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Identifying the dimensions and components influencing health literacy and self-care in endometriosis: a scoping review

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Abstract

Background Endometriosis is a chronic, progressive inflammatory disorder affecting nearly 10% of reproductive-age women, yet it remains substantially underdiagnosed. Limited health literacy, inadequate access to reliable information, and reliance on variable-quality digital resources hinder timely symptom recognition and effective self-management. Understanding the determinants of health literacy and self-care is therefore essential to improving disease outcomes.

Methods This scoping review followed the Arksey and O'Malley framework, refined by Levac et al., and reported in accordance with PRISMA-ScR guidelines. A systematic search of PubMed, Scopus, Web of Science, and Google Scholar identified English-language studies published between 2014 and 2024 related to endometriosis, health literacy, self-care, and digital health. Eligible qualitative, quantitative, and mixed-methods studies were independently screened by two reviewers, charted using a standardized extraction form, and synthesized thematically across four domains: educational, psychosocial, technological, and structural/systemic components.

Results Across 20 included studies, four major domains were identified. Educational findings revealed persistent gaps in disease knowledge and symptom recognition, with targeted educational programs and digital tools shown to improve literacy and support earlier diagnosis. Psychosocial findings highlighted significant emotional distress, stigma, and social isolation; family support, peer networks, and online communities played crucial roles in promoting coping and engagement in self-care. Technological findings showed that mobile health (mHealth) applications, symptom-tracking platforms, and supportive text-based interventions can enhance awareness, self-management, and patient-provider communication, despite concerns about inconsistent online information quality. Structural findings emphasized diagnostic delays, inadequate provider awareness, and limited access to specialized services; emerging digital screening tools and machine learning models show promise but require integration into broader health system reforms.

Conclusion This review indicates that effective endometriosis management requires a multidimensional approach. Limited women awareness of the disease and treatment options remains a major barrier to informed decision-making and self-care, underscoring the need for targeted educational interventions. Digital health tools, such as symptom-tracking applications, can enhance health literacy and self-management, though their impact depends on the

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availability of reliable resources and adequate digital health literacy. Overall, integrating educational, psychosocial, technological, and system-level strategies holds promise for improving early diagnosis, symptom management, and quality of life among women with endometriosis, particularly in resource-constrained settings.

Keywords Health Literacy, Self-care, Endometriosis, Digital Health

Introduction

Endometriosis is a chronic, often progressive, inflammatory disease characterized by the presence of endometrium-like tissue outside the uterine cavity. It affects approximately 10% of women of reproductive age, equating to nearly 190 million women worldwide [1, 2]. Endometriosis significantly affects various dimensions of an individual's physical, mental, and social well-being. The condition manifests with a constellation of symptoms including dysmenorrhea, chronic pelvic pain, dyspareunia, gastrointestinal discomfort, and infertility, and is associated with substantial psychological distress (e.g., anxiety, depression), impaired quality of life, and social disruption [3]. Endometriosis significantly affects various dimensions of women's physical, mental, and social health. One of the major challenges associated with this condition is delayed diagnosis; the average diagnostic delay is estimated at about 8 years in the UK and 12 years in the United States [4]. This disease profoundly impacts women's lives, particularly those who lack the knowledge or resources to manage their condition, are unaware of available treatment options, or have limited access to specialized care [5].

Despite its relatively high prevalence, endometriosis remains one of the lesser-known conditions in public health systems and even among women themselves. Qualitative studies and systematic reviews have highlighted that diagnostic delays, the absence of reliable information, and women's inability to manage symptoms independently are among the major challenges associated with the disease [1, 5, 6]. As endometriosis has no definitive cure and requires long-term management, self-management and self-care have been recognized as key strategies in disease control. Self-management involves the active participation of individuals in managing their chronic conditions and is associated with enhanced knowledge, self-efficacy, engagement in self-care tasks, and improvement in some aspects of health status [7, 8]. Moreover, knowledge gaps and insufficient health literacy among women and even clinicians impede symptom recognition, timely healthcare seeking, and meaningful participation in care. Health literacy, broadly defined as the ability to obtain, understand, evaluate, and apply health information, plays a crucial role in enabling self-management of chronic conditions [9, 10].

In theory, improved literacy about menstruation, pain, and endometriosis may facilitate earlier recognition, reduce delays, and empower women in symptom

management. A pilot study showed that a low-cost online intervention could improve health literacy, provide effective self-management options for menstrual-related conditions, and encourage young women to seek medical consultation [11]. In parallel, women increasingly turn to the Internet and mobile applications for health information and self-management tools. Online search queries such as "What is endometriosis?" are highly frequent, but many digital resources suffer from poor readability, conflicting content, and lack of evidence validation raising the risk of confusion or anxiety. Agencies such as NIH and AMA recommend that women education materials be written at around a sixth-grade reading level (or no higher than 6th–8th grade) to ensure accessibility; unfortunately, many online health resources exceed these levels. Mobile health (mHealth) apps (e.g. symptom trackers, reminders, visual feedback) have shown promise in supporting self-care across diverse chronic diseases, but the evidence in endometriosis is nascent [11, 12].

Given these converging challenges diagnostic delay, limited health literacy, and the proliferation of digital health tools there is a pressing need to map and synthesize what is known about the components, dimensions, and determinants of health literacy and self-management in women with endometriosis. Such mapping can guide the design of evidence-informed educational strategies and digital interventions, especially tailored to specific contexts. Because of the rapid growth of mHealth applications, their use in the management of endometriosis is regarded as a promising approach [13]. The effectiveness of mobile apps in supporting self-management for chronic pain and other long-term conditions has been demonstrated. These platforms allow for symptom logging, reminder notifications, and real-time visualization of data in the form of interactive calendars and graphs [14].

In this scoping review, we aim to systematically identify and conceptualize the key components and dimensions influencing health literacy and self-care (including, but not limited to, digital health modalities) among women with endometriosis. By mapping the broader landscape of influencing factors from educational interventions and psychosocial support to technological tools and systemic enablers this review seeks to provide a holistic evidence base to guide the design of multifaceted, context-sensitive strategies for improving women empowerment, early diagnosis, and quality of life.

Materials and methods

Scoping review framework

This scoping review was conducted following the methodological framework outlined by Arksey and O'Malley [15], with refinements by Levac et al. [16] to enhance rigor and clarity.

The review explicitly followed the Population-Concept-Context (PCC) framework to clearly define the scope and boundaries of the study.

Population: Individuals diagnosed with or suspected of having endometriosis (including women and adolescent girls).

Concept: Dimensions, components, determinants, and strategies related to health literacy and self-care/self-management.

Context: All healthcare and community settings globally.

The review aimed to systematically map and synthesize evidence on the dimensions and components influencing health literacy and self-care among women and adolescent girls with endometriosis.

Search strategy

A comprehensive search strategy was developed to identify relevant literature published between January 2014 and 2024. The search was conducted across four electronic databases: PubMed, Scopus, Web of Science, and Google Scholar. The search strategy combined Medical Subject Headings (MeSH) and free-text terms, including "Endometriosis," "Health Literacy," "Self-Care," "Self-Management," "Digital Health," "eHealth," "mHealth," "Mobile Health," and "Health Education." Boolean operators (AND, OR) and truncation were utilized to optimize retrieval of relevant studies. The search was limited to English-language publications.

Inclusion and exclusion criteria

Studies were included if they: (a) addressed health literacy, self-care, self-management, or digital health interventions for women or adolescent girls with endometriosis; (b) were published in English between 2014 and 2024; (c) employed qualitative, quantitative, or mixed-methods designs; and (d) reported outcomes related to educational, psychosocial, technological, or structural components of endometriosis management.

Exclusion criteria included: (a) studies not specifically addressing endometriosis; (b) articles lacking full-text access; (c) non-peer-reviewed sources (e.g., editorials, commentaries) Although commentaries and editorials may provide contextual insights, they were excluded as they do not provide primary empirical evidence; (d) Gray literature (to enhance methodological rigor, ensure consistency in reporting standards, and maintain a transparent and reproducible body of peer-reviewed evidence) ;

and (e) studies not reporting outcomes relevant to health literacy or self-care.

Study selection

The initial database searches across PubMed, Scopus, Web of Science, and Google Scholar yielded 218 records. Following the removal of duplicates using reference management software (EndNote), two reviewers (ZR, LN) independently screened titles and abstracts of 159 unique records for eligibility. Discrepancies were resolved through discussion or consultation with a third reviewer (PM). Full texts of potentially eligible studies were retrieved and assessed against the inclusion criteria, resulting in 20 studies selected for data extraction.

Countries, regions, and basic demographics were noted to allow assessment of literature scope and diversity.

The selection process adhered to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) guidelines and is summarized in a PRISMA flow diagram (Fig. 1).

Data extraction and analysis

Data were extracted using a standardized form developed for this review, capturing: 1- publication details (year, country); 2- study design; 3- population characteristics; 4- type of intervention (if applicable); 5- dimensions examined (educational, psychosocial, technological, structural/systemic); and 6- outcomes related to health literacy and self-care. Two reviewers (ZR, LN) independently performed data extraction, with discrepancies resolved through consensus.

Data were analyzed thematically to identify patterns and key findings. Extracted data were categorized into four conceptual domains: 1- Educational Components (e.g., knowledge provision, health education programs); 2- Psychosocial Components (e.g., psychological support, coping strategies); 3- Technological Components (e.g., mobile health applications, digital platforms for symptom tracking); and 4- Structural/Systemic Components (e.g., patient–physician interactions, access to specialized care). Findings were synthesized descriptively and presented in tabular and narrative formats to highlight key themes and gaps in the literature (Table 1).

Quality assessment

As scoping reviews aim to map evidence rather than appraise study quality, no formal quality assessment was conducted. However, study designs and methodological limitations were noted to contextualize findings.

Results

Educational domain

Education represents a fundamental dimension in enhancing health literacy among women with

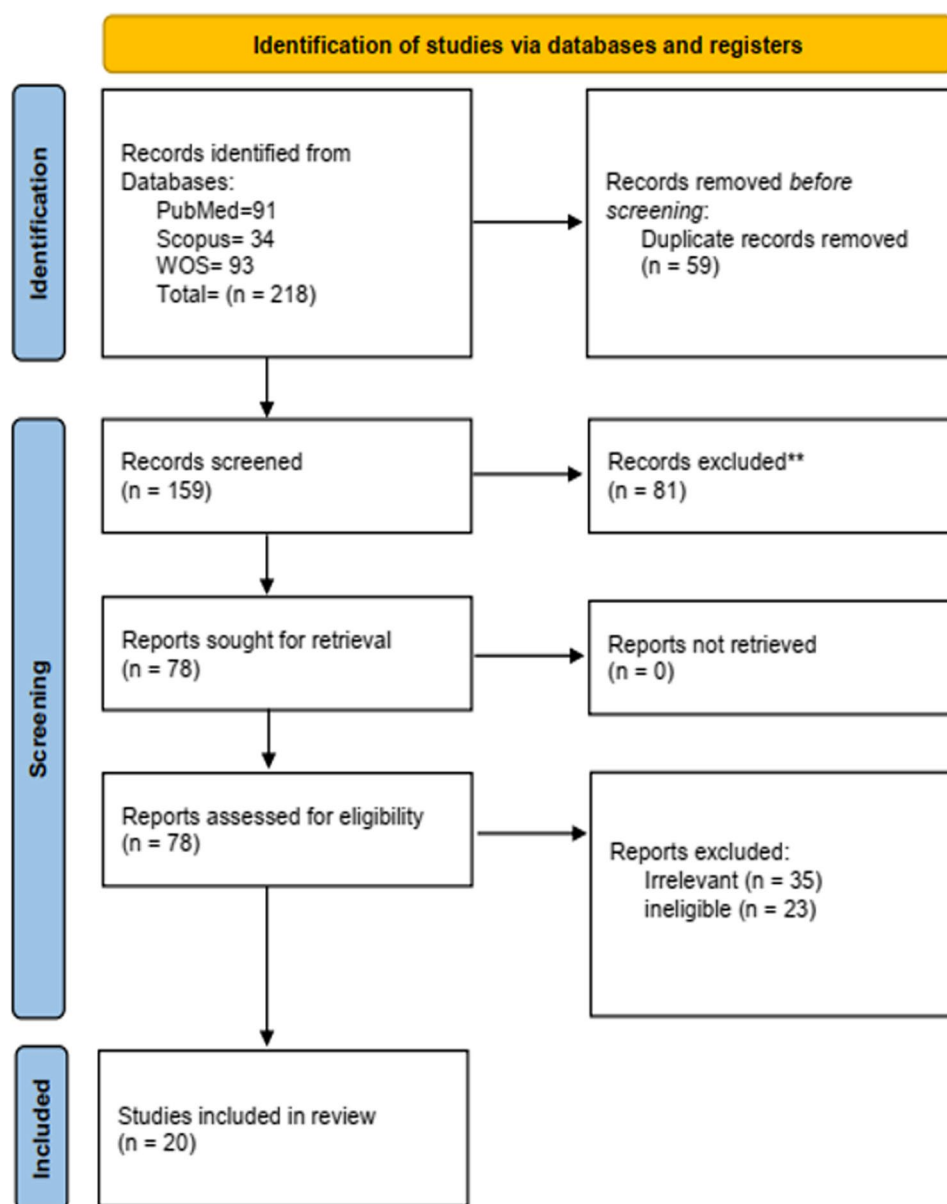


Fig. 1 PRISMA flow diagram of study selection process

endometriosis. Numerous studies have identified insufficient knowledge about the disease's nature, early symptoms, and available treatment options as major barriers to timely diagnosis and effective management.

Davenport et al. [1], in a systematic review, attributed diagnostic delays not only to patient unawareness but also to limited recognition of symptoms among healthcare providers. Similarly, Simpson et al. [4] emphasized that improving public awareness and providing targeted educational initiatives for adolescents and young women could play a decisive role in early detection.

A qualitative study by Namazi et al. revealed that many women with endometriosis lacked basic knowledge of their condition, which contributed to anxiety, confusion,

and impaired decision-making regarding treatment. These findings underscore the need for culturally tailored educational interventions [5]. This underscores the need for culturally tailored educational interventions. A pilot study by Petit et al. demonstrated that assessing women's health literacy levels at specialized centers can provide a foundation for designing targeted educational programs [17].

Moreover, education should extend beyond women to include families and healthcare professionals. Nienfuehr et al., in a conceptual review, emphasized the importance of raising awareness among adolescents, young adults, and healthcare providers [6]. Thus, the educational domain represents not only an individual but

Table 1 Summary of Studies on Health Literacy and Self-Care in Endometriosis Patients

Article Title	Author/ Year	Study Type	Main Objective	Key Components	Main Findings	Country/ region
Barriers to a Timely Diagnosis of Endometriosis	Davenport, 2023 [1]	Qualitative Systematic Review	Identify diagnostic delays and barriers	Structural, Educational	Delayed diagnosis; need for provider education	United Kingdom
Combating Diagnostic Delay via Educational Awareness	Simpson, 2021 [4]	Systematic Review	Reduce diagnostic delay through education	Educational, Preventive	Education facilitates earlier diagnosis	USA
Exploring the Impact of Endometriosis on Women's Lives	Namazi, 2021 [5]	Qualitative Study	Examine psychosocial impacts of endometriosis	Psychosocial, Structural	Significant psychological impact; need for comprehensive care	Iran
Barriers That Adolescents and Young Adults with Endometriosis Experience	Niedenfuehr & King, 2024 [6]	Conceptual Review	Explore care barriers in adolescents	Educational, Structural	Pain ignored, social stigma, diagnostic delays	USA
Self-Management Strategies Among Australian Women	Armour, 2019 [7]	National Online Survey	Identify self-management approaches	Self-care, Psychosocial	Use of complementary therapies; need for reliable resources	Australia
App-Based Self-Management and Quality of Life	Rohloff, 2024 [8]	Observational Study	Assess impact of apps on quality of life	Technological, Psychosocial	Improves symptom management and patient engagement	Germany
Digital Symptom Checkers for Diagnosis	Wickham, 2024 [9]	Survey	Evaluate digital diagnostic tools	Technological, Diagnostic	Helps monitor and track symptoms	United Kingdom / USA
Symptom Diary Mobile Apps	Scheck., 2023 [10]	Survey	Evaluate use of apps for symptom tracking	Technological, Self-care	Apps increase awareness and patient-provider interaction	New Zealand
Living with Endometriosis	Sbaffi & King, 2020 [13]	Descriptive Study	Examine role of internet in diagnosis and support	Technological, Informational	Online resources important but sometimes inconsistent	USA
High-Quality eHealth Websites for Endometriosis	Sirohi., 2024 [14]	Systematic Search	Evaluate quality of online information	Technological, Educational	Conflicting information; increases patient anxiety	United Kingdom
Mobile Applications for Endometriosis Management Functionalities	Moumane & Idri, 2023 [15]	Functionality Analysis	Assess apps for disease management	Technological, Self-care	Apps help track symptoms and provide education	Morocco
Health Literacy of Patients in a Specialized Center	Petit, 2024 [16]	Pilot Study	Assess health literacy of patients	Educational, Informational	Low literacy; need for educational interventions	France
EndoSMS Supportive Text Messages	Sherman, 2024 [17]	Pilot RCT	Evaluate supportive SMS intervention	Technological, Psychosocial	Increases support and treatment adherence	United Kingdom / Australia
Women's Use of Self-Care Interventions for Endometriosis Pain	Norman, 2021 [18]	Survey	Identify self-care strategies among women	Psychosocial, Self-management	Use of complementary therapies; need for reliable information	USA
Educational App for Women at Risk	Langarizadeh, 2022 [19]	Design & Evaluation Study	Design a health app for at-risk women	Educational, Technological	App increased knowledge about disease nature, early symptoms, and preventive options; interactive tool facilitated patient empowerment	Iran
Evaluation of Risk Advisor App	Nezhat, 2023 [20]	Pilot Study	Assess non-invasive screening app	Technological, Diagnostic	<i>Free Endometriosis Risk Advisor</i> helps identify women with chronic pelvic pain or unexplained infertility and increases awareness of need for medical follow-up	USA
Educational Website for Endometriosis-Associated Dyspareunia	Abdulai, 2022 [21]	Usability Study	Design web resource for dyspareunia	Technological, Informational	Increases usability and reduces stigma	United Kingdom/ USA
Flo App and Health Literacy	Cunningham, 2024 [22]	Pilot RCT	Assess impact of Flo app on health literacy	Technological, Educational	Improves health literacy and wellbeing	United Kingdom/ USA

Table 1 (continued)

Article Title	Author/ Year	Study Type	Main Objective	Key Components	Main Findings	Country/ region
Quality of Life Management with App	Rohloff, 2024 [23]	Observational Study	Evaluate impact of app on quality of life	Technological, Psychosocial	Mobile self-management program improved quality of life and enhanced symptom management and anxiety reduction	Germany
Early Diagnosis Using Machine Learning	Balogh, 2024 [24]	Study Protocol	Use self-reported patient data for diagnosis	Technological, Structural	Patient data can provide non-invasive diagnostic tools	Multicenter / Europe & USA

also a systemic and social component in endometriosis management.

Recent digital interventions further support this approach. Langerizadeh et al. reported that the development of an educational mobile application for at-risk women improved knowledge of disease mechanisms, early symptoms, and preventive options, thereby enhancing patient empowerment through interactive and experiential learning [18].

Similarly, Nezhat et al. introduced the *Free Endometriosis Risk Advisor* app as a non-invasive screening tool for identifying women with chronic pelvic pain or unexplained infertility, increasing awareness of the need for timely medical follow-up [19]. Collectively, these studies illustrate that educational interventions whether community-based or technology-enabled are critical for improving disease literacy, supporting early diagnosis, and promoting self-management among women with endometriosis.

Psychosocial domain

Endometriosis extensively affects women's mental health and social interactions. In the qualitative study by Namazi et al., women reported experiences of loneliness, severe anxiety, and social stigma among women with endometriosis, driven by chronic pain and societal misconceptions about menstruation [5]. Similarly, Nienfuehr et al. observed similar phenomena among adolescents and young adults, where social stigma related to menstrual pain and fertility concerns, exacerbating psychological distress [6].

Social support plays a decisive role in improving self-care. Norman et al. reported that women frequently adopt non-pharmacological self-care interventions, such as yoga, dietary adjustments, or mind-body techniques, for pain management. However, the effectiveness of these interventions is closely tied to the availability of robust family and social support networks [20]. In Abdulai et al.'s study, designing an educational website for women with endometriosis-associated dyspareunia not only increased awareness but also reduced social stigma and enhanced self-confidence [21].

Online support groups also play a pivotal role. Sbaifi et al. found that digital platforms facilitate peer-to-peer knowledge exchange, offering emotional support and compensating for deficiencies in familial or community networks. These platforms foster a sense of community, which is particularly valuable for women in regions with limited access to specialized care [13].

These findings underscore the importance of addressing psychosocial factors alongside educational and technological interventions to enhance health literacy, self-care, and overall quality of life for women with endometriosis.

Technological domain

Advancements in digital health technologies have created significant opportunities to enhance health literacy and empower women with endometriosis. mHealth applications have emerged as pivotal tools in this domain.

Moumane et al. found that endometriosis-specific apps, offering features such as symptom tracking, pain logging, and personalized recommendations, facilitate proactive disease management [22]. Similarly, Scheck et al., reported in a cross-sectional survey that using symptom-tracking apps not only increased women's awareness of pain and bleeding patterns but also improved their interactions with healthcare providers [10].

Other digital interventions have also been explored. Sherman et al., conducted a pilot randomized controlled trial showing that supportive text message interventions (EndoSMS) reduced anxiety and enhanced women's sense of empowerment [23]. Cunningham et al. reported the effectiveness of the *Flo* application in improving health literacy and overall well-being among women [24].

However, challenges persist with web-based resources. Sirohi et al. assessed the quality of endometriosis-related health websites and found that only a limited proportion of online sources provide up-to-date and reliable information [14]. Similarly, Sbaifi et al. reported that the dispersion and inconsistency of online information often lead to women confusion [13]. Nevertheless, Rohloff et al. emphasized that self-management apps can significantly improve women's quality of life [25]. Their study further demonstrated that an app-based self-management

program enhanced symptom management and reduced anxiety among women with endometriosis [8].

Collectively, these findings highlight that while digital technologies cannot replace in-person care, they serve as valuable complementary tools for education, symptom management, and women empowerment. Addressing the quality and consistency of online resources remains critical to maximizing their impact in endometriosis care.

Structural and systemic domain

Systemic barriers within healthcare systems significantly influence the quality of care for women with endometriosis. Davenport et al. identified key contributors to diagnostic delays, including limited physician awareness, societal stigma surrounding menstrual pain, and the normalization of women's pain, which collectively hinder timely diagnosis and intervention [1].

Similarly, Simpson et al. emphasized that gaps in medical education, particularly regarding endometriosis symptomatology, perpetuate these delays and exacerbate women outcomes [4].

Technological solutions have been proposed to address structural barriers. Balogh et al. explored the use of machine learning algorithms (FEMaLe) for early detection of endometriosis based on patient-reported data, identifying it as a promising tool for reducing diagnostic delays [26]. Wickham et al. suggested using digital systems for symptom screening to facilitate the diagnosis of women's health conditions, including endometriosis [9].

Furthermore, patient–physician interaction and access to specialized services are integral structural components. Petit et al. reported that low women health literacy leads to communication challenges with physicians, highlighting the need for educational programs for healthcare professionals to enhance communication skills and responsiveness to patients' needs [17].

Collectively, these findings highlight that without targeted improvements in health policy, diagnostic and treatment infrastructure, and patient–physician interactions, efforts to enhance health literacy and self-care among women with endometriosis will remain limited. Integrating technological innovations with healthcare system reforms is critical to overcoming systemic barriers, improving diagnostic efficiency, and optimizing care delivery for this population.

Discussion

Endometriosis, a chronic inflammatory condition, significantly impacts women's physical, psychological, and social well-being [27]. This scoping review highlights the necessity of a multidimensional approach to enhance health literacy and self-care among women with endometriosis. Integrating educational, psychosocial, technological, and structural interventions is essential to address

the complex challenges associated with the condition and to improve women outcomes and quality of life.

In the educational domain, women's lack of knowledge regarding the disease, early symptoms, and treatment options represents a primary barrier to effective disease management [1, 4]. Qualitative studies have shown that many women with endometriosis lack fundamental disease awareness, leading to heightened anxiety, confusion, and impaired treatment decision-making [5]. These observations underscore the need for culturally tailored and targeted educational interventions for women, families, and healthcare providers to enhance understanding and facilitate early diagnosis [6, 17]. Assessing women's health literacy levels provides a foundation for designing targeted educational programs [13]. Education of families and healthcare professionals, especially providers serving adolescents and young women, plays a crucial role in early diagnosis [6, 17]. Use of digital educational tools, including mobile applications, further facilitates women empowerment. Interactive tools, such as the *Free Endometriosis Risk Advisor* app, have been shown to enhance women knowledge, promote empowerment, and facilitate timely medical follow-up [18, 19]. These interventions underscore the potential of interactive digital platforms to support women education and self-management in endometriosis care.

In the psychosocial domain, endometriosis significantly impacts women's mental health and social interactions. Feelings of loneliness, anxiety, and social stigma are common among affected women [5, 6]. Social support from family, peers, and online groups effectively enhances self-care [13, 20, 21]. In the technological domain, digital innovations provide new opportunities for improving health literacy and women empowerment. Mobile applications enable symptom tracking, pain logging, personalized recommendations, and enhanced interactions with healthcare providers [22]. Other digital interventions, such as supportive SMS programs (EndoSMS) and the *Flo* app, have demonstrated effectiveness in improving health literacy and reducing anxiety [23–25]. However, online health resources are often fragmented and inconsistent, highlighting the need for reliable sources and digital health literacy education [13, 14]. Despite limitations in online resources, self-management technologies can improve quality of life and women's ability to manage symptoms [8, 13, 14]. In the structural and systemic domain, diagnostic delays and healthcare system barriers, including physician unawareness and inadequate diagnostic infrastructure, pose significant challenges [1, 4]. Machine learning algorithms and digital systems can support early diagnosis, but without improvements in healthcare infrastructure and patient–physician interactions, their effectiveness is limited [9, 17, 26]. Effective patient–physician communication and access to

specialized services are essential for enhancing health literacy and self-care [1].

This scoping review reveals several important gaps in the existing evidence base. Conceptually, there is a predominant focus on individual-level factors (e.g., women knowledge, app use) with less depth in exploring macro-level structural and policy determinants of health literacy. In terms of population, the literature predominantly reflects the experiences of adult, cisgender women in high-income Western settings. There is a striking lack of research involving adolescents at symptom onset, transgender and non-binary individuals, and populations from low- and middle-income countries. Regarding settings, most studies were situated in clinical or digital environments, with minimal investigation into community-based, workplace, or school-based interventions. Filling these conceptual, demographic, and contextual gaps is essential for developing a comprehensive understanding of health literacy and self-care that is generalizable and effective across diverse global populations.

While this review mapped a range of components influencing health literacy and self-care, considerations of equity, gender, and accessibility were underexplored in the included literature, representing a critical gap. The identified structural barriers such as diagnostic delays and limited access to specialized care disproportionately affect individuals based on socioeconomic status, geographic location, ethnicity, and gender identity. For instance, none of the included studies explicitly examined the experiences of transgender or non-binary individuals with endometriosis, nor did they systematically analyze how race, income, or rurality intersect to compound barriers to information and care. Furthermore, while digital tools were highlighted as promising, their potential to widen the “digital divide” for those with limited internet access, lower digital literacy, or financial constraints was rarely addressed. The psychosocial findings related to stigma are deeply gendered, rooted in societal norms about menstruation and women’s pain, yet the literature lacked a robust analysis of how these gendered perceptions vary across cultural contexts. Future research must intentionally center these dimensions to ensure that strategies for improving health literacy and self-care are truly inclusive and effective for all individuals affected by endometriosis.

This review has several limitations that should be considered when interpreting the findings. Methodologically, our search was restricted to English-language publications, which may have excluded relevant studies in other languages and introduced geographic bias. While scoping reviews do not typically assess study quality, the inclusion of varied study designs (e.g., pilot studies, cross-sectional surveys) means the strength of the evidence differs across findings. Furthermore, our focus on peer-reviewed

literature may have omitted valuable insights from grey literature or community reports. The conceptual mapping relied on the included studies’ foci, which may not capture all relevant dimensions of the lived experience of endometriosis. These limitations highlight the need for future systematic reviews on specific interventions and more inclusive primary research that addresses the identified gaps.

Overall, this scoping review underscores that optimizing endometriosis management requires a multidimensional approach integrating educational interventions, psychosocial support, digital technologies, and strengthened healthcare system infrastructure. Culturally tailored educational programs, peer-support platforms, and reliable mHealth tools, such as symptom-tracking apps, can enhance women’s knowledge, reduce anxiety, and promote self-management. However, gaps in content quality, accessibility, and equity must be addressed to ensure all patients benefit. Simultaneously, systemic reforms addressing diagnostic delays and improving access to care are essential to support these interventions. This holistic strategy holds the potential to facilitate timely diagnosis, improve symptom management, and enhance quality of life for women with endometriosis. Equity, gender, and accessibility considerations remain underexplored in the literature, highlighting critical gaps for future research.

Conclusion

The evidence synthesized in this scoping review indicates that a multidimensional approach, integrating educational, psychosocial, technological, and structural-systemic strategies, is essential for enhancing health literacy and self-care among women with endometriosis. Culturally tailored educational programs, robust psychosocial support through family and online communities, and reliable digital tools, such as mobile applications and symptom-tracking platforms, are pivotal in empowering women and improving disease management. Additionally, systemic reforms to address diagnostic delays and strengthen healthcare infrastructure are critical to support these interventions. By fostering women empowerment, facilitating earlier diagnosis, and promoting effective symptom control, such integrated strategies can significantly enhance quality of life and active engagement in self-care for women with endometriosis.

The synthesized evidence is going to benefit women with endometriosis, healthcare providers, researchers, and policymakers by informing the design of targeted interventions, educational programs, and health system reforms.

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Authors' contributions

All authors contributed to the study conception and design. The interviews were collected by [Zahra Rostami]; implementation, analysis by [Leila Nemati Anaraki], [Shahram Sedghi], [Parvaneh Mirabi] and [Razieh Zahedi Anaraki]. The first draft of the manuscript was written by [Zahra Rostami]. Writing – review and editing final of the manuscript was written by [Zahra Rostami], [Parvaneh Mirabi], [Leila Nemati Anaraki] and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

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Data availability

The datasets formed and analyzed during the current study are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

The study procedure was approved by the Medical Ethics Committee of Iran University of Medical Sciences [date: 2024, ID: IR.IUMS.REC.1403.174] As part of the doctoral dissertation as “Developing conceptual model of application to Enhancing health literacy and self-care of endometriosis in Iran”. The current study included only somebody who supplied their informed consent. All participants' information was private and nameless; there was no personal information that could link the answers with any of the participants in the present study. All methods in the study were in accordance with relevant regulations & guidelines (General Ethical Guidance for Medical Research with Human Participants in the Islamic Republic of Iran).

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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