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'It should be more outspoken and not hushed away, not like put in a dark box': An interpretative phenomenological analysis of experiences of menopause voiced by women with learning disabilities

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Abstract

Background: There is little research into experiences of menopause voiced by women with learning disabilities, who can be neglected in academic research. There is a particular lack of knowledge around the psychological and social experiences of menopause in this population, and how changes are managed. This study sought to explore these experiences.

Methods: Experiences of five women with lived experience of menopause, being seen by community National Health Services specialising in learning disabilities, were captured with semistructured interviews and analysed using interpretive phenomenological analysis.

Findings: Five superordinate themes were identified, involving the importance of having information about menopause, challenges of periods, observable changes in menopause, the importance of social connection, and managing menopause independently.

Conclusions: This study highlights the need for clinicians and carers to understand the variety of impacts menopause can have on women with learning disabilities, including emotional and social aspects, and the need to initiate conversations regarding menopause and available treatments.

KEYWORDS

interpretive phenomenological analysis, learning disability, lived experience, menopause

Accessible summary

- Menopause is when a woman stops having periods. It is natural and happens when women get older.
- Five women with learning disabilities told us what menopause was like for them. We asked them about changes to their body, moods and relationships.

Disclosures: This research was completed as part of the first author's Doctorate in Clinical Psychology. The author has received £70 from the University of Plymouth, all of which has been given to consultants and participants in vouchers as reimbursement for their time.

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- Periods and symptoms linked to menopause can cause problems. It can be hard talking about menopause and receiving treatment for its symptoms.
- It was important for women to have information about menopause, to spend time with other people, to talk to people who have also experienced menopause, and to manage menopause independently.
- Carers and people working in healthcare can use this information to understand how menopause affects women with learning disabilities and better support them.

1 | INTRODUCTION

This paper reports qualitative research exploring the experiences of menopause among women with learning disabilities who are being seen by community NHS learning disability services in South-West England. It reflects on aspects of menopause which were salient to the experiences of participants, which have implications for both clinical practice and future research. This research was codesigned alongside consultants with learning disabilities and lived experience of menopause, as well as experienced clinicians.

1.1 | Positionality statement

As a clinician who has worked with people with learning disabilities in various services for several years, I (the first author) have observed people with learning disabilities being spoken for rather than with and am aware that this is echoed in the paucity of research undertaken with this population. As such, I value opportunities for people to voice their own experiences, particularly in relation to sensitive topics such as one's own reproductive health.

I am concerned with women's health issues and how they can be hidden or dismissed in Western society. I am keen to support such issues to be discussed more openly, so that they can be better understood and supported. Despite years of clinical training and employment, I have not had any experiences of menopause being considered in training or clinical formulation before this research. I therefore consider it important to provide a forum allowing women with learning disabilities opportunities to voice their personal experiences of this phenomenon.

1.2 | Menopause

Menopause is a natural biological process for women, signified by the cessation of menstruation and consequent loss of fertility. Considered one of the most critical stages of a woman's life, menopause is associated with an aggregation of physical, psychological and social changes, described by Parand avar et al. (2014) as 'crises'. All of these aspects have been explored within research undertaken with the neurotypical population (Hoga et al., 2015), including investigations into incidents of mental health difficulties in menopause. An association with mental health problems in vulnerable, predisposed women has been revealed, although this has complex interactions

with other factors including life events, relationships, lifestyle and culture (Deeks, 2003; Riecher-Rössler, 2020).

In Western culture, menopause has traditionally been constructed negatively (Utian, 1997), and like menstruation, is viewed as taboo (Harper et al., 2022). Menopause is associated with aging, perceived lack of attractiveness and loss of cognitive skills (Krajewski, 2019). It can cause physical and psychological symptoms that can cause problems managing work demands (Geukes et al., 2016), contributing to Western evaluations of older women having no designated social role (Wilk & Kirk, 1995). Conversely, menopause is embraced in the parts of Asia where the elderly are traditionally revered, with a lower prevalence of menopausal symptoms reported (Sohail, 2014). Thus, how we think about menopause is culturally related and needs to be considered within the wider socio-historical context.

Recent research into menopausal experiences highlights impacts on mood and behaviour, with increased anger, irritability, bad-temperedness and aggression, which can adversely impact social relationships (Harper et al., 2022; Refaei et al., 2022). Desires to be understood by others and connect with peers sharing similar experiences were also identified, and 'Menopause Cafés' are hosted throughout the United Kingdom to enable this (Weiss, 2020). Singer (2012) highlighted the negative psychological impacts of premature menopause, including low self-esteem, anxiety, depression, and cognitive challenges, although these were rarely addressed. Such symptoms are at risk of diagnostic overshadowing in mental health contexts, resulting in misdiagnosis and potentially inappropriate referrals and treatments (Collier & Clare, 2021).

Socio-demographic variables (Pajalić & Raboteg-Šarić, 2020) and emotional intelligence (Bauld & Brown, 2009) have been identified as predictors for menopausal symptoms. Given that learning disabilities may influence both, in addition to discrimination faced by women with learning disabilities who may not be accepted as adults with sexual or reproductive identities (McCarthy, 1999), menopause research with the general population may not be transferrable. It is therefore important that research exploring menopause is undertaken specifically with women with learning disabilities.

1.3 | Menopause in women with learning disabilities

There is evidence that women with learning disabilities, particularly those with Down's syndrome, experience menopause earlier than the

general population (Carr & Hollins, 1995), which in turn is associated with increased risk of earlier onset of dementia and death (Coppus et al., 2010). The mechanism behind this association, however, is undetermined. Although menopause is widely considered an important topic concerning premature deaths of people with learning disabilities among experts internationally, the existing evidence base is considered inadequate (Robertson et al., 2021). The Confidential Inquiry into premature deaths of people with learning disabilities (Heslop et al., 2013) in South-West England revealed weaknesses in the quality of Annual Health Checks, such as omitting to ask about postmenopausal bleeding, which could be an indicator of uterine cancer. Thus, lack of knowledge regarding menopause in women with learning disabilities, particularly lacking understanding of potential concerns associated with postmenopausal bleeding, could have serious, and potentially fatal, consequences.

The National Institute for Health and Care Excellence (NICE, 2018) highlights the risk of diagnostic overshadowing in older people with learning disabilities, which may arguably be compounded by the risk of menopausal symptoms being misidentified (Collier & Clare, 2021). Research has demonstrated difficulties disentangling physical and psychological symptoms of menopause from pre-existing causes among women with learning disabilities (McCarthy & Millard, 2003a; Willis, 2008) and their carers (Willis et al., 2010), further strengthening the risk of menopause going unrecognised within this population, and emotional symptoms potentially being dismissed as 'challenging behaviour' (Down's Syndrome Association, 2018).

The lack of research concerning menopause in women with learning disabilities has been repeatedly highlighted by researchers in the field. Existing studies have largely focussed on data gathered from carers and clinicians or assessing the knowledge of women with learning disabilities. Research has demonstrated a lack of discussion about menopause between caregivers and women with learning disabilities (Chou et al., 2013; Willis, 2008), and revealed carers feeling poorly trained and resourced to support women to understand menopause (Willis et al., 2011). Although some resources have been published to support carers with this (e.g., McCarthy & Millard, 2003b), they appear to be mostly unknown or unavailable to care organisations (Willis et al., 2011). It is therefore unsurprising that studies have highlighted a paucity of knowledge about menopause among women with learning disabilities, including lacking understanding of its significance in terms of reproductive capacity (McCarthy, 2002; McCarthy & Millard, 2003a; Willis et al., 2011).

Five published studies in which the self-expressed lived experiences of menopause among women with learning disabilities were explored have been located via a systematic review of literature¹. Of

the emergent articles, the most recently published was a decade old (Chou et al., 2013), and all but one (Willis, 2008) included nonmenopausal women in the sample. Findings have mainly focussed on knowledge and physical experiences of menopause, to the detriment of psychological and social impacts. Hot flushes are salient across existing literature, identified as the one clear symptom reported by participants. However, there are varying reports regarding how troublesome or embarrassing they are (McCarthy, 2002; Willis et al., 2011), and symptoms could be attributed to environmental factors (Willis et al., 2011). It has been suggested that psychological and emotional reactions to menopause are unlikely to be reported by women with learning disabilities (McCarthy & Millard, 2003a), and psychological consequences are difficult to separate from other circumstances (Willis et al., 2011). Little is known about how changes experienced in menopause are managed by women with learning disabilities, with little evidence relating to use of hormone replacement therapy (HRT) within this population (McCarthy & Millard, 2003b).

1.4 | Attending to voices of people with learning disabilities

The learning-disabled population possesses a long history of marginalisation, with research largely being done about them from the perspectives of carers, professionals or advocates, rather than inviting the voices of people with learning disabilities themselves (Welsby & Horsfall, 2011). Barriers to their participation include the challenges in engaging mediators necessary to access research participants (gatekeepers), ethical considerations, inaccessible materials and lack of resources (Banas et al., 2019).

Some researchers (e.g., Wiseman & Ferrie, 2020) have expressed concerns that voices of women with learning disabilities have been particularly silenced, even within feminist literature, leading to issues faced by this intersection of the population being misunderstood or ignored. Johnson and Traustadóttir (2000) have noted academic communities being unaccepting of women with learning disabilities, with perceptions that they are less able to express experiences in 'acceptable' ways. Consequently, women with learning disabilities may be particularly vulnerable to exclusion from research.

Regardless, people with learning disabilities have the right and desire to participate in research and may feel empowered by experiences of being listened to and helping others through participation (Tuffrey-Wijne et al., 2008). Moreover, their involvement is essential to improving knowledge of learning disabilities, evidence-based practice and the services they receive (Crook et al., 2015). Although there is much literature that advocates for hearing the voices of women with learning disabilities (e.g., Johnson & Traustadóttir, 2000; Welsby & Horsfall, 2011; Wiseman & Ferrie, 2020), this is not followed up in published research to the same extent. It is therefore vital that current research positions people with learning disabilities as the experts of their own

¹The systematic literature review was conducted utilising six databases encompassing the social and medical sciences [AMED, CINAHL, MEDLINE (EBSCO), PsycINFO, SocINDEX and Web of Science] and Google Scholar, and Boolean search strings relating to population (learning disabilities: 'Intellectual* disab*' (intellectual disabilities, intellectually disabled) OR 'Learning disab*' (learning disabilities, learning disabled) OR 'Intellectual developmental disorder' OR 'Learning difficult*' (learning difficulty, learning difficulties) OR 'Down's Syndrome') and topic (menstruation and menopause: Menstru* (menstruation, menstruating, menstruate, menstrual) OR Menses OR Menopaus* (menopause, menopausal) OR 'menstrual cycle' OR 'reproductive cycle' OR 'monthly period' OR 'women's period').

experience, making efforts to overcome challenges posed to their participation.

1.5 | Aims of the study

This research aims to build on the little research previously undertaken into the experiences of menopause in women with learning disabilities, by interviewing women who have personal experience of menopause and are being seen by community National Health Services (NHS) specialising in learning disabilities, with the hope that their experiences can inform the services they receive. The psychological, social and physical experiences of menopause will be explored in this study, in addition to how these experiences are responded to and managed.

2 | METHODOLOGY

2.1 | Design

A qualitative design was utilised to invite the voices of women with learning disabilities, and gather rich information about their experiences of menopause. Semistructured interviews were supplemented with visual resources (standardised images used by NHS learning disability services, alongside simplified text to support verbal interview questions), to enable participants to express their experiences. The nature of semi-structured interviews offered participants structure while allowing for flexibility, prompts and follow-up questions for further exploration. Interpretive phenomenological analysis (IPA; Smith & Osborn, 2008) was employed as this approach aims to provide detailed examinations of personal lived experience and identify common patterns in the experiences of individuals, relevant to the research aims. Due to the depth of the analysis, IPA is appropriate to handle data gathered from a small number of participants, which was anticipated in this study due to the intersectionality of the intended sample and potential challenges in recruitment.

IPA was utilised, rather than Thematic Analysis, as it provides a methodology which allows for a dual focus on both commonalities and unique characteristics in the lived experiences of participants in a homogenous sample, through the coding and theme development of each transcript in turn, rather than across the entire data set (Larkin et al., 2006). Thus, IPA allows researchers to remain close to the data, uplifting the voices and personal experiences of participants, while also identifying broader patterns, and allowing the researcher to consider what it means for participants to express their experiences within their particular context.

Consultation was sought on study design from two women with learning disabilities experiencing menopause, recruited through a charity for people with a learning disability, as well as clinicians in NHS learning disability services. Consultants contributed to the design of accessible resources used throughout the study, and were given a £10 voucher of their choice for each hour they contributed to the research.

2.2 | Participants

Purposive sampling was used to recruit participants from two NHS Trusts in South-West England. All clinicians working within community NHS learning disability services across the Trusts were asked to identify current service users who satisfied the following participation criteria:

Inclusion criteria

- Biologically female.
- Diagnosis of a mild/moderate learning disability.
- Experiencing or have experienced menopause (i.e., will not have menstruated in the last year, or diagnosed with perimenopause).
- Able to provide informed consent to participate.

Exclusion criteria

- Never menstruated.
- Not menstruating as a result of surgery and/or taking medication in the last year.
- Diagnosis of dementia or an acute mental health condition that would impact on their ability to participate.
- Severe level of learning disability that would impact on their ability to provide informed consent.

Despite the research being welcomed by recruiting services, recruitment proved pragmatically challenging, resulting in all participants being recruited through a single gatekeeper, a Senior Learning Disability Liaison Nurse. Seven potential participants were identified; one was not eligible due to queried onset of dementia, and one declined to participate.

Five women provided informed consent to participate. All participants lived in the same area of a rural county in South-West England. Four participants were White British, resulting in a largely ethnically homogenous sample that mirrors the mainly White British population of the geographical recruitment area. None of the participants had children. Table 1 reflects participant demographics.

2.3 | Ethical considerations

Ethical approval was received by:

- University Faculty Research Ethics and Integrity Committee.
- Health Research Authority (HRA).
- Two NHS Research, Development and Innovation teams in South-West England.

Participants were given the option to invite companions to attend the interview with them, to support their wellbeing and help them feel more comfortable to voice their experiences. All participants chose to be accompanied, but it was only the voices of the women themselves that were invited during interviews.

Capacity to consent to participation was assessed by the interviewer before the commencement of the interview using accessible

TABLE 1 Participant demographics

| Pseudonym | Age | Menopause status | Health conditions (in addition to learning disabilities) | Others present in interview |
|-----------|-----|---|--|---|
| Helen | 47 | Perimenopausal | DiGeorge syndrome Paranoid schizophrenia | Senior learning disability liaison nurse |
| Sunshine | 58 | Ceased menstruating >6 years ago | Spina bifida Club foot | Senior learning disability liaison nurse Mother |
| Louise | 54 | No menstruation following removal of contraceptive implant 3 years ago | Seasonal affective disorder | Senior learning disability liaison nurse |
| Beryl | 50 | Ceased menstruating 2 years ago | Autism spectrum condition Dyslexia | Assistant practitioner in learning disability liaison nursing |
| Jane | 60 | No menstruation following cessation of combined contraceptive pill (used to manage perimenopause) 7 years ago | Mild cerebral palsy | Senior learning disability liaison nurse |

materials. Participants were informed that they could decline to participate at any stage during the interview, and that their support would not change as a result of their decision. Participants were made aware of confidentiality and safeguarding processes, and chose their own pseudonyms. Following the interview, participants were debriefed, and support was offered by the interviewer and clinician. Following interviews, participants were offered accessible information on keeping healthy during menopause, and a £10 voucher of their choice in recognition of their contribution to the research.

2.4 | Interview schedule

The interview schedule was cocreated with two consultants with learning disabilities and lived experience of menopause in relation to the aims of the research, and the wording refined with the support of a Speech and Language Therapist and the gatekeeper. The interview schedule included questions on the emotional, cognitive, physical, social and behavioural experiences of menopause, selfidentity, experiences of treatment, and factors that have been helpful and unhelpful. Interview questions were supplemented with visual aids, including images and simplified wording, co-created with a Speech and Language Therapist to support communication.

3 | PROCEDURE

Potential participants were given an accessible participant information sheet by their clinician. Initial phone calls were made with women who expressed an interest in participating to build rapport, talk about the research and provide opportunities for any questions. Participants were interviewed in their own home. Informed consent was obtained with the support of an accessible consent form.

Interviews were conducted with the support of visual prompts, were audio-recorded and transcribed.

Participants were sent accessible summaries of their interview to validate, outlining the main points the participant discussed alongside supporting images, presented in an 'easy read' format. Each participant was invited to review their summary and make any amendments, strengthening the credibility of the research and providing participants additional agency over their data.

The transcripts were analysed using IPA, following the six-step framework outlined by Smith et al. (2009). Each transcript was read multiple times and initial exploratory notes were made before emergent themes were developed. Extracts of transcripts were cocoded and reviewed by a research supervisor and an IPA research group composed of fellow Trainee Clinical Psychologists and researchers experienced in IPA. Connections were made across themes. This process was repeated for each transcript, and patterns across participants emerged. The data was physically handled, manually moving initial themes into emerging superordinate and subordinate themes. Due to the interpretive nature of IPA, the resulting themes are cogenerated between researchers and participants, while ultimately maintaining a focus on the participant voice (Smith et al., 2009). Bracketing interviews (Tufford & Newman, 2012) were held with research supervisors to allow the analysis to remain as close to the participants' experiences as possible.

4 | FINDINGS

Five superordinate themes and 11 subordinate themes emerged from the analysis. All superordinate themes comprise of data from all participants, as recommended by Smith et al. (2009). Themes are named with participant quotes. Themes are outlined in Table 2, described in turn, and illustrated with quotes.

TABLE 2 Overview of themes

| Superordinate themes | Subordinate themes |
|--|---|
| 'It's just knowing what to do' | 'I didn't really know what was happening' |
| | 'Like to have the information' |
| 'I don't want it to come back again 'cause it's horrible experience' | 'Very heavy, horrible to deal with' |
| | 'It causes a lot of problems' |
| 'She can always tell' | 'Body's changing' |
| | 'The moods have gone different' |
| 'I feel good today... I've seen you' | 'I get on really well with people' |
| | 'I've got better talking about it' |
| | 'We don't chat about that' |
| 'I just get on with it' | 'I didn't try no medication' |
| | 'I just help meself' |

4.1 | 'It's just knowing what to do'

Lacking knowledge and understanding was an important aspect of the experience of menopause for participants. Menopause, symptoms, menstruation and future expectations were unclear and questioned, with women desiring more information to support their understanding.

4.1.1 | 'I didn't really know what was happening'

Most participants had experienced a lack of knowledge around menopause, which inhibited their understanding of changes and symptoms they experienced. Helen was sheltered from her mum's difficult experiences of menopause by being removed from the situation when the doctor was called out, impacting her understanding: 'I didn't really understand what it was all about 'cause my cousin got me out the house'. Lack of knowledge was experienced as anxiety provoking and 'a bit frustrating' (Jane).

Many did not understand their symptoms at onset and tried to make sense of their experiences in terms of weather or other physical issues: 'I thought there was something wrong with me because I was... getting hot all the time, and I thought it was because that I was overweight' (Beryl). Jane, who did not experience hot flushes, did not understand them but was anxious to know if she would experience them: 'I don't know nothing about that yet... Will it come today?'. Questions were asked by participants about what to expect in the future, such as how long symptoms would last.

For those who had previously used medical intervention to suppress their periods, there was uncertainty as to whether they would menstruate again in future: 'It feels like, is it gonna come back?' (Jane), resulting in

them preparing themselves with menstrual products. Louise attempted to make sense of why her periods had not returned, disregarding menopause due to believing that menopause would feel worse: 'Periods haven't... restarted again. It could be 'cause I had it when I was a poorly'.

4.1.2 | 'Like to have the information'

Most participants desired more information to be available about menopause, through talking with others or having informational resources: 'It should be more out there really in the community and, not like, just brushed off like, you know' (Helen). Some participants wanted information to enable them to support others through menopause: 'Then I can understand if somebody else asks me that I could help them' (Jane).

When obtained, information about menopause was considered helpful to managing it: 'I feel better in myself because I know what I'm going through and like, I know, I can cope with it' (Beryl). However, time was needed to process information given: 'After she explained it... I thought it was gonna take me a few days to register this one in' (Jane).

4.2 | 'I don't want it to come back again 'cause it's horrible experience'

All participants experienced difficulties associated with periods, before and/or during perimenopause. Those for whom menstruation had ceased were united in their relief from the challenges posed by and associated with periods.

4.2.1 | 'Very heavy, horrible to deal with'

Every participant shared experiences of having to manage heavy periods. Some experienced heavier bleeding during perimenopause, which was unexpected: 'It's not gone lighter it's going heavier' (Helen).

Heavy periods caused hassle in terms of not knowing when to expect them, being prepared with menstrual products, and remembering to take them when leaving the house: 'Cause you go and take STs [sanitary towels] with you or... tampon things' (Louise). Jane highlighted the frequency with which she had needed to procure menstrual products, and the challenges of acquiring the appropriate products without support: 'Sometimes if I'm on my own, uh, I get a bit embarrassed 'cause I don't know what to get'.

However, there was a shared sense of relief not having to be concerned with menstrual products once periods ceased. This was represented by not having to carry a handbag constantly, and relief from invasive management strategies: 'It's nice not to be putting that up in your body' (Louise).

Heavy periods were experienced as 'difficult to cope with' (Louise), illustrated by accounts of uncontrollable bleeding: 'I've

had it go through my clothes, and it's a bit embarrassing' (Helen). However, ceasing menstruation was experienced positively in terms of easing maintenance of personal hygiene: 'Nice and clean' (Sunshine).

4.2.2 | 'It causes a lot of problems'

Physical impacts of menstruation were highlighted by all participants, including migraines, backache, feeling tense and 'sluggish' (Helen).

Well, just feel bloated all the time. Felt sick all the time because when you come on you've like, really like, really lightheaded and like, horrible. 'Cause like you're really heavy and you feel like you don't wanna do nothing. (Beryl)

The cessation of periods represented relief from these physical complaints: "It was lovely. No more pain!" (Beryl).

Louise experienced difficulties with endometriosis and urinary tract infections (UTIs) before her periods ceased, and she had not suffered any UTIs since. These infections preceded psychological difficulties that led to inpatient mental health admissions, which again have not been repeated since the cessation of periods: 'But now I'm out of hospital thank goodness, touch wood, fingers crossed'.

Most participants shared emotional challenges related to periods, including feeling upset, flat and bad-tempered. Furthermore, periods impacted on confidence and ability to go out, engage in activity and socialise: 'I've been really bad with it before where I was going somewhere and I just couldn't go, out with my friends' (Helen). Conversely, the absence of periods was experienced by some as being 'easier...'cause I can do things' (Sunshine), and better enabling social interaction.

4.3 | 'She can always tell'

Observable differences were used by all participants to illustrate their experiences of menopause. This included physical and emotional changes which were experienced as visible to others.

4.3.1 | 'Body's changing'

Primary concerns for all participants who did not suppress their periods through medical intervention before menopause were hot flushes and sweats. They were experienced as horrible, intense, and frequent, and were often described in terms of how they appeared to others: '[My boss] knew there was something wrong with me... I went red and hot, I was really hot, I am

sweating it was so hot... It felt like I was gonna faint but you don't, it's horrible' (Beryl).

'My face goes like a tomato. Really bluey red doesn't it... it seems a long time but it's not, it looks like I'm having a heart attack' (Helen).

Most participants also experienced change in their weight. The cause of weight gain was unclear, but visible: 'I well, look at the photos that I used to be a size 12 and now I'm like a size 22 and it's not good' (Helen). Some participants made efforts to reduce their weight, which were also observed: 'He said me "you've gone down in size in clothes" I went "yeah I have"' (Beryl).

Some participants experienced tiredness and less energy. Although this was understood as a result of keeping busy or medication, they resulted in altered sleep routines: 'I go to bed early and then people knock on my door I say "I'm going to sleep!"... I'm in bed before 10 o'clock!... I used to stay up really late' (Jane).

4.3.2 | 'The moods have gone different'

All participants reported changes in mood, although they presented differently. For some, mood changes were characterised by feeling unhappy or flat: 'I'm usually a happy person and sometimes I get, like, quite miserable with it' (Helen).

Some experienced grumpiness or anger, which could present through shouting or snapping at others: 'So [sister] says "come on girl, you're having a bad day". I says "yes I know I'm having a bad day"'. She knows straight away' (Louise). Fluctuations in mood were common, with no identifiable triggers noted other than by Louise who experienced seasonal affective disorder.

Some found difficulty generating words to represent their emotional experiences, using noises to express themselves: 'I used to be quite, quite good tempered in the mornings, but sometimes, some mornings I'm bit sorta ergh' (Helen).

Some experienced improvements in their mood, which were attributed to either the cessation of their periods: 'Happier' (Sunshine), or moving house: 'When I came to here... they knew I was happy... they knew the difference in me' (Beryl).

4.4 | 'I feel good today... I've seen you'

All participants valued social connection. Participants experienced a number of barriers to discussing menopause, but those who did have experiences of sharing with others found them beneficial.

4.4.1 | 'I get on really well with people'

Social connections were important for all participants. They enjoyed engaging in social activities, attending social groups, day centres, or

going to work because of the opportunities they provided to connect with others: 'Yeah it's quite fun, 'cause you meet, you meet other people, and you meet lots of friends' (Jane). Participants enjoyed relationships they shared with female family members and friends who represented sources of support: 'I see [sister] every day. My sister every day she checks on me' (Louise).

Some experienced their social connections increasing since menopause. Sunshine felt that others interact with her more since her periods ceased. Having started attending a new day centre during menopause, she was able to develop new relationships: 'Lots-lots friends there for, new friends see. New friends'.

Conversely, others missed social connections they enjoyed previously due to moving away from family and COVID-19 restrictions: 'Went to the day centre... I had people to talk to... And they would help me if I needed any support... they shut it because of the COVID... I miss that 'cause I miss all my friends' (Jane).

4.4.2 | 'I've got better talking about it'

Talking about menopause with others was helpful, allowing participants to better understand menopause and their experiences: 'I talked to my mum and mum said "it sounds like you're going through the change"' (Helen).

Talking with others allowed them to receive advice regarding strategies to manage menopausal symptoms: 'She just says "well just have a cold drink or, just go outside in the cold air"' (Helen), or support to seek treatment: 'I said to [sister] about it and she said me "well we'll go and see the woman and see what she says"' (Beryl).

Having positive relationships with family, friends or clinicians, and conversations with them about menopause helped participants feel supported and prepared: '[Senior Learning Disability Liaison Nurse] tells me exactly what- what to expect don't you?' (Louise). Talking with other women experiencing menopause allowed them to connect through shared experiences: 'All of a sudden I just had to take a top off, and she went to me "you're going through the menopause int ya?" I went "yeah" she said "welcome to my country, my life"' (Beryl).

It was important for participants to talk to others in a one-to-one conversation which remained confidential: 'Yeah she doesn't tell anybody or anything' (Helen). Participants felt better having spoken about menopause, even within the confines of the interview: 'I th-think I've felt more happier today because I've talked about it' (Jane).

4.4.3 | 'We don't chat about that'

Despite conversations about menopause being helpful, there were barriers to engaging in them. Menopause was experienced as taboo: 'In our family we just don't talk about it really... They sort of look at you think, don't talk, don't, don't go there' (Helen). It was considered private and embarrassing, which prevented participants from asking

about it: 'That's questions that I've never asked yet... embarrassment probably... I don't know, how much yet to ask' (Louise).

Discussions were limited or prevented by the availability of others. Jane experienced limited time with support staff which centred around practical support: 'Don't have- have people to talk to. Except for [support staff] on a Wednesday... But we don't talk about that very often...'Cause she's got other people to see... We talk about shopping... and medication'.

Participants felt limited in who they could speak with about menopause, naming only close female relatives, trusted clinicians and the interviewer. It was important for participants to speak with women only, 'cause the men don't wanna hear that' (Helen). The exception was with doctors, although Louise maintained a preference for females: 'There's sometime where I speak to, a female doctor rather than him... probably easier I think, rather than talk to him actually although he's, very understanding as a male'. It was important that they could speak to someone they know and trust, who has experienced menopause themselves, which prevented participants sharing with others: 'Cause they're all younger than me. The staff was. They wasn't really going through the- the change... I never really talked about it really' (Helen).

4.5 | 'I just get on with it'

All participants experienced menopause as something they dealt with independently. Women experienced barriers to accessing treatment and managed the challenges themselves.

4.5.1 | 'I didn't try no medication'

Despite the intensity of symptoms experienced, no participant was receiving prescribed treatment for menopause. Some described sensitivities to medications, causing side effects: 'I can't take any contraception tablets or nothing...'cause I swell up like a balloon' (Beryl). Helen was advised by her mum not to take prescribed medication for menopausal symptoms, fearing side effects: 'My mum said it would make you more worse that what you already are so, my mum read all the list of what it could do'.

Sunshine was the only participant to have tried HRT patches, but physical discomfort resulted in her decision to stop after 3 months. She described them being sticky and itchy on her skin: 'Had to wash in the body and got 'em wet and, wet and sticky'.

Lacking information about treatment options also formed a barrier to accessing them. Some were unaware of treatment outcomes for others, or lacked knowledge of available treatments. Beryl believed tablets were the only available treatment, dissuading her from pursuing prescribed medication: 'I hate taking tablets is the thing... I mean I take nine tablets now'. Helen did not try prescribed medication for menopausal symptoms because of its interactions with alcohol, which represented an important part of familial identity, and was unaware of alternatives:

Well it's, in our family I s'pose... we are like drinkers and, when we get together we do have a, bit of a to-do like, you know sometimes, even my mum will lay off one or two of her medications.

4.5.2 | 'I just help meself'

Participants managed physical and emotional challenges alone, moving to a private location such as a bedroom or bathroom to manage independently: 'Just uh, stay away from people until I sort myself out' (Helen). Relaxing, solitary activities were deemed beneficial for both physical and emotional difficulties, but could be interrupted with responsibilities: 'Although I looked at myself thinking I ought to take the dog up for a walk' (Louise). Walking was helpful for many, and Beryl experienced a sense of pride managing her mood with walks: 'I need to get out and go for a walk and I feel fine. It clears my head and thinking wow, I've done that' (Beryl).

Some managed their emotions through screaming or 'shouts... [at] myself' (Sunshine). Attempts were made to monitor themselves, using relaxation strategies to de-escalate: 'You gotta be careful what you saying to people like, I count to 10 sometimes' (Helen). Some found activity, including household chores, helpful to feeling more positive: 'Try and keep myself active, take my mind off it' (Louise).

All who experienced hot flushes used cooling strategies in efforts to feel more comfortable, including cold drinks, fans, opening windows, changing bedding and clothing. Thought was given to preparing these strategies in advance, not knowing when they would be needed: 'Just thinking of what you can do next to sort things out the next time round it comes' (Helen).

Efforts were made to make symptoms more manageable. Helen sequenced her symptoms to make them more predictable: 'I know when the voices come on that I'm due on for my periods and that's when I start getting the hot flushes'. Beryl took vitamin D and flaxseed to manage her hot flushes: 'Since I been taking them, it's not, I'm not getting like, hot hot'.

Participants made independent efforts to manage their weight through diet and exercise, but Jane found it unhelpful when others instructed her, and wanted more kindness: 'People will say to me, "oh Jane, don't eat too much sugar, you're gonna put too much weight on." And I just say "well that's not helping me is it if you keep saying that to me"'.

5 | DISCUSSION

Here, the five superordinate themes – the importance of knowledge, difficulties with periods, observable physical and emotional changes in menopause, the importance of social connection, and the need to manage independently – are considered in terms of the wider literature, and implications for clinical practice and future research are suggested.

Complementing previous research (e.g., McCarthy & Millard, 2003a; Willis et al., 2011), this study highlights the importance of women with learning disabilities being given accessible information in a form that can be retained. The findings indicate difficulties in seeking information themselves, and not feeling comfortable or permitted to ask questions regarding menopause. This prevents women from preparing themselves for change, understanding symptoms at onset, knowing available treatment options, and understanding the potential risks associated with postmenopausal bleeding. Lacking understanding can cause concern and result in generating alternative explanations for symptoms, which begs the question of how women who are never told about menopause make sense of and cope with their experiences.

Physical aspects of menopause, and challenges managing these, form a common thread throughout the transition. Unlike McCarthy's (2002) findings, participants experienced hot flushes as intensely uncomfortable, and the common strategy employed to move to a private location suggests embarrassment. Perceptions that menopausal symptoms are observable to others added to their problematic description. Phillips (2007) previously demonstrated how older women with learning disabilities are subject to surveillance and recording of their actions and bodily functions, which 'served to centralise the female body form in the public arena' (p. 512). Phillips suggested that these women tell their stories through their bodies, which may help explain the emphasis participants placed on physical symptoms and appearance. The findings may therefore be indicative of wider societal attitudes towards women with learning disabilities and scrutiny they endure, which translates into their experience of menopause as being observed through their bodies.

However, the perceived observable nature of their emotions appeared to be experienced more positively. Perhaps, considering difficulties in verbalising internal states, it was helpful for participants to have their emotions recognised, and feel understood by others. This study revealed various emotions experienced by participants in menopause, ranging from misery to anger to happiness. Difficult feelings could be managed with behaviours such as screaming and shouting, which may be misunderstood or perceived as challenging. Participants demonstrated some awareness of this through attempts to monitor themselves and adopt different strategies. It is important to consider these responses as methods of coping with internal challenges that may be difficult to verbalise, to avoid diagnostic overshadowing.

Research within the general population has focused on negative impacts of menopause on mental wellbeing (Riecher-Rössler, 2020), but this study indicated potential improvements in mood and mental health, seemingly resulting from the immense difficulties associated with menstruation. Variations in mood are undoubtedly also related to external life events which can and did occur at this time of life. Interestingly, those who reported positive changes in mood also experienced more social connectedness during menopause, complementing research conducted within the general population (Deeks, 2003). Three participants had moved home in the past year, which was associated with independent living, loss of a parent,

moving away from or towards family. It is important to recognise that menopause may come at a time when women with learning disabilities are experiencing other significant life changes. The greater sense of independence participants may be assuming in other areas of life may help to explain the emphasis placed on managing menopause independently.

This study has contributed understanding into the importance of social connections among women with learning disabilities in menopause, particularly with those sharing similar experiences. Although this is already recognised within the neurotypical population (Refaei et al., 2022), in-depth consideration of the value of social connections in menopause is novel to literature pertaining to experiences of women with learning disabilities. For some, menopause represented improved ability and confidence to go out, engage in activity and socialise. However, it is possible that women with learning disabilities have less opportunity to connect with others experiencing menopause, considering the perceived taboo, and greater reliance they may have on others to start conversations and organise events. Although 'Menopause Cafés' have been set up throughout the United Kingdom (Weiss, 2020), groups tailored for women with learning disabilities have not received the same attention.

It is noteworthy that all participants engaged with an unknown, young, female interviewer with no lived experience of menopause. The process of this research may therefore suggest that, even in the absence of others experiencing menopause, having dedicated time with someone interested in their experiences is valuable.

It is recognised that this research was undertaken under the context of COVID-19, a time when social connections have been widely threatened, perhaps especially for people with learning disabilities who are considered particularly vulnerable (Courtenay & Cooper, 2021). Therefore, this may be a time in which social connections are especially pertinent and important to nurture.

Although this study did not set out to explore experiences of menstruation specifically, it appeared important for participants to acknowledge and discuss when considering menopause. Participants were unanimous in their negative experiences of menstruation and peri-menopausal bleeding, which impacted various aspects of their wellbeing, and thus menopause represented relief from challenges associated with their periods. The additional challenges that women with learning disabilities may face in managing menstruation compared with the general population, such as keeping track of menstrual cycles, maintaining privacy, accessing appropriate menstrual products and pain relief (Ditchfield & Burns, 2004; Rodgers, 2001), may account for why menopause was experienced in this way, rather than the overwhelmingly negative construction in traditional Western culture (Utian, 1997).

It is noteworthy that common physical symptoms of menopause (e.g., vaginal dryness and discomfort, thinning hair, increased facial hair, change in skin), and impact on fertility, were not commonly identified or discussed by participants. This may be explained by different factors, including lack of knowledge that these result from menopause (McCarthy, 2002; McCarthy & Millard, 2003a; Willis, 2008; Willis et al., 2011), difficulty acknowledging these

changes (McCarthy & Millard, 2003a), embarrassment talking about these issues, challenges of recalling previous symptoms that may no longer be affecting them, or simply that these were not important aspects of their experience. Considering the regulations people with learning disabilities can experience regarding their sexuality, and pressure they may feel from others against having children (Fitzgerald & Withers, 2013), it is conceivable that participants may have held long-standing beliefs/decisions that they would not experience motherhood, and thus fertility was not salient to their experience.

The findings offer novel insights into the challenges of receiving treatment for menopausal symptoms. These relate to the lack of information provided to people with learning disabilities about medications, echoing experiences of other prescribed medications within this population (Smith et al., 2019). Given previous difficult experiences with medications, participants were fearful of potential side effects and were unaware of alternative options. O'Dwyer et al. (2018) have highlighted issues with pharmacology in older adults with learning disabilities, including increased sensitivity to medications and risk of adverse effects. Thus, reticence regarding treatment for menopause, and decisions to decline or stop taking them, are understandable. However, it is important that information is offered about alternative options to enable informed decisions regarding treatment.

5.1 | Reflections on methodology

Although a small sample size was anticipated within the design, difficulties experienced with recruitment resulted in fewer participants than were sought, all of whom were recruited through a single gatekeeper. Such challenges may contribute to gaps in knowledge regarding experiences of people with learning disabilities. Consequently, it is important that future research does not underestimate recruitment challenges, and dedicates adequate time and resources to building relationships with gatekeepers and potential participants, to ensure that valuable insights offered by those with lived experience are captured.

All participants chose to invite a trusted person into interviews with them, which risks potential influence. This could be overcome in future research if more time was available for researchers to build relationships and rapport with participants before conducting interviews, potentially alleviating the need to be accompanied in the presence of a known interviewer. Despite the potential bias an observing clinician can introduce, it is also worth noting the benefits this can offer. The gatekeeper attended the majority of interviews, heard the experiences shared and, following data collection, met with participants to discuss them further, adapting care plans and agreeing new interventions. Thus, participants gained direct clinical benefit, further highlighting the importance of inviting conversations regarding menopause.

5.2 | Implications for clinical practice and policy

Research highlighting personal experiences of service users is vital to informing policy and clinical practice, to facilitate meaningful service

development. This research has indicated a number of implications, which are summarised below:

- Confidential, one-to-one conversations about menopause should be initiated by female carers and clinicians, demonstrating that it is an acceptable topic to discuss within such relationships, and challenging the perceived taboo. Careful attention needs to be paid to menopausal experiences when they are expressed, and questions about menopause need to be invited, without assuming women will ask them spontaneously, to offer meaningful insights into individual experience.
- Accessible information about menopause needs to be provided, both within conversations and in a visual format to allow time for processing and to provide a resource to refer to when needed. Information is required before onset, to support women to understand their experiences as they occur, avoiding unnecessary anxiety regarding their physical and mental health. Information may need tailoring to the individual, to meet their communication abilities and to make links between their personal experiences and menopause.
- Treatment needs to be carefully considered with women, providing accessible information regarding different options. The likelihood of side effects and interactions with other substances need to be considered in relation to the individual woman's health, experiences and lifestyle. Sensory sensitivities require deliberation, particularly regarding skin patches and prescribed treatments require follow-up to offer advice, reassurance, or alternative options.
- Menopausal women with learning disabilities should have opportunities to connect with others with similar experiences to allow them to be normalised. Peer support groups may offer a helpful forum to discuss such issues.
- Social activity more generally may be helpful to women experiencing menopause, to offer the relationships which are highly valued by participants.
- To effectively support the above recommendations, carers and clinicians working with people with learning disabilities, both qualified and in training, should receive training to support understanding of the various impacts menopause can have on women with learning disabilities. This should include potential impacts on physical and mental health, and relationships, both positive and negative. It is hoped that this will contribute to informed formulations and interventions, and may offer alternative hypotheses for behaviours that challenge.

5.3 | Future research

Findings suggested some differences in the experiences of women who had used medication to suppress their periods before menopause, compared to those who had not, within the small, and otherwise fairly homogenous sample. More extensive data is required within research adopting different methodologies to generate generalisable findings and identify variables within this population that can influence experience.

Creative, flexible approaches are required to involve women with more severe levels of learning disability who may be nonverbal, and those who have never been informed about menopause. Collaboration with Speech and Language Therapists may support the development of accessible materials to enable their experiences to be expressed, and to explore how they make sense of these.

Importantly, future research should recognise the unique value of seeking direct experiences of women with learning disabilities, further uplifting their voices and encouraging their perspectives to actively inform policy and practice improvements.

6 | CONCLUSIONS

This study aimed to provide insights into the experiences of menopause in women open to NHS learning disability services, through semistructured interviews exploring psychological, social and physical implications. The findings contribute to the limited existing literature by indicating that menopause is perceived as an observable phenomenon, demonstrating the need for female carers and clinicians to be proactive in initiating conversations about menopause and treatment options, and highlighting the importance of social connections. This research offers unique contributions by attending to the voices of women with learning disabilities, shining a light on lived experiences of menopause and the impact it can have on relationships, physical health and mental wellbeing.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

Research data are not shared. Research participants have not consented to having the raw data shared outside of the research team.

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