Awareness of Early Detection of Endometriosis Among Primary Care Professionals: A Scoping Review

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Abstract. Endometriosis is a chronic gynecological disease that frequently experiences diagnostic delays due to its non-specific symptoms. One of the causes of diagnostic delay is the inability of primary healthcare providers, particularly general practitioners and midwives, to detect endometriosis early in primary care facilities. Delayed diagnosis may worsen disease severity, increase comorbidities, and significantly reduce patients' quality of life. Therefore, this scoping review aims to identify existing literature regarding the awareness of general practitioners and midwives concerning the early detection of endometriosis in primary care facilities, as well as the factors influencing this awareness. A scoping review was conducted following the PRISMA-ScR guidelines. Literature searches were performed in PubMed, Scopus, ScienceDirect, Wiley, and Sage Journals for English-language articles published between 2014-2024. Eligible studies discussed awareness of early detection of endometriosis among general practitioners and/or midwives. Article selection was conducted independently using Rayyan.ai, and study quality was assessed using the Joanna Briggs Institute Critical Appraisal Tools. A total of 4 research articles were identified as having similarities with the intended inclusion criteria. The review results indicated that research on endometriosis detection emphasizing the awareness of general practitioners and midwives has not yet been conducted. Most articles examining the knowledge or attitudes of general practitioners and midwives regarding endometriosis. This review highlights a critical gap in the literature, revealing that specific research on the awareness of general practitioners and midwives regarding the early detection of endometriosis has not yet been conducted. Existing studies are predominantly limited to assessing general knowledge and attitudes. Given the profound impact of diagnostic delays on patient outcomes, there is an urgent need for targeted future research and structured educational interventions to enhance early detection capabilities among primary healthcare providers.

Keywords: Endometriosis, Early detection, General practitioners, Midwives, Scoping review.

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K. M. Ariesaka and D. Fauziah (eds.), *Proceedings of the 3rd Malang International Conference on Medical and Health Sciences (MICROMEDHS 2026)*, Advances in Health Sciences Research 96,
https://doi.org/10.2991/978-94-6239-807-8_11

1 Introduction

Endometriosis is defined as the presence of endometrium-like tissue outside the uterine cavity, which induces a chronic inflammatory reaction.[1] One of the frequently normalized symptoms of endometriosis is dysmenorrhea. This condition affects 60–80% of women with endometriosis, whereas dyspareunia is reported in 20–40%.[2] Dysmenorrhea in endometriosis' patients is characteristically accompanied by cyclic pelvic pain, which initiates pre-menstrually, peaks 1–2 days prior to menstruation, and gradually subsides with the onset of menses. Furthermore, this dysmenorrhea and pelvic pain are commonly associated with dyspareunia, abnormal vaginal bleeding, urinary and bowel symptoms, and infertility.[3] Although exact worldwide rates remain challenging to pinpoint, current estimates suggest endometriosis affects 2% to 10% of women globally,[4] with other data suggesting that pelvic endometriosis specifically affects approximately 6–10% of this population.[5]

Endometriosis is a progressive disease. Once it has developed, the inflammatory processes involved may trigger scarring across the peritoneal surfaces, subsequently elevating the synthesis of proinflammatory molecules such as prostaglandins, metalloproteinases, cytokines, and chemokines.[6] These microenvironment of endometriosis known as oxidative stress, is believed to contribute significantly to both infertility and carcinogenesis.[7] Furthermore, inflammatory activity accompanied by aberrant immune response is also considered to support the persistence of ectopic endometrial tissue, thereby contributing to the continued progression of the disease.[6]

Despite this, nearly half of affected women remain asymptomatic, leaving the disorder undetected.[8] Because ectopic endometrial tissue undergoes estrogen-driven proliferation across the hormonal cycle, clinical manifestations typically align with menstruation and include dysmenorrhea, hypermenorrhea, and menorrhagia. However, clinical manifestations may also vary depending on the anatomical location of the lesions, giving rise to symptoms such as dysuria, dyspareunia, and dyschezia.[9] Because the clinical presentation of endometriosis can be highly nonspecific, the condition is often misunderstood or misinterpreted, which consequently contributes to in misinterpretation and diagnostic delay.[10]

Diagnostic delay represents a significant obstacle to effectively managing endometriosis, as the majority of patients remain undiagnosed and do not receive timely intervention.[5] A study by Khan et al. (2022) indicated that patients generally encounter diagnostic delays ranging from 8 to 12 years.[11] Furthermore, a scoping review by Fryer et al. (2024)[12] demonstrated an overall diagnostic delay of 6.8 years, with an average of 2.9 years elapsing between the initial primary care consultation (with general practitioners or midwives) and the definitive diagnosis.[12] While prolonged diagnostic delays correlate with increased severity of endometriosis, the ability of primary healthcare providers, particularly general practitioners and midwives, to detect endometriosis early in primary care facilities is needed.[13] Delayed diagnosis may worsen disease severity, increase comorbidities, and significantly reduce patients' quality of life.

Therefore, this scoping review maps current research regarding the awareness of general practitioners and midwives concerning the early detection of endometriosis in primary care facilities, as well as the factors influencing this awareness.

2 Methods

Guided by the PRISMA-ScR framework (Tricco et al., 2018), this systematic search established the novelty of the study.[14] The protocol was registered in the Open Science Framework (https://osf.io/9ycd6), and relevant literature was retrieved from PubMed, Scopus, ScienceDirect, Wiley, and Sage Journals. The search process was specifically directed toward identifying studies on the awareness of general practitioners and midwives regarding early detection of endometriosis. The keywords applied throughout the search process included: 1) General practitioner; 2) Midwife; 3) Awareness; 4) Endometriosis; and 5) Early detection.

2.1 Inclusion and exclusion criteria

Articles considered met the eligibility criteria for this study comprised experimental and quasi-experimental studies investigating awareness of general practitioners and midwives concerning the early detection of endometriosis in primary care facilities and factors influencing it. The selected publications were limited to articles published in English between 2014 and 2024. Conversely, studies categorized as secondary research, theses, public policy documents, guidelines, and articles without accessible full-text versions were excluded from the review process. Full eligibility criteria for study inclusion are detailed in Table 1.

2.2 Search strategy

Literature retrieval was conducted across PubMed, Scopus, Science Direct, Wiley, and Sage Journals databases by applying search strategies based on Boolean operators. The combination of keywords utilized in each database was adjusted according to the characteristics of the respective database search system. Detailed search keywords and combinations applied across the databases is detailed in Table 2.

Table 1. PCC inclusion and exclusion criteria

Criteria	Included	Excluded
Population	General practitioners and midwives	Primary care providers in non-primary care settings
Concept	Investigating awareness about early detection of endometriosis and factors influencing it	Investigating other kind of awareness
Context	Primary health care	Secondary or tertiary healthcare facilities
Study design	*Research Article* or *Original Article*	Secondary research such as: scoping reviews or systematic reviews, thesis literature, public policies, guidelines, and if *full text* was not available

Table 2. Final search strategy

Databases	Keyword	Number of identified articles
PubMed	((((((((((General Practitioner[Title/Abstract]) OR (Practitioner, General[Title/Abstract])) OR (Practitioners, General[Title/Abstract])) OR (Physicians, General Practice[Title/Abstract])) OR (General Practice Physician[Title/Abstract])) OR (General Practice Physicians[Title/Abstract])) OR (Physician, General Practice[Title/Abstract])) OR (Practice Physicians, General[Title/Abstract]) AND (fft[Filter])) OR ((((((Midwives[Title/Abstract]) OR (Midwife[Title/Abstract])) OR (Traditional Birth Attendant[Title/Abstract])) OR (Birth Attendants, Traditional[Title/Abstract])) OR (Birth Attendant, Traditional[Title/Abstract])) OR (Traditional Birth Attendants[Title/Abstract]) AND (fft[Filter]))) AND (((Awareness[Title/Abstract]) OR (Aware[Title/Abstract])) OR (Understand[Title/Abstract]) AND (fft[Filter]))) AND ((((((((((Screening) OR (Screenings)) OR (Mass Screenings)) OR (Screening, Mass)) OR (Diagnostic Screening Program)) OR (Program, Diagnostic Screening)) OR (Programs, Diagnostic Screening)) OR (Screening Program, Diagnostic)) OR (Screening Programs, Diagnostic)) OR (Diagnosis, Early)) OR (Early Detection of Disease)) OR (Disease Early Detection) AND (fft[Filter]))) AND ((((Endometriosis) OR (Endometrioses)) OR (Endometrioma)) OR (Endometriomas) AND (fft[Filter]))	9
Scopus	((TITLE-ABS-KEY (general AND practitioner) OR TITLE-ABS-KEY (practitioner, AND general) OR TITLE-ABS-KEY (practitioners, AND general) OR TITLE-ABS-KEY (physicians, AND general AND practice) OR TITLE-ABS-KEY (general AND practice AND physician) OR TITLE-ABS-KEY (general AND practice AND physicians) OR TITLE-ABS-KEY (physician, AND general AND practice) OR TITLE-ABS-KEY (practice AND physicians, AND general))) OR ((TITLE-ABS-KEY (midwives) OR TITLE-ABS-KEY (midwife) OR TITLE-ABS-KEY (traditional AND birth AND attendant) OR TITLE-ABS-KEY (birth AND attendants, AND traditional) OR TITLE-ABS-KEY (birth AND attendant, AND traditional) OR TITLE-ABS-KEY (traditional AND birth AND attendants))) AND ((TITLE-ABS-KEY (awareness) OR TITLE-ABS-KEY (aware) OR TITLE-ABS-KEY (understand))) AND ((TITLE-ABS-KEY (screening) OR TITLE-ABS-KEY (screenings) OR TITLE-ABS-KEY (mass AND screenings) OR TITLE-ABS-KEY (screening, AND mass) OR TITLE-ABS-KEY (screenings, AND mass) OR TITLE-ABS-KEY (diagnostic AND screening AND program) OR TITLE-ABS-KEY (program, AND diagnostic AND screening) OR	9

Databases	Keyword	Number of identified articles
	TITLE-ABS-KEY (programs, AND diagnostic AND screening) OR TITLE-ABS-KEY (screening AND program, AND diagnostic) OR TITLE-ABS-KEY (screening AND programs, AND diagnostic) OR TITLE-ABS-KEY (diagnosis, AND early) OR TITLE-ABS-KEY (early AND detection AND of AND disease) OR TITLE-ABS-KEY (disease AND early AND detection))) AND ((TITLE-ABS-KEY (endometriosis) OR TITLE-ABS-KEY (endometrioses) OR TITLE-ABS-KEY (endometrioma) OR TITLE-ABS-KEY (endometriomas)))	
Science Direct	(“endometriosis”) AND ("early detection" OR "early diagnosis" OR "screening") AND (“Awareness" OR "Aware" OR "Understand”) AND (“General Practitioner” OR “Midwife”)	166
Wiley	“General Practitioner OR “Practitioner, General” OR “Practitioners, General” OR “Physicians, General Practice” OR “General Practice Physician” OR “General Practice Physicians” OR “Physician, General Practice” OR “Practice Physicians, General” OR Midwives OR Midwife OR “Traditional Birth Attendant” OR “Birth Attendants Traditional” OR “Birth Attendant Traditional” OR “Traditional Birth Attendants”” anywhere and “Awareness* OR Aware* OR Understand*” anywhere and “Screening OR Screenings OR “Mass Screening” OR “Screening, Mass” OR “Screenings, Mass” OR “Diagnostic Screening Program” OR “Program, Diagnostic Screening” OR “Programs, Diagnostic Screening” OR “Screening Program, Diagnostic” OR “Screening Programs, Diagnostic” OR “Diagnostic, Early” OR “Early Detection of Disease” OR “Disease Early Detection”” anywhere and “Endometriosis OR Endometrioses OR Endometrioma OR Endometriomas” anywhere	2.188
Sage Journals	Endometriosis OR Endometrioses OR Endometrioma OR Endometriomas AND General Practitioner OR “Practitioner, General” OR “Practitioners, General” OR “Physicians, General Practice” OR “General Practice Physician” OR “General Practice Physicians” OR “Physician, General Practice” OR “Practice Physicians, General” OR Midwives OR Midwife OR “Traditional Birth Attendant” OR “Birth Attendants Traditional” OR “Birth Attendant Traditional” OR “Traditional Birth Attendants” AND Awareness* OR Aware* OR Understand* AND Screening OR Screenings OR “Mass Screenings” OR “Screening, Mass” OR “Screenings, Mass” OR “Diagnostic Screening Program” OR “Program, Diagnostic Screening” OR “Programs, Diagnostic Screening” OR “Screening Program, Diagnostic” OR “Screening Programs, Diagnostic” OR “Diagnosis, Early” OR “Early Detection of Disease” OR “Disease Early Detection”	513

2.3 Data collection

Two authors (AH and BSW) independently completed study screening in sequential stages. First, reviewing titles and abstracts against inclusion criteria, then assessing full texts for eligibility. Differences in judgment were resolved through group discussion.

To enhance the efficiency and organization of the screening procedure, the researchers utilized Rayyan.ai, a web-based platform specifically developed to support and simplify systematic review processes. The preliminary search strategy, which employed predefined titles and keyword combinations, successfully identified a total of 2,885 records. Following the elimination of 207 duplicated entries, 2,678 articles proceeded to the subsequent evaluation stage. Initial title and abstract screening led to the exclusion of 2,597 studies. Thereafter, an in-depth assessment of the remaining full-text articles was conducted comprehensively, resulting in the final inclusion of 13 eligible studies. A complete illustration of the article selection procedure is presented in Figure 3.

2.4 Quality assessment

Methodological quality of included studies was evaluated using Joanna Briggs Institute (JBI) critical appraisal instruments.

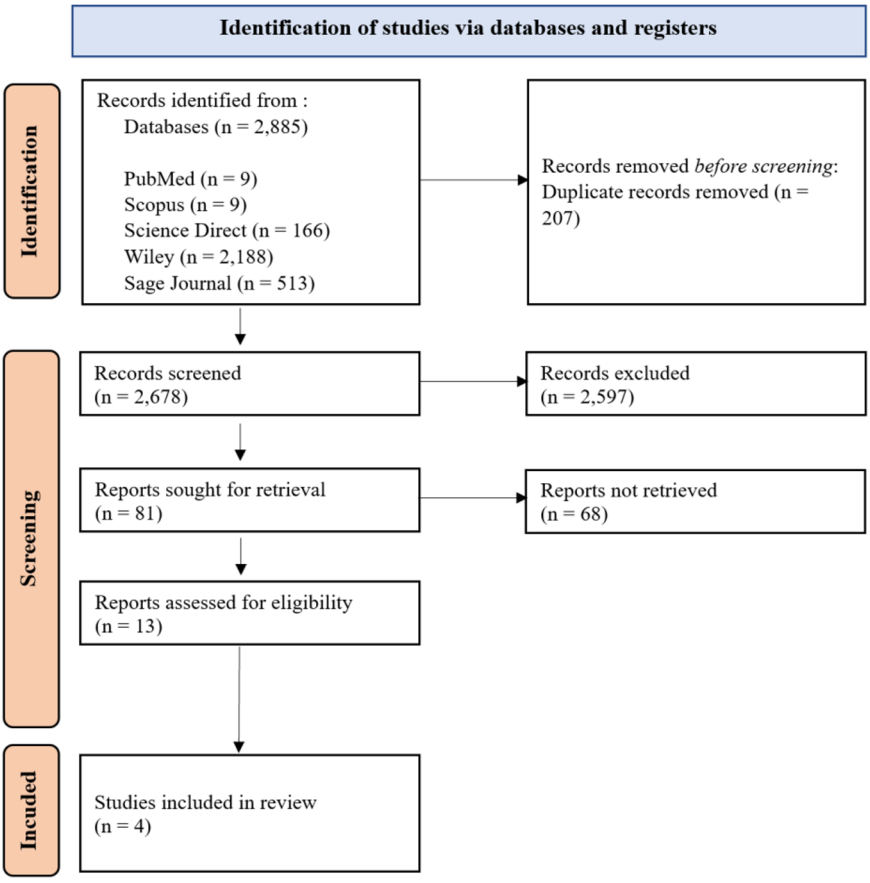


Fig. 1. PRISMA flowchart

3 Results

3.1 Data extraction

Data synthesis was performed on the eligible articles, capturing essential parameters, including: study identity, study location and design, participant, assessed domains, and key findings. Of the thirteen articles reviewed, none met all the established criteria. However, four articles demonstrated significant similarities, particularly regarding their study populations. A comprehensive summary of these extracted variables is presented in Table 3.

Table 3. Data extraction results

No.	Study Identity	Study Location and Design	Participant	Assessed Domains	Key Findings
1.	*Knowledge of, and Treatment Strategies for, Endometriosis among General Practitioners*. [15]	The study was located in Arnhem, Netherlands. It was a cross-sectional study using questionnaires related to general practitioners' knowledge of endometriosis, diagnostic and treatment strategies, and self-assessment of their knowledge.	General practitioners (n=101)	Knowledge of endometriosis	The findings indicated that gaps in general practitioner awareness often prevented the timely identification of symptomatic women, resulting in delays in diagnosis and treatment.
2.	*Survey of General Practitioner Perspectives on Endometriosis Diagnosis, Referrals, Management and Guidelines in New Zealand*.[16]	This study was conducted in New Zealand, using an anonymous online survey distributed to 869 clinics throughout New Zealand. The survey measured physician familiarity with the 2020 New Zealand endometriosis guidelines, self-assessed clinical expertise, symptom weighting, treatment practices, and referral rationale.	General practitioners (n=185)	• Awareness of a guideline in New Zealand • Implement ation of a guideline in New Zealand • Knowledge of endometrio sis	The findings demonstrated the need to improve general practitioners' awareness of endometriosis and to disseminate guidelines in order to enhance practitioners' knowledge and patient care.

No.	Study Identity	Study Location and Design	Participant	Assessed Domains	Key Findings
3.	*General Practitioners and Endometriosis : Level of knowledge and the impact of training*.[17]	This study was carried out in France. This study employed a descriptive anonymous epidemiological survey methodology to evaluate general practitioners' clinical comprehension and attitudes regarding endometriosis.	General practitioners (n=105)	• Knowledge of endometriosis • Attitudes regarding endometriosis	The findings showed that only 25% of general practitioners felt they possessed sufficient knowledge about endometriosis for routine practice. These findings indicate a significant need for enhanced training and education on endometriosis among general practitioners to reduce diagnostic delays.
4.	*"A Challenge" – Healthcare Professionals' Experiences When Meeting Women With Symptoms That Might Indicate Endometriosis*.[18]	This qualitative study that was conducted in Sweden, employed semi-structured interviews with healthcare professionals, including midwives, general practitioners, and obstetricians-gynecologists. Data analysis was conducted verbatim without the use of software assistance.	• Midwives (n=9) • General practitioners (n=6) • Ostetricians-gynecologists (n=10)	Perceptions of endometriosis	The findings revealed that healthcare professionals experienced challenges and demands for specific competencies when dealing with patients showing indications of endometriosis. Healthcare providers held divergent views on what constitutes normal menstrual, ovulatory, and intercourse-related pain. They also perceived the need to possess competencies to act and respond appropriately when such symptoms indicate endometriosis.

3.2 Characteristics of the included studies

Across the period spanning from 2014 to 2024, most of the study employed cross-sectional approaches alongside qualitative research methodologies as the primary study designs. In terms of geographical distribution, these studies originated from Europe and New Zealand, thereby reflecting a diverse international perspective on the issue.

3.3 Key findings regarding awareness and factors influencing

An analysis of the four selected studies reveals that research regarding endometriosis in primary care predominantly focuses on the knowledge levels, clinical strategies, and professional experiences of healthcare practitioners (HCPs), including general practitioners (GPs) andmidwives. A study conducted in the Netherlands involving 101 general practitioners indicated that while GPs take appropriate action once endometriosis is suspected, they frequently fail to recognize early symptoms due to the low frequency of cases encountered in daily practice. This contributes to an average diagnostic delay of 5.5 years.[19] Similarly, a New Zealand-based survey of 185 GPs found that only 52% felt they possessed sufficient knowledge for routine practice. Furthermore, despite 65% awareness of the 2020 national guidelines, only 35% had actually read them.[16]

The French study reported even lower levels of perceived competence, with only 25% of GPs feeling they had adequate knowledge. However, participation in continuing medical education (CME) or holding a university diploma in gynecology significantly enhanced practitioners' confidence and technical knowledge.[17] Finally, a qualitative study from Sweden involving gynecologists, GPs, and midwives highlighted the challenge of differentiating "normal" menstrual pain from pathological symptoms. Midwives, in particular, tended to view their role as supporting "healthy" individuals and often felt less competent in identifying disease, preferring to refer patients directly to specialists without conducting in-depth early detection. Collectively, these articles confirm a persistent global diagnostic delay ranging from 4 to 12 years.[20]

4 Discussion

This review confirms a critical literature gap regarding specific awareness of the early detection of endometriosis. Current research primarily assesses general knowledge and attitudes rather than structured early detection mechanisms in primary care settings. Diagnostic delay, the span from initial symptoms to confirmed diagnosis, remains a persistent global issue, largely driven by the normalization of menstrual pain by both patients and providers.[12]

There are several factors contribute to diagnostic delays: (1) Symptom dismissal or normalization, wherein healthcare professionals perceive dysmenorrhea as a normal physiological condition, thereby neglecting further investigations or diagnostic procedures such as laparoscopy; (2) Inadequate clinical knowledge, characterized by a limited understanding of the prevalence and signature symptoms of endometriosis among general practitioners, midwives, and other healthcare providers, which often

leads to misdiagnosis. This knowledge gap also results in excessive symptomatic prescribing, where analgesics and hormonal therapies are frequently utilized to manage pain without a definitive diagnosis. Consequently, while these treatments may temporarily mask symptoms, they ultimately delay a definitive diagnosis; and (3) The absence of standardized screening and diagnostic protocols, which induces high clinical variability in medical approaches and subsequently perpetuates diagnostic delays. Moreover, the effectiveness of clinical guidelines is hindered by low readership among primary care practitioners. As seen in the New Zealand context, the mere availability of guidelines does not guarantee implementation if practitioners lack the time or incentive to engage with the material.[12,16,19,21–26] Deficiencies in healthcare providers' knowledge regarding endometriosis can adversely affect their professional awareness, which in turn influences their clinical attitudes toward early detection.[11,17]

Crucially, the role of general practitioners within primary healthcare facilities is paramount for the early detection and timely referral of patients to specialists when necessary.[17,20] The role of midwives in primary care is also a critical focal point. In Sweden, midwives often perceive their professional identity as being centered on normal reproductive health, leading them to "miss" pathological signs of endometriosis which they consider outside their domain.[20]

5 Conclusion

This scoping review highlights a critical gap in the literature, revealing that specific research on the awareness of general practitioners and midwives regarding the early detection of endometriosis has not yet been conducted. Existing studies are predominantly limited to assessing general knowledge and attitudes. Given the profound impact of diagnostic delays on patient outcomes, there is an urgent need for targeted future research and structured educational interventions to enhance early detection capabilities among primary healthcare providers.

Acknowledgments. The authors would like to express their gratitude and appreciation to Indonesian Education Scholarship (BPI), Center for Higher Education Funding and Assessment (PPAPT) Ministry of Higher Education, Science, and Technology of Republic Indonesia, and Indonesia Endowment Funds for Education (LPDP) for supporting this research through a Doctoral Scholarship Scheme.

Disclosure of Interests. None declared.

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