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ORIGINAL ARTICLE

## Impact of endometriosis on quality of life and mental health: pelvic pain makes the difference

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### Abstract

**Introduction:** No prior study of endometriosis has investigated the psychological impact of having asymptomatic endometriosis versus endometriosis with pelvic pain in a systematic way. This study aimed at examining the impact of endometriosis on quality of life, anxiety and depression by comparing asymptomatic endometriosis, endometriosis with pelvic pain, and healthy, pain-free controls. The psychological impact of different types of endometriosis pain was also tested.

**Methods:** One hundred and ten patients with surgically diagnosed endometriosis (78 with pelvic pain and 32 without pain symptoms) and 61 healthy controls completed two psychometric tests assessing quality of life, anxiety and depression. Endometriosis participants indicated on a numerical rating scale the intensity of four types of pain (dysmenorrhea, dyspareunia, non-menstrual pelvic pain and dyschezia).

**Results:** Endometriosis patients with pelvic pain had poorer quality of life and mental health as compared with those with asymptomatic endometriosis and the healthy controls. No significant differences were found between asymptomatic endometriosis and the control group. Dysmenorrhea had significant effects only on physical quality of life; non-menstrual pelvic pain affected all the variables; no significant effects were found for dyspareunia and dyschezia.

**Conclusions:** Pain significantly affects women's experience of endometriosis. The medical treatment of endometriosis with pain may not be sufficient and psychological intervention is recommended.

### Keywords

Anxiety, depression, endometriosis, pelvic pain, quality of life

### History

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### Introduction

Endometriosis is a chronic inflammatory disease characterized by the presence of endometrial tissue outside the uterine cavity, which affects between 5% and 10% of women of reproductive age [1,2]. Up to 80% of women with endometriosis suffer from chronic pain (such as dysmenorrhea, dyspareunia, non-menstrual pelvic pain and dyschezia, i.e. the inability to defecate without pain or difficulty) and only 20–25% of patients are asymptomatic; 30–50% of women with endometriosis have infertility [3]. For this reason, endometriosis is considered as a disabling condition that may significantly affect women's everyday life, social relationships, sexuality and mental health [4].

Medical research has demonstrated the link between inflammatory diseases and mood disorders [5,6]. As regards endometriosis, significant correlations were found between immunopathogenetic factors, resulting in imbalanced production of pro- (IL-1 $\beta$ , IL-2 and IFN- $\gamma$ ) and anti-inflammatory (IL-4) cytokines, and the severity of women's shifts in mood, anxiety and mental health in general [7]; peripheral immunological changes may stimulate the neural central system to induce the so called "sickness response", which involves behavioral changes (i.e. depression-like behavior, fatigue, hypophagia, dysregulation of appetite, sleep, or sexual habits, anhedonia, sadness) that may negatively affect social interactions and intimate relationships [4,8,9]. The psychoneuro-immune nature of the disease may enhance women's perception of depressive symptoms and distress [4,7]; acute and chronic stress, depression and anxiety may negatively affect the immune system with the development of a vicious circle of inflammation, sickness behavior and depression [4].

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Other studies have demonstrated that endometriosis, whether symptomatic or pain-free, impairs quality of life, work productivity and mental health (e.g. anxiety and depression) [10–18], as it is characterized by uncertainty about the course of the disease and the future in general, with pervading concerns about crucial aspects of a woman's life, such as sexuality and infertility [17]. Advancing age may be associated with more emotional suffering caused by endometriosis [17,18]

Other studies [19–25] have emphasized the negative effects of pelvic pain on women's mental health (e.g. anxiety and depression) and quality of life (e.g. loss of working ability, limitations in social activities, lack of understanding and support from the others), although overall endometriosis research investigating the impact of pain on women's life and mental health provided mixed findings [26]. This inconsistency may be due to the role of individual differences (e.g. personality traits, coping strategies, beliefs about the pain) in pain subjective perception. Moreover, medical research has been unable to establish a correlation between pelvic pain and the localization or severity of the disease [21,27,28]: women with mild endometriosis may present intense pelvic pain and patients with more severe endometriosis may suffer less from chronic pain [26,29].

No studies have systematically investigated whether the quality of life and mental health of women with endometriosis were negatively affected by endometriosis itself as a chronic inflammatory illness, or exclusively by the presence of pelvic pain. Moreover, although research has investigated the impact of pelvic pain and pain intensity on the lives of patients with endometriosis, no studies have examined whether different types of endometriosis pain may have different impacts on these women.

### The current study

In this study, we compare the impact of asymptomatic endometriosis versus endometriosis with pelvic pain and healthy controls on women's quality of life and mental health. Overall, we expect that endometriosis with pain will be associated with worse psychological conditions as compared with the other two groups, because the research has demonstrated the negative effects of chronic pelvic pain in women with endometriosis [19–25]. Moreover, we test two specific hypotheses: the “disease-focused hypothesis” and the “pain-focused hypothesis”. According to the “disease-focused hypothesis”, women's quality of life and mental health will be negatively influenced by the fact of having a chronic inflammatory disease such as endometriosis, although asymptomatic, for two main reasons: first, the psychoneuro-immune nature of endometriosis as an inflammatory disease may enhance women's perception of depressive symptoms and distress on the basis of the vicious circle described in the literature [4,7]; second, living with a chronic gynecological illness characterized by high prognostic uncertainty, as well as by the threat of infertility, may negatively affect mental health and quality of life. Therefore, if the “disease-focused hypothesis” is true, we expect to find lower quality of life and mental health in patients with asymptomatic endometriosis as compared with healthy controls.

According to the “pain-focused hypothesis”, women's mental health and quality of life will be negatively affected only by the presence of pelvic pain associated with endometriosis [21]; thus, endometriosis patients with pelvic pain will have worse quality of life and mental health relative to the other two conditions, but no differences are expected between asymptomatic endometriosis and healthy controls.

Another goal of this study is to test the impact of type and severity of pelvic pain on the quality of life and mental health of women with endometriosis: we investigate whether the four most common types of endometriosis pain (i.e. dysmenorrhea, dyspareunia, non-menstrual pelvic pain and dyschezia) have different impacts on women's quality of life, anxiety and depression. Overall, better outcomes are expected for women with low pain intensity.

## Methods

### Procedures and participants

This study is part of a larger research on endometriosis, pelvic pain and their associations with several psychological dimensions. In this work, we consider three of these variables: quality of life, anxiety and depression. The research was conducted at the [removed for blind review] (for a more detailed description of the center see [removed for blind review] [30]), from October 2012 to April 2014 after ethical approval from the local Ethics Committee.

The original research design involved 60 women with a diagnosis of endometriosis who were treated with estrogen–progestogen combination or oral progestogen, 50 women with endometriosis who were not treated with hormonal therapies, and a control group composed of 61 women without endometriosis recruited during a routine gynecological visit for contraception, screening for cervical cancer or pelvic ultrasound examination. Of the 110 patients with endometriosis, 32 (29.1%) did not have pelvic pain (no pelvic pain endometriosis group [NoPPEG]) and 78 (70.9%) were suffering from pelvic pain symptoms associated with endometriosis (pelvic pain endometriosis group [PPEG]). Because the majority of women with endometriosis suffer from pelvic pain [3], the proportion of women with pain in our sample can be considered to represent the corresponding proportion of cases in the population. In this study, we consider these two subgroups of women (NoPPEG and PPEG) and the original control group (CG).

Women were eligible if they were Caucasians, could speak and understand Italian, were aged between 18 and 40 years, and had no previous pregnancies. Women with psychiatric disorders and a history of drug and alcohol abuse were not included in the study. Only women who had a surgical diagnosis (laparoscopy or laparotomy) of endometriosis with histopathological confirmation of the condition in the past 2 years were included in the study. The 50 patients without treatment were having their first gynecological visit at our endometriosis center (with no current treatments for endometriosis), or had decided not to take hormonal therapy for several reasons (e.g. desire for pregnancy, medical contraindications, or other personal, non-medical reasons).

Women using gonadotrophin-releasing hormone analogue (GnRH-a) therapy in the past 6 months were not included in

the study because this kind of treatment may be associated with depression [31–33]. Other exclusion criteria were: obstructive uropathy or bowel stenosis; previous abdominal surgery for reasons other than endometriosis; sexually transmitted diseases including pelvic inflammatory disease; genital malformations; pelvic varices; urologic, gastrointestinal, orthopedic, rheumatologic and autoimmune disease. Inclusion criteria for the control group were: absence of any kind of gynecological problem and pelvic pain; no previous abdominal surgery; absence of urologic, gastrointestinal, orthopedic, rheumatologic and autoimmune diseases. All the participants were informed about the aims and the methods of the study and provided written consent. The women recruited in the study completed all measures individually in a quiet room; trained researchers were available to clarify any aspect of the questionnaires administered.

### Measures

Sociodemographic data (i.e. participants' age, level of education, current occupation and intimate relationship status), anthropometric variables and gynecological information (i.e. infertility and type of endometriosis) were collected in order to provide comprehensive sample description. The presence of pelvic pain among patients with endometriosis was assessed using a dichotomous variable (i.e. 'yes', coded 1 and 'no', coded 0). A 0- to 10-point numerical rating scale (NRS), with '0' indicating no pain and '10' indicating the worst possible pain, was then administered and women were asked to rate the current intensity of dysmenorrhea, dyspareunia, dyschezia and non-menstrual pelvic pain.

The Short Form-12 (SF12) is a self-administered 12-item instrument that measures patients' perception of their general health status during the past 4 weeks. The 12 items evaluate 8 domains: physical functioning, physical role functioning (i.e. role limitations due to physical health problems), emotional role functioning (i.e. role limitations due to emotional problems), social role functioning, bodily pain, general health, vitality and mental health. These domains are combined to create two summary measures: the Physical health Composite Score (PCS) and Mental health Composite Score (MCS). Higher numbers indicate better quality of life [34,35].

The Italian version of the Hospital Anxiety and Depression Scale (HADS) [36,37] was used to assess women's anxiety and depression. The HADS is a self-administered questionnaire aimed at assessing anxiety and depression in the setting of hospital out-patient clinics [37]. The questionnaire is divided in two 7-item scales, one for anxiety (HADS\_A) and one for depression (HADS\_D); responses are scored on a 0–3 scale, with 3 indicating higher symptom frequency and severity [38]. Although a total score can be calculated, each scale can be scored and treated independently. Scores range from 0 to 21, with higher scores denoting poorer psychological conditions.

### Data analysis strategy

Data analysis was performed using SPSS (Statistical Package for Social Sciences, SPSS Inc., Chicago, IL) software version 15. Preliminary analyses (one-way ANOVAs) were conducted

to examine whether endometriosis patients who were under hormonal therapy differed from those who were not under treatment on each outcome variable, because research has highlighted that hormonal therapies may affect the psychological status of women with endometriosis [17].

The impact of endometriosis and pelvic pain on the four dependent variables (i.e. mental quality of life [MCS12], physical quality of life [PCS12], anxiety [HADS\_A] and depression [HADS\_D]) was investigated using a multivariate strategy, taking into account potential confounders. We compared the three groups on the four scales using multivariate analyses of covariance (MANCOVAs), controlling for the effects of the sociodemographic variables (age, level of education, current occupation and intimate relationship status). Two MANCOVAs were conducted; the dependent variables were PCS12 and MCS12 in the first MANCOVA, and HADS\_A and HADS\_D in the second MANCOVA. To provide effect sizes, we report partial eta squared ( $\eta_p^2$ ) for the main effect of group (NoPPEG, PPEG, CG) on each dependent variable. Small, medium and large effect sizes are associated with  $\eta_p^2$  values of 0.01, 0.06 and 0.14, respectively. Pairwise comparisons were conducted using Bonferroni's correction to further explore between-group differences.

Four multiple linear regressions were conducted to investigate the impact of type and severity of pelvic pain (measured using the NRS) on each of the SF12 and the HADS subscales. Only the two endometriosis groups ( $N=110$ ) were included in these analyses, because the NRS was not administered to the healthy controls.

## Results

### Sample description

Participants were 171 women aged from 20 to 40 years old ( $M=31.05$ ;  $SD=5.45$ ); 60.2% ( $n=103$ ) of them was graduate, 33.9% ( $n=58$ ) had a high school diploma and 5.8% ( $n=10$ ) quit studying after middle school. Most participants (74.9%;  $n=128$ ) had a regular job and were in a stable relationship (60.8%;  $n=104$ ) when the study was conducted. As regards the type of endometriosis, overall 70% of the patients ( $n=77$ ) had ovarian endometriosis, 17.3% ( $n=19$ ) had rectovaginal endometriosis, 8.2% ( $n=9$ ) had ovarian and rectovaginal endometriosis, 1.8% ( $n=2$ ) had umbilical endometriosis, and the remaining 2.7% ( $n=3$ ) had bladder endometriosis. Twelve endometriosis patients (10.9%) had infertility. All the participant variables by study group are displayed in Table 1.

### Psychological impact of endometriosis and pelvic pain

Means ( $M$ ) and SDs of all the dependent variables by study group are reported in Table 2. Preliminary analyses did not reveal a significant effect of hormonal therapy on any one of the four outcome variables ( $ps>0.05$ ). The two MANCOVAs conducted revealed the presence of significant between-group effects for all the dependent variables (PCS12:  $F[2,148]=12.284$ ;  $p<0.001$ ;  $\eta_p^2=0.142$ ; MCS12:  $F[2,148]=4.622$ ;  $p=0.011$ ;  $\eta_p^2=0.06$ ; HADS\_A:  $F[2,148]=12.268$ ;  $p<0.001$ ;  $\eta_p^2=0.142$ ; HADS\_D:  $F[2,148]=8.551$ ;

Table 1. Participant variables by study group.

Variable	Study group (N=171)		
	NoPPEG (n=32)	PPEG (n=78)	CG (n=61)
<b>Socio-demographic</b>			
Age [M, (SD)]	33.2 (4.4)	32.7 (5.5)	27.9 (4.4)
Level of education [n, (%)]			
University	18 (56.3)	40 (51.3)	45 (73.8)
High school/middle school	14 (43.8)	38 (48.7)	16 (26.2)
Regular job [n, (%)]			
Yes	30 (93.8)	59 (75.6)	39 (63.9)
No	2 (6.3)	19 (24.4)	22 (36.1)
In a stable relationship [n, (%)]			
Yes	22 (68.8)	55 (70.5)	27 (44.3)
No	10 (31.3)	33 (29.5)	34 (55.7)
<b>Anthropometric</b>			
Height (m) [M, (SD)]	1.65 (0.06)	1.65 (0.06)	1.67 (0.06)
Weight (kg) [M, (SD)]	57.2 (11.5)	58.4 (8.1)	58.05 (7.5)
BMI (kg/m <sup>2</sup> ) [M, (SD)]	20.9 (3.9)	21.5 (2.7)	20.9 (2.9)
<b>Gynecological</b>			
Infertility [n, (%)]			
Yes	4 (12.5)	8 (10.3)	1 (1.6)
No	28 (87.5)	70 (89.7)	60 (98.4)
Type of endometriosis [n, (%)]			
Ovarian	22 (68.8)	55 (70.5)	–
Rectovaginal	8 (25)	11 (14.1)	–
Ovarian and rectovaginal	1 (3.1)	8 (10.3)	–
Umbilical	–	2 (2.6)	–
Bladder	1 (3.1)	2 (2.6)	–

Table 2. Means and SDs of each dependent variable by study group.

Variable	Study group (N=171)					
	NoPPEG (n=32)		PPEG (n=78)		CG (n=61)	
	M	SD	M	SD	M	SD
PCS12	51.91	6.69	45.54	8.69	53.43	5.91
MCS12	46.77	9.58	40.78	10.70	43.44	9.30
HADS_A	6.22	3.23	8.24	4.19	6.49	3.45
HADS_D	3.84	2.93	6.67	3.50	4.71	3.12

$p < 0.001$ ;  $\eta_p^2 = 0.104$ ). Pairwise comparisons on the adjusted means conducted with Bonferroni's correction showed that the PPEG had lower quality of life and mental health as compared with the CG (PCS12:  $p < 0.001$ ; 95% CI:  $-12.97, -4.17$ ; MCS12:  $p = 0.04$ ; 95% CI:  $-12.17, -0.133$ ; HADS\_A:  $p < 0.001$ ; 95% CI:  $1.92, 6.12$ ; HADS\_D:  $p = 0.017$ ; 95% CI:  $0.31, 4.23$ ) as well as with the NoPPEG (PCS12:  $p = 0.002$ ; 95% CI:  $-14.37, -2.64$ ; MCS12:  $p = 0.024$ ; 95% CI:  $-16.93, -0.88$ ; HADS\_A:  $p = 0.005$ ; 95% CI:  $0.89, 6.49$ ; HADS\_D:  $p = 0.001$ ; 95% CI:  $1.48, 6.71$ ). No significant differences were found between the NoPPEG and the CG ( $ps > 0.05$ ).

### Psychological impact of type and severity of endometriosis pain

Overall, the pain experienced by the patients was not particularly intense (dysmenorrhea:  $M = 4.65$ ;  $SD = 3.41$ ; dyspareunia:  $M = 3.06$ ;  $SD = 3.02$ ; non-menstrual pelvic pain:  $M = 2.74$ ;  $SD = 3.1$ ; dyschezia:  $M = 2.3$ ;  $SD = 3.12$ ). The impact of the different types of pelvic pain considered on each dependent variable was tested using a set of four

multiple linear regressions. These analyses revealed significant effects for two of the four types of pain (Table 3): dysmenorrhea and non-menstrual pelvic pain. Specifically, dysmenorrhea affected only PCS12 ( $B = -0.582$ ;  $SE = 0.199$ ;  $p = 0.004$ ), so that women with more severe dysmenorrhea had worse physical quality of life; non-menstrual pelvic pain had a significant impact on all the outcome variables (PCS12:  $B = -0.537$ ;  $SE = 0.270$ ;  $p = 0.048$ ; MCS12:  $B = -1.342$ ;  $SE = 0.381$ ;  $p = 0.001$ ; HADS\_A:  $B = 0.391$ ;  $SE = 0.143$ ;  $p = 0.007$ ; HADS\_D:  $B = 0.583$ ;  $SE = 0.124$ ;  $p < 0.001$ ). Thus, non-menstrual pelvic pain was the most pervasive type of pain, as it was associated with worse quality of life and mental health.

### Discussion

In the current study, we investigated the impact of endometriosis on quality of life and mental health by comparing three conditions: asymptomatic endometriosis, endometriosis with pelvic pain, and healthy, pain-free controls. Two hypotheses were tested: the “disease-focused hypothesis” (i.e. significant differences were expected between asymptomatic endometriosis as a chronic inflammatory disease and the control condition) and the “pain-focused hypothesis” (i.e. significant differences were expected only between endometriosis with pelvic pain and the other two groups due to the presence of pain, but not between asymptomatic endometriosis and the control condition).

Significant between-group effects were found, with effect sizes ranging from medium to large (see the  $\eta_p^2$  values), and our findings provided support to the “pain-focused hypothesis”, as they revealed that only pelvic pain had a negative impact on all the dependent variables and was associated with lower quality of life and higher anxiety and depression relative to the other two conditions. Patients with asymptomatic endometriosis did not differ from healthy controls on any dependent variable. These findings suggest that the mere fact of having endometriosis, when asymptomatic, is not necessarily associated with poorer quality of life and psychological health.

The current study also aimed at investigating the associations between four specific types of pain (i.e. dysmenorrhea, dyspareunia, non-menstrual pelvic pain and dyschezia) on endometriosis patients' quality of life and mental health. We found that dysmenorrhea, whose intensity was higher as compared with the other types of pain, affected only physical quality of life. These findings provide support to the idea that relying on objective measures, although fundamental for the diagnosis of the disease, is not sufficient to understand the subjective illness experience. It might be that because many healthy women have dysmenorrhea, and not only those with endometriosis, this type of pain is considered as more physically invalidating during the short menstrual period, but yet relatively “normal”: women are supposed to have menstrual pain. The negative consequences of this spread belief have been shown by several studies [17,39] demonstrating the importance of giving the pain of endometriosis the right status; the pathway of these patients before the diagnosis is often characterized by negative experiences with doctors dismissing their suffering from pain as exaggerated,

Table 3. Impact of endometriosis pain on the dependent variables: significant effects.

Type of pain	Variable	Significant effects ( $n = 110$ )					
		<i>B</i>	SE	$\beta$	<i>p</i>	95% CI	
Dysmenorrhea	PCS12	-0.582	0.199	-0.248	0.004	-0.975	-0.190
Non-menstrual pelvic pain	PCS12	-0.537	0.270	-0.182	0.048	-1.07	-0.004
	MCS12	-1.342	0.381	-0.371	0.001	-2.094	-0.591
	HADS_A	0.391	0.143	0.285	0.007	0.108	0.674
	HADS_D	0.583	0.124	0.474	0.000	0.338	0.828

or even unreal, with significant delays in the diagnosis of the disease [39].

In this study, we found that non-menstrual pelvic pain, although less severe than dysmenorrhea, affected all the dependent variables; dyspareunia and dyschezia had no significant effects at all. We can hypothesize that the experience of non-menstrual pelvic pain is more pervasive because it is not short lived as menstrual pain; moreover, a smaller percentage of women suffer from this type of pain and for this reason it cannot be interpreted as a normal female condition: having permanent pelvic pain may be considered by these patients as the incontrovertible evidence of the presence of a pathological, abnormal gynecological condition that makes them different as compared with the other women and for this reason it is associated with poorer psychological health. The localization of the pain may represent another crucial dimension influencing the emotional reaction of women; for instance, the pain caused by dyschezia is not “genital” and for this reason it might be that it is not meant by the women as directly affecting their femininity. Dyspareunia did not affect any outcome variable and this is surprising if we consider that 55 (70.5%) of our endometriosis patients with pain were in a stable relationship; these results suggests that this type of pain was not experienced as particularly “invalidating” by these women. However, because endometriosis participants were not asked about their subjective perception of the illness, these comments should be taken cautiously and systematically tested by future studies.

Overall, our study suggests that chronic pelvic pain should be considered as an important component of having endometriosis: although the pain experienced by our patients was not particularly intense, the presence of pelvic pain had a negative impact on all the dependent variables. These results raise an important issue that has been addressed by qualitative research on endometriosis [17]: given that some patients may be asymptomatic (although diagnosed with extensive gynecological disease according to the linear biomedical criteria), the mere diagnosis is not necessarily associated with the impossibility of living a normal life with good mental health.

This is not obvious, because research has demonstrated that the simple fact of being diagnosed with endometriosis may significantly affect women’s psychological well-being [17]. Having endometriosis, although asymptomatic, implies living with a chronic disease that affects the “core” of femininity, as it may involve sexual problems, as well as the risk of infertility. The mere awareness of having endometriosis may be associated with negative feelings (e.g. being

“different”, being sick, being an “incomplete” woman). These words are very often used by the patients that we encounter in our everyday clinical practice. In this regard, our findings may provide a positive message: painless endometriosis is compatible with a normal life and does not necessarily involve psychological pain.

However, our study presents several limitations. First, the fact that the original research design and group assignment (i.e. endometriosis patients with and without hormonal treatment versus healthy controls) were not exclusively oriented by the main research question addressed by the current study represents a methodological limitation that should be considered in the interpretation of our findings. Moreover, the control group differed slightly from the other two groups with regard to the sociodemographic variables (Table 1); although the effects of these potential confounders were controlled in our statistical analyses, these differences should be considered as a limitation of our study.

Second, we did not assess diagnostic factors, such as the time between symptom onset and diagnosis, and women’s age at the time of diagnosis. The research has demonstrated that diagnostic factors may have a significant impact on women’s psychological health [40].

Third, because only 12 of our 110 endometriosis patients had infertility, we decided not to control for the effects of this variable; in this regard, the impact of infertility on women’s mental health and quality of life might be underestimated in our study. Although the threat of infertility is a crucial aspect of the endometriosis experience [17] and up to 50% of endometriosis patients have infertility [3], there is very limited research on the psychological impact of having endometriosis and infertility. There is need of studies comparing endometriosis with and without infertility on mental health, as it is plausible that the two illness experiences are significantly different.

Fourth, given that research has demonstrated the influence of subjective and socio-cultural factors on pain perception [26], the fact that these dimensions were not investigated in this study should be considered as a limitation. Future qualitative studies should explore the way in which women interpret the different endometriosis pain symptoms and the extent to which different emotional reactions are determined by different aspects of the pain (e.g. subjective meaning, socio-cultural beliefs and representations, pain localization). The biopsychosocial perspective [41] represents a valid theoretical framework for research on endometriosis, as it assumes that the illness experience is complex and influenced by multiple dimensions related to the individual as well as to his/her relationships [42,43].

In conclusion, our findings suggest that when the problems caused by endometriosis primarily involve pelvic pain, the medical treatment (which should be aimed at the symptomatic relief) may not be sufficient. Our findings suggest that these patients may significantly benefit of psychological interventions; in this regard, there is evidence of the effectiveness of group-based [44] and mindfulness-based [45] interventions, and cognitive behavioral therapy [46].

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### Declaration of interest

The authors report no conflicts of interest.

### References

- Damewood M, Kresch AJ, Metzger D, Begany T. Current approaches to endometriosis. *Patient Care* 1997;31:34–43.
- Viganò P, Parazzini F, Somigliana E, Vercellini P. Endometriosis: epidemiology and etiological factors. *Best Pract Res Clin Obstet Gynaecol* 2004;18:177–200.
- Bulletti C, Coccia ME, Battistoni S, Borini A. Endometriosis and infertility. *J Assist Reprod Genet* 2010;27:441–7.
- Siedentopf F, Tariverdian N, Rütcke M, et al. Immune status, psychosocial distress and reduced quality of life in infertile patients with endometriosis. *Am J Reprod Immunol* 2008;60:449–61.
- Steiner J, Walter M, Gos T, et al. Severe depression is associated with increased microglial quinolinic acid in subregions of the anterior cingulate gyrus: evidence for an immune-modulated glutamatergic neurotransmission? *J Neuroinflammation* 2011;8:94.
- Wium-Andersen MK, Ørsted DD, Nielsen SF, Nordestgaard BG. Elevated C-reactive protein levels, psychological distress, and depression in 73, 131 individuals. *JAMA Psychiatry* 2013;70:176–84.
- Nasyrova RF, Sotnikova LS, Baystrukova NV, et al. Psychoimmune interactions in women of reproductive age with endometriosis. *Bull Exp Biol Med* 2011;152:93–7.
- Avitsur R, Cohen E, Yirmiya R. Effects of interleukin-1 on sexual attractiveness in a model of sickness behavior. *Physiol Behav* 1997;63:25–30.
- Watkins LR, Maier SF. The pain of being sick: implications of immune-to-brain communication for understanding pain. *Annu Rev Psychol* 2000;51:29–57.
- De Graaff AA, D'Hooghe TM, Dunselman GA, et al. The significant effect of endometriosis on physical, mental and social wellbeing: results from an international cross-sectional survey. *Hum Reprod* 2013;28:2677–85.
- Denny E. Women's experience of endometriosis. *J Adv Nurs* 2004;46:641–8.
- Huntington A, Gilmour JA. A life shaped by pain: women and endometriosis. *J Clin Nurs* 2005;14:1124–32.
- Jones G, Jenkinson C, Kennedy S. The impact of endometriosis upon quality of life: a qualitative analysis. *J Psychosom Obstet Gynecol* 2004;25:123–33.
- Nnoaham KE, Hummelshoj L, Webster P, et al. World Endometriosis Research Foundation Global Study of Women's Health consortium. Impact of endometriosis on quality of life and work productivity: a multicenter study across ten countries. *Fertil Steril* 2011;96:366–73.
- Oehmke F, Weyand J, Hackethal A, et al. Impact of endometriosis on quality of life: a pilot study. *Gynecol Endocrinol* 2009;25:722–5.
- Simoens S, Dunselman G, Dirksen C, et al. The burden of endometriosis: costs and quality of life of women with endometriosis and treated in referral centres. *Hum Reprod* 2012;27:1292–9.
- Denny E. I never know from one day to another how I will feel: pain and uncertainty in women with endometriosis. *Qual Health Res* 2009;19:985–95.
- Sepulcri Rde P, do Amaral VF. Depressive symptoms, anxiety, and quality of life in women with pelvic endometriosis. *Eur J Obstet Gynecol Reprod Biol* 2009;142:53–6.
- Cox H, Henderson L, Andersen N, et al. Focus group study of endometriosis: struggle, loss and the medical merry-go-round. *Int J Nurs Pract* 2003;9:2–9.
- Kumar A, Gupta V, Maurya A. Mental health and quality of life of chronic pelvic pain and endometriosis patients. *J Projective Psychol Mental Health* 2010;17:153–7.
- Lorençatto C, Petta CA, Navarro MJ, et al. Depression in women with endometriosis with and without chronic pelvic pain. *Acta Obstet Gynecol Scand* 2006;85:88–92.
- Peveler R, Edwards J, Daddow J, Thomas E. Psychosocial factors and chronic pelvic pain: a comparison of women with endometriosis and with unexplained pain. *J Psychosom Res* 1996;40:305–15.
- Souza CA, Oliveira LM, Scheffel C, et al. Quality of life associated to chronic pelvic pain is independent of endometriosis diagnosis – a cross-sectional survey. *Health Qual Life Outcomes* 2011;10:41.
- Tripoli TM, Sato H, Sartori MG, et al. Evaluation of quality of life and sexual satisfaction in women suffering from chronic pelvic pain with or without endometriosis. *J Sex Med* 2011;8:497–503.
- Waller KG, Shaw RW. Endometriosis, pelvic pain, and psychological functioning. *Fertil Steril* 1995;63:796–800.
- Eriksen HL, Gunnarsen KF, Sørensen JA, et al. Psychological aspects of endometriosis: differences between patients with or without pain on four psychological variables. *Eur J Obstet Gynecol Reprod Biol* 2008;139:100–5.
- Vercellini P, Fedele L, Molteni P, et al. Laparoscopy in the diagnosis of gynecologic chronic pelvic pain. *Int J Gynaecol Obstet* 1990;32:261–5.
- Nunnink S, Meana M. Remembering the pain: accuracy of pain recall in endometriosis. *J Psychosom Obstet Gynecol* 2007;28:201–8.
- Hurd WW. Criteria that indicate endometriosis is the cause of chronic pelvic pain. *Obstet Gynecol* 1998;92:1029–32.
- Vercellini P, Buggio L, Somigliana E, Barbara G, Viganò P, Fedele L. Attractiveness of women with rectovaginal endometriosis: a case-control study. *Fertil Steril* 2013;99:212–8.
- Ferrero S, Remorgida V, Ragni N. Prevalence of depression in women with endometriosis. *Acta Obstet Gynecol Scand* 2007;86:111.
- Warnock JK, Bundren JC, Morris DW. Depressive symptoms associated with gonadotropin-releasing hormone agonists. *Depress Anxiety* 1998;7:171–7.
- Warnock JK, Bundren JC, Morris DW. Depressive mood symptoms associated with ovarian suppression. *Fertil Steril* 2000;74:984–6.
- Gandek B, Ware JE, Aaronson NK, et al. Cross-validation of item selection and scoring for the SF-12 Health Survey in nine countries: results from the IQOLA Project. International Quality of Life Assessment. *J Clin Epidemiol* 1998;51:1171–8.
- Apolone G, Mosconi P, Quattrociochi L, et al. Questionario sullo stato di salute SF-12. Versione italiana [SF-12 health survey. Italian version]. Milano: Guerini e Associati Editore; 2001.
- Zigmond AS, Snaith RP. The hospital anxiety and depression scale. *Acta Psychiatr Scand* 1983;67:36170.
- Costantini M, Musso M, Viterbori P, et al. Detecting psychological distress in cancer patients: validity of the Italian version of the Hospital Anxiety and Depression Scale. *Support Care Cancer* 1999;7:121–7.
- Whelan-Goodinson R, Ponsford J, Schönberger M. Validity of the Hospital Anxiety and Depression Scale to assess depression and anxiety following traumatic brain injury as compared with the Structured Clinical Interview for DSM-IV. *J Affect Disord* 2009;114:94–102.
- Manderson L, Warren N, Markovic M. Circuit breaking: pathways of treatment seeking for women with endometriosis in Australia. *Qual Health Res* 2008;18:522–34.

40. Culley L, Law C, Hudson N, et al. The social and psychological impact of endometriosis on women's lives: a critical narrative review. *Hum Reprod Update* 2013;19:625–39.
41. Engel GL. The need for a new medical model: a challenge for biomedicine. *Science* 1977;196:129136.
42. Margola D, Molgora S, Facchin F. Psicosomatica, stress e qualità della vita. Un'introduzione [Psychosomatics, stress, and quality of life. An introduction]. In: Saita E, ed. *Pensare alla salute e alla malattia: legami tra mente, corpo e contesto di appartenenza* [Thinking about health and illness: relationships between mind, body, and social context]. Milano: Educatt; 2011:29–52.
43. Saita E. *Psico-oncologia: una prospettiva relazionale* [Psycho-oncology: a relational perspective]. Milano: Unicopli; 2009.
44. Wingfield MB, Wood C, Henderson LS, Wood RM. Treatment of endometriosis involving a self-help group positively affects patients' perception of care. *J Psychosom Obstet Gynec* 1997;18:255–8.
45. Kold M, Hansen T, Vedsted-Hansen H, Forman A. Mindfulness-based psychological intervention for coping with pain in endometriosis. *Nord Psychol* 2012;64:2–16.
46. Mendes N, Figueiredo B. Psychological approach to endometriosis: women's pain experience and quality of life improvement. *Psicologia Saúde Doenças* 2012;13:36–48.

#### ► Current knowledge on the subject

- Several studies have demonstrated that endometriosis impairs women's quality of life and mental health.
- Some of these studies have investigated the impact of endometriosis as a chronic inflammatory gynecological disease and some others have specifically focused on the effects of pelvic pain as the most common endometriosis symptom.

#### ► What this study adds

- We investigate whether the quality of life and mental health of women with endometriosis are negatively affected by the fact of having a chronic inflammatory disease such as endometriosis, although asymptomatic, or only by the presence of pelvic pain associated with endometriosis.
- We demonstrate that the mere fact of having endometriosis (when asymptomatic) may not necessarily affect women's quality of life and mental health (i.e. anxiety and depression).
- We highlight that having pelvic pain leads to poorer quality of life and mental health.
- We show that four different types of endometriosis pain (i.e. dysmenorrhea, dyspareunia, non-menstrual pelvic pain and dyschezia) have different effects on women's quality of life and mental health and we address new ideas for future research and clinical intervention with endometriosis patients.