

Barriers to a Timely Diagnosis of Endometriosis: A Qualitative Systematic Review.

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1 **Barriers to a Timely Diagnosis of Endometriosis: A Systematic**
2 **Review and Qualitative Synthesis**

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5 **PRECIS**

6 Delays and barriers to an endometriosis diagnosis is multifactorial; this qualitative systematic review

7 highlighted themes of individual, interpersonal, healthcare and knowledge factors with the

8 condition.

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23 **ABSTRACT**

24 **OBJECTIVE**

25 The diagnosis of endometriosis, a common gynaecological condition, is characterised by delays of up
26 to eleven years. During this time, women may experience persistent symptoms that affect their
27 quality of life, productivity, and relationships, and the disease may progress. It is therefore a priority
28 for us to understand the factors that contribute towards this delay so that the diagnostic pathway
29 can be improved. We sought to examine the barriers to the timely diagnosis of endometriosis, from
30 the perspective of affected women and healthcare professionals, using a qualitative evidence
31 synthesis.

32

33 **DATA SOURCES**

34 We searched MEDLINE, PsycINFO and CINAHL using combinations of the synonyms of
35 “endometriosis”, “diagnosis”, and “qualitative research”. The search was restricted to English-
36 language articles from database creation until May 2022.

37

38 **METHODS OF STUDY SELECTION**

39 The initial search yielded 899 articles. Studies were included if they explored the experiences or
40 views of affected women and/or healthcare professionals on the diagnosis of endometriosis, used
41 qualitative methods for data collection and data analysis. Risk of bias was assessed using the CASP
42 checklist.

43

44 **TABULATION, INTEGRATION, AND RESULTS**

45 Thirty seven articles were considered for full review, with thirteen eligible papers, identified for
46 inclusion. Thematic synthesis was used to identify four key themes; a) individual factors (n=6), b)
47 interpersonal influences (n=6), c) health system factors (n=13), and d) factors specific to
48 endometriosis (n=8). These encompassed twelve sub-themes which represented barriers to the
49 diagnosis of endometriosis; a) difficulty establishing pathological symptoms from normal
50 menstruation, b) menstrual stigma and the normalisation of menstrual pain, c) poor attitudes and
51 lack of training for healthcare professionals, delayed referrals to specialist services, poor explanation
52 of oral contraceptive pill use in the diagnostic process, and d) variability in presenting symptoms,
53 overlap with other conditions, lack of a non-invasive method of diagnosis, and concerns about the
54 value of a diagnosis.

55

56 **CONCLUSION**

57 This review identified barriers to the timely diagnosis of endometriosis from the perspective of
58 affected individuals and healthcare professionals. It highlights areas for improvement along the
59 diagnostic pathway, which may guide future strategies to reduce the delay. Further research to
60 identify the facilitators to diagnosis and would be beneficial.

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68 INTRODUCTION

69 Endometriosis is an inflammatory condition affecting women, in which endometrial tissue (the lining
70 of the uterus) is found at sites outside of the uterus¹. Approximately 10% of women of reproductive
71 age are affected (190 million women worldwide)^{2,3}. The symptoms associated with endometriosis
72 exert a substantial burden on the lives of individuals and on society as a whole⁴. Endometriosis is
73 associated with reduced health-related quality of life (HR-QOL), reduced mental wellbeing, adverse
74 effects on intimate relationships, and reduced social activity^{4,6}. It is also associated with reduced
75 productivity at work or school⁴, which contributes towards a significant loss of income⁵.
76 Endometriosis is estimated to cost the United Kingdom (UK) economy over £8.2 billion a year due to
77 lost productivity and healthcare costs, which is comparable to other chronic conditions, such as
78 diabetes mellitus and rheumatoid arthritis⁷.

79

80 The burden of endometriosis is prolonged by a well-established diagnostic delay; there is an average
81 of between four and eleven years from the onset of the first symptom to receiving a diagnosis⁵. This
82 delay is seen worldwide, even in countries with access to universal healthcare⁵.

83 There has been limited research to ascertain the reasons for the diagnostic delay in endometriosis.
84 This systematic review aimed to explore the barriers to the timely diagnosis of endometriosis from
85 the perspective of affected women and the healthcare professionals involved in the diagnosis.

86

87 SOURCES

88 A scoping search was undertaken to provide an overview of the literature and identify relevant
89 search terms for a subsequent systematic review. The SPIDER framework⁸ was used to identify key
90 concepts, including “endometriosis”, “diagnosis” and “qualitative research”, which provided free-
91 text terms for initial searches of MEDLINE, The Web of Science, and Google Scholar. The first 100

92 results from each database were screened. The titles, abstracts, and index terms of relevant studies
93 were reviewed, and a list of additional search terms was developed (Supplementary Tables 1-2).

94 The Cochrane Library and PROSPERO were searched to identify systematic reviews on the topic,
95 using the key terms “endometriosis” and “diagnosis” to ensure this review did not repeat any
96 previously published or ongoing reviews.

97 The research question was divided into key concepts based on the SPIDER framework⁸.

98 Combinations of the free-text terms and Medical Subject Headings (MeSH) that had been identified
99 by the scoping search were then trialed for each concept until an acceptable balance between
100 sensitivity and specificity was reached.

101 Qualitative search filters, designed by the University of Texas were also added to the final search
102 strategy⁹. Filters to further narrow the search, for example, based on the characteristics of the study
103 population, date of publication, or study design were not used.

104 Three databases were used to identify relevant studies:

105 MEDLINE via Ovid (1946-May 2022)

106 PsycINFO via Ovid (1887- May 2022)

107 The Cumulative Index to Nursing and Allied Health Literature (CINAHL) via EBSCO (1937- May 2022).

108 Searches were initially carried out in July 2021 and then repeated in May 2022; all identified records
109 were exported to Rayyan¹⁰. A supplementary search was also performed using the CLUSTER
110 (Citations, Lead Authors, Unpublished materials, Scholar searches, Theories, Early examples, and
111 Related Projects)¹¹ procedure.

112 Following the identification of key “pearl” papers, forward citation searches were carried out using
113 the Web of Science and the ‘Related Article’ functions on MEDLINE and CINAHL. The reference lists
114 of included studies and the name of the lead author were also searched. Authors were not

115 contacted directly, but efforts to identify their work included searching their publications lists and
116 institutional repositories. Finally, all volumes of the ‘British Journal of Obstetrics and Gynaecology’
117 and the ‘Journal of Endometriosis and Pelvic Pain Disorders’ published between January 2011-May
118 2022 were searched for relevant articles using the key terms “endometriosis” and “diagnosis”.

119 Studies were selected using pre-determined inclusion and exclusion criteria. To be included in the
120 review, the study population must have included women with a diagnosis of endometriosis, and/or
121 healthcare professionals (regardless of speciality) that had experience of diagnosing the condition.
122 The ESHRE guidelines¹² suggest a two-step approach in which a diagnosis can be made clinically
123 (based on the history, pelvic examination, and ultrasound imaging) before a trial of treatment, or by
124 direct visualisation during laparoscopic surgery¹³. Accordingly, laparoscopy is usually offered only to
125 patients with negative imaging results or where empirical treatment was unsuccessful or
126 inappropriate¹². We therefore included patients that had been diagnosed in either way. This
127 definition was used successfully in a previous Cochrane review and ensured that the review captured
128 patients’ experiences of both methods¹⁴.

129

130 There were no limitations placed on the age of the participants, the severity of the endometriosis,
131 the period of time since diagnosis, or the sample size. As a range of healthcare professionals may be
132 involved in the diagnosis, studies involving any specialist with experience of the condition were
133 included. This review was limited to studies available in the English language, and published studies,
134 but there was no limit placed on the date of publication for searches via OVID.

135

136 As this study aimed to explore participants’ experiences and reflections on the existing factors
137 contributing to the delayed diagnosis of endometriosis, only non-interventional, qualitative studies
138 focusing on the participants’ views on the diagnostic pathway were included. Studies focusing on the

139 general experience of having the condition, treatment, second-hand accounts, or on a specific
140 intervention were therefore excluded.

141 Qualitative studies were sought as, by design, these approaches delve deeper into the experiences
142 of a patients' condition; something quantitative surveys for example, would struggle to achieve.
143 Included studies must therefore have used an appropriate qualitative method for data collection and
144 data analysis such as focus groups or interviews analysed using thematic analysis, framework
145 analysis, content analysis or constant comparison. Data was also extracted from the qualitative
146 elements of relevant mixed-methods studies if there was adequate information to do so.

147

148 **STUDY SELECTION**

149 Records were filtered by a single reviewer (lead author). A title search was undertaken followed by a
150 review of the abstracts and those which did not meet the eligibility criteria were excluded. The full
151 texts of the remaining studies were retrieved using the research centre online search tool or by
152 contacting the research centre library, and those that met the inclusion criteria were chosen for the
153 data synthesis.

154 All decisions were recorded on Rayyan¹⁰ and any uncertainties about the eligibility of a study were
155 discussed with the corresponding author. Multiple reports from the same study were treated as a
156 single study, with reference made to all publications.

157 Relevant studies were appraised using the Critical Appraisal Skills Programme (CASP) checklist for
158 qualitative research¹⁵ but were included in the final review, regardless of methodological quality.

159 The CASP checklists are freely available, and easy to use materials to aid health professionals to
160 critique journal articles by highlighting the key areas to focus; different checklists are available for
161 varying study designs. Both Cochrane and CASP themselves recommend against rejecting studies

162 based on an arbitrary cut-off¹⁶ as including studies of lower quality may strengthen the evidence for
163 findings in the synthesis^{17 p.33}.

164 Standardised data extraction forms were used to provide consistency, reduce the risk of bias, and
165 improve the validity of the data collection process¹⁷. The author, year of publication, country, setting,
166 research question and aim, study design, the participant characteristics, the method of data
167 collection, and the method of data analysis were recorded. Quotes from study participants ('first
168 order constructs'), along with existing author interpretations ('second-order constructs') were then
169 collected. Thematic synthesis was used to analyse the findings of the included papers¹⁸. We
170 acknowledged the positionality of the lead author, a White female working as a junior doctor in the
171 UK, and reflected on how we could minimise its influence on the interpretation of results.

172 GRADE-CERQual¹⁹ was then used to evaluate the findings of this review and was recorded in a
173 GRADE Evidence Profile. This is an approach to judge how much confidence to hold in qualitative
174 evidence synthesis, assessing four key areas of methodological limitations, coherence, adequacy,
175 and relevance. A GRADE Evidence Profile is the name ascribed to the summary presentation of key
176 information from the articles in the synthesis. Due to the original nature of this project (a Masters
177 dissertation) the review protocol was not pre-registered.

178

179 **RESULTS**

180 995 records were identified, including 936 records from the electronic databases and 59 potentially
181 relevant records from the supplementary searches. Following the removal of duplicates, 899 unique
182 papers remained. 826 papers were excluded during the title review and 36 following the abstract
183 review. A further 24 papers were excluded following the full-text review: nine focused on an aspect
184 of endometriosis other than the diagnosis, six focused on a disease other than endometriosis, four
185 did not have an appropriate qualitative research design, three did not explore the diagnosis from the

186 perspective of affected women or healthcare professionals, and one was a conference abstract of an
187 included study. In addition, one paper²⁰ could not be retrieved, despite assistance from the library
188 within the research centre and attempted contact with the author.

189 In total, 13 papers, reporting on 12 studies, were included in the qualitative synthesis (Figure 1); the
190 titles and characteristics of the included papers are provided in Table 1. All were published as journal
191 articles between 2003 and 2022. Of these, five were conducted in the United Kingdom (UK)²¹⁻²⁵,
192 three in Australia²⁶⁻²⁹, two in the United States of America (USA)^{30,31}, one in Sweden³², and one in the
193 Netherlands³³. All studies were therefore carried out in high-income countries, with the majority
194 having universal health coverage.

195 Ten of the studies used a qualitative research design^{21-25, 27-29,31-33} and two used mixed methods with
196 adequate information provided to extract the qualitative data^{26,30}. Three studies used a narrative
197 approach^{21,24,27,28}, two used grounded theory^{22,25}, and one used phenomenology²⁹. The remaining
198 studies did not specify their methodological background.

199 The samples of nine studies^{21-24,26-29,31,32} were made up exclusively of women with endometriosis and
200 one³⁰ included women with endometriosis as part of their larger sample. The sample sizes ranged
201 from 9 to 222, with data being collected from 476 participants in total. The age of participants
202 ranged from 16-78 years, although one study did not report the age of their participants²¹. Few
203 papers reported further demographic information; those that did described a predominantly white,
204 working class population^{27/28,31}. In most of the studies, participants were recruited using convenience
205 sampling methods from specialist endometriosis centres and non-profit organisations, with snowball
206 sampling used as an additional method in two studies^{21,30}.

207 Six of the studies only included participants who had received a laparoscopic diagnosis of
208 endometriosis^{21-24,29,31}, whereas three included those who had received a clinical diagnosis²⁶⁻²⁸. The
209 severity of endometriosis was only discussed in one paper²², which stated 58.4% of the women had
210 mild endometriosis, 33.3% had moderate to severe endometriosis, and 8.3% had deep infiltrating

211 endometriosis. Most participants had experienced a delay from the onset of symptoms to diagnosis,
212 which ranged from an average of 3.8 to 8.1 years.

213 The samples of the remaining two studies were made up exclusively of healthcare professionals that
214 either had experience of diagnosing endometriosis^{25,33}, or were expected to diagnose endometriosis
215 as part of their primary job role²⁵. Zale³⁰ also included healthcare professionals in their sample in
216 addition to patients. The number of healthcare professionals included in these samples ranged from
217 4-43, with data collected from 89 professionals in total; 85 general practitioners, two physicians that
218 had specialised in obstetrics and gynaecology (neither specialising in endometriosis), one radiologist,
219 and one internal medicine physician. Participants were recruited using convenience methods from
220 physician registers and from professional events. The number of years of experience in diagnosing
221 endometriosis ranged from 0 (doctors in training) to >20 years.

222 The phenomenon of interest in all studies was the diagnosis of endometriosis. Four studies gathered
223 information on affected women's experiences of receiving a diagnosis of endometriosis
224 specifically^{23,24,26,32}, five focused on women's experiences of endometriosis in general, with the
225 diagnosis as a significant topic^{21,22,27-29,31}, and two aimed to explore healthcare professionals'
226 experiences of diagnosing and managing endometriosis^{25,33}. Zale (2020)³⁰ explored both patient's
227 and physician's experiences.

228 The primary outcome of all studies was the experiences, views, beliefs, or attitudes of the affected
229 women and/or the healthcare professionals. Seven studies gathered this information using semi-
230 structured interviews^{21-25,30,32}, one used unstructured interviews^{27/28}, three used focus groups^{26,29,33}
231 and one used an open-ended questionnaire³¹. All interviews and focus groups were audio-recorded
232 and were transcribed for analysis. Eight of the studies used inductive thematic analysis^{21,23-24,26-28,30,31}
233 with grounded theory²², the Modified Stevick-Colaizii-Keen method³², content analysis³³, and
234 framework analysis²⁵ all used in one study each. The methodological quality of the studies was
235 generally very good, including one²² which was of the best quality according to CASP¹⁵ (Table 2).

236 Thematic analysis of the studies highlighted multiple factors, that act as barriers to the timely
237 diagnosis of endometriosis. These were categorised into four overarching analytical themes focusing
238 on a) individual factors, b) interpersonal influences, c) health system factors, and d) factors specific
239 to our knowledge of endometriosis. Twelve sub-themes are presented within these categories.
240 Verbatim quotations, taken directly from the primary studies, are used throughout to illustrate the
241 themes and to provide evidence for the reviewer's interpretations³⁴.

242 Individual factors

243 Individual factors contributed to the prolonged period between the onset of symptoms and the
244 seeking of medical advice, which accounted for up to half of the diagnostic delay²⁷. This concept was
245 explored in six of the studies included in this review^{22,23,27-29,32}, resulting in the identification of two
246 sub-themes.

247 As reported in all six studies, affected individuals struggled to distinguish their pathological
248 symptoms from the normal experience of menstruation. Having had painful periods from menarche,
249 they often assumed that their symptoms were within the spectrum of normal and something that all
250 women endured²⁷. This assumption remained even when symptoms were severe and disruptive,
251 with many individuals reporting that they thought they were 'unlucky' to have 'problematic periods'
252 rather than unwell.

253 This was reinforced by their relatives. Participants in Markovic²⁸ explained that they drew primarily
254 on the experiences of their mothers and grandmothers to learn about menstruation, and so, if they
255 too had gynaecological problems, they learned to regard severe period pain as normal. This is
256 particularly relevant given that endometriosis has a genetic component³⁵. In these situations,
257 affected women were unlikely to recognise their own symptoms as atypical or in need of medical
258 attention.

259

260 *"I had witnessed my mum with so many problems in her life, she used to get a shot of*
261 *pethidine every month, so when I started to get period pain in teenage years, I just*
thought that was fairly normal." [Patient] (Manderson)²⁷.

262 These beliefs about the normality of the symptoms of endometriosis often delayed help-seeking
263 until a "circuit breaker" event forced the affected women to reconstruct their experience as
264 pathological²⁷. For example, participants reported that they only sought medical advice when their
265 symptoms began to affect their ability to perform everyday tasks, when a significant other
266 encouraged them to seek help, or when they failed to conceive²⁷.

267 *"I remember one day someone [at school] saying, 'You shouldn't have any pain, that's*
268 *not normal'".* [Patient] (Manderson)²⁷.

269 Another common theme was the use of self-care techniques to manage symptoms. Participants in
270 Jones²², Ballard²³ and Manderson²⁷ reported that they developed a wide range of coping strategies,
271 including spending time in bed, using hot water bottles and heating pads, withdrawing from social
272 activities, and taking analgesia, which enabled them to mask their symptoms for some time. They
273 delayed seeking medical advice until self-management became unfeasible or an acute problem
274 arose.

275 Interpersonal Influences

276 Findings related to interpersonal factors were collated into two sub- themes; a) menstrual stigma
277 and b) the societal normalisation of menstrual pain. These concepts emerged from six of the studies
278 and discourage individuals from seeking advice for their symptoms^{22,23,25,29,30,33}.

279 Firstly, affected individuals reported that they felt that talking about their menstrual problems was
280 socially unacceptable, seeing it as potentially embarrassing or shameful^{22,23,29}. They often concealed
281 their symptoms from others, which exacerbated the difficulties they had in differentiating normal
282 from pathological menstruation. As menstruation was rarely discussed, they missed out on the
283 opportunity to gain comparative evidence to suggest that their experience was abnormal.

284 If they did discuss with peers, the social narrative around painful periods being a normal part of
285 womanhood was influential in deterring women from seeking help^{22,24}. Participants reported that
286 their symptoms were often dismissed by their relatives, peers, and colleagues as “just period pain”.
287 Their symptoms were often trivialised, and they were made to feel that there was a problem with
288 how they coped with pain, rather than an underlying disease. Interestingly, this phenomenon was
289 reported in studies as recent as 2021, suggesting that this persists^{3,31,32,33}.

290 *“I am sure people thought she is making it up again. Oh god, everybody has a time of*
291 *the month, why can’t she just snap out of it” [Patient] (Jones)²².*

292 From the perspective of healthcare professionals, the stigma around “women’s issues” and sense
293 that discussion could be embarrassing and uncomfortable made it difficult to gather enough
294 information to make a diagnosis²⁵. Patients rarely disclosed information about their symptoms in
295 the initial consultation, meaning that healthcare professionals often had to see a patient multiple
296 times before they could get an accurate impression of their experience.

297 *“They might not want to tell you the first time they meet you that they’re actually*
298 *having really painful sex, and they might be quite worried about that. Or they might*
299 *not want to open up to you about that, but maybe once you’ve seen them once or*
twice, they might say” [GP] (Dixon)²⁵.

300

301 Health system factors and factors specific to endometriosis

302 Delays to diagnosis once the individual had sought medical help for their symptoms were a
303 recurring theme in all 13 studies.²¹⁻³³. Barriers relating to the health system and endometriosis itself
304 were grouped into sub-themes which have been explored from the view of both patients and
305 healthcare professionals. They have been discussed together to allow deeper analysis of the way in
306 which the factors interact.

307 Firstly, participants described a sense of being dismissed or treated with scepticism by their general
308 practitioner (GP) when they sought help^{21,23,24,27,29-32}. Indeed, most participants in Ballard²³ cited their
309 doctors' disbelief of the severity of their symptoms as the "least helpful aspect of their treatment".
310 Patients felt that their symptoms were trivialised as "just period pain", which were not worthy of
311 medical attention²³. Some women, particularly in Grundstrom³², perceived healthcare professionals
312 as distant and nonchalant, getting the impression that they were not interested in hearing about
313 'women's problems'.

314 *"He [the GP] brushes it off and says its period pain, and you can get on with it. That's
315 his entire attitude, have some ibuprofen and get on with it" [Patient] (Denny)²⁴.*

316 *"It's a shame women have to endure years of physicians making light of their pain and
317 being told 'it's part of being a woman'" [Patient] (Mikesell)³¹.*

317 When they continued to seek help after the initial dismissal, participants often reported that they
318 were accused of exaggerating or "imagining" their symptoms^{21-24,28,30,31}. The impact of this, alongside
319 the women's lack of knowledge about 'normal' menstruation, led to some questioning their own
320 experiences, with participants in Ballard²³ stating they felt they were "going mad". This theme was
321 repeated, with many affected women discouraged from seeking further help as they felt they must
322 be wasting the doctor's time.

323 *"I was experiencing a lot of pain on penetration...I went to the doctors and they did an
324 internal and said 'Look, everything is perfectly normal' and suggested that it might be
325 a psychological problem, and I might just be anxious" [Patient] (Denny)²¹*

326 Another issue was that patients perceived healthcare professionals to have poor knowledge of
327 endometriosis. Participants expressed frustration that their doctors appeared to lack even basic
328 awareness of the condition^{31,32} as "there is an expectation that clinicians have expertise in the
329 diseases that they treat"³⁰. This was seen as a major barrier to diagnosis, as the healthcare

330 professional must have known enough about the condition to 'think of it in the first place' and to
331 make an appropriate referral³⁰.

332 *"My doctor did not have a great deal of knowledge in that area. With two of my*
333 *doctors, I had to explain to them what endometriosis is and how to treat it. So I can't*
334 *exactly go to them and ask for help with my treatment" [Patient] (Moradi)²⁹.*

334 This was also recognised by the healthcare professionals themselves^{25,30,33}. GPs in Van der Zanden³³
335 reported that their knowledge of endometriosis was limited, admitting they found it difficult to
336 differentiate between normal menstruation and pathological conditions like endometriosis. Without
337 adequate knowledge of the disease, the doctors struggled to identify the 'right' questions to ask and
338 could not perform an appropriate examination.

339 *"You have to think of it in the first place. You have to know the condition before it even*
340 *occurs to you. And if you don't think of it, you will not find the information you need"*
341 *[GP] (Van der Zanden)³³.*

341 This was attributed to a lack of clinical training and experience, with physicians stating that
342 endometriosis was not emphasised or covered comprehensively during their medical training^{25,30,33}.
343 Multiple GPs and non-specialist gynaecologists also reported that they did not have access to clear
344 guidelines for diagnosing endometriosis^{30,33}. They suggested that clinical guidelines, developed by a
345 multidisciplinary team would be useful to advise them in which therapies they can start themselves,
346 when referral is advised, and what actions may be taken in secondary care^{30,33}. However, this was
347 not identified as a problem in Dixon²⁵, a study carried out with GPs in England. This suggests that this
348 problem is country-specific, with guidelines varying in quality and accessibility.

349 The variability in the symptoms of endometriosis was also identified as a barrier to diagnosis from
350 the perspective of healthcare professionals^{25,30,33}. The symptoms of endometriosis can be vague,
351 ranging from chronic pelvic pain, to dyspareunia, bowel problems, urinary symptoms, and chronic
352 fatigue³⁶. This made it difficult for healthcare professionals to differentiate it from other
353 gynaecological and gastrointestinal problems. Particularly, endometriosis was often masked by a

354 diagnosis of irritable bowel syndrome (IBS). These conditions may present with similar symptoms,
355 and indeed, often co-occur in the same individual, making them difficult to distinguish.

356 From the perspective of professionals, misdiagnosis was therefore an inevitable part of the process.
357 GPs are trained to work through a clinical hierarchy, where 'red flags' indicating serious disease must
358 be excluded before other diagnoses (including endometriosis) can be considered. As the symptoms
359 of endometriosis overlap with other conditions, and because endometriosis cannot be reliably
360 diagnosed in primary care, the tests offered were predominantly used to rule out other causes of the
361 symptoms. Once the life-threatening conditions were ruled out, a referral for specialist
362 endometriosis care could be made.

363 *"Always as a GP, we're terrified of missing something horrible, so you think about red
364 flags" [GP] (Dixon)²⁵.*

365 This is in line with clinical guidelines³⁴ but appeared to be poorly explained to the patients, who felt
366 that their concerns about endometriosis were being ignored. Participants also reported that there
367 was a delay before other diagnoses, such as endometriosis, were considered after the first line
368 treatment for alternative conditions (such as IBS) failed²². This could therefore act as a barrier to
369 diagnosis, as affected women could become disengaged and fail to return to their doctor when
370 symptoms persisted.

371 *"They had to test for everything first and never once mentioned endometriosis as a
372 possibility" [Patient] (Denny)²⁴.*

373 Another miscommunication appeared to occur with the use of the oral contraceptive pill (OCP).
374 From the perspective of the healthcare professionals, a trial of treatment with the OCP could be
375 informative to the diagnostic process. As recommended in the ESHRE guidelines¹², the OCP was
376 often started early. If symptoms improved, it increased the likelihood that they were due to
377 endometriosis and therefore contributed to reaching the correct diagnosis²⁵. However, if the

378 purpose of the trial of the OCP was not adequately explained to the patient, they often became
379 disengaged, believing that their symptoms were being “masked” rather than treated^{22,23,25,28,33}.
380 Patients reported that they did not want to take a medication without knowing the underlying cause
381 of their symptoms²¹. They also worried that the diagnostic pathway would need to begin again as
382 soon as they could no longer use the OCP, for example, if they wanted to conceive or if they
383 experienced side effects^{22,23,25}.

384 *“You have to really try and positively engage the patient to come back and really*
385 *convince them that you want them to come back. Because you know if you give them*
386 *a 3-month trial of treatment, it doesn’t help, and they think ‘Well nothing really*
387 *happened last time, I’m not bothered, I’m going to leave it 6 months, and then I’m*
388 *going to come back’, the years slip so quickly in that kind of timescale” [GP] (Dixon²⁵).*

388 When further investigations were carried out, the lack of an accurate, non-invasive method of
389 diagnosis became an issue^{23-25,29,30,32,33}. This delayed diagnosis in two ways; unspecific, non-
390 discriminatory investigations were often used to inappropriately rule out endometriosis as a
391 diagnosis, or diagnosis was delayed due to concerns about the risks of a laparoscopic procedure.

392 In both Ballard²³ and Mikesell³¹, patients reported that a diagnosis of endometriosis was discounted
393 following a normal transvaginal ultrasound, which falsely reassured their doctors that further
394 investigation or treatment was not necessary. This is an inappropriate use of the imaging modality
395 as, although the ESHRE guidelines recommend the use of ultrasound in the diagnostic work-up for
396 endometriosis, a negative finding cannot be used to exclude endometriosis, particularly in superficial
397 peritoneal disease or in cases of high clinical suspicion¹².

398 *“It was awful just going for these flipping internals all the time and being told there’s*
399 *nothing there. To actually keep going backwards and forwards and having it, and*
400 *there’s nothing showing up. And when I’ve mentioned about having the... is it the*
laparoscopy – having that done, they’re ‘Well, no, it won’t be done because there’s
nothing showing up on these [ultrasounds]!’” [Patient] (Ballard²³).

401 The misconception amongst healthcare professionals that a diagnosis can only be made by
402 laparoscopic surgery also acted as a barrier. Individuals with endometriosis in six of the papers
403 reported that there was a delay from the first consultation in primary care to receiving a referral to a
404 specialist endometriosis service^{21-24,26,27,31,32}. Participants in Denny²⁴ perceived that their GP was
405 reluctant to refer them, with most affected women reporting that they didn't think they were
406 referred to secondary care soon enough.

407 From the GPs' perspective in Dixon²⁵ and Van der Zanden³³, this was due to a difficulty in
408 determining when a referral was appropriate. In some cases, for example, if there were concerns
409 about fertility, referral was straightforward, but for patients with mild or vague symptoms, GPs
410 reported that they struggled to determine whether a referral would be in the best interest of the
411 patient³³. They were mindful that, traditionally, diagnosis required an invasive procedure with
412 potential risks, and some therefore saw it as a last resort³³.

413 *"The only way you can really make it is with a laparoscopy and you don't really want*
414 *to put a woman through that unless you've reached the absolute end of the road" [GP]*
415 *(Dixon)²⁵.*

416 This was exacerbated by doubts about the added value of establishing a definitive diagnosis, since
417 the treatment options often appeared to be the same whether the diagnosis was confirmed or not.
418 Several GPs described experiences where specialists had prescribed medications that they could
419 have given themselves³³. This led to some GPs opting to trial treatment before making a referral to
420 secondary care.

421 Others expressed doubt about the value of a diagnostic label at all. In Dixon²⁵, healthcare
422 professionals cautioned that having a diagnosis might not address all the patients' concerns, and
423 could instead lead to further anxiety and distress. This led to a low sense of urgency for some of the
424 GPs, with participants stating that they would prefer to see if a trial of treatment with the OCP
425 worked before even raising endometriosis as a possible diagnosis.

425 *“Moderator: For example a young girl, 16 years old, who comes to your office with*
426 *complaints about her menstruation, would you tell her, you consider endometriosis*
when you prescribe her the pill? GP3: I wouldn’t even think of it. GP2: No, me neither”.
427 *(Van der Zanden)³³.*

428 Notably, participants did not share this sentiment. The majority of affected women in seven of the
429 studies reported that getting a diagnosis for their symptoms was positive, allowing them to process
430 their experience and access specialist support^{21-24, 26,29,32}.

431 Finally, participants in Zale (2020)³⁰, a study carried out in the USA, which does not have universal
432 health coverage, also identified financial barriers to seeking a diagnosis. Even patients with access to
433 health insurance reported constraints on the providers that they were able to visit, the tests that
434 they could access, and ultimately their treatment options due to high co-pays and deductibles. This
435 meant diagnosis was often delayed due to financial restraints.

436

437 **DISCUSSION**

438 Thirteen papers, reporting twelve studies, were included identifying twelve barriers that delayed
439 diagnosis of endometriosis. Affected individuals reported that they struggled to differentiate
440 pathological symptoms from normal menstruation, which was reinforced by the societal
441 normalisation of menstrual pain and the lack of opportunity to discuss menstrual problems with
442 others. This prevented them from seeking medical advice until an acute event caused them to
443 reinterpret their experience as abnormal, prolonging the delay to seek medical advice. During this
444 time, many patients with endometriosis used self-management strategies to cope with symptoms,
445 further delaying their presentation to a medical professional. This suggests that there is a need to
446 provide education about what constitutes ‘normal’ menstruation, potentially at secondary school as
447 the symptoms of endometriosis often start in adolescence, and to raise awareness of menstrual
448 conditions. This would have multiple potential benefits; affected women may be encouraged to seek

449 advice earlier, and their family members, peers, and employers may be more supportive if they have
450 better understanding of the condition.

451 Once affected individuals sought medical advice, they experienced delays before being referred to
452 secondary care. From the patients' perspective, this was caused by dismissal of their symptoms by
453 GPs, and the perception that doctors did not have adequate knowledge of the condition, leading to
454 misdiagnosis and the use of non-discriminatory tests.

455 GPs and non-specialist gynaecologists themselves reported that they had insufficient knowledge
456 about the symptoms, diagnosis and treatment of endometriosis, and some struggled to know when
457 to refer patients to secondary care. Additional mandatory training about menstrual conditions is
458 required during medical school, as well as comprehensive in-service education, and clear, evidence-
459 based guidelines for reference.

460 As participants in the studies consistently reported feeling dismissed by healthcare professionals,
461 there may also be an opportunity to reflect on the 'gender health gap', a term used to describe the
462 disparities in the way that women access and experience healthcare³⁷. Opportunities for healthcare
463 professionals to enhance their knowledge of women's health and challenge their unconscious biases
464 may be helpful, as may workshops to improve communication skills given that misunderstandings
465 were frequently reported.

466

467 Strengths and Limitations

468 This review was the first to specifically explore barriers to the diagnosis of endometriosis from a
469 qualitative perspective. Previous reviews by Young (2015)³⁸ and Culley (2013)⁶ have explored
470 diagnostic delay as part of their wider scope. Consistent with our findings, Young (2015)³⁸ found that
471 the normalisation of symptoms by the patient, their peers, and their GPs was a significant problem,
472 as was the misdiagnosis of symptoms as psychological or as irritable bowel syndrome. Similarly,

473 Culley (2013)⁶ reported that diagnostic delays occurred at the patient level due to poor awareness of
474 the condition, and at the medical professional level due to the dismissal of symptoms.

475 This review was also the first to explore the barriers to diagnosis from the perspective of both
476 affected women and healthcare professionals, giving more balanced impression. The findings are
477 based on good quality data and provide valuable information, especially as the improvement of the
478 diagnosis delay is one of the top ten research priorities for endometriosis³⁹.

479 However, all of the primary studies included were conducted in high-income countries, most of
480 which had universal healthcare, potentially limiting generalisability to other contexts (it is likely that
481 this review underestimates the effect of financial barriers to seeking a diagnosis). Additionally, whilst
482 not all of the studies reported on the demographics of the participants, of those that did, the
483 majority of participants were White women. The review may therefore be unrepresentative of the
484 experiences of people of Colour, especially as the prevalence and diagnosis of endometriosis is
485 suspected to be influenced by ethnicity⁴⁰.

486 All studies focusing on the views of affected women recruited their participants from specialist
487 gynaecology clinics or from support organisations, which generally support those with severe
488 disease. Therefore, the samples may not be skewed towards those with more complex, debilitating
489 disease. Finally, the papers focusing on the views of healthcare professionals exclusively recruited
490 doctors, the majority of which were GPs, so the views of other healthcare professionals, including
491 endometriosis specialists, could not be analysed.

492 The review was also conducted by a single reviewer (the lead author) which may have increased the
493 risk bias or methodological error¹⁷. Future reviews could include additional databases and journals,
494 unpublished material and non-English papers to identify more eligible studies and reduce the risk of
495 publication and language biases.

496 Future research priorities

497 Identification of factors that facilitate diagnosis and demonstrations of good practice are necessary
498 to guide the production of evidence-based, decision-making resources. Additionally, the 2022 ESHRE
499 guidelines suggest a two-step approach in which empirical treatment is started based on clinical
500 suspicion and imaging (rather than laparoscopic findings)¹², and so further research to analyse the
501 effect of this on the time to diagnosis and patients' experiences is warranted.

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Table 1: The Characteristics of the Included Studies.

Author(s) (Year)	Title	Setting of Research	Study Aim	Sampling Method	Sample size (age range of participants in years)	Data Collection Method	Data Analysis Method
Denny E (2004) ¹⁹	Women's experiences of endometriosis.	Birmingham, United Kingdom.	To explore women's experiences of living with endometriosis.	Convenience sampling via the message board of a self-help group, and the gynaecology department of a local hospital, and snowball sampling.	15 patients (not given).	Semi-structured interviews.	Inductive thematic analysis.
Jones G, Jenkinson C, Kennedy S (2004) ²⁰	The impact of endometriosis upon quality of life: a qualitative analysis.	Oxford, United Kingdom.	To identify and understand, from the patient's perspective, the areas of HRQoL that are affected by endometriosis.	Convenience sampling from the gynaecology outpatient clinic at John Radcliffe Hospital.	24 patients (21-44).	Semi-structured interviews.	Grounded theory.
Ballard K, Lowton K, Wright J (2006) ²¹	What's the delay? A qualitative study of women's experiences of reaching a	Southeast England, United Kingdom.	To investigate the reasons that women experience delays in the diagnosis of endometriosis and the impact of this on women's	Purposive sampling of women attending a pelvic pain clinic due to suspected endometriosis.	28 patients (16-47).	Semi-structured interviews.	Inductive thematic analysis.

	diagnosis of endometriosis.		experiences of the condition.				
Denny E, Mann C (2008) ²²	Endometriosis and the primary care consultation.	Birmingham, United Kingdom.	To explore the experience of women with endometriosis in the primary care setting.	Purposive sampling from a dedicated endometriosis clinic.	30 patients (19-44).	Semi-structured interviews.	Inductive thematic analysis.
Dixon S, McNiven A, Talbot A, Hinton L (2021) ²³	Navigating possible endometriosis in primary care: a qualitative study of GP perspectives.	Oxford, United Kingdom.	To explore what GPs identify as important considerations when caring for women with symptoms that raise the possibility of endometriosis.	-Purposive sampling from Local Clinical Research Network teams, followed by snowball sampling.	42 general practitioners (not given).	Semi-structured interviews.	Inductive framework analysis.
Cox H, Henderson L, Andersen N, Cagliarini G, Ski C (2003) ²⁴	Focus group study of endometriosis: Struggle, loss and the medical merry-go-round.	Victoria, Australia	To increase awareness of women's experiences of endometriosis and the lack of support for women sufferers.	Convenience sampling from a specialist endometriosis centre and a charity organisation.	61 patients (20-64).	Semi-structured focus groups.	Inductive thematic analysis.
Manderson L, Warren N,	Circuit breaking: pathways of treatment	Victoria, Australia.	To we explore the circumstances under which the	Purposive sampling from community newspapers, and	40 patients (20-78).	In-depth	

Markovic M (2008) ²⁵	seeking for women with endometriosis in Australia.		cycle of personal- or professional-induced delay in endometriosis was interrupted.	notice boards and from snowballing.		unstructured interviews.	Inductive thematic analysis.
Markovic M, Manderson L, Warren N (2008) ²⁶	Endurance and contest: women's narratives of endometriosis.		To enrich our understanding of the relationship between the patient's socio-demographic background and health-related phenomena, by identifying distinctive differences among women's narratives.		30 patients (20-78).		
Moradi M, Parker M, Sneddon A, Lopez V, Ellwood D (2014) ²⁷	Impact of endometriosis on women's lives: a qualitative study.	Canberra, Australia.	To explore women's experience of endometriosis and its impact.	Convenience sampling from a dedicated endometriosis centre, and from a general practice in the community.	35 patients (17-53).	Semi-structured focus groups.	Inductive thematic analysis.
Zale M, Lambert E, LaNoue MD,	Shedding light on endometriosis: Patient and	Multiple cities, United States of America.	1) To assess the perceptions and awareness of endometriosis	-Convenience sampling of providers from conferences and	4 providers (not given).	Semi-structured interviews.	Inductive thematic analysis.

Leader AE (2020) ²⁸	provider perspectives on a challenging disease.		amongst providers who diagnose and treat endometriosis and 2) to assess the endometriosis patient experience in the United States.	seminars for physicians in gastroenterology, obstetrics and gynaecology, internal medicine and primary care. -Convenience sampling of patients from the social media page of a national endometriosis charity.	12 patients (20-43).		
Grundström H, Alehagen S, Kjølhede P, Berterö C (2016) ²⁹	The double-edged experience of healthcare encounters among women with endometriosis: a qualitative study.	Östergötland County, Sweden.	To identify and describe the experiences of healthcare encounters among women with endometriosis.	Purposive sampling from an outpatient gynaecology clinic.	9 patients (25-55).	Semi-structured interviews.	Modified Stevick-Colaizzi-Keen method of analysis.
van der Zander M, Teunissen DA, van der Woord I, Braat D, Nelen WL,	Barriers and facilitators to the timely diagnosis of endometriosis	The Netherlands.	To identify barriers and facilitators to the timely diagnosis of endometriosis	Purposive sampling of group practices from the College of General Practitioners based	43 providers (not given).	Semi-structured focus groups.	Content analysis.

Nap AW (2020) ³⁰	in primary care in the Netherlands.		from the GPs' perspective.	on geographical spread.			
Mikesell L, Bontempo AC (2022). ³¹	Healthcare Providers' Impact on the Care Experiences of Patients with Endometriosis: The Value of Trust	Multiple cities, United States of America.	1) To explore how patients with endometriosis perceive healthcare professionals to serve as barriers and facilitators to the their and 2) to assess the role that trust in healthcare professionals plays in shaping care experiences.	Convenience sampling of patients from the social media pages of endometriosis organisations.	222 patients (18-64)	Open-ended questionnaire.	Inductive thematic analysis.

Table 2: The findings of the CASP Qualitative Checklist¹³ for each study. ✓ represents a 'Yes' decision and ? represents a 'Cannot Tell' decision. X represents a 'No' decision.

Study	Clear Aims	Appropriate Methodology	Appropriate design	Recruitment	Data Collection	Researcher Relationship	Ethical Issues	Data Analysis	Clear Findings	Value	Overall Assessment
Denny (2004) ¹⁹	✓	✓	✓	✓	✓	?	✓	✓	✓	✓	Minor concerns
Jones (2004) ²⁰	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	No or very minor concerns
Ballard (2006) ²¹	✓	✓	✓	✓	✓	?	✓	✓	✓	✓	Minor concerns
Denny (2008) ²²	✓	✓	✓	✓	✓	?	✓	✓	✓	✓	Minor concerns
Dixon (2021) ²³	✓	✓	✓	✓	✓	?	✓	✓	✓	✓	Minor concerns
Cox (2003) ²⁴	✓	✓	✓	?	✓	?	?	✓	✓	✓	Moderate Concerns
Manderso n (2008) ²⁵ and	✓	✓	✓	✓	✓	?	?	✓	✓	✓	Minor concerns

Markovic (2008) ²⁶											
Moradi (2014) ²⁷	✓	✓	✓	✓	✓	?	✓	✓	✓	✓	Minor concerns
Zale (2020) ²⁸	✓	✓	✓	✓	✓	?	✓	✓	✓	✓	Minor concerns
Grundström (2016) ²⁹	✓	✓	✓	✓	✓	?	✓	✓	✓	✓	Minor concerns
van der Zander (2020) ³⁰	✓	✓	✓	✓	✓	?	?	✓	✓	✓	Minor concerns
Mikesell (2022) ³¹	✓	✓	✓	?	?	?	?	✓	✓	✓	Moderate concerns

Supplementary Table 1: Search Strategy for MEDLINE via Ovid

Database: Ovid MEDLINE(R) and Epub Ahead of Print, In-Process, In-Data Review & Other Non-Indexed Citations and Daily	
	Search Term
1	Exp endometriosis/
2	Endometrio*.mp.
3	“Chronic pelvic pain”.mp. OR Pelvic Pain/
4	Dysmenorrhea/
5	Menstruation Disturbances/
6	Dyspareunia/
7	Dyschezia.mp.
8	1 or 2 or 3 or 4 or 5 or 6 or 7
9	exp Diagnosis/
10	exp Delayed Diagnosis/
11	exp Missed Diagnosis/
12	“Late Diagnosis”.mp.
13	Time Factors/ and diagnos*.mp.
14	9 or 10 or 11 or 12 or 13
15	8 and 14

16	exp qualitative research/
17	Interviews as topic/ or Interview/
18	Focus groups/
19	Narration/
20	“Semi-structured” or semistructured or unstructured or informal or “in-depth” or indepth or “face-to-face” or structured or guide.mp.
21	Discussion or questionnaire*.ti,ab
22	Qualitative or ethnograph* or fieldwork or “field work”.mp.
23	16 or 17 or 18 or 19 or 20 or 21 or 22
24	Patient Satisfaction/
25	Health Knowledge, Attitudes, Practice/
26	Attitude of Health Personnel/
27	Attitude* or experience* or view* or reflect* or perception*
28	24 or 25 or 26 or 27
29	23 and 28
30	15 and 29

Supplementary Table 2: Search Strategy for APA PsycINFO

Database: APA PsycInfo via Ovid	
	Search Term
1	Endometrio*.mp.
2	("Chronic Pelvic Pain" or Pelvic Pain).mp.
3	Exp Dysmenorrhea/
4	Exp Menstrual disorders/
5	Exp Dyspareunia/
6	Dyschezia.mp.
7	1 or 2 or 3 or 4 or 5 or 6
8	Exp Diagnosis/
9	"Delayed diagnosis".mp.
10	"Missed diagnosis".mp.
11	"Late diagnosis".mp.
12	Time factors and diagnos*.mp.
13	8 or 9 or 10 or 11 or 12
14	7 and 13
15	Exp Qualitative Methods/
16	qualitative.tw.

17	Exp Interviews/ or interview.tw.
18	Exp Focus Group/
19	("Semi-structured" or semistructured or unstructured or informal or "in-depth" or indepth or "face-to-face" or structured or guide or guides).ti,ab,id.
20	Ethnograph* or fieldwork or "field work" or discussion*.ti,ab,id.
21	15 or 16 or 17 or 18 or 19 or 20
22	Exp Client satisfaction/
23	Exp Health Attitudes/ or Exp Health Knowledge/
24	Exp Health Personnel Attitudes/
25	Attitude* or experience* or view* or reflect* or perception*.mp.
26	22 or 23 or 24 or 25
27	21 or 26
28	14 and 27

Supplementary Table 3: Search Strategy for EBSCO CINAHL

Database Searched: EBSCO CINAHL	
	Search Term
1	(MH "Endometriosis") or "chronic pelvic pain" or (MH "Pelvic Pain") or (MH Menstruation Disorders+) or (MH "Dysmenorrhoea") or (MH "Dyspareunia") or "dyschezia"
2	(MH "Diagnosis") or (MH "Diagnosis, Delayed") or (MH "Failure to Diagnose") or (MH "Time Factors")
3	(MH "Qualitative Studies+") or MH ("Interviews+") or (MH "Semi-structured interview") or (MH "Structured interview") or (MH "Unstructured interview") (MH "Focus Groups") or (MH "Ethnographic Research") or (MH "Discussion") or (MH "Fieldwork") OR "Qualitative"
4	(MH "Patient Satisfaction+") or (MH "Attitude to Health") or (MH "Attitude of Health Personnel"+) or "attitude" or "experience" or "view" or "reflection" or "perception"
5	3 or 4
6	1 and 2 and 5