**Title: The experiences of endometriosis patients during primary healthcare encounters: A systematic review of qualitative evidence.**

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**Abstract:** Endometriosis affects 10% of those assigned-female-at-birth worldwide. Diagnosis typically takes between 5-12 years. This qualitative systematic review explored endometriosis patients’ experiences with primary healthcare professionals from presentation before diagnosis to post-diagnosis follow-up. Six electronic databases were searched: CINAHL, MEDLINE, Embase, PubMed, Scopus, and PsycINFO. A total of 37 articles were included and synthesised thematically. Findings showed common issues that patients were experiencing during their interactions with primary healthcare professionals, including dismissal regarding their symptoms, delayed referral to secondary care, and lack of knowledge regarding endometriosis. This review highlights a need for improved education and awareness surrounding endometriosis amongst primary healthcare professionals.

**Keywords:** Endometriosis, Primary Healthcare/General practice, Patient Experience, Qualitative Research, Systematic Review

**Word Count:** 5800 words

1. **Introduction**

Endometriosis is a chronic gynaecological condition characterised by the presence of endometrial-like tissue outside the uterus, leading to symptoms such as dysmenorrhea (pain associated with menstruation), chronic pelvic pain, dyspareunia (pain during or after sexual intercourse), and infertility (Zondervan et al., 2018). Delays in diagnosis persist (De Graaff et al., 2013) and patients report feeling dismissed or misunderstood by healthcare professionals, with diagnostic delays that can exceed eight years on average (Hudelist et al., 2012). Barriers to timely diagnosis and effective treatment not only exacerbate the physical impacts of the condition, but can result in profound psychological distress, further compromising patient wellbeing (Facchin et al., 2017; Maulenkul et al., 2024).

Primary healthcare professionals are often the first point of contact for individuals experiencing symptoms of endometriosis in the UK, with the vast majority of these interactions for initial symptoms of endometriosis being with general practitioners (GPs) or family doctors. However, evidence suggests that a lack of awareness from primary healthcare professionals about the condition and inconsistent clinical guidelines across countries contribute to suboptimal patient experiences (Seear, 2009; van der Zanden et al., 2021). Qualitative studies with both patients and practitioners highlight themes of disbelief by GPs about the severity of symptoms, normalisation of menstrual pain, misdiagnosis, and inadequate symptom management, as recurring issues within primary healthcare interactions (Davenport et al., 2023; Moradi et al., 2014). In a focus group study with 26 women with endometriosis, 13 of the 26 participants believed that knowledge of abnormal menstruation symptoms and endometriosis should be improved amongst GPs, to reduce diagnostic delays (van der Zanden et al., 2021).

Currently, the average time reported between the first consultation with a primary healthcare professional and referral to secondary care is 36-months (Davenport et al., 2023). Whilst recent studies suggest diagnostic delay and sub-optimal treatment, no qualitative systematic reviews have focused solely on interactions between endometriosis patients and primary healthcare professionals, and patient perspectives on these interactions (Cunnington et al., 2024; Davenport et al., 2023; Maulenkul et al., 2024). Therefore, this review aims to identify key barriers to effective diagnosis and management in primary care, providing insights into how healthcare systems can better support individuals with endometriosis.

1. **Methodology**

This review adhered to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRSIMA) guidelines (Moher et al., 2009) and was registered in PROSPERO (CRD42024510120). Ethical approval was not required for this study as there was no human participation.

**2.1 Eligibility criteria**

For inclusion, papers had to be published in peer-reviewed journals. They had to be primary research studies that reported on the experiences of adolescents and adults with endometriosis, regarding their interactions with primary healthcare professionals before diagnosis for presenting symptoms and/or post-diagnosis related to their endometriosis, and their views and perceptions of these interactions. It is important to note that whilst the term ‘women with endometriosis’ is used throughout this paper, endometriosis also impacts gender-diverse individuals. Inclusion criteria were not limited to those who only identified as female.

Only papers that published qualitative, or mixed methods results, where the qualitative results could be distinguished, were included. Since this review included international papers, several alternative terms for primary healthcare professionals were included in the search strategy to ensure that all relevant papers were included to reflect varied terminology between countries (e.g., general practitioner or family doctor) (Jamoulle et al., 2017). A decision aid tool was designed using the PICO ((P) Patient/Population, (I) Intervention, (C) Comparison, (O) Outcome) framework (Appendix 1) to aid in the screening process (Methley et al., 2014).

Papers including those without a formal clinical diagnosis of endometriosis, or other participants in combination with those with endometriosis (such as partners or medical professionals), were excluded, unless the data of the experiences of women with diagnosed endometriosis could be separated. This decision was made by the research team to ensure that the focus of the review remained on endometriosis, and not on other conditions for which patients may present with similar symptoms.

* 1. **Search Strategy & Study selection**

An initial exploratory search provided an overview of the literature and identified relevant search terms for a systematic review. The Cochrane Library and PROSPERO were also searched to identify systematic reviews on the topic using key terms related to endometriosis and interactions with primary healthcare professionals and ensure this review did not repeat any previously published or ongoing reviews. The University of Nottingham Research Librarian Team aided in the finalisation of search terms.

Six electronic databases were searched from their respective inception dates to March 2024: CINAHL, MEDLINE, Embase, PubMed, Scopus and PsycINFO. A full list of search terms for each database can be found in Appendix 2. The reference lists of included studies were also screened for additional studies. All studies were imported into Rayyan software and duplicates were removed (Ouzzani et al., 2016). Titles and abstracts were double screened against the eligibility criteria. SH screened all titles and abstracts, and independent second screening was conducted by MB, LJT, and NQ with 30% each, and KR with the remaining 10%. Full texts of potentially relevant articles were then obtained and double screened. SH screened all full-texts, and the rest of the research team independently screened 25% each. Those that failed to meet the inclusion criteria were excluded. Any discrepancies between the two independent screeners at title/abstract and full-text stages were resolved through discussion between SH and the other reviewer, with a third reviewer involved if further resolution was needed.

* 1. **Quality Appraisal**

All studies were assessed for quality using the Critical Appraisal Skills Programme (CASP) tool for qualitative research (Long et al., 2020). The toolkit consists of 10 questions that were used to assess the study’s rigor, relevance, appropriateness of research design, methods of data collection, and analysis, as well as ethical considerations. Studies were not excluded based on the quality assessment, but the CASP checklist was used to inform the overall assessment of the strength of the evidence presented in the review (Walsh & Downe, 2005). A CASP Checklist for the included studies can be found in Appendix 3.

* 1. **Data extraction**

Relevant data from the studies was extracted by SH. After piloting the form on 10% of the included studies, the extracts were discussed with the research team to ensure that the appropriate data was being retrieved. The following data was extracted; author(s), year of publication, country of study, methodology, number of participants, age and ethnicity of participants, and all text data for data synthesis: results from findings that were relevant to primary care (e.g., themes identified), text from the discussion section that was relevant to primary care (i.e., drawing on results and author explanations of findings), and all direct quotes from participants cited in the paper or any appendices.

Figure 1. Data Synthesis Process

* 1. **Data synthesis**

Included studies were imported into NVivo 15 for analysis (Welsh, 2002). Data was analysed using thematic synthesis (Harden & Thomas, 2008). Content from the studies that mentioned patient interactions with primary healthcare professionals (e.g., quotes from participants, relevant results, study author interpretations) was extracted for analysis, to ensure that only content relevant to the topic was analysed.

Data synthesis comprised several stages. The initial stages involved data familiarisation (reading and re-reading), before then going through each line of text and applying a code to indicate meaning and content. This was done by SH, who then discussed the codes with the research team to ensure validity. The following stages involved examining the codes for similarities and differences and then developing descriptive themes; this was done by SH, with MB also independently developing descriptive themes for 10% of studies. Descriptive themes were then grouped together and discussed with the entire research team, which led to refinements ahead of the final stage of the synthesis.

The final stage involved the generation of analytical themes, the purpose of which was to go beyond the content of the original research papers. This allowed for the revelation of new and systematic understandings of experiences of endometriosis patients during primary healthcare encounters based on the interpretation of the reviewer.

* 1. **Reflection on the review process**

SH was the primary researcher in this study. This research was conducted as part of their PhD research into barriers to endometriosis diagnosis in primary care. As well as this, SH has lived experience of receiving a delayed endometriosis diagnosis and subsequently interacting with primary healthcare professionals about endometriosis symptoms. All members of the research team were made aware of this, and were therefore able to identify when they thought the personal experiences of SH were influencing the review. Frequent discussions with the supervisory team (MB, LJT, NQ) allowed SH to reflect throughout the process and limit the risk of bias (Mann et al., 2009).

1. **Results**

3.1 Search outcomes

The search strategy identified 4540 articles (Figure 1). Following removal of duplicates, and screening of titles/abstracts and full papers against the inclusion and exclusion criteria, a total of 37 papers were included in the review.



Figure 2. PRISMA flow diagram of study inclusion process.

3.2 Characteristics of included studies

The 37 studies were conducted in 10 different countries: Australia (n=14), United Kingdom (n=12 ), United States (n=5), Ireland (n=1), Canada (n=1), Kenya (n=1), France (n=1), New Zealand (n=1), Sweden (n=1), and The Netherlands (n=1). 36 of the papers were from high-income countries, with only one study being from a low-income country. Semi-structured interviews were predominantly used, however other methods included focus groups and open-ended surveys. Participants were recruited through a variety of methods, including through endometriosis organisations, as well as through hospitals and endometriosis specialist centres. Participants ranged from ages 12 to 78. The ethnicity of participants was described in 10 studies, however even these studies consisted primarily of participants who identified as White. Sample sizes varied from 9 individuals to 2017 individuals, with the larger study samples being survey respondents. For analysis, Braun and Clarke’s method of Thematic Analysis was used by most studies, however other analysis methods included Grounded Theory, Narrative Analysis, and Interpretive Phenomenological Analysis. A table with characteristics of the included studies can be found in Appendix 4.

3.3 Thematic Synthesis

Five analytical themes were generated; (1) *The Journey Begins: Seeking Help Amid Uncertainty*, (2) *The Struggle to be Heard: Advocacy Against Dismissal,* (3) *Navigating the Maze: Delays and Fragmented Care*, (4) *Emotional Repercussions and Glimpses of Relief* and, (5) *Areas of Improvement: Changing a Broken System*. Each analytical theme is described in detail below.

3.3.1 The Journey Begins: Seeking Help Amid Uncertainty

A recurring experience reported across six of the studies was that endometriosis symptoms began during adolescence, often within a few years of menarche (E. Denny, 2004; Denny & Mann, 2008; Moradi et al., 2014; Rowe et al., 2021; van der Zanden et al., 2021; Whelan, 2007). Many young women initially believed their symptoms – commonly severe menstrual pain and heavy bleeding – were a normal part of menstruation due to the widespread societal belief that menstrual discomfort is to be expected. This normalisation delayed the recognition of these symptoms requiring medical attention – “*I had witnessed my mum with so many problems in her life… So, that’s what she endured, so when I started getting period pain in my teenage years, I just thought that was fairly normal in actual fact*” (Markovic et al., 2008, p.355).

In some cases, patients described being encouraged by their parents to seek medical advice out of concern of abnormality of their symptoms. However, even when concerned parents advocated for their daughters, they were often met with dismissive attitudes from primary healthcare professionals. For instance, one participant recalled being told by her doctor that severe pain was simply something she would have to endure, reinforcing the expectation that menstrual suffering was inevitable – *“When I continued to be ill, when I had my period, my mother took me to the family doctor and he said, this is just, this is what a women has to put up with – I can still remember the words – and this is your child’s lot in life...*” (Markovic et al., 2008, p.356). The normalisation of menstrual problems by both the patient and healthcare professionals was reported on in half of the included studies.

For many women, embarrassment and stigma surrounding menstrual health resulted in them delaying or avoiding further medical consultations. The taboo nature of discussing reproductive health meant that women often internalised their symptoms, sometimes for decades, before seeking help. For example, one participant shared that she endured twenty years of suffering before receiving a diagnosis, emphasising the role of silence and shame in prolonging delays – “*I also internalised shame and the taboo of speaking up about it, which meant 20 years of suffering before having a diagnosis*” (Krebs & Schoenbauer, 2020, p.1019).

When women did consult a primary healthcare professional, they reported being prescribed oral contraceptives – colloquially referred to as ‘the Pill’ - or painkillers as the first line of treatment. While some experienced temporary relief, others rejected this option due to concerns about side effects or inefficacy. Many patients felt that these treatments merely masked their symptoms rather than addressing the underlying cause and voiced their frustration at this - “*I don’t want to be on the Pill! I want to know what’s causing the pain*” (Ballard et al., 2006, p.1298). Whilst guidelines, as well as recent findings, have reported that the use of oral contraceptives is beneficial in suppressing the menstrual cycle, this justification is rarely explained to patients by their primary healthcare professional, leaving them concerned as to what the root cause of their symptoms could be. As well as this, it is necessary for primary healthcare professionals to identify the reason for the patients symptoms, not just to identify a suitable treatment plan for patients, but also to ensure that they feel as if their concerns have been ‘listened to’ and addressed, as highlighted in the above quote.

Despite reporting ongoing pain, endometriosis was not commonly considered as a potential diagnosis during initial medical visits. In some cases, primary healthcare professionals conducted investigations such as blood work or ultrasounds. Whilst these investigations were perhaps beneficial to rule out other potential pathologies, this - compounded with inconclusive results related to suspected endometriosis - further delayed recognition of the disease. One participant expressed frustration over what investigations were understood to be necessary for diagnosis - “*I later learnt that the excessive persistence of my male GP to perform these types of investigations was pointless, as endometriosis can only be diagnosed by undergoing a laparoscopy/laparotomy procedure*” (Walkden, 2024, p.2).

The normalisation of menstrual pain was perceived to play a common role in delaying diagnosis. Many women were told by doctors that their symptoms were simply an unfortunate but typical aspect of being a female. One participant recalled being dismissed with the comment, “*You are unlucky. You suffer from bad periods*” (Elaine Denny, 2004, p.644). This normalisation, by both patients and primary healthcare professionals, suggested to patients that there was no need for further investigation, or any investigation at all.

3.3.2 The Struggle to be Heard: Advocacy Against Dismissal

As women continued their medical journeys, many encountered repeated dismissal and invalidation from primary healthcare professionals. A common theme across studies was the need to attend multiple appointments with a primary healthcare professional before their concerns were acknowledged (Walkden, 2024) – “*It took numerous years and visits to my GP to get this addressed. It makes you feel as though you are making symptoms up, before you are finally referred to gynaecology*” (Hearn et al., 2024, p.6).

Another common experience reported amongst women who had taken oral contraceptives for multiple years, was that they only discovered their condition once they stopped using the Pill. After they stopped using oral contraceptives, they found their symptoms returned or worsened. Ironically, some primary healthcare professionals then used this as a reason to dismiss their concerns, claiming that women on the Pill no longer understood what “real” menstrual pain felt like – “*The doctor told me that the problem nowadays is that because women take the Pill, they don’t know what a real period is. It’s just the most dismissive, unhelpful comment ever*” (Ballard et al., 2006, p.1298).

Dismissal by primary healthcare professionals was not limited to early consultations. Many women continued to feel unheard even after years of seeking medical attention: “*My GP had never taken me seriously. Eighteen years I’ve been putting up with the pain*” (Denny & Mann, 2008, p.113). The cumulative effect of these repeated dismissals had profound emotional and psychological consequences, leading many women to question the legitimacy of their own pain – “*The damage that occurred through GPs not listening, not taking symptoms seriously, trivialising these women’s experiences and telling young women that their symptoms were ‘in their heads’ was deep and serious*” (Cox et al., 2003, p.7).

In addition to minimising symptoms, some primary healthcare professionals perpetuated harmful myths about endometriosis. Several participants reported being advised to become pregnant as a means of managing their symptoms – “Some of the women reported that their GP would repeat medical myths that the woman knew to be untrue, such as that having a baby would cure their pain” (Denny & Mann, 2008, p.113). Others were incorrectly informed that a hysterectomy would cure their condition, despite medical evidence to the contrary – “*Notable examples include advice from a GP to ‘embrace feeling unwell*’ *and the suggestion to a woman in her mid-twenties that a hysterectomy was the only remaining treatment option*” (Lightbourne et al., 2024, p.318). This theory has been disproven, with studies finding it is still possible for endometriosis symptoms to continue in some patients after a hysterectomy (Rizk et al., 2014).

Faced with persistent medical dismissal, many women became self-advocates conducting independent and seeking support from online communities. For some, this knowledge empowered them to demand referrals to specialists, while others took it upon themselves to educate their primary healthcare professional about endometriosis. In one particular case, a participant noted that her self-advocacy not only secured her diagnosis but also encouraged her doctor to be more aware of the condition for future patients – “…*my GP now said she knows more as a result of having me as a patient and has read more and would like to know more in depth information on endometriosis*” (Sbaffi & King, 2020, p.10).

3.3.3 Navigating the Maze: Delays and Fragmented Care

Misdiagnosis was a common theme across several of the studies. Due to the complexity and variability of endometriosis symptoms, the condition was often mistaken for other disorders such as irritable bowel syndrome (IBS) or depression – “*My GP’s daughter had [endometriosis] and never even mentioned a word about it but misdiagnosed me with IBS. Didn’t even place me on the pill. Just given Buscopan [antispasmodic for IBS]. I believed I had IBS as this is what I was told and did not look any further, I assumed my GP was a well-educated man*” (Sbaffi & King, 2020, p.10-11). One study found that seven women were initially diagnosed with IBS by their primary healthcare professional (Denny & Mann, 2008), despite only one experiencing gastrointestinal symptoms, while others were misdiagnosed with anxiety or told their pain was psychological – “*I was told by two male GPs that I was neurotic and depressed*” (Krebs & Schoenbauer, 2020, p.1019).

Structural barriers within healthcare systems were also perceived to contribute to delays in diagnosis and treatment. In many countries, patients must first consult a primary healthcare professional before being referred to a specialist. This system, while intended to streamline care, often led to prolonged delays, as primary healthcare professionals acted as gatekeepers, viewed as reluctant to escalate cases – “*He was always very reluctant to pass me on [to a gynaecologist] which has been a lot of wasted time*” (Denny & Mann, 2008, p.113) . Some women reported that they had to push aggressively for referrals, while others resorted to “*doctor-shopping*,” visiting multiple physicians until one took their concerns seriously (Cox et al., 2003; Evans et al., 2022; Krebs & Schoenbauer, 2020; Manderson et al., 2008; Sirohi et al., 2023).

Younger patients faced additional challenges, as primary healthcare professionals hesitated to conduct certain examinations or refer adolescents to specialists as they were deemed “too young” to have a ‘serious’ gynaecological condition (Denny & Mann, 2008, p.113; van der Zanden et al., 2021, p.336).

3.3.4 Emotional Repercussions and Glimpses of Relief

The emotional toll of medical dismissal was profound. Many women internalised the message that their pain was unimportant, leading to feelings of isolation and hopelessness. In some cases, patients even began to doubt that their pain was real and started to question whether it was in their heads – “..*you just get convinced that “no I’ve checked it all out and everybody says I’m OK so I must be OK*”” (Lightbourne et al., 2024, p.314). Some stopped seeking medical help altogether, believing that further attempts would only result in more invalidation – “*I ignored it [the advice to get pregnant] and continued with my high school studies. But it likely led to me actively avoiding having to visit that GP*” (Sirohi et al., 2023, p.6).

Despite these negative experiences, receiving an official diagnosis provided a sense of validation for many women. After years of questioning their own experiences and internalising the disbelief of primary healthcare professionals, a confirmed diagnosis affirmed to patients that their pain was real. For some, this moment was pivotal in their journey, allowing them to pursue appropriate treatment and support – “*Receiving a diagnosis was constructed as a relief because the trivialisation of symptoms they have experienced, especially from medical professionals such as GPs, had led them to doubt their own bodily experiences and their own sanity*” (Cole et al., 2020, p.181).

Despite all of the included studies reporting on frequent negative encounters with primary healthcare professionals, nine of the 36 studies also reported on positive interactions with primary healthcare practitioners, who provided compassionate care. One woman described a supportive primary healthcare practitioner who not only facilitated her diagnosis but also connected her with a counsellor to help her manage the psychological impact of her condition – “*I’m really lucky that my GP… did have an in-house counsellor… the illness was giving me major anxiety, so I actually end(ed) up seeing the inhouse counsellor about that (anxiety) which was really helpful*” (Handelsman et al., 2023, p.3).

3.3.5Areas for Improvement: Changing a Broken System

Across studies, participants and researchers identified key areas for improvement at patient, professional and systematic levels. Many women had never heard of endometriosis before their diagnosis, highlighting a critical gap in public awareness – “*Prior to diagnosis 39 out of 49 women had not heard about endometriosis highlighting a significant lack of community awareness and knowledge about endometriosis*” (Fernley, 2021, p.42). Some suggested incorporating menstrual health education into school curriculums to help young women recognise symptoms earlier (Seear, 2009, p.1225).

At a service level, studies showed that primary healthcare professionals needed better training in recognising endometriosis. Some participants reported that their primary healthcare professional had never heard of the condition – “*He actually said to me “I don’t know this condition at all*” (Denny & Mann, 2008, p.113).

Several studies suggested that systematic changes, such as following self-referral to specialists and improving diagnostic pathways, could further reduce delays (Denny & Mann, 2008; Fernley, 2021; Moradi et al., 2014; Requadt et al., 2024; Rowe et al., 2021; Seear, 2009). Some study authors suggested, based on their findings, that patients in countries with direct access to gynaecologists received diagnoses sooner than those in referral-based systems – “*The national French health system enables self-referral to a gynaecologist and does not place restrictions around the ordering of MRIs by general practitioners*” (Ilschner et al., 2022, p.6).

A couple of studies suggested that improving endometriosis care requires a multi-pronged approach, addressing public awareness, medical education, and systemic barriers (Ballard et al., 2006; Elaine Denny, 2004). Study authors suggested that by fostering a culture of empathy and informed decision-making, healthcare systems can work toward reducing diagnostic delays and improving the overall experience of women with endometriosis.

**4. Discussion**

This systematic review highlights the persistent challenges faced by individuals with endometriosis when seeking care within primary healthcare settings. Findings highlight medical dismissal, misdiagnosis, and fragmented care as significant negative experiences for women across their endometriosis journey. This journey stretched from seeking a diagnosis, (which is often delayed) to ongoing management typically involving suppressing the menstrual cycle and treating pain, as well as any other symptoms.

A key theme across all studies was the normalisation of menstrual pain, both by patients and primary healthcare professionals. Many women were socialised to believe that severe pain was a normal part of menstruation, leading to delayed healthcare-seeking behaviour (Seear, 2009). Seear further suggested that the societal discourse around menstruation contributes to self-silencing and reluctance to report symptoms. Additionally, primary healthcare professionals often reinforced these beliefs by dismissing concerns or providing reassurances rather than investigations, which echoes previous findings that gender biases in medicine, such as the normalisation of gynaecological pain, contribute to the trivialisation of women’s pain (Samulowitz et al., 2018).

The prescription of oral contraceptives and analgesics as a first-line response was common in patient encounters, mirroring existing research that highlights how hormonal treatments are often used as a default strategy (Husby et al., 2003). While hormonal therapy can alleviate symptoms for some women, primary healthcare professionals often utilise them for what patients perceive as a temporary solution that masks underlying pathology, thereby delaying referral to gynaecologists (Greene et al., 2009). As seen in our findings, some participants were frustrated by these prescriptions, as they felt that they were used to suppress symptoms rather than explore the root cause of their pain. These findings are of concern as practice appears to contravene guidelines; for instance, according to National Institute for Clinical Excellence (NICE) guidelines for Endometriosis, oral contraceptives are only to be recommended for those with a confirmed diagnosis of the disease, only after they have had surgical intervention (NICE, 2024).

Whilst recent studies have shown that hormonal treatment can be beneficial for patients with endometriosis as they can aid in suppressing the menstrual cycle, thereby minimising the progression of the disease (Piriyev et al., 2025), this fact is not often explained to patients. It is unclear as to whether this is due to a lack of knowledge on the part of the primary healthcare physician, or due to other factors, such as time constraints in consultations. Nonetheless, these findings suggests that the prescription of oral contraceptives, such as the Pill or the Mirena Coil, should be considered by primary healthcare physicians, but should not be solely relied on, and should also discussed in detail with patients, so that they are aware as to why they have been prescribed these treatment options and not left feeling like this is a ‘temporary solution’.

Another common experience shared by study participants was being misdiagnosed with conditions such as IBS or depression, reflecting findings from Ballard et al. (2008), which indicate that women with endometriosis are more likely to receive an alternative diagnosis before an endometriosis diagnosis (Ballard et al., 2008). This highlights the overlap between the endometriosis symptoms and other chronic conditions, which may contribute to physician uncertainty and diagnostic confusion. A potential solution offered amongst some of the included studies involves interdisciplinary diagnostic teams, where gastroenterologists, gynaecologists, and pain specialists collaborate to differentiate between endometriosis and similar conditions more effectively. A multidisciplinary approach to treating persistent pelvic pain has previously been found to be effective, by reducing the number of patients presenting to emergency departments with these symptoms (Wilkinson et al., 2021).

It was evident that repeated medical dismissal had severe psychological consequences, with many patients reporting feelings of self-doubt, frustration, and hopelessness. This aligns with previous studies that found that women with chronic pain conditions often feel unheard and dismissed by healthcare providers, exacerbating psychological distress and medical gaslighting (Braksmajer, 2018; Werner & Malterud, 2003). The emotional burden of delayed diagnosis extends beyond the frustration of untreated symptoms, as it also fosters mistrust in healthcare systems (Ballard et al., 2006). Some participants in this review reported actively avoiding GP consultations due to prior experiences of invalidation, a finding consistent with Denny (2009), who noted that many women with endometriosis develop avoidance behaviours due to repeated negative medical interactions.

Despite frequent negative encounters with primary healthcare practitioners, another emerging theme in this review was self-advocacy as a means of overcoming medical barriers. Many women reported independently seeking out information and research on the condition to self-educate, joining patient advocacy groups, or actively educating their doctors about endometriosis. This aligns with research by Culley et al. (2013) which emphasises the critical role of patient networks in endometriosis care. Social media and online communities have increasingly provided a platform for knowledge and exchange, allowing women to identify their symptoms, push for referrals, and seek alternative therapies (Whelan, 2007).

However, while self-advocacy and self-education is empowering, it also places an undue burden on patients, who must fight to be taken seriously. The expectation that women must persistently challenge their doctors to receive adequate care reflects a broader failure within primary healthcare systems. Increased healthcare professional education and awareness campaigns may help to shift some of this burden away from patients and onto healthcare providers, ensuring that women do not have to “prove” the validity of their own pain.

Furthermore, the intersection of gender and pain perception likely plays a role in the way endometriosis is managed in primary care. Research suggests that women’s pain is more likely to be perceived as psychological rather than physiological, leading to increased rates of antidepressant prescriptions or misdiagnoses such as anxiety or depression (Hamberg, 2008). Our findings reinforce this, as several participants were told that their pain was “in their head” or due to stress, contributing to a cycle of diagnostic delay and psychological distress (Culley et al., 2013; Krebs & Schoenbauer, 2020).

Another issue highlighted in this review is the fragmentation of care and the challenges women face in accessing specialist treatment. Many participants described a gatekeeping dynamic in primary care, where GPs acted as barriers to specialist referrals rather than facilitators of care. This issue has been previously noted in studies analysing the structural inefficiencies of referral-based healthcare systems (Dantkale & Agrawal, 2024). In countries where direct specialist access is permitted, such as France, diagnostic delays appear to be reduced (Chapron et al., 2019). This suggests that restrictive referral pathways exacerbate diagnostic delays, making self-referral mechanisms or expedited gynaecological assessments a potential avenue for system-level reform.

4.1 Recommendations for Improvement

The findings from the included studies in this review suggest several areas for systemic improvement in endometriosis care. First, medical education must be enhanced to improve primary healthcare professional’s awareness and recognition of endometriosis symptoms, with a specific focus on how to make a provisional diagnosis of endometriosis after ruling out other underlying conditions, as well as the use of hormonal treatments to suppress the menstrual cycle and prevent the disease from worsening. Despite its prevalence, research suggests that medical curricula devote limited time to menstrual health disorders, leading to knowledge gaps among primary healthcare professionals (Dixon et al., 2021). Increased training in gynaecological pain conditions at both undergraduate and postgraduate medical training, may lead to earlier consideration of endometriosis as a differential diagnosis.

Second, diagnostic pathways should be standardised, ensuring that patients presenting with severe dysmenorrhea receive timely referrals to gynaecologists. Some studies suggest that implementing clinical guidelines for suspected endometriosis – such as mandatory gynaecological evaluation for patients with chronic pelvic pain – could reduce diagnostic delays and improve early intervention rates (Tewhaiti-Smith et al., 2022)

Third, healthcare policies should be reformed to reduce barriers to specialist access. Given that delayed referrals are a major factor in prolonged diagnosis, self-referral pathways or direct access to secondary care for patients with who suspect they have endometriosis should be considered (Chapron et al., 2019).

4.2 Strengths and Limitations

This is the first review to examine the experiences of endometriosis patients with primary healthcare professionals and it provides valuable insight into barriers and factors that play a role in the endometriosis pathway. However, unclear titles or abstracts and poor indexing could have left out relevant studies. Another limitation of this review is the exclusion of studies that did not specify whether the healthcare professionals mentioned were primary healthcare professionals or associated with secondary care – for example, if a study only referred to healthcare professionals as “doctors” and did not specify the speciality, this study was not included, even though it potentially may have been referring to primary care medical professionals. Therefore, it may have possible that relevant studies were excluded due to the terminology used by patients, or even researchers themselves.

Whilst all studies were screened by two reviewers at both the title and abstract screening and full-text screening stages, thematic analysis of the data from the included studies was undertaken by the lead author. However, findings and themes were discussed with the research team at each stage of the analysis process.

Most of the included studies were conducted in Western countries and concentrated on female patients’ experiences. Whilst there have been some studies more recently that have reported specifically on the experiences of gender diverse individuals with endometriosis, these studies did not meet the inclusion criteria as they did not report specifically on interactions with primary healthcare professionals (Carvalho et al., 2024; Eder & and Roomaney, 2024; Jeffrey et al., 2024). This highlights a need for further research to be done on experiences of endometriosis patients with primary healthcare professionals in developing countries and amongst those who do not identify as female or are from minority backgrounds.

**5. Conclusion**

In 2024 the UK Parliament published a report on reproductive health conditions, which highlighted the lack of adequate care for those seeking care for reproductive health conditions, such as endometriosis. The report highlighted a prevalent ‘lack of education and “medical misogyny” across the country. In particular, it was clear through the report that primary care played a significant role in this lack of adequate care, and there was a need for GPs in particular to receive better education and training on conditions such as endometriosis. The report also called for improvements to current NICE guidelines, and further systems to be put in place to support those with endometriosis (Committee, 2024).

The findings from this systematic review echo the remarks made in this report, by highlighting persistent challenges faced by endometriosis patients in primary care, including medical dismissal, delayed diagnosis, and structural barriers. Contributing factors include normalisation of menstrual abnormalities, lack of awareness, and fragmented healthcare. Addressing these issues requires systemic reforms such as improved healthcare professional education, standardised diagnostics, and better referral pathways. While patient advocacy is important, the management and referral process should be agreed between healthcare professionals and patients, with expeditious further investigations in primary and specialist care to confirm or exclude diagnosis. A shift in the knowledge and practice of primary care professionals is essential to ensure timely and compassionate treatment.

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**Declaration of Interest Statement**

The authors declare that they have no conflict of interests.

**Data Availability Statement**

The data generated in this study are included in this published article or in the supplementary material.

**Appendix**

* Appendix 1: Decision Aid Tool
* Appendix 2: Search Terms
* Appendix 3: Critical Appraisal Table
* Appendix 4: Study Characteristics Table

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