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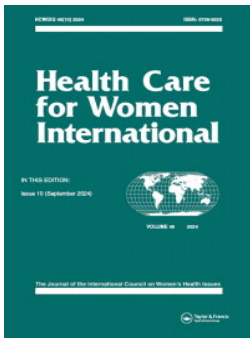
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Understanding diagnostic delay for endometriosis: A scoping review using the social-ecological framework

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ABSTRACT

Diagnostic delay for endometriosis is a well-established phenomenon. Despite this, little is known about where in the health care system these delays occur or why they occur. Our review is the first attempt to synthesize and analyze this international evidence. A systematic scoping review with a pre-specified protocol incorporated the literature on diagnostic delay for endometriosis using the social-ecological theoretical framework. Four databases (PubMed, MEDLINE, EMBASE, PsychINFO) were searched from inception to September 2023. The search yielded 403 studies, 23 of which met the inclusion criteria. Most were from high-income country researchers. The average diagnostic delay reported across studies was 6.8 years (range 1.5–11.4 years) but this masked the very wide differences reported between countries. Considering the impact on individuals and the health system, addressing diagnostic delay for endometriosis must remain a priority for researchers, health care providers and policy makers.

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Endometriosis is currently difficult to diagnose. This results in delays in diagnosis which negatively impacts those suffering and increases the severity of pain and extent of the disease with increased costs to healthcare systems. Despite this, little is known about where in the healthcare system these delays occur or why they occur. Our review is the first attempt to synthesize and analyze this evidence using the global literature.

Background

Endometriosis is an estrogen dependent gynecological condition characterized by the presence of active endometrial tissue lying outside of the uterus, typically in the pelvic region (Olšarová & Mishra, 2020). It

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is a chronic, progressive inflammatory disease which affects more than 170 million women worldwide (Della Corte et al., 2020). Endometriosis mainly affects women of reproductive age (15–49 years), with up to 1 in 10 believed to have the condition, although it is estimated that as many as 60% of endometriosis cases remain undiagnosed (Agarwal et al., 2019; Della Corte et al., 2020). Prevalence estimates of endometriosis are generally poor and highly varied, ranging from 4 to 50% although the most consistent estimates suggest a prevalence ranging from 6 to 10% (Zhang et al., 2021). Despite the progressive nature of endometriosis, a correct diagnosis takes an average of 10 years and at least 7 visits to a health practitioner (Bach et al., 2016; Eisenberg et al., 2022). This lengthy delay is reflected in the disease burden in which gynecological diseases are reported as the leading cause of Disability Adjusted Life Years (DALYs) and Years Lived with Disability (YLD) among the 15–49-year age group (GBD Compare). This is despite clear clinical diagnostic indicators including chronic pelvic pain (CPP), dysmenorrhea (painful, heavy menstruation), dyspareunia (painful intercourse), that are known for 82.9% of women (Becker et al., 2021; Olšarová & Mishra, 2020). Apart from the YLD the economic impact includes increased costs to the individual, to healthcare providers, and to the wider economic infrastructure (Surrey et al., 2020). The current ‘gold standard’ for diagnosis is a laparoscopy, although surgeons may be hesitant to perform this due to the invasive nature of the procedure (Becker et al., 2021; NICE, 2017). There is also evidence that symptoms may be dismissed as ‘normal’ by health care practitioners (Bullo, 2020; Olšarová & Mishra, 2020). The researchers’ aim for this review was to explore the delay faced by those attempting to obtain a diagnosis of endometriosis. The socio-ecological model has been used to exemplify multifaceted issues arising as a result of delayed endometriosis diagnosis and provides the opportunity to develop effective interventions at the micro, meso and macro levels.

Methods

The study protocol was registered on the Open Science Framework OSF: [10.31219/osf.io/yzuvb](https://osf.io/yzuvb)

Patient and public involvement

Women who have experienced diagnostic delay for endometriosis were involved in designing the research. The research question was informed by their priorities, experiences and preferences. Dissemination of this research will be facilitated through charities focused on endometriosis.

Data sources and search strategy

The development of our search strategy was guided by the SPIDER framework to ensure key concepts were captured in the searches (Booth et al., 2016). Four databases were searched from inception to September 2023. They included PubMed, MEDLINE, EMBASE and PsycINFO. No date limits were set on the searches. Search terms included key terms derived from search strings relating to ‘endometriosis’ and ‘diagnostic delay’ and were adapted for each database; For example, the search strategy for MEDLINE was: ‘Endometriosis.mp. or (exp Pelvic Pain/or exp Chronic Pain/)) and exp Delayed Diagnosis/’.

Eligibility criteria

Included studies were primary studies in English involving the pelvic region or reproductive organs only, that mentioned pelvic pain with a suspicion of endometriosis, and diagnostic delay (in the context of endometriosis).

Screening and data extraction

All studies were screened by one reviewer (JF) with a 10% sample checked by a second reviewer (SM) and any disagreements resolved by a third reviewer (AW/AMJ).

We extracted data on a predeveloped and piloted data extraction form and included study characteristics, methods and design, and demographic characteristics of the population. Additionally, we recorded the most frequently reported symptoms, length of and reason for delay.

Data analysis

We grouped studies by themes identified from the individual included studies (Braun & Clarke, 2006) and contextualized them to form a public policy perspective using the socio-ecological model (Lee et al., 2017). No formal quality appraisal was undertaken in line with methodological guidance for scoping reviews (Grant & Booth, 2009).

Results

Our searches yielded 403 studies following deduplication. Title and abstract screening and full-text screening resulted in 23 studies encompassing the views and experiences of over 9167 participants (Figure 1).

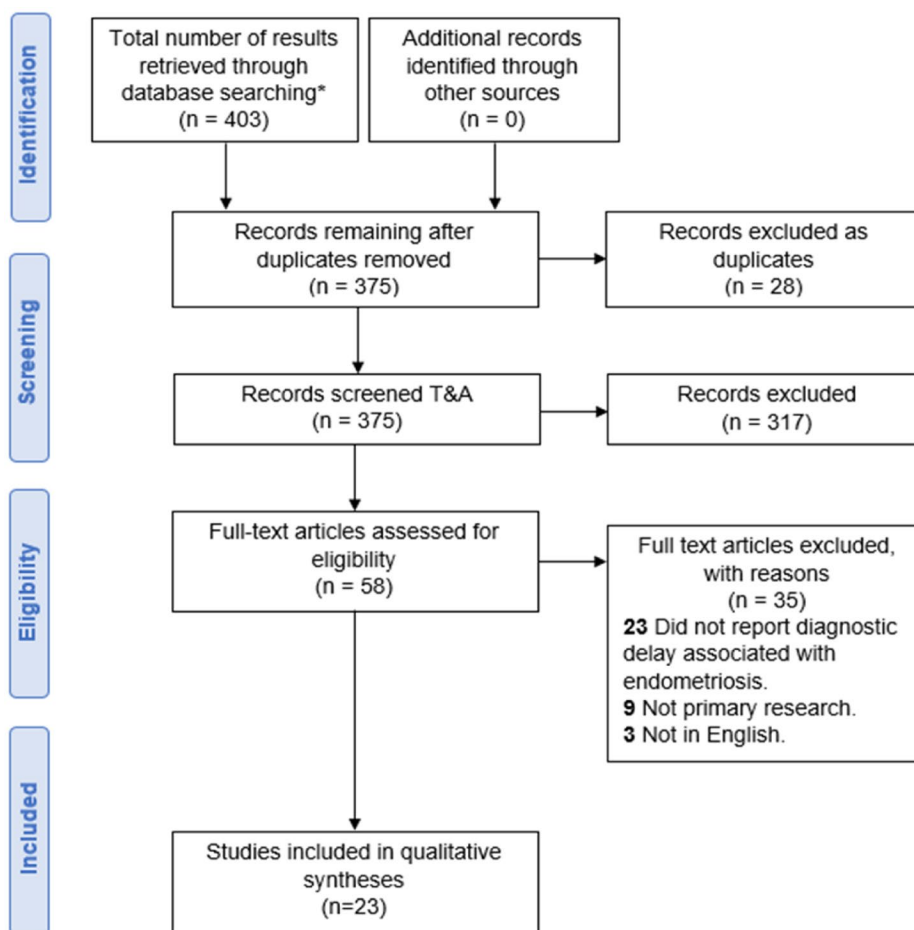


Figure 1. PRISMA flow diagram.

Study characteristics

Table 1 provides an overview of the included studies and highlights the diversity of methods used by researchers. Six studies were qualitative and 17 were quantitative. Over a third of the studies (9/23) were published from 2020 onwards. Sixteen studies were conducted by researchers based in high-income countries including the UK (Ballard et al., 2006; Ghai et al., 2020), US (As-Sanie et al., 2019; DiBenedetti et al., 2018; DiVasta et al., 2018; Dmowski et al., 1997; Soliman et al., 2017), the Netherlands (Staal et al., 2016; van der Zanden et al., 2021), Norway (Fernandes et al., 2020; Husby et al., 2003), Canada (Singh et al., 2020), Australia (Armour et al., 2020), New Zealand (Tewhaiti-Smith et al., 2022), and Italy (Lukic et al., 2016; Pino et al., 2023). Three were conducted by researchers in middle income countries; Brazil (Andres et al., 2014; Santos et al., 2012) and Iran (Riazi et al., 2014) and four were conducted by researchers in multiple countries (Hudelist et al., 2012; Lamvu et al., 2020; Nnoaham

Table 1. Table of included studies.

First author, year, country	Study design	Participants and methods	Main finding(s)
Quantitative			
Andres et al., 2014, Brazil	Retrospective study	21 Patients (aged 13–20) with histologically confirmed endometriosis after undergoing surgery.	Need for increased awareness of adolescent onset of endometriosis. Current imaging techniques are inadequate. Gynecologists fail to recognize symptoms.
Armour et al., 2020, Australia	Cross-sectional study	409 Participants (aged 18–45), 340 with endometriosis, 69 without. Recruited via survey link.	ESHRE guidelines reduced diagnostic delay from 9.9 years before 2005 to 1.5 years as of 2013 onwards. Year medical attention is sought, number of doctors seen and delayed health seeking all increase diagnostic delay.
DiVasta et al., 2018, United States	Cross-sectional longitudinal cohort study	670 Participants (aged 12–49), 402 with self-reported endometriosis, 268 controls. Recruited from 2 tertiary centers.	Need to understand changing symptom patterns and symptom base more – particularly how this may differ between an adult and adolescent population. Acyclic pain appears to increase with age – potentially due to increased severity of endometriosis at surgery.
Dmowski et al., 1997, United States	Retrospective study	693 Patients (aged 15–40), 377 with CPP symptoms, 336 infertility +/- pain. Evaluated at the Institute for the Study and Treatment of Endometriosis.	Diagnostic delays were found to be longer in women who were symptomatic earlier in life. Longer delays led to more advanced disease at laparoscopy. These findings were only significant in the pain group. Diagnostic delay steadily decreased between 1979 and 1995. Delays were longer in the pelvic pain group than the infertility group.
Ghai et al., 2020, United Kingdom	Retrospective cross-sectional study	101 Women with surgically confirmed endometriosis recruited via written postal questionnaire.	Women often have their pain normalized and do not feel their pain is taken seriously. Misdiagnosis, menstrual cramps during adolescence, earlier symptom onset and delays between presenting with symptoms and onward referral all increased diagnostic delays. Shorter delays were found when women changed to a more understanding gynecologist.
Hudelist et al., 2012, Austria and Germany	Cross-sectional study	171 Patients (aged >18) with histologically confirmed endometriosis recruited from tertiary referral centers for diagnosis and treatment of endometriosis.	Increasing number of misdiagnoses, patient impression of not been taken seriously, normalization of symptoms, women with cramps during adolescence, and whose mothers viewed menstruation as a negative event all experienced increased diagnostic delays. Medication use, extent of disease and main symptomatic complaint were all non-significant factors.
Husby et al., 2003, Norway	Cross-sectional study	261 Patients with pain and endometriosis, 223 members of the Norwegian Endometriosis Association, 38 nonmembers.	There were no statistically significant differences in the mean diagnostic delay between 1978–2001. Delays did not differ between those with pain only and pain and infertility, additionally, there was no difference in diagnostic delay between members and nonmembers. Most of the delays were from seeing a GP to diagnosis.
Lamvu et al., 2020, United States, Australia, Canada, Ireland, New Zealand, South Africa, and the United Kingdom	Cross-sectional study	451 Respondents (aged 19–60) with or without endometriosis. Recruited through 'My Endometriosis Team'.	Respondents described discussing their symptoms more than 20 times and were commonly misdiagnosed with both mental and physical conditions. About half of respondents waited over 6 years for a diagnosis while almost a quarter waited 11 or more years. Longer delay was associated with more pelvic symptoms. Many women felt doctors did not listen and that their recommendations were inconsistent with what they wanted.

(Continued)

Table 1. Continued.

First author, year, country	Study design	Participants and methods	Main finding(s)
Lukic, 2016, Italy	Cohort study	67 Patients with deep dyspareunia diagnosed with pelvic endometriosis attending an endometriosis unit.	Women often suffer from pathology for a long time before presenting to health services. Both signs and symptoms of endometriosis need to be better recognized or women need to be clearer in describing signs and symptoms to allow diagnosis. Roughly two-thirds of women don't consult their GP for sexual dysfunction.
Nnoaham et al., 2011 (Belgium, Brazil, China, Ireland, Italy, Nigeria, United Kingdom, United States and Spain)	Multicentre cross-sectional study with prospective recruitment	1,418 Premenopausal women (aged 18–45) without previous surgical diagnosis of endometriosis. 745 with endometriosis, 587 symptomatic, 86 sterilized. Recruited in hospital before surgery.	Delays were increased when state funded care was sought when compared to self-funded care or through insurance. Patients with longer delays had more pelvic symptoms and a higher Body Mass Index (BMI), even when adjusting for potential confounders. Most of the delay was due to length of time between referral from primary care to a gynecologist. Women with endometriosis had a longer delay than symptomatic controls without endometriosis at surgery. Diagnostic delays ranged from 3.3 years to 10.7 years.
Pino et al., 2023, Italy	Cross-sectional study	689 Women with endometriosis.	The mean diagnostic delay was 11.4 years and the mean time from symptom onset to diagnosis (14.8 years) was significantly longer for adolescents than for older women.
Santos et al., 2012, Brazil	Retrospective study	262 Women (aged 17–49) with surgically confirmed endometriosis. Recruited through an outpatient clinic for endometriosis and CPP.	Diagnostic delay differed between different age categories; however, the difference was found to be non-significant. Women with dysmenorrhea and deep dyspareunia had a longer delay, which those with dyspareunia (not deep) and acyclic pain had a shorter delay. Women experiencing infertility experienced a longer delay than their fertile counterparts. Site and severity of disease were not significant factors.
Singh et al., 2020, Canada	Cross-sectional survey	2004 Women (aged 18–49) were recruited via email using 3 independent survey sampling panels.	Delays in health seeking were longer than physician-related delays. On average women saw 3 different physicians before receiving a diagnosis. The odds of receiving a diagnosis of endometriosis were highest when women experienced infertility, cyclic pelvic pain or cramping, and pelvic pressure.
Soliman et al., 2017, United States	Cross-sectional study	683 Respondents (aged 18–29) recruited from 3 market research panels.	Younger age at symptom onset and white ethnicity were associated with a longer diagnostic delay. Patients with constipation, bloating or diarrhea were diagnosed sooner than those with pain during sex. Delays were also shorter among women having a diagnostic procedure, women seen by a gynecologist and women diagnosed via non-surgical methods.
Staal et al., 2016, Netherlands	Retrospective cross-sectional study	47 Patients (aged 14–29) diagnosed with endometriosis by surgery or MRI.	Diagnostic delay was shorter for patients who consulted their GP due to subfertility rather than pain. A longer delay from presenting to a GP to referral was experienced by patients who were a young age when they developed symptoms, misdiagnosed or their symptoms were normalized – the same delays were not experienced between referral to a gynecologist and diagnosis.

(Continued)

Table 1. Continued.

First author, year, country	Study design	Participants and methods	Main finding(s)
Tewhaiti-Smith et al., 2022, New Zealand	Cross-sectional study	800 Respondents (aged 18–74), 620 with endometriosis, 180 with CPP. Recruited using social media, flyers, and through targeted dissemination.	Diagnostic delay was longer in patients with endometriosis than those experiencing CPP. On average women saw 4.8 doctors before they were diagnosed with endometriosis. Year of first doctors visit was negatively correlated with the number of doctors consulted suggesting health-seeking delays are reducing over time.
Van Niekerk et al., 2022, Australia, Oceania, United Kingdom and North America	Cross-sectional study	318 Women (23 of whom with symptoms of perimenopause, 35 in medical menopause and 7 in surgical menopause). Recruited via online advertising on social media.	Overall diagnostic delay was reduced by 6.5 years by the introduction of guidelines. Longer diagnostic delays, number of endometriosis-related symptoms, depression, anxiety, pain after sexual intercourse and during urination were all negative predictors of self-compassion. Women with longer diagnostic delays were found to have higher levels of endometriosis-related distress are likely to report lower levels of self-compassion and would benefit from early engagement in psychological interventions.
Qualitative			
As-Sanie et al., 2019, United States	Qualitative study – interactive discussion	Interdisciplinary group of expert researchers, clinicians, and patients put together The Society for Women's Health Research.	Identified themes impacting diagnostic delay through guided interactive discussion. These included diagnostics, barriers to diagnosis, the future of diagnostics, treatment, barriers to treatment and the future of treatment – with several subthemes including stigma and understanding.
Ballard et al., 2006, United Kingdom	Qualitative, interview-based study	32 Women (aged 16–47) attending a pelvic pain clinic. 28 diagnosed with endometriosis.	Delays occur at every stage of the diagnostic pathway. Delays occur at both the patient-level and medical-level, with normalization being a common factor. Others include stigma, nonspecific testing, and improper use of treatments.
DiBenedetti et al., 2018, United States	Qualitative cross-sectional study with an interview element	16 Women (aged 24–48), 11 with endometriosis and 5 healthy controls. Recruited via 2 qualitative research facilities.	A painful periods screening tool was developed to aid in the recognition of pathological symptoms of endometriosis. The tool was found have face validity and content validity, clearly and concisely able to assess core symptoms and distinguish between normal and pathological symptoms.
Fernandes et al., 2020, Norway	Qualitative interview-based study	13 Doctors – 8 gynecologists and 5 General Practitioners (GPs) identified via google search.	Patients attending clinic often feel embarrassed and disbelieved regarding symptoms. Doctors do not like to take responsibility for diagnosis due to not being specialized in women's health issues. Diagnosis is often delayed due to multiple misdiagnoses.
Riazi et al., 2014, Iran	Qualitative interview-based study	12 Endometriosis patients (aged 22–37) and 6 gynecologists	Dyspareunia was noted as one of the most important symptoms of the disease. Women's recognition of this symptom is often delayed due to delayed marriage (and so delayed intercourse). Beliefs around dysmenorrhea being normal and common during virginity also delay diagnosis. From a medical viewpoint, unreliability of diagnostic markers, misdiagnosis and mismanagement all increase diagnostic delay.
Van der Zanden et al., 2022, Netherlands	Qualitative focus group-based study	23 Women (aged 29–45) placed in 6 focus groups. Recruited by social media, through a patient interest group and through a center of expertise in endometriosis	Health-seeking behavior is often influenced by peers, normalization leads to delays. Nondiscriminatory tests, being referred to the wrong specialist and given pain medication without proper indication for use were all attributed to diagnostic delays. Referral was faster in women with menstruation specific complaints. Not all doctors have equal knowledge and some women received incomplete examination.

et al., 2011; Van Niekerk et al., 2022). The age range of participants was between 12 and 74 years old with an average age of 28.7 years.

Age of onset of endometriosis

The mean age at onset of endometriosis symptoms was 14.1 years old for adolescents (range 13–15.3 years), and 20.4 years old for adults (range 20–23.2 years). One study including both adults and adolescents found the mean age at onset of endometriosis symptoms was 18.4 years (range 9–45 years). The average age at diagnosis was 16 for adolescents and 28.8 for adults (range 22–32). The average age of the first visit to primary care was 14 for adolescents and 25.8 years for adults (range 20–32.6).

Diagnostic delay

The definition of diagnostic delay was consistent across studies and was defined as the time between symptom onset and diagnosis. The average diagnostic delay was 6.8 years with an average of 1.5 years in Australia (Armour et al., 2020) and just over 11 years in the US and (DiBenedetti et al., 2018; Pino et al., 2023). However, there was a wide range between the shortest and longest delay reported by researchers. The shortest delay reported for adults was 1 year, and the longest delay was 27 years (Ballard et al., 2006). The shortest delay experienced by adolescents was 0.5 years in Brazil and Italy (Andres et al., 2014; Pino et al., 2023), and the longest delay was 35 years in Italy (Pino et al., 2023). Some researchers reported specific points at which delays occurred. These were from symptom onset to primary care/general practitioner (GP) consultation (As-Sanie et al., 2019; Ballard et al., 2006; DiBenedetti et al., 2018; DiVasta et al., 2018; Hudelist et al., 2012; Husby et al., 2003; Singh et al., 2020; Soliman et al., 2017; Staal et al., 2016; Tewhaiti-Smith et al., 2022; van der Zanden et al., 2021); Referral for gynecology consultation (Ballard et al., 2006; Ghai et al., 2020; Hudelist et al., 2012; Staal et al., 2016; van der Zanden et al., 2021); Gynecology referral to final diagnosis (Ballard et al., 2006; Ghai et al., 2020; Hudelist et al., 2012; Staal et al., 2016; van der Zanden et al., 2021). Mean delays through this pathway reported across the studies were 2.0, 2.5, and 2.8 years, respectively. Time from primary care presentation to diagnosis was reported by some researchers without mention of transition to secondary care (DiVasta et al., 2018; Ghai et al., 2020; Husby et al., 2003; Singh et al., 2020; Soliman et al., 2017). The average diagnostic delay between primary care presentation and diagnosis was 2.9 years (Figure 2).

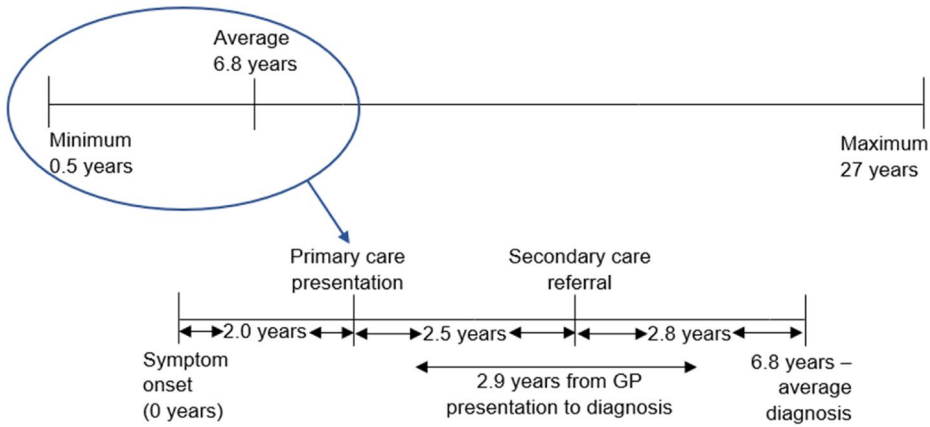


Figure 2. Schematic representation of the global average of diagnostic delay for endometriosis.

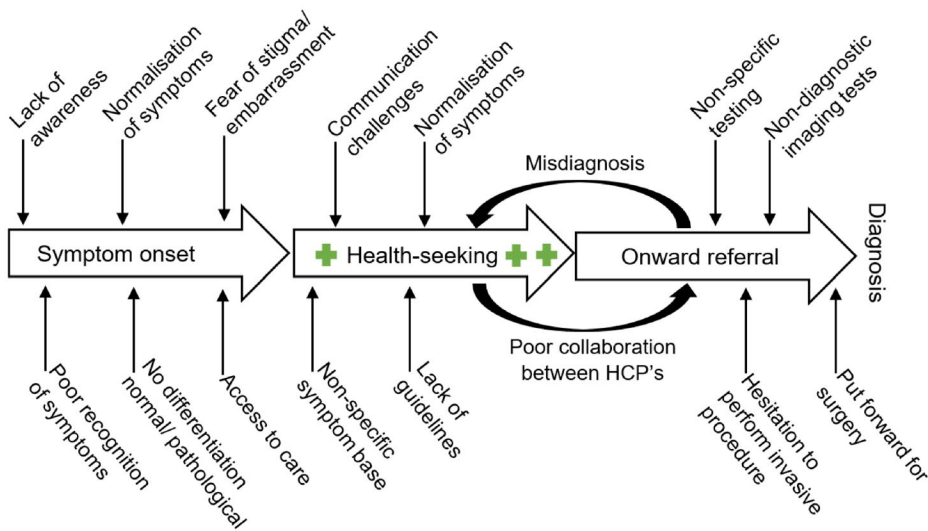
Reasons for diagnostic delay

Nearly all included studies conducted by researchers focused on the patients' perspective, two focused on the health care provider (HCP) perspective, and one included both perspectives. There were 6 main themes identified by researchers with a range of factors contributing to diagnostic delay. We show a summary of these in [Table 2](#) and [Supplementary Figure 2S](#).

Researchers revealed that access to care differed depending on the specific health system in place. Financial barriers to access were mentioned for those requiring private healthcare, whilst physical access to care was more frequently noted for those seeking public healthcare services. Researchers in only one study compared waiting times between those seeking public healthcare and insurance or self-funded healthcare (Nnoaham et al., 2011). They found that waiting times for endometriosis care were significantly longer for those seeking public rather than private healthcare (8.3 years vs. 5.5 years). Both HCPs and patients shared similar views on the reasons for diagnostic delay although they expressed the delays differently. Where HCPs thought frequently presenting patients were somatizing, patients stated they presented frequently because they felt unheard by HCPs. This was reflected by the number of doctors seen, which averaged 2.0 for adolescents (DiVasta et al., 2018) and 4.1 for adults (range 2.5–7) (DiVasta et al., 2018; Hudelist et al., 2012; Nnoaham et al., 2011; Singh et al., 2020; Tewhaiti-Smith et al., 2022) and the number of times symptoms were discussed before diagnosis. Over a quarter of women reported discussing symptoms more than 20 times (Lamvu et al., 2020) with healthcare practitioners. None of the researchers' studies evaluated the number of consultations with all HCPs prior to referral or the effect of diagnostic delay on the patient based on the type or gender of HCP consulted.

Table 2. The main themes and contributing factors relating to diagnostic delay.

	Main theme	Contributing factors
1	Access to healthcare	Physical access to care, financial barriers, stigma, embarrassment, not being aware of endometriosis, religious beliefs and normalization of symptoms.
2	Knowledge limitations	Poor recognition of symptoms (patients and HCPs), HCP thinking endometriosis is a 'rare' disease, inability to define between normal and pathological symptoms (patients and HCPs), lack of awareness and lack of training and evidence available to HCPs.
3	Misdiagnosis	Differential presentation of symptoms between women, atypical symptoms, comorbidities, communication challenges between different HCPs, lack of specificity in testing, lack of definitive diagnostic testing, and use of non-definitive tests.
4	Stigmatization	Stigma, normalization, dismissal, patient unable to properly verbalize pain and/or symptoms causing communication challenges between patient and HCPs.
5	Method of diagnosis	Hesitation to refer for more invasive definitive tests, age, HCP uncomfortable with requirement to perform physical exam (particularly on adolescents), perceived need for surgical over clinical diagnosis in some health systems.
6	Lack of guidelines	No screening tools available, inconsistency in available patient reported outcome measures (PROMs) and guidelines, poor interdisciplinary handling of patients, and need for involvement of multiple HCPs.

**Figure 3.** Pathways to diagnostic delay for endometriosis.

The themes identified by researchers highlighted increasing diagnostic delay of endometriosis at each time point along the diagnostic pathway from symptom onset to diagnosis. This resulted in delay which led to increases in both the severity of pain and the extent of disease (Dmowski et al., 1997; Soliman et al., 2017) (Figure 3). Both patients and HCPs appeared to demonstrate an overall lack of understanding and education about endometriosis. This meant that even patients who overcame barriers to healthcare (such as financial barriers or feelings of embarrassment) were often unable to find the words to describe their symptoms appropriately. As a result, HCPs were often reported to be dismissive leading

to misdiagnosis. Furthermore, the lack of clinical guidelines appeared to compound the lack of knowledge by health care providers. Invasive diagnostic testing was not favored by either HCPs or patients.

Interventions to address diagnostic delay

Four studies conducted by researchers included interventions to tackle diagnostic delay at various points in the healthcare pathway. Of these, two teams reported reduced time to diagnosis following the introduction of clinical guidelines (Armour et al., 2020; Tewhaiti-Smith et al., 2022). One study team found diagnostic delays were reduced by the introduction of specialist endometriosis centers in the US but not in the UK (Ghai et al., 2020) and the final intervention study reported by researchers found that becoming a member of an endometriosis society had no effect on diagnostic delay (Nnoaham et al., 2011). One study team quantified the reduction in delay (8.4 years), whilst others reported a ‘downward trend’ in diagnostic delays (Armour et al., 2020; Ghai et al., 2020; Tewhaiti-Smith et al., 2022).

A range of interventions to reduce diagnostic delay for endometriosis were suggested by researchers including education and awareness campaigns, collaborative multidisciplinary working between HCPs, promoting health-seeking behavior for patients, the use of screening tools, increased research into endometriosis, improving access to medical records, clinical guidelines written in the native language, the use of reliable diagnostic indicators and early intervention. These interventions span the entirety of the socio-ecological framework (Figure 4). This multi-level approach to intervention allows for the introduction of all encompassing, yet targeted and effective interventions tailored according to individual factors and behaviors (Lee et al., 2017) and the wider health care system. Using this framework for diagnostic delay in endometriosis is useful to visualize the complexity involved whilst providing a range of options for intervention.

The breadth of interventions identified by researchers was aided by the diversity of participants included in the studies and was enhanced by the inclusion of views from a range of HCPs (As-Sanie et al., 2019; Fernandes et al., 2020; Riazi et al., 2014).

Discussion

Prior to our review it was not clear where in the health care system diagnostic delay occurred in the health system or why they occurred. Our review is the first attempt to synthesize and analyze this evidence. On average, the diagnostic delay for endometriosis was 6.6 years across the included studies conducted by researchers and ranged from 1.5 to 11.3 years. Adolescents often face increased obstacles in obtaining a diagnosis. They

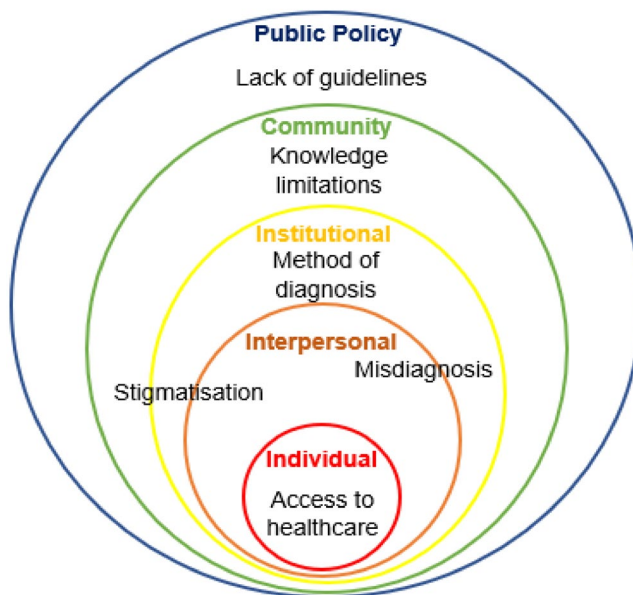
How each 'theme' relates to the Socio-Ecological Model

Figure 4. The socio-ecological model of endometriosis.

had the longest diagnostic delay reported by researchers. Delays were identified at all stages from symptom onset to receiving a diagnosis. The longest average delay was the time from gynecology referral to diagnosis (2.8 years), followed by primary care presentation to diagnosis (2.5 years), and finally, from symptom onset to primary care presentation (2.0 years). Only two study teams included a comparator group, while two included healthy controls. None of the researchers' studies provided information on women with negative findings at laparoscopy. The discrepancy in effectiveness of the introduction of specialist endometriosis centers may be due to differences in health care systems including access to care, service use, service cost, referral pathways and diagnostic guidelines.

We acknowledge the limitation of the scoping review methodology. The inclusion criteria meant that we excluded non-English language research papers and those researchers' studies focused on specific biomarkers. Additionally, all researchers' studies relied on patient recall identifying the start of their symptoms rather than prospectively tracking patients throughout their diagnostic journey or using medical records for verification. Nevertheless, the strength of our study was a clear focus following a pre-published protocol including a wide range of researchers' scholarship from all over the world whilst locating the problem and potential solutions within the socio-ecological theoretical framework.

Although the range of average delay was wider than previously reported of 3.3 – 11.7 years, the average diagnostic delay was consistent with

previous researchers' findings of 6.7 years (Nnoaham et al., 2011). Therefore, an area in critical need of further research is closer tracking of patients throughout their diagnostic journey. This should include the time from presentation to diagnosis, including cases where patients have met all criteria to be considered for surgery but do not have endometriosis, their differential diagnoses and the differences between women with a positive and negative laparoscopy. This may be facilitated by reporting endometriosis as a differential diagnosis earlier along the diagnostic journey and by ensuring primary and secondary care are better coordinated so that the diagnostic journey can be efficiently mapped. Additionally, it may be useful to have the details of the HCPs available during this journey and their role such as primary care practitioner/GP or gynecologist, and demographic details such as their gender, age, and length of service, all of which may be associated with time to diagnosis. The definition and calculation of diagnostic delay is also an area that requires further attention. Rather than studies describing the time from symptom onset to diagnosis, the current definition of diagnostic delay that was used across researchers' studies, it may be more beneficial to determine *excess delay*. This could provide comparative regional, national and international estimates of diagnostic delay for endometriosis based on average waiting times for primary care appointments, referral to gynecology and for treatment/surgery. This would enable direct comparisons of care to be made and identify differences in diagnostic delay between public and private healthcare for endometriosis. The length of delay matters in terms of cost and severity for women and the wider health system. Quicker diagnosis results in less pain, reduced severity of disease and lower incidence of comorbidities.

Accurate calculation of diagnostic delay for endometriosis may be the first step to improving guidelines, diagnostic measures, and diagnosis more broadly. Additionally, it is important to establish and address barriers to diagnosis. More investigation is needed on the effect of diagnostic delay to determine the cost-benefit of reducing diagnostic delay (Cromeens et al., 2021). Though there remains much to be done, our findings can provide the basis for further research and innovations in practice to prevent unnecessary suffering resulting from the diagnostic delays of endometriosis. The socio-ecological framework can be used to assess where improved policies may be effective, how widespread the effects might be and to provide a benchmark for their perceived benefit (financial and otherwise). Further research studies would benefit from utilizing medical records to track the number of consultations, range of HCPs, and time elapsed from initial referral to a final diagnosis and treatment. Our review provides a starting point for others to improve our understanding of where changes need to be made.

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