Preliminary insights on the relation between endometriosis, pelvic pain, and employment

Running head: ENDOMETRIOSIS, PELVIC PAIN AND EMPLOYMENT

Facchin, F., Ph.D.,¹ Buggio, L., M.D.,² Ottolini F., M.D.,² Barbara, G., M.D.,² Saita, E., Ph.D.,¹ Vercellini, P., M.D.²

¹Faculty of Psychology, Catholic University of Milan, Largo A. Gemelli 1, Milan 20123, Italy.
²Department of Clinical Sciences and Community Health, Università degli Studi, and Fondazione IRCCS Ca’ Granda Ospedale Maggiore Policlinico, Via della Commenda 12, Milan 20122 Italy.

*Corresponding author at: Faculty of Psychology, Catholic University of Milan, Largo A. Gemelli 1, Milan, MI 20123 Italy. Tel.: +39 02 7234 5942; fax: +39 02 7234 5962.

E-mail address: federica.facchin@unicatt.it
Abstract

Aims: The economic burden of endometriosis and pelvic pain involves direct and indirect healthcare costs due to work loss and decreased productivity. However, the relation between endometriosis, pelvic pain, and employment remains underinvestigated. This study aimed at providing preliminary insights into this topic. Methods: We compared employment status (having vs not having a job) in 298 consecutive endometriosis patients and in 332 women without a history of endometriosis (control group). We also examined the association between pelvic pain and employment status. Results: Women with endometriosis were less likely to be employed compared to women without endometriosis (odds ratio = .508; 95% CI = .284-.908; P = .022). Women with symptomatic endometriosis were less likely to be employed relative to controls (odds ratio = .345; 95% CI = .184-.650; P = .001), as well as to asymptomatic endometriosis patients (odds ratio = .362; 95% CI = .167-.785; P = .01). No significant differences emerged between asymptomatic endometriosis and the control group (P > .05). Greater severity of dysmenorrhea, dyspareunia, chronic pelvic pain, and dyschezia was found in unemployed endometriosis patients (vs employed endometriosis participants). Conclusion: Endometriosis symptoms may significantly affect women’s professional life, with important socioeconomic, legal, and political implications. Community-based participatory research is encouraged.

KEYWORDS: Endometriosis, pelvic pain, employment, endometriosis symptoms, impact of endometriosis
Introduction

As a chronic gynecological condition often associated with pelvic pain—either cyclic and temporary (such as dysmenorrhea, dyspareunia, and dyschezia), or chronic [1,2]—endometriosis negatively affects women’s quality of life and psychological health [3-5]. Painful endometriosis involves remarkable limitations in everyday activities, including education and work [6-8]. This is a major problem if one considers that endometriosis mostly affects women in the reproductive period, with the greatest risk among women aged 25-35 [9]. In a survey with 107 Puerto Rican women diagnosed with endometriosis [10], 66% reported physical limitations affecting their working capacity, with an overall noticeable decrease in the quality of their work (85%), to the point of not being able to work because of pain (20%); 69% of patients reported that they continued working despite pain, which may also lead to reduced productivity at work—a phenomenon referred to as presenteeism [11].

The disruptive impact of endometriosis on women’s lives and plans for the future raises concerns not only for its negative consequences on women’s psychological and physical wellbeing [8], but also for the economic costs of the disease to patients, employers, and society [12-14]. In a retrospective cohort study, Soliman et al. [15] found that women with endometriosis had significantly higher direct healthcare costs, as well as indirect costs due to work loss through absenteeism and short-/long-term disability relative to control participants without a history of endometriosis. As underlined by Hummelshoj [16], treatment costs account for only one third of the total annual economic burden of endometriosis (estimated at €9579 per woman [11]), because two thirds of this cost is caused by productivity loss due to pain symptoms [11,17]).

Although these findings suggest that endometriosis, especially when painful, causes remarkable economic costs not only to the women affected, but also to the healthcare system and society, there is a paucity of research on the extent to which endometriosis and its pain symptoms affect women’s professional life, especially in the Italian context.
Given this scenario, we conducted the current study to provide preliminary insights into the relation between endometriosis, pelvic pain, and employment status (having vs not having a job).

Our hypotheses were that: (1) endometriosis participants would have lower probability of having a job compared to women without a history of endometriosis (control group); (2) symptomatic (ie, painful) endometriosis involves decreased probability of being employed compared to asymptomatic endometriosis and the control group. In order to provide further evidence to this second hypothesis, we also compared the severity of pelvic pain (dysmenorrhea, dyspareunia, dyschezia, and chronic pelvic pain) in endometriosis patients without an occupation vs employed endometriosis participants.

Material and methods

This article presents findings from secondary analyses of data derived from two broader research projects on the psychological impact of endometriosis approved by the competent Institutional Review Board (Milan Ethics Committee, Area B, project 1: determination #275/2013, approval date February 12, 2013; project 2: determination #1018/2016, approval date May 24, 2016). Data were collected between 2013 and 2017 in a tertiary endometriosis referral center located in an academic hospital in Northern Italy. In this study we considered data reported by 630 consecutively recruited women aged 25-45 years. Young women aged 18-24 were not included in these analyses because most of them were high school or university students and overall did not represent the typical Italian working-age female population. Students aged ≥ 25 were excluded from this study, whose specific focus was the relation between endometriosis and employment status.

Of the 630 total participants, all of whom had signed a written informed consent form prior to recruitment, 298 were endometriosis patients, of which 290 with surgical diagnosis and 8 with current non-surgical diagnosis (for further information regarding the reliability of non-surgical diagnosis of endometriosis see Nisenblat et al. [18]; Somigliana et al. [19]; Vercellini et al. [20]; see also Facchin et al. [7]). The other 332 participants were women without a history of endometriosis...
attending our hospital for routine gynecological visits (including cervical cancer screening program and contraception). Exclusion criteria were: uterine fibroids malignancy; sexually transmitted, urologic, rheumatologic, autoimmune, coronary, hepatic, or renal diseases; hypertension; diabetes; diagnosed mental illness.

In this study, our main variables of interest were employment status and pelvic pain severity. All participants provided demographic information, including employment status ("Are you currently employed?"; dichotomous variable coded “Yes”/ “No”). Women with endometriosis rated on a 0 (no pain at all) – 10 (the worst imaginable pain) Numerical Rating Scale (NRS) the severity of four types of pelvic pain: dysmenorrhea, dyspareunia, chronic pelvic pain, and dyschezia. Of the 298 endometriosis participants, those who reported NRS scores > 5 for at least one of these four types of pelvic pain were assigned to the symptomatic endometriosis subgroup, while the remaining were included into the asymptomatic endometriosis subgroup.

Statistical analyses were conducted with SPSS (Statistical Package for Social Sciences, SPSS Inc., 162 Chicago, IL, USA) software version 17. A three-step analytic approach was used to test our hypotheses. First, a binary logistic regression was conducted to generally determine the likelihood of having a job (dependent variable) in the endometriosis group (overall) vs the control condition, controlling for demographic factors (age, level of education, marital status, having vs not having children). Second, we performed two hierarchical binary logistic regressions to compare employment status in the two endometriosis subgroups (symptomatic and asymptomatic) and the control group, controlling for the effects of demographic factors (these potential confounders were entered in block 1 in all the regressions conducted). Reference groups were the control condition in the first regression, and asymptomatic endometriosis in the second regression, such that all the possible between-group comparisons were performed. Third, a multivariate analysis of covariance (MANCOVA) controlling for age was conducted only on the endometriosis group to evaluate pelvic pain severity (dysmenorrhea, dyspareunia, chronic pelvic pain, and dyschezia) in employed vs unemployed women with endometriosis. Significance tests were performed at $P < .05$. 
Results

The mean ± standard deviation age of the 630 participants was 35.3 ± 5.7. The majority of women had an occupation (568 [90%]), went to university (346 [55%]), were unmarried (379 [60%]), and did not have children (440 [70%]). The endometriosis group included 188 patients (63%) with ovarian endometriomas, 79 (27%) with rectovaginal nodules, 11 (4%) with deep lesions infiltrating the pouch of Douglas and parametria, 10 (3%) with peritoneal endometriosis, 7 (2%) with bladder endometriosis, and 3 (1%) with bowel endometriosis. As regards hormonal treatment, 161 (54%) endometriosis participants were under therapy.

Of the total 298 endometriosis patients, 154 (52%) reported NRS scores > 5 for at least one of the four types of pelvic pain considered in this study and were included in the symptomatic endometriosis subgroup, while the remaining 144 (48%) patients were assigned to the asymptomatic endometriosis subgroup. Demographic characteristics by study group and the severity of endometriosis-related pelvic pain symptoms are reported in Table 1.

The first binary logistic regression conducted revealed that women with endometriosis were less likely to have a job compared to the control group (odds ratio = .508; 95% CI = .284-.908; P = .022). Secondly, we found that women with symptomatic endometriosis were less likely to be employed compared not only to control participants (odds ratio = .345; 95% CI = .184-.650; P = .001), but also to asymptomatic endometriosis patients (odds ratio = .362; 95% CI = .167-.785; P = .01), while no significant differences were found between asymptomatic endometriosis and the control group (P > .05).

A third set of analyses examined the association between pelvic pain symptoms and employment status using MANCOVA. Among women with endometriosis, those who did not have a job reported greater dysmenorrhea ($F[1,294] = 4.45; P = .036$), dyspareunia ($F[1,294] = 5.09; P = .025$), dyschezia ($F[1,294] = 6.59; P = .011$), and chronic pelvic pain ($F[1,294] = 5.54; P = .019$).
Discussion

In our study, aimed at exploring the relation between endometriosis, pelvic pain symptoms, and employment status, women with endometriosis had lower probability of having a job relative to women without a history of endometriosis. The fact that endometriosis has a negative impact on women’s professional life is neither new, nor surprising [3,4,6]. A recent review of the literature [21] highlighted that the economic burden of endometriosis is associated with both direct costs (inpatient and outpatient costs, pharmacological treatments, and other healthcare services) and indirect costs due to decreased work productivity, sick leave and time off to attend medical appointments, or even loss of employment, although with great worldwide variations (see also 22-25). Of the 12 studies included in this 2016 review by Soliman et al. [21], only one [26] was conducted in Italy and reported drug regimen costs per patient per six months, while a 10-country study by Nnoaham et al [17] showed that Italian endometriosis patients reported the highest absenteeism-related costs (US$231/wk) and the second highest presenteeism costs (around US$230/wk) after the USA.

However, our Italian study may fill a gap in the endometriosis research literature by highlighting the effects of endometriosis-related pelvic pain symptoms (dysmenorrhea, dyspareunia, dyschezia, and chronic pelvic pain) on a ‘hard’ dichotomous outcome (having vs not having a job). In fact, our endometriosis participants with symptomatic, painful endometriosis had decreased probability of being employed compared with asymptomatic endometriosis patients and control participants, while no significant differences were found between asymptomatic endometriosis and the control group. Moreover, higher pain severity on all four types of pelvic pain was found among unemployed endometriosis patients compared with employed endometriosis participants.

Thus, our findings confirm that symptomatic, painful endometriosis can be a very disabling condition, to the point of preventing women from working. On the other hand, asymptomatic endometriosis (ie, pain-free, or with mild pain) seems to be compatible with a relatively ‘normal’ life, as also demonstrated by other studies on the psychological impact of the disease [3].
The role of chronic fatigue, which is another important symptom of endometriosis (although underinvestigated), should be clarified by future research, as well as the impact of sleep disorders, comorbidities, and surgical interventions. The fact that we did not investigate the effects of symptoms other than the main forms of pelvic pain, as well as the role of surgical and medical treatment, should be acknowledged as a limitation of our study.

Moreover, although we controlled for the effects of several demographic variables, other factors such as women’s socioeconomic level, time after graduation, job availability in the area of study, length and type of employment, may influence employment status and thus moderate the impact of endometriosis on women’s professional life. Longitudinal and mixed-method studies including qualitative research techniques such as individual interviews and focus groups may allow a more in-depth and comprehensive exploration of the association between endometriosis, pelvic pain, and women’s working life (for instance, do pain symptoms affect women’s choices in terms of type of employment and time spent at work?).

Our findings, although preliminary, may also provide ideas for future lines of inquiry by suggesting the importance of investigating the association between endometriosis-related symptoms and ‘soft’ work functioning outcomes, such as productivity, absenteeism/presenteeism, income, and job satisfaction. This avenue of investigation appears crucial, not only to assess women’s quality of life, but also to address political, economic, and social issues regarding the disabling nature of the disease.

The importance of recognizing endometriosis as a social disease has been underlined in the scientific literature [8-17]. Reaching out to politicians is an important initial step to promote recognition of the social and economic burden of endometriosis [27]. In this regard, the role of patient associations is fundamental [28]. In Europe, several endometriosis support organizations approached the European Parliament to explain the multiple challenges entailed by living with the disease [27]. These initiatives led to the publication of a Written Declaration of Endometriosis (in March 2005) by a group of Members of the European Parliament [29]. An Italian patient association
(Associazione Progetto Endometriosi—A.P.E. Onlus), together with EndoFrance (Association française de lutte contre l’endométriose), recently took part in the First Awareness Conference of Endometriosis at the European Parliament in Brussels (20th February 2018). The importance of a strategic collaboration between healthcare professionals (including psychologists/psychotherapists), researchers, patients, and legislators has already been highlighted by Bianconi et al. [27]. Research can provide all the instruments to develop evidence-based social policies and welfare programs to meet the needs of women with endometriosis. Specifically, community-based participatory research (CBPR), which equitably involves scientists and professionals, community members, and organizational representatives, may lead to multiple benefits, such as defining research topics that actually reflect major issues identified by the community, increasing trust between professionals/scientists and community, and facilitating the translation of research evidence into healthcare policies and practices [29,30]. Our study findings may help encourage this type of research.

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**Disclosure statement**

All authors declare that there is no conflict of interest.
References


Table 1  
Participant variables by study group.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Study Groups (N = 630)</th>
<th>Endometriosis subgroups (n = 298)</th>
<th>Control group (n = 332)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Endometriosis (overall) (n = 298)</td>
<td>Symptomatic endometriosis (n = 154)</td>
<td>Asymptomatic endometriosis (n = 144)</td>
</tr>
<tr>
<td>Socio-demographic Age [M, (SD)]</td>
<td>35.6 (5.4)</td>
<td>35.5 (5.2)</td>
<td>35.8 (5.5)</td>
</tr>
<tr>
<td>Level of education [n, (%)]</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>University</td>
<td>134 (45)</td>
<td>55 (36)</td>
<td>79 (55)</td>
</tr>
<tr>
<td>High school</td>
<td>133 (45)</td>
<td>79 (51)</td>
<td>54 (37)</td>
</tr>
<tr>
<td>Middle school</td>
<td>31 (10)</td>
<td>20 (13)</td>
<td>11 (8)</td>
</tr>
<tr>
<td>Employed [n, (%)]</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>257 (86)</td>
<td>123 (80)</td>
<td>134 (93)</td>
</tr>
<tr>
<td>No</td>
<td>41 (14)</td>
<td>31 (20)</td>
<td>10 (7)</td>
</tr>
<tr>
<td>Marital status [n, (%)]</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Married</td>
<td>137 (46)</td>
<td>73 (47)</td>
<td>64 (44)</td>
</tr>
<tr>
<td>Unmarried</td>
<td>161 (54)</td>
<td>81 (53)</td>
<td>80 (56)</td>
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<tr>
<td>Pelvic pain [M, (SD)]</td>
<td></td>
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<td></td>
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<tr>
<td>Dysmenorrhea</td>
<td>Employed</td>
<td>3.5 (3.5)</td>
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<tr>
<td></td>
<td>Unemployed</td>
<td>4.8 (3.9)</td>
<td></td>
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<tr>
<td>Dyspareunia</td>
<td>Employed</td>
<td>2.7 (3.1)</td>
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<tr>
<td></td>
<td>Unemployed</td>
<td>3.9 (3.5)</td>
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<tr>
<td>Dyschezia</td>
<td>Employed</td>
<td>1.5 (2.6)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Unemployed</td>
<td>2.7 (3.3)</td>
<td></td>
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<td>Chronic pelvic pain</td>
<td>Employed</td>
<td>1.4 (2.6)</td>
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<tr>
<td></td>
<td>Unemployed</td>
<td>2.6 (3.3)</td>
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</tr>
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