Long-term impact of chronic pelvic pain on quality of life in women with and without endometriosis

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Background: Chronic pelvic pain (CPP) has a significant impact on patients' health-related quality of life (HRQoL). Endometriosis is a common cause of CPP. Data is lacking on long-term HRQoL outcomes in patients with endometriosis-associated chronic pelvic pain (EACPP) versus other causes of chronic pelvic pain (OCPP). *Methods*: In this retrospective single-survey study, 198 patients completed the EHP-30 and the patient-reported outcomes measurement information system (PROMIS) Global Health validated questionnaires to assess health-related quality of life (HRQoL) 8–10 years after index surgery. *Results*: Demographic comparison revealed significant differences in racial demographics and disability status between the EACPP and OCPP groups. There was no significant difference in EHP-30, PROMIS Global Physical, or Global Mental scores between the two groups. Patients with lower stage endometriosis (stage I/II) reported diminished HRQoL in the EHP-30 and Global Physical scores as compared to patients with higher stage (stage III/IV) endometriosis or OCPP. Additionally, no differences were found between incidence of abuse history and EHP-30 and PROMIS scores between the two groups. Higher age and higher PROMIS Global Physical scores were associated with lower pain and higher HRQoL scores on the EHP-30. Persistently high rates of sexual dysfunction were seen across both groups. *Discussion*: This study demonstrates that women with EACPP and OCPP appear to have similar natural histories and quality of life on long term follow-up. Race, age, disability, and physical health status may play key roles in perceived quality of life. The high rate of persistent sexual dysfunction is concerning and requires increased clinician intervention.

Keywords

Endometriosis; Quality of life; Abuse; EHP-30; Sexual dysfunction; PROMIS

1. Introduction

Chronic pelvic pain (CPP) is a major women's health concern that has a significant impact on patient's quality of life. Worldwide prevalence of CPP ranges between 5.7 to 26.6% [1]. The etiology is often multifactorial and elusive, including other conditions such as gastrointestinal disorders, genitourinary disorders, musculoskeletal pain, and myofascial dysfunction [2].

Endometriosis is an important source of CPP with an estimated prevalence as high as 10% in women of childbearing age [3]. Associated symptomology varies in type and severity, commonly including dyspareunia, dysmenorrhea, dyschezia, and generalized CPP [4–6]. Several existing studies have indicated that women with symptomatic endometriosis report lower scores on quality of life scales, across physical, mental, and social domains [6, 7].

One study evaluating contributors to CPP found that pain severity was similar in women with and without endometriosis [2]. However, few studies have examined the differing natural histories and quality of life in women with endometriosis-associated chronic pelvic pain (EACPP) versus other chronic pelvic pain (OCPP) many years after diagnosis and index surgery. Given their differing pathophysiologies and treatments, the experiences of the two groups should be considered separately in order to understand the expected course of their disease. In this study, we compared pain and health-related quality of life (HRQoL) scores in women with EACPP vs. OCPP in long-term follow-up after their index surgery.

2. Materials and methods

Women ages 18 to 45 at index surgery were identified through the electronic medical record using ICD-9 codes associated with CPP. Women who had undergone gynecologic surgery at the Cleveland Clinic between 2008 and 2010 were included. Only those who had current contact information could be contacted. Any respondents with documented history of gynecologic cancer were excluded.

1147 patients who met these criteria were mailed two letters in series. The first letter served as informed consent; it explained the study, risks and benefits, and provided a phone number for patients to decline participation or contact with questions. The second letter included the study questionnaire. After four weeks, non-responding patients were called and offered the survey over the telephone or through an on-

line secure link through REDCap, an electronic data capture software. All responding participants were entered into a raffle for ten $50 giftcards. Surveys were labeled with random numbers and entered into REDCap. Numbers corresponding with patient names were stored in a separate password-protected document.

Participants were separated into two groups: those with diagnosed EACPP at the time of index surgery, and those with OCPP. Other causes of CPP were varied, including findings of fibroids, cysts, adenomyosis, pelvic adhesions, primary dysmenorrhea, pelvic floor dysfunction and idiopathic pelvic pain. Endometriosis was confirmed by review of the operative or pathology report from the index surgery. The survey contained three components: the Endometriosis Health Profile-30 (EHP-30), the PROMIS short form global item scale (PROMIS v.1.1-Global), and a supplementary questionnaire including questions regarding self-reported demographics, medical history, and history of abuse. Data on abuse history was collected using single-item questions answered with yes/no/prefer not to answer choices.

The EHP-30 is a validated method of measuring HRQoL in endometriosis patients across five core areas: pain, control and powerlessness, social support, emotional well-being, and self-image. It also contains modular sections that measure quality of life within professional life, relationships with children, sexual relationships, interactions with the medical profession, treatment experiences, and infertility. The EHP-30 is scored on a scale of 0–100, where higher scores represent a greater impact of symptoms on HRQoL [8, 9]. The PROMIS short form global health scale (v.1.1) is another validated form consisting of 10 questions that evaluate participants' physical and mental health, functioning, and HRQoL. Calculation of a mental health score includes several factors such as mood, emotional problems, relationship satisfaction, and ability to think. Higher PROMIS scores represent better health status. More information can be found at www.nihpromis.org [10, 11]. The final component of the survey asked participants for demographic information, gynecologic history, and CPP treatments utilized. In designing the study, we sought to include both EHP-30 which has been validated for measuring endometriosis-related health status, and PROMIS which has been validated for studying HRQoL in varied chronic illnesses, given that some of our participants had endometriosis while others did not, so as to study HRQoL across the broader spectrum of the population.

The institutional review board of the Cleveland Clinic Foundation approved this study methodology in September 2016.

Sample size calculation was originally based on a two-sample t-test. According to the responsiveness testing by Jones $et\ al.$ [9], the minimum important difference for the pain subscale of the EHP-30 is 25 points. Standard deviations in different endometriosis populations vary from 18 to 26. We conservatively assumed a standard deviation of 25. In order to have an 80% power to detect at least a 25-point difference between groups at a significance level of 0.05, seventeen subjects per group were required. Although our final analyses for the EHP-30 were based on Kruskal-Wallis tests, our final sample size was about five times larger than this number.

Approximately normally-distributed continuous measures including PROMIS Global Health scores were summarized using means and standard deviations, and compared between the two groups using a t-test or ANOVA. Ordinal measures and continuous measures that show departure from normality including EHP-30 scores, were summarized using medians and quartiles and compared using, Wilcoxon Rank Sum test or Kruskal-Wallis tests. Categorical factors were summarized using frequencies and percentages and were compared using Pearson's chi-square tests or Fisher's Exact tests. Post-hoc pairwise comparisons were done using the Bonferroni adjustment to compare low-stage EACPP, high-stage EACPP, and OCPP groups.

Exploratory multivariable linear regression models were built based on stepwise selections of pre-specified variables, candidate variables including the research group (EACPP vs. OCPP), current age, race, PROMIS Global Physical score, current disability, pregnancy, physical abuse, history of emotional abuse, history of sexual abuse, current hormone therapy, and currently seeing a pain specialist. Response variables were the five core scores reported in the EHP-30. PROMIS Global Mental score was not included to avoid collinearity with PROMIS Physical score, thus similar procedures were done by including mental health score instead of Physical score.

All analyses were done using SAS (version 9.4, The SAS Institute, Cary, NC, USA) and a $p < 0.05$ was considered statistically significant. Variables used in t-test or ANOVA were visually checked by histogram to meet normal distribution assumptions. Wilcoxon Rank Sum test or Kruskal-Wallis test do not assume data having a known distribution. For the liner regressions in Table 5, the true relationship between outcomes and predictors might not be linear, and errors might not be normally distributed in some models, however, given the exploratory nature of these regressions the violation can be accepted.

3. Results

198 unique survey responses meeting inclusion criteria were returned, reflecting a 17.3% response rate. Six were excluded due to a history of gynecologic cancer. 192 surveys were analyzed, with N = 82 EACPP patients and N = 110 OCPP patients.

Table 1 presents demographic characteristics of the two groups. The OCPP group was on average two years older than the EACPP group at the time of index surgery (35.7 vs. 33.5) and survey response (43.9 vs. 41.6). The groups also had significant differences in race ($p = 0.007$). In the EACPP group, 85.4% of participants identified as White and 7.3% as African American, while in the OCPP group, 67.6% identified as White and 24.1% as African American. Compared to

the OCPP group, the EACPP group had lower rates of self-reported current disability (3.7% vs. 12.8%, p = 0.019). Marital status, history of pregnancy, history of abuse, education history, and household income did not differ significantly between the two groups. Findings in a subgroup analysis with endometriosis staging is included as a **Supplemental Table 1** with similar findings.

Table 2 presents a summary of HRQoL scores for both groups. EHP-30 scores range from 0 (best) to 100 (worst). The EACPP group reported a median EHP-30 pain score of 13.6 (quartiles: 0.00, 47.7), while the OCPP group reported a median pain score of 14.8 (quartiles: 0.00, 47.7); however, the difference was not significant (p = 0.56). Additionally, EHP-30 scores in all other categories such as infertility, emotional well-being, work life, interactions with children, social support, self-image, sexual intercourse, and others were similar between groups. Few participants indicated that the modular EHP-30 domains applied to them, with the exception of sexual intercourse. A high modular score was reported in the sexual intercourse category (worse HRQoL), with a median EHP-30 score of 45.0 for all participants, while lower scores (better HRQoL) were reported in work life and interactions with children. No significant difference was found in PROMIS Global Physical or Mental scores between EACPP and OCPP groups.

Table 3 presents a summary of treatments utilized by participants. Nearly 25% of total participants were on hormone therapy in the years following surgery, and of these, a higher percentage of EACPP patients were using hormone therapy (p = 0.016). More than 25% of participants had been seen by a pain specialist at one time, and 18.1% were on medications for pain control. 12.7% of women had tried pelvic floor therapy, but only 3.2% were currently utilizing it.

Table 4 presents subgroup analyses splitting the EACPP group into patients with lower severity endometriosis (Stage I/II) and patients with higher severity endometriosis (Stage III/IV). Significant differences were found in several HRQoL categories. Interestingly, stage I/II endometriosis reported higher impact of symptoms on perceived pain, control and powerlessness, emotional well-being, social support, self-image, and work life, and reported lower global physical scores than stage III/IV endometriosis. They also reported more dissatisfaction with emotional well-being, social support, self-image, and work life than OCPP patients. Although stage III/IV patients seemingly had different scores in some HRQoL categories, no statistically significant difference was found in the post-hoc comparisons for those categories; this might be due to the small subgroup sample size and the conservative nature of the Bonferroni adjustment.

For all five regression models, stepwise selection consistently selected current age, Global Physical score, and current disability for the final models. However, considering the collinearity issue between the Global Physical score and current disability, the variable of current disability was dropped. The new stepwise selections then consistently selected the

variables of current age and Global Physical score. Table 5 presents these results. Generally, higher age and higher Global Physical score (better health status) were associated with lower EHP-30 scores (lower impact of symptoms) for all five core scores. It is noteworthy to mention that stepwise selection did not maintain the EACPP vs. OCPP group effect in any models tested. A similar trend was observed in PROMIS mental health scores, however the result was not included to avoid redundancy. As with any regression analysis, these data represent associations and do not imply causation.

Participants were also asked to report history of abuse (Table 1). As seen in Tables 6,7,8, no difference was seen between EACPP and OCPP groups in the incidence of emotional (26.8% vs. 22.7%), sexual (14.6 vs. 15.5%), or physical abuse (12.2% vs. 13.6%). Additionally, no differences were found in EHP-30 scores between groups who experienced physical, emotional, or sexual abuse versus those who did not. There was, however, a difference in PROMIS Global Physical and Global Mental scores for those who experienced emotional abuse.

4. Discussion

Regardless of CPP etiology, the HRQoL of EACPP and OCPP patients appears similar in the long term, with the exception of greater numbers of current disability in OCPP patients (Tables 1,2). This finding is supported by Yosef et al. [2] who found that women with EACPP and OCPP reported similar pain severities. Prior research has established baseline EHP-30 scores in endometriosis patients. One study of endometriosis patients age 18 or older found that pre-operative mean EHP-30 scores ranged from 51.2–54.2 for pain, 68.1–69.3 for control and powerlessness, 42.5–43.9 for emotional well-being, 46.3–47.5 for social support, 38.6–45.5 for self-image, 42.5–45.5 for work, 33.6–35.6 for interactions with children, 49.9–59.3 for sexual intercourse, 24.8–25.9 for feelings toward medical professionals, 53.3–61.1 for treatment, and 44.6–62.8 for conception [12]. Compared to these historical baseline scores, our EACPP and OCPP participants reported lower scores at a median of 8.35 years following surgery, likely indicating improved HRQoL in CPP patients over time.

Higher age was associated with higher HRQoL on the EHP-30. The estrogen-dependence of endometriosis may be partially responsible for better HRQoL in older EACPP patients, due to declining estrogen levels taming disease [13, 14]. Given that our dataset consisted of women of average age 42.9 with a standard deviation of 7.1 years at the time of survey, the alterations of estrogen levels seen in the perimenopause and the menopausal transition may have been a contributing factor to improvement in pain and HRQoL. CPP syndromes overall are also more likely to be reported in reproductive-age women, suggesting that increased pain burden in younger patients may be associated with lower HRQoL [15]. Additionally, age in the 50–60s has been associated with a greater satisfaction with quality of life, outside of the effects of CPP [16].

Table 1. Demographic summary.

	N	Total CPP (%) N = 192	EACPP (%) N = 82	OCPP (%) N = 110	p-value
Age at surgery	192	34.8 ± 7.1	33.5 ± 7.1	35.7 ± 7.1	0.033[a]
Current age	192	42.9 ± 7.1	41.6 ± 7.1	43.9 ± 7.1	0.025[a]
Years since surgery	192	8.2 ± 0.74	8.1 ± 0.79	8.2 ± 0.70	0.29[a]
Race	190				0.007[b]
Other		15 (7.9)	6 (7.3)	9 (8.3)	
Black or African American		32 (16.8)	6 (7.3)	26 (24.1)	
White		143 (75.3)	70 (85.4)	73 (67.6)	
Hispanic/Latina	186	11 (5.9)	7 (8.8)	4 (3.8)	0.21[c]
Marital status	192				0.65[c]
Married		128 (66.7)	53 (64.6)	75 (68.2)	
Single (never married)		25 (13.0)	12 (14.6)	13 (11.8)	
Cohabitating		6 (3.1)	2 (2.4)	4 (3.6)	
Legally separated		1 (0.52)	0 (0.00)	1 (0.91)	
Divorced		30 (15.6)	13 (15.9)	17 (15.5)	
Widowed		2 (1.04)	2 (2.4)	0 (0.00)	
Highest education completed	190				0.28[c]
Some high school		4 (2.1)	3 (3.7)	1 (0.93)	
High school or GED		62 (32.6)	21 (25.6)	41 (38.0)	
Associate degree		34 (17.9)	14 (17.1)	20 (18.5)	
Bachelor's degree		51 (26.8)	25 (30.5)	26 (24.1)	
Postgraduate degree		39 (20.5)	19 (23.2)	20 (18.5)	
Current household income	184				0.49[d]
Less than $25,000		19 (10.3)	8 (10.1)	11 (10.5)	
$25,000–$50,000		39 (21.2)	15 (19.0)	24 (22.9)	
$50,000–$75,000		37 (20.1)	18 (22.8)	19 (18.1)	
$75,000–$100,000		28 (15.2)	8 (10.1)	20 (19.0)	
Greater than $100,000		61 (33.2)	30 (38.0)	31 (29.5)	
Currently on disability	191	17 (8.9)	3 (3.7)	14 (12.8)	0.027[b]
History of pregnancy	189	149 (78.8)	64 (78.0)	85 (79.4)	0.82[b]
History of physical abuse	192				0.94[c]
Yes		25 (13.0)	10 (12.2)	15 (13.6)	
No		163 (84.9)	70 (85.4)	93 (84.5)	
Prefer not to answer		4 (2.1)	2 (2.4)	2 (1.8)	
History of emotional abuse	192				0.64[c]
Yes		47 (24.5)	22 (26.8)	25 (22.7)	
No		138 (71.9)	58 (70.7)	80 (72.7)	
Prefer not to answer		7 (3.6)	2 (2.4)	5 (4.5)	
History of sexual abuse	192				0.56[c]
Yes		29 (15.1)	12 (14.6)	17 (15.5)	
No		157 (81.8)	66 (80.5)	91 (82.7)	
Prefer not to answer		6 (3.1)	4 (4.9)	2 (1.8)	

Statistics presented as Mean ± SD, N (%).

p-values: [a] Results of t-test, [b] Pearson's chi-square test, [c] Fisher's Exact test, [d] Wilcoxon Rank Sum test.

Lower stage EACPP (stage I/II) patients had worse health status across multiple categories when compared to higher stage EACPP (stage III/IV) and OCPP patients. Prior studies demonstrate that higher histological staging of endometriosis does not necessarily correlate with symptom severity [17, 18]. It is possible that women with higher stage endometriosis may actually experience greater post-operative pain relief [19]. Persistent current symptoms in lower stage EACPP patients suggest that endometriosis may not be the primary cause of pain in these patients long-term, and that therapeutic intervention should be multidisciplinary and not solely endometriosis-focused. Furthermore, patients with early stage disease develop altered brain chemistry that may resemble those with other causes of chronic pain, including sensitization of adjacent organs [20, 21]. Additionally, statistically equal percentages of EACPP (20.7%) and OCPP (23.6%) patients underwent a hysterectomy after their index surgery. This suggests ongoing pain symptoms in both groups, as the

Table 2. EHP-30 and PROMIS health-related quality of life scores.

	N	Total CPP (%)	EACPP (%)	OCPP (%)	p-value
		N = 192	N = 82	N = 110	
EHP-30 scores					
Core categories					
Pain	192	13.6 [0.00, 47.7]	13.6 [0.00, 47.7]	14.8 [0.00, 47.7]	0.56[d]
Control and powerlessness	192	25.0 [0.00, 54.2]	29.2 [0.00, 54.2]	16.7 [0.00, 54.2]	0.71[d]
Emotional well-being	192	20.8 [0.00, 41.7]	29.2 [0.00, 50.0]	16.7 [0.00, 37.5]	0.25[d]
Social support	190	21.9 [0.00, 56.3]	31.3 [0.00, 59.4]	9.4 [0.00, 50.0]	0.15[d]
Self-image	190	16.7 [0.00, 50.0]	33.3 [0.00, 58.3]	8.3 [0.00, 50.0]	0.12[d]
Modular categories					
Work life	135	0.00 [0.00, 30.0]	2.5 [0.00, 35.0]	0.00 [0.00, 25.0]	0.17[d]
Sexual intercourse	165	45.0 [0.00, 75.0]	47.5 [5.0, 75.0]	40.0 [0.00, 70.0]	0.38[d]
Children	136	0.00 [0.00, 25.0]	0.00 [0.00, 25.0]	0.00 [0.00, 25.0]	0.95[d]
Medical profession	126	3.1 [0.00, 43.8]	28.1 [0.00, 53.1]	0.00 [0.00, 43.8]	0.17[d]
Treatment	99	16.7 [0.00, 58.3]	25.0 [0.00, 58.3]	12.5 [0.00, 50.0]	0.22[d]
Infertility	81	31.3 [0.00, 75.0]	37.5 [0.00, 62.5]	25.0 [0.00, 75.0]	0.99[d]
PROMIS global scores					
Global physical	190	14.1 ± 3.2	14.1 ± 3.2	14.0 ± 3.2	0.92[a]
Global mental	190	13.1 ± 3.4	12.6 ± 3.5	13.5 ± 3.4	0.085[a]

Statistics presented as Mean $\pm$ SD, Median [P25, P75].

p-values: [a]Results of t-test, [d]Wilcoxon Rank Sum test.

Table 3. Treatments utilized.

Treatments	N	Total CPP (%)	EACPP (%)	OCPP (%)	p-value
		N = 192	N = 82	N = 110	
Hysterectomy	192	43 (22.4)	17 (20.7)	26 (23.6)	0.63[b]
Currently using hormone therapy	190	45 (23.7)	26 (32.1)	19 (17.4)	0.019[b]
History of pelvic floor physical therapy	189	24 (12.7)	10 (12.3)	14 (13.0)	0.90[b]
Currently undergoing pelvic floor physical therapy	190	6 (3.2)	3 (3.7)	3 (2.8)	0.70[c]
Currently taking narcotic medications for pain relief	189	14 (7.4)	7 (8.6)	7 (6.5)	0.57[b]
Currently on any of the following medications: gabapentin, pregabalin, sertraline, fluoxetine, bupropion, amitriptyline, nortriptyline	188	34 (18.1)	12 (14.8)	22 (20.6)	0.31[b]
History of using complementary medicine for pain relief	190	31 (16.3)	16 (19.5)	15 (13.9)	0.30[b]
Currently using complementary medicine for pain relief	190	8 (4.2)	4 (4.9)	4 (3.7)	0.73[c]
History of appointment with a pain specialist	190	51 (26.8)	20 (24.4)	31 (28.7)	0.51[b]
Currently utilizing a pain specialist	191	15 (7.9)	6 (7.3)	9 (8.3)	0.81[b]

Statistics presented as N (column %).

p-values: [b]Pearson's chi-square test, [c]Fisher's Exact test.

decision to undergo a hysterectomy is based on persistence of pain rather than the presence of endometriosis.

Prior studies report conflicting associations between abuse and risk of endometriosis, with one study claiming an association between early sexual and physical abuse and increased endometriosis risk later in life, while another study found no correlation between these events [22, 23]. In our study, the rates of reported history of abuse did not differ between groups and was generally lower than the rates of intimate partner abuse reported in the US [24]. Comparisons of physical, emotional, and sexual abuse did not reveal a difference in EHP-30 scores for pain, control, emotional well-being, social support, or self-image between patients reporting history of any type of abuse versus no history of abuse.

However, lower PROMIS Global Mental and Physical scores were observed in participants who reported history of emotional abuse compared with those who did not report emotional abuse, indicating a need for further investigation.

EHP-30 scores indicated sexual dissatisfaction in both EACPP (47.5) and OCPP (40.0) groups. A prior EACPP study showed significant post-operative improvement in sexual functioning, with average EHP-30 scores of 23.6–36.2 at six months post-surgery, however our participants reported worse scores at long-term follow-up [12]. The finding that sexual dysfunction remains equally high in both CPP groups highlights the often multifactorial nature of pelvic pain. Myofascial syndromes and central pain sensitization may contribute to CPP and lead to persistent dyspareunia [25]. Even

Table 4. EHP-30 and PROMIS scores for EACPP participants by stage of endometriosis versus OCPP participants.

	N	Endometriosis stage I–II Average score N = 37	Endometriosis stage III–IV Average scores N = 45	OCPP Average scores N = 110	p-value
EHP-30 scores					
Core categories					
Pain	192	38.6 [0.00, 61.4][d]	4.5 [0.00, 40.9][c]	14.8 [0.00, 47.7]	0.045[a]
Control and powerlessness	192	41.7 [12.5, 66.7][d]	4.2 [0.00, 41.7][c]	16.7 [0.00, 54.2]	0.028[a]
Emotional well-being	192	37.5 [20.8, 58.3][de]	4.2 [0.00, 41.7][c]	16.7 [0.00, 37.5][cd]	0.004[a]
Social support	190	43.8 [18.8, 62.5][de]	0.00 [0.00, 56.3][c]	9.4 [0.00, 50.0][c]	0.010[a]
Self-image	190	50.0 [25.0, 66.7][de]	0.00 [0.00, 50.0][c]	8.3 [0.00, 50.0][c]	0.006[a]
Modular categories					
Work life	135	35.0 [5.0, 57.5][de]	0.00 [0.00, 5.0][c]	0.00 [0.00, 25.0][c]	<0.001[a]
Sexual intercourse	165	55.0 [30.0, 80.0]	25.0 [0.00, 65.0]	40.0 [0.00, 70.0]	0.13[a]
Children	136	0.00 [0.00, 31.3]	0.00 [0.00, 0.00]	0.00 [0.00, 25.0]	0.15[a]
Medical profession	126	37.5 [0.00, 65.6]	0.00 [0.00, 43.8]	0.00 [0.00, 43.8]	0.079[a]
Treatment	99	33.3 [8.3, 66.7]	20.8 [0.00, 58.3]	12.5 [0.00, 50.0]	0.26[a]
Infertility	81	34.4 [0.00, 59.4]	37.5 [0.00, 75.0]	25.0 [0.00, 75.0]	0.99[a]
PROMIS global scores					
Global physical	190	13.1 ± 3.1[d]	14.9 ± 3.1[c]	14.0 ± 3.2	0.042[b]
Global mental	190	11.9 ± 3.2	13.1 ± 3.6	13.5 ± 3.4	0.067[b]

Statistics presented as Mean ± SD, Median [P25, P75].

p-values: [a]Kruskal-Wallis test, [b]ANOVA, [c]Significantly different from Endometriosis stage 1–2, [d]Significantly different from Endometriosis stage 3–4, [e]Significantly different from OCPP.

Post hoc pairwise comparisons were done using the Bonferroni adjustment.

Table 5. Regression model of EHP-30 Scores by global physical score and age.

EHP-30 core scores	Global physical score				Current age				R-square
	Estimate	Lower CL[a]	Upper CL[a]	p-value	Estimate	Lower CL[a]	Upper CL[a]	p-value	
Pain	−4.57	−5.55	−3.58	<0.001	−0.71	−1.16	−0.26	0.002	0.34
Control and powerlessness	−5.62	−6.80	−4.43	<0.001	−0.86	−1.40	−0.33	0.002	0.35
Emotional well-being	−4.59	−5.57	−3.61	<0.001	−0.73	−1.18	−0.29	0.001	0.35
Social support	−5.21	−6.391	−4.02	<0.001	−0.90	−1.44	−0.35	0.001	0.32
Self-image	−5.37	−6.56	−4.17	<0.001	−1.02	−1.56	−0.47	<0.001	0.34

[a]CL, Confidence limit; 95% confidence limits were calculated.

Stepwise selections were performed by proc glmselect slentry = 0.15 slstay = 0.05 in SAS 9.4, list of excluded variables: research group (EACPP vs. OCPP), race, Global Physical score, pregnancy, physical abuse, history of emotional abuse, history of sexual abuse, current hormone therapy, and currently seeing a pain specialist.

for EACPP patients, surgical treatment alone may not offer a lasting benefit in sexual functioning.

Low rates of treatment utilization were seen across both study groups. Several studies have also shown poor utilization of treatments for CPP [26, 27], which reflects our present difficulty with effectively helping patients with chronic pelvic pain. There is a greater need to encourage patients to pursue effective non-surgical treatment approaches. In particular, rates of physical therapy (PT) utilization were low across all participants; only 12.7% had tried pelvic floor PT and 3.2% were currently using it. Myofascial pain syndromes may be responsive to PT as an adjunct to conventional medical and surgical therapy [28]. While some studies have demonstrated the efficacy of PT, additional research is necessary to determine its true impact on improving HRQoL [29–31].

There were several limitations to this retrospective study. Only patients with valid contact information 8–10 years after surgery were reachable. The low response rate (17.3%) may have been due to the lengthy survey and prolonged follow-up time. Participants experiencing extreme satisfaction or dissatisfaction with their surgery may have been more likely to participate. Additionally, the study sample primarily consisted of White female respondents, underrepresenting the African American community and other racial groups which make up a small portion of the total sample (Table 1). Most questions focused on the past 4 weeks to limit recall bias. Sensitive questions (e.g., abuse) may have been susceptible to response bias. Additionally, although experienced surgeons examined the pelvis during index surgery for presence of endometriosis, there remains the potential that subtle endometriosis was missed for a small subset of patients.

Table 6. History of physical abuse and HRQoL scores.

	N	All participants N = 192	Physical abuse history N = 25	No physical abuse history N = 163	*p*-value
		EHP-30 scores			
Core categories					
Pain	188	13.6 [0.00, 47.7]	9.1 [0.00, 52.3]	13.6 [0.00, 47.7]	0.78[d]
Control and powerlessness	188	25.0 [0.00, 54.2]	20.8 [0.00, 75.0]	25.0 [0.00, 54.2]	0.86[d]
Emotional well-being	188	20.8 [0.00, 41.7]	16.7 [0.00, 41.7]	20.8 [0.00, 41.7]	0.97[d]
Social support	186	21.9 [0.00, 56.3]	25.0 [0.00, 68.8]	18.8 [0.00, 50.0]	0.76[d]
Self-image	186	16.7 [0.00, 50.0]	25.0 [0.00, 50.0]	16.7 [0.00, 50.0]	0.89[d]
Modular categories					
Work life	135	0.00 [0.00, 30.0]	0.00 [0.00, 35.0]	0.00 [0.00, 30.0]	0.87[d]
Sexual intercourse	162	40.0 [0.00, 70.0]	50.0 [0.00, 75.0]	40.0 [0.00, 70.0]	0.49[d]
Children	133	0.00 [0.00, 25.0]	12.5 [0.00, 25.0]	0.00 [0.00, 25.0]	0.19[d]
Medical profession	124	3.1 [0.00, 43.8]	31.3 [0.00, 43.8]	0.00 [0.00, 43.8]	0.34[d]
Treatment	99	16.7 [0.00, 58.3]	16.7 [0.00, 58.3]	16.7 [0.00, 58.3]	0.97[d]
Infertility	80	31.3 [0.00, 75.0]	0.00 [0.00, 62.5]	31.3 [0.00, 75.0]	0.27[d]
		PROMIS global scores			
Global physical	186	14.1 ± 3.2	13.5 ± 3.3	14.2 ± 3.2	0.34[a]
Global mental	186	13.1 ± 3.4	11.9 ± 3.2	13.3 ± 3.5	0.053[a]

Statistics presented as Mean ± SD, Median [P25, P75].

p-values: [a] Results of *t*-test, [d] Wilcoxon Rank Sum test.

Table 7. History of emotional abuse and HRQoL scores.

	N	All participants N = 192	Emotional abuse history N = 47	No emotional abuse history N = 138	*p*-value
		EHP-30 scores			
Core aategories					
Pain	185	13.6 [0.00, 47.7]	13.6 [0.00, 47.7]	14.8 [0.00, 47.7]	0.89[d]
Control and powerlessness	185	25.0 [0.00, 54.2]	29.2 [0.00, 66.7]	22.9 [0.00, 54.2]	0.81[d]
Emotional well-being	185	20.8 [0.00, 41.7]	25.0 [0.00, 58.3]	16.7 [0.00, 41.7]	0.31[d]
Social support	184	18.8 [0.00, 56.3]	43.8 [0.00, 68.8]	18.8 [0.00, 50.0]	0.38[d]
Self-image	184	16.7 [0.00, 50.0]	33.3 [0.00, 66.7]	16.7 [0.00, 50.0]	0.18[d]
Modular categories					
Work life	132	0.00 [0.00, 30.0]	0.00 [0.00, 35.0]	0.00 [0.00, 30.0]	0.99[d]
Sexual intercourse	160	40.0 [0.00, 70.0]	47.5 [7.5, 77.5]	36.3 [0.00, 70.0]	0.18[d]
Children	133	0.00 [0.00, 25.0]	0.00 [0.00, 25.0]	0.00 [0.00, 25.0]	0.38[d]
Medical profession	123	6.3 [0.00, 43.8]	25.0 [0.00, 56.3]	0.00 [0.00, 43.8]	0.31[d]
Treatment	98	16.7 [0.00, 58.3]	20.8 [0.00, 58.3]	16.7 [0.00, 58.3]	0.47[d]
Infertility	79	31.3 [0.00, 75.0]	50.0 [0.00, 81.3]	31.3 [0.00, 62.5]	0.46[d]
		PROMIS global scores			
Global physical	184	14.1 ± 3.2	12.9 ± 3.0	14.5 ± 3.1	0.002[a]
Global mental	184	13.1 ± 3.5	11.2 ± 3.3	13.8 ± 3.3	<0.001[a]

Statistics presented as Mean ± SD, Median [P25, P75].

p-values: [a] Results of *t*-test, [d] Wilcoxon Rank Sum test.

Our study demonstrates the first comprehensive comparison of long term HRQoL between women with EACPP and other causes of pelvic pain. The similar pain and quality of life scores between EACPP and OCPP suggest that existing literature on HRQoL in endometriosis patients may be useful in predicting quality of life outcomes in OCPP patients. This may have clinical relevance when advising women with CPP, especially of idiopathic origin, in the likely course of their disease. Long-term outcomes show persistent symptoms in both groups which require intervention, and providers should pay particular attention to ongoing sexual dysfunction in this population. History of abuse may be critical to these outcomes and requires further study to define its precise relationship with CPP. In addition, further prospective research on HRQoL factors with a larger sample size is necessary to optimize quality of life outcomes and ease the daily disease burden for women struggling with chronic pelvic pain.

Table 8. History of sexual abuse and HRQoL scores.

	N	All participants	Emotional abuse history	No sexual abuse history	p-value
		N = 192	N = 29	N = 157	
EHP-30 scores					
Core categories					
Pain	186	14.8 [0.00, 47.7]	0.00 [0.00, 52.3]	18.2 [0.00, 47.7]	0.92[d]
Control and powerlessness	186	27.1 [0.00, 54.2]	8.3 [0.00, 50.0]	29.2 [0.00, 54.2]	0.71[d]
Emotional well-being	186	20.8 [0.00, 41.7]	16.7 [0.00, 45.8]	20.8 [0.00, 41.7]	0.80[d]
Social support	184	18.8 [0.00, 56.3]	18.8 [0.00, 56.3]	18.8 [0.00, 56.3]	0.99[d]
Self-image	184	16.7 [0.00, 50.0]	16.7 [0.00, 50.0]	16.7 [0.00, 50.0]	0.59[d]
Modular categories					
Work life	132	0.00 [0.00, 32.5]	0.00 [0.00, 40.0]	0.00 [0.00, 30.0]	0.65[d]
Sexual intercourse	159	40.0 [0.00, 75.0]	50.0 [5.0, 90.0]	36.3 [0.00, 70.0]	0.15[d]
Children	132	0.00 [0.00, 25.0]	0.00 [0.00, 25.0]	0.00 [0.00, 25.0]	0.89[d]
Medical profession	120	6.3 [0.00, 46.9]	12.5 [0.00, 46.9]	6.3 [0.00, 46.9]	0.89[d]
Treatment	95	16.7 [0.00, 58.3]	8.3 [0.00, 58.3]	16.7 [0.00, 58.3]	0.88[d]
Infertility	80	31.3 [0.00, 71.9]	50.0 [0.00, 75.0]	31.3 [0.00, 68.8]	0.72[d]
PROMIS global scores					
Global physical	184	14.1 ± 3.2	13.8 ± 3.7	14.1 ± 3.1	0.64[a]
Global mental	184	13.1 ± 3.4	12.0 ± 4.3	13.3 ± 3.2	0.13[e]

Statistics presented as Mean ± SD, Median [P25, P75].

p-values: [a] Results of t-test, [d] Wilcoxon Rank Sum test, [e] Satterthwaite t-test.

Abbreviations

HRQoL, health-related quality of life; EACPP, endometriosis-associated chronic pelvic pain; OCPP, other chronic pelvic pain.

Author contributions

TF participated in design of the study and overseeing research. SB performed the research, with help from RF, MY analyzed the data with guidance from RF. SB wrote the manuscript. All authors contributed to editorial changes in the manuscript. All authors read and approved the final manuscript.

Ethics approval and consent to participate

All subjects gave their informed consent for inclusion before they participated in the study. The study was conducted in accordance with the Declaration of Helsinki, and the protocol was approved by the Institutional Review Board of the Cleveland Clinic Foundationn, approval number: IRB #16-1184.

Conflict of interest

The authors declare no conflict of interest.

Supplementary material

Supplementary material associated with this article can be found, in the online version, at https://ceog.imrpress.com/EN/10.31083/j.ceog4804135.

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