

Factors associated with chronic pelvic pain in women with endometriosis: A national study on clinical and sociodemographic characteristics, lifestyles, quality of life, and perceptions of quality of care, during the COVID-19 pandemic

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Abstract

Background: Endometriosis is a persistent inflammatory condition that affects women of reproductive age and causes pelvic pain. Chronic pelvic pain is a chronic regional pain syndrome involving the pelvic area.

Objectives: This survey aimed to characterize the clinical and sociodemographic characteristics, lifestyles, quality of life, and perceptions of quality of care in women with endometriosis who reported chronic pelvic pain during the Covid pandemic.

Design: We conducted a cross-sectional survey among the Italian population from July to September 2021.

Methods: Snowball sampling was used to interview a large sample of adult women who reported a diagnosis of endometriosis, through a self-reported questionnaire. Univariate and multivariable logistic regression analyses were performed to identify the factors associated with chronic pelvic pain. The primary outcome was describing women who reported chronic pelvic pain.

Results: A total of 661 out of 1045 (63%) women who responded to the survey reported chronic pelvic pain. The multivariable analysis evidenced that chronic pelvic pain was related to physical and mental quality perception, pelvic floor disorders (adjusted odds ratio = 1.58; 95% CI = 1.10–2.27; p=0.012), dyspareunia (adjusted odds ratio = 1.87; 95% CI = 1.31–2.65; p < 0.001), adhesions syndrome (adjusted odds ratio = 1.49; 95% CI = 1.05–2.11; p=0.026), and the delay in diagnosing endometriosis (adjusted odds ratio = 1.04; 95% CI = 1.00–1.09; p=0.034). The only social factor associated with chronic pelvic pain was marital status (adjusted odds ratio = 0.66; 95% CI = 0.46–0.93; p=0.019).

Conclusion: In the pandemic period, there was a very high prevalence of chronic pelvic pain in women with endometriosis in Italy. The pandemic highlighted the need for careful attention to diagnose endometriosis and the need for psychological and partner support, which would allow better pain management and prevent chronicity.

Keywords

chronic pelvic pain, endometriosis, quality of care, quality of life, women

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Introduction

Endometriosis is a persistent and frequently painful gynaecological illness affecting 5%–10% of women globally.^{1–3} Several studies have demonstrated that endometriosis has an impact on women's quality of life (QoL) and mental health. Endometriosis has been linked to decreased psychological and social well-being and has a detrimental effect on all aspects of QoL.^{4–6}

According to the World Health Organization (WHO), endometriosis is a persistent inflammatory condition that affects women of reproductive age causing pelvic pain and infertility due to the development of scar tissue.⁷ Because of the heterogeneity of the disease, women may have a range of incapacitating symptoms that adversely impact their QoL, which is in proportion to the severity of the symptoms.^{5–9}

Chronic pelvic pain (CPP) typically manifests 12 months after menarche and progressively worsens.⁸ It is a form of chronic regional pain syndrome involving the pelvic area. Comorbidities are often useful in the diagnostic process and are associated with the development of CPP.10 Irritable bowel syndrome, major depressive disorder, and pelvic inflammatory syndrome with sexual dysfunction and symptoms are associated problems or precipitating factors that assist in the diagnosis.^{11,12} The aetiology of CPP may be related to functional somatic pain syndrome or a form of centralized pain, which changes from acute regional pain to chronic with neuropathic features. Endometriosis is suspected to be the main cause of CPP: women with endometriosis experience cyclical pain due to recurrent bleeding from the endometriotic implants. In this case, the pain is suspected to be associated with engorged and dilated pelvic veins, causing decreased venous washout, with a related pelvic congestion syndrome.

Furthermore, increased levels of prostaglandins, combined with compression and/or infiltration of the pelvic nerves, can be responsible for pain development and persistence.¹² Secondary dysmenorrhoea typically appears 12 months post-menarche and is associated with progressively worsening pain which can result in CPP.¹³ Approximately two-thirds of women with dysmenorrhoea are diagnosed with endometriosis and experience pain from adolescence.¹⁴ Unfortunately, early pelvic pain related to endometriosis in adolescents can remain incorrectly diagnosed and treated, resulting in CPP. An Italian study comparing women with surgically diagnosed endometriosis and healthy controls showed that different types of endometriosis pain had different effects on the QoL and mental health of women.¹⁵

This study aimed to investigate the clinical and sociodemographic characteristics, lifestyles, and perceptions of QoL and quality of care (QoC) among Italian women with endometriosis with or without CPP, and the factors associated with CPP.

Method

This study was part of a larger project named 'Quality of care and perception of quality of life in women with endometriosis in the covid era', which was an online cross-sectional survey carried out from July to September 2021 and authorized by the Internal Review Board (IRB) of the University of L'Aquila (Protocol No. 26/2021). This project aimed to investigate the QoL in women with endometriosis and the eventual impact on it or the QoC.⁶ The STROBE Guidelines were used to ensure the reporting of this observational study.

Recruitment of participants

As reported in a previous study,⁶ Italian women older than 18 years who suffered from endometriosis completed an online questionnaire after providing informed consent and authorization for data processing. Each participant was guaranteed anonymity and respect for privacy.

Questionnaire

A self-reported questionnaire on the Google Forms web platform that included the Italian version of the Health Questionnaire SF-36 V2 Standard was used for the survey.¹⁶

The choice of the Health Questionnaire SF-36 V2 Standard in this study was grounded in its well-established reputation as a comprehensive and widely utilized instrument for evaluating health-related QoL. In particular, The SF-36 V2 Standard encompasses a broad spectrum of physical, mental, and social aspects of health, providing a holistic view of an individual's well-being.

The physical component summary (PCS) and mental component summary (MCS) were used to evaluate the standardized components. Higher scores indicate a better QoL.¹⁷ The questionnaire included 12 items for assessing the QoC perception: 11 items were from a validated questionnaire;18,19 we revisited it for endometriosis, and we added an item about preventive anti-Covid measures. Four items evaluated perceived quality of the structure (opening hours of the structure, accessibility of the rooms, cleanliness, and agreeability, and preventive anti-Covid measures), three items evaluated personnel (courtesy and helpfulness, understandable explanations, and being listened to), three items were for the waiting time evaluation (waiting times from booking to the visit, waiting time from arrival to the hospital/clinic, and waiting time from arrival to visit), one item was for the cooperation evaluation, the last item was for the overall rating of the service offered in the past 12 months.

Each item had two options for positive perception and two options for negative perception. We calculated a satisfaction index varying from 0 to 36 by assigning a score from 0 to 3 for each option.

	CPP n=661 (63%) 95% CI = 60%–66%	No CPP n=384 (37%) 95% CI = 34%-40%	<i>p</i> -value	
	Mean (SD) or n (%)	Mean (SD) or <i>n</i> (%)		
Age	34.7 (7.8)	35.2 (7.9)	0.342	
Residence				
South	255 (63%)	147 (37%)	0.566	
Centre	134 (60%)	88 (40%)		
North	272 (65%)	149 (35%)		
Marital status				
Married/cohabiting	369 (60%)	243 (40%)	0.018	
Single	292 (67%)	141 (33%)		
Living alone				
Yes	77 (68%)	37 (32%)	0.314	
No	584 (63%)	347 (37%)		
Education				
High (degree or above)	271 (59%)	185 (41%)	0.024	
Low (secondary school)	390 (66%)	199 (34%)		
Employed				
Yes	406 (60%)	271 (40%)	0.003	
No	255 (69%)	113 (31%)		
Physical activity				
Yes	253 (59%)	177 (41%)	0.013	
No	408 (66%)	207 (34%)		
Smoking habit				
Yes	149 (68%)	70 (32%)	0.099	
No	512 (62%)	314 (38%)		
Alcohol consumption				
Yes	153 (58%)	112 (42%)	0.031	
No	508 (65%)	272 (35%)		

Table I. Comparison of sociodemographic and lifestyles data between women with and without CPP - % within row.

CPP: chronic pelvic pain; CI: confidence interval; SD: standard deviation.

Sociodemographic information, behavioural habits, including smoking and alcohol consumption (intake of at least one drink per day), and clinical information regarding body mass index (BMI), time of endometriosis diagnosis, pregnancy, treatment, complications related to endometriosis, and comorbidities were also collected. These have been reported in more detail by Cofini et al.⁶ The questionnaire created was pre-tested on a group equal to 5% of the study population (n=55).

Sample size

Snowball sampling was used to interview participants via emails, social media networks, and instant messaging applications. The sample size was estimated at 1032 units considering a precision of $\pm 3\%$ with a 95% confidence interval (CI) to a response level of 50% for a single parameter. For sample size determination, we utilized the Raosoft sample size calculator (Available at http://www.raosoft. com/samplesize.html). We opted for the most conservative assumption (50%) for the response distribution as we did not have prior knowledge of the population proportion. In total, 1065 responses were recorded.

Statistical analysis

In the present work, the item 'Do you have chronic pelvic pain as a complication due to endometriosis: yes/no?' was used to classify participants into two groups: women with or without CPP. Absolute frequencies and percentages or means and standard deviations were calculated depending on the nature of the variables. Comparisons between categorical or continuous variables were performed using the chi-squared test or chi-square test for trend and Student's *t*-test.

Factors significantly associated with CPP in the univariate analysis (as reported in Tables 1–3) were analysed using a multiple logistic regression model for the *adjusted* analyses, with CPP (yes/no) as the binary outcome. Adjusted odds ratios were reported as AOR with 95% CI. All analyses (with the exclusion of pregnant women) were performed with STATA 14/MP (StataCorp LLC, Texas,

Mean (SD) or 1 (%)	
22.19 (4.46)	0.331
	0 1 2 0
101 (33%)	0.130
283 (38%)	
ne from sympto	oms to
122 (61%)	$< 0.001^{a}$
83 (33%)	
73 (32%)	
106 (29%)	
ctive)	
241 (36%)	0.320
143 (39%)	
· /	
201 (29%)	<0.001
183 (54%)	
()	
113 (22%)	< 0.001
271 (51%)	
9 (24%)	0.089
375 (37%)	
71 (22%)	< 0.00
313 (44%)	
132 (35%)	0.438
252 (38%)	
33 (31%)	0.159
351 (37%)	
51 (36%)	0.933
333 (37%)	
40 (38%)	0.824
344 (37%)	
30 (25%)	0.006
354 (38%)	
-	
56 (37%)	0.925
328 (37%)	
-	
23 (43%)	0.360
361 (36%)	
- *	
20 (29%)	0.166
364 (37%)	
	328 (37%) 23 (43%) 361 (36%) 20 (29%) 364 (37%)

 Table 2. Comparison of clinical data between women with and without CPP.

Table 2. (Continued)

	CPP	No CPP	p-value	
	Mean (SD) or n (%)	Mean (SD) or n (%)	-	
Adhesions				
Yes	419 (73%)	158 (27%)	<0.001	
No	242 (52%)	226 (48%)		
Surgical intervent	tion for endometrie	osis		
Yes	397 (63%)	235 (37%)	0.717	
No	264 (64%)	149 (36%)		
Comorbidities				
Yes	396 (69%)	178 (31%)	<0.001	
No	265 (56%)	206 (44%)		

CPP: chronic pelvic pain; SD: standard deviation.

^aMantel Haenszel for trend.

Table 3.	Perceived	quality c	of life and	quality of	care:
comparisc	on between	women	with and	without	CPP.

	CPP Mean (SD)	No CPP Mean (SD)		
Quality of life (SF36 sco	ore)			
	n=661	n=384	p-value	
Physical component summary	35.27 (9.48)	44.88 (9.55)	<0.001	
Mental component summary	32.96 (10.50)	37.06 (11.74)	<0.001	
Quality of care				
	n = 570	n = 305	p-value	
Satisfaction care index	22.72 (5.73)	24.74 (4.83)	<0.001	

CPP: chronic pelvic pain; SD: standard deviation.

Quality of care analysis: women who had a medical visit for endometriosis in the past 12 months.

USA), and alpha was set at 0.05. Data from participants who did not provide consent or reported being pregnant (n=20) were not included in the analysis because pregnancy could be linked to a different QoL²⁰ and medical visits may be related to pregnancy.

Results

A total of 1065 women participated in the survey. Pregnant women were excluded, and the remaining 1045 responses were analysed; 63% (661/1045) reported CPP. As reported in Table 1, there were no significant differences between the groups (women with and without CPP) with respect to age, residence, solitary living, and smoking habits. Significant differences were found between the groups for all other factors investigated. With respect to social determinants and healthy or unhealthy behaviours, Table 1 shows that the proportion of CPP was higher among women who were single than those who were married or cohabiting (67% versus 60%), had lower education (66% versus 59%), and were unemployed versus employed (69% versus 60%). Among women who did not report daily alcohol consumption, the proportion of CPP was lower in women who drank (58%) compared with that reported by women who did not drink alcohol (65%), whereas the proportion of CPP was higher in sedentary women than in women who reported physical activity (66% versus 59%).

CPP was significantly associated with the diagnostic delay of endometriosis. The proportion of women with CPP increased with increase in the number of years of delay (chi-squared trend=45; p < 0.001). Among the complications reported by the participants, dyspareunia, pelvic floor disorders, neuropathy/nerve disorders, intestinal stenosis, and adhesions were significantly associated with CPP (p < 0.05). The presence of other diseases was also a significant factor associated with CPP (p < 0.001) (Table 2).

As reported in Table 3, women with pelvic pain reported a perception of QoL that was lower than that in women without pelvic pain, for the physical component of SF36 questionnaire (PCS: 35.27 (9.48) versus 44.88 (9.55), p < 0.001) and for the psychological component (MCS: 32.96 (10.50) versus 37.06 (11.74), p < 0.001). Among women who had a medical visit for endometriosis in the past 12 months (n=875), the satisfaction care index was lower in the CPP group than that in the no CPP group (22.72 (5.73) versus 24.74 (4.83), p < 0.001).

Multiple logistic regression analysis (Table 4) revealed that CPP was related to QoL perception. The perception of CPP was lower in women with higher levels of the two SF-36 components; the PCS component had AOR=0.92 (95% CI = 0.90-0.94; p < 0.001) and MCS had AOR = 0.97 (95% CI = 0.96-0.99; p=0.001). The risk of CPP was statistically higher in women who reported pelvic floor disorders (AOR=1.58; 95% CI = 1.10-2.27; p=0.012), dyspareunia (AOR = 1.87; 95% CI = 1.31-2.65; p < 0.001), and adhesions syndrome (AOR=1.49; 95% CI = 1.05-2.11; p=0.026). The diagnostic delay of endometriosis, also was related to CPP, evidencing that the proportion of CPP is higher if the diagnosis of endometriosis is delayed (AOR = 1.04; 95% CI = 1.00 - 1.09; p = 0.034). The only social factor associated with CPP was marital status; the proportion of CPP perception was lower in women who were married or cohabiting (AOR=0.66; 95% CI = 0.46-0.93; p=0.019).

Discussion

This was a web-based survey of a sample of Italian women suffering from endometriosis, with a focus on women who self-reported CPP. Data were extracted from the larger

Table 4.	Multiple logistic regression: CPP-dependent variable
(n = 875).	

	OR	95% CI	p-value
Marital status (married/ cohabiting vs single)	0.66	0.46-0.93	0.019
Education level (high vs low)	1.11	0.78-1.58	0.548
Occupation (yes vs no)	0.79	0.54-1.15	0.215
Physical activity (yes vs no)	0.88	0.62-1.25	0.490
Alcohol consumption (yes vs no)	1.06	0.72–1.55	0.780
Physical component summary (score)	0.92	0.90–0.94	<0.001
Mental component summary (score)	0.97	0.96–0.99	0.001
Satisfaction care index (score)	0.97	0.94–1.01	0.109
Diagnostic delay of endometriosis (year)	1.04	1.00-1.09	0.034
Comorbidities (yes vs no)	1.02	0.72-1.44	0.920
Dyspareunia (yes vs no)	1.87	1.31-2.65	<0.001
Pelvic floor disorders (yes vs no)	1.58	1.10–2.27	0.012
Neuropathy/nerve disorders (yes vs no)	1.74	1.15–2.64	0.008
Intestinal stenosis (yes vs no)	0.96	0.54–1.70	0.890
Adhesions (yes vs no)	1.49	1.05-2.11	0.026

CPP: chronic pelvic pain; OR: odds ratio; CI: confidence interval. Pregnant women were excluded from the analysis. n=875, because the satisfaction index included as a predictor was calculated for women who had a medical visit in the past 12 months.

database of the research project named 'Quality of care and perception of quality of life in women with endometriosis in the covid era', as reported in a previous study.⁶

CPP was estimated to affect 63% of the study participants (661/1045; 95% CI = 60%-66%), indicating that among women with endometriosis, approximately 6/10 suffer from CPP. A recent review reported that approximately 26% of women worldwide and 15% of women in the United States suffer from CPP.²¹ The relationship between CPP and endometriosis is poorly understood. The diagnosis of superficial endometriotic lesions requires laparoscopy; the recognition, particularly of subtle endometriosis, is variable and related to epidemiology and differences between races.²² In addition, many endometriotic lesions are probably not recognized, especially in adolescents.Adolescents may experience endometriosis-related CPP at the time of menarche. Unfortunately, menstrual cycle-related pain remains misunderstood and is consequently underdiagnosed and undertreated.¹² Thus, the evaluation, diagnosis, and therapy of endometriosis-related CPP are delayed, resulting in a chronic syndrome with neuropathic disturbances from continuous acute pain.²³

Regarding the sociodemographic factors investigated in this study, univariate analysis showed that the proportion of CPP was significantly higher among single women, those with a low level of education, and unemployed and sedentary women. This rate was also higher among no-drinkers.

After entering these factors into the multiple regression model, only marital status was confirmed to be a significant factor related to CPP (AOR=0.66; 95% CI = 0.46– 0.93; p=0.019). This finding is interesting and indicates that support from a sentimental relationship may help women manage their pain. Communication factors such as listening, openness, and dialogue with the partner establish trust and are central to the positive management of pain in accordance with the principles of complementary and alternative medicine (CAM). Sentimental involvement and empathy with a lover are factors that can encourage the patient to communicate the illness experience, make a clinical assessment, and engage in shared decision-making for proper pain-centred care.²⁴

An important finding of this study was that the diagnostic delay of endometriosis was significantly associated with CPP (AOR=1.04; p=0.034). Endometriosisrelated symptoms may be recognized as non-specific in the CCP diagnostic process, despite the prolonged persistence of pain. Hence, these conditions are subcontracted as part of a more complex CPP syndrome. Thus, the elapsed time for the diagnostic process can result in a delay in appropriate therapy, with the consequent worsening of symptoms and development of chronic pelvic disturbances. Furthermore, while this regional syndrome involving the pelvic area persists over time, the pain and related neuropathic disturbances (hyperalgesia, allodynia, or dysesthesia) become chronic as a form of centralized syndrome.¹³ Table 3 shows that surgical intervention did not influence the perception of CPP, except in those who had been diagnosed with pelvic adhesions and intestinal stenosis. Although intestinal stenosis was associated with CPP, this was not confirmed by the multiple logistic regression. Interventions such as hysterectomy, ovariectomy, salpingectomy, intestinal resection, bladder resection, urostomy, and hormonal treatments did not significantly increase CPP. Indeed, a prospective study by Brandsborg et al.,²⁵ which described pain before and up to 4 months after hysterectomy, suggested that both physiological and psychosocial factors are involved in chronic pain after hysterectomy, but the relative contribution of the surgery itself is small. With respect to clinical complications related to endometriosis, in our study, the proportion of CPP was higher in women with dyspareunia, pelvic floor disturbances, neuropathy or nerve disorders, and adhesions, which were statistically associated with CPP after controlling for all other factors investigated (Table 4). As reported in the literature, these conditions are often combined with preexisting neuropathic disturbances such as hyperesthesia and allodynia of the pelvic area and external genitalia.

The persistence of CPP can result in reflex dystony of the pelvic muscle plan, a consequence of pelvic floor dysfunction with dyspareunia development, where there is both a neurological and a psychological component to the symptoms.²⁶ These factors can be self-maintained, resulting in worse sexual dysfunction due to coexisting dyspareunia, pelvic floor dysfunction, neuropathy, or pelvic adhesion syndrome.²⁷ The combination of these disturbances can adversely influence sentimental relationships and empathy with a partner or lover, which is detrimental to pain-centred care and treatment.

The presence of other diseases, even in the univariate analysis, was associated with CPP but was not a significant factor for CPP in women with endometriosis in the multiple regression analysis.

CPP was significantly related to the OoL; in fact, the physical and mental components were associated with CPP in both univariate and multivariate analyses. The CPP perception was lower in women with higher levels of PCS (AOR=0.92; 95% CI = 0.90-0.94) and MCS components (AOR=0.97; 95% CI = 0.96-0.99). As reported by Dydyk et al.,⁹ the history of CPP in women often includes precipitating and alleviating factors associated with disturbances in the menses, pain during urination, related to sexual activity, bowel movements, labour history, caesarean delivery, and surgical history. The diagnosis of CPP may only identify some of the patient's pelvic disturbances, suggesting that it is the 'tip of the iceberg' of more complex gynaecologic and psychological dysfunctions. Thus, it is possible to hypothesize that CPP can have not only a visceral source but also a non-visceral source, including psychological comorbidities (generalized anxiety disorder, major depressive disorder, and post-traumatic stress disorder), emotional state, and stress levels.²⁸ Our findings are in line with those of Facchin et al.,¹⁵ who found that patients with endometriosis and pelvic pain had a lower QoL and mental health than those with asymptomatic endometriosis and healthy controls.

Balneogynecology offers new prospects of treatment of chronic gynaecological conditions, including endometriosis. This innovative approach is proving promising in improving the QoL of patients affected by such diseases by ensuring a positive impact on pain management and the psychophysical well-being of patients.²⁹

In Table 3, the satisfaction care index showed a significant difference between women with and without CPP. Multiple logistic regression analysis of the same index, as shown in Table 4, showed a non-significant association (AOR=0.97; 95% CI = 0.94-1.01). Regression analysis was adjusted for all significant variables in patients with CPP (Table 2). These findings can be explained by the diagnostic delay typical of endometriosis. We hypothesize that this correction was due to patients who received appropriate healthcare for CPP. This study had several limitations. First, it was a crosssectional study, and estimated only the factors associated with CPP; thus, the interpretation of the results is limited. Furthermore, the data were self-reported. Clinical data and diagnosis of endometriosis were reported directly by the participants through an online questionnaire, with a risk of recall bias or selection bias.³⁰

Another limitation is that the study design did not allow us to ascertain the eventual psychological disorders of the participants.

Despite these limitations, our study contributes significantly to this topic by raising awareness about the importance of the timing of diagnosis of endometriosis and the need for medical and psychological support for patients. Endometriosis is associated with early menarche³¹ and the sensitization of health authorities and health practitioners to this topic could help prevent eventual pelvic pain chronicity.³²

Conclusion

CPP is an important complication related to endometriosis that negatively affects the QoL of women. The prevalence of CPP is very high among women with endometriosis, and delayed diagnosis of endometriosis is associated with CPP. More attention should be given to the diagnosis of endometriosis and related pelvic pain to allow better pain management and prevent chronicity.

Declarations

Ethics approval and consent to participate

This study was approved by the Internal Review Board (IRB) of the University of L'Aquila (Protocol No. 26/2021). Written informed consent was obtained from all individual participants included in the study.

Consent for publication

We received written consent to publish from all individual participants included in the study.

Author contribution(s)

Vincenza Cofini: Conceptualization; Formal analysis; Investigation; Supervision; Writing – original draft; Writing – review & editing.
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Emiliano Petrucci: Writing – original draft.
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Franco Marinangeli: Writing - original draft.

Leila Fabiani: Writing – original draft.

Stefano Necozione: Conceptualization; Writing - original draft.

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Competing interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Availability of data and materials

This is not applicable as we do not wish to upload our study data file to protect the confidentiality and anonymity of participants.

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Supplemental material

Supplemental material for this article is available online.

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