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The impact of endometriosis on educational and professional pathways: a cross-sectional online study

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Abstract

Background Symptoms of endometriosis often emerge during adolescence and intensify in early adulthood, critical periods for educational and career development. However, evidence on its impact on women's broader life trajectories, particularly in education and work, remains limited. This study aimed to examine how endometriosis influences these trajectories and to identify the underlying factors and mechanisms involved.

Methods This cross-sectional study was conducted online using Qualtrics. Participants were 971 women with a clinical or surgical diagnosis of endometriosis. Sociodemographic and clinical data were collected, along with measures of educational (6 items) and occupational (8 items) impact using two researcher-developed, disease-specific question sets. Items were rated on 5-point Likert scales, with a "not applicable" option included. Psychological health was assessed using the Hospital Anxiety and Depression Scale (HADS). Both descriptive and inferential statistical analyses were conducted.

Results Endometriosis had a moderate to high impact on education for 17%-23% of women and on work for 22%-28%, with participants also reporting social injustices such as workplace discrimination and job downgrading. The greatest impact was observed among those with both adolescent symptom onset and diagnostic delay. The assessment tools used showed strong psychometric properties. Path analysis revealed the role played by younger age at symptom onset and diagnostic delay. Among women under 45, more severe physical and psychological symptoms were linked to greater disruption in education and work.

Conclusion Symptomatic endometriosis can significantly impact women's education and careers, especially when symptoms begin in adolescence and diagnosis is delayed, with effects extending beyond health to broader life trajectories and social inequalities.

Keywords Adolescence, Diagnostic delay, Education, Endometriosis, Life trajectories, Pelvic pain, Psychological health, Work

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Background

Endometriosis is a chronic, hormone-dependent inflammatory disease characterized by the presence of ectopic endometrial-like tissue and a highly variable clinical presentation [1–4]. Common symptoms include dysmenorrhea, dyspareunia, dyschezia, dysuria, chronic pelvic pain, fatigue, and sleep disturbances [3, 5]. The condition frequently co-occurs with comorbidities such as fibromyalgia, migraines, autoimmune disorders, and adenomyosis [3]. While laparoscopy is no longer considered the diagnostic gold standard, non-invasive approaches like gynaecological examination and transvaginal ultrasound are now widely employed [2]. The prevalence of endometriosis is estimated at 3–5% in the general female population of reproductive age [6], but it is substantially higher in specific subgroups: up to 30% among women with infertility, 50% among those with chronic pelvic pain, and 65–75% in symptomatic adolescents [7–10]. The disease often persists beyond the age of 40 and symptoms may continue after menopause [2].

The psychological burden is well documented, with elevated rates of anxiety, depression, and psychological distress [11, 12], all of which contribute to a reduced quality of life [13] and impaired sexuality and intimate relationships [12, 14]. Endometriosis also entails significant economic costs due to medical expenses, absenteeism, and productivity loss [15–17]. A register-based Danish study further showed that women with endometriosis lose more years of working life due to sick leave and disability pension [18]. A major concern remains the diagnostic delay, defined as the time between symptom onset and diagnosis, which ranges from 5 to 12 years [19], especially when symptoms begin during adolescence [20].

Endometriosis symptoms frequently emerge and worsen during adolescence and early adulthood, critical phases for educational and career development, as well as family planning [21]. Symptomatic endometriosis often compels women to forgo academic and career opportunities, with pain being a major disabling factor [21]. Among adolescents, dysmenorrhea is a leading cause of school absenteeism, while adult women often shift to part-time or less demanding jobs [22, 23]. Moreover, those with severe symptoms frequently report a diminished outlook on the future and a reduced sense of life potential [24]. Despite growing evidence, little research has directly examined how endometriosis affects women's life trajectories, particularly in relation to education and work.

The current study

The primary aim of this exploratory and descriptive study was to investigate the impact of endometriosis on educational and occupational trajectories in a large Italian sample. A secondary objective was to identify contributing factors, with a particular focus on age at symptom onset and diagnostic delay. We hypothesized that a younger age at symptom onset—particularly during adolescence—and the presence of diagnostic delay would be associated with a greater negative impact on both education and work. This hypothesis was grounded in prior evidence linking early symptom onset to delayed diagnosis [20], as well as in the well-documented adverse consequences of delayed diagnosis, including symptom progression, reduced quality of life, and increased healthcare burden [19, 25]. Associations with current endometriosis-related and psychological symptoms were also explored to further characterize women reporting higher levels of impact on education and work.

Materials and methods

This cross-sectional study was conducted via Qualtrics, hosted by the first author's institution. Data were collected between October 4, 2023, and January 25, 2024, using snowball sampling. Participants were recruited through social media and the newsletter of the largest Italian endometriosis patient association (Associazione Progetto Endometriosi [APE-Odv]). Eligible participants were women aged 18 or older with a self-reported clinical or surgical diagnosis of endometriosis. Informed consent was obtained online after participants reviewed a detailed description of the study. The findings reported in this article are from the first part of a larger research on the impact of endometriosis on women's life trajectories, focusing on education and work (part one), and reproductive plans including medically assisted reproduction (part two). Ethical approval was granted by the Ethics Commission for Research in Psychology at the Department of Psychology, Università Cattolica del Sacro Cuore (protocol 86 – 23; approval date: October 2, 2023).

Measures

We designed a survey to collect sociodemographic and endometriosis-related data, including diagnosis type, age at symptom onset and diagnosis (open-ended questions), experiences of incorrect or delayed diagnosis (yes/no), endometriosis stage, surgeries, hormonal therapy, type of endometriosis, adenomyosis, and comorbidities. Age at symptom onset was analysed both as a continuous variable and dichotomized as symptom onset during adolescence (up to age 19, as defined by the World Health Organization) versus adulthood. Pain severity over the last six months was measured on a numerical rating scale (NRS) from 0 ("no pain at all") to 10 ("the worst imaginable pain"). Chronic fatigue and sleep quality over the past 12 months were assessed with two 5-point Likert scales (1 to 5). For chronic fatigue, participants responded to: "Thinking about the past 12 months, have you experienced fatigue or tiredness that was not relieved by rest?" (1 = "never"; 5 = "always"). For sleep quality, the question was: “Thinking about the past 12 months, how would you rate the quality of your sleep?” (1 = “very poor”; 5 = “excellent”).

The impact of endometriosis on educational and professional trajectories was assessed using researcher-developed, disease-specific items informed by existing literature [21, 24] and clinical practice. The survey included six items on education (set 1) and eight on professional impact (set 2), originally in our native language with an English translation provided as supplementary material (Supplemental Table 1). Responses used a 5-point Likert scale (1 = “not at all” to 5 = “very much”) plus a “not applicable” option to allow skipping irrelevant items, consistent with previous studies [24]. Although not aiming to develop a validated questionnaire, we assessed the psychometric properties of the two question sets to support analysis reliability. “Not applicable” answers were coded as missing in SPSS and excluded from the global score of each set, which was calculated as the mean of valid responses if at least 50% of the items were applicable (3 out of 6 for education, 4 out of 8 for work). Scores range from 1 to 5, with higher scores indicating a greater perceived impact of endometriosis on educational and professional paths.

Psychological health (symptoms of anxiety and depression) was assessed with the Hospital Anxiety and Depression Scale (HADS [26]; Italian validation by Costantini et al. [27]). This 14-item self-report questionnaire measures symptoms on a 0–3 scale; higher scores indicate greater severity. In our study, Cronbach’s alpha was 0.80 for Depression, 0.82 for Anxiety, and 0.88 for the global score.

Statistical analyses

SPSS 29 (IBM Corp.) and Jamovi 2.6.26 were used for statistical analyses. Descriptive statistics (mean ± SD, or frequencies and percentages) described participant characteristics. Chi-squared tests assessed associations between categorical variables of interest (diagnostic delay, misdiagnosis, symptom onset during adolescence) to determine statistical significance. Normality of continuous variables was evaluated via skewness and kurtosis, with values between − 2 and + 2 indicating normality [28].

We began by descriptively analysing the impact of endometriosis on education and work, categorising responses into “no to low impact” (scores 1–2) and “moderate to high impact” (scores 3–5). This dichotomisation—applied solely for descriptive purposes—was based on the structure of the Likert scale used, in which scores of 1 (“not at all”) and 2 (“a little”) reflect no or minimal perceived impact, whereas a score of 3 (“moderately”) already represents a moderate but meaningful impact. Given that our aim was to capture the presence of any relevant impact, rather than limiting the analysis to the most severe cases, this categorisation enabled a more realistic understanding of how endometriosis can affect education and work. Frequencies were calculated for the entire sample, as well as for subgroups defined by adolescent symptom onset, diagnostic delays, and the combination of both. Next, we assessed the psychometric properties of the two question sets using principal axis factoring with Promax rotation, KMO, Bartlett’s test, factor loadings, and Cronbach’s alpha, as done in previous research [29].

Path analysis was then conducted using Jamovi’s “pathj” module and the Maximum Likelihood estimation method to examine a hypothesized model describing the relationships among the dependent variables—impact of endometriosis on education and work—entered as endogenous variables, and the predictors age at symptom onset (continuous exogenous covariate) and diagnostic delay (categorical exogenous factor coded 0 [no] or 1 [yes]). We used the Maximum Likelihood estimation method—rather than the Weighted Least Squares Means and Variance adjusted estimator for ordinal data—because the path analysis involved the two composite scores reflecting the impact of endometriosis on education and work. These scores were normally distributed according to the criteria adopted in this study, and the sample size was sufficiently large to support this estimation method. This approach allowed for the assessment of both direct and indirect effects within the model framework, and assuming that the independent variables were correlated.

Preliminary analyses were performed to assess the relationships between all variables individually, employing Pearson’s correlation for continuous variables and independent samples *t*-tests for group comparisons, as appropriate. In the path analysis, model fit was assessed considering the chi-square test, the root mean square error of approximation (RMSEA), the comparative fit index (CFI), the adjusted goodness-of-fit index (AGFI), and the standardized root mean square residual (SRMR). The model was considered to have an acceptable fit if it showed a non-significant chi-square value, RMSEA below 0.08, CFI and AGFI above 0.90, and SRMR below 0.08 [30]. To assess the invariance of the final model across age groups, multigroup analyses were conducted comparing women under 45 years to those aged ≥ 45. In these analyses, a non-significant χ^2 difference test suggests that the relationships among variables are statistically similar across groups, thereby supporting model invariance.

A final set of analyses was conducted using Pearson’s correlation to examine the association between impact on education and work and current endometriosis-related and psychological symptoms. These analyses were restricted to participants under 45 years of age because we did not collect information on spontaneous menopause.

We followed the indications by Schönbrodt and Perugini [31], which recommend a minimum sample size of 250 for stable correlations, and data collection ended once responses ceased. Statistical significance was set at $p < 0.05$. Analyses included all participants who provided complete responses to the two sets of questions on education and work. Missing data were not imputed.

Results

A total of 1,258 women accessed the online survey (see Fig. 1 for further details on survey participation). Of these, 971 participants (77%) completed all the questions related to the impact of endometriosis on education (set 1) and work (set 2). Table 1 presents the characteristics of the study population. Participants' age ranged from 19 to 70 years. A clinical diagnosis of endometriosis was reported by 67%, predominantly ovarian (75%), with a large proportion also reporting adenomyosis (74%). Diagnostic delay was common (82%), as was misdiagnosis (75%); 94% of those with diagnostic delay had also been misdiagnosed, and the association between diagnostic delay and misdiagnosis was statistically significant (χ^2 = 291.984, $p < 0.001$). Symptom onset occurred during adolescence in 58% of the 937 participants. Three provided invalid responses to the open-ended question on age at symptom onset ("I don't remember", "Since the beginning of menstruation", "Always, before, during, and after menstruation, never diagnosed until total hysterectomy at age 50"), and 31 (3%) reported no symptoms. Endometriosis was therefore symptomatic in the majority of participants. Among those with adolescent onset, 92% ($n = 503$) also experienced diagnostic delays. This association was statistically significant ($\chi^2 = 73.668$; $p < 0.001$).

Impact of endometriosis on education and work: descriptive analysis

As shown in Table 2, the impact of endometriosis on both education and work was evident across all items, with severity increasing from the overall sample to participants who experienced both adolescent symptom onset and diagnostic delay. Regarding education, while 17% of the full sample reported a moderate to high overall impact, this proportion rose to 20% among those with diagnostic delay, 22% among those with adolescent symptom onset, and peaked at 23% in the combined

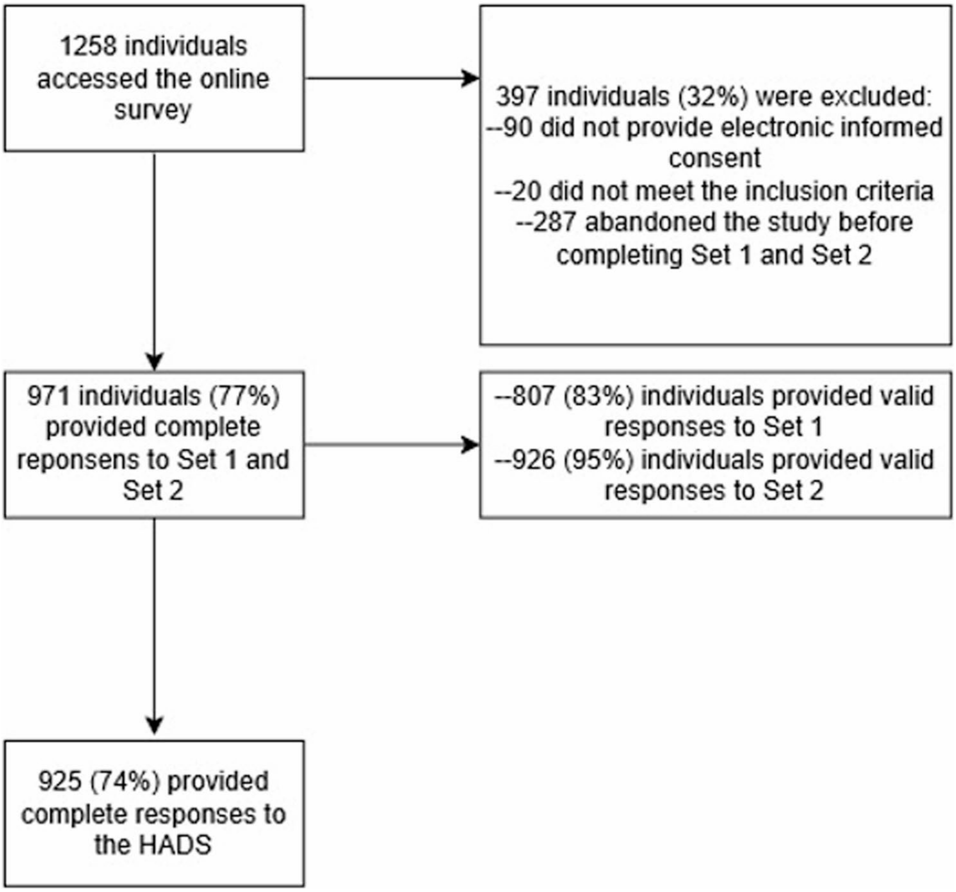

Fig. 1 Participant flowchart

Table 1 Characteristics of the study population ($N = 971$)

Sociodemographic data		
Age in years (M ± SD)		36.62 ± 7.49
Relationship status (n [%])	In a relationship (cohabiting)	693 (71.4)
	In a relationship (not cohabiting)	111 (11.4)
	Single	167 (17.2)
Marital status (n [%])	Married	467 (48.1)
	Unmarried	444 (45.7)
	Separated/divorced	77 (5.9)
	Widowed	3 (0.3)
Sexual orientation (n [%])	Bisexual	21 (2.2)
	Heterosexual	924 (95.2)
	Homosexual	12 (1.2)
	Prefer not to answer	14 (1.4)
Country (n [%])	Italy	956 (98.5)
	Other countries	15 (1.5)
Level of education (n [%])	Postgraduate	153 (15.8)
	Graduate (master)	213 (21.9)
	Graduate (bachelor)	153 (15.8)
	High school	395 (40.7)
	Middle school	57 (5.9)
Employment status (n [%])	Homemaker	50 (5.1)
	Unable to work due to disability	13 (1.3)
	Retired	3 (0.3)
	Unemployed	85 (8.8)
	Full-time job	574 (59.1)
	Part-time job	205 (21.1)
	Student (with a job)	16 (1.6)
	Student (without a job)	25 (2.6)
Children (n [%])	Yes	354 (36.5)
	No	617 (63.5)
Current pregnancy (n [%])	Yes	12 (1.2)
	No	959 (98.8)
Endometriosis-related information		
Diagnostic delay (n [%])	Yes	797 (82.1)
	No	174 (17.9)
Misdiagnosis (n [%])	Yes	728 (75)
	No	243 (25)
Type of diagnosis (n [%])	Laparoscopy with histological confirmation	319 (32.9)
	Clinical diagnosis	652 (67.1)
Age at symptom onset (in years) (M ± SD)		19.87 ± 7.22
Symptom onset during adolescence for participants with symptomatic endometriosis (n, %)	Yes	545 (58.2)
	No	392 (41.8)
Age at diagnosis (in years) (M ± SD)		30.01 ± 6.41
Rectovaginal endometriosis (n [%])		599 (61.7)
Ovarian endometriosis (n [%])		731 (75.3)
Adenomyosis (n [%])		719 (74)
Peritoneal, bladder, bowel, parametrial or ureteral endometriosis (n [%])		489 (50.4)
Extrapelvic endometriosis (n [%])		85 (8.8)
Endometriosis stage (Asrm) (n [%])	Stage I	56 (5.8)
	Stage II	65 (6.7)
	Stage III	116 (11.9)
	Stage IV	463 (47.7)
	Not known	271 (27.9)

Table 1 (continued)

Endometriosis-related information		
Surgical interventions (n [%])	Yes	709 (73)
	No	262 (27)
Hormonal therapy (n [%])	Yes	616 (63.4)
	No	355 (36.6)
Type of hormonal therapy (n [%])	Estroprogestins	240 (39)
	Progestins	332 (53.9)
	GNRH analogues	20 (3.2)
	Medicated Intrauterine Device	24 (3.9)
Comorbidities other than adenomyosis and infertility (n [%])	Yes	407 (41.9)
	No	564 (58.1)
Infertility (n [%])	Yes	425 (43.9)
	No	543 (56.1)
Severity of non-menstrual pelvic pain (M ± SD)		4.88 ± 3.10
Severity of dysmenorrhea (M ± SD)		5.69 ± 3.72
Severity of dyschezia (M ± SD)		4.03 ± 3.27
Severity of dysuria (M ± SD)		1.96 ± 2.67
Severity of dyspareunia (M ± SD)		5.40 ± 3.11
Chronic fatigue (M ± SD)		3.85 ± 0.94
Sleep quality (M ± SD)		2.35 ± 0.92
Psychological health		
HADS (M ± SD)	HADS-A	10.22 ± 4.35
	HADS-D	9.31 ± 4.32
	HADS-Total	19.53 ± 8.00

group. Specific educational disruptions followed the same pattern. The most affected areas included frequent school absences (rising from 40% overall to 55% in the combined group), impaired academic performance (28% to 38%), and reduced ability to prepare for exams (24% to 34%). The disease also influenced participants' educational choices.

The impact of endometriosis on work was also substantial. Again, the negative outcomes were more prevalent among those with both early symptom onset and diagnostic delay. A moderate to high overall impact was reported by 22% of participants, increasing to 25% with diagnostic delay, 27% with adolescent symptom onset, and 28% in the combined group. Reduced productivity was strikingly high (75% overall and 80% in the combined group). Work absences were common, with 48% reporting frequent missed days, rising to 52% in the combined subgroup. Other reported consequences included earning less than one's potential (28% overall, 33% combined), giving up desired jobs (27% to 34%), workplace discrimination (24% to 29%), the need to choose part-time work (22% to 26%), job loss (18% to 22%), and job downgrading (13% to 17%). Detailed Likert scale response distributions are presented in Supplemental Table 2.

Participants who responded "not applicable" to more than 50% of items represented a small proportion of the sample (17% for education and 5% for work). For this reason, systematic comparisons with the other participants were not feasible. However, Supplemental Table 3 shows that women who frequently responded "not applicable" to education and work items were characterized by an older age at symptom onset compared to the mean of the full sample.

Psychometric properties of the two sets of questions

The statistical properties of the two question sets developed to assess the impact of endometriosis on education and work were evaluated using factor analysis and Cronbach's alpha to measure internal consistency. For both sets, a single factor was extracted, explaining 59% of the variance for set 1 and 53% for set 2. Bartlett's test was statistically significant (set 1: $\chi^2 = 2444.621$, $p < 0.001$; set 2: $\chi^2 = 3425.267$, $p < 0.001$), and the Kaiser-Meyer-Olkin measure ranged from 0.86 for set 1 to 0.90 for set 2, indicating very good to excellent suitability of the data for factor analysis. Factor loadings ranged from 0.651 to 0.865 for set 1, and from 0.419 to 0.832 for set 2. Internal consistency was also satisfactory, with Cronbach's alpha values of 0.893 for set 1 and 0.891 for set 2. The mean scores reflecting the perceived impact of endometriosis were 1.96 (± 0.98) for education and 2.17 (± 1.06) for work. The skewness and kurtosis values for the two composite scores ranged from 0.266 (kurtosis for the impact of endometriosis on work) to 1.203 (skewness for the impact on education), indicating that the distributions were normal according to the criteria applied in the current study. Additional information on skewness and kurtosis values for each item is reported in Supplemental

Table 2 Descriptive analysis of the impact of endometriosis on education and work overall, in participants who experienced symptom onset during adolescence, diagnostic delay, and both situations (combined group)

Set 1: education		**Valid responses**	**No to low impact (*n*,%)**	**Moderate to high impact (*n*,%)**	**Not applicable (*n*,%)**
1-I missed many days of school due to endometriosis	Overall	971	415 (42.7)	388 (40)	168 (17.3)
	Symptom onset during adolescence	545	195 (35.8)	293 (53.8)	57 (10.5)
	Diagnostic delay	797	315 (39.5)	360 (45.2)	122 (15.3)
	Combined group	503	174 (34.6)	277 (55.1)	52 (10.3)
2-I gave up an educational path I was interested in because of endometriosis	Overall	971	610 (62.8)	180 (18.5)	181 (18.6)
	Symptom onset during adolescence	545	346 (63.5)	129 (23.7)	70 (12.8)
	Diagnostic delay	797	495 (62.1)	167 (21)	135 (16.9)
	Combined group	503	319 (63.4)	122 (24.3)	62 (12.3)
3-I chose a specific course of study solely because I thought it would be more compatible with managing the disease	Overall	971	648 (66.7)	123 (12.7)	200 (20.6)
	Symptom onset during adolescence	545	367 (67.3)	90 (16.5)	88 (16.1)
	Diagnostic delay	797	532 (66.8)	110 (13.8)	155 (19.4)
	Combined group	503	339 (67.4)	83 (16.5)	81 (16.1)
4-I was unable to study for tests and exams because of endometriosis	Overall	971	554 (57.1)	235 (24.2)	182 (18.7)
	Symptom onset during adolescence	545	294 (53.9)	176 (32.3)	75 (13.8)
	Diagnostic delay	797	441 (55.3)	220 (27.6)	136 (17.1)
	Combined group	503	265 (52.7)	169 (33.6)	69 (13.7)
5-Endometriosis negatively affected my academic performance	Overall	971	542 (55.8)	270 (27.8)	159 (16.4)
	Symptom onset during adolescence	545	289 (53)	198 (36.3)	58 (10.6)
	Diagnostic delay	797	427 (53.6)	251 (31.5)	119 (14.9)
	Combined group	503	258 (51.3)	190 (37.8)	55 (10.9)
6-I had to interrupt an educational path because of endometriosis	Overall	971	664 (68.4)	120 (12.4)	187 (19.3)
	Symptom onset during adolescence	545	380 (69.7)	86 (15.8)	79 (14.5)
	Diagnostic delay	797	545 (68.4)	108 (13.6)	144 (18.1)
	Combined group	503	350 (69.6)	78 (15.5)	75 (14.9)
Global impact on education*	Overall	807	667 (82.7)	140 (17.3)	/
	Symptom onset during adolescence	484	378 (78.1)	106 (21.9)	/
	Diagnostic delay	675	542 (80.3)	133 (19.7)	/
	Combined group	446	345 (77.4)	101 (22.6)	/
Set 2: work					
1-I missed many days of work due to endometriosis	Overall	971	475 (48.9)	464 (47.8)	32 (3.3)
	Symptom onset during adolescence	545	244 (44.8)	281 (51.6)	20 (3.7)
	Diagnostic delay	797	363 (45.5)	409 (51.3)	25 (3.1)
	Combined group	503	223 (44.3)	262 (52.1)	18 (3.6)
2-Despite being in pain from endometriosis symptoms, I went to work but was unable to be productive	Overall	971	218 (22.5)	727 (74.9)	26 (2.7)
	Symptom onset during adolescence	545	94 (17.2)	432 (79.3)	19 (3.5)
	Diagnostic delay	797	143 (17.9)	631 (79.2)	23 (2.9)
	Combined group	503	80 (15.9)	404 (80.3)	19 (3.8)
3-I lost a job because of endometriosis	Overall	971	712 (73.3)	177 (18.2)	82 (8.4)
	Symptom onset during adolescence	545	386 (70.8)	117 (21.5)	42 (7.7)
	Diagnostic delay	797	567 (71.1)	163 (20.5)	67 (8.4)
	Combined group	503	352 (70)	110 (21.9)	41 (8.2)
4-I was downgraded at work because of endometriosis	Overall	971	750 (77.2)	129 (13.3)	92 (9.5)
	Symptom onset during adolescence	545	407 (74.7)	87 (16)	51 (9.4)
	Diagnostic delay	797	597 (74.9)	120 (15.1)	80 (10)
	Combined group	503	369 (73.4)	84 (16.7)	50 (9.9)
5- I experienced workplace discrimination due to endometriosis	Overall	971	666 (68.6)	237 (24.4)	68 (7)
	Symptom onset during adolescence	545	358 (65.7)	151 (27.7)	36 (6.6)
	Diagnostic delay	797	521 (65.4)	217 (27.2)	59 (7.4)
	Combined group	503	324 (64.4)	144 (28.6)	35 (7)

Table 2 (continued)

Set 2: work					
6-I had to choose a part-time job because of endometriosis	Overall	971	655 (67.5)	216 (22.2)	100 (10.3)
	Symptom onset during adolescence	545	346 (63.5)	137 (25.1)	62 (11.4)
	Diagnostic delay	797	515 (64.6)	193 (24.2)	89 (11.2)
	Combined group	503	314 (62.4)	129 (25.6)	60 (11.9)
7-I had to give up the job I wanted because of endometriosis	Overall	971	646 (66.5)	257 (26.5)	68 (7)
	Symptom onset during adolescence	545	332 (60.9)	178 (32.7)	35 (6.4)
	Diagnostic delay	797	501 (62.9)	240 (30.1)	56 (7)
	Combined group	503	298 (59.2)	170 (33.8)	35 (7)
8-I earned less than I could have because of endometriosis	Overall	971	617 (63.5)	270 (27.8)	84 (8.7)
	Symptom onset during adolescence	545	320 (58.7)	176 (32.3)	49 (9)
	Diagnostic delay	797	477 (59.8)	247 (31)	73 (9.2)
	Combined group	503	288 (57.3)	168 (33.4)	47 (9.3)
Global impact on work*	Overall	926	722 (78)	204 (22)	/
	Symptom onset during adolescence	522	383 (73.4)	139 (26.6)	/
	Diagnostic delay	759	568 (74.9)	191 (25.1)	/
	Combined group	480	348 (72.5)	132 (27.5)	/

*Derived from the mean of the items, calculated excluding "not applicable" responses and including only data from participants who provided 50% of responses ≠ from "not applicable" for each set

Table 3 Path analysis: Model 1

				95% Confidence Intervals			
		Estimate	**SE**	**Lower**	**Upper**	**β**	***p***
Paths	Age at symptom onset – Education	-0.03632	0.00539	-0.04688	-0.0258	-0.2479	< 0.001
	*Diagnostic delay – Education	-0.30991	0.10061	-0.50710	-0.1127	-0.1132	0.002
	Age at symptom onset – Work	0.00705	0.00426	-0.00130	0.0154	0.0453	0.098
	*Diagnostic delay – Work	-0.24659	0.07779	-0.39905	-0.0941	-0.0848	0.002
	Education – Work	0.76231	0.02791	0.70761	0.8170	0.7171	< 0.001
Covariance	*Age at symptom onset – Diagnostic delay	0.816	0.09221	0.635	0.996	0.339	< 0.001

*Diagnostic delay was coded as a binary variable (0 = no delay, 1 = delay). Parameter estimates and Betas represent the contrast defined as 0–1, meaning the difference between no delay and delay groups. Consequently, negative values indicate higher values for the delay group relative to the no delay group, and positive values indicate the opposite

Table 4. Almost all items met the normality criteria adopted in our study. Two items (Education_item6 and Work_item4) that did not fully meet these criteria were retained because: (a) the study was explorative and descriptive, (b) our analyses were not intended to validate a new questionnaire, (c) these items were deemed relevant based on existing literature and clinical experience.

Variables associated with the impact of endometriosis on education and work

Preliminary analyses showed a strong positive correlation between the impact of endometriosis on education and work ($r = 0.725$, $p < 0.001$). Earlier age at symptom onset was associated with greater impact on both education (r = -0.276, $p < 0.001$) and work (r = -0.165, $p < 0.001$). Women who experienced a diagnostic delay reported significantly younger age at symptom onset ($t(196.21)$ = -10.10, $p < 0.001$; means: 18.73 ± 6.49 vs. 25.62 ± 7.99), as well as higher impact on education ($t(224.30) = 7.33$, $p < 0.001$; means: 2.05 ± 0.99 vs. 1.48 ± 0.78) and work ($t(363.20) = 9.46$, $p < 0.001$; means: 2.29 ± 1.09 vs. 1.65 ± 0.71) compared with women who did not report a delayed diagnosis.

Path analysis was then conducted. In Model 1, we hypothesized associations among all exogenous and endogenous variables. Educational impact was specified as a predictor of work-related impact, due to their strong correlation and the typical chronological precedence of education over work. However, the path analysis revealed poor model fit, as indicated by the chi-square value ($\chi^2(6) = 733$, $p < 0.001$). Additionally, the direct path from age at symptom onset to work-related impact was not significant, consistent with a theoretically plausible indirect association through educational impact (see Table 3). In line with this, the indirect effect of age at symptom onset on work-related impact via educational impact was statistically significant (β = -0.178, $p < 0.001$). Based on these findings, we tested a revised and more parsimonious Model 2 excluding this non-significant direct path. Model 2 showed very good fit ($\chi^2(1) = 2.73$, $p = 0.098$; RMSEA = 0.048; CFI = 0.998; AGFI = 0.998; SRMR = 0.010), explaining 9.3% of the variance in educational impact (R^2 = 0.093, $p < 0.001$) and 52.5% in

Table 4 Path analysis: Model 2

		Estimate	SE	95% Confidence Intervals Lower	 Upper	β	*p*
Paths	Age at symptom onset – Education	-0.0363	0.00539	-0.0469	-0.0258	-0.2479	< 0.001
	*Diagnostic delay – Education	-0.3099	0.10061	-0.5071	-0.1127	-0.1132	0.002
	*Diagnostic delay – Work	-0.2079	0.07431	-0.3535	-0.0622	-0.0715	0.005
	Education – Work	0.7513	0.02716	0.6981	0.8046	0.7068	< 0.001
Covariate	*Age at symptom onset – Diagnostic delay	0.816	0.09221	0.635	0.996	0.339	< 0.001

*Diagnostic delay was coded as a binary variable (0 = no delay, 1 = delay). Parameter estimates and Betas represent the contrast defined as 0–1, meaning the difference between no delay and delay groups. Consequently, negative values indicate higher values for the delay group relative to the no delay group, and positive values indicate the opposite

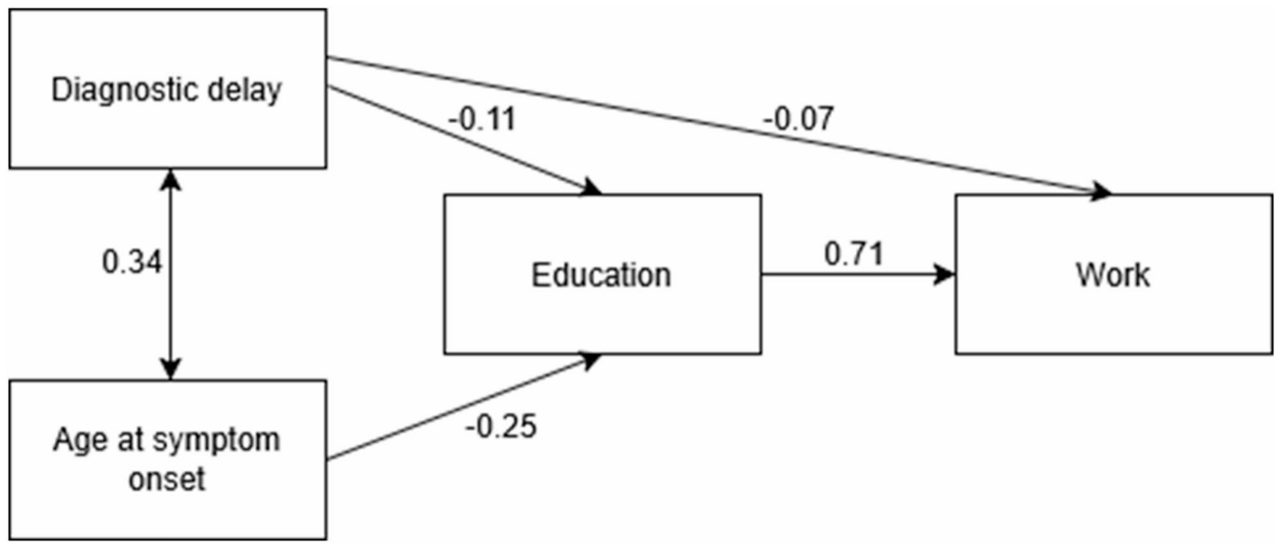

Fig. 2 Graphical representation of Model 2

Table 5 Pearson's correlations between impact of endometriosis on education and work, and endometriosis-related and psychological symptoms in women aged < 45 years

	Non menstrual pelvic pain	Dysmenorrhea	Dyschezia	Dysuria	Dyspareunia	Fatigue	Sleep	HADS-A	HADS-D	HADS-Total
Education	0.309**	0.228**	0.320**	0.347**	0.256**	0.335**	-0.215**	0.263**	0.262**	0.286**
Work	0.287**	0.193**	0.305**	0.328**	0.267**	0.381**	-0.308**	0.353**	0.339**	0.374**

**$p < 0.001$

work-related impact ($R^2 = 0.525$, $p < 0.001$). All estimated direct paths were statistically significant (see Table 4; Fig. 2). Age at symptom onset was negatively associated with educational impact (β = -0.248, $p < 0.001$), while the presence of diagnostic delay was associated with higher educational (β = -0.113, $p = 0.002$) and work-related impact scores (β = -0.072, $p = 0.005$); for diagnostic delay, the negative value of β reflects the between-groups contrast (0 = no delay versus 1 = delay). Educational impact was positively associated with work-related impact ($\beta = 0.707$, $p < 0.001$). Two significant indirect effects emerged: the effect of age at symptom onset on work-related impact was fully mediated by educational impact (IE1: β = -0.175, $p < 0.001$), while the effect of diagnostic delay was partially mediated through education (IE2: β = -0.080, $p = 0.002$). Multigroup analyses confirmed model invariance across age subgroups (< 45 and ≥ 45 years), with a non-significant χ^2 test ($\chi^2(2) = 3.84$, $p = 0.147$), indicating that the same pattern of structural relationships among variables applied consistently across the two age groups. Complete results from these analyses are reported in Supplemental Table 5.

As reported in Table 5, among participants under the age of 45 ($n = 707$), significant positive correlations were found between the impact of the disease on education and work, endometriosis-related symptoms (including chronic fatigue), and psychological health (i.e., symptoms of anxiety and depression). The negative association between the impact of endometriosis on education and work and sleep quality indicates that participants who experienced a greater impact of the condition in these two areas also reported poorer sleep. Additional information regarding this subgroup of participants is provided in Supplemental Table 6.

Discussion

This study aimed to assess the impact of endometriosis on women's educational and professional trajectories using two sets of endometriosis-specific questions: six items related to education and eight related to work, both of which demonstrated very good psychometric properties. The study employed both descriptive and inferential quantitative analyses. Descriptive findings indicated that endometriosis had a moderate to high impact on education for approximately 1 in 6 women (17%), increasing to nearly 1 in 4 (23%) among those who experienced symptom onset during adolescence and reported diagnostic delay. The condition affected work trajectories in 1 in 5 women overall (22%), rising to approximately 1 in 4 (28%) within the same subgroup. Drawing from a large, geographically diverse sample of 971 women across Italy, the results offer meaningful insight into the national landscape. Based on estimates reported by the Italian National Institute of Health (ISS; data updated as of 27 March 2025) indicating that 1.8 million women in Italy are living with diagnosed endometriosis, our findings suggest that approximately 306,000 may encounter significant educational challenges, while around 396,000 could experience moderate to severe work-related difficulties. Importantly, both the ISS estimates and our study sample include only women with a medical diagnosis of endometriosis. As a result, these projections may not capture the experiences of women living with symptoms who have not yet received a diagnosis, which is particularly relevant given the well-documented diagnostic delay and misdiagnosis associated with endometriosis. Additionally, since most of our study participants reported symptomatic endometriosis, our estimates capture the disease's impact on education and work when symptoms are present. This is further supported by the observation that participants who responded "not applicable" to more than 50% of education and work items had a higher age at symptom onset compared with the mean of the full sample (descriptive data shown in Supplemental Table 3).

When examining the specific domains contributing to the overall impact of endometriosis on education and work, *absenteeism* (frequent absences from school or work) and *presenteeism* (being physically present but unable to function productively due to symptoms) emerged as the most affected areas, findings that align with previous research [32]. A recent qualitative study by Hvala and Hammarberg [33] supports and contextualizes these results, illustrating how limited options for symptom management in the workplace—such as prolonged sitting, standing while in pain, or wearing restrictive clothing—can exacerbate presenteeism, especially when individuals feel compelled to work through severe discomfort. Their findings also emphasize that many employees exhaust their available sick leave due to endometriosis-related absences or treatment demands, including fertility care, which in turn contributes to additional financial strain. These patterns are consistent with Soliman et al. [34], who highlighted the significant direct and indirect costs associated with the condition. Furthermore, many participants in the present study reported moderate to high impacts on academic performance, as well as on educational and career decision-making.

Our findings further underscore the role of endometriosis in reinforcing *social inequalities*, including reduced income, job loss, part-time work, career downgrading, and workplace discrimination. Notably, discrimination was reported by 24% of participants overall and nearly 29% in the combined subgroup (almost 1 in 3 women). The results also show that endometriosis significantly shapes educational and career decisions, often compelling women to abandon studies or professional aspirations due to the limitations imposed by the disease. In this sense, our findings reinforce the pervasive and disruptive nature of endometriosis, which extends far beyond reproductive health [35].

An important contribution of our study is the identification of two interrelated factors, age at symptom onset and diagnostic delay, that impact educational and professional trajectories in women with endometriosis, along with the mechanisms linking them to these outcomes. Path analysis showed that earlier symptom onset is directly associated with impaired educational trajectories and indirectly with work through educational disruption, revealing a "cascading process". Previous research has highlighted that managing a chronic condition during adolescence poses additional educational challenges, including absenteeism, grade repetition, academic difficulties, lower attainment, and higher dropout rates compared to peers without chronic conditions [36]. This is especially concerning given evidence that low education and dropout during adolescence increase risks of adverse health outcomes, unemployment, and underemployment [37].

Our findings confirm this pattern in the endometriosis population, showing that disease symptoms can have lasting effects on career paths by shaping educational experiences early in life. In an interesting register-based study by Rasp et al. [38], a surgical diagnosis of endometriosis at a young age was associated with negative educational and occupational outcomes in early adulthood. Our results help clarify that the key factor may not be the diagnosis itself, but rather experiencing endometriosis symptoms from an early age, which is directly linked to poorer educational outcomes and, consequently, to negative professional outcomes. The situation is aggravated by diagnostic delay, whose impact on work is partially mediated by education, but also retains direct associations with both education and work trajectories. While prior studies noted the link between delayed diagnosis and reduced work ability [23], our results clarify how diagnostic delay may contribute to these negative outcomes. Path analysis revealed that the model held consistently across women aged < 45 and ≥ 45 years. This is a discouraging finding, as it suggests that little has changed over time in the lived experience of endometriosis, despite growing awareness of the condition [39].

Notably, our findings showed that most participants with adolescent symptom onset also experienced a diagnostic delay. This aligns with previous Italian studies, which found that the average diagnostic delay—estimated at 11 years—can extend by up to 4 additional years when symptoms begin before the age of 20 [20]. In most cases, the diagnostic delay observed in our study was linked to misdiagnosis. This highlights both the diagnostic complexity of endometriosis and a persistent lack of awareness among healthcare professionals, as previously noted in the literature [40].

Our study also indicates that women under 45 who report a stronger educational and work-related impact from endometriosis are more likely to currently experience pelvic pain and other symptoms such as chronic fatigue, poor sleep quality, and symptoms of anxiety and depression, which further underscores the role of endometriosis symptoms. Notably, 74% of all participants reported adenomyosis. Given the frequent co-occurrence of endometriosis and adenomyosis in adolescents and young women (aged 12–25) with severe dysmenorrhea and heavy menstrual bleeding [41], much attention should be given to this condition in young women because it may indirectly reveal the presence of endometriosis and shorten time to diagnosis. Noteworthy, hormonal treatments for endometriosis and adenomyosis typically overlap. Future studies focusing specifically on women with adenomyosis are encouraged, as the condition remains under-researched.

Strengths and limitations

The limitations that endometriosis imposes on women's educational and professional trajectories, particularly when symptomatic, have been highlighted in previous research [21]. However, our study is the first to explore this issue using two sets of disease-specific items with strong psychometric properties, offering tools for future cross-national comparisons. In this context, our findings provide a clearer picture of the Italian scenario, addressing not only well-documented impacts such as absenteeism and presenteeism, but also the influence of endometriosis on educational and career decisions and its broader social burden in terms of inequality and injustice. To our knowledge, this is the first study in Italy to quantify these dimensions, shedding light on the role of factors beyond pelvic pain—i.e., age at symptom onset and diagnostic delay—and the mechanisms through which they shape women's educational and professional trajectories.

Several limitations should be acknowledged. First, our findings cannot be generalized to countries outside of Italy. Even though the results may be similar in other Western countries, robust inferences cannot be drawn for different cultural contexts. Second, we did not examine the impact of endometriosis on the educational and professional lives of specific groups, including transgender and gender-diverse individuals, who may face an additional burden due to longer diagnostic delays and greater barriers to accessing care [42]. Third, our findings were based on self-reported data reflecting participants' subjective experiences, rather than on official sources such as national registries, which enable access to larger and potentially more representative samples (see, for example, Røssell et al. [18]). While the self-reported nature of the data allowed us to investigate participants' subjective experiences, it prevented us from testing hypotheses regarding the impact of medical variables—such as type of diagnosis or surgical interventions—on education and work. This information was used solely for descriptive purposes; future research should examine the role of factors such as surgical interventions and medical visits. It is also important to consider that the data were retrospectively recalled in a cross-sectional study, which limited our ability to systematically explore causal mechanisms and temporal relationships. In addition, self-selection bias—whereby women more severely affected by the condition may have been more likely to participate—may have contributed to an overestimation of the phenomena under investigation. This is particularly relevant, as nearly all participants experienced endometriosis-related symptoms.

Future implications

Our findings suggest important avenues for future research, which should aim to clarify the underlying reasons for the significant impact of endometriosis on women's educational and professional pathways. Relying on the published literature [43–45], we hypothesize that endometriosis-related stigma, along with gender bias, may contribute to explain the scenario depicted by our findings. It would also be valuable to investigate *gaslighting*—a form of psychological abuse characterized by the deliberate instillation of self-doubt in another person's mind [46]—in the context of endometriosis, to explore how this relational dynamic may unfold in workplace settings and contribute to the marginalization and delegitimization of individuals living with the condition.

In terms of practical applications, our findings can help patient associations and policymakers advocate for institutional protections and targeted support in educational and occupational settings. The data suggest that the needs of young women with endometriosis are often overlooked in schools and universities, and that flexible work arrangements, such as remote work, are not always accessible, even when feasible. Published evidence shows that young people with various chronic conditions or disabilities face higher rates of unemployment and workplace discrimination, often due to employers' misconceptions and lack of awareness [47]. Adapting educational and professional environments to the needs of those with chronic illnesses could reduce both the burden of the disease and the inequalities it creates. Awareness-raising initiatives across schools, universities, and workplaces may be especially effective.

Conclusion

Combined with persistent gender inequality in the workplace [48], the body of evidence gathered in our research raises significant concerns, particularly considering that endometriosis is often described as an invisible illness or a "missed disease" [49]. Overall, our results clearly indicate that adolescence is a critical period during which the trajectory of a woman with endometriosis is shaped, including the course of her future educational and professional life. Early diagnosis of endometriosis is essential, and our study demonstrates that it can profoundly impact women's overall quality of life, extending beyond physical and psychological health.

Abbreviations

AGFI	Adjusted Goodness-of-Fit Index
APE-Odv	Associazione Progetto Endometriosi-Organizzazione di Volontariato
CFI	Comparative Fit Index
HADS	Hospital Anxiety and Depression Scale
KMO	Kaiser–Meyer–Olkin
NRS	Numerical Rating Scale
RMSEA	Root Mean Square Error of Approximation
SRMR	Standardized Root Mean Square Residual

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s40359-026-04112-5.

Supplementary Material 1.

Supplementary Material 2.

Supplementary Material 3.

Supplementary Material 4.

Supplementary Material 5.

Supplementary Material 6.

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Authors' contributions

FF and ES conceived and designed the study. FF was responsible for data collection and performed the statistical analyses. FF also drafted the original version of the manuscript. ES and PV contributed to data interpretation and critically revised the manuscript for important intellectual content. All authors read and approved the final version of the manuscript.

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Data availability

The data supporting this article will be shared upon reasonable request to the corresponding author.

Declarations

Ethics approval and consent to participate

Ethical approval was granted by the Ethical Commission for Research in Psychology, Department of Psychology, Catholic University of the Sacred Heart (protocol 86 – 23; approval date: October 2, 2023). The research was conducted in accordance with the Declaration of Helsinki. Electronic informed consent was obtained from all the participants on the Qualtrics platform before initiating the survey.

Consent for publication

Not applicable.

Competing interests

FF is a member of the Editorial Board of Human Reproduction. PV is a member of the Editorial Boards of Human Reproduction Open, the Journal of Obstetrics and Gynaecology Canada, and the International Editorial Board of Acta Obstetricia et Gynecologica Scandinavica; has received royalties from Wolters Kluwer for chapters on endometriosis management in the clinical decision support resource UpToDate; and maintains both public and private gynaecological practices. ES is Editor-in-Chief of Human Reproduction Open; discloses payments from Ferring, IBSA and Gedeon-Richter for research grants and honoraria from IBSA and Gedeon Richter for lectures; and maintains both public and private gynaecological practices.

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