged 60)	Post-menopausal (menopausal symptoms pinpointed at mid-late 40s)	7	21
2	55	Non-binary					
3	56	Female	British	Diagnosed (aged 49)	Post-menopausal (menopausal symptoms pinpointed at age 38)	3	32
4	53	Female	South African	Diagnosed (aged 44)	Post-menopausal (menopausal symptoms pinpointed at age 43)	7	Could not complete
5	52	Female	British	Diagnosed (aged 50)	Post-menopausal (menopausal symptoms pinpointed at age 46)	9	27
6	49	Female	British	Diagnosed (aged 42)	Post-menopausal (menopausal symptoms pinpointed at age 47)	8	37
7	56	Female	British	Diagnosed (aged 55)	Post-menopausal (menopausal symptoms pinpointed at age 40)	8	39

AQ: Autism Spectrum Quotient; RAADS-R: Ritvo Autism Asperger Diagnostic Scale–Revised.

for focus group research (Bloor et al., 2012; Wilkerson et al., 2014), aforementioned experiences of the menopause in non-autistic and physically disabled women (Kalpakjian et al., 2007), and the noticeable *lack* of information on the menopause in autism. The seven questions (see the Supplemental material) were used as a springboard for discussion. They covered current knowledge of the menopause and targets for research; whether the menopausal experience would be expected to differ for autistic people, and how; extant support and ideas for optimal support. A concluding, eighth question gave participants the opportunity to add any final comments.

Study design and procedure

In consideration of the sensitivity of the topic and the needs of a cohort who might struggle with face-to-face or telephone interaction, the focus group occurred online. In addition to convenience and cost, online focus groups boast several advantages for qualitative research (Bouchard, 2016; Forrestal et al., 2018; Reisner et al., 2018; Wilkerson et al., 2014; Woodyatt et al., 2016). According to these authors, the anonymity of an online forum decreases social influence and facilitates disclosure around sensitive topics. Further benefits are that the setting better equalizes participants, as they can respond at the same time; the synchronous formats mimic real-time discussion; and very importantly, recruitment is not limited to the geographic area. As participants in online focus groups tend to respond more concisely and pointedly, data quality and the number of themes produced are not compromised (Abrams et al., 2015; Schneider et al., 2002; Underhill & Olmsted, 2003; Woodyatt et al., 2016).

Although prior knowledge of the questions forfeits the spontaneity of responses (Reisner et al., 2018), it was seen as highly appropriate to mitigate the anxiety and uncertainty for this cohort. As such, alongside instructions for

logging into the chat room, participants were sent the focus group questions, as well as some safety requests (e.g. mindful use of language, anonymity and non-disclosure of the discussion to others).

A private chat room was set up on an online server (www.chatzy.com), and participants were given an identity number with which to sign in at an agreed date and time. The researchers followed the recommended approach of establishing rapport over email exchange during the arrangement of the focus group, and starting the session with an informal, friendly introduction (Wilkerson et al., 2014). They then proceeded to post the numbered questions one by one, allowing time for participants to think and respond.

Ethics

The study was approved by the Bournemouth University Research Ethics Committee. As described above, the design of the study aimed to facilitate convenience and comfort of participants, as well as ensuring confidentiality, anonymity and safety.

Data analysis

Thematic analysis lends itself to contextually attuned analysis of both manifest and latent content which may not be explicitly present in participants' actual words (Vaismoradi et al., 2013). Two of the authors (R.L.M. and J.M.T.C.) independently followed the six-step analysis pipeline for inductive thematic analysis described by Braun and Clarke (2012). Having established familiarity with the data, codes were devised, revised and refined to label descriptive and abstract features or ideas in the data. Perceived links between and clustering of codes allowed for construction of themes and subthemes, ideas that 'capture something important about the data in relation to the research question' (Braun and Clarke, 2012: 63), which were checked back against the

data. To ensure the credibility and dependability of our interpretation (Anney, 2014), the authors compared and discussed their own analyses and discussed discrepancies before proceeding with shared agreement to define the final themes and subthemes. Furthermore, they returned to the data 1 month after coding to code it again to note any changes in interpretation over this time.

Thematic analysis is an active process of construction influenced by the experience and interests of the researcher. Reflexive considerations of the authors may be seen in the Supplemental material.

Results

Our participants, recruited from online support groups, seemed quick to acclimatize to the online environment. The dynamic of the group was one of respect, support and concern. Participants checked on each others' comfort with proceedings, allowed each other time to post responses before continuing, apologized for potential misunderstandings and showed concern when one participant dropped out. The views expressed were largely unanimous, hence their inclusion in themes below. With responses expressed as a percentage of all utterances (312) in the 1.5-h discussion, participant 4 was most active (31%), followed by participant 6 (20.8%), participant 5 (15.1%), participant 1 (13.5%), participant 3 (9.6%), participant 7 (9%) and participant 2 (1%).

The three themes interpreted from the data, each with a number of subthemes, can be seen in Figure 1. Quotations from participants are followed by their identifier number (e.g. participant (P) *x*) and the number of the question (Q) that preceded the response. Items categorized under each theme and subtheme can be seen in full in the Supplemental material.

Lack of knowledge and understanding

The dearth of knowledge and understanding of the menopause in autism emerged starkly both in response to a direct question ('Is much known about how autistic women experience the menopause?') and throughout the focus group. Three subthemes emerged within this theme:

Professional versus patient expertise. On the part of professionals, participants perceived 'lack of any clue . . . as to how best help . . . zero clue and zero interest' (P2, Q2). They recognized that the autism research field mainly focuses on infants, children and young people. This lack of information had markedly negative consequences for some of our participants, who had, on experiencing menopausal symptoms, been concerned about their mental health:

Not knowing you're autistic on the first place – and then suddenly experiencing unprecedented phenomena which

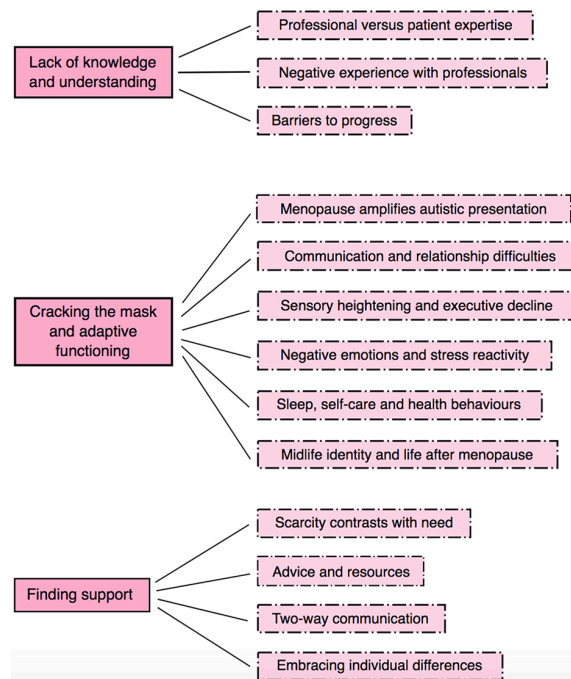


Figure 1. Themes and subthemes from thematic analysis.

don't correlate with 'regular' menopause, so you don't know if it's menopause or not. So you wonder whether you're going nuts, or have some disease, or what. (P4, Q2)

This lack of interest from professionals was juxtaposed by the proactive efforts of participants to educate themselves with independent study and attendance at autism conferences. Knowledge about the menopause was thus perceived to exist only in dispersed pockets of the autistic community, where individuals were independent seekers of knowledge who were, at times, fighting 'an uphill battle' (P4, Q5) to have their voices heard by professionals. Participants highlighted a need for future research to systematically compare the menopausal transition in autistic and non-autistic people. Furthermore, they highlighted the need for longitudinal research to study, in autistic people, the changes from pre-menopausal function and their effect on communication and relationships, sensory sensitivities, everyday function and mental health.

Negative experience with professionals. Relatedly, participants expressed low expectations based on negative experiences with professionals (GPs (general practitioners, family doctors), psychiatrists): 'Doctors are (in my experience) relatively clueless about the biology of menopause' (P4, Q2). Psychologists and researchers within the autism field, too, were viewed with scepticism, participants sarcastically challenging established 'facts' about autism.

Barriers to progress. A number of factors were recognized as impediments to knowledge around menopause in autism. As a generic barrier, participants recognized that menopause tends to be perceived as somewhat distasteful and thus taboo. Furthermore, the likelihood of lacking a social networking might make it difficult for autistic people ‘to establish what is perhaps normal for those entering menopause’ (P2, Q2), and left our own participants alone with their experiences: ‘you don’t know what is “normal” only that it isn’t “normal” to you, let alone anyone else’ (P3, Q2). The characteristic difficulties that autistic people face in expressing their thoughts, emotions and experiences, including alexithymia and interoceptive awareness, were another barrier to information and communicating with doctors: ‘At times I can remember not being able to identify or communicate any of what I was experiencing’ (P7, Q7). The participants recognized that autistic people with ID and/or minimal spoken communication might suffer greatly from being unable to communicate their experience. Participants also suggested that undiagnosed and/or unrecognized autism might bar individuals from finding peer support, from finding relevant information and from communicating their experiences to others. A lack of diagnosis might also be a barrier to coping with the menopause; participants queried ‘whether a diagnosis helps with self-awareness and therefore helps with coping with the big M’ (P5, Q6). They implied that *knowing themselves* might have made them slightly kinder to themselves and aware of their limits. Recognizing autism would give individuals a frame of reference for understanding themselves and both general and menopause-related difficulties. Being able to understand the menopausal experience through the light of autism was apparently critical for some participants: ‘I would probably have ended up out of work, mentally ill if I didn’t find out I am autistic’ (P4, Q7).

Cracking the mask and adaptive functioning

A major theme underpinning several streams of discussion was the effect of the menopause across daily life, cognitive and emotional functioning.

Menopause amplifies autistic presentation. Interestingly, those of our participants with formal autism diagnoses (P3, P4, P5, P6, P7) had been diagnosed in midlife, with two participants (P4 and P5) making reference to menopausal changes preceding their diagnosis. It appeared that the menopause exacerbated pre-existing issues and brought on new problems that led them to seek clinical assessment for autism or other difficulties. Introducing the term *masking*, participants noted that this had become much more difficult and previous effective coping skills were failing:

When I talk about that time, I say, ‘My autism broke’. Before that, my autism was working fairly well for me, providing me with good job skills. (P4, Q2).

Communication and relationship difficulties. Participants reported a worsening of social communication difficulties; as purported above, ‘the cracks in the mask started to appear’ (P6, Q3). Empirical investigation of this deterioration, which was linked to sensory changes and ‘overwhelm’ (P1, Q4), was a research target for several participants in response to the questions around what researchers needed to focus on. Due perhaps in part to communication impairment alongside other changes, participants also reported an impact of the menopause on friendships, familial and marital relationships. Menopausal symptoms affecting sexual relationships could cause confusion for participants (‘sensory pain makes you think it’s a relationship thing – like, why don’t I want to be touched there? Maybe I don’t love him?’ (P4, Q8)). While participants were aware of the impact of their menopausal struggles on other people, they also expressed a high degree of dependence on others, namely, husbands and family members.

Sensory heightening and executive decline. The heightening of extant sensitivities and the emergence of new ones, such as to food, was a major topic for participants. Several participants noted that menopausal hot flushes might be especially difficult for autistic people with sensory sensitivity (‘Those of us who are sensitive to heat and cold, with other sensory difficulties, will be doubly disadvantaged by the sudden hot flushes’ (P2, Q2)), as would be the change in periods. As well as affecting communication, sensory difficulties were linked to mood. Several participants mentioned meltdowns in the context of sensory sensitivity:

During menopause I was on 3 meltdowns per week at times . . . My meltdowns were of the nature that people would call a ‘basket case’. . . Would strip down to underwear sometimes during a meltdown at work. (P4, Q3)

At the same time, as sensory sensitivities increased, participants commented on a deterioration of executive function which affected work and studying and required further investigation. Previous struggles with inattention were heightened, one participant’s comorbid ADHD reaching ‘HECTIC’ (P4, Q3) levels.

Negative emotions and stress reactivity. Participants reported an increase in anxiety and depression and the emergence of new mental health difficulties, such as panic attacks. The menopause brought on a lack of control over circumstances *and* emotions (‘I really couldn’t control my emotions—quite embarrassing sometimes’ (P5, Q3)), which might be more extreme, labile, and which could emerge explosively in meltdowns:

Violence, self-injury, all these negative things which people associate with autism. Loss of speech at times – NOT selective mutism. Writhing and grimacing. Hitting head. Sitting in corner rocking. (P4, Q3)

With the decline in mental health associated with the menopause, several participants mentioned feeling suicidal:

I think that the extra stress all the above brings can result in feeling too tired and overwhelmed to carry on . . . It's like, your everyday life, just to appear 'normal' is bad enough, but when M [the menopause] happens, it all gets too much . . . I wonder if the low life expectancy for autistic women is linked to menopause because it all gets too much. (P6, Q4)

Sleep, self-care and health behaviours. Participants reported that the menopause affected pre-existent struggles with daily living and self-care. The sleep problems common to menopause seemed to have a broad impact on cognition and daily coping skills, and made participants worry about their health ('Sleep issues may well lead us into Alzheimers sadly' (P6, Q1)).

Midlife identity and life after menopause. The menopause appeared as *one* aspect of a midlife period already in flux. While enduring menopausal changes, autistic people might also navigate the reduction or reshaping of support networks ('Losing partners, kids moving out etc and menopause all at the same time . . . losing parents too' (P5, Q4)), changes to pre-existent chronic conditions and future health concerns. There was some suggestion that post-menopausal life might improve, though the extent of the improvement was mixed:

Being postmenopausal is grrrrrrrrrrreat! (Except for not being able to achieve 25% of what I used to due to constant exhaustion and focus issues.). (P4, Q8)

Finding support

Our participants had experienced that support for changes related to the menopause was difficult to obtain. The discussion highlighted the gaps in present provision and the nature of the kind of support that might be suitable.

Scarcity contrasts with need. The aforementioned lack of professional knowledge and understanding around menopause in autism was naturally reflected in very limited, non-autism-specific resources for managing the menopause. As individuals, participants reported some helpful interactions with primary healthcare staff and online discussions with other autistic people, but access and availability of these resources was obviously unreliable.

Advice and resources. Participants highlighted the need for appropriately written resources described as 'sciency information translated into layman's language' (P4, Q7), and for practical advice around heightened sensory sensitivity, maintaining mental health, self-care, and executive function difficulties. Support should have a peer-led element, too.

Two-way communication. This subtheme incorporated bidirectional communication between autistic people and their health practitioners. Autistic individuals might need support communicating their experience to clinicians, in line with the aforementioned communication, alexithymia and interoceptive difficulties. However, to optimize the kind of support that health providers can offer, participants emphasized that professionals should *also* hear their perspectives and experiences of autistic people as central to building a body of knowledge and support resources. Furthermore, participants highlighted the need for cross-disciplinary communication between professionals. They commented that doctors should be trained in systems medicine, and autism professionals schooled in biopsychosocial approaches, highlighting the consequences of insufficient training ('if you don't understand a bit of biology, you are sooooo much less effective as a professional' (P4, Q7)). They also stressed that communication should be facilitated between autism researchers to resolve the silo situation among scientists, pointing out that 'the biomed guys and the psych guys don't seem to talk much' (P4, Q5).

Embracing individual differences. According to participants, optimal support should, like research, recognize holistic and contextual factors (e.g. culture, socioeconomic status, gender identity, ID, ethnicity, on top of the general heterogeneity of the autistic population) that might affect the menopausal experience and the types of support required.

Discussion

As a major transition point in the female reproductive lifespan, the menopause, with its physiological, cognitive and emotional changes, and elevated risk of physical and mental ill-health, poses substantial challenges for neurotypical women. The current analysis is the first of its kind to investigate the state of knowledge and the potential difficulties that autistic people might face during the menopause. We identified themes remarkably similar to those raised in one previous study around autistic perspectives on menstruation (Steward et al., 2018). Our participants similarly suggested that the menopause might magnify and even generate new difficulties with sensory sensitivities, communication, emotion regulation and everyday living. Our participants also expressed difficulties 'identifying their own normal', given the lack of knowledge, interest and support from professionals. In important contrast, while efforts have been made to understand and help autistic people cope with menstruation, our focus group suggested that when seeking support for menopausal difficulties, their experience has been unreliable and challenged by a number of factors. While these initial findings are only sampled from a small group of autistic people, they suggest that empirical investigation of the menopausal transition is vital in building a knowledge base and much needed support in an ageing

autistic population. The lack of professional expertise identified in our analysis, and eagerness for autism dogma to be challenged, also corroborates the importance of refocusing towards autistic involvement in order to drive progress in this area (Fletcher-Watson et al., 2018).

In trying to understand how autistic people might experience the menopause, we noticed an element of duality in our analysis. Participants made reference to the exacerbation of autistic difficulties by the menopause, which ‘cracked the mask’ and amplified the visibility of their autism. Our participants, proactive seekers of information, may have been familiar with scientific interest in the camouflage skills of autistic adults, especially females (Hull et al., 2017; Lai et al., 2016; Tierney et al., 2016), and with concerns around the cost of masking (Cage & Troxell-Whitman, 2019; Cassidy et al., 2018). As extant masking and coping skills failed, two participants who were undiagnosed at the start of menopause explicitly linked their learning about their autism to the difficulty of this time. While the menopause appeared in some to heighten their autistic difficulties, the participants also recognized that self-identifying as autistic (regardless of a formal diagnosis) might be important for coping with the changes.

With reference to the heightening of autistic difficulties with the menopause, it is unfortunate that previous qualitative investigations with late-diagnosed autistic women (some aged 40 or above) do not explore the reasons that prompted their participants to seek diagnosis (Bargiela et al., 2016; Jones et al., 2014; Kanfisz et al., 2017; Leedham et al., 2019; Lewis, 2016a, 2016b; Milner et al., 2019). They do, however, reveal a multitude of emotions on receiving an autism diagnosis, including initial anxiety, anger or grief, but also vindication of their struggles, relief, even elation at finally understanding. Afterwards, many find it possible to connect with community, better manage sources of stress and reframe life events from a more self-compassionate perspective. Only one of our participants was diagnosed at the point of menopause, and the group discussion likewise suggested that unrecognized autism prevented some participants from finding peer support and information that could have helped, leaving them isolated without a frame of reference to understand their experience. The basic agency inherent in understanding oneself appeared to be fundamental for mental health (Leedham et al., 2019). Although we did not ask our participants about their experiences of self-identifying/being diagnosed during the focus group, the data seemed to suggest that this self-knowledge was beneficial to being able to cope with the menopause and dispel concerns around mental health (‘going nuts’). In some sense, in ‘cracking the mask’, menopause may help some people to a place of greater understanding and acceptance.

Our analysis also recognized the menopause as a time of immense change situated within a broader epoch, midlife, characterized by changing relationships and life circumstances. This instability would naturally be expected

to pose greater challenges for autistic individuals (Hirvikoski & Blomqvist, 2015; Mazefsky et al., 2013). Our participants spoke of ‘losing their supports’, making the need to investigate the menopause within the broader context of ageing ever more palpable.

That mental health issues and suicidal ideation seemed to be exacerbated is unsurprising, given the difficulties and overall instability during midlife. This is concerning given the already high rates of psychiatric illness and suicidality in the autistic population (Cassidy et al., 2018; Lai et al., 2019). Our analysis suggests that there are unmet health needs for autistic people experiencing the menopause, though the data also reflected the diversity of individuals in different geographic locations and, even within the UK, under different local health services. Summary statements about autistic access to healthcare must contend with huge variation nationally and internationally. This aside, our participants’ negative encounters with health professionals are consistent with literature purporting that autistic people have difficulty accessing healthcare (Crane et al., 2019; Mason et al., 2019), and that health professionals feel that they lack training, knowledge and confidence in treating patients with potentially complex needs (Morris et al., 2019). Some of the barriers we identified around seeking information and support for the menopause – isolation, difficulties with communication and expression, including alexithymia – are among those identified by recent reviews in autism (Bradshaw et al., 2019; Mason et al., 2019). Some of the recommendations raised by these authors, such as the ‘Know Your Normal’ toolkit, might be highly appropriate when it comes to gynaecological health around menopause. So too would the recommendations of Steward et al. (2018) around supporting younger people through menstruation: making ‘sciency’ information accessible, outlining what to expect and giving practical advice, with incorporation of autistic perspectives in the development of such resources.

Limitations and future directions

Where validity and reliability are upheld in quantitative science, qualitative research strives for credibility, dependability, confirmability and transferability (Anney, 2014; Schwandt et al., 2007). We have striven for a sound and rigorous analytic process by providing thick description for the purpose of replication and complying with recommendations to uphold the credibility and dependability of our interpretation (Anney, 2014). Our aim, in this first, participatory form of research, was to inform future academic approaches to autistic stakeholders. We believe the insights from our group are of much importance in opening up this neglected area, but they cannot be generalized to all biologically female autistic people. Further research of a multifaceted, qualitative and quantitative nature is required to characterize the menopausal transition and the challenges it poses for this group.

As succinctly phrased by one of our participants, ‘It’s really important that any research has as its focus improving the lives of autistic women’ (P1). Support and resources, however, have their roots in understanding, which is presently lacking in this entirely nascent field. Participants requested that research explore ‘changes in physiology, hormones, communication, sensory issues, cognitive function, moods, suicide ideation or actual suicide’ (P7). In-depth scrutiny of individual experiences would be important and could be achieved via interpretative phenomenological analysis (IPA). However, this question would also necessitate a quantitative battery of tests, in a longitudinal or cross-sectional approach, which might chart these differences between younger and older autistic women. Within such an approach, it would further be important to identify physical and psychological moderators of the menopausal experience, such as have been documented in non-autistic women (Deeks, 2003; Duffy et al., 2013; Pérez-López et al., 2014). Another key question posed by participants involved identifying the differences between the menopausal experiences of autistic and non-autistic people.

Where some studies in non-autistic people have attempted to link menopausal symptoms (or their severity) to physiological indices of steroid hormones (Bromberger et al., 2010; Freeman et al., 2006; Randolph et al., 2005; Woods et al., 2014), we made no attempt, here, to identify the hormonal status of our participants. This was beyond our aims in this pilot study, but the problematic implications of relying purely on symptom reporting are several. First, in non-autistic women, menopausal symptoms change across the transition period (Koebele et al., 2017; Woods & Mitchell, 2016). If the same is true for autistic people, then comparison of menopausal groups (whether with younger autistic people or non-autistic people) may be obfuscated by individual differences in transition stage. In being unable to confirm whether symptoms are indeed associated with changing androgens, it is impossible to differentiate which symptoms or difficulties are related specifically to menopause and which are a function of ageing (its biological and psychosocial components) more generally – this is certainly true of qualitative studies such as this. We were cautious to avoid screening participants for well-known (non-autistic) menopausal symptoms. It is possible that differences in menopause symptom presentation (presently unknown to us) could introduce a sampling bias if autistic participants with non-normative symptoms are turned away, but without means of ascertaining whether participants really are entering the menopausal transition, this hinders tight experimental control over sampling. Problematically, steroid hormones require measurement through expensive and invasive means (e.g. as measured in urine, blood serum or plasma). For all this trouble, these methods still lack standardization, accuracy and precision (Ceglarek et al., 2010; Rosner et al., 2013; Stanczyk & Clarke, 2014; Wang et al., 2016), so optimal means of

studying menopause in autism require further thought and discussion. Some studies have linked menopausal symptoms and distress to cortisol, adrenaline and noradrenaline, associated with the HPA axis and the autonomic nervous system, respectively (Gerber et al., 2017; Reed et al., 2016; Woods et al., 2014). Cortisol levels are robustly related with mental and physical health outcomes (Adam et al., 2017), so this may also be a worthy physiological index to compare between groups and examine alongside symptom-reporting, given that (a) physical and mental health often decrease with menopause in the non-autistic population (Hoyt & Falconi, 2015), and (b) autistic people are already vulnerable to increased morbidity and mortality (Croen et al., 2015; Hirvikoski et al., 2016). Determining whether biologically female autistic people are more vulnerable to physical and mental illness at this time of life, and the biochemical mechanism of this vulnerability, would be an important research goal. The importance and impact of other factors on health and well-being, such as autistic-identity and awareness, access to healthcare and social support, would also pave the way towards understanding where interventions are needed.

Several methodological limitations must be borne in mind when interpreting our findings. By advertising on social media groups where autistic people socialized and supported one another, we introduced a selection bias where only those who were comfortable with online communication saw and responded to the advertisement. The advertisement may not have been visible to those with literacy problems, or who have difficulty typing or with technology. Though we attempted to advertise in a neutrally valenced way, the study may have been most salient to individuals who had experienced a particularly difficult menopause. Moreover, in being immersed in the online autism community, our participants were highly knowledgeable about autism, autism research, and were science-minded – the quintessential ‘expert patients’ (Department of Health, 1999). Knowing autism from the inside gave them a valuable perspective in a preliminary imagining of where the menopause might raise difficulties for autistic people, but they may have been unlikely representatives of the autistic community as a whole. Autistic people who are minimally verbal with ID tend to be a forgotten group (Tager-Flusberg et al., 2017) who were certainly not included in our sample. Although our participants were considerate of the extra difficulties this population might face with the menopause, the experiences of these groups require specific examination. It is also important to note that although all of our participants would be classified as post-menopausal on the basis of not menstruating for (at least) a 12-month period, there was a huge range in the length of time since participants experienced their last menstrual period. Participant 6, 49 years old, for instance, estimated that they had experienced menopausal symptoms 2 years ago when aged 47, but for participants 1, 3 and 7, a period of more than

10 years had passed since they experienced their last menstrual period. Other researchers have warned of the unreliability of retrospective reporting of menopausal symptoms (Taffe & Dennerstein, 2000), and it is certainly possible that recall bias affected a large proportion of the participants in our study, who were recalling experiences from a more distant point in time.

The Internet is an excellent medium for reaching specialist or clinical groups, especially when they are geographically remote, and our approach likely suited the needs of our participants while allowing them to speak frankly in the safety of anonymity. The concern that participants in a fast-moving, chaotic chat room will keep their responses brief has not been supported in previous non-autistic studies (Woodyatt et al., 2016), but online studies are characterized by greater perceived (and actual) distance between researcher and participant that can affect their rapport. Lacking non-verbal cues, researchers can struggle to monitor the emotional impact of the discussion on individual participants, and misunderstanding can occur (Bouchard, 2016; Mann & Stewart, 2000; Reiser et al., 2018; Wilkerson et al., 2014), as was the case for one of our participants who dropped out. There was furthermore no opportunity to observe spontaneous responses to our questions. Future research would benefit from closer contact between researchers and participants that would allow for scrutiny of subtle social or emotional cues in our participants (Markham, 2004). It might also reduce the problem that participants in group discussions such as this do not all contribute equally, as is clearly evident here. We did not want to put any of our participants 'on the spot', so we did not seek or demand contributions to each question. Working with people individually would reduce this problem, and forthcoming work from our group does attempt to represent the voices of our quieter participants by hearing their stories.

With the inclusion of individuals without formal autism diagnoses, we followed recent practice and convincing arguments from within the academic community (Au-Yeung et al., 2019; Lewis, 2016a; Milner et al., 2019). As female autism has only recently been better understood by professionals and the public, there are likely many older women who have never been diagnosed, especially given the accessibility barriers in place (Lewis, 2017) and the sex-bias in primary healthcare screening tools and 'gold standard' diagnostic measures (Gould, 2017; Lundin et al., 2019; Moseley et al., 2018; Murray et al., 2017, 2019). Until our ability to identify female autism improves, it may be important for studies of ageing autistic people to include those who have self-identified. Despite their limitations, autism assessment tools (such as the Autism Diagnostic Observation Schedule (ADOS)) afford rich data. Until superior diagnostic tools are in common use for autistic girls and women, future research might therefore benefit from conducting extent assessments on self-identifying and diagnosed participants to assure as

much homogeneity within autistic samples as possible, and to allow for relationships to be drawn between autistic features and menopausal changes.

Conclusion

Our focus group suggested that the menopausal transition may be a time of heightened vulnerability for autistic people. The lack of knowledge around the menopause in autism should, we suggest, be of high concern, particularly given the suggested increase in mental ill-health and suicidal thoughts. Furthermore, the potential exacerbation of social difficulties could thwart communication with health providers at a most vital time. Support needs of the ageing autistic population are currently unmet, and should be a vital goal for future research.

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The author(s) declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

Ethics

The study was approved by the Bournemouth University Research Ethics Committee. As described above, the design of the study aimed to facilitate convenience and comfort of participants, as well as ensuring confidentiality, anonymity and safety.

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Supplemental material

Supplemental material for this article is available online.

Notes

1. Menopause is not a singular event, but a gradual transition through decreasing fertility to complete termination of menses. Terminology differs across countries, but we comply with popular British usage (National Institute of Health and Care Excellence (NICE), 2015), where a person has *reached* or *passed through* the menopause, or *is post-menopausal*, at the point of having 12 consecutive months

free from periods. We refer to the symptomatic time before this point as (the) *perimenopause*, when reproductive hormones are dysregulated but the individual has not experienced 12 months free of periods. We refer to the *menopausal transition* or the *menopause* to describe the *entirety* of this reproductive transition point (perimenopause to being postmenopausal). We refer to *menopausal symptoms* to describe symptoms that can occur during the perimenopausal period and/or after menopause has been reached.

2. With the term ‘women’ or ‘woman’, we refer to those individuals whose biological sex was assigned as female at birth, disregarding the distinct aspect of gender identity. As it is common for autistic people to be gender non-conforming (George & Stokes, 2017; Glidden et al., 2016; Strang et al., 2014; Van Der Miesen et al., 2016; van Schalkwyk et al., 2015), here and thereafter, we use the gender-neutral term ‘people’ so that we make no assumptions about whether these individuals identify as female, male, non-binary or other.

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