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

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4 Running head: ENDOMETRIOSIS, PELVIC PAIN AND EMPLOYMENT

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21 **Abstract**

22 **Aims:** The economic burden of endometriosis and pelvic pain involves direct and indirect
23 healthcare costs due to work loss and decreased productivity. However, the relation between
24 endometriosis, pelvic pain, and employment remains underinvestigated. This study aimed at
25 providing preliminary insights into this topic. **Methods:** We compared employment status (having
26 vs not having a job) in 298 consecutive endometriosis patients and in 332 women without a history
27 of endometriosis (control group). We also examined the association between pelvic pain and
28 employment status. **Results:** Women with endometriosis were less likely to be employed compared
29 to women without endometriosis (*odds ratio* = .508; *95% CI* = .284-.908; *P* = .022). Women with
30 symptomatic endometriosis were less likely to be employed relative to controls (*odds ratio* = .345;
31 *95% CI* = .184-.650; *P* = .001), as well as to asymptomatic endometriosis patients (*odds ratio*
32 = .362; *95% CI* = .167-.785; *P* = .01). No significant differences emerged between asymptomatic
33 endometriosis and the control group (*P* > .05). Greater severity of dysmenorrhea, dyspareunia,
34 chronic pelvic pain, and dyschezia was found in unemployed endometriosis patients (vs employed
35 endometriosis participants). **Conclusion:** Endometriosis symptoms may significantly affect
36 women's professional life, with important socioeconomic, legal, and political implications.
37 Community-based participatory research is encouraged.

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39 **KEYWORDS:** Endometriosis, pelvic pain, employment, endometriosis symptoms, impact of
40 endometriosis

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42 **Introduction**

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

54 The disruptive impact of endometriosis on women’s lives and plans for the future raises
55 concerns not only for its negative consequences on women’s psychological and physical wellbeing
56 [8], but also for the economic costs of the disease to patients, employers, and society [12-14]. In a
57 retrospective cohort study, Soliman et al. [15] found that women with endometriosis had
58 significantly higher direct healthcare costs, as well as indirect costs due to work loss through
59 absenteeism and short-/long-term disability relative to control participants without a history of
60 endometriosis. As underlined by Hummelshoj [16], treatment costs account for only one third of the
61 total annual economic burden of endometriosis (estimated at €9579 per woman [11]), because two
62 thirds of this cost is caused by productivity loss due to pain symptoms [11,17]).

63 Although these findings suggest that endometriosis, especially when painful, causes
64 remarkable economic costs not only to the women affected, but also to the healthcare system and
65 society, there is a paucity of research on the extent to which endometriosis and its pain symptoms
66 affect women’s professional life, especially in the Italian context.

67 Given this scenario, we conducted the current study to provide preliminary insights into the
68 relation between endometriosis, pelvic pain, and employment status (having vs not having a job).
69 Our hypotheses were that: (1) endometriosis participants would have lower probability of having a
70 job compared to women without a history of endometriosis (control group); (2) symptomatic (ie,
71 painful) endometriosis involves decreased probability of being employed compared to
72 asymptomatic endometriosis and the control group. In order to provide further evidence to this
73 second hypothesis, we also compared the severity of pelvic pain (dysmenorrhea, dyspareunia,
74 dyschezia, and chronic pelvic pain) in endometriosis patients without an occupation vs employed
75 endometriosis participants.

76

77 **Material and methods**

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

88 Of the 630 total participants, all of whom had signed a written informed consent form prior
89 to recruitment, 298 were endometriosis patients, of which 290 with surgical diagnosis and 8 with
90 current non-surgical diagnosis (for further information regarding the reliability of non-surgical
91 diagnosis of endometriosis see Nisenblat et al. [18]; Somigliana et al. [19]; Vercellini et al. [20]; see
92 also Facchin et al. [7]). The other 332 participants were women without a history of endometriosis

93 attending our hospital for routine gynecological visits (including cervical cancer screening program
94 and contraception). Exclusion criteria were: uterine fibroids malignancy; sexually transmitted,
95 urologic, rheumatologic, autoimmune, coronary, hepatic, or renal diseases; hypertension; diabetes;
96 diagnosed mental illness.

97 In this study, our main variables of interest were *employment status* and *pelvic pain severity*.
98 All participants provided demographic information, including employment status (“Are you
99 currently employed?”; dichotomous variable coded “Yes”/ “No”). Women with endometriosis rated
100 on a 0 (no pain at all) – 10 (the worst imaginable pain) Numerical Rating Scale (NRS) the severity
101 of four types of pelvic pain: dysmenorrhea, dyspareunia, chronic pelvic pain, and dyschezia. Of the
102 298 endometriosis participants, those who reported NRS scores > 5 for at least one of these four
103 types of pelvic pain were assigned to the symptomatic endometriosis subgroup, while the remaining
104 were included into the asymptomatic endometriosis subgroup.

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

119 Results

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

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

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

139 A third set of analyses examined the association between pelvic pain symptoms and
140 employment status using MANCOVA. Among women with endometriosis, those who did not have
141 a job reported greater dysmenorrhea ($F[1,294] = 4.45$; *P* = .036), dyspareunia ($F[1,294] = 5.09$; *P* =
142 .025), dyschezia ($F[1,294] = 6.59$; *P* = .011), and chronic pelvic pain ($F[1,294] = 5.54$; *P* =
143 .019).

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145 **Discussion**

146 In our study, aimed at exploring the relation between endometriosis, pelvic pain symptoms,
147 and employment status, women with endometriosis had lower probability of having a job relative to
148 women without a history of endometriosis. The fact that endometriosis has a negative impact on
149 women's professional life is neither new, nor surprising [3,4,6]. A recent review of the literature
150 [21] highlighted that the economic burden of endometriosis is associated with both direct costs
151 (inpatient and outpatient costs, pharmacological treatments, and other healthcare services) and
152 indirect costs due to decreased work productivity, sick leave and time off to attend medical
153 appointments, or even loss of employment, although with great worldwide variations (see also 22-
154 25). Of the 12 studies included in this 2016 review by Soliman et al. [21], only one [26] was
155 conducted in Italy and reported drug regimen costs per patient per six months, while a 10-country
156 study by Nnoaham et al [17] showed that Italian endometriosis patients reported the highest
157 absenteeism-related costs (US\$231/wk) and the second highest presenteeism costs (around
158 US\$230/wk) after the USA.

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

167 Thus, our findings confirm that symptomatic, painful endometriosis can be a very disabling
168 condition, to the point of preventing women from working. On the other hand, asymptomatic
169 endometriosis (ie, pain-free, or with mild pain) seems to be compatible with a relatively 'normal'
170 life, as also demonstrated by other studies on the psychological impact of the disease [3].

171 The role of chronic fatigue, which is another important symptom of endometriosis (although
172 underinvestigated), should be clarified by future research, as well as the impact of sleep disorders,
173 comorbidities, and surgical interventions. The fact that we did not investigate the effects of
174 symptoms other than the main forms of pelvic pain, as well as the role of surgical and medical
175 treatment, should be acknowledged as a limitation of our study.

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

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

190 The importance of recognizing endometriosis as a social disease has been underlined in the
191 scientific literature [8-17]. Reaching out to politicians is an important initial step to promote
192 recognition of the social and economic burden of endometriosis [27]. In this regard, the role of
193 patient associations is fundamental [28]. In Europe, several endometriosis support organizations
194 approached the European Parliament to explain the multiple challenges entailed by living with the
195 disease [27]. These initiatives led to the publication of a Written Declaration of Endometriosis (in
196 March 2005) by a group of Members of the European Parliament [29]. An Italian patient association

197 (Associazione Progetto Endometriosi—A.P.E. Onlus), together with EndoFrance (Association
198 française de lutte contre l’endométriose), recently took part in the First Awareness Conference of
199 Endometriosis at the European Parliament in Brussels (20th February 2018). The importance of a
200 strategic collaboration between healthcare professionals (including psychologists/psychotherapists),
201 researchers, patients, and legislators has already been highlighted by Bianconi et al. [27]. Research
202 can provide all the instruments to develop evidence-based social policies and welfare programs to
203 meet the needs of women with endometriosis. Specifically, community-based participatory research
204 (CBPR), which equitably involves scientists and professionals, community members, and
205 organizational representatives, may lead to multiple benefits, such as defining research topics that
206 actually reflect major issues identified by the community, increasing trust between
207 professionals/scientists and community, and facilitating the translation of research evidence into
208 healthcare policies and practices [29,30]. Our study findings may help encourage this type of
209 research.

210

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214 **Disclosure statement**

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

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304 **Table 1**

305 Participant variables by study group.

			Study Groups (<i>N</i> = 630)			
			Endometriosis subgroups (<i>n</i> = 298)			Control group (<i>n</i> = 332)
Variable			Endometriosis (overall) (<i>n</i> = 298)	Symptomatic endometriosis (<i>n</i> = 154)	Asymptomatic endometriosis (<i>n</i> = 144)	
Socio- demographic	Age [<i>M</i> , (<i>SD</i>)]		35.6 (5.4)	35.5 (5.2)	35.8 (5.5)	34.9 (5.9)
	Level of education [<i>n</i> , (%)]	University	134 (45)	55 (36)	79 (55)	212 (64)
		High school	133 (45)	79 (51)	54 (37)	104 (31)
		Middle school	31 (10)	20 (13)	11 (8)	16 (5)
	Employed [<i>n</i> , (%)]	Yes	257 (86)	123 (80)	134 (93)	311 (94)
		No	41 (14)	31 (20)	10 (7)	21 (6)
	Marital status [<i>n</i> , (%)]	Married	137 (46)	73 (47)	64 (44)	114 (34)
Unmarried		161 (54)	81 (53)	80 (56)	218 (66)	
Pelvic pain [<i>M</i> , (<i>SD</i>)]	Dysmenorrhea	Employed	3.5 (3.5)			
		Unemployed	4.8 (3.9)			
	Dyspareunia	Employed	2.7 (3.1)			
		Unemployed	3.9 (3.5)			
	Dyschezia	Employed	1.5 (2.6)			
		Unemployed	2.7 (3.3)			
	Chronic pelvic pain	Employed	1.4 (2.6)			
		Unemployed	2.6 (3.3)			

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