

# INPLASY

## Assessing healthcare needs in endometriosis: a scoping review protocol

INPLASY202430109

doi: 10.37766/inplasy2024.3.0109

Received: 26 /March 2024

Published: 26 March 2024

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### ADMINISTRATIVE INFORMATION

**Support** - Agency under grant number APVV-22-0587.

**Review Stage at time of this submission** - Completed but not published.

**Conflicts of interest** - None declared.

**INPLASY registration number:** INPLASY202430109

**Amendments** - This protocol was registered with the International Platform of Registered Systematic Review and Meta-Analysis Protocols (INPLASY) on 26 March 2024 and was last updated on 26 March 2024.

## INTRODUCTION

**Review question / Objective** The research questions and aims of this scoping review were formed by applying the Population—Concept—Context (PCC) framework. This led to the primary research aim: To identify the cross-cultural studies that have been performed internationally within the context of medical encounters (context) concerning the diagnostic pathways (factors associated with timing/delay in diagnosis), management pathways (barriers and facilitators in management of disease), patients' needs and HCPs' perspective (concepts) in women with endometriosis and HCPs across all age groups (population). To identify the needs of women with endometriosis and assess HCPs' perspectives in the management of endometriosis the two main research questions were stated: (a) What are the main barriers to diagnosis and

efficient management of endometriosis from patients' and HCPs' perspectives? (b) What are the main facilitators in the diagnosis and management of endometriosis from patients' and HCPs' perspectives?

**Rationale** In recent years, only a few studies synthesized women's experiences that partially involved the context of medical encounters (e.g. Young et al., 2015; Pettersson et al., 2020), or focused on a single country (e.g. Westwood et al., 2023). Davenport et al. (2023) conducted a qualitative review of the barriers to the timely management of endometriosis from the perspective of affected individuals as well as HCPs. However, to our best knowledge, no prior synthesis with current qualitative and quantitative data on the perspectives of both, HCPs and patients, has been undertaken. Thus, this scoping review aims to map scientific literature on barriers

and facilitators in the diagnosis and management of endometriosis from patients' and HCPs' perspectives. As a wide range of data collection and analysis techniques were employed in included studies and our study uses a broad research question that includes the perspective of both, patients and HCPs', we decided to conduct the systematic scoping review.

**Condition being studied** Approximately 10% of women of reproductive age are affected by endometriosis (Mikells and Bontempo, 2022), a chronic burdensome gynecological disease characterized by the presence of endometrial-like tissue outside the uterine cavity, which causes an inflammatory response (Kuznetsov et al., 2017; Lamvu et al., 2020). The most common symptoms of endometriosis are dysmenorrhea, chronic pelvic pain, dyspareunia, abnormal menstruation, and heavy menstrual bleeding (Delanerolle et al., 2021; Márki et al., 2022). Symptoms are often progressive, cyclical, and non-specific while lesions are located in different parts of the body, not only in the urogenital tract (Davis and Goldberg, 2017; Holloway and Tye, 2019). Other common symptoms may include chronic fatigue (Lamvu et al., 2020; Peterson et al., 2023). Endometriosis was found to affect brain areas related not only to pain processing but also to emotion, cognition, self-regulation, and reward (Maulitz et al., 2022). It seems that approximately one-third of endometriosis patients suffer from mental health problems (Maulitz et al., 2022) - mostly depression or anxiety (Maulitz et al., 2022; Estes et al., 2021; Delanerolle et al., 2021; Márki et al., 2022). Many women with endometriosis may also suffer from sexual dysfunction, and approximately 30–50% of those who are diagnosed with endometriosis struggle with infertility as well (La Rosa et al., 2020). Thus, it is not surprising that endometriosis-related symptoms may significantly affect women's identity (Cole et al., 2021). Women with endometriosis experience diminished quality of life (QoL) (La Rosa et al., 2020), adverse effects on intimate relationships, limitations in daily functioning, reduced social participation, decreased productivity and income, chronic comorbidities, higher utilization of healthcare services, all of which are associated with significant direct and indirect costs (Soliman et al., 2017; Surrey et al., 2018; Agarwal, 2019; Facchin et al., 2020; Eisenberg et al., 2022).

A recent approach to the diagnosis considers endometriosis a complex systemic disease (e.g. Taylor, 2021) associated with an increased risk of autoimmune conditions such as systemic lupus erythematosus, Sjogren's syndrome, multiple

sclerosis, rheumatoid arthritis, or cardiovascular diseases (Nielsen, et al. 2011; Harris et al., 2016; Mu et al., 2016). Although is a benign condition, greater risk for the occurrence of malignant transformation such as ovarian cancer and non-Hodgkin's lymphoma are slightly more common in women with endometriosis (Schleedoorn et al., 2016). Several studies also showed that endometrial cancer, thyroid cancer, breast cancer, and cutaneous melanoma in patients with endometriosis may be more prevalent (e.g. Yu et al., 2015; Surrey et al., 2018; Vassilopoulou et al., 2019; Kvaskoff et al., 2021). Therefore, timely diagnosis, close follow-up, and clinically based management of endometriosis considering patients' history together with the prevention of comorbidities (Chapron et al., 2019; Agarwal et al., 2019) seem crucial, especially for women who have a higher chance of malignant transformation (Zhang et al., 2021). Although most endometriosis is found in the pelvis, it has been identified in various body areas with diverse effects on multiple organ systems (Davis and Goldberg, 2017; Holloway and Tye, 2019). Considering the variability in the manifestation and progression of endometriosis, the fact that it is often misdiagnosed is less surprising (e.g. Chapron et al., 2019; Agarwal et al., 2019). As non-invasive physical examination often does not show evidence of endometriosis, its diagnosis should include also women's anamnesis and experience. However, within the depersonalized healthcare system, women's knowledge is often dismissed, the symptoms are normalized (Bach et al., 2016; Mikesell and Bontempo, 2022), and patient-centered communication and care are considered unnecessary for the diagnostic process (Krebs and Schoenbauer, 2019; Dancet et al., 2023).

## METHODS

**Search strategy** The search strategy was based on the three-step process recommended by JBI (Peters et al., 2020). We compiled a list of potential search terms after an initial broad search in databases. We searched and identified studies based on reviewing titles, and abstracts, followed by the keywords. The reference lists of the relevant papers were searched for additional resources. Search terms in our review were identified as endometriosis, health care, clinical care, gynecologist, physician, nurse, needs, barriers, and facilitators. To identify potentially relevant documents the following bibliographic databases were searched from 2012 to 2022 in scientific databases including Web of Science, PsychInfo, PubMed, CINAHL, Embase, and Cochrane Library by two authors (VT, PM). The search was repeated

before the submission of the scoping review results for publication (in December 2023). Titles, abstracts, and keywords were screened to identify potentially relevant studies. If the suitability of an article was uncertain, the full text was screened. Finally, the reference lists of the relevant papers and Google Scholar were searched for additional resources. Clinical trial registries were searched to identify unpublished studies or any outcomes that may have been selectively omitted from a study publication.

Example:

Search Strings, EMBASE

(endometriosis:ti AND 'health care':ti,ab,kw OR 'clinical care':ti,ab,kw OR gynecologist:ti,ab,kw OR physician:ti,ab,kw OR general practitioner:ti,ab,kw OR nurse:ti,ab,kw) AND needs:ti,ab,kw OR barriers:ti,ab,kw OR facilitators:ti,ab,kw #1 AND 'endometriosis'/dm YEARS 2012-2023.

**Participant or population** The research questions and aims of this scoping review were formed by applying the Population—Concept—Context (PCC) framework. This led to the primary research aim: To identify the cross-cultural studies that have been performed internationally within the context of medical encounters (context) concerning the diagnostic pathways (factors associated with timing/delay in diagnosis), management pathways (barriers and facilitators in management of disease), patients' needs and HCPs' perspective (concepts) in women with endometriosis and HCPs across all age groups (population). Study sample Most studies included female patients only (n=35). A total of 10 studies included HCPs such as gynaecologists, GPs, midwives, and nurses. Another 5 studies included mixed samples of women and HCPs. Patients in 21 studies had clinically confirmed a diagnosis of endometriosis and the diagnosis was self-reported in 13 studies. In three studies, study samples consisted of both, women with confirmed diagnoses and self-reported/suspected diagnoses of endometriosis. Two studies did not report on the details of the diagnosis. Patients with endometriosis were recruited in clinical settings in a total of 11 studies while two of those were clinics specialised in endometriosis and pain. Most studies used self-help groups, digital posters, organization forums, or social media (n=16). Some studies on women with endometriosis used email (n=3), postal mail (n=1), health magazines (n=2), newspapers, flyers, and internet ads (n=1). Three studies used a mix of social media, email, patient/community groups, and research centers, clinical settings; and two studies analysed blogs and online narratives. The majority of HCPs were recruited at clinical settings, schools, medical databases and associations

(n=11), mixed with conferences (n=2), and education meetings or roundtables (n=2). In studies that included HCPs (n=15), the majority of study samples consisted of GPs (n=9) and/or gynaecologists (n=6) One study included gynaecological nurses, one study included midwives, and two studies included HCPs with different specializations (Table 1, Supplement 2). Number of included participants varied from 9 to 10.738 for women and 6 to 53 for HCPs.

**Intervention** NA.

**Comparator** NA.

**Study designs to be included** Qualitative, quantitative, mixed-method.

**Eligibility criteria** The eligibility criteria were built on the PCC framework and were in line with the aims of our review. The inclusion criteria were peer-reviewed journal papers with an explicit focus on patients with endometriosis and the perspective of HCPs (such as gynaecologists, GPs, nurses, midwives, and physicians). As diagnostic processes and healthcare systems may have changed over the past years, we only included scientific papers published in the past decade (from 2012 to 2023). We included original qualitative, quantitative, and mixed-method studies that involved human participants to consider different aspects of healthcare needs in endometriosis. We excluded commentaries, dissertations, economic evaluations, guidelines, technical reports, conference abstracts, letters, reviews, and meta-analyses. No language restrictions were applied (following Peters et al., 2020).

**Information sources** To identify potentially relevant documents the following bibliographic databases were searched from 2012 to 2022 in scientific databases including Web of Science, PsychInfo, PubMed, CINAHL, Embase, and Cochrane Library by two authors (VT, PM). The search was repeated before the submission of the scoping review results for publication (in December 2023). Titles, abstracts, and keywords were screened to identify potentially relevant studies. If the suitability of an article was uncertain, the full text was screened. Finally, the reference lists of the relevant papers and Google Scholar were searched for additional resources. Clinical trial registries were searched to identify unpublished studies or any outcomes that may have been selectively omitted from a study publication.

**Main outcome(s)** Multiple barriers may negatively affect the diagnostic process, healthcare encounters, and the efficient management of endometriosis. This scoping review identified three prominent themes in assessing barriers in the management and diagnosis of endometriosis. These themes were related to (1) external social and cultural factors, (2) individual HCPs factors and structural healthcare-related factors, (3) communication between patients and healthcare providers/professionals (HCPs), and (4) patient-related factors. While several studies focused on perceived barriers in the diagnosis and treatment of endometriosis, attention has been also paid to facilitators that may improve diagnostic accuracy and management of endometriosis. Three main groups of factors facilitating the management of endometriosis were identified as (1) healthcare-related factors, (2) facilitators in patient-provider communication, and (3) patient and community-related factors.

**Additional outcome(s)** Main barriers in the management of endometriosis

Theme 1 Socio-cultural factors  
 Subtheme 1 Discourse of psycho-abnormality and psycho-somatization  
 Subtheme 2 Sex bias in medicine  
 Subtheme 3 Myths, stigma, and taboos  
 Theme 2 Individual HCPs factors and structural healthcare-related factors  
 Subtheme 1 Perception of women with endometriosis as challenging patients  
 Subtheme 2 Insufficient awareness, training, and knowledge about the diagnosis of endometriosis  
 Subtheme 3 Lack of empathy, lack of fidelity, and patronizing  
 Subtheme 4 Limitations of current diagnostic tools and inaccessibility of healthcare  
 Subtheme 5 Barriers to delivery of diagnosis  
 Subtheme 6 Limitations to determining the most effective treatment and follow-up approach  
 Theme 3 Patient-related factors  
 Subtheme 1 Preference of complementary and alternative medicine/information sources as a challenge  
 Subtheme 2 Lack of awareness  
 Theme 4 Barriers to doctor-patient communication  
 Subtheme 1 Challenging communication about infertility  
 Subtheme 2 Challenging communication of pregnancy as a treatment option  
 Subtheme 3 Challenging communication about life-impairing pain

Main facilitators in the management of endometriosis

Subtheme 1 To be believed

Subtheme 2 Being heard with empathy and respect

Subtheme 3 Shared decision making

Subtheme 4 Counselling patients to seek evidence-based resources of information

Theme 2 Patient and community-related factors

Subtheme 1 Increased patients and public awareness and knowledge

Theme 3 Healthcare-related facilitators

Subtheme 1 Increased awareness and competence of specialists and non-specialists

Subtheme 2 Knowledge, information sharing, and emotional support

Subtheme 3 Efficient pain management

Subtheme 4 An empathetic approach to fertility needs and priorities

Subtheme 5 Multi-disciplinary care and continuity following diagnosis and treatment plans as a foundation for a biopsychosocial approach.

**Data management** NA.

**Quality assessment / Risk of bias analysis** The quality of the included studies was assessed following Reardon et al. (2017) using modified versions of the two checklists developed for qualitative and quantitative studies by Kmet et al. (2004). In quantitative studies, we assessed whether there was: (1) the objective sufficiently described; (2) the study design appropriate; (3) the method of subject/information selection appropriate; (4) the subject description appropriate; (5) the outcome and measures well defined; (6) the sample size appropriate; (7) analytics method described/appropriate; (8) the estimate of variance reported for the main results; (9) control of confounding; (10) results reported in sufficient detail; and (11) the conclusions supported by results. The maximum score was 22 points or 18 points, depending on if criterion number 5 and 8 are applicable.

In quantitative studies, we assessed whether there was: (1) the objective sufficiently described; (2) the study design appropriate; (3) the context for the study clear; (4) the connection to a theoretical framework clear; (5) the sampling strategy clear and relevant; (6) data collection clearly described; (7) data analysis clear and systematic; (8) verification procedures used to establish credibility; (9) conclusions supported by results; (10) reflexivity of the account. The maximum score was 20 points. When the two independent authors disagreed about the quality they tried to reach a consensus. If consensus was not achieved, a third author (IN) was invited in.

**Strategy of data synthesis** Data extraction - Two reviewers (VT and PM) independently charted the

data. A preliminary data extraction tool was created in line with JBI (Peters et al., 2020) based on the PCC framework, the aims of our study, and the research questions. Two authors (VT, PM) extracted the following information from each study: a) general: title, country, and year of publication; b) methods: study design, setting; primary method, c) participants: type (HCP/patient); type of HCP involved; the number of participants; the age of the participant, race/ethnicity/country of origin of the participant; recruitment method; and diagnosis assessed as clinically proven endometriosis or self-reported diagnosis. Finally, we abstracted the data related to outcomes of interest related to barriers and facilitators in the management of endometriosis (e.g. attitudes, bias, myths, stigma, taboos, knowledge, diagnostic tools and management methods, communication gaps and challenges, and various unintended consequences/factors) from the perspective of HCPs and patients. In case of disagreement in data extraction, consensus was achieved by discussion between the two authors (VT, PM). If needed, a third author (IN) was invited to resolve disputes. Data analysis and synthesis of results.

The results of the search strategy, screening process, and study selection were reported in line with the PRISMA-ScR recommended method using a flow diagram (Tricco et al., 2018). We described the studies by the study design, settings, and study sample. We grouped the information retrieved from the studies by the key themes related to the barriers and facilitators in the medical encounters they assessed.

**Subgroup analysis** NA.

**Sensitivity analysis** NA.

**Language restriction** No language restrictions were applied (following Peters et al., 2020).

**Country(ies) involved** Slovakia, United Kingdom.

**Other relevant information** The majority of studies included women with endometriosis mostly from Western countries (n=36), of those, two studies included also women from South Africa. Only two studies included women exclusively from non-Western countries (Iran and Puerto Rico). In one study country was not clearly defined as it analysed online comments and posts. Race/ethnicity of women with endometriosis was not reported in the majority of studies (n=27). Study samples where ethnicity/race was reported (n=13) consisted mostly of white women with endometriosis (82-100%), with one study that

included 73.2% of white women. All studies that involved HCPs were conducted in Western countries, except one study that involved gynecologists from Iran. (Table 1, Supplement 2).

**Time span**

The majority of the included papers (67.9%) were published in the last 5 years (from 2019 onwards), indicating increasing interest in this research area.

**Keywords** endometriosis; patient's needs; diagnostic delay; healthcare; barriers; facilitators.

**Dissemination plans** Publication in Q1 or Q2 international Journal with IF.

#### **Contributions of each author**

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