Maindal *et al. BMC Women's Health* (2025) 25:187
https://doi.org/10.1186/s12905-025-03731-1

BMC Women's Health

RESEARCH **Open Access**

Co-developing a digital mindfulness- and acceptance-based intervention for endometriosis management and care: a qualitative feasibility study

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Abstract

Background MY-ENDO (Mind Your ENDOmetriosis) is a mindfulness- and acceptance-based endometriosis self-management intervention aimed at teaching women with symptomatic endometriosis how to manage and reduce negative physical, psychological, and social consequences of endometriosis. This study aimed at involving women with endometriosis in the co-development process of a digital version of MY-ENDO to investigate their experiences with and attitudes toward the intervention.

Methods The study was designed as a qualitative feasibility study. The empirical material consisted of 35 interviews with seven women who self-reported a diagnosis with endometriosis, based on a semi-structured interview guide. Each participant completed the first four sessions of the intervention and was interviewed before the first and after each of the four sessions (five times in total) during participation. The study was based on a phenomenological approach and the data were analyzed using Braun and Clarke's thematic analysis strategy.

Results Analysis indicated that the two parts of the program called 'knowledge of the disease' and 'management of the disease' with eight related subthemes were crucial for participants' outcomes. In addition, a generic theme called 'motivation and alliance' was identified.

Conclusion The digital self-management intervention MY-ENDO was generally experienced and evaluated as positive. It was considered an advantage that the program was specifically tailored to and targeting endometriosis as well as developed in collaboration with patients. Having a contact person was deemed important with regard to maintenance and motivation suggesting potential consequences for the implementation of this digital solution in clinical practice.

Keywords Endometriosis, Digital mental health, Mindfulness-based intervention, Self-management intervention, Patient co-development, Qualitative feasibility study

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Background

Evidence indicates a persistent issue of systemic gender bias in healthcare and research. This bias can be partly attributed to an enduring androcentric perspective and the resulting disparities in research funding allocation [1, 2]. Endometriosis is one such example [3, 4], a chronic condition estimated to affect up to 10% of women of childbearing age worldwide [5]. Despite its prevalence, research on endometriosis remains insufficient, spanning from understanding its causes to improving diagnosis, treatment, and long-term management [6, 7].

Endometriosis is a chronic condition characterized by the growth of endometrial-like tissue outside the uterus, typically in the pelvic region, leading to bleeding, inflammation, and adhesions [8]. It is associated with a broad spectrum of physical, psychological, and social consequences, including cyclical and chronic pelvic pain, dyspareunia, infertility, and fatigue. Additionally, those with endometriosis face an increased risk of stress, anxiety, and depression [9–11]. The negative impact on quality of life, as well as physical and mental health, is well documented and appears to correlate with the frequency and severity of pain symptoms [12–14].

The diagnostic delay ranging from on average 7–9 years from symptom onset to diagnosis [8–10] implies an appertaining risk of exacerbation of the disease, symptom worsening, and consequently impairment of quality of life and workability. Treatment options are limited and consist of hormonal treatment and/or surgery combined with pain medications [9]. The actual combination of treatments depends on the specific symptoms and individual needs and preferences of the patient, but treatments can be intrusive, cause significant side effects, and in some cases be without significant effect leaving the patient to manage the symptoms and consequences on her own [15].

To help those with endometriosis to better self-manage these negative physical, psychological, and social symptoms and consequences of endometriosis, a mindfulness- and acceptance-based intervention called MY-ENDO (Mind Your ENDOmetriosis) has been developed [16]. This intervention was originally developed as a face-to-face group-based intervention consisting of a manualized 10-week program, including one weekly three-hour session focusing on patient education and group therapy around different endometriosis-related themes. In addition, a range of mindfulness and yoga exercises are practiced during treatment sessions and homework.

The face-to-face MY-ENDO intervention has shown significant and positive effects compared to medical treatment on endometriosis-related quality of life despite an ongoing pain experience in women with symptomatic endometriosis and may therefore act as a supplementary and health promoting treatment for affected women [16]. However, delivering and participating in a face-to-face intervention can be expensive and time-consuming. Limitations of the study demonstrated that many patients were unable to participate in the MY-ENDO intervention due to geographical distance, long transportation time, difficulties with scheduling time due to work or educational commitments, physical disability, or lack of energy.

To overcome some of these limitations, a digital version of the self-administered program has been developed and internet delivered. The digital materials were developed to provide knowledge and information about endometriosis and its management but also to guide and encourage patients to acquire new skills, such as pain management strategies, emotional regulation, stress reduction techniques, and self-care routines to help manage difficulties and adaptively change behavior. Also, digitalization of MY-ENDO allows the patients to gain access to therapeutic content at any time in the comfort of own homes and can provide a higher degree of patient anonymity and reduce the potential stigma associated with attending interventions in mental health settings [17].

Including patients in health research for the purposes of creating impact and meaningful change in outcomes is increasingly practiced [18], with more than 65 frameworks designed to propel patient partnerships in research being developed [19]. Inviting patients to co-develop MY-ENDO *digital* will secure access to their perspective on the content, delivery, and acceptability of the specific elements of the intervention, which can guide potential changes and refinement of the intervention, thereby securing a tailored and user-approved intervention [20, 21].

Aim

By demonstrating the co-development process and conducting feasibility test of MY-ENDO *digital*, the aim of this study was to examine how women with symptomatic endometriosis experienced a digitalized mindfulness- and acceptance-based intervention. Particularly, we explored possible common tendencies in their experiences, including identifying any barriers or facilitators to complete the intervention.

Methods

Design

The study was designed as a qualitative feasibility study with a phenomenological approach using semi-structured individual interviews to capture accurate descriptions gained from subjective narratives [22].

Participants and procedure

Participants were recruited through the Danish Endometriosis Patient Association based on a convenience sample. Inclusion criteria were: (1) 18–45 years, (2) a diagnosis of endometriosis, and (3) subjectively feeling challenged by endometriosis in relation to pain, fatigue, or quality of life. The diagnosis was self-reported and not confirmed by a medical doctor Furthermore, participants had to be willing to engage in the intervention program and participate in interviews along the side. An information letter was sent to interested women giving a more detailed description of the intervention. After signing up for participation they all gave written informed consent regarding data collection and video- and audio recording.

Interviews were based on a semi-structured interview guide [23] and completed in February and March 2022. All interviews were conducted virtually via an online video connection. Participants were invited into the co-development process when solely the first four digital sessions had been developed. The first interview was conducted prior to the first session to build rapport and map previous experience with mindfulness-based interventions, motivation for participating, and expectations. Interviews 2–5 were conducted weekly after each session. Interviews were recorded and transcribed to structure the interview material in a form suitable for analysis. Each interview was adjusted to the weekly endometriosis theme and content and included questions related to both the patient educational material and the practical parts of the intervention to capture participants' attitudes towards and experiences with each session.

The intervention: MY-ENDO *digital*

To accommodate the request for methodology, accuracy, and repeatability, a treatment manual was developed, as seen in Table 1. The full intervention consists of an introduction followed by 10 sessions, one session each week for a period of 10 weeks. The first four sessions teach and guide different endometriosis-related themes: (1) Endometriosis, (2) Pain, (3) Stress, and (4) Thoughts and feelings and includes written assignments, mindfulness practices, and yoga. The patient's homework was mindfulness and yoga training for 30–45 min a day, 5–7 days a week during the four weeks. Participants were gained access to a new session each week.

Data analysis

All empirical material was analyzed using Braun and Clarke's six-phased thematical analysis to identify trends or patterns of opinions in the empirical data and support

Table 1 MY-ENDO *digital* content session 1–4

	Session 1, Endometriosis	**Session 2, Pain**	**Session 3, Stress**	**Session 4, Thoughts and emotions**
'Knowledge of'	About MY-ENDO, experiences, content, and effects. Knowledge about endometriosis, symptoms, and consequences, traditional- and supplementary treatments.	Knowledge of pain, the pain experience, pain mechanisms. Pain symptoms in endometriosis.	Knowledge about stress, interconnection between stress, chronic diseases, and pain. The nervous system.	Knowledge about thoughts, emotions and feelings, anxiety, insecurity, depressions, anger, and worries.
'Management of'	Mindfulness and the practice of mindfulness.	Pain management, pain and suffering, interdisciplinary pain treatment, feelings, thoughts, and tensions.	Management of stress, prevention, mindfulness, and brain activity.	Management of thoughts and emotions.
Worksheets	'My endometriosis history' 'What do you notice?'	'Pain diary' 'What do you notice?'	'What do you notice?'	'What do you notice?'
Mindfulness exercises	Body scan, long (26.07 min)	Body scan, long (26.07 min) Body scan, short (4.30 min)	Presence of normal breath (11.28 min) The stamp (11.08 min) Body scan, short (4.30 min)	From thinking to sensing (4.42 min) Clouds in the sky (2.11 min) The conveyor belt (2.56 min) Presence of normal breath (11.28 min) The stamp (11.08 min)
Yoga exercises	Savasana Savasana with ball Chakravakasana Pada hastasana Balasana Jathara Parivartanasana	Savasana Savasana with ball Supta Baddha Konasana Pavanamuktasana Janushirshasana Upavishta Konasana Jathara Parivartanasana	Savasana Savasana with ball Chakravakasana Adho mukha svanasana Pada hastasana Ashwa-sanchalanasana Balasana Jathara Parivartanasana	Repetition of previous weeks

descriptions of the phenomenon under study [24]. An inductive approach was selected to explore the phenomenon from the perspective of empirical data, enabling the creation or connection of theories and propositions based on observed realities. This approach was chosen because applying a predefined theory to marginalized or vulnerable groups risks silencing their unique perspectives and experiences [25]. All analytical work happened in NVivo 1.6.2., 2022.

In the first phase of the analysis, transcriptions were read thoroughly to become *familiar with the data*. Familiarity came naturally since the data was collected, transcribed, and analyzed by the same researcher. In the second phase the *initial codes* were developed. In this phase, narrow and specific codes based on the immediate impression of the empirical material are recommended. All codes emerged inductively and were not tied to any theoretical premises. A total of 23 codes were identified, as described in Fig. 1.

In phase three codes were assembled into *overarching themes*, some as main themes and others as sub-themes. A total of 12 themes were identified. To create an overview of the themes presented in the analysis, the fourth phase included *revisiting the themes*. Here, some themes were merged into a broader theme, while others were discarded as they did not contain enough data to support them. A total of eight themes were identified. The fifth phase concerned *defining and naming the themes*. All theme-names were refined and defined with descriptions. Lastly, the sixth phase involved *producing the report* and disseminating the findings of the analysis.

Ethical considerations

The research was conducted, based on the principles of the American Anthropological Association Guidelines for Ethics, specifically the *Principles of Professional Responsibility* [26], and the study was pre-registered at the Danish Data Protection Agency via Aarhus University's internal registration (number: 2016-051-000001, running number: 2332).

Results

A total of eight participants were recruited, as shown in Table 2, one of whom had to withdraw from the study due to illness. There were 35 interviews in total, each lasting between 15 and 35 minutes. Analyses revealed that two main elements of the intervention were found crucial for participants' experiences, respectively: 'knowledge of the disease' (part 1) and 'management of the disease' (part 2). Furthermore, data analysis revealed a generic theme and some specific suggestions (presented in a following section).

Part 1: knowledge of the disease

Increasing endometriosis-related literacy

Nearly all participants described MY-ENDO as a simple and accessible overview of information on endometriosis diagnosis, symptoms, and consequences that provided new and more detailed knowledge through the patient education material. This included becoming aware of the link between their physical and psychological well-being which led them to feel more equipped to understand and manage the consequences of endometriosis. In addition, more participants highlighted that they achieved a more nuanced language and felt more confident talking about endometriosis, their concerns, and thoughts:

> *"I think the program can be used if you find it difficult to explain stuff related to endometriosis. It gives you the chance to share the information which the program provides to you, instead of figuring the words out on your own." (P1).*

However, two participants reported feeling emotionally affected when they read about the physical, psychological, and social consequences of endometriosis. They described feeling sad and overwhelmed because they were reminded of the many negative consequences of endometriosis that they had suffered.

Acknowledgement and community

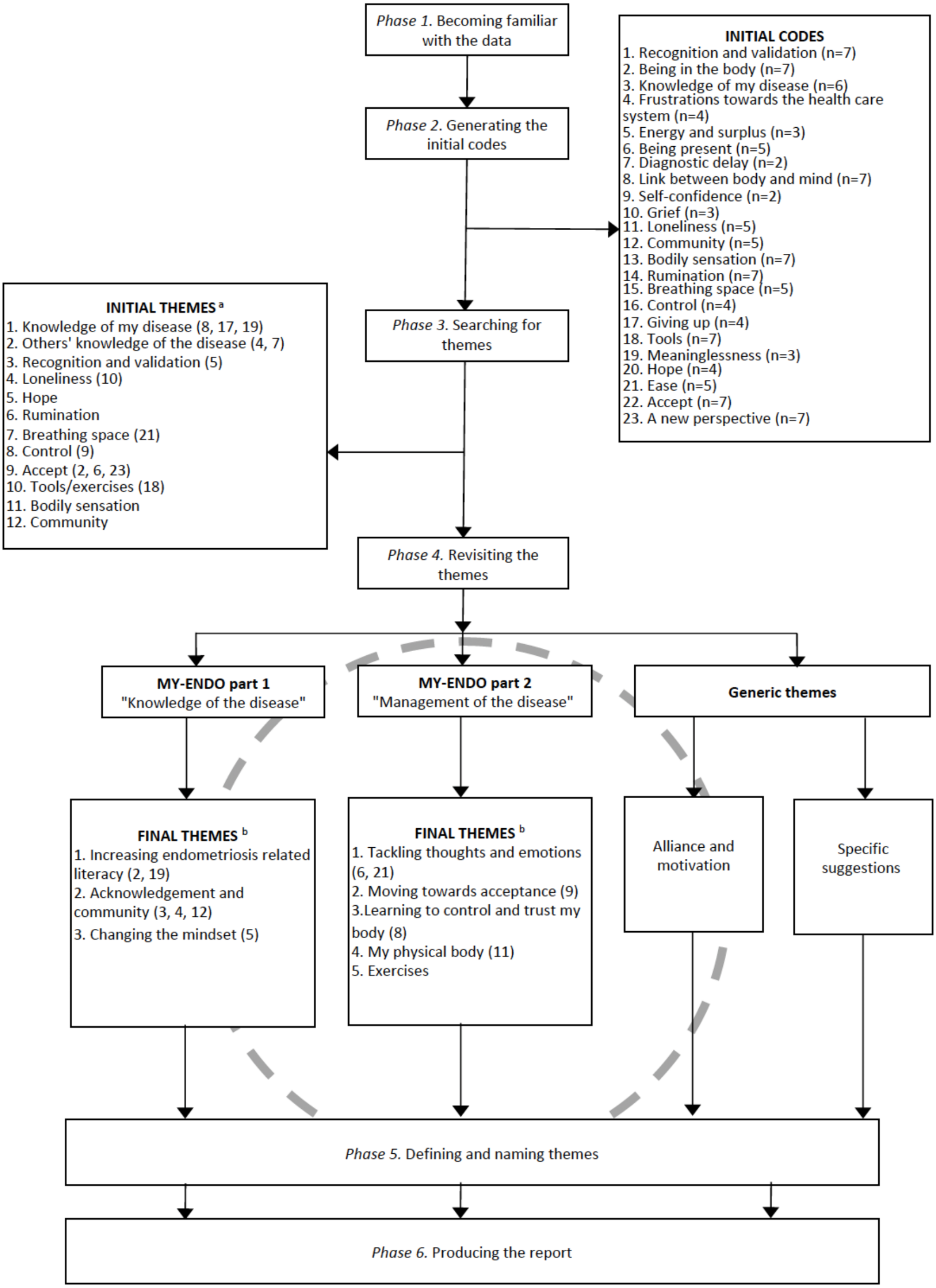
Participants stated that they were able to see themselves reflected in the patient education material and reported that they felt recognized, validated, and acknowledged in the descriptions of experiences, symptoms, thoughts, and feelings. Also, the material helped participants personally better recognize and understand their own emotional reactions, patterns of action, and habits:

> *"It was nice that someone finally put into words that it's okay to feel the way I do and that I'm not wrong for feeling this way. And the habits I have had and still have. There is a reason for them too! There is actually some knowledge supporting it." (P6).*

Participants stated that recognition made them feel less isolated and alone. On the contrary, it made them feel part of a community:

> *"Well, what I experience is that I feel I am not alone with being ill. The knowledge I receive confirms me that I am not totally crazy. And it is quite natural to ruminate and overthink." (P6).*

However, one participant explained that she did not recognize herself in sessions two (pain) and three (stress) but explained this was neither bothersome nor problematic;



[a] (x) = Initial codes incorporated into the theme. [b] (x)= Initial themes merged.

Fig. 1 Thematic analysis flow diagram

Table 2 Participants' characteristics

Participant number	Age (years)	Time since diagnosis (years)	Current treatment	Civil status	Children	Years of education*	Employment status
1	45	9	Hormones	Married	0	< 5 years	Sick leave (due to endometrioses)
2	37	6	Pain killers, artificial menopause	Married	1	< 5 years	Part time (due to endometriosis)
3	40	5	Hormones	Married	2	> 5 years	Full time
4	44	2	Hormones	Married	2	< 5 years	Disability pension (due to endometriosis)
5	32	1	Painkillers	In a relationship	0	> 5 years	Full time
6	33	8	Hormones	Married	0	> 5 years	Full time
7	23	1	Hormones	Single	0	> 5 years	Student

*Refers to years of education following Danish high school (*Gymnasium*)

it merely had the advantage of making the intervention comprehensive.

Changing the mindset

Several participants described that the patient education material educated them about treatments, tools, and coping strategies that could help them manage endometriosis. Several participants reported that this information gave them new hope for healing related to endometriosis and its consequences:

> *"The program has changed my view on having endometriosis. I have always felt like I cannot do anything about it. That I just had to live with it. But it has given me a renewed hope or a new mindset. I have a different attitude. I can use my thoughts to change how I feel." (P7).*

Part 2: management of the disease

Managing thoughts and emotions

Participants consistently described previous worries and negative emotions related to what their future life would be like if the pain persisted, but reported that the mindfulness exercises in particular helped them to calm their thoughts and feel calmer:

> *"I have felt it in my body, or that I had a better sleep, or felt less stressed and ruminated less. Because I kind of cleansed everything (with the mindfulness exercises) and then went to bed." (P4).*

Other participants described using the exercises strategically. One participant explained that it seemed like a break or a bath when she practiced the exercises instead. Another described that the mindfulness techniques helped her intervene before panic set in, preventing it from escalating.

> *"I think that the short mindfulness exercise has been really good. Because I haven't experienced that panic, which I tend to build up. I just feel relaxed afterwards. And then the pain does not get as bad." (P2).*

Acceptance

Several participants consistently described having difficulty accepting the debilitating effects of endometriosis. One participant explained that she used to try to ignore the limitations which endometriosis imposed on her daily life—such as having to cancel plans, call in sick to work, or withdraw from social activities—because otherwise, she would have felt frustrated. Participating in MY-ENDO helped her better accept the consequences and focus more on what she could actually do rather than the limitations:

> *"Of course, the pain is there and always will be. And you have to learn how to live with it. But you cannot overburden yourself. Don't suppress the pain and continue doing what you know is not good for you." (P5).*

However, two participants found it difficult to be present, attentive, and to let go of thoughts and other distractions while practicing mindfulness or yoga but recognized the value and possibilities of the exercises:

> *"First of all, I find it difficult to stay focused. I do understand the thinking behind it, how thoughts are fleeting, and they have to pass. I just have trouble to fully settle into it." (P3).*

Learning to control and trust my body

Participants reported that they had previously felt powerless in the face of their bodies' physical reactions to endometriosis, experiencing sudden pain, discomfort, or anxiety without a way to manage it. However, several participants described that MY-ENDO gave them a sense of agency and the ability to respond effectively to their symptoms, making them feel more in control:

> *"And somehow, having the exercises to practice makes me feel in control. I know that if I complete them, there is actually a relatively good chance that I will feel better afterwards. This option makes me feel more empowered, because I have a specific tool that is easy and accessible." (P1).*

Similarly, another participant explained that while she previously would have canceled plans or avoided activities when experiencing pain, she now had tools and techniques to manage it. Rather than eliminating symptoms entirely, this newfound ability to engage with her body's reactions helped her feel less helpless and more confident in her ability to cope.

My physical body

During the interviews, several participants reported to experience tension in muscles and joints, particularly around the hip area and lower back. Nearly all participants felt a change in their bodies during the practical exercises. One participant stated that her tension had eased after the yoga practice:

> *"I have felt an improvement in relation to the tension I feel in my hips. I think it's especially due to the yoga exercises; butterfly, knee to chest, one leg forward and stretch and the child's pose." (P1).*

In addition, several participants described feeling more relaxed as a result of the exercises, which led to a reduction in overall pain intensity:

> *"I am no longer as tense around my sacrum, and my sciatic nerve does not hurt as much. The exercises have physically given me relief in the pain I experience." (P6).*

However, some participants explained that the pain returned afterwards or in the following days.

Practical exercises

Throughout the interviews participants reported that the practical exercises served as easily accessible and tangible tools for managing many of the consequences associated with endometriosis, and they highlighted the advantage of having the exercises 'at hand'. They described them as a toolbox from which they could select the most appropriate tools for their needs:

> *"You can find a lot of videos on YouTube and everything. But to be able to log into MY-ENDO and have these videos and audio files that are tailored exactly to endometriosis and is accessible and available. That is really good." (P1).*

Several participants commented that they felt better able to manage their pain, thoughts, and feelings, but some had difficulty finding the time to practice in their hectic daily lives and found it difficult to practice at home where they were distracted by children, partners, pets, etc.

Generic themes and specific suggestions

Alliance and motivation

Throughout the interviews some participants expressed concern about how to stay motivated throughout the ten weeks. They stressed that being committed to not only themselves but also to the interviewer had decreased the risk of dropout and helped them to stay motivated:

> *"Well, when I have committed to something and know that I have a responsibility towards someone, then I am going to complete it. [...]. I think it is good that you commit to something otherwise I would have dropped out a long time ago." (P6).*

Participants emphasized the importance of a contact person and suggested to create digital groups that could provide a channel of communication among MY-ENDO participants, stimulate conversations and the sharing of experiences and challenges to increase chances of full participation in the intervention.

Specific suggestions

Participants came up with five specific suggestions to increase feasibility of the intervention:

- *Less reading, more pictures, printing opportunities, and audio files*: To increase the ease of reading fewer technical terms could be used, more pictures could be added. Printing opportunities and audio files (of the text) would help those who are in pain while sitting still.
- *App delivery*: An app version may increase both accessibility and manageability.
- *Psychological 'hotline'*: Participants had a contact person (the interviewer) while completing the intervention. They stressed the importance of having this contact person or alternatively a psychological 'hotline' in case one would feel overwhelmed and in need for more advice and support while participating.

- *Implementation in everyday life*: More advise on how to implement the program and practical exercises in everyday life was demanded.
- *Advice on how to communicate*: Participants suggested that the intervention should include 5–10 tips on how to communicate their endometriosis challenges to healthcare professionals.

Discussion

Principal results

This qualitative feasibility study investigated the experiences and attitudes toward MY-ENDO *digital* from the perspective of women with symptomatic endometriosis. Overall, the intervention was well evaluated, suggesting that it was predominantly perceived as positive and useful. In particular participants emphasized the significance of a disease-specific intervention tailored to the symptoms and consequences of endometriosis, as opposed to a broad and generic approach. A few participants reported feeling overwhelmed by the information and struggled to engage with the program as recommended. These findings highlight potential challenges in adherence and should be further explored to ensure the intervention provides adequate support for all users.

Although this study included only seven participants and the results should be interpreted as indicative rather than conclusive, the findings offer valuable insights. Thematic saturation was achieved within the participant group; however, the possibility remains that additional participants could have contributed new perspectives. Therefore, we encourage future research to involve a larger and more diverse sample to confirm and extend these observations.

Comparison with prior work

Participants experienced a new understanding of endometriosis and felt better equipped to manage endometriosis-related challenges. For example, it was emphasized how mindfulness and yoga exercises helped relieve rumination, anxiety, and pain. Similar results have been found in previous research demonstrating that mindfulness reduces rumination [27], and increases activity in the brain's frontoparietal control network, which is important for cognitive and emotional control, meta-awareness, and cognitive modulation of pain [28–30], and a reduction in thalamic activity, which can reduce the experience of pain [31].

Some participants also reported that their perspective on pain had changed from being associated with limitations - such as social withdrawal, fatigue, difficulty maintaining employment, and persistent discomfort - they became more aware that pain could be understood and approached in different ways. This newfound awareness also helped them develop new strategies for managing their thoughts and worries. This can be referred to as 'reframing' [32], and available evidence supports that mindfulness practice can decrease rumination and change one's perspective on a current situation [33].

Most participants found the patient education material valuable, insightful, and eye-opening. However, two participants felt emotionally overwhelmed when confronted with the consequences of endometriosis. This may be related to sampling bias, as some participants may have had different levels of need or readiness for such an intervention. At the same time, their descriptions suggest that the feelings of being overwhelmed arose because they strongly identified with the material. Research indicates that emotional distress related to participation in digital interventions can contribute to increased dropout risk [34, 35]. Therefore, it is important to consider whether the intervention itself might evoke strong emotional responses and how best to support participants in managing these reactions.

Another dropout risk relates to challenges in completing the exercises, which two out of seven participants (almost 30%) found difficult due to disruptions at home, lack of motivation, and routine. While these issues may stem from individual circumstances, the relatively high proportion suggests that the intervention itself may not have provided sufficient support to sustain engagement. This highlights the need for further exploration of potential barriers within the intervention design. Therefore, maintenance could be supported by suggestions for exercise planning, such as a weekly schedule or practical exercise scheme, as well as clinicians' engagement or 'implementation champions' [36–38]. Importantly, when delivering a self-guided digital intervention without therapeutic contact, ethical responsibility must be considered in case of possible unintended negative consequences or adverse events [39]. Therefore, it is crucial to explore options for a more accessible and direct way of seeking advice, such as a psychological hotline or contact person assignment.

Limitations

There are some limitations to this study. First, there is a risk that the methodological choices will influence the findings [40]. In this aspect continuous interviews might increase the risk of a Hawthorne effect, in which behavioural changes are attributed to the interviewer's interest, care, and/or attention rather than to the potential mechanisms of the intervention [41]. Moreover, the data were collected and analyzed by just one researcher, which could prospectively compromise the reliability or validity of the findings. Including external audits has shown to increase the overall reliability and trustworthiness of a study [40, 42]. Furthermore, interviews were conducted virtually, which may interfere with the building of rapport between interviewer and informant [43].

However, the virtual interview also has some advantages. It allows for geographically dispersed recruitment of participants and may be appropriate when discussing sensitive topics, where the participant may feel less confrontational with the interviewer [44]. Other strengths of the study include the direct involvement of endometriosis patients in the development phase, which helps to increase the feasibility, usability, and acceptance of MY-ENDO *digital*, ultimately improving successful implementation [21]. Furthermore, the data collection process, analysis, and results are presented transparently and openly, which increases confirmability and dependability [40, 42].

Future perspectives and implications for practice and policy

As a next step, researchers and clinicians should investigate the full length of MY-ENDO *digital* to (1) determine whether participants experience a saturation point or any lack of motivation; (2) evaluate the efficacy and effectiveness of the intervention in a large sample; and (3) assess the importance of therapist contact for maintenance and efficacy. Particularly, the difference between delivering a therapist-guided versus a self-guided intervention has clear implications for the implementation in clinical practice. For this reason, politicians and policymakers should support initiatives that enable more research funding targeting digital solutions for endometriosis management and care. It seems that both the health and the social economy could benefit from healthcare providers and patients continuing to embrace the role that digitalization can play in broadening access to care and the co-development and implementation of digital interventions.

Conclusions

MY-ENDO *digital* seems to be a feasible, acceptable, and relevant intervention for women with symptomatic endometriosis. The study indicated that participants experienced several benefits from completing the first four sessions related to a better management of difficult thoughts and emotions and a changed pain experience. Participants considered it an advantage that the program was specifically targeting endometriosis as well as being co-developed with patients. The results indicate that participants found personal contact with the interviewer essential to staying motivated. The experiences and suggestions of the participants will be used to further refine the intervention and guide the development of the remaining six sessions before a feasibility pilot of the full intervention will be conducted.

Acknowledgements
Not applicable.

Author contributions
NM generated the initial idea, design, and methodology, conducted the interviews, performed the analyses, wrote the first draft of the paper, and reviewed the manuscript drafts. KEH contributed to the initial idea, design, and methodology, and reviewed the manuscript drafts. UBK secured funding and reviewed the manuscript drafts. All authors have read and agreed to the published version of the manuscript.

Funding
Funding was provided by the FEMaLe Project, which received funding from the European Union's Horizon 2020 research and innovation program (Grant ID: 101017562). The funders had no role in the study's design, data collection and analysis, decision to publish, or manuscript preparation.

Data availability
Due to ethical considerations, we are unable to share the raw data from this study. The informed consent obtained from participants was based on a template designed for projects conducted as part of a master's thesis. This template does not explicitly include permission to share raw data, and we cannot assume that participants consented to such data sharing. Furthermore, the study includes only seven participants, which presents a significant risk of re-identification if raw data were to be made publicly available. Given these ethical constraints, data sharing is not feasible while ensuring compliance with participant confidentiality and ethical guidelines.

Declarations

Ethics approval, consent to participate and for publication
The project has been conducted in adherence with the rules in the 2024 Helsinki-Declaration [45]. The project is registered at Aarhus University (case no. 2016-051-000001-2332). The study was deemed to be exempt from ethics approval according to Denmark's Act on Research Ethics Review of Health Research projects (§ 14.2). All participating patients received written material and verbal orientation describing the study, and all patients who participated in interviews signed a written consent form prior to the interviews.

Competing interests
The authors declare no competing interests.

Received: 15 February 2025 / Accepted: 10 April 2025

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