

Development of a menopause education programme for women with a learning disability

Background

Menopause is the permanent cessation of menstrual cycles for 12 consecutive months¹ (WHO, 1996) that typically occurs between 46-52 years.² All women experience menopause, including those with a learning disability (LD). However, those with a LD typically experience menopause earlier than the general population³ In addition, they often experience disparities in relation to sexual and reproductive health services and information,^{4,5} and are typically not adequately prepared for menopause.⁶

Previous research has demonstrated that menopausal education programmes in general can improve knowledge of menopause,^{7,8,9} symptoms associated with menopause^{10,11} and quality of life^{12,13} in menopausal people. They can also empower individuals to manage the signs and symptoms of menopause when they arise.¹⁴ However, people with LD have reduced ability to understand new or complex information,¹⁵ and thus a menopausal education programme for the general population should be adapted and delivered using a variety of methods, such as role-playing, reinforcement and corrective feedback,¹⁶ and quizzes.¹⁷ Despite menopause being an inevitable event for women with LD, to date there has been no research evaluating menopausal education programmes for this population. A PPI survey sent to LD organisations in the Northwest region of Northern Ireland was reflective of the research findings. From the 26 respondents, most (46.15%) reported their general knowledge of menopause was not good and most (79.19%) had not supported anyone with a LD with menopause. Most respondents (96.17%) were not aware of any educational programs to support women with LD around menopause, with the majority choosing to signpost any women to their GP for support however most identified that education would help them better to support women with a LD around menopause.

The aim of this study was therefore to design, deliver and evaluate a menopause education programme for women with LD and establish its acceptability and potential impact on knowledge. The study also aimed to determine any adaptations required for the programme and the acceptability of evaluation measures from the perspectives of women with LD.

Methods

Education programme design

A multifaceted approach was used to design the education programme. The education programme was co-developed by researchers from Ulster University in collaboration with a community partner organisation, Informing Choices NI. Additionally, a rapid review of menopause programmes was conducted to inform the programme's content. The community partner then worked with key stakeholders to further refine the intervention. This process included in-person discussions about the intervention with women with learning disabilities, support workers, and a manager from a lived experience organisation.

The initial iteration of the programme consisted of 6 sessions, designed to be delivered in 1 hour using a variety of mediums (Table 1).

Implementation and evaluation

A mixed methods quasi experimental design was used to implement the programme with six groups of women with a learning disability in the community setting.

Participants / Eligibility

Community organisations currently supporting women with learning disabilities were identified within the Northwest region of Northern Ireland. The organisations were asked to share study information with women with LD aged 18 years and over and their carers, who attend their organisation. To be eligible for participation, women needed to be able to provide informed written consent, via adapted communication aids and approaches to meet their communication preferences (if required). The participants also had to be able to communicate their views within a group setting. Individuals not known to one of the recruiting organisations, and those who could not commit to taking part in the intervention were excluded from the study. Translation services were not available and thus people who were unable to communicate in English were unable to participate.

The community partner (member of the research team) then visited the organisations to meet with those interested in taking part. At this meeting, the researcher confirmed eligibility of participants, answered any questions about the study and those who agreed to participate completed a paper consent form.

Consenting participant organisations received an appointment letter confirming the dates, times, and location of the menopause education sessions.

Education programme

Sessions were held in person on the premises of the relevant LD organisations; therefore, participants were to be only able to attend their member organisation's session. The education programme was designed to be delivered across **six** groups (one per LD organisation) of 5-10 participants. Participants were asked to attend weekly sessions, one hour per week for six weeks. Participants were encouraged to attend the sessions independently and a member of staff from the LD organisation was present for safeguarding purposes. All sessions were led by the community partner researcher who has over 19 years of experience working with adults with LD. All education sessions were audio-recorded and used by the session facilitator to write a reflective log regarding acceptability of the sessions and to identify any changes required.

Evaluation

The primary outcome, acceptability of menopausal education programme, was explored through focus groups conducted at the end of the final group session. These were led by an independent experienced researcher, using a focus group schedule. Focus groups lasted approximately 30 minutes and were audio recorded.

Knowledge of menopause was explored through a tool previously developed by the researcher. The measure was used pre and post completion of the education programme and at follow up, 12 weeks post completion of the programme. The score obtained based on obtaining a correct versus incorrect answer based on a pre-defined answer sheet, for example answering 5 out of the 10 answers correctly resulted in a score of 50%. The measure was completed independently by participants; where required, a member of staff from the LD organisation offered additional support. After the initial two groups it was identified that the knowledge of menopause questionnaire was not suitable for the LD population therefore a more suitable questionnaire was designed and delivered to the final four groups. As a result, evaluation will be reported at an individual group level, in accordance with the outcome measure employed.

To support the programme evaluation, the facilitator kept a reflective diary after each session. This focused on all aspects including both positive and negative experiences. This log also provided a tool for the facilitator to personally reflect on any changes needed for the next session.

Data analysis

SPSS was used to analyse quantitative data (objectives 1 and 2). Descriptive statistics outlining the differences in outcome measurements between pre- and post-intervention, using mean difference and 95% confidence intervals were reported.

A reflexive thematic analysis was conducted for both the focus groups and facilitator reflections, using NVivo, to identify themes within the data, based on Braun and Clarke 6 stage process.¹⁸ This involved familiarisation of the data, independently by two researchers followed by creation of initial codes. Codes were then sorted into broader themes independently before reviewing and refinement of each theme. Between each stage, the two researchers met to discuss their findings until consensus was reached.

Results

Educational programme design and delivery

A six-week education programme was developed and supported by a range of interactive activities (Table 1). Each session was delivered one hour each week, across six weeks, at six different community venues.

Table 1; Educational programme overview

Week	Topic	Methods	Time (mins)
1	Group contract and confidentiality	Group discussion; Co-design rules for the group with support from the facilitator. Recorded on flipchart.	10
	What do you know about menopause?	Group discussion with use of flipchart paper/ markers to draw / write ideas. Smaller group discussion with feedback to main group.	20
	Which of these are signs and symptoms of menopause?	Facilitator led interactive quiz. Participants individually answer questions in a medium that suits them (verbally, written, multiple choice)	25
	Close	Final comments and feedback	5
2	Group contract and confidentiality	Group discussion; Revisit contract, add/change as needed	5
	Using the proper language for body parts	Group activity with use of paper/markers focusing on the proper words for the private parts of the body. Use of resources to discuss what these parts look like and why it's important to use the proper words.	20
	Body changes throughout our lives	Smaller groups; Draw outline of girl and draw/write in all the body changes that happen throughout life. Feedback to whole group and discuss	30
	Close	Final comments and feedback	5

3	Group contract and confidentiality	Group discussion; Revisit contract, add/change as needed	5
	Periods	Group discussion; with use of flipchart paper / markers to feedback what people know/think about periods. Animated video looking at what happens when a women has a period. Art exercise around how we can make periods 'better'	50
	Close	Final comments and feedback	5
4	Group contract and confidentiality	Group discussion; Revisit contract, add/change as needed	5
	Symptoms of menopause	Revisiting week 1 quiz. Group discussion focusing on other symptoms. Short video around symptoms.	25
	What to do when you experience symptoms and who you can talk to	Group discussion; How symptoms can make you feel, ways to make you feel better. Discussion on scenarios of women experiencing symptoms and who the group think they should talk to. Looking at options including support staff/family as well as health professionals	25
	Close	Final comments and feedback. Ask the group to think of their favourite way to relax for next week (could be a song/tv show/film/bath...)	5
5	Group contract and confidentiality	As previous week	5
	Ways to help/deal with menopause	Group discussion; from previous week around symptoms. Multiple choice quiz around different ways to help ease symptoms.	20
	Mindfulness/Self care	Discussion around ways to relax when we're feeling anxious/stressed. Looking at what participants chose as their favourite ways to relax. Short mindfulness session on breathing techniques.	25
	Close	Final comments and feedback	5
6	Revisit group contract	As previous week	5
	Quiz around what has been learned (quiz)	Similar quiz as first session with some extra questions	30
	Feedback	Discussion around what participants thought of the programme. Everything written up on flipchart	20
	Close	Give group my details if they need to contact me for information or support after the programme has ended. Ask group if it is ok to follow up in a few weeks' time to look at any further feedback.	5

Acceptability of the intervention

This focus on participation, attendance and participant experiences identified via focus groups.

Participation

A total of 43 women with LD, aged between 19 years and 53 years, participated in one of six groups. The total number of participants per session ranged from 4-8, with some sessions also having support staff present from the voluntary organisation (Table 2). Their role was to support individual participants within the group.

Table 2; Participation overview per group per week

Group	Session					
	1	2	3	4	5	6
Group 1	6P 2S, 1V	7P 2S 1V	6P 2S	6P 3S 1V	6P 3S 1V	6P 3S 1V
Group 2	6P 3S	7P 3S	7P 2S	6P 2S	6P 2S	6P 1S
Group 3	8P 2S	4P 1S	5P 1S	5P	4P 1S	5P 1S
Group 4	4P 1S	5P 1S	6P 1S	6P 1S	5P 1S	6P 1S
Group 5	4P 0S	5P 0S	5P 0S	5P 0S	3P 0S	0
Group 6	7P 2S	8P 2S	8P 1S	8P 1S	8P 1S	8P 1S

P = Participant, S = staff, V = volunteer

Attendance

Session attendance was high. Discounting one session, in which there was an error in organisation, session attendance ranged from 50%-100% with the average being 85% (Table 3).

Table 3; Attendance breakdown per group, per week

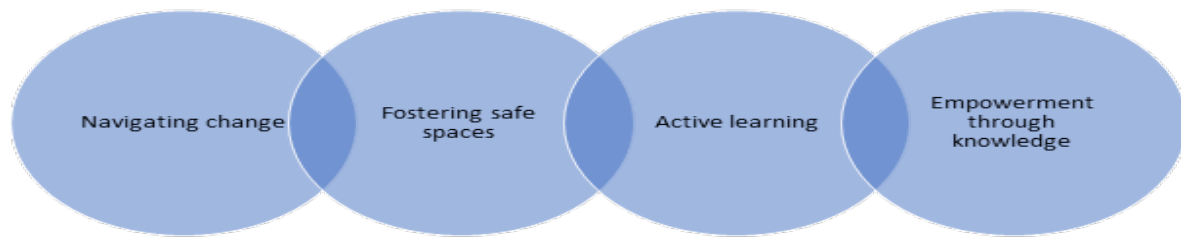
Group	Session					
	1	2	3	4	5	6
1	67%	67%	67%	100%	100%	100%
2	86%	100%	100%	86%	86%	86%
3	100%	50%	63%	63%	50%	63%
4	67%	83%	100%	100%	85%	100%
5	80%	100%	100%	100%	60%	0%*
6	88%	100%	100%	100%	100%	100%

*error in organisation; rearrangements could not occur

Participant experience

A total of 33 from the 46 participants participated in one of six focus groups (range 5-8 participants per focus group). Across the six focus groups, four main themes were identified; Navigating change, fostering safe spaces, active learning and empowerment through knowledge (figure 1). The overall description of the depth of discussion around the themes are provided rather than counting the number of times a theme was mentioned. ¹

Figure; Focus group themes



Overview of themes

Theme 1; Navigating change

During the focus groups, participants identified how useful the education sessions were to support them in discussing changes they were currently experience or would experience in the future.

P1: It was good to talk about things. You know, the symptoms that you have or side effects or something like that there. Really good to know

In particular participants reflected on the positive impact on exploring how changes relating to menopause affect many aspects of life and the support options open to women with LD.

P3: And you could talk to your key workers about it.

Theme 2; Fostering safe spaces

Participants felt the education sessions provided a safe space where participants felt comfortable expressing themselves. Being with other women with LD was important and this resulted in them being more confident to discuss the topic of menopause.

P2: I like the group best because you get different, you get different point of views. You'll see how other people would handle it. In here we're a mix of ages so we can all see what each other are going through.

For some they identified it as the only setting they felt they could discuss it, highlighting the need for such programmes in the future.

P6: It's kind of like spending time on your own with the group because the other boys cannot hear what we are saying. We have to keep it on here.

Theme 3; Active learning

How the sessions were delivered was a positive experience for participants.

P3: I liked too that (the quiz) last week whenever we did it, there was a question on it to name five symptoms of menopause. So , you really were thinking right ok, so it really shows that what you have learned than before and it's kind of like an assessment type thing.

The use of visuals, colouring, interactive activities to support learning was key to support the women to engage with the content.

P3: Deborah, showed us a video about the menopause on her laptop. It showed us what the menopause does to you. It was very, very good.

Theme 4; Empowerment through knowledge

Participants identified how being prepared and knowing what to expect when menopause occurs give them confidence.

*P3: You know what symptoms you're going to get.....If you get sweaty you know what it is.
P3: I'd be more confident like if somebody in my family was going through it, I'd be more confident to talk about it now than beforehand because I didn't know in detail what was menopause or like any of the symptoms really.*

This confidence also reduced concerns in how to manage such symptoms. For others they identified how they could support others with the knowledge they had learned during the sessions.

P2: Or how you could help others because you know, you can kind of help others because I could have a family member or friend who could be going through it now.

Reflections from Deborah

Six main themes were identified (table 4) from the reflective log maintained by the session facilitator; knowledge, successful learning and engagement strategies, challenges, support network identification, inclusivity/ participant support and room conditions/ environment. A summary of the main aspects of each theme are provided below.

Table 4; Researcher reflections

Theme	Overview
Knowledge	<ul style="list-style-type: none"> • Participants expressed limited knowledge about menopause, eager to learn • Participants expressed surprise at the breadth of symptoms, fostering discussing on coping strategies • Notable interest from peri-menopausal participants • Clarification provided regarding menopause not being a disease but a natural phase of life for women • Clear barriers identified in accessing healthcare support
Successful learning and engagement strategies	<ul style="list-style-type: none"> • Educational videos for knowledge gaps • Artistic activities lighten and foster positive discussions • Quiz sessions • Drawing • Interactive discussions on body changes from childhood to menopause facilitated understanding and camaraderie within the group. • Visual aids e.g. empty HRT packages • Incorporation of breathing exercises met with enthusiasm • Practical applications suggested for management of stress
Challenges	<ul style="list-style-type: none"> • Other activities scheduled causing sessions to be delayed • Challenge to switch focus if participants attending straight after another activity • Staff shortages in the support organisation impacting session organisation • Initial session, some groups were quiet – unfamiliar with the facilitator
Support network	<ul style="list-style-type: none"> • Importance of support networks highlighted including family, friends, support workers • Organisational buy-in to programme key to support participation • Close relationships amongst participants contributed to a supportive / inclusive atmosphere

	<ul style="list-style-type: none"> Identified need for womens support group going forward and dedicated space in centre
Inclusivity / participant support	<ul style="list-style-type: none"> Personalised assistance due to literacy challenges Sensitivity to individual needs important with adjustments made to terminology and support networks.
Room conditions and environment	<ul style="list-style-type: none"> Relaxed seating arrangements needed to support delivery Room environment was key; one room was unsuitable due it being a computer suite (this was rectified), another had an activity occurring next door with frequent interruptions from the other activity Active participation from support staff supported engagement from participants

Impact on knowledge

Thirty-six participants completed the original knowledge questionnaire prior to completing the education sessions. The overall mean score was 58.7% (range 6-100%), with the two participants who scored 100% reporting they were currently experiencing menopause. After completion of the education sessions, 21 participants repeated the questionnaire. An average score of 98.6% was achieved (71-100%). All participants, except 1, scored 100%.

A small number of participants (n=14) completed the revised version of the questionnaire, based on a Likert scale. Post intervention participants reported their knowledge had 'improved a lot' across 61 items within the questionnaire and 'improved a little' across 23 items. In terms of specific knowledge, at baseline the most common incorrect answers were identified as 'who you can talk to about menopause' and 'who can give you support'. Post intervention, the most common correct answers related to 'what age do periods end' and 'what can help you'.

Discussion

Educational Programmes for Women with Learning Disabilities

Educational programmes tailored to specific populations, such as women with learning disabilities (LD), play a crucial role in addressing their unique needs and enhancing their quality of life.²⁰ This study aimed to design, deliver, and evaluate a menopause education programme for women with LD, recognising significant gaps in their knowledge and support regarding menopause. The findings emphasise the importance of such education initiatives in empowering this population to navigate the challenges associated with menopause effectively. Furthermore, the importance of commencing such education prior to menopause occurring is highlighted.

Challenges in Accessing Sexual and Reproductive Health Information

Women with LD often encounter challenges in accessing sexual and reproductive health information and services, leaving them ill-prepared for menopause.²¹ This study highlighted that many participants lacked fundamental knowledge about menopause, including its symptoms and available support options. This aligns with previous studies²⁰ where the need for readily available,

appropriately-tailored menopausal education materials is recognised, highlighting a gap in research specifically focused on menopause and the LD population.

Improving Knowledge through Tailored Education Programmes

The findings of this study indicate that participants showed potentially significant improvements in knowledge after engaging in a tailored education programme. This highlights the effectiveness of targeted educational interventions in addressing knowledge gaps and enhancing understanding among women with LD. Such an approach has also been recommended in previous research²⁰ and the implementation of such interventions identified as a current gap in the existing literature.²¹ The group facilitator's observations also noted the limited knowledge among participants regarding menopause, highlighting their eagerness to learn and their surprise at the breadth of symptoms. This emphasises the necessity for educational initiatives tailored to this population.

Group Setting, Teaching and Learning approaches, and Training Needs

The group setting emerged as a cornerstone of the educational intervention, providing a nurturing environment where participants felt empowered to engage in open dialogue and learning. This finding highlights the importance of fostering supportive group dynamics to facilitate meaningful discussions around menopause-related topics among women with learning disabilities. Peer support and shared experiences played a pivotal role in cultivating this conducive atmosphere, allowing participants to feel more at ease when addressing sensitive aspects of menopause. Support for the effectiveness of group-based interventions in promoting open discussion and learning can be found in studies conducted with other populations including LGBTQ Youth and Mental Health.^{22,23} These studies emphasise the significance of creating safe spaces where individuals feel comfortable sharing their experiences and learning from one another.

Furthermore, the integration of interactive activities, discussions, and visual aids during group sessions significantly contributed to the active engagement and learning experiences of the participants. This participatory approach is consistent with recommendations from educational psychology literature²⁴ which has demonstrated its effectiveness in enhancing knowledge retention and comprehension among individuals with diverse learning needs. The use of a variety of teaching methods and a supportive approach, wherein the facilitator/educator demonstrates a genuine interest in the participants, are considered the most effective approaches to support teaching and learning for adults with learning disabilities.²⁵ These principles were reflected in the current study and supported by the observations of the group facilitator. Their insights suggested that the range of learning and engagement strategies employed were effective in facilitating learning and fostering positive interactions within the group. These findings are consistent with recommendations for employing varied teaching methods and supportive approaches specific to this population.²⁶

Additionally, the use of mutual support, a model of peer support has been demonstrated as a well-established method to support participation and ultimately learning.²⁷ However, it is important to note that the effectiveness of group settings may vary depending on various factors such as group dynamics, facilitator expertise, and individual preferences. A recent scoping review²¹ suggested most women with LD do not have access to group educational programmes and women that do seek support receive this support on an individual 1:1 basis usually from key workers, doctors, family and friends. Therefore, while group interventions can be beneficial, such educational group interventions may not be available or suitable for everyone, and alternative approaches should be considered

based on individual needs and preferences. Improving the knowledge of individuals who frequently interact with the LD population, such as key workers, on the topic of menopause and boosting their confidence in discussing it with persons with LD, should help bridge the gap where access to educational interventions is lacking. This approach wouldn't aim to substitute contact with GPs; instead, it would empower individuals with LD to access healthcare more readily, thereby reducing health inequalities.²⁸ Future research therefore should consider a mixed approach whereby group education is scaffolded with individual support sessions, conducted by those in most regular contact with the LD population, such as key workers. The positive outcomes observed within the group setting highlight the potential of tailored educational interventions to empower individuals with learning disabilities to actively participate in their learning journey and foster a supportive community of mutual learning and understanding, therefore access to such services is much needed to fill this gap.

Addressing Gaps and Promoting Inclusivity

Despite the positive outcomes of the education programme, the study identified several gaps in support and resources for women with LD in the context of menopause. These included limited access to healthcare professionals knowledgeable about LD and menopause, as well as insufficient awareness among general practitioners (GPs) about the specific needs of this population. Furthermore, women with LD identified that they valued the support provided by those working in charitable and voluntary organisations, outside of their family and formal support networks. The role of such charitable and voluntary organisations should be considered for future funding and the rollout of educational interventions.

Moreover, the group facilitator's observations outlined challenges such as scheduling conflicts and staff shortages, indicating the need for organisational support and resource allocation to ensure smooth session delivery. The importance of support networks, both within the sessions and beyond, was highlighted, emphasising the role of family, friends, and support workers in facilitating participation and inclusivity. The group facilitator also noted the significance of room conditions and the environment in supporting effective delivery, emphasising the need for relaxed seating arrangements and conducive spaces for learning. These reflections reinforce the importance of considering environmental factors in designing educational interventions for individuals with LD. This study highlights the lack of tailored support services and educational resources for women with LD transitioning through menopause. There is therefore a need for enhanced collaboration between healthcare providers, community organisations, and advocacy groups to develop inclusive and accessible support programmes for women with LD. Additionally, to support the future healthcare workforce and actively reduce health inequalities, it is imperative to address these gaps through targeted interventions and systemic changes.³⁰ This may involve providing training for key workers and healthcare professionals, including GPs, to improve their understanding of LD and menopause and enhance their ability to provide inclusive care. Additionally, ensuring medical students at the undergraduate level are equipped to provide this tailored support will ensure a long-term sustainable impact.²⁹ Furthermore, continued collaboration with community organisations and LD advocacy groups is essential to ensure the ongoing development and delivery of tailored support programmes. Securing funding from public health authorities to sustain these initiatives and expand their reach to other regions is also crucial for promoting the health and well-being of women with LD.

While the positive outcomes of this research were captured, the optimal evaluation tools to support the evaluation of knowledge with this population are unknown. While we present one option to evaluate this impact, our results are limited due to the change in outcome for the final two groups.

Conclusion

Overall, the findings highlight the importance of education, peer support, and collaborative efforts in empowering women with LD to navigate the menopausal transition with confidence and dignity. This research identified a successful method to support women with LD with menopause and identified ideas for future development to this under researched area.

Declarations

- Ethics approval and consent to participate; Ethical approval was granted from the Ulster University Research Ethics committee in July 2023 (reference; REC/23/0042). All participants were provided with a participant information sheet outlining the purpose and methods to be used in the study. Participants were reassured that participation was voluntary, with an option to withdraw at any stage. Contact information for the research team was provided in addition to confidentiality and data handling procedures to be used during the study.
- Consent for publication; Participants were informed within the participant information sheet that anonymised data may be published. A subsequent written consent form was completed based on this.
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