

Effectiveness of a Nurse-Led Online Health Education Programme on Empowerment, Pain Catastrophizing, and Perceived Health Improvement in Women with Endometriosis: A Longitudinal Quasi-Experimental Study

Georgina Feixas

gfeixas@clinic.cat

Hospital Clínic de Barcelona

Marta Garcia

Hospital Clínic de Barcelona

Sandra Parés

Hospital Clínic de Barcelona

Lara Quintas-Marquès

Hospital Clínic de Barcelona

Meritxell Gracia

Hospital Clínic de Barcelona

Mariona Rius

Hospital Clínic de Barcelona

Francisco Carmona

Hospital Clínic de Barcelona

María-Ángeles Martínez- Zamora

Hospital Clínic de Barcelona

Research Article

Keywords: Endometriosis, Patient Empowerment, Pain Catastrophizing, Advanced Practice Nursing, Health Education, Patient-Centered Care

Posted Date: October 11th, 2026

DOI: <https://doi.org/10.21203/rs.3.rs-10851644/v1>

License: © ⓘ This work is licensed under a Creative Commons Attribution 4.0 International License.
[Read Full License](#)

Additional Declarations: No competing interests reported.

Abstract

Background

Endometriosis is a chronic condition associated with physical and emotional challenges over time. Although hormonal and surgical treatments are important for symptom management, they do not fully address the informational, emotional, and self-management needs of many women. This study evaluated the short- and long-term effects of a nurse-led Online Health Education Programme for Women with Endometriosis (e-HEPE) on patient empowerment, pain catastrophizing, and perceived health improvement.

Methods

A longitudinal, quasi-experimental, single-group pre-post design study with 12-month follow-up was conducted among women aged 18–45 years with a confirmed diagnosis of endometriosis recruited from a tertiary referral unit. The intervention consisted of a nurse-led online educational programme comprising four weekly sessions addressing disease-related education, emotional regulation, and pain management. Empowerment was assessed using the Spanish-validated Patient Empowerment in Long-Term Conditions Scale (CEPEC-47), pain catastrophizing using the Pain Catastrophizing Scale (PCS), and perceived health improvement using the Patient Global Impression of Improvement (PGI-I) scale. Outcomes were measured at baseline, 1 month, and 12 months after e-HEPE completion.

Results

Of 71 women enrolled, 51 completed baseline and 1-month assessments, and 46 completed the 12-month follow-up. Empowerment scores increased significantly from baseline to 1-month follow-up and remained stable at 12 months. Pain catastrophizing decreased significantly, from a mean score above the clinical threshold at baseline to below threshold at 1 month, with continued reduction at 12 months. The earliest improvements were observed in the rumination subscale. Participant satisfaction was high: 96.1% reported that the e-HEPE had positively contributed to their health, and 90.2% would recommend it to other women with endometriosis at 1 month, rising to 95.7% at 12 months.

Conclusions

This nurse-led e-HEPE was associated with sustained improvements in empowerment and reductions in pain catastrophizing among women with endometriosis over a 12-month period, alongside high patient satisfaction and acceptability. These findings support the potential contribution of Advanced Practice Nurses in delivering empowerment-focused, patient-centered interventions for this population, although confirmation in controlled studies is warranted.

1. Background

Endometriosis is a chronic, estrogen-dependent inflammatory disease affecting approximately 10% of women worldwide. [1–3]. It is associated with pain, infertility, and substantial impairment in physical, psychological, social, and occupational well-being [4–6]. Diagnostic delays of up to ten years remain common [4, 7], and prolonged symptom normalization and uncertainty may negatively affect women's understanding of the disease, psychological well-being, and ability to develop coping strategies [5, 8].

Pain is the predominant symptom [9, 10], and pain catastrophizing has been associated with greater pain intensity, poorer health-related quality of life, psychological distress [11–13], and pain related disability [14].

Women with endometriosis frequently report unmet needs regarding reliable information, emotional support, communication with healthcare professionals, and involvement in healthcare decisions [15].

Patient empowerment is considered a core element of health promotion [16]. Originally associated with emancipatory approaches to education and subsequently incorporated into healthcare and nursing practice [17–19], empowerment can be understood as the process through which individuals gain greater control over decisions and actions affecting their health by developing knowledge and skills and accessing appropriate information and resources [20–21]. In women with endometriosis, empowerment has recently been conceptualized as comprising effective communication with healthcare professionals, access to information and support, informed decision-making, self-management, advocacy, and access to psychosocial and community resources [22]. Strengthening these elements may help women participate actively in their care and manage the long-term consequences of the disease.

Advanced Practice Nurses (APNs) combine expert knowledge, advanced decision-making skills, and expanded clinical competencies [23], placing them in an appropriate position to promote patient education and active participation in care [24–27]. In endometriosis, APNs and specialist nurses contribute through education, counseling, symptom management, care coordination, psychosocial support, and promotion of self-management [28–31]. Nurse-led educational interventions have improved empowerment and self-management in other chronic conditions [32, 33], while endometriosis-specific self-care counseling has reduced anxiety and improved quality of life [34]. However, evidence on structured nurse-led programmes designed to enhance empowerment and reduce pain catastrophizing in women with endometriosis remains limited, particularly regarding long-term persistence of their effects [35].

Since 2022, our tertiary referral endometriosis unit has implemented an Online Health Education Programme for Women with Endometriosis (e-HEPE), combining disease education, emotional regulation, pain management strategies, and peer support. This study aimed to evaluate the short- and long-term impact of the e-HEPE on patient empowerment, pain catastrophizing, and perceived health improvement.

2.Methods

Study design and setting

This was a longitudinal, single arm, quasi-experimental pre-post study designed to evaluate the short- and long-term effects of an Advanced Practice Nurse (APN)-led Online Health Education Programme for Women with Endometriosis (e-HEPE) on patient empowerment, pain catastrophizing, and perceived health improvement. Assessments were conducted at baseline, 1 month after completion of the programme, and 12 months after completion.

The study was conducted at the APN outpatient clinic of the Endometriosis unit of the Hospital Clínic of Barcelona, a tertiary referral unit for the diagnosis and treatment of endometriosis. Participants were recruited between June 2023 and April 2024.

The study protocol was approved by the Ethics Committee of Hospital Clínic de Barcelona (reference HCB/2023/0851) and conducted in accordance with the ethical principles of the Declaration of Helsinki [36]. All participants provided written informed consent before enrolment. Data were handled confidentially in accordance with Spanish data protection legislation.

Participants

Women attending their first in-person consultation at the APN outpatient clinic were assessed consecutively for eligibility and invited to participate in the e-HEPE.

Participants who attended all four e-HEPE sessions were considered programme completers. The primary short-term analysis included completers with available baseline and 1-month assessments. The longitudinal analysis included participants with complete data at baseline, 1 month, and 12 months. The analytic sample therefore corresponded to a per-protocol population.

Inclusion and exclusion criteria

Inclusion criteria were: women aged 18–45 years with a confirmed diagnosis of endometriosis, with or without associated adenomyosis, and access to an internet-enabled device. Exclusion criteria were: age under 18 or over 45 years, postmenopausal status, lack of internet access, or inability to provide informed consent due to cognitive impairment.

Sample Size

Sample size was estimated for paired comparisons of proportions. Assuming an alpha risk of 0.05, a beta risk of 0.15 in a one-sided test, an expected change in the primary outcome proportion from 0.5 to 0.2, and an anticipated 10% loss to follow-up, 46 participants were required. The calculation was performed using the GRANMO Sample Size Calculator, version 7.12 (Institut Municipal d'Investigació Mèdica, Barcelona, Spain; April 2012).

Online Health Education Programme for Women with Endometriosis (e-HEPE)

The Online Health Education Programme for Women with Endometriosis (e-HEPE) was developed collaboratively by the unit's gynecologists specialized in endometriosis, the APN, and the unit's psychologist. Programme development was informed by a previous exploratory study in our population, which identified four priority areas: improvement of patient care; information and communication; training for professionals and patients; and promotion of patient participation [15]. Accordingly, the e-HEPE included information on pharmacological and non-pharmacological treatment options, pain management strategies, emotional support, disease self-management, healthy lifestyles and peer support.

The e-HEPE was delivered in groups of eight to ten participants and consisted of four weekly online sessions lasting 150 minutes each. Each session included three components:

- Educational content providing evidence-based information about endometriosis and pain mechanisms.
- Emotional and pain management content addressing emotional regulation, coping strategies, self-management, and pain control.
- A 30-minute experiential activity involving guided practice of a pain- or –stress-management technique related to the content of that session.

The unit’s psychologist recorded each experiential exercise as an audio file, which was shared with participants after the corresponding session to facilitate continued practice. The content of the four sessions is summarized in Table 1.

Table 1
Content and structure of the Online Health Education Programme for Women with Endometriosis (e-HEPE).

Components	Session 1	Session 2	Session 3	Session 4
Educational content	Programme presentation, objectives, and general knowledge of endometriosis	Pain mechanisms	Nutrition and healthy lifestyles	Sexuality and endometriosis: dyspareunia, vulvodynia, and sexual desire
Emotional and pain management	Emotional factors associated with pain (stress and anxiety)	Cognitive factors associated with pain and emotional validation	Pain management strategies and time-management activities	Endometriosis-focused meditation
Experiential activity	Breathing exercises	Body scan	Guided visualisation	Endometriosis-focused meditation

All sessions were delivered by the same APN to ensure consistency across cohorts. An interactive format was used to encourage questions, open discussion, and active participation. Participants were invited to share their experiences of living with endometriosis, and structured opportunities for peer support were provided throughout the programme. Attendance was recorded at every session. Seven cohorts were conducted, with a new cohort beginning approximately every five to six weeks.

Outcomes and data collection

The primary outcomes were patient empowerment, assessed using the Patient Empowerment in Long-Term Conditions Scale (CEPEC-47), and pain catastrophizing, assessed using the Pain Catastrophizing Scale (PCS). Perceived health improvement, assessed with the Patient Global Impression of Improvement (PGI-I), was included as a secondary, exploratory outcome.

All questionnaires were administered electronically through the Hospital Clínic of Barcelona Lime Survey platform. The baseline assessment was completed one week before the first e-HEPE session. This baseline survey included sociodemographic and clinical variables, the CEPEC-47, the PCS, and an ad-hoc item assessing expectations regarding the e-HEPE content.

Patient Empowerment

The CEPEC-47 is a Spanish culturally adapted version of the Patient Empowerment in Long-Term Conditions Scale, with high internal consistency (Cronbach's $\alpha > 0.90$) [35]. It comprises 47 items rated on a 5-point Likert scale, ranging from 1 ("strongly disagree") to 5 ("strongly agree"). Total scores range from 47 to 235, with higher scores indicating greater empowerment. Scores below 140 indicate low empowerment, scores between 140 and 175 indicate moderate empowerment, and scores above 175 indicate high empowerment [37].

Pain Catastrophizing

The PCS comprises 13 items rated on a 5-point Likert scale ranging from 0 ("never") to 4 ("always"). It provides a total score and three subscales: rumination, magnification, and helplessness. The Spanish validation of the PCS was used [38]. Although this version was originally validated in patients with fibromyalgia rather than specifically in women with endometriosis, the PCS is widely used in chronic pain populations. Total scores range from 0 to 52, with scores of 30 or higher indicating clinically relevant pain catastrophizing. The Spanish version has shown acceptable internal consistency (Cronbach's $\alpha = 0.79$) [38].

Perceived health improvement

The PGI-I is a single-item, patient-reported measure of perceived change in health status. Responses are recorded on a 7-point ordinal scale ranging from 1 ("very much improved") to 7 ("very much worse") [39]. Although the PGI-I has not been formally validated specifically in women with endometriosis or in Spanish, it has previously been used in Spanish-speaking populations [40, 41]. It was therefore included

as an exploratory measure. Responses of "very much improved" or "much improved" (scores 1–2) were categorized as marked perceived improvement.

Follow-up assessments

At the 1-month follow up, participants completed the CEPEC-47, PCS, and PGI-I. They also completed a study-specific questionnaire assessing the educational and emotional/pain management content, overall satisfaction with the e-HEPE, regular practice of the proposed exercises or audio recordings, perceived contribution of the program to their health, and willingness to recommend the program to other women with endometriosis

At 12-month follow-up, the CEPEC-47, PCS, and PGI-I were administered again. Participants were also asked whether they attributed any perceived health improvement to the e-HEPE, and whether they would recommend the programme to other women with endometriosis.

Statistical analysis

Continuous variables were summarized as means and standard deviations, and categorical variables as absolute and relative frequencies. The distribution of continuous outcome variables was evaluated using the Shapiro-Wilk test and visual inspection of Q-Q plots.

The primary short-term analysis compared baseline and 1-month CEPEC-47 and PCS scores using paired-sample t-tests. Changes in these outcomes across baseline, 1 month, and 12 months were analyzed using repeated-measures analysis of variance restricted to participants with complete data at all three time points. Bonferroni-adjusted pairwise comparisons were used for post hoc analyses.

Because the PGI-I is an ordinal measure, scores at 1 and 12 months were compared using the Wilcoxon signed-rank test and were also described according to their response categories. Satisfaction, perceived contribution of the program, adherence to the proposed exercises, and willingness to recommend the e-HEPE were analyzed descriptively.

Analyses were based on complete available cases. Statistical significance was set at $p < 0.05$. All analyses were performed using SPSS version 27.0.

3. Results

3.1 Participant Flow

Between June 2023 and April 2024, 71 women with endometriosis were enrolled in the e-HEPE across seven e-HEPE cohorts and received the intervention. Of these, 51 participants (71.8%) completed all four sessions and both the baseline and 1-month assessments and were included in the primary analyses. The remaining 20 participants did not complete sessions and/or the required assessments. At 12-month

follow-up, data were available for 46 participants of the 51, corresponding to a retention rate of 86.3%. The longitudinal complete-case analyses included 46 participants. Participant flow is shown in Fig. 1.

3.2 Baseline Characteristics

The mean age of participants was 36.7 ± 7.1 years. Most participants had completed university or postgraduate education (66.7%), were employed (78.4%), and were receiving hormonal treatment at baseline (68.6%). Twelve participants (23.5%) had a previous diagnosis of chronic pelvic pain, and 14 (27.5%) had undergone surgery for endometriosis. Baseline demographic and clinical characteristics are presented in Table 2.

At baseline, the mean CEPEC-47 score was 160.6 ± 26.4 . The mean PCS score was 30.6 ± 10.9 , slightly above the proposed cut-off 30 points.

Table 2
Baseline sociodemographic and clinical characteristics of
the study sample (n = 51)

Age (years)	36.7 ± 7.1
Education Attainment	
Primary Education	1 (2.0)
Secondary Education	16 (31.4)
University/postgraduate education	34 (66.7)
Occupation	
Employed (including students who work)	40 (78.4)
Sick Leave	6 (11.8)
Unemployed/not working /leave of absence	5 (9.8)
Ethnicity	
White or Caucasian	49 (96.1)
Living Arrangement	
Living alone	5 (9.8)
Recognized disability	6 (11.8)
Non-smoker	44 (88.2)
Nulliparous	31 (60.8)
Chronic Pelvic Pain Diagnosis	12 (23.5)
Prior Surgical treatment	14(27.5)
Receiving hormonal therapy	35 (68.6)

Results are expressed as mean ± SD or n (%).

3.3 Changes in Empowerment and Pain Catastrophizing

At 1-month follow-up, CEPEC-47 scores increased significantly from 160.6 ± 26.4 to 173.6 ± 25.2 ($p = 0.026$). Among the PCS subscales, a statistically significant reduction was observed in rumination (10.0 ± 3.5 vs. 8.7 ± 3.1 ; $p = 0.006$), whereas changes in magnification and helplessness were not statistically significant at 1-month follow-up. Among participants with complete data at all three time points ($n = 46$), the mean CEPEC-47 score at 12 months was 174.9 ± 26.5 and remained significantly higher than at baseline ($p < 0.001$). The mean total PCS score decreased further to 20.9 ± 13.2 at 12 months and was significantly lower than both the baseline value ($p < 0.001$) and the 1-month value ($p = 0.01$). The overall time effects and Bonferroni-adjusted pairwise comparisons are presented in Table 3.

Table 3
Results of the Patient Empowerment in Long-Term Conditions Scale (CEPEC-47) to assess empowerment, Pain Catastrophizing Scale (PCS) to evaluate pain-related catastrophizing and its subscales (Rumination, Magnification and Helplessness) at baseline, 1-month and 12-month follow-up.

Variables	Baseline	1-month follow-up	12-month follow-up	p-value*
CEPEC-47	160.6 ± 26.4^a	173.6 ± 25.2^b	174.9 ± 26.5^c	a-b p = 0.026 b-c p = 0.176 a-c p < 0.001
PCS Total	30.6 ± 10.9^a	27.4 ± 9.6^b	20.9 ± 13.2^c	a-b p = 0.027 b-c p = 0.01 a-c p < 0.001
PCS-Rumination	10 ± 3.5^a	7.7 ± 3.1^b	6.8 ± 4.7^c	a-b p = 0.006 b-c p = 0.058 a-c p < 0.001
PCS-Magnification	7.2 ± 2.6^a	6.7 ± 2.6^b	4.9 ± 3.3^c	a-b p = 0.153 b-c p = 0.017 a-c p < 0.01
PCS- Helplessness	11.5 ± 4.9^a	10.3 ± 4.3^b	9.1 ± 5.8^c	a-b p = 0.125 b-c p = 0.649 a-c p = 0.076

Results expressed as mean ± standard deviation. CEPEC: Patient Empowerment in Long-Term Conditions Scale. PCS: Pain Catastrophizing Scale.* p-values corresponds to Bonferroni-adjusted pairwise comparisons following repeated-measures ANOVA.

3.4. Perceived Health Improvement

Median PGI-I scores were 3 (IQR 3–4) at 1-month follow-up and 3 (IQR 2–3) at 12-month follow-up. No statistically significant difference was observed between the two assessments according to the Wilcoxon signed-rank test ($p = 0.15$). Among the 46 participants with complete PGI-I data at 1-month follow-up, 13 (28.3%) were classified as responders (scores 1–2), 22 (47.8%) reported minimal

improvement (score 3), 9 (19.6%) reported no change (score 4), and 2 (4.3%) reported worsening (scores 5–7).

At 12-month follow-up, 22 (47.8%) participants reported a clinically meaningful improvement (scores 1–2), fourteen (30.4%) reported minimal improvement (score 3), eight (17.4%) reported no change (score 4), and two (4.3%) reported worsening (scores 5–7).

3.5 Patient-Reported Experience and Acceptability

At 1-month follow-up, the mean rating for the educational content was 8.84 ± 1.58 , the mean rating for the emotional and pain-management content was 8.68 ± 1.61 , and overall satisfaction with the e-HEPE was 8.76 ± 1.48 , all on a 0–10 scale. Nineteen participants (37.3%) reported regularly practicing the proposed exercises or listening to the audio recordings. Forty-nine participants (96.1%) considered that the e-HEPE had positively contributed to their health, and 46 (90.2%) stated that they would recommend the program to other women with endometriosis.

At 12 months, 31 of the 46 participants (67.4%) attributed their perceived improvement to the e-HEPE, two (4.3%) did not attribute it to the program, and 13 (28.3%) were uncertain. Forty-four of the 46 participants assessed at 12 months (95.7%) stated that they would recommend the e-HEPE to others. Patient-reported experience and acceptability are summarized in Tables 4 and 5.

Table 4
Patient-reported experience regarding content and acceptability of the e-HEPE at 1-month follow-up (n = 51)

Patient-Reported Experience	1-Month Follow-Up (n = 51)
Educational content rating (0–10)	8.84 ± 1.58
Emotional and pain management content rating (0–10)	8.68 ± 1.61
Overall e-HEPE satisfaction (0–10)	8.76 ± 1.48
Reported regular practice of exercises/audio recordings	19 (37.3)

Results expressed as mean $\pm$ standard deviation, except where indicated as n (%).

Table 5

Patient-Reported Perceptions attribution of health improvement to the e-HEPE and recommendation of the programme.

Item	1-Month Follow-Up (n = 51)	12-Month Follow-Up (n = 46)
No change in health status	2 (3.9)	8 (17.4)
Worsening health status	0 (0.0)	2 (4.3)
Improvement attributed to the e-HEPE	49 (96.1)	31 (67.4)
Improvement not attributed to e-HEPE	0 (0.0)	2 (4.3)
Uncertain attribution of improvement	2 (3.9)	13 (28.3)
Would recommend the e-HEPE to others	46 (90.2)	44 (95.7)

Results expressed as n (%).

4. Discussion

This longitudinal, quasi-experimental study examined the short- and long-term changes in empowerment, pain catastrophizing, and perceived health after participation in a nurse-led online health education programme (e-HEPE) for women with endometriosis. Empowerment increased 1-month after completion of the programme and these gains were sustained at 12 months. Pain catastrophizing also decreased over time, with the earliest change observed in the rumination subscale. Satisfaction and acceptability were high, and most respondents perceived a health benefit and would recommend the program to other women with endometriosis. However, given the single-group design, these findings should be interpreted as changes observed after the intervention rather than as evidence of a causal effect.

4.1 Effects on empowerment

The observed increase in empowerment in this study is consistent with findings from nurse-led educational interventions in other chronic disease populations, including diabetes and renal transplantation, in which education delivered by APNs has been associated with a greater sense of control, improved self-management, and more active participation in care [32, 33]. Cardoso et al. similarly found that patient-centered empowerment interventions based on knowledge, acquisition, self-management skills, shared decision-making, and problem-solving strategies promote autonomy and active participation in health management [42]. Knowledge acquisition and information sharing have also been identified as important enablers of empowerment and self-management in individuals with chronic diseases [43]. The persistence of higher empowerment scores at 12 months is relevant, because many educational interventions report only short-term changes that may diminish after active reinforcement ends [32]. Although the mechanisms were not directly evaluated, these sustained scores

may indicate that participants continued to use some of the knowledge and skills acquired during the e-HEPE. This interpretation is consistent with the concept of empowerment as an internal and potentially self-sustaining process [20, 21], as well as with evidence that group-based empowerment interventions can improve self-efficacy and self-management in people with chronic conditions [44].

4.2 Effects on pain catastrophizing

The reduction in pain catastrophizing is consistent with previous evidence linking catastrophizing to poorer pain-related quality of life and greater psychological distress in chronic pain populations [11–13]. This finding may be particularly relevant in endometriosis because pain catastrophizing has been associated with disability and functional impairment in affected women [14]. At the 1-month follow-up, the reduction was most apparent in rumination, whereas changes in magnification and helplessness were not statistically significant. One possible explanation is that the educational and emotional-regulation components of the e-HEPE helped participants better understand their symptoms and reconsider recurrent pain-related thoughts. However, this mechanism was not directly assessed and should be regarded as a hypothesis. Previous work suggests that psychoeducational approaches may preferentially influence cognitive and attentional dimensions of catastrophizing rather than its more affective components [6, 12]. Because pain catastrophizing has received limited attention as a potentially modifiable outcome in endometriosis, these findings provide preliminary evidence that warrants confirmation in controlled studies.

The high levels of satisfaction and perceived benefit, together with the fact that more than 90% of participants would recommend the e-HEPE at both follow-up assessments, are consistent with previous qualitative and mixed-methods studies showing that endometriosis-specific nurse-led services and educational interventions are highly valued when they include peer support, validation of the disease experience, and accessible, structured information [28–30, 34]. However, only 37.3% of participants reported regularly practicing the self-management exercises or listening to the audio recordings. This discrepancy between high satisfaction and relatively limited regular use of these resources should not be interpreted as evidence that one component of the program was more influential than another. Further qualitative research could help clarify which components participants found most useful and how they applied them in daily life.

4.3 Potential contribution of Advanced Practice Nurses

These findings support the potential contribution of Advanced Practice Nurses to endometriosis care beyond symptom management, particularly through structured, empowerment-oriented education within multidisciplinary teams [28–31]. The content of the e-HEPE is also consistent with recent conceptual work identifying education, support, self-management, and informed decision-making as dimensions through which APNs may contribute to the empowerment of women with endometriosis [22]. Delivered online to small groups, the e-HEPE provides a structured model that may be adaptable to other tertiary or secondary care settings. Online delivery may also facilitate access for women who face geographic,

mobility, or symptom-related barriers to in-person care. Nevertheless, the feasibility, cost-effectiveness, scalability, and implementation of the program in other settings were not evaluated in this study.

4.4 Strengths

The study has several strengths. The 12-month follow-up allowed assessment of whether the observed changes were sustained beyond the immediate post-intervention period, which is uncommon in studies of nurse-led educational interventions for endometriosis. The use of the CEPEC-47, a validated empowerment instrument for long-term conditions, together with the established PCS measure, strengthens the assessment of the main outcomes. Delivery of all sessions by the same APN also improved consistency across intervention groups. In addition, retention between the 1-month and 12-month assessments was relatively high.

4.5 Limitations

Several limitations must be acknowledged. First, the single-group design without a comparator precludes causal inference. The observed changes may reflect natural fluctuations in the disease, regression to the mean, concurrent medical treatment, or nonspecific effects of clinical attention, group participation, and peer support. The design also does not allow the contributions of online delivery, group interaction, educational content, and emotional or pain-management exercises to be distinguished.

Second, the analysis was largely restricted to program completers. Although 71 women were enrolled, only 51 completed all required sessions and assessments and were included in the primary analysis. Excluding 20 participants after enrolment may have introduced completer or adherence bias if women who completed the program differed systematically from those who did not. This could have led to an overestimation of both the observed changes and program acceptability. Third, convenience sampling from a single tertiary referral unit may limit the generalizability of the results to women with less severe disease, those without access to specialized care, or those managed in primary care. Loss to follow-up may also have introduced selection bias if the women retained at 12 months differed from those who were not assessed. Fourth, the PGI-I was an exploratory, ordinal outcome and has not been formally validated in women with endometriosis. Its analysis using numerical scores should therefore be interpreted cautiously. The PCS was originally validated in a population with fibromyalgia rather than endometriosis, which may affect its measurement properties in this population. The study-specific satisfaction questionnaire was not formally validated, and all outcomes were self-reported. Finally, the study did not include direct measures of pain intensity, endometriosis-related quality of life, or functional impairment, limiting the ability to determine the broader clinical relevance of the observed changes. The number of outcomes and pairwise comparisons should also be considered when interpreting individual statistically significant findings.

These preliminary findings should be confirmed in randomized controlled trials comparing the e-HEPE with usual care or an active control condition. Future studies should include direct measures of pain severity, endometriosis-related quality of life, and functional status, together with empowerment and catastrophizing outcomes. Qualitative research could help identify the components and mechanisms

most valued by participants, while implementation studies could evaluate feasibility, scalability, and cost-effectiveness in different care settings. Future research should also examine whether booster sessions or ongoing peer-support structures improve the durability of the observed changes and should promote the development and validation of empowerment instruments specifically designed for women with endometriosis.

5. Conclusions

This nurse-led online health education programme (e-HEPE) was associated with significant and sustained improvements in patient empowerment among women with endometriosis, together with a progressive and substantial reduction in pain catastrophizing over a 12-month period, driven primarily by improvements in rumination. High levels of participant satisfaction and acceptability were maintained across both follow-up assessments, and most participants attributed their perceived health improvement to the e-HEPE.

These findings support the value of structured, empowerment-oriented educational interventions delivered by Advanced Practice Nurses as part of comprehensive, multidisciplinary care for women with endometriosis, and suggest that such interventions may support women's cognitive and emotional adaptation to living with a chronic, often under-recognized condition.

Given the single-group, non-controlled design of this study, these results should be interpreted as preliminary evidence rather than confirmatory proof of efficacy. Randomized controlled trials, incorporating active or usual-care comparator groups and objective pain measures, are needed to confirm these findings and to clarify the specific mechanisms and components driving the observed benefits. Nonetheless, this study contributes novel longitudinal evidence to a scarcely studied area, supporting the expanded role of Advanced Practice Nurses in delivering patient-centered, empowerment-focused care for women with endometriosis.

List of abbreviations

APN Advanced Practice Nurse

APNs Advanced Practice Nurses

CEPEC-47 Patient Empowerment in Long-Term Conditions Scale

e-HEPE Online Health Education Programme for Women with Endometriosis

ICGON Institute of Obstetrics, Gynaecology and Neonatology

PCS Pain Catastrophizing Scale

PGI-I Patient Global Impression of Improvement

Declarations

Ethics approval and consent to participate

The study protocol was approved by the Ethics Committee of Hospital Clínic of Barcelona (reference HCB/2023/0851) and was conducted in accordance with the ethical principles of the Declaration of Helsinki. All data were handled confidentially in compliance with Spanish data protection legislation (Organic Law 3/2018 on the Protection of Personal Data). Written informed consent was obtained from all individual participants included in the study. Data were collected anonymously without personal identifiers and protecting participant confidentiality.

Consent for publication

Not applicable

Competing Interests

The authors declare no conflicts of interest.

Funding

This study received no specific grant from any funding agency in the public, commercial or not-for-profit sectors.

Author Contribution

GF: Conceptualization, Methodology, Investigation, Data Curation, Project administration, Writing - Original Draft. Prepared Figure 1.MG;SP;LQ;MG and MR: Investigation, Writing - review & editing.FC and MM: Conceptualization, Methodology, Formal analysis, Supervision, Writing- review & editing.All authors reviewed the manuscript.

Acknowledgement

The authors would like to express their sincere gratitude to all women who participated in this study for their time, commitment, and valuable contribution. Special thanks go to Mrs Ana Carrión, Advanced Practice Nurse in Endometriosis, who initiated this project with great enthusiasm and professionalism. We also thank Ms Aïda Mallorquí for her advice on psychological aspects of the programme, Mr Gustavo

Gomez for his support with participant recruitment, and finally to the Observatory Patient Experience Group of Hospital Clínic of Barcelona for its contribution to the programme development.

Data Availability

The data supporting the findings of this study are not publicly available because of privacy and ethical restrictions but are available from the corresponding author on reasonable request.

References

1. International Working Group of AAGL, ESGE, ESHRE, Tomassetti WES, Johnson C. An international terminology for endometriosis, 2021. *J Minim Invasive Gynecol.* 2021;28(11):1849–59. 10.1016/j.jmig.2021.08.032.
2. Smolarz B, Szyłło K, Romanowicz H. Endometriosis: epidemiology, classification, pathogenesis, treatment and genetics (review of literature). *Int J Mol Sci.* 2021;22(19):10554. 10.3390/ijms221910554.
3. World Health Organization. Endometriosis [Internet]. Geneva, World Health Organization. : 2023 Mar 24 [cited 2026 Aug 11]. Available from: <https://www.who.int/news-room/fact-sheets/detail/endometriosis>
4. Taylor HS, Kotlyar AM, Flores VA. Endometriosis is a chronic systemic disease: clinical challenges and novel innovations. *Lancet.* 2021;397(10276):839–52. 10.1016/S0140-6736(21)00389-5.
5. Culley L, Law C, Hudson N, Denny E, Mitchell H, Baumgarten M, Raine-Fenning N. The social and psychological impact of endometriosis on women's lives: a critical narrative review. *Hum Reprod Update.* 2013;19(6):625–39. 10.1093/humupd/dmt027.
6. Maulenkul T, Kuandyk A, Makhadiyeva D, et al. Understanding the impact of endometriosis on women's life: an integrative review of systematic reviews. *BMC Womens Health.* 2024;24(1):524. 10.1186/s12905-024-03369-5.
7. Agarwal SK, Chapron C, Giudice LC, Laufer MR, Leyland N, Missmer SA, Singh SS, Taylor HS. Clinical diagnosis of endometriosis: a call to action. *Am J Obstet Gynecol.* 2019;220(4):354. e1-354.e12.
8. Helgeson VS, Zajdel M. Adjusting to chronic health conditions. *Annu Rev Psychol.* 2017;68:545–71. 10.1146/annurev-psych-010416-044014.
9. Chen Y, Li T. Unveiling the mechanisms of pain in endometriosis: comprehensive analysis of inflammatory sensitization and therapeutic potential. *Int J Mol Sci.* 2025;26(4):1770. 10.3390/ijms26041770.
10. Mitchell AM, Lensen S, Kamper SJ, et al. The most impactful endometriosis symptom: an international, cross-sectional, two-round survey study. *Acta Obstet Gynecol Scand.* 2024;103(9):1736–44. 10.1111/aogs.14927.

11. Kalfas M, Chisari C, Windgassen S. Psychosocial factors associated with pain and health-related quality of life in endometriosis: a systematic review. *Eur J Pain*. 2022;26:1827–48. 10.1002/ejp.2006.
12. McPeak AE, Allaire C, Williams C, Albert A, Lisonkova S, Yong PJ. Pain catastrophizing and pain health-related quality-of-life in endometriosis. *Clin J Pain*. 2018;34(4):349–56. 10.1097/AJP.0000000000000539.
13. Zarbo C, Brugnera A, Compare A, et al. Psychological and cognitive factors implicated in pain experience in women with endometriosis. *Health Care Women Int*. 2022;43(1–3):142–59. 10.1080/07399332.2021.1959592.
14. Levang SL, Pukall CF. An Investigation of Associations between Pain Catastrophizing and Pain Disability in a Diverse Sample of Persons with Endometriosis. *J Obstet Gynaecol Can*. 2024;46(4):102340. 10.1016/j.jogc.2023.102340.
15. Martínez-Zamora MA, Feixas G, Palou E, et al. Unmet needs of endometriosis patients with respect to health care services: a qualitative study using a patient training workshop. *J Clin Med*. 2025;14(10):3504. 10.3390/jcm14103504.
16. Aujoulat I, d'Hoore W, Deccache A. Patient empowerment in theory and practice: polysemy or cacophony? *Patient Educ Couns*. 2007;66(1):13–20. 10.1016/j.pec.2006.09.008.
17. Cortina R, Winter M. Paulo Freire's pedagogy of liberation. *Curr Issues Comp Educ*. 2021;23(2). 10.52214/CICE.V23I2.8577.
18. Freire P. *Pedagogy of the oppressed*. Harmondsworth: Penguin; 1972.
19. Angelmar R, Berman PC. Patient empowerment and efficient health outcomes. *Financing Sustainable Healthcare in Europe: New Approaches for New Outcomes*. Luxembourg: Ministry of Health, Grand Duchy of Luxembourg; 2007. pp. 139–62.
20. Kuokkanen L, Leino-Kilpi H. Power and empowerment in nursing: three theoretical approaches. *J Adv Nurs*. 2000;31(1):235–41. 10.1046/j.1365-2648.2000.01241.x.
21. World Health Organization. Health promotion glossary of terms 2021 [Internet]. Geneva: World Health Organization. 2021 [cited 2024 Feb 25]. Available from: <https://iris.who.int/bitstream/handle/10665/350161/9789240038349-eng.pdf?sequence=1>
22. Feixas G, Adamuz J, López Jiménez MM, Fabrellas N, Juvé-Udina ME, Martínez-Zamora MÁ, et al. Empowerment of women with endometriosis from the Advanced Practice Nurse care perspective: a concept analysis. *Nurs Res Rev*. 2026;16:601705. 10.2147/NRR.S601705.
23. International Council of Nurses. Guidelines on advanced practice nursing 2020 [Internet]. Geneva: International Council of Nurses. 2020 [cited 2023 Jun 20]. Available from: https://www.icn.ch/sites/default/files/2023-06/ICN_APN%20Report_ES_WEB_0.pdf
24. World Health Organization, Regional Office for Europe. *Health 2020: a European policy framework and strategy for the 21st century*. Copenhagen: WHO Regional Office for Europe. 2013. Available from: https://www.euro.who.int/__data/assets/pdf_file/0011/199532/Health2020-Long.pdf

25. Organisation for Economic Co-operation and Development. Caring for quality in health: lessons learnt from 15 reviews of health care quality. Paris: OECD. 2017. Available from: <https://www.oecd.org/els/health-systems/Caring-for-Quality-in-Health-Final-report.pdf>
26. European Commission. Blocks: tools and methodologies to assess integrated care in Europe. Report of the Expert Group on Health Systems Performance Assessment. Luxembourg: Publications Office of the European Union; 2017.
27. European Commission, European Union. Consumers, Health, Agriculture and Food Executive Agency. Radical changes to improve Europe's health systems: EU support to health system efficiency. Luxembourg: Publications Office of the ; 2019. Available from: <https://op.europa.eu/en/publication-detail/-/publication/e6c91cd7-e952-11e8-b690-01aa75ed71a1/language-en>
28. Mao AJ, Anastasi JK. Diagnosis and management of endometriosis: the role of the advanced practice nurse in primary care. *J Am Acad Nurse Pract*. 2010;22(2):109–16. 10.1111/j.1745-7599.2009.00475.x.
29. Chen Y, Mo Z, Cao J, Su Z, Zhang Y, Chen F, Wang J. Application of doctor-nurse-patient integration management mode in patients with endometriosis. *Iran J Public Health*. 2018;47(10):1546–1552. Available from: <https://pmc.ncbi.nlm.nih.gov/articles/PMC6277728/>
30. Norton W, Mitchell H, Holloway D, Law C. The role of endometriosis clinical nurse specialists in British Society for Gynaecological Endoscopy registered centres: a UK survey of practice. *Nurs Open*. 2020;7(6):1852–60. 10.1002/nop2.574.
31. Royal College of Nursing. Clinical nurse specialist in endometriosis. London: Royal College of Nursing; 2021. p. 009923.
32. Ibrahim AM, Gano FA, Abdel-Aziz HR, Elneblawi NH, Zaghamir DEF, Negm LMM, et al. Tailoring nursing interventions to empower patients: personal coping strategies and self-management in type 2 diabetes care. *BMC Nurs*. 2024;23:926. 10.1186/s12912-024-02573-w.
33. Hsiao CY, Lin LW, Su YW, Yeh SH, Lee LN, Tsai FM. The effects of an empowerment intervention on renal transplant recipients: a randomized controlled trial. *J Nurs Res*. 2016;24(3):201–10. 10.1097/jnr.000000000000115.
34. Farshi N, Hasanpour S, Mirghafourvand M, Esmaeilpour K. Effect of self-care counselling on depression and anxiety in women with endometriosis: a randomized controlled trial. *BMC Psychiatry*. 2020;20:391.
35. Schumann ME, Coombes BJ, Gascho KE, Geske JR, McDermott MC, Morrison EJ, Reynolds AL, Bernau JL, Gilliam WP. Pain catastrophizing and pain self-efficacy mediate interdisciplinary pain rehabilitation program outcomes at posttreatment and follow-up. *Pain Med*. 2022;23(4):697–706. 10.1093/pm/pnab210.
36. World Medical Association. WMA Declaration of Helsinki: ethical principles for medical research involving human participants. Adopted by the 75th WMA General Assembly, Helsinki, Finland,

- October 2024 [Internet]. [cited 2026 Aug 11]. Available from: <https://www.wma.net/policies-post/wma-declaration-of-helsinki/>
37. Garcimartín Cerezo P. Adaptación cultural y validación al español del cuestionario Patient Empowerment in Long-Term Conditions [doctoral thesis]. Barcelona: Universitat de Barcelona; 2018. Available from: https://diposit.ub.edu/dspace/bitstream/2445/127058/1/PGC_TESIS.pdf
 38. García Campayo J, Rodero B, Alda M, Sobradíel N, Montero J, Moreno S. Validation of the Spanish version of the Pain Catastrophizing Scale in fibromyalgia. *Med Clin (Barc)*. 2008;131(13):487–93. 10.1016/s0025-7753(08)72289-3.
 39. Guy W. ECDEU assessment manual for psychopharmacology. Rockville, MD: US Department of Health, Education, and Welfare. Public Health Service, Alcohol, Drug Abuse, and Mental Health Administration. National Institute of Mental Health, Psychopharmacology Research Branch, Division of Extramural Research Programs; 1976.
 40. García-Escrivá A, López-Hernández N, Lezcano M, Berenguer L. Experiencia en el tratamiento de la neuropatía diabética dolorosa con acetato de eslicarbazepina. *Neurologia*. 2016;31:639–40.
 41. Díez Itza I, Espuña Pons M, GISPEM. Evaluación de los resultados de la cirugía de incontinencia urinaria de esfuerzo utilizando criterios objetivos y subjetivos. *Suelo Pélvico*. 2011;7(3):48–53.
 42. Cardoso Barbosa H, de Queiroz Oliveira JA, Moreira da Costa J, de Melo Santos RP, Gonçalves Miranda L, de Carvalho Torres H et al. Empowerment-oriented strategies to identify behavior change in patients with chronic diseases: An integrative review of the literature. *Patient Educ Couns* [Internet]. 2021 Apr 1 [cited 2026 Feb 14];104(4):689–702. Available from: <https://www.sciencedirect.com/science/article/abs/pii/S0738399121000380>
 43. Vainauskienė V, Vaitkienė R. Enablers of Patient Knowledge Empowerment for Self-Management of Chronic Disease: An Integrative Review. *Int J Environ Res Public Health*. 2021;18(5):2247. 10.3390/ijerph18052247. Published 2021 Feb 24.
 44. Stepanian N, Larsen MH, Mendelsohn JB, Mariussen KL, Heggdal K. Empowerment interventions designed for persons living with chronic disease - a systematic review and meta-analysis of the components and efficacy of format on patient-reported outcomes. *BMC Health Serv Res*. [Internet]. 2023 [cited 2026 Feb 14];23(1):911. Published. 2023 Aug 25. 10.1186/s12913-023-09895-6

Figures

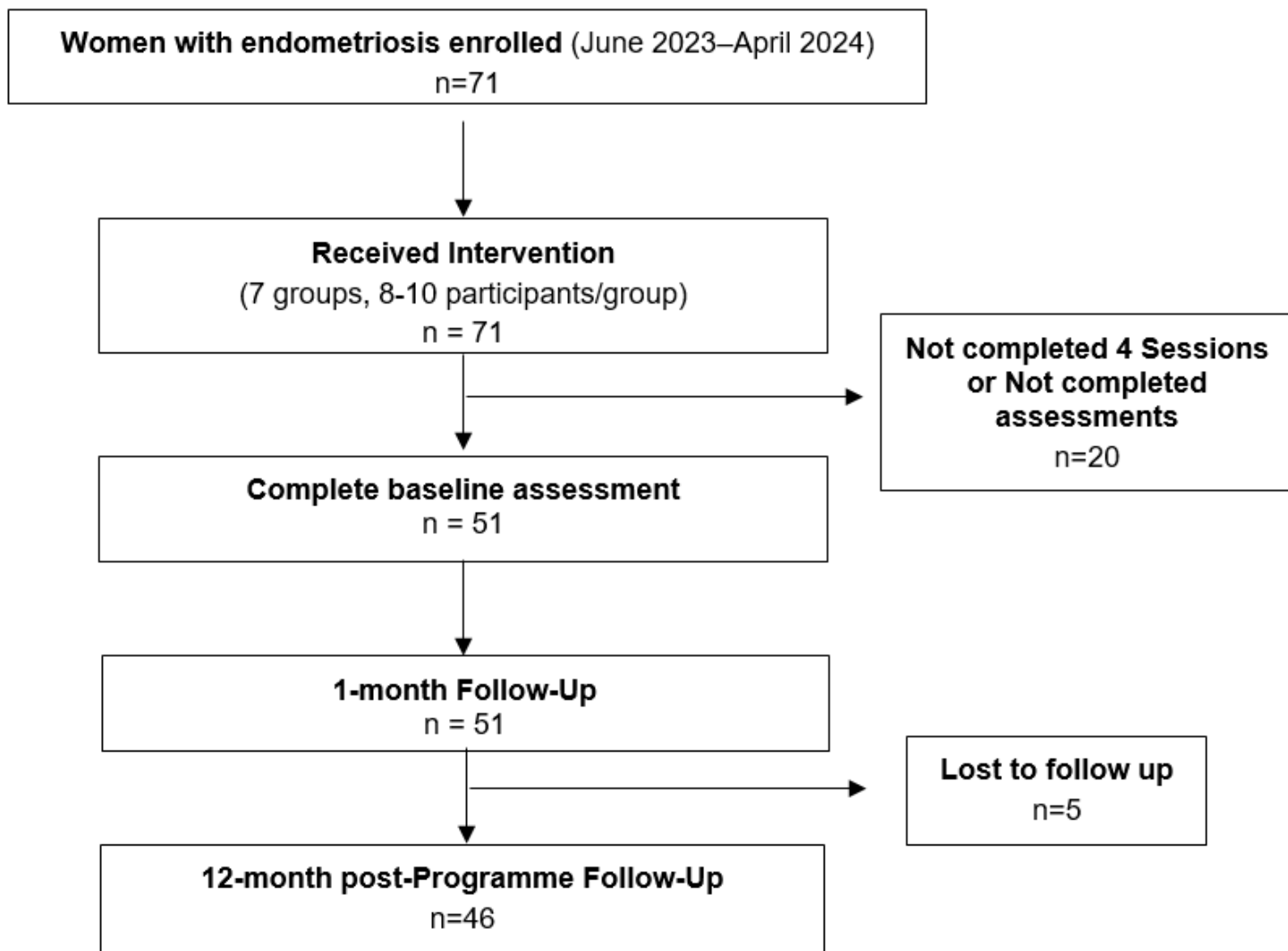


Figure 1

Flow diagram of participant recruitment and 12-month follow up in the e-HEPE.