## Unravelling the diagnostic delays and disease burden associated with endometriosis: A targeted literature review

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## BACKGROUND

**Context**: Endometriosis affects approximately 10-15% of women of reproductive age worldwide.<sup>1</sup> It occurs when endometrium-like tissue grows outside the uterus.<sup>1</sup> Endometriosis symptoms include pelvic pain, dysmenorrhea, deep dyspareunia and subfertility. Symptoms can also be nonspecific causing diagnostic delays.<sup>2</sup>

Diagnosis is often delayed due to symptom normalization, misdiagnosis, and reliance on invasive laparoscopy for confirmation of disease.<sup>4</sup> As a result, many women face prolonged pain, reduced quality of life, and increased humanistic and economic burden.<sup>3</sup> lt is also proven that health care costs are higher with longer delays before confirmatory diagnosis.<sup>4</sup> Hospitalizations, surgeries, infertility treatments, pain and anxiety increased these costs.<sup>2</sup>

Endometriosis is linked to other conditions like fibromyalgia, Inflammatory bowel disease (IBD), and autoimmune disorders, which delay diagnosis and add to patient burden. Increased risks of breast and ovarian cancer have also been reported.<sup>5</sup>

Nevertheless, there is limited evidence on the impact of diagnostic delays and disease burden associated with endometriosis.

Aim: To assess the diagnostic delays, humanistic, and economic burden associated with endometriosis.

## METHODS

A targeted literature review was conducted using Embase and Google Scholar databases from January 2019 to December 2024. Disease terms were combined with diagnosis-related and burden-related terms. Only full papers and English-language articles were included. The primary focus was on burden of diagnostic delay with endometriosis.



Studies were excluded if they focused on populations without endometriosis (e.g., cervical cancer) or were interventional, experimental, case reports, systematic reviews, or conference abstracts.



range



Delay Short

Interr

Long

15 10

Abbreviations: Avg: Average; GP: General practitioner; HC: Healthcare; HCRU: Health care resource utilization; HRQoL: Health related quality of life; TLR: Targeted literature review.

## "Early diagnosis $\rightarrow$ Better outcomes $\rightarrow$ Lower burden"

Endometriosis imposes a significant economic and humanistic burden on patients and healthcare system. Early detection and effective diagnosis may help in improving patient outcomes and optimize management to reduce healthcare cost and address this unmet need

### **Overview of results from the TLR**



Туре	HCRU Category	Endometriosis- Related (Mean, SD)		
Delay	Ambulatory Visits	2.4 (2.9)		
	<b>Emergency Visits</b>	0.1 (0.5)		
	Inpatient Stays	0.02 (0.2)		
ediate Delay	Ambulatory Visits	5.0 (5.5)		
	<b>Emergency Visits</b>	0.3 (0.9)		
	Inpatient Stays	0.03 (0.2)		
elay	Ambulatory Visits	6.6 (7.4)		
	<b>Emergency Visits</b>	0.4 (0.9)		
	Inpatient Stays	0.05 (0.3)		
9.99				
	7.85			
		1.21 0.89		
		tal Cantanta nar Vacr		
GP Contacts per Year Hospital Contacts per Year				
Endometriosis (Mean) Control (Mean)				

Study name	Category	Cost
Surrey 2020	Avg. all-cause HC costs (60 months pre diagnosis)	\$28,376
Surrey 2020	Avg. endometriosis- specific cost (60 months pre diagnosis)	\$3,553
Swift 2023	Annual Per-Case HC and indirect cost (Mean)	\$9864
Darbà 2021	Hospital Setting Costs (Per Patient)	€3,566
Chen 2019	Total hospital costs per case (5- year)	\$3,143

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## RESULTS

- The search retrieved 280 citations, of which 16 studies were included for analysis.
- Included studies were from US and Canada (n= 6), Europe (n=5), and other regions (n=5).
- The mean age of women diagnosed with endometriosis ranged from 28.8 to 53.8 years.
- Economic burden was assessed in 9 studies, with 2 specifically linking higher costs to diagnostic delays. Of 3 Health-Related Quality of Life (HRQoL) studies, 2 reported increase in burden associated with diagnostic delays on patients' quality of life.
- The mean/median diagnostic delays reported in 9 of 16 studies varied from 2.1 to 12 years.
- Patients with longer diagnostic delay had more emergency visits, hospitalizations, and significantly higher healthcare cost, averaging \$21,489, \$30,030, and \$34,460 for short ( $\leq 1$  year), intermediate (1–3) years), and long delays (3–5 years), respectively (p < 10.001 for all comparisons).<sup>3</sup>
- HCRU associated with diagnostic delay was higher for endometriosis patients compared to control group. General practitioner and hospital contact rates higher among the endometriosis group (GP: 9.99 vs. 7.85; hospital: 1.21 vs. 0.89).
- Women with endometriosis reported lower HRQoL scores compared to both symptomatic and asymptomatic controls, especially in bodily pain (63.75 vs. 65.42 and 70.54), mental health (62.87 vs. 61.09 and 66.20), and physical functioning (87.39 vs. 89.05 and 87.84). These findings highlight the greater symptom burden in the endometriosis group, with an overall prevalence of 5.4% (95% CI: 4.9– 5.9%).<sup>6</sup>

### DISCUSSION

- ✓ Endometriosis places a significant burden on patients and healthcare systems, mainly due to delays in diagnosis. It leads to increased healthcare resource utilization, higher direct and indirect costs, and a greater likelihood of disease progression.
- $\checkmark$  Patients often face years of misdiagnosis and multiple healthcare visits before receiving appropriate care, which exacerbates their physical, emotional, and financial burden.
- ✓ Early detection and standardized care has potential to reduce costs and improve quality of life. Addressing these gaps needs focused healthcare policies to improve awareness, enable timely diagnosis, and ensure patientcentered, multidisciplinary care.

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\*Note: References of studies included in the review



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