How Endometriosis Patients in the Netherlands Cope with Pain and Fatigue: Exploring Self-Management Experiences and Needs

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Abstract

Background: Endometriosis is a gynaecological condition characterised by varying pain and fatigue symptoms, which can significantly impact well-being. Treatment often overlooks contributing factors and psychological consequences. While self-management strategies may be helpful in these challenges, treatment guidelines in the Netherlands lack clear recommendations, and effective coping may require tailored support. Research on self-managing endometriosis-related pain and fatigue in the Netherlands is limited, highlighting a knowledge gap that this study aims to address.

Methods: A mixed-methods design using an online survey was employed. Recruitment primarily occurred through the Endometriosis Foundation. A total of 195 participants (age 18-64 years) with a self-reported diagnosis or suspicion of endometriosis were included in the analysis. Data were analysed using descriptive statistics and thematic analysis.

Results: The results revealed that endometriosis self-management was experienced as a personal process of discovering helpful strategies. Problem-focused approaches such as physical activity, diet changes, and balancing activities with rest were commonly used and perceived as effective. Support needs were primarily reported on comprehensive and accessible information on various coping techniques (e.g., diet), peer contact, and professional guidance (e.g., coaching), ideally delivered via mobile applications. Experiences and needs were similar for pain and fatigue.

Conclusion: This study advances understanding of coping with endometriosis-related pain and fatigue from the Dutch patient perspective. Similar to prior research, the findings emphasise the importance of centring the patient in self-management and identify specific effective coping approaches and support needs. Future support efforts should focus on enabling patient self-awareness and experimentation while providing the necessary resources for support. Further research is needed to prioritise the disclosed support needs and to explore patient characteristics (e.g., symptom presentation) that influence the accommodation of these needs.

Keywords: Endometriosis, Self-Management, Pain and Fatigue, Support Needs

Introduction

Endometriosis is a gynaecological condition characterised by the growth of endometrial-like tissue outside the uterus, leading to chronic inflammation (Kennedy et al., 2005). This condition affects approximately 2-10% of women of reproductive age worldwide (World Health Organization, 2023; Máxima Medisch Centrum, 2024). Its presentation varies among individuals, with some being asymptomatic while others experience a range of symptoms (Rogers et al., 2009). These symptoms may include infertility (Horne & Missmer, 2022; Maggiore et al., 2024), heavy menstrual bleeding (Martire et al., 2020), (chronic) fatigue (Ramin-Wright et al., 2018), and several forms of pain (e.g., pelvic pain, dysmenorrhea/menstrual pain) that may occur in episodic or constant patterns (Horne & Missmer, 2022; Hickey et al., 2014). Furthermore, comorbid conditions, such as chronic fatigue syndrome, asthma, and fibromyalgia, may also arise (Sinaii et al., 2002; Shafrir et al., 2021). Due to its heterogeneity, endometriosis can be challenging to diagnose (De Kok et al., 2024), reflected in long diagnostic delays ranging from 7.4 to 10.4 years (Staal et al., 2016; Hudelist et al., 2012).

Both pain and fatigue are common, debilitating symptoms of endometriosis. The majority of patients (72.6%) suffer from pelvic pain or menstrual pain, combined with at least one form of pain (e.g., during sexual intercourse) (Mechsner et al., 2009). In approximately half of endometriosis patients, such pain was noted as chronic (Leuenberger et al., 2022). Furthermore, fatigue was frequently reported by 50.7% of patients, while 27.1% disclosed it occurred occasionally (Ramin-Wright et al., 2018). In addition, endometriosis-related fatigue was typically experienced as moderate (52%) or severe (28%) (Álvarez-Salvago et al., 2020). As a result of the prevalence of both symptoms, many patients are exposed to their negative consequences. Pain and fatigue have been attributed to worse emotional well-being, a lower quality of life, and depression and anxiety (Facchin et al., 2015; Lorençatto et al., 2006; Soliman et al., 2017; DiBenedetti et al., 2020). Moreover, physical fitness can also be affected, with fatigue resulting in reduced balance and back strength (Álvarez-Salvago et al., 2020; DiBenedetti et al., 2020), and pain limiting walking and sitting abilities (Leuenberger et al., 2022). This may negatively impact patients' daily functioning and activities,

including their professional and social lives (Huntington & Gilmour, 2005; Lorençatto et al., 2006; Leuenberger et al., 2022; Soliman et al., 2017; Missmer et al., 2021; DiBenedetti et al., 2020). To elaborate, fatigue has been described as disruptive by forcing patients to cancel or modify their social plans, while pain has been associated with reduced socioeconomic prospects (Huntington & Gilmour, 2005; Lorençatto et al., 2006). Furthermore, endometriosis-related pain can worsen sleep quality (Leuenberger et al., 2022), whereas fatigue may heighten patients' sensitivity to pain stimuli, exacerbating their pain experiences (Lautenbacher et al., 2006; Irwin et al., 2012).

These consequences demonstrate a clear need for adequate treatment, yet existing approaches may be insufficient. As no curative treatment is available, endometriosis care primarily focuses on symptom control, often by medically suppressing (e.g., hormonal therapies) or surgically removing endometriosis lesions (As-Sanie et al., 2019; Allaire et al., 2023). Moreover, pain-relieving medications, including analgesics (e.g., paracetamol) and non-steroidal anti-inflammatory drugs (NSAIDs), are commonly used (Ferrero et al., 2018). Although there are indications these medical management strategies may improve endometriosis-related pain and fatigue (Mettler et al., 2014; Surrey et al., 2019), other studies highlight the persistence and recurrence of symptoms despite treatment adherence (Singh et al., 2019; Álvarez-Salvago et al., 2020). This may be understood by the factors underlying endometriosis-related pain and fatigue. Both symptoms can occur through inflammation (Howard et al., 2009; Louati & Berenbaum, 2015; Karshikoff et al., 2017), which is likely targeted by present treatment approaches. However, psychological elements such as anxiety, worry traits, and depression also contribute to the symptoms' occurrence and severity (Zarbo et al., 2021; Laganà et al., 2015; Van Barneveld et al., 2021; Mundo-López et al., 2020; Roberts & Duong, 2014). Notably, these elements are sparsely addressed. In the Netherlands, the European Society of Human Reproduction and Embryology (ESHRE) guideline for gynaecologists acknowledges the impact of endometriosis on mental well-being, yet provides no specific recommendations for psychological care due to unclear benefits and harms (Becker et al., 2022; ESHRE Endometriosis Guideline Development Group, 2022). These studies demonstrate that medical treatment approaches may not

sufficiently address all facets of pain and fatigue symptoms, suggesting that comprehensive care is needed.

The Chronic Care Model (CCM) may offer a solution to the management challenges of endometriosis-related pain and fatigue symptoms. Unlike conventional medical management strategies, the CCM focuses on long-term effects, is patient-centred, includes self-management support, and integrates expertise from multiple disciplines to treat and manage symptoms comprehensively (Pickett et al., 2023; Agarwal et al., 2019; Wagner, 1998; Bodenheimer et al., 2002). Previous treatment approaches based on the CCM improved health outcomes and quality of care for chronic conditions (Coleman et al., 2009). The self-management component may be particularly relevant in endometriosis. This refers to "the ability of the individual, in conjunction with family, community, and healthcare professionals, to manage symptoms, treatments, lifestyle changes, and psychosocial, cultural, and spiritual consequences of health conditions" (Richard & Shea, 2011, p.261). Management techniques recognised in endometriosis may be divided into two broad categories: problem-focused and emotion-focused (Leonardi et al., 2020; Roomaney & Kagee, 2016). Problem-focused coping directly addresses the issue, while emotional coping alleviates the feelings that arise from it (Folkman & Moskowitz, 2004). Endometriosis-related studies have indicated that problem-focused strategies include patient education, fostering social connections, scheduling activities around the menstrual cycle, ensuring restful sleep, engaging in physical activity, dietary alterations, using heat, taking analgesics, and seeking social support. Emotion-focused techniques involve relaxation, mindfulness, acceptance, positive thinking, self-talk, and spirituality (Leonardi et al., 2020; Roomaney & Kagee, 2016; Armour et al., 2019; Norman et al., 2021). When practised, these self-management approaches can enhance patient well-being by reducing stress, depressive symptoms, and improving quality of life (Donatti et al., 2017; González-Echevarría et al., 2018). Furthermore, patients receiving support in self-managing endometriosis significantly improved their anxiety, physical and mental quality of life, pain and fatigue symptoms, and self-efficacy (Farshi et al.,

2020; Rohloff et al., 2024). This underscores the potential of the CCM and self-management in enhancing care of endometriosis-related pain and fatigue beyond medical approaches.

Although desirable, effective self-management may be difficult to attain in the Netherlands. Due to the limited guidance on psychological care in the ESHRE guideline, Dutch health professionals may not recognise the daily challenges of living with endometriosis, leaving patients to navigate these on their own. However, not all patients sufficiently understand their condition to manage their symptoms (Farley et al., 2019). Moreover, a lack of knowledge, beliefs about personal capabilities, social influences, goals, and available resources pose barriers to self-managing endometriosis (Huijs et al., 2023). Conversely, support and developing expertise can positively impact patients' self-management abilities (Schulman-Green et al., 2012). Therefore, adequate support and information are essential to realise the benefits of coping with endometriosis. To be effective, support interventions require careful consideration of the informational content, the process (how the content is taught), the format (e.g., technology-based), and their alignment with patient characteristics, including culture and family support (Lorig & Holman, 2003). Technology-based formats may be especially promising, as they can provide tailored content, graphics, functionality, and behaviour change strategies (Ten Klooster et al., 2024). While endometriosis self-management experiences have been studied from the patient perspective in countries such as Australia (Armour et al., 2019), South Africa (Roomaney & Kagee, 2016; Sibande & Roomaney, 2022), and the United States (Norman et al., 2021), there is a lack of such research in the Dutch context. This limits the understanding of Dutch patients' support needs and complicates the alignment of care, posing an additional barrier to effective self-management.

In summary, the negative consequences of endometriosis-related pain and fatigue symptoms necessitate adequate treatment. However, as these symptoms often persist or recur despite treatment adherence, the prevailing medical treatment approaches appear insufficient. This may be due to underlying psychological factors beyond the scope of medical treatment. The CCM provides a comprehensive approach, particularly through self-management. However, barriers to self-

management exist in the Netherlands, where care guidelines offer limited information on coping for healthcare providers, although patients may require support. Such support is likely effective when aligned with patients' experiences and needs. However, as no studies have examined this from the Dutch patients' perspective yet, a gap in research is identified.

The present mixed-methods study addresses the knowledge gap regarding how Dutch endometriosis patients manage pain and fatigue, by capturing their coping strategies and identifying the informational content, guidance processes, and technological formats necessary for adequate self-management. The following research questions are examined:

1. What are the experiences of endometriosis patients in the Netherlands concerning self-management of pain and fatigue symptoms, and how do they perceive the effectiveness of these strategies?
2. What unmet needs for information, guidance, and technological formats do patients in the Netherlands identify concerning pain and fatigue self-management?

Method

Study Design

The study used a mixed-methods cross-sectional design to explore pain and fatigue self-management experiences and needs from the perspective of Dutch endometriosis patients. Data collection occurred through an online survey with open- and closed-ended questions. Ethical approval was obtained from the Behavioural, Management, and Social Sciences (BMS) Ethics Committee of the University of Twente on January 6th, 2025 (application number: 241186).

Participants and Recruitment

Individuals aged 18 or older, fluent in Dutch, and diagnosed or suspected of having endometriosis were allowed to participate in the study. Suspected endometriosis was accepted due to the recognised delays in receiving a diagnosis. To focus on pain and fatigue self-management and minimise potential discomfort, participants were excluded if they experienced neither pain nor

fatigue, or felt uncomfortable answering questions related to endometriosis diagnosis, treatment, or symptoms.

The study aimed to recruit 100 participants, based on sample sizes in previous self-management survey studies in endometriosis and related inflammatory conditions (e.g., rheumatoid arthritis) (Norman et al., 2021; Van den Haspel et al., 2022; Lawson et al., 2011). Participants were primarily recruited through purposive sampling via the Dutch Endometriosis Foundation (*Endometriose Stichting*), which distributed the online survey in their email newsletter, Facebook (group), and Instagram. Data collection occurred between January 17th and February 11th, 2025. A total of 266 participants initiated the survey. After excluding 34 individuals due to incomplete consent or not meeting the inclusion criteria, 24 for insufficient demographic responses, and 13 for not responding to at least one item relevant to the research questions, 195 participants remained for analysis. The final sample sizes varied across analyses due to incomplete item responses.

The sample (N = 195) primarily consisted of participants aged 25 to 44 years. Most lived with a partner, were employed part-time, and had completed tertiary education. All participants had a confirmed or suspected endometriosis diagnosis, with many being diagnosed over a year ago, and diagnostic delays of more than 10 years commonly occurring. Most participants had received treatment, frequently including hormonal therapies. Over half reported comorbidities, often related to stomach and psychological complaints (see Table 1).

Table 1

Participant Characteristics: Demographics and Endometriosis-Related

Characteristic		*n*	%
Age			
	18 – 24	32	16.4%
	25 – 34	71	36.4%
	35 – 44	68	34.9%
	45 – 54	18	9.2%
	55 – 64	6	3.1%
Household			
	Alone	27	13.8%
	Partner/Children	141	72.4%
	Other (e.g., housemates)	27	13.9%
Education			
	Secondary education or lower (e.g., vocational education)	83	42.6%
	Tertiary education (hbo, wo)	106	54.3%
	Other	6	3.1%

Characteristic	*n*	%
Employment*		
Part-time	93	47.7%
Full-time	36	18.5%
Student	16	8.2%
Unemployed	4	2.1%
Unable to work	54	27.7%
Other	10	5.1%
Time since diagnosis		
< 1 year ago	56	28.7%
> 1 year ago	133	68.2%
Diagnostic delay		
< 1 year	8	4.1%
1-5 years	47	24.1%
6-10 years	49	25.1%
> 10 years	85	43.6%
Treatment history		
Currently receiving treatment	137	70.3%
Past treatment only	44	22.6%
Never been treated	14	7.2%
Treatment type*		
Hormonal treatment	164	84.1%
Operative treatment	118	60.5%
Fertility treatment	32	16.4%
Other medication	122	62.6%
Other	95	48.7%

Note. Items marked with * allowed multiple answers.

Procedure

Participants were invited to contribute to an anonymous online survey hosted on Qualtrics. Before receiving the survey items, an information sheet was presented to clarify the study's purpose and participants' rights (see Appendix A), followed by consent statements requiring confirmation via checkboxes. Once consent was provided, participants proceeded to the survey. This included open- and closed-ended questions on demographics, endometriosis characteristics, pain and fatigue self-management experiences, and related support needs. Survey administration took approximately 20 minutes. At the end of the survey, participants could voluntarily provide an email address for potential follow-up research. They were then debriefed by restating information on data use and contact information, and thanked for their time and input. Questionnaire logic was implemented throughout the survey to ensure that individuals who did not consent or did not meet the inclusion criteria were redirected to the end screen. After data collection concluded, the dataset was exported from Qualtrics and securely stored.

Materials

The online survey (see Appendix B) consisted of 29 items and was structured to first collect demographic and endometriosis-related information. Subsequent sections focused on participants'

experiences with pain and fatigue self-management, as well as their perceived needs for information, guidance, and technology. All items were presented in Dutch, with the majority developed and adapted specifically for the present study. The survey included Likert-scale, multiple-choice, and ordinal scale items. Open-ended questions and sensitive response options (e.g., 'prefer not to disclose') were also used and supported participant inclusivity.

Demographic measures included age group, household, education level, and employment status. Endometriosis characteristics were captured in diagnosis, diagnostic delay, treatment history, presentation of pain and fatigue symptoms, and their impact. Treatment items aligned with the ESHRE guideline (ESHRE Endometriosis Guideline Development Group, 2022). Questions on forms of pain and pain patterns aligned with existing endometriosis studies (Cozzolino et al., 2019; Drabble et al., 2020). To assess pain severity and impact, three numeric rating scale items from the Pain, Enjoyment, and General Activity (PEG) scale were adapted in wording and scale anchors and translated into Dutch (Krebs et al., 2009; Gerlinger et al., 2010). Categorical differentiation was used, reflecting *no pain* (0), *mild pain* (1-3), *moderate pain* (4-6), and *severe pain* (7-10) for pain severity (Bourdel et al., 2014). Pain impact categories reflected *mild interference* (0-3), *moderate interference* (4-6), and *severe interference* (7-10) (Von Korff et al., 2016).

Fatigue severity and impact were assessed using the Dutch version of the PROMIS Fatigue Short Form 6A, a validated six-item self-report scale with strong reliability in endometriosis ($\alpha = .93$) and the general Dutch population ($r > .90$) (Terwee et al., 2014; Pokrzywinski et al., 2020; Terwee et al., 2022). An example item included '*In the past 7 days, how fatigued were you on average?'.* The items used a 5-point Likert-scale (1 = *Not at all* to 5 = *Very much*) and inquired about the past seven days (Terwee et al., 2014). Raw scores were converted to T-scores based on Dutch-Flemish scoring tables, reflecting *normal* (<55), *mild* (55-59), *moderate* (60-70), or *severe* (>70) fatigue (Terwee et al., 2022; HealthMeasures Group, 2024a).

Self-management experiences were measured in participants' use and perceived effectiveness of coping techniques identified in endometriosis literature (see Appendix C) (Leonardi

et al., 2020; Roomaney & Kagee, 2016; Armour et al., 2019; Sibande & Roomaney, 2022). Peer advice items provided qualitative insights by reflecting personal health-related experiences (Rueger et al., 2020). Information and support needs were assessed through reformulated barriers to self-management (O'Hara et al., 2019) alongside the self-management techniques on which participants indicated their needs. Technological support preferences were captured in patient views on attractive features and formats recognised in digital health research (Slattery et al., 2019; Heapy et al., 2015; Weatherly et al., 2024). Three qualitative items further investigated needs by asking participants to describe their ideal self-management intervention.

Data Analysis

Missing data

Missingness was addressed by removing participants with considerable missing data on demographic and endometriosis characteristics. Mode imputation was used for categorical variables with minimal missing data. Within-participant mean imputation was applied to pain severity and impact measures for up to two missing items. Concerning the standardised PROMIS Fatigue Short Form 6A six-item scale, responses to fewer than four items were excluded, per the scoring guidelines (HealthMeasures Group, 2024b). To utilise the scoring tables, complete responses were required (Dutch-Flemish PROMIS National Center, 2023). Therefore, mode imputation was applied when only four or five items were completed.

Descriptive Statistics

Descriptive statistics were conducted using IBM SPSS Statistics (Version 29). Data were analysed to summarise demographics, endometriosis characteristics, self-management experiences, and needs. Categorical variables were described in frequencies and percentages, and ordinal variables were reported as frequencies, medians, and interquartile ranges. Results were presented in tables or bar charts.

Qualitative Analysis

Qualitative responses were analysed in ATLAS.ti (version 25), using inductive thematic analysis to identify patterns in the data and understand participants' perspectives (Kiger & Varpio, 2020; Braun & Clarke, 2006). Following Braun and Clark's (2006) six-step procedure, data were first carefully read, and initial codes were generated based on similarities in participant responses. These codes were grouped in overarching themes and subthemes, which were then reviewed, refined, and reduced to ensure clarity and the representativeness of all codes. The analysis concluded with defining and naming the (sub)themes as preparation for presentation in tables.

Results

Endometriosis Characteristics: Pain and Fatigue Symptoms

The majority of the participants experienced moderate to severe endometriosis-related pain, which often had a severe impact on their joy in life and daily functioning. Menstrual pain and pelvic pain were the most commonly reported forms. Sixty-eight participants reported other forms of pain, of whom 67 specified that these primarily included abdominal pain, back pain, limb pain, and nerve pain. Pain generally occurred in one of three patterns: continuous yet worsening during the menstrual cycle, continuous regardless of the cycle, or completely cyclical. Most participants also reported some level of fatigue, with moderate fatigue being most common (see Table 2).

Table 2

Pain and Fatigue Symptoms

Characteristic	*n*	%
Pain type*		
Pelvic pain	157	80.5%
Dysmenorrhea (menstrual pain)	162	83.1%
Dysuria/dyschezia (pain when toileting)	131	67.2%
Dyspareunia (pain during/after intercourse)	135	69.2%
Other	68	34.9%
Unspecified	2	1%
No pain	3	1.5%
Pain pattern		
Cyclical	30	15.4%
Constant	39	20%
Constant, but worse during menstruation/cycle	94	48.2%
Intermittent	16	8.2%
Other	16	8.2%
Pain severity (median = 6, IQR = 5 – 7)		
No pain (0)	5	2.6%
Mild pain (1-3)	27	13.8%
Moderate pain (4-6)	75	38.5%

Characteristic	*n*	%
Severe pain (7-10)	88	45.1%
Pain impact: joy in life (median = 6, IQR = 4 – 8)		
Mild interference (0-3)	38	19.5%
Moderate interference (4-6)	63	32.3%
Severe interference (7-10)	94	48.2%
Pain impact: activities (median = 7, IQR = 4 – 8)		
Mild interference (0-3)	42	21.5%
Moderate interference (4-6)	47	24.1%
Severe interference (7-10)	106	54.4%
Fatigue (median t-score = 63.7, IQR = 59.4 – 66.4)		
Normal	19	9.7%
Mild fatigue	30	15.4%
Moderate fatigue	119	61%
Severe fatigue	27	13.8%

Note. Items marked with * allowed multiple answers.

Research Question 1: Self-Management Experiences

Self-Management Lived Experiences: Qualitative Insights

Based on their lived experiences, participants provided peer advice on self-managing endometriosis-related pain and fatigue. These qualitative insights were organised into nine overarching themes for pain self-management and eight related to fatigue self-management. The following are the most common themes.

For pain self-management (N = 128), a frequently reported theme was *physical activity and rest*. Participants described seeking adequate rest, engaging in movement to maintain energy and cope with pain, and finding a balance to prevent overexertion. As one participant advised: “Find a good balance between activity and rest. You need more recovery than the average person”. Over a third of participants also disclosed *medical strategies*, including the use of prescribed pain medication, consulting specialists when pain persisted, and considering dietary changes. One participant shared: “Pay attention to your diet, look at which foods have an anti-inflammatory effect, for example”. Another common theme was *personalised pain management,* reflecting the individual process of coping with endometriosis. In this context, participants advised being attentive to one’s body by acknowledging physical boundaries and experimenting with different techniques to determine what is effective. A participant reported: “Listen to your body for what you need at that moment and not to anyone else”. Detailed results are available in Appendix D, Table D1.

Concerning fatigue (N = 69), *personalised management* was again a central theme. Participants described recognising their physical boundaries and adjusting their schedule accordingly.

In addition, to discover what is most helpful, they often reported engaging in various strategies. As one participant indicated: “If you are tired, take a nap or leave the activities or housework for a while”. *Physical rest* also emerged as a key theme, with participants frequently advising rest, sleep, and relaxation. One participant recommended: “If possible, schedule a fixed rest period during the day. Or more if necessary”. Finally, a few participants highlighted the *interconnection of pain and fatigue* symptoms, noting: “they come hand in hand”. For detailed results, see Appendix D, Table D2.

Self-Management Lived Experiences: Quantitative Findings

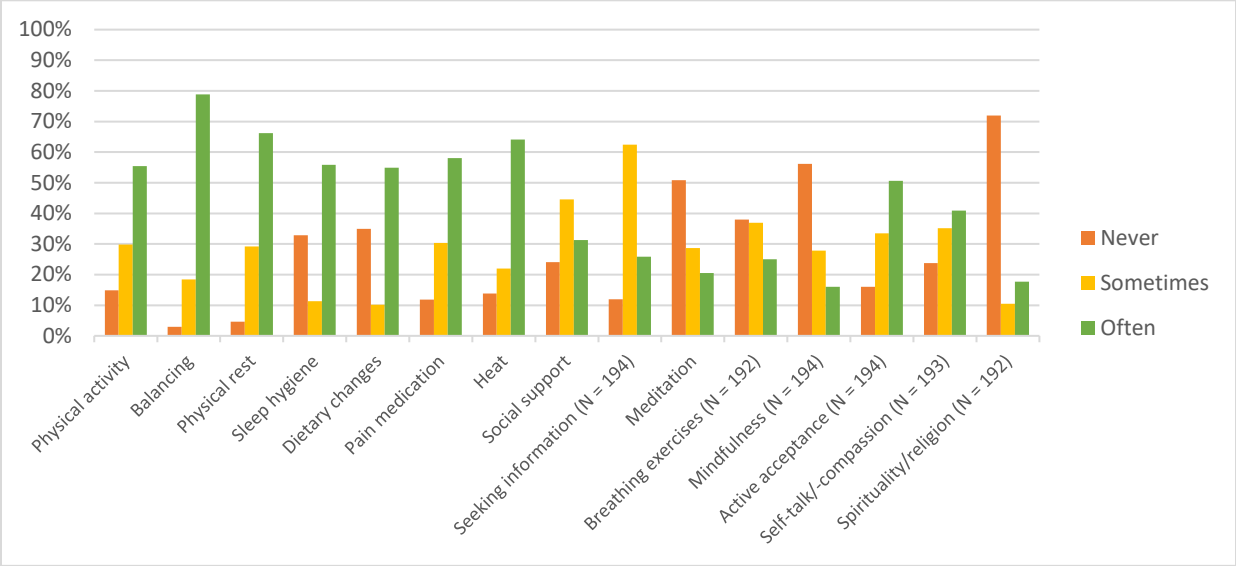
Numerical survey results on experiences with pain and fatigue self-management techniques complement the qualitative findings presented above. All self-management strategies were reported to be used to some degree in pain and fatigue management (see Figures 1 and 2). To manage pain (see Figure 1), participants most frequently (several times a week/daily) engaged in problem-focused techniques, including *balancing their activities and rest*, *physical rest* and *exercise*, *applying heat,* and medical management (*dietary changes* or *over-the-counter painkillers*). Participants also commonly used *acceptance* as an emotion-focused strategy. Conversely, other emotion-focused techniques were infrequently reflected in participants’ experiences, specifically *spirituality/religion*, *mindfulness*, or *meditation*.

Concerning fatigue management (see Figure 2), participants primarily reported *balancing activities and rest*, engaging in *physical rest*, and practicing *sleep hygiene*. The most frequently used emotion-focused strategies included *active acceptance* and *self-talk/-compassion*. Other emotional coping techniques (e.g., *spirituality/religion*) were infrequently used.

Beyond these approaches, participants disclosed *other* pain management (31.1%) and fatigue management (10.7%) techniques in written responses. They reported that these included seeking distraction, relaxation, and comfort, using a Transcutaneous Electrical Nerve Stimulation (TENS) device, and receiving support from medical specialists (e.g., pelvic physiotherapy, psychologists) to cope with pain. Additional fatigue management strategies included nutritional supplements and medication (e.g., antidepressants), and scheduling, planning, and monitoring one’s day and activities.

Figure 1

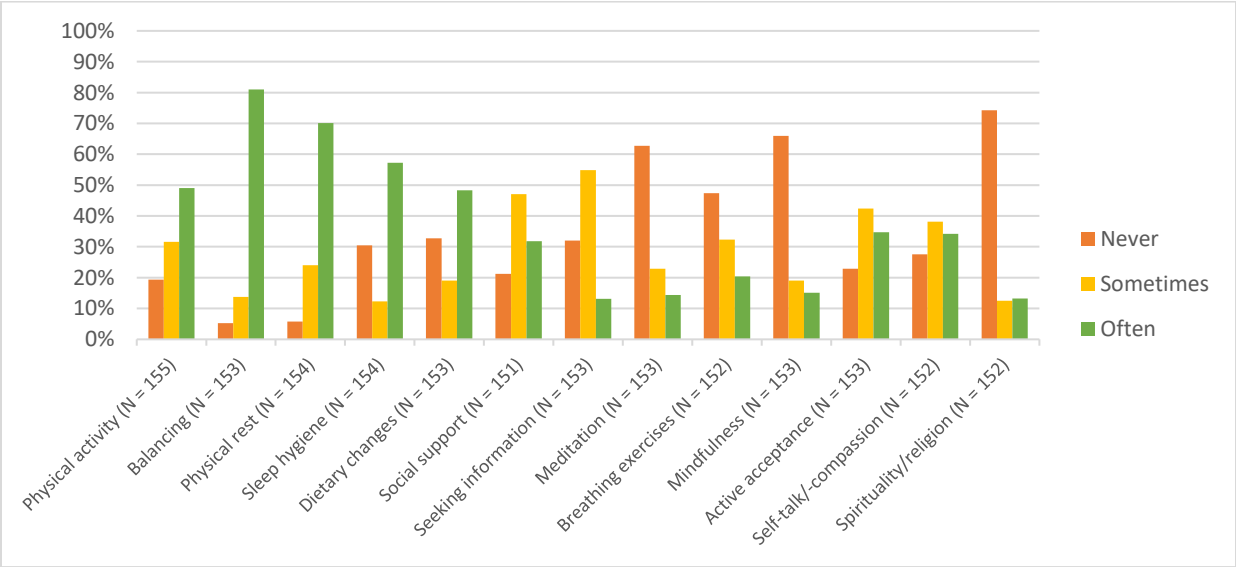
Use of Pain Self-Management Techniques



Note: The sample size was N = 195 unless stated otherwise.

Figure 2

Use of Fatigue Self-Management Techniques



Similar to the frequency of use, *balancing activities and rest*, *physical rest*, *heat* for pain relief, and *sleep hygiene* for fatigue management were perceived as most effective (see Table 3). Infrequently used techniques, including *spirituality/religion* and *mindfulness*, were reported as less helpful. Considerable interquartile ranges were observed across techniques (e.g., in pain

management, mindfulness: median = 2, IQR = 1 – 6), suggesting varying opinions on effectiveness may exist.

Table 3

Perceived Effectiveness Ratings Self-Management Techniques – Distribution, Central Tendency

	Pain			Fatigue		
Self-management techniques	*n*	Median	IQR	*n*	Median	IQR
Physical activity	167	5	3 – 6	130	5	2 – 7
Balancing activities and rest	172	7	5 – 8	139	7	6 – 8
Physical rest	172	7	5 – 8	137	7	5 – 8
Sleep hygiene	154	6	3 – 8	122	7	3 – 8
Dietary changes	146	5	3 – 8	116	5	1 – 7
Over-the-counter painkillers	169	6	4 – 8	-	-	-
Heat	166	7	5 – 8	-	-	-
Social support	160	5	3 – 7	129	2	3 – 7
Seeking information	152	4	1.5 – 5.5	107	3	1 – 5
Meditation	125	3	1 – 6	87	3	0 – 6.5
Breathing exercises	135	4	1.5 – 6	92	2	1 – 7
Mindfulness	114	2	1 – 6	83	4	0 – 6
Active acceptance	153	5	2 – 6	112	4	1 – 6
Positive self-talk/self-compassion	142	5	2 – 7	109	4	1 – 6
Spirituality/religion	101	1	0 – 5	77	1	0 – 5

Note: Tukey's hinges were used to compute the interquartile range (IQR). Effectiveness ratings were provided on a scale from 0 to 10, where 0 = "not at all effective/helpful" and 10 = "completely effective/helpful". Medians reflect the central tendency of the responses.

Research Question 2: Self-Management Support Needs (Information, Guidance, and Technology)

Self-Management Support Needs: Quantitative Findings

Self-management support needs were identified through numerical survey results, highlighting areas where participants require support and preferences for technological formats. To effectively self-manage endometriosis, participants disclosed various areas for improvement (see Table 4). For approximately half of the participants, *healthcare providers' knowledge of endometriosis* and *empathy* were essential for proper self-management. The majority also required *support to manage severe or worsening symptoms*. Additionally, many emphasised the importance of *affordable products and services* that assist with symptom management, alongside a *sense of control and empowerment*. More than one-third of participants perceived a *lack of knowledge regarding endometriosis*. Based on their written elaborations, this primarily referred to the limited (public) awareness of endometriosis characteristics (e.g., symptoms) and potential care approaches. A few participants described *other* areas for improvement, mainly relating to financial reimbursement, access to specialised treatment, and workplace understanding and adaptation.

Table 4

Areas for Improvement In Endometriosis Self-Management

Areas for Improvement	*n*	%
Knowledge of endometriosis	74	37.9%
Knowledge of self-management techniques	49	25.1%
Sense of control/Empowerment	81	41.5%
Support on what to do when symptoms are severe	103	52.8%
Affordable products and services	88	45.1%
Solutions to practical barriers (e.g., limited time)	51	26.2%
Health providers: knowledge of endometriosis	116	59.5%
Health providers: empathy and understanding	89	45.6%
Other	23	11.8%
I have all the support I need	5	2.6%

Note. N = 195.

Besides the broad areas for improvement, participants required information or guidance on specific pain and fatigue self-management techniques (see Table 5). In both symptoms, all presented strategies were reported as relevant to some extent, suggesting diverse needs exist. To cope with endometriosis-related pain, approximately a third of participants required support to change their *diet*, find an appropriate *balance between activities and rest*, and be *physically active*. Furthermore, a quarter indicated needing such support in learning to *accept* their pain symptoms. Similar needs were disclosed for managing fatigue, as participants commonly required support with *balancing their activities and rest*, modifying their *diet*, *resting*, and engaging in *physical activities*. Conversely, several participants did not require any additional information or guidance.

Table 5

Self-Management Techniques: Support and Information Needs

	Pain		Fatigue	
Techniques	*n*	%	*n*	%
Physical activity	56	28.7%	44	22.6%
Balancing activities and rest	57	29.2%	70	35.9%
Physical rest	29	14.9%	47	24.1%
Sleep hygiene	21	10.8%	41	21%
Dietary changes	74	37.9%	48	24.6%
Over-the-counter painkillers	26	13.3%	11	5.6%
Heat	26	13.3%	14	7.2%
Social support	30	15.4%	23	11.8%
Seeking information	25	12.8%	20	10.3%
Meditation	23	11.8%	25	12.8%
Breathing exercises	30	15.4%	27	13.8%
Mindfulness	22	11.3%	19	9.7%
Active acceptance	48	24.6%	33	16.9%
Positive self-talk/self-compassion	30	15.4%	17	8.7%
Spirituality/religion	4	2.1%	4	2.1%
Other	10	5.1%	7	3.6%
I don't need more support/information to manage endometriosis-related pain/fatigue	27	13.8%	35	17.9%

Note. N = 195.

Preferences for technological formats in self-management interventions were also reflected in the numerical results (see Table 6). Approximately half of the participants had a preference for *mobile applications*. A third of participants found *websites* and blended care *online consultations* relevant. *Other* preferred technological formats were reported by a few participants, including peer-support groups (e.g., forum) or blended care, reflecting a desire for human interaction. Facilitating personalisation and flexibility of use were highlighted as the main attractive features of technological formats.

Table 6

Forms of Technology and Attractive Features

Technology Forms	*n*	%	Attractive Technology Features	*n*	%
Mobile application	94	48.2%	Anytime access	95	48.7%
Website	66	33.8%	Personalisation	88	45.1%
Video	38	19.5%	Anywhere access	94	48.2%
Activity tracker	40	20.5%	Peer connectivity	54	27.7%
Virtual reality	13	6.7%	Other	4	2.1%
Online consult (blended care)	62	31.8%	None	8	4.1%
Other	15	7.7%			
None	5	2.6%			

Note. N = 195.

Self-Management Support Needs: Qualitative Insights

Complementing the numerical results, participants provided their support needs as the information, guidance, and technological formats they require in an ideal self-management intervention. These qualitative insights were grouped into eight information-related themes, seven themes reflecting guidance, and 11 themes on technological formats. The most frequently reported themes are described below.

Concerning information, participants (N = 80) frequently reported the theme of *comprehensive self-management information.* This reflected their need to understand the working mechanisms of self-management strategies and how these may alleviate specific symptoms. Moreover, participants desired to know how they may use and implement (combinations of) such strategies. One participant reported: “Basically, an overview of all the different options that are available and what they entail. Where you could get them, but also what you should take into

account, for example, your physical reaction. Both positive and negative". Over a quarter of participants also disclosed their need for *information on specific self-management techniques.* They primarily required information on lifestyle and physical well-being strategies, while a few participants mentioned regulating emotions and reducing stress, and balancing and adapting to boundaries. To exemplify, one participant required: "Information about dietary changes and what impact they have on symptoms". Detailed results are available in Appendix E, Table E1.

Beyond information, participants (N = 83) reported various forms of guidance that their ideal self-management intervention should provide. *Peer-to-peer contact* was the most commonly reported theme. Specifically, participants desired to share illness and care experiences with other endometriosis patients and to support one another in this process. One participant noted: "…sharing stories and experiences with other endometriosis patients to help each other". Approximately a quarter of participants required guidance on *presenting and structuring information,* preferring it to be easily accessible, aligned to the individual, with step-by-step instructions and explanations. A participant described this as: "A kind of manual with all kinds of useful tips and information about all the options [techniques] mentioned to understand endometriosis and make it a little bearable". One-fifth of participants also sought *coaching*, in general or from a professional, to guide them in self-managing endometriosis. One participant stated: "Receive coaching from a professional. Who can teach you acceptance and self-love". Additionally, several participants disclosed the theme *of care provider support* related to the condition, medical treatment, or self-management techniques. For example, one participant required guidance from a "Nutritionist". For detailed results, see Appendix E, Table E2.

Regarding intervention formats, participants (N = 87) were primarily interested in *mobile apps,* due to their flexibility and potential features. One participant reported their ideal intervention consisting of: "App with training, diet, pain diary, communication with doctor, etc". One-fifth of participants desired *audio-visual technology*. They specifically disclosed video (training) formats, combining audio and imagery, or virtual reality for an immersive experience. Several participants

reported *the level of human interaction* as a relevant theme in intervention formats, preferring blended care approaches. One participant reported this as: “Also [using an application] to process your menstruation, physical pain complaints, but also mental blockages so that, for example, the gynaecologist can see how a month has passed and apply a treatment plan accordingly”. Conversely, few expressed a reluctance to use technology. Instead, they desired in-person self-management interventions (see Appendix E, Table E3 for detailed results).

Discussion

This study explored the pain and fatigue self-management experiences and support needs of endometriosis patients in the Netherlands. Pain and fatigue emerged as common symptoms, for which participants often reported similar management approaches and needs. Participants frequently utilised active, problem-focused strategies, including dietary changes, balancing activity with rest, applying heat to reduce pain, and sleep hygiene to manage fatigue. Some participants disclosed emotional coping techniques (e.g., acceptance), although problem-focused approaches were generally more helpful. Managing pain and fatigue symptoms was emphasised as a personal process, formed by individual boundaries and self-experimentation. To guide this process, participants primarily required accessible and comprehensive self-management support, utilising technological or blended-care formats.

A Need For Comprehensive Support

The results revealed a strong desire for comprehensive, symptom-specific information on the workings of multiple self-management strategies. Participants also valued peer contact, professional guidance (e.g., coaching), and accessible step-by-step content delivery. Preferred intervention formats included mobile apps and blended care approaches. Overall, participants’ needs aligned with existing literature. For example, Senyel et al. (2025) described that endometriosis patients often sought information on treatment options, side effects, and symptoms. The positive contributions of peer contact (Shoebotham & Coulson, 2016), professional guidance (Farshi et al., 2020), modular information presentation (Nishikawara et al., 2023), and mobile apps (Rohloff et al., 2024) in

interventions and healthcare have also been well-documented. Additionally, the needs participants disclosed in relation to pain and fatigue self-management were similar, potentially due to an interconnectedness of these symptoms. Pain and fatigue may exacerbate each other (Leuenberger et al., 2022; Lautenbacher et al., 2006; Irwin et al., 2012), and common underlying factors have been recognised (e.g., anxiety, worry, and depression) (Zarbo et al., 2021; Laganà et al., 2015; Van Barneveld et al., 2021; Mundo-López et al., 2020; Roberts & Duong, 2014), providing a plausible explanation for the resemblance in support needs. Taken together, these findings reinforce the relevance of the identified needs across both pain and fatigue, indicating enhanced endometriosis self-management may be reached by accommodating these needs in support efforts.

Notably, participants were primarily recruited via a patient organisation that already offers the information and guidance (e.g., peer contact) they reported needing (Endometriose Stichting, n.d.). However, the available resources may not have been sufficiently aligned with patient capabilities to accommodate their needs effectively. To elaborate, most participants disclosed moderate to severe pain and fatigue symptoms, occurring in various patterns. These have been connected to cognitive difficulties such as reduced attention in fibromyalgia (Moore et al., 2019) and slower information processing in chronic fatigue syndrome (Cockshell & Mathias, 2010), hindering learning from available resources (Baxter et al., 2025). The reported need for accessible presented information (e.g., step-by-step explanations) in the present study may mitigate cognitive difficulties and support engagement and effective use of self-management support (Baxter et al., 2025). Moreover, presenting support in alignment with patients' fluctuating symptom severity might allow key resources to be available at times when patients can process them. An existing modular German endometriosis self-management intervention had positive effects on patient coping and well-being (Rohloff et al., 2024; Rohloff & Schäfer, 2024). While the exact contribution of its modular presentation is unclear, its alignment with participants' expressed needs highlights the importance of how support is delivered. These findings suggest that adapting support to patients' symptoms and cognitive capabilities may better accommodate their needs, highlighting specific patient

characteristics that require consideration in clinical practice. Patients may use their symptom severity as an indicator of their capacity to engage with and process support resources at a given time. Future research is needed to examine the precise role of delivery format, particularly in patients with severe pain and fatigue.

Preferences For Problem-Focused Self-Management Techniques

Participants' experiences and needs related to specific self-management techniques demonstrated a general preference for problem-focused strategies over emotion-focused coping. Specifically, dietary alterations, physical activity, rest, and the balance between these two were deemed most relevant and effective. Previous studies support these findings, with strategies such as adapting physical activity, dietary changes, and scheduling being well-documented in the self-management of coronary artery disease, diabetes, hypertension, chronic obstructive pulmonary disease, and fibromyalgia (Riegel et al., 2020; Kengen Traska et al., 2011; Chen, 2016). Furthermore, in Australian, American, German, Austrian, and Swiss endometriosis populations, problem-focused strategies were among the most commonly employed and reported effective self-management techniques (Norman et al., 2021; Armour et al., 2019; Werner et al., 2025). The preference for problem-focused approaches may depend on treatment status and perceived effectiveness of care. In chronic breast cancer, decreasing treatment efficacy resulted in distress, which patients managed by shifting focus toward everyday life and positive events for emotional relief (Ciria-Suarez et al., 2021). As participants in the present study frequently received medical treatment, they were likely focused on pursuing active symptom relief, which they found to be effective. This may have left them unaware of, or without an immediate need for, emotion-focused approaches, which might explain the present findings. Aligning with existing research, these findings highlight the importance of problem-focused techniques. They also suggest that treatment status and perceived effectiveness of care shape patient awareness and the relevance of self-management techniques. Problem-focused strategies may be preferred during active treatment, with emotional coping becoming more relevant if treatment effectiveness declines. For patients and healthcare providers, understanding the

relevance of problem-focused strategies and recognising the shifts in coping preferences may guide the tailoring of self-management. Future research is needed to investigate how the treatment status influences self-management needs in endometriosis and how evolving treatment effectiveness affects coping preferences.

Self-Management as a Personal Process

Based on their experiences, participants explicitly reported self-management of endometriosis-related pain and fatigue as a personal process. Participants had to be aware of personal limitations and capabilities, and experiment with coping strategies to discover effective approaches. This self-awareness and experimentation are suggested in existing endometriosis literature (Norman et al., 2021; Moore et al., 2024). Moreover, this process was recognised in the chronic condition polycystic ovary syndrome, where patients engaged in various management strategies to discover useful approaches, necessitated by the absence of clear treatment options (Chopra et al., 2021). Similarly, the limited clarity surrounding psychological care and the ineffectiveness of treatment in endometriosis may have contributed to the present findings. As the harms or benefits of specific self-management strategies are unknown, the ESHRE treatment guideline offers no clear recommendations (Becker et al., 2022; ESHRE Endometriosis Guideline Development Group, 2022). Furthermore, endometriosis-related pain and fatigue symptoms often persist and recur despite medical treatment, highlighting its insufficiency (Singh et al., 2019; Álvarez-Salvago et al., 2020). Additionally, the unique symptom presentation of endometriosis (e.g., multiple, fluctuating symptoms) likely contributes to these findings by giving rise to diverse management needs (Mick et al., 2024; Lunde et al., 2024; Moore et al., 2024). Together, the lack of clear management strategies, limited treatment efficacy, and complex symptoms may compel patients to be self-aware of their boundaries and to self-experiment with various coping strategies to accommodate their coping needs. Acknowledged by both patients and existing research, these findings underscore coping with endometriosis as a process of discovery. Implications for clinical practice include the importance of empowering patients in their experimentation with various

strategies, providing them with appropriate resources, and supporting their reflective abilities to discern effective approaches. For patients, these findings may normalise diverse responses to self-management techniques and encourage persistence in identifying personally helpful strategies.

Strengths and Limitations

A key strength of the present study is its application of a mixed-methods approach. This allowed for a rigorous exploration of the study topic, strengthening confidence in the findings (Evans et al., 2021; Heale & Forbes, 2013). This is complemented by the broad exploration of self-management experiences and needs, contributing to a comprehensive understanding of coping in endometriosis. Additionally, literature suggests that engaging patients can support new care approaches and positively influence quality of care (Marzban et al., 2022). As the patient perspective was central to this study, this may enhance the clinical relevance of the findings.

This study had several limitations. First, the extensive survey may have contributed to survey fatigue (Brown et al., 2024), which is associated with lower-quality responses and incomplete data (De Koning et al., 2021). Evidence of this was observed in Item non-responses and reduced response quality (e.g., brief answers, repeating provided examples), particularly for open-ended items and those concerning technological formats. This may have affected the reliability of certain findings and warrants cautious interpretation. Second, some items may have been ambiguously formulated, leading to unclear open-ended responses requiring the researcher's interpretation. While attempts were made to remain close to the original answers, the interpreted findings may not entirely reflect participants' intended meanings. Third, recruitment primarily occurred through the Endometriosis Foundation, risking self-selection bias. Participants acquainted with the foundation likely had access to their self-management resources, potentially making them more knowledgeable in managing endometriosis. Schreurs et al. (2020) found that only 8.8% of Dutch and Belgian endometriosis patients were self-reported members of a patient organisation. Therefore, predominantly recruiting these patients may have reduced the external validity and generalisability (Fox et al., 2022). Despite

the limitation, the extensive findings can guide patient self-management and clinical improvements in endometriosis, benefiting all patients.

Future Recommendations

In addition to the previously reported implications, future research is needed among a representative sample to determine the generalisability and validity of the present findings. Further exploration of technological preferences is also warranted due to limited responses. Concerning clinical practice, it is recommended that care providers and intervention developers provide patients with the required comprehensive support. Future studies may be needed to prioritise patients' extensive needs. Besides patient needs, support interventions could consider tailoring the information, content presentation, and delivery formats to patients' symptom profiles and limitations. These interventions should also empower patients by encouraging self-experimentation and facilitating reflection. Treatment status may help explain the coping strategies patients gravitate toward. Co-creation is recommended to keep patients' perspectives central and positively affect the acceptability of interventions (Sherman et al., 2022). Existing research on self-management in other chronic conditions may be relevant, as similar coping practices were observed across conditions. The findings may also be used to evaluate the feasibility of existing self-management interventions for the Dutch endometriosis context.

Practical patient recommendations include centralising the self and building a self-management regime around one's symptoms and related limitations. Specifically, patients could engage in extensive guidance and information when capable, and use reminders or small-scale support when symptoms are severe. While in active treatment, attention may be on problem-focused strategies. However, patients should remember that self-management evolves and can include emotional coping when needed. Finally, reflecting on management attempts can help develop a personal coping approach.

Conclusion

To conclude, this patient-centred study highlights the primary reliance of Dutch endometriosis patients on problem-focused strategies to manage pain and fatigue, with similar techniques reported across both symptoms. In addition, establishing an endometriosis self-management approach was reflected in patient experiences as a highly personal and evolving process. The diverse support needs highlighted a strong desire for comprehensive, accessible information, particularly concerning problem-focused strategies. Various forms of inter-personal guidance and technological delivery formats were also deemed necessary elements of self-management support. These findings support common pain and fatigue self-management strategies in endometriosis, while underscoring the importance of a personal focus for individual care plans. Patients and care providers are recommended to use the findings as a guide toward tailored support and management. Future research should examine how endometriosis symptom presentation and treatment factors (e.g., perceived effectiveness) influence the accommodation of self-management support needs and the selection of coping strategies.

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Appendix A

Participant Information Letter

You are being asked to participate in a study on **self-management experiences, needs, and technological preferences in managing pain and fatigue symptoms of endometriosis** in the Netherlands. To make a well-informed decision on your participation, please take time to read the information carefully. If questions remain after reading the information, you can contact the researcher using the contact information at the end of the information sheet.

What this study is about

Pain and fatigue are common symptoms of endometriosis that can have a big impact on daily life and well-being. Unfortunately, in current treatment, support in dealing with these symptoms is not always enough and people often need to find out how to manage endometriosis and its consequences on their own.

Self-management in endometriosis includes coping with endometriosis symptoms, treatment(s), and the effects these can have on the body, social life, and psychological well-being. To help deal with pain and fatigue symptoms, self-management skills can be developed, strengthened, and used. One way to develop and/or improve these skills is via support programs (e.g. online, using virtual reality) that offer needed information and guidance (e.g. on self-management techniques).

To ensure such a program is interesting and useful for you, the provided information and support should align with your needs and wishes. Moreover, it should provide the information in a form you like (e.g. mobile application, online program). Because of this, this study aims to understand how self-management is used already, what support is needed or desired to effectively cope with pain and fatigue symptoms of endometriosis (self-management needs), and the preferences in using technology in self-management support programs of endometriosis patients in the Netherlands. In the future, these results may be used to expand endometriosis management care and support in the Netherlands.

What participation involves

Participating in the study includes completing an online survey via Qualtrics that will take approximately 20 minutes to complete. The survey consists of multiple-choice questions and a few open questions. When starting the survey, you are asked to finish the questions on one occasion. Questions ask about your endometriosis diagnosis, treatment, pain and fatigue symptoms, self-management experiences, self-management needs in managing pain and fatigue, and your technological preferences in self-management support programs.

At the end of the survey, you have the option to leave your e-mail address so you may be contacted to participate in a future related study.

Possible advantages and discomfort of participation

Participating in the study may introduce you to self-management techniques that were previously unknown to you. Additionally, long term, your participation and answers may guide the development of new self-management support programs that might expand and complement endometriosis management care in the Netherlands.

Participating in the study and survey is expected to not lead to harm. However, for some, questions on endometriosis diagnosis *(e.g. 'are you diagnosed with endometriosis?')*, treatment *(e.g. 'have you received treatment(s) for endometriosis (symptoms)?')*, and experiences of pain and fatigue symptoms in the last 7 days *(e.g. 'how fatigued were you on average?')*, may be found uncomfortable.

Information about participation: confidentiality, voluntariness, data-use, and consent

Confidentiality

All information you provide in this survey will be treated as confidential. Your data will be fully anonymous. This means no personal information will be included in the data and your answers cannot be traced back to you.

If you decide to leave your email address for a potential follow-up study, your data will be anonymised. This means your email address will be removed from the data and stored separately before analysing the survey data, to ensure your answers cannot be traced back to your personal information.

Survey data and potentially your email address will be stored on a protected University of Twente Google Drive. Anonymous survey data will also be stored on a password-protected computer. During the study, survey data and email addresses will be accessible to the researcher and supervisors from the University of Twente. After this study concludes, the

supervisors from the University of Twente and researchers of related studies at this university will have access to the data and email addresses for up to three years.

Voluntariness

Participating in the study is completely voluntary, meaning you are free to decide whether you want to participate or not. If you have decided to participate you are free to withdraw from the survey at any given time while filling out your answers without explanation or consequences. In this case, your answers will not be used in the study.

Because your answers on the survey are anonymous and anonymously processed, it is not possible to remove your answers from the study after submitting the survey.

If you have shared your email address, you can retract this at any given time without explanation or consequences by contacting the researcher (during the study) or the University of Twente supervisors (after this study has concluded, from May 2025 onwards) (see contact information below).

Data (re)use

Data will be used for a research report, in which the information from multiple anonymous participants will be combined to better understand endometriosis self-management experiences and needs and the technological preferences of endometriosis patients in the Netherlands.

The data will be used within this study and potentially in a future related study among endometriosis patients. No other people than the researcher of this study, the University of Twente supervisors, and future researchers on related projects at the University of Twente will have access to the data.

Email addresses will only be used in a future related study among endometriosis patients to contact potential participants. This information can only be accessed by the researcher (until May 2025), University of Twente supervisors and future researchers of this related project at the University of Twente.

Consent

Your consent to participate in this study will be valid for the duration of this study (January 2025 – May 2025) and, for the use of data, for up to three years after the completion of the study.

Contact information
If questions remain after reading this information sheet, you can contact the researcher of this study for elaboration. The contact information can be found below.

Researcher

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University of Twente Supervisors

First supervisor:

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If you have questions about your rights as a research participant, or wish to obtain information, ask questions, or discuss any concerns about this study with someone other than the researcher(s), please contact the Secretary of the Ethics Committee/domain Humanities & Social Sciences of the Faculty of Behavioural, Management and Social Sciences at the University of Twente by ethicscommittee-hss@utwente.nl

Appendix B

Survey

Endometriosis: Pain and Fatigue Self-Management Experiences, Needs, and Technological Preferences

Welcome! You are invited to participate in a study on pain and fatigue self-management experiences, needs and technological preferences of endometriosis patients in the Netherlands.

Explanation about participation and the background of the study can be found in **this** information letter. Please read this information carefully. The aim of this study is to clarify self-management of endometriosis-related pain and fatigue, the need for support in this and the wishes regarding the use of technology in providing this support. The questionnaire consists of open and multiple choice questions and participation takes approximately 20 minutes. Participation is voluntary and you can always decide not to participate without consequences or giving a reason. If you have any questions about the study, you can contact the researcher via: j.c.ross-1@student.utwente.nl

CONSENT Please read the following points before participating in the survey and select your answer. *"I have read the information letter and..."*

	Yes	No
I understand that participation in the study is voluntary and that I can withdraw from the study at any time while completing the questionnaire, without consequences and without giving any reason.	○	○
I understand that some of the questions are about my experiences with endometriosis-related pain and fatigue and I feel comfortable answering these types of questions	○	○
I give permission for my responses to be used anonymously to create a research report to clarify self-management experiences, needs and technology preferences in endometriosis.	○	○
I agree that my anonymous responses (and my email address if I choose to share it at the end of the questionnaire) may be stored in a secure manner for up to 3 years for possible future research and education purposes.	○	○

Demographics and Condition Characteristics

Q1 What is your age?

- ○ Under 18 years old
- ○ 18-24 years old
- ○ 25-34 years old
- ○ 35-44 years old
- ○ 45-54 years old
- ○ 55-64 years old
- ○ 65+ years old

Q2 What does your household look like?

- ○ I live alone
- ○ I live with my partner
- ○ I live with my partner and child(ren)
- ○ I live with my child(ren)
- ○ I live with housemates
- ○ Other, namely... _____

Q3 What is the highest degree or level of school you have **completed**?

- ○ Elementary school
- ○ Highschool: vmbo/mavo
- ○ Highschool: havo
- ○ Highschool: vwo
- ○ Middelbaar beroepsonderwijs (mbo)
- ○ Hoger beroepsonderwijs (hbo)
- ○ Wetenschappelijk onderwijs (wo)
- ○ Other, namely... _____

Q4 What is your current employment status? *Please select all that apply to you*

- ☐ I work parrtime
- ☐ I work fulltime
- ☐ I am a parttime student
- ☐ I am a fulltime student
- ☐ I am unemployed
- ☐ I am unable to work
- ☐ I am retired
- ☐ Other, namely... _____

The questions in the next section of the questionnaire are about your experiences surrounding the endometriosis diagnosis process, your treatment experiences and any other health complaints you may be experiencing.

Q5 Are you formally diagnosed with endometriosis?

- ○ Yes
- ○ No

Q5.1 Do you think you have endometriosis? *(Presented If "Are you formally diagnosed with endometriosis?" = No*)

- ○ Yes, I think I have endometriosis but I am not yet diagnosed
- ○ No, I think I do not have endometriosis

Q5.2 When did you receive the diagnosis? *(Presented If "Are you formally diagnosed with endometriosis?" = Yes*)

- ○ Less than 6 months ago
- ○ Between 6 months and 1 year ago
- ○ More than 1 year ago

Q5.3 How much time passed between your first endometriosis symptoms and receiving the diagnosis?

(Presented If "Are you formally diagnosed with endometriosis?" = Yes)

- ○ Less than 1 year
- ○ 1-5 years
- ○ 6-10 years
- ○ More than 10 years

Q6 Have you received treatment for endometriosis (symptoms)?

- ○ Yes, I am currently receiving treatment
- ○ Yes, I am currently receiving treatment and I have received treatment in the past
- ○ Yes, I have received treatment in the past, but do not currently receive treatment
- ○ No, I have never received treatment for endometriosis (symptoms)

Q6.1 What treatment(s) have you received for endometriosis (symptoms)? *Please select all that apply to you*

(Presented If "Have you received treatment for endometriosis (symptoms)" = Yes)

- ☐ Hormonal treatment (e.g. hormonal contraceptives)
- ☐ Surgical treatment (e.g. surgical removal of endometriosis)
- ☐ Infertility treatment (e.g. IVF)
- ☐ Other medication (e.g. prescription painkillers)
- ☐ Other (e.g. physical therapy, acupuncture), namely... _____

Q7 Do you experience other health complaints besides endometriosis?

- ○ No, I do not experience any other health complaints besides endometriosis
- ○ Yes, in addition to endometriosis, I also experience other health complaints, namely... _____

Endometriosis can have a big impact on your life through various symptoms, such as pain and fatigue. To better understand these symptoms, the following questions are about your experiences with endometriosis-related **pain.**

Q8 What type(s) of endometriosis-related pain do you experience? *Please select all that apply to you*

- ☐ Pelvic pain
- ☐ Menstrual pain (before and during menstruation)
- ☐ Pain when using the bathroom (when urinating/pooping)
- ☐ Pain during or after sexual intercourse
- ☐ Other, namely... _____
- ☐ I experience endometriosis-related pain, but I do not want to specify which type of pain
- ☐ I do not experience endometriosis-related pain symptoms

Q9 What best describes the pain you experience?

(Presented if "What type(s) of endometriosis-related pain do you experience?" = Pain type)

- ○ The pain is mainly present during or around my menstruation (cyclical pain)
- ○ The pain is present (almost) every day (constant pain)
- ○ The pain is present (almost) every day, but it is worse during or around my menstruation
- ○ The pain comes and goes randomly (random/intermittent pain)
- ○ Other (e.g. triggered by specific things), namely... _____

Q10 Looking back on the **last 7 days**, what **level of endometriosis pain** have you experienced? Positioning the slider on the **far left** indicates **you have not experienced any level of endometriosis-related pain** in the last 7 days. The **far right** indicates **the presence of unbearable endometriosis-related pain** in the last 7 days.

	Absence of pain 0 1 2 3 4 5 6 7 8 9 10 Unbearable pain
Looking back on the last 7 days, what level of endometriosis pain have you experienced?	

Q11 Looking back on the **last 7 days**, to what degree has **endometriosis pain interfered with your enjoyment of life** and **your general daily activities** (e.g. work, household chores)? Positioning the slider on the **far left** indicates **pain has not interfered in the last 7 days**. The **far right** indicates **pain has completely interfered in the last 7 days.**

	Did not interfere 0 1 2 3 4 5 6 7 8 9 10 Completely interfered
Looking back on the last 7 days, how much has endometriosis pain interfered with your enjoyment of life?	
Looking back on the last 7 days, how much has endometriosis pain interfered with your general daily activities (e.g. work, household chores)?	

The following questions are about your experiences with **fatigue** as a symptom of endometriosis.

Q12 Please respond to each statement by marking one box per row. **During the past 7 days...**

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I feel fatigued	○	○	○	○	○
I have trouble starting things because I am tired	○	○	○	○	○

Q13 Please respond to each question by marking one box per row. **In the past 7 days...**

	Not at all	A little bit	Somewhat	Quite a bit	Very much
How run-down did you feel on average?	○	○	○	○	○
How fatigued where you on average?	○	○	○	○	○
How much were you bothered by your fatigue on average?	○	○	○	○	○
To what degree did your fatigue interfere with your physical functioning?	○	○	○	○	○

Self-Management Experiences

In previous questions, you have shared your experiences with **pain** as a symptom of endometriosis. In the next section, the questions focus on **what you do to cope with this symptom**. More specifically, what self-management techniques you use to manage the pain you experience.

Q14 **On average**, **how often** in the past 6 months have you used the following self-management techniques to cope with **endometriosis-related pain**?

	Never	Less than once a week	Once a week	2-6 times a week	Daily or multiple times a day
Physical activity (e.g. walking, jogging, swimming, going to the gym)	○	○	○	○	○
Balancing activities and rest	○	○	○	○	○
Physical rest (e.g. napping)	○	○	○	○	○
Sleep hygiene (e.g. sticking to a regular sleep schedule)	○	○	○	○	○
Dietary changes (e.g. gluten-free, vegan)	○	○	○	○	○
Taking over-the-counter painkillers (e.g. paracetamol)	○	○	○	○	○
Heat (e.g. heat pack, hot water bottle, sauna)	○	○	○	○	○
Social support (e.g. ask for advice, ask for help with chores)	○	○	○	○	○
Seeking information on endometriosis (symptoms)	○	○	○	○	○
Meditation	○	○	○	○	○
Breathing exercises	○	○	○	○	○
Mindfulness	○	○	○	○	○
Actively accepting the condition/symptom	○	○	○	○	○
Positive self-talk	○	○	○	○	○
Spirituality (e.g. prayer)	○	○	○	○	○

Q15 In addition to the techniques in the previous questions, have you used any **other self-management techniques** to cope with e**ndometriosis-related pain** in the past 6 months?

- ○ Yes, namely... _____
- ○ No

Q16 **How effective** do you find the following self-management techniques in managing **endometriosis-related pain**? *Use the slider to indicate the effectiveness of each technique. The **left side** indicates you find the technique **totally ineffective** in managing endometriosis-related pain, whereas the **right side** indicates you find the technique **totally effective.***

Q17 Based on your experiences, what advice on **self-management of pain symptoms** would you give someone who is newly diagnosed with endometriosis?

_____

_____

In earlier questions, you have also shared your experiences with **fatigue** as a symptom of endometriosis. In the next section, the questions focus on **what you do to cope with this symptom**. More specifically, which self-management techniques you use to manage the fatigue you experience.

Q18 **On average, how often** in the past 6 months have you used the following self-management techniques to cope with **endometriosis-related fatigue**?

	Never	Less than once a week	Once a week	2-6 times a week	Daily or multiple times a day
Physical activity (e.g. walking, jogging, swimming, going to the gym)	○	○	○	○	○
Balancing activities and rest	○	○	○	○	○
Physical rest (e.g. napping)	○	○	○	○	○
Sleep hygiene (e.g. sticking to a regular sleep schedule)	○	○	○	○	○
Dietary changes (e.g. gluten-free, vegan)	○	○	○	○	○
Social support (e.g. ask for advice, ask for help with chores)	○	○	○	○	○
Seeking information on endometriosis (symptoms)	○	○	○	○	○
Meditation	○	○	○	○	○
Breathing exercises	○	○	○	○	○
Mindfulness	○	○	○	○	○
Actively accepting the condition/symptom	○	○	○	○	○
Positive self-talk	○	○	○	○	○
Spirituality (e.g. prayer)	○	○	○	○	○

Q19 In addition to the techniques in the previous questions, have you used any **other self-management techniques** to cope with e**ndometriosis-related fatigue** in the past 6 months?

- ○ Yes, namely... _____
- ○ No

Q20 **How effective** do you find the following self-management techniques in managing **endometriosis-related fatigue**? *Use the slider to indicate the effectiveness of each technique. The **left side** indicates you find the technique **totally ineffective** in managing endometriosis-related fatigue, whereas the **right side** indicates you find the technique **totally effective.***

	Totally ineffective 0 1 2 3 4 5 6 7 8 9 10 Totally effective
Physical activity (e.g. walking, jogging, swimming, going to the gym)	
Balancing activities and rest	
Physical rest (e.g. napping)	
Sleep hygiene (e.g. sticking to a regular sleep schedule)	
Dietary changes (e.g. gluten-free, vegan)	
Social support (e.g. ask for advice, ask for help with chores)	
Seeking information on endometriosis (symptoms)	
Meditation	
Breathing exercises	
Mindfulness	
Actively accepting the condition/symptom	
Positive self-talk	
Spirituality (e.g. prayer)	
Other, namely...	

Q21 Based on your experiences, what **advice** about **self-management of fatigue symptoms** would you give to someone who has just been diagnosed with endometriosis?

_____

_____

Needs In Achieving Effective Pain and Fatigue Self-Management

In the previous questions you shared your experiences with using different self-management techniques, such as changing your diet or seeking support from friends or family (social support). The following questions are about what information or support you might still need with self-management to better cope with endometriosis-related pain and fatigue.

Q22 What do you feel is **missing or needed** to help you (better) self-manage endometriosis-related symptoms (pain and fatigue)? *Please select all that apply to you.*

- ☐ More knowledge about endometriosis (e.g. treatment options, symptoms) (please specify) _____
- ☐ More knowledge of self-management techniques (e.g. what techniques can be used, how to use them) (please specify) _____
- ☐ Feeling in control and empowered in managing endometriosis symptoms
- ☐ Support on how to self-manage when symptoms are severe (e.g. what to do when feeling too much pain to be physically active)
- ☐ Access to affordable products and services (e.g. in dietary changes: affordable food products, low cost program)
- ☐ Solutions to overcoming practical barriers (e.g. support with time constraints)
- ☐ Better knowledge of endometriosis (symptoms) among healthcare providers
- ☐ More understanding and empathy from healthcare providers
- ☐ Other, namely _____
- ☐ Nothing feels missing or lacking, I have all the support I need to self-manage endometriosis symptoms

Q23 Information and support can be provided via a range of self-management techniques. Which techniques would you like to receive **more information and/or support on** to be able to manage **endometriosis-related pain** (more) effectively? *Please select all that apply to you.*

- ☐ Physical activity (e.g. walking, jogging, swimming, going to the gym)
- ☐ Balancing activities and rest
- ☐ Physical rest (e.g. napping)
- ☐ Sleep hygiene (e.g. sticking to a regular sleep schedule)
- ☐ Dietary changes (e.g gluten-free, vegan)
- ☐ Taking over-the-counter painkillers (e.g. paracetamol)
- ☐ Heat (e.g. heat pack, hot water bottle, sauna)
- ☐ Social support (e.g. ask for advice, ask for help with chores)
- ☐ Seeking information on endometriosis (symptoms)

- ☐ Meditation
- ☐ Breathing exercises
- ☐ Mindfulness
- ☐ Actively accepting the condition/symptom
- ☐ Positive self-talk
- ☐ Spirituality
- ☐ Other, namely _____
- ☐ I do not need to receive more information/support to manage endometriosis-related pain effectively

Q24 Which techniques would you like to receive more information and/or support on to be able to manage **endometriosis-related fatigue** (more) effectively? *Please select all that apply to you.*

- ☐ Physical activity (e.g. walking, jogging, swimming, going to the gym)
- ☐ Balancing activities and rest
- ☐ Physical rest (e.g. napping)
- ☐ Sleep hygiene (e.g. sticking to a regular sleep schedule)
- ☐ Dietary changes (e.g gluten-free, vegan)
- ☐ Taking over-the-counter painkillers (e.g. paracetamol)
- ☐ Heat (e.g. heat pack, hot water bottle, sauna)
- ☐ Social support (e.g. ask for advice, ask for help with chores)
- ☐ Seeking information on endometriosis (symptoms)
- ☐ Meditation
- ☐ Breathing exercises
- ☐ Mindfulness
- ☐ Actively accepting the condition/symptom
- ☐ Positive self-talk

☐ Spirituality

☐ Other, namely _____

☐ I do not need to receive more information/support to manage endometriosis-related fatigue effectively

Imagine that you can create a program that provides exactly the information and support you want and need to best manage the endometriosis symptoms you experience (pain, fatigue). In this scenario, there are no budget, time, or other restrictions: anything is possible. To explain the difference between information and support for self-management: **information** for self-management is about **providing accurate and sufficiently comprehensive information** about, for example, endometriosis, symptoms, self-management techniques or treatments. Whereas, **support** for self-management is about **how and with whose help** you can best apply the information in your daily life.

Q25 What **information** would your ideal self-management program provide you? *For example: what meditation is and what it can do for you, which techniques might work best for a particular symptom*

_____

_____

Q26 What **support** would your ideal self-management program offer you? *For example: sharing experiences with other endometriosis patients, a step-by-step explanation of how to apply a certain technique, receiving coaching from a professional on how to deal with endometriosis symptoms*

_____

_____

Technological Preferences

Technological developments have made it possible to offer and use self-management programs in more ways than ever before. For example, internet programs and programs in the form of a mobile application have made it possible to get support in your own environment. In addition, virtual reality can immerse you in a completely different environment when practicing self-management techniques. In short, much is possible with the help of technology.

Q27 In the previous question, you have described your ideal self-management program to help you with effectively managing endometriosis-related symptoms. If **anything were possible**, what form(s) of technology would you like to use in your ideal self-management program? (e.g. mobile application, virtual reality, video training, multiple forms)

_____

Q28 What **forms of technology** do you like best in supporting you in self-managing endometriosis-related symptoms (pain and fatigue)? *Please select all that apply*

- ☐ Mobile application (app)
- ☐ Website
- ☐ Video
- ☐ Activity tracker
- ☐ Virtual reality
- ☐ Online consultations with a healthcare provider
- ☐ Other, namely... _____
- ☐ None, I am not open to using technology for this purpose

Q29 What makes the use of technology in self-management appealing to you? *Please select all that apply to you.*

- ○ Technology can be used whenever I want
- ○ Technology can be personalised to my wishes and needs
- ○ Technology can be used in my own environment/home
- ○ Technology allows me to be in touch with other patients
- ○ Other, namely... _____
- ○ Using technology in self-management is not appealing to me

Q30 In the future, a follow-up study may be done to gain a deeper understanding of self-management experiences and needs in endometriosis. If you would like to potentially be included in such a follow-up study, you may leave your email address below. *Note: Leaving your email address below means you might be contacted in the future, asking for participation in a follow-up study.* ***It is also possible you will not be contacted.***

- ○ My email address is... _____
- ○ I do not want to share my email address

Appendix C

Self-Management Techniques List

Table C1

Self-Management Techniques Used in Pain-Related Items

Self-management techniques
1. Physical activity (e.g. walking, jogging, swimming, going to the gym)
2. Balancing activities and rest
3. Physical rest (e.g., napping)
4. Sleep hygiene (e.g., sticking to a regular sleep schedule)
5. Dietary changes (e.g., gluten-free, vegan)
6. Taking over-the-counter painkillers (e.g., paracetamol)
7. Heat (e.g. heat pack, hot water bottle, sauna)
8. Social support (e.g. ask for advice, ask for help with chores)
9. Seeking information on endometriosis (symptoms)
10. Meditation
11. Breathing exercises
12. Mindfulness
13. Actively accepting the condition/symptom
14. Positive self-talk/self-compassion
15. Spirituality and religion (e.g., prayer)

Table C2

Self-Management Techniques Used in Fatigue-Related Items

Self-management techniques
1. Physical activity (e.g. walking, jogging, swimming, going to the gym)
2. Balancing activities and rest
3. Physical rest (e.g., napping)
4. Sleep hygiene (e.g., sticking to a regular sleep schedule)
5. Dietary changes (e.g., gluten-free, vegan)
6. Social support (e.g. ask for advice, ask for help with chores)
7. Seeking information on endometriosis (symptoms)
8. Meditation
9. Breathing exercises
10. Mindfulness
11. Actively accepting the condition/symptom
12. Positive self-talk/self-compassion
13. Spirituality and religion (e.g., prayer)

Appendix D

Results: Self-Management Experiences

Table D1

Self-Management Experiences: Pain-Related Peer Advice

Theme	Subtheme	Description	Example quote	*n* (%)
Personalised pain management (n = 46, 35.9%)	Personal approach	Participants recognised pain self-management as a personal approach that varies per patient.	"Everything works differently for everyone."	11 (8.6%%)
	Physical boundaries	Participants described each endometriosis patient as having their unique physical boundaries that affect pain perception.	"Listen to your body for what you need at that moment and not to anyone else."	24 (18.8%)
	Explore: Trial and error	Participants shared that experimentation and exploration are needed to find appropriate self-management approaches.	"Try different things to see what works for you."	17 (13.3%)
Medical management strategies (n = 46, 35.9%)	Specialised care	Participants shared that seeking medical or specialised care may be a form of management of pain symptoms (e.g., physiotherapist, psychologist, endometriosis specialised gynaecologist).	"And if your pains don't get any better, then definitely ask your doctors for help. Then more is needed."	14 (10.9%)
	Pain medication	Participants shared pain medication as a form of medical pain management (e.g., taking over-the-counter or prescribed pain medication)	"Also take the painkillers as prescribed by the doctor. Don't be stubborn about it."	26 (20.3%)
	Dietary changes	Managing pain symptoms by altering one's diet (e.g., an inflammatory-reducing diet) was recognised as a form of medical management by participants.	"Pay attention to your diet, look at which foods have an anti-inflammatory effect, for example."	13 (10.2%)
Physical pain management strategies (n = 29, 22.7%)	Heat	According to participants, applying heat to one's body (e.g., via a shower or hot water bottle) can alleviate pain.	"And heat helps enormously: heating pad, showering, etc."	22 (17.2%)
	TENS (Transcutaneous Electrical Nerve Stimulation)	Participants recommended using mild nerve stimulation via a TENS machine to relieve pain (e.g., nerve pain, muscle pain).	"I definitely recommend the TENS."	7 (5.5%)

Theme	Subtheme	Description	Example quote	*n* (%)
	(Self)massages	Massaging one's body as a form of physical pain management (e.g., relieving muscle pain) was described by participants.	"Body massages."	3 (2.3%)
Physical activity and rest (n = 49, 38.3%)	Rest and sleep	Participants described that adequate rest and sleep may affect pain.	"Having a rhythm, rest... good sleep is very important."	28 (21.9%)
	Movement	As described by participants, physical movement may alleviate pain.	"Sports sometimes help to reduce pain and give you energy."	22 (17.2%)
	Balance: Rest and activities	Participants shared the importance of balancing physical activity and inactivity, as the pain necessitates it.	"Find a good balance between activity and rest. You need more recovery than the average person."	12 (9.4%)
Emotion regulation and self-care (n = 39, 30.5%)	Acceptance and self-validation	Participants described self-validation and learning to accept one's condition, symptoms, and limitations as a form of emotional pain management.	"Adapt your life to your condition instead of the other way around (accepting instead of fighting it)."	25 (19.5%)
	Relaxation and mindfulness practices	Reducing stress, tension, and worry to manage pain by relaxing or supporting one's body and mind (e.g., breathing techniques to puff the pain away) was introduced by participants as emotional pain management.	"Find ways to relax your body (pilates, breathing exercises, mindfulness)."	14 (10.9%)
	Self-kindness	Participants described the importance of being kind to oneself or reminding oneself of the importance of empathy in the context of emotional pain management.	"Be kind to yourself."	7 (5.5%)
	Distraction	Participants recognised seeking distractions in the context of emotional pain management.	"Seek distractions."	2 (1.6%)
Self-education	-	Participants described that self-education allows patients to actively partake in the self-management process of the symptoms.	"Go to specialists or hospitals and collect information yourself."	8 (6.3%)
Social interaction (n = 17, 13.3%)	Talk and share	According to participants, talking about the condition may aid pain management by allowing others to understand and offer support.	"Talk to those around you so that they can understand you, be considerate, and help you."	10 (7.8%)
	Peer support	Participants shared that peer support may lead to finding comfort, a sense of belonging, and guidance in mutual experiences.	"Ask for advice and tips from fellow sufferers. Don't suffer alone; know that you are not alone!"	5 (3.9%)
	Asking for help	Participants indicated that reaching out for instrumental support may be a form of management.	"Ask for help, for example, with household chores and work."	5 (3.9%)

Theme	Subtheme	Description	Example quote	*n* (%)
	Healthcare communication	To ensure the validation of symptoms, participants indicated the importance of maintaining good communication with doctors.	"Make sure you have good contacts with the gynaecologist and are taken seriously."	1 (0.8%)
Complementary treatment	-	Participants described that pain management may be expanded with complementary treatment options (e.g., supplements, acupuncture, osteopathy).	"Seek help in the alternative sector, they can help and support you in this process."	7 (5.5%)
Limitations of self-management	-	Pain self-management was insufficient to help some participants cope with their (severe) pain.	"None. There is nothing that helps!!"	2 (1.6%)
Unknown	-	Pain management was difficult for some participants, and it was unknown what could potentially be recommended to help with this.	"No idea, I'm desperately searching myself."	5 (3.9%)

Note. Percentages were calculated based on respondents to this item (*N* = 128).

Table D2

Self-Management Experiences: Fatigue-Related Peer Advice

Theme	Subtheme	Description	Example quote	*n* (%)
Personalised fatigue management (n = 43, 62.3%)	Adjust schedule: Balance and energy management	Participants recognised that in the context of fatigue management, one's schedule should be adjusted based on their needs and/or boundaries.	"If you are tired, take a nap or leave the activities or housework for a while."	25 (36.2%)
	Acknowledge physical boundaries	Participants described that patients have unique physical boundaries in relation to their fatigue symptoms.	"Pushing through it won't get you anywhere. Listen carefully to your boundaries."	22 (31.9%)
	Explore: Trial and error	To alleviate fatigue, participants described the importance of aligning management strategies with personal boundaries, experience of fatigue, and needs.	"Getting to know yourself and making sure you know what works for you."	10 (14.5%)
Physical rest (n = 33, 47.8%)	Rest	According to participants, physically resting and sleeping are important in fatigue management.	"If possible, schedule a fixed rest period during the day. Or more if necessary."	30 (43.5%)
	Relaxation	Participants described relaxation in the context of fatigue management (e.g., meditation).	"Just like advice on pain, stress reduction."	4 (5.8%)
Move and energise (n = 6, 8.7%)	Movement	Despite fatigue, participants recognised that movement may help them feel better when managing their fatigue symptoms.	"However, I do try to do some exercise almost every day, such as a walk after lunch/dinner or some gentle yoga in the evening."	5 (7.3%)
	Energising activities	Participants recommend that patients participate in activating events.	"Do things that give you some energy."	1 (1.5%)
Medical management strategies (n = 5, 7.3%)	Specialised care	Participants described seeking specialised healthcare (e.g., physiotherapist) as part of fatigue management.	"If the fatigue is severe, then definitely visit an occupational therapist and physiotherapist to help with this."	2 (2.9%)
	Medication	Medication in fatigue management was described as potentially providing relief or having counterproductive effects.	"ADHD medication helps me stay awake, but when I don't take it or it wears off, it's twice as bad."	3 (4.4%)
Acceptance and (self-)validation	-	Self-validation and learning to accept one's condition, symptoms, and limitations were described by participants in fatigue management.	"Learn to be content with less and accept that this is it for today. Tomorrow is a new day and maybe then you'll have more energy to do something."	13 (18.8%)
Social interaction (n = 10, 14.5%)	Peer support	Participants shared that peer support may help to find comfort and guidance in mutual experiences.	"If you feel guilty about this [taking rest], it can help to seek advice from others in the same situation."	2 (2.9%)

Theme	Subtheme	Description	Example quote	*n* (%)
	Talk, share, and ask	In the context of fatigue management, participants described reaching out, sharing experiences, and discussing solutions or a need for support.	"For example, talk to your employer about how you can organise this."	8 (11.6%)
Pain-fatigue link	-	Participants mentioned that pain and fatigue cannot be seen as separate entities in endometriosis management.	"I find it strange that you separate the pain symptoms from the fatigue because they come hand in hand. I also find it difficult to answer them separately."	4 (5.8%)
Unknown	-	Participants described fatigue management to be difficult, and it was unknown what could potentially help.	"No idea. I don't know what works. I can't make the fatigue go away."	7 (10.1%)

Note. Percentages were calculated based on respondents to this item (*N* = 69).

Appendix E

Results: Self-Management Support Needs

Table E1

Ideal Self-Management Intervention: Information (Content)

Theme	Subtheme	Description	Example quote	*n* (%)
Comprehensive self-management information (n = 50, 62.5%)	Understanding mechanisms and symptom relief	Comprehensive information is desired by participants to increase their understanding of self-management techniques, their functioning mechanisms, and what symptoms they may alleviate.	"Basically, an overview of all the different options that are available and what they entail. Where you could get them, but also what you should take into account, for example, your physical reaction. Both positive and negative."	26 (32.5%)
	Symptom-specific self-management information	Participants indicated they want to receive self-management information directly related to specific symptoms (e.g., pain, fatigue).	"Lots of detailed information about the various options for combating pain; such as TENS devices, medication, breathing exercises, diet and exercise."	17 (21.3%)
	Holistic self-management approach	Complete information on many varying techniques and how they connect (e.g., strengthen the other) to apply self-management holistically was described by participants.	"And especially about how you can best use this in combination."	11 (13.8%)
	Implementation and use	Comprehensive information on how to use and implement all self-management techniques is desired by participants to use/start using self-management.	"I feel like light exercise would really help my fatigue and cramps but I have no idea where to start so it would be nice if that information was more available."	9 (11.3%)
Information on specific self-management techniques (n = 22, 27.5%)	Lifestyle and physical well-being	Participants want information on specific self-management techniques related to their lifestyle and physical well-being (diet, physical exercise).	"Information about dietary changes and what impact they have on symptoms."	10 (12.5%)
	Emotion regulation and stress reduction	Participants shared they want information on specific self-management techniques related to regulating their emotions and reducing their stress (mindfulness, meditation, breathing exercises).	"How to get started with meditation and what type of meditation might suit you."	7 (8.8%)
	Balancing and adaptation	Participants indicated they would like to receive information on specific self-management techniques	"What balance is best and when is it okay to cross boundaries versus when is it wise to rest."	7 (8.8%)

Theme	Subtheme	Description	Example quote	*n* (%)
		related to balancing activities and rest, and adapting to having the condition/symptoms (acceptance, balancing, rest, self-compassion).		
	Self-education and external support	Participants shared they want information on specific self-management techniques related to information and support, to apply these in their lives (seeking information, social support).	"Ask for and accept help."	2 (2.5%)
Medical information (n = 12, 15%)	Medical (treatment) information	Participants shared they would like information on the medical treatment used in endometriosis (e.g., medication), to understand what may be used and its effects.	"Which medication and what effect it has on both the pain symptoms and the rest of the body."	8 (10%)
	Non-medical treatment alternatives	Participants may dislike available medical treatment approaches and shared that they need information on alternative ways to manage the condition.	"It is especially important that more information is available than just hormonal treatments or surgery."	4 (5%)
Endometriosis-related information (condition information)	-	Participants indicated they want information on what endometriosis is as a condition, what its effects are, and why these occur.	"It has helped me the most to understand more about what endometriosis is exactly and why it causes such a range of symptoms. More information about what the disease exactly entails and which processes in your body are involved (e.g. also your immune system and the relationship with fertility) would be nice."	8 (10%)
Resource library (n = 10, 12.5%)	(External) resources	A single location to find useful (external) resources was desired by participants to allow them to find what is interesting or helpful for them in self-managing endometriosis.	"Based on the symptoms I have, I would like to receive a list of resources that are relevant for me to read."	6 (7.5%)
	Reliable information	When presenting resources, participants wished for reliable, trustworthy, and supported information to be well-informed in (self-managing) their condition.	"The right information about what endometriosis is, as there is a lot of misinformation out there."	4 (5%)
Support in self-management(n = 5, 6.3%)	Specialist contact and coaching	Participants shared that they would like specialist (e.g., health care providers) support or coaching to aid their self-management.	"A coach to help you make decisions and discuss your plan and what works and what doesn't. What options still need to be explored, etc."	5 (6.3%)
	Peer contact	Participants indicated a need for contacting peers and sharing experiences.	"Perhaps even one [intervention] where you can spar with fellow sufferers."	2 (2.5%)

Theme	Subtheme	Description	Example quote	*n* (%)
Presentation of self-management (n = 6, 7.5%)	Personalised information delivery	Participants shared a need for presenting information in a personalised manner, fitting with their symptoms/complaints/need for support.	"In line with what my body needs. Every body is different and experiences this differently, but everyone's life also looks different."	4 (5%)
	Practical examples	The use of practical examples may aid participants in applying self-management in practice.	"Lots of examples of it [mindfulness, meditation, breathing exercises] and explanations of what it is and how to do it."	2 (2.5%)
Communicating and advocating for needs	-	Participants indicated a need for information on how to communicate and advocate for their condition-related/ self-management needs.	"Being able to deal better with the pain and fatigue and also being able to communicate this well to an employer, for example."	2 (2.5%)
Unknown	-	Participants may not always know what information they need to self-manage the condition.	"I hardly ever do this myself and therefore don't know what my needs would be."	6 (7.5%)

Note. Percentages were calculated based on respondents to this item (*N* = 80).

Table E2

Ideal Self-Management Intervention: Guidance (Process)

Theme	Subtheme	Description	Example quote	*n* (%)
Presentation and structuring of information (n = 23, 27.7%)	Centralisation and accessibility	Participants expressed a need for information to be centrally and accessibility presented.	"A kind of manual with all kinds of useful tips and information about all the options [techniques] mentioned to understand endometriosis and make it a little bearable."	10 (12.1%)
	Step-by-step instructions	A desire for step-by-step instructions (e.g., on using and selecting self-management) was indicated by participants.	"Step-by-step plans on how to try out a diet yourself, for example (as dieticians are expensive), but also what steps you should take if you feel that your doctor is not taking you seriously, and who you should contact if you can accept it (psychological help)."	5 (6%)
	Explanations	Participants indicated they would like information to be formulated to explain its meaning (e.g., what self-management techniques entail, and how they may be used).	"Explaining techniques and how to apply them would also be very helpful. Also in the area of studying whilst having endometriosis."	4 (4.8%)
	Personalised and tailored	Participants expressed they would like information to be presented in a personalised and tailored manner, aligned to their personal experiences and needs (e.g., presenting information at specific times).	"A suitable plan that aligns with me as a person, with steps and information at the right times."	4 (4.8%)
	Motivational language and reminders	According to participants, they would prefer the presentation of information to be done using motivating and encouraging language (e.g., reassurance, reminders).	"Reminders from an app or coach about whether you have had enough rest this week and how you could improve your week."	3 (3.6%)
Coaching (n = 19, 22.9%)	Coaching (general)	Participants shared that they would like to receive coaching as guidance in their self-management.	"Personal coaching in areas I know little about or am not sufficiently aware of."	10 (12.1%)
	Coaching by professionals	Participants expressed that they would like to receive coaching from professionals to aid their self-management.	"Receive coaching from a professional. Who can teach you acceptance and self-love."	9 (10.8%)
Activity guidance	-	Participants shared that guidance in partaking in self-management activities (e.g., exercise class, meditation tutorial) may be helpful.	"Guidance on sports, what is and what is not..."	9 (10.8%)

Theme	Subtheme	Description	Example quote	*n* (%)
Peer-to-peer contact (n = 24, 28.9%)	Sharing experiences	Participants expressed that self-management guidance may be provided by peers through sharing experiences.	"…In addition, sharing stories and experiences with other endometriosis patients to help each other."	14 (16.9%)
	Peer support	Participants indicated that guidance in self-management may be provided by peers through supporting each other.	"An app for peers that includes a forum." "A support group in the region would be nice."	10 (12.1%)
Care provider support (n = 17, 20.5%)	Related to condition and (medical) treatment	As mentioned by participants, self-management guidance would ideally be provided by health care providers in relation to the condition and treatment (e.g., nurse).	"I think that guidance is appropriate here, such as a nurse or something similar who you can contact with questions and who can refer you if necessary."	13 (15.7%)
	Related to self-management techniques (e.g., diet)	Participants indicated wanting to receive professional guidance in relation to self-management (techniques) (e.g., dietician, yoga teacher)	"Someone with the background and expertise to provide guidance in this [self-management]." "Nutritionist."	6 (7.2%)
Accessibility and barriers in ideal support (n = 10, 12.1%)	Treatment and diagnostic process limitations	Participants indicated there are several barriers related to treatment and the diagnostic process in endometriosis that would benefit from improvements, which may affect their management of the condition.	"Better available support in dealing with illness and misunderstanding in daily life, a year on a waiting list for mental health care is simply untenable, and in my experience psychologists can do very little with this. Which results in years of being sent from pillar to post."	6 (7.2%)
	Government and institutional understanding	The understanding of endometriosis and related needs by the government and institutional organisations (e.g., health insurers) was recognised by participants as something that could benefit from improvement, which may affect the management of the condition.	"Support from the health insurer. The visits to the mindfulness practice were reimbursed, but from the physiotherapy resources."	3 (3.6%)
	Financial barriers	Participants indicated financial reasons could hinder their self-management by limiting accessibility.	"Osteopathy, etc., is often at your own expense, and I once purchased a TENS myself, which is also not financially possible for everyone, and you often cannot have a fulltime job because of the complaints."	2 (2.4%)
Unrelated	-	Participants shared information unrelated to their ideal support forms or by whom these could be provided (e.g., information needs, description of what works for them).	"More recognition and more knowledge about endometriosis and its consequences." "Exercise produces endorphins and helps against pain."	12 (14.5%)

Note: Percentages were calculated based on respondents to this item (*N* = 83).

Table E3

Ideal Self-Management Intervention: Technology (Format)

Theme	Subtheme	Description	Example quote	*n* (%)
Mobile application	-	Participants shared their interest in using a mobile application in a self-management intervention (e.g., because it can have many features such as tracking).	"App with training, diet, pain diary, communication with doctor, etc."	45 (51.7%)
Audiovisual technology (n = 18, 20.7%)	Video(training)	Participants indicated that self-management information and support may be provided via a video(training), combining visual and auditory aspects.	"A video training is especially useful when learning actions (e.g. breathing exercises). Then visualization is nice."	12 (13.8%)
	Virtual reality	Participants shared that self-management information and support may be provided via virtual reality for an immersive visual and auditory experience.	"Virtual reality with meditation seems like a great self-management tool to me against pain and fatigue. [In VR] Someone can be taken along and distracted during a severe period of pain to a self-chosen world that seems real. I think that can have a pain-reducing/dampening effect."	5 (5.8%)
	Audio-based technology	Participants indicated that self-management information and guidance may be provided via audio-based forms of technology (e.g., podcasts, exercises).	"A wide selection of audio meditation and mindfulness specifically aimed at pain and fatigue, self-compassion and peace."	2 (2.3%)
Digital trackers	-	Participants shared that they would like to use digital trackers (e.g., incorporated in an app) to keep track of their condition, symptoms, and self-management experiences.	"Extensive tracking options to monitor symptoms and self-management techniques applied."	11 (12.6%)
Webpages/Documents	-	Participants indicated they would like a webpage or document in which relevant, comprehensive information may be presented, all in one place.	"One website where everything [information, support] is collected."	2 (2.3%)
(Online)training	-	Participants indicated they would like to receive self-management support and/or information via online training.	"Online training on pain relief."	1 (1.2%)
Artificial intelligence	-	Participants shared that they would like to see artificial intelligence used in their ideal self-management intervention.	"VR, videotrainig, AI."	1 (1.2%)
Physical technology	-	Participants indicated they would like to receive physical technology, specifically a TENS device, for their endometriosis self-management.	"Also TENS devices for anyone who wants to try them out!"	1 (1.2%)

Theme	Subtheme	Description	Example quote	*n* (%)
Multiple forms of technology	-	Participants shared that their ideal self-management intervention would likely use multiple forms of technology to support/inform them.	"A combination of different forms of technology."	12 (13.8%)
Level of human interaction (n = 17, 19.5%)	Blended care: Technology and human contact	Participants shared they would like to receive a self-management intervention that combines technology and human contact (e.g., using technology to support patient-physician contact).	"Also [using an application] to process your menstruation, physical pain complaints, but also mental blockages so that, for example, the gynaecologist can see how a month has passed and apply a treatment plan accordingly."	14 (16.1%)
	In-person intervention	Participants indicated they would not want to use technology in their ideal self-management intervention, but rather have an in-person intervention.	"I prefer face-to-face contact with someone."	3 (3.5%)
Unknown/ Difficult to answer	-	Participants indicated they did not know what forms of technology they would like to use in their ideal self-management intervention.	"I am not familiar with this, so it is difficult to answer."	5 (5.8%)
Unrelated	-	Participants responded unrelated to the use of technology in a self-management intervention.	"Targeted pain management."	5 (5.8%)

Note. Percentages were calculated based on respondents to this item (*N* = 87).

Appendix F

AI Statement

During the preparation of this work, I occasionally used Grammarly and ChatGPT to evaluate the spelling and grammar of my written parts. After using this tool/service, I thoroughly reviewed and edited the content as needed, taking full responsibility for the final outcome.