

Patient and Practitioner: The Impact of Social Factors on Diagnostic Delay for Endometriosis



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Abstract

Introduction: Endometriosis is a gynaecological disease with diverse symptoms that are often shared with other disorders and is characterized by long diagnostic delays. Delayed diagnosis prevents patients from receiving access to care and negatively impacts both physical and mental health. While technical limitations of the diagnostic procedure contribute to the delay, there is also significant delay in first seeking consultation as well as getting referred to specialized care that point to social differences rather than medical factors. This literature review aims to identify social determinants that contribute to these delays in endometriosis diagnosis.

Methods: A literary search was conducted using PubMed, PsycInfo, and Web of Science. The search yielded a total of 549 articles. Of these, 22 articles were selected based on established search terms and criteria including that the articles had to present original data, be written in English, be published no earlier than 2012, and have full-text availability.

Results: Factors contributing to diagnostic delay can be related to one of two groups: the patient and the practitioner. Patient factors that increase delay include certain demographic characteristics, the extent of pain normalization, the stigma surrounding women's health, and the lack of self-advocacy. Practitioner factors that increase diagnostic delay include dismissive attitudes, the lack of knowledge and technical competence concerning endometriosis, and their relationship with patients as a position of authority.

Discussion: Many identified factors share similar themes but are manifested differently amongst patients and practitioners, particularly those relating to the lack of familiarity with endometriosis and the normalization or dismissal of symptoms. Shared findings point to larger societal factors influencing both patients and practitioners.

Conclusion: The findings of this review provide insight into social determinants that contribute to the long delays associated with endometriosis diagnosis. Future research should be aimed at establishing interventions for identified factors and also address larger shared social beliefs and misconceptions that maintain stigmas about women's health.

Keywords: endometriosis; diagnosis; delay; social determinants; health

Introduction

Endometriosis is a gynaecological disease characterised by the presence of endometrial-like tissue located outside of the uterus, resulting in chronic inflammation, pelvic pain, and infertility [1]. The tissue is typically located anywhere in the pelvic cavity, including the uterosacral ligaments, rectouterine pouch, ovaries, bowel, and bladder, but it can also arise in distant sites, including the lungs, liver, and brain [1-3]. The heterogeneity of the disease has been well appreciated, with symptoms of endometriosis including dysmenorrhoea, pelvic pain, dyspareunia, abdominal pain, menorrhagia, irritable bowel syndrome, constipation, and intermenstrual pain, among others [4]. Their symptoms can negatively affect their ability to work, engage in social events, exercise, do

housework, and maintain relationships with colleagues and family [5].

Overall, those with endometriosis report lower well-being and may have higher levels of chronic stress compared to women without endometriosis [6, 7]. The exact prevalence of endometriosis is unknown, but approximations range from 1% to 10% [8, 9]. Prevalence is much higher amongst women suffering from infertility and chronic pelvic pain, estimated to be 47% and 42%, respectively [10, 11]. Unfortunately, until the accuracy of diagnostic measures improves and education among community members and HCPs increases, the exact prevalence of endometriosis will remain unknown.

At present, there are no non-invasive tools or biomarkers to diagnose endometriosis reliably. The most widely used diagnostic tool is laparoscopy with additional

confirmation from histology [12]. Transvaginal ultrasounds are used as supportive evidence to guide laparoscopic surgery [12, 13]. Considering the invasive nature of laparoscopy, healthcare professionals (HCPs) often treat symptoms empirically rather than finding underlying pathology [12-14].

Globally, people with endometriosis face severe diagnostic delays, defined as the time between the onset of symptoms and the diagnosis of the disease [15]. A study comparing the diagnostic delays in the United States and the United Kingdom reported the average delays to be 11.7 years and 8 years, respectively [16]. Several studies have demonstrated that diagnostic delays are highly variable across countries; the exact delay ranges from 1 year to 27 years [15-20]. These delays are often due in part to the patient's lack of recognition of a medical issue, believing their symptoms to be disruptive, but not worthy of being reported to a medical professional [17, 21]. Once the symptoms have been disclosed, practitioners have difficulty classifying the symptoms, leading to a misdiagnosis or a lack of diagnosis altogether [17, 19].

Delays in diagnosis prolong the suffering of those affected by endometriosis with many stating that their symptoms, general health, and quality of life were negatively impacted [16]. Furthermore, diagnostic delay poses a substantial financial burden on those affected and the healthcare system, due to loss in productivity and healthcare expenses [21].

Alongside research aimed at medical limitations of diagnostic tools, it is essential to investigate causal factors that contribute to diagnostic delays. Social determinants of health, defined as non-medical factors that impact health, have been implicated in a broad range of health-related outcomes across various settings and populations [22]. Social determinants of health encompass the relation between social factors such as level of education, societal resources and systems, race, and health [22]. The goal of this review is to identify current health inequities and social determinants that lead to these diagnostic delays among people with endometriosis. This insight will aid in the development of interventions to diminish these delays, ultimately improving the quality of life among those affected. Endometriosis diagnosis provides access to symptom treatment, including pain reduction and infertility prevention, as well as decreases the psychological distress seen in those without a diagnosis [23].

Methods

Criteria

This literature review analyzed articles investigating health inequities and social determinants contributing to diagnostic delay among people with endometriosis. Only studies published in English with full-text availability were selected for review. Additionally, articles were limited to those published from January 2012 to December 2022.

Articles that did not contain original data, such as reviews, were excluded.

Review Methods

Searches were conducted on PubMed, PsycInfo and Web of Science. The following string search was used on all databases: “(delay* OR diagnosis OR diagnostic delay* OR social determinant* OR health inequit* OR health determinant* OR social inequit* OR social OR environmental factor* OR environmental determinant*) AND (endometriosis)”. All results yielded were manually reviewed by three reviewers (KD, HF, KT).

Results

The searches yielded 264 articles on PubMed, 63 articles on PsycInfo, and 222 on Web of Science, resulting in 549 articles in total. After reviewing the yielded articles, 16 duplicates were removed. 7 articles from PubMed, 12 articles from PsycInfo and 3 articles from Web of Science were selected based on the established exclusion criteria. Additionally, 384 were irrelevant to the research question, 104 did not contain original data, and 23 were unavailable in English. Thus, 22 articles were included in this literature review (see [Figure 1](#)). See [Table 1](#) for a summary of results.

Various factors contributing to the delay in endometriosis diagnosis emerged following a thorough examination of the literature. Themes surrounding the perception of symptoms, the interpersonal dynamics that permeate consultations, and an overall unfamiliarity with the disease consistently appeared throughout the selected articles. Although not the sole contributing factors, the authors elected to divide the findings into patient-related factors and HCP-related factors as documented by a past analysis of healthcare use and social determinants [20].

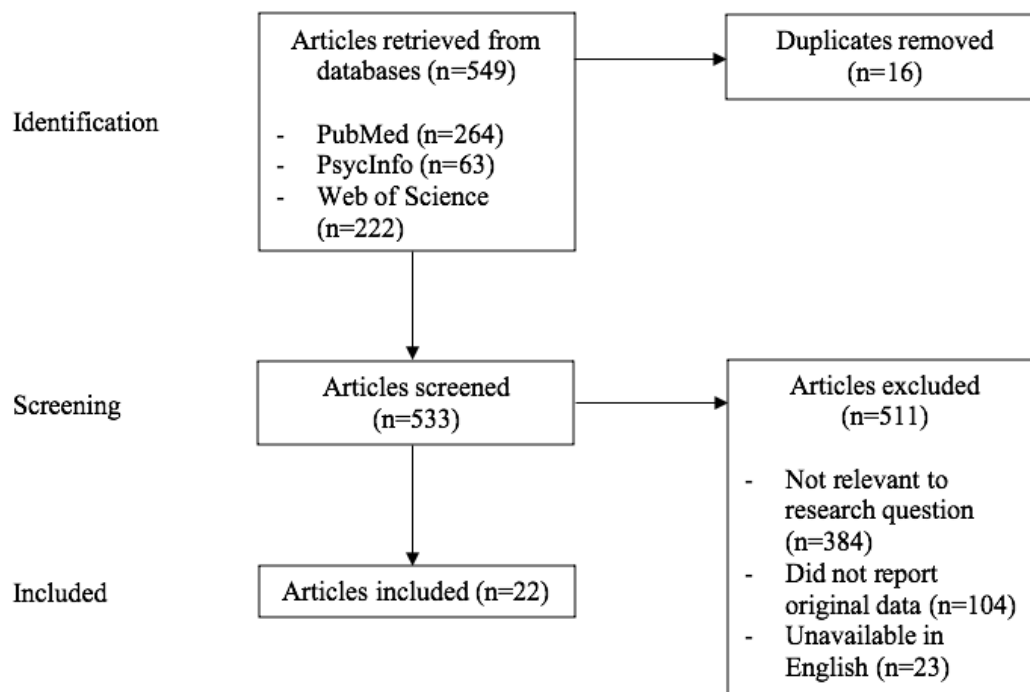
Patient Characteristics

There are several patient characteristics that impact speed of endometriosis diagnosis including age, ethnicity, and knowledge about endometriosis [24-28]. Furthermore, the normalization of pain, the internalized stigma surrounding women's health, and the capacity to self-advocate are also important contributors [18, 25, 28-36].

Social Demographics

One study within the literature review suggests that doctors' biases towards the ethnicity of their patients can impact the diagnostic process for endometriosis [26]. van der Zanden et al., interviewed 43 general practitioners (GPs) in the Netherlands with varying degrees of experience. They found that some of the GPs reported being quicker to refer patients to a specialist if they were of a different ethnicity than themselves [26]. These doctors claimed the variability in diagnosis according to ethnicity was related to communication. For example, one GP reported perceived communication discrepancies when discussing pain and treatment options with non-western European patients,

particularly [26]. Thus, the study suggests that biases held by doctors towards the ethnicities of their patients can contribute to how quickly they issue referrals to specialists.



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Figure 1. Flow diagram of article selection.

Table 1. Summary of review results

Study	Sample Size	Sample Characteristics	Methods	Factors Related to Diagnostic Delay
[5]	n=34	British women (between ages of 22-56 years) with self-reported medical diagnosis of endometriosis	Self-report questionnaires	<i>HCP-related factors:</i> Dismissive attitude
[18]	n=171	Austrian and German women (mean age of 32 years) with histologically diagnosed endometriosis	Self-report questionnaires	<i>Patient-related factors:</i> Normalization of pain <i>HCP-related factors:</i> Lack of knowledge and technical competence
[24]	n=638	American women (between ages of 18-49 years) with diagnosis or suspected diagnosis by physician of endometriosis	Self-report questionnaires	<i>Patient-related factors:</i> Social demographics
[25]	n=26	Australian women (mean age of 34.4 years) with a surgical diagnosis of endometriosis	Semi-structured interviews	<i>Patient-related factors:</i> Social demographics, stigma surrounding women's health issues, self-advocacy
[26]	n=43	Dutch general practitioners	Semi-structured focus group discussions	<i>Patient-related factors:</i> Social demographics, self-advocacy

Study	Sample Size	Sample Characteristics	Methods	Factors Related to Diagnostic Delay
				<i>HCP-related factors:</i> Lack of knowledge and technical competence, power imbalance
[27]	n=49	Publicly available online posts by Australian women with endometriosis	Autobiographical written accounts	<i>Patient-related factors:</i> Social demographics
[28]	n=14	South Korean women (mean age of 37.7 years) with surgical or laparoscopic diagnosis of endometriosis	Semi-structured interviews	<i>Patient-related factors:</i> Social demographics, normalization of pain, stigma surrounding women's health issues, self-advocacy
[29]	n=74	Caucasian Italian women (between ages of 24 to 50 years) with surgical diagnosis of endometriosis	Unstructured interviews and self-report questionnaires	<i>Patient-related factors:</i> Normalization of pain <i>HCP-related factors:</i> Lack of knowledge and technical competence, power imbalance
[30]	n=101	British women with laparoscopic and confirmatory histologic diagnosis of endometriosis	Self-report questionnaires	<i>Patient-related factors:</i> Normalization of pain
[31]	n=80	Narrative blog posts by women with endometriosis	Autobiographical written accounts	<i>Patient-related factors:</i> Normalization of pain, stigma surrounding women's health issues <i>HCP-related factors:</i> Dismissive attitude
[32]	n=34	British women (mean age of 33.5 years) with reported diagnosis of endometriosis	Self-report questionnaires	<i>Patient-related factors:</i> Normalization of pain <i>HCP-related factors:</i> Dismissive attitude
[33]	n=59	Australian women (mean age of 31 years) with endometriosis, general practitioners and a gynecologist	Online discussion groups and semi-structured interviews	<i>Patient-related factors:</i> Stigma surrounding women's health issues <i>HCP-related factors:</i> Lack of knowledge and technical competence, power imbalance
[34]	n=997	International adult patients (mean age of 35.4 years) with self-reported clinical or surgical diagnosis of endometriosis	Self-report questionnaires	<i>Patient-related factors:</i> Social demographics, self-advocacy <i>HCP-related factors:</i> Dismissive attitude, lack of knowledge and technical competence, power imbalance
[35]	n=895	International, English-speaking individuals with surgical diagnosis or clinically suspected endometriosis	Self-report questionnaires and semi-structured interviews	<i>Patient-related factors:</i> Self-advocacy
[36]	n=67	Dutch gynaecologists	Self-report questionnaires	<i>HCP-related factors:</i> Lack of knowledge and technical competence

Study	Sample Size	Sample Characteristics	Methods	Factors Related to Diagnostic Delay
[37]	n=451	International women (from ages of 19 to over 60 years) with self-reported diagnosis of endometriosis	Self-report questionnaires	<i>Patient-related factors:</i> Social demographics
[38]	n=25	South African women (mean age of 33 years) with laparoscopic diagnosis of endometriosis	Semi-structured interviews	<i>HCP-related factors:</i> Lack of knowledge and technical competence
[39]	n=131	British and Irish women (from ages of 19 to over 60 years) with self-reported diagnosis of endometriosis	Self-report questionnaires	<i>HCP-related factors:</i> Dismissive attitude, power imbalance
[40]	n=9	Swedish women (between ages 18-55 years) with laparoscopic diagnosis of endometriosis	Semi-structured interviews	<i>HCP-related factors:</i> Dismissive attitude, lack of knowledge and technical competence
[41]	n=25	Italian Adult women (mean age of 27 years) with diagnosis of endometriosis	Unstructured interviews	<i>HCP-related factors:</i> Dismissive attitude
[42]	n=18	Iranian gynecologists and patients (between ages 22-37 years) with confirmed diagnosis of endometriosis	Semi-structured interviews	<i>HCP-related factors:</i> Lack of knowledge and technical competence

Age is an additional barrier to diagnosis [25, 26]. Younger patients report having their HCPs insist that they are too young to present with endometriosis [25] although symptoms appear in some individuals shortly after first menstruation [27]. An international survey found that some individuals experienced the symptom onset of endometriosis at age 16 or younger [37]. However, women aged 40-49 years experienced shorter delays in receiving consultation and diagnosis compared to younger individuals [24].

Additionally, it is noted that patients must be aware of available information on endometriosis and insist that their HCPs consider it as a possible cause of their symptoms [25, 34]. However, a qualitative thematic analysis found that most women were not knowledgeable about endometriosis [28]. In one study, approximately 76% of women were unaware of endometriosis prior to their diagnosis [27]. Patients demonstrate a lack of knowledge about symptom presentation of endometriosis and treatment [28].

Normalization of Pain

Normalization of women’s menstrual pain is cited as paramount to diagnostic delay for endometriosis [29]. Notably, one study found that women whose pain was initially categorized as normal received a diagnosis approximately six years later than those whose pain was not normalized [30]. Women reported beliefs that menstrual pain was normal, and sometimes considered an essential part of becoming a woman [31]. Moreover, when family members of patients experienced similar menstrual pain, it further delayed some patients from seeking diagnosis as their

family maintained that pain is expected during menstruation [31].

Many women believed that the pain they experienced during menstruation was a universal experience [18, 28]. This hindered the realization that pain, including severe pain, could indicate a problem or illness [28]. The consistent normalization or dismissal of discomfort and pain caused some patients to re-evaluate their interpretations of their symptoms and the difficulties these symptoms cause in their lives [32].

Stigma Surrounding Women’s Health Issues

Pervasive stigmas about women’s health issues are another critical reason for diagnostic delays [28, 33]. Women seeking endometriosis diagnosis or care have stated that they must proceed carefully with their HCPs in order to not be considered hysterical, crazy, or paranoid about their symptoms [25]. Women may face accusations of fabricating their symptoms, of being weak, neurotic, and attention-seeking [31]. In some societies, it can be particularly difficult for unmarried women to seek care from specialists without fear of judgement [28]. For example, a woman from South Korea who participated in a qualitative study stated that despite receiving a referral, she delayed seeing a gynaecologist due to concerns about how she would be perceived by others [28].

Self-Advocacy

The lack of support from HCPs led some patients to consult the internet for information and immerse themselves

in a supportive community in order to gather tools to help advocate for themselves [28, 34, 35]. Women in one study reported that self-advocacy was crucial in order to receive a referral to a specialist who was in the position to provide proper intervention [34]. Additionally, GPs reported providing more referrals or considering endometriosis as a diagnosis to women who were active in their own medical discourse and presented their own research to their GPs [26, 36]. Those who advocated for themselves are found to have shorter diagnostic delays in contrast to women who were more passive [26, 36]. A study participant reported that women with endometriosis must educate themselves in order to effectively advocate for their treatment and ensure that their doctors possess enough expertise to manage their cases [34]. Self-advocacy was crucial in obtaining a diagnosis. Some women resorted to diagnosing themselves with endometriosis, then continuously asking their HCP to diagnose them and provide necessary interventions and treatments [25, 34].

Health Care Practitioner and System

The healthcare system contributes greatly to the delay in endometriosis diagnosis with contributing factors including lack of time to spend with patients [28, 38], inadequate measures to assess pain specific to the disorder [39], and the lack of standardized diagnostic guidelines [26]. However, the attitudes and abilities of HCPs also play an important role in the delay.

Dismissive Attitude

One of the most prominent contributors to the delay of endometriosis diagnosis is the dismissive attitudes of HCPs. As noted by Krebs and Schoenbauer in their thematic analysis of women's diagnostic experience, the dismissive attitudes adopted by HCPs can be divided into two subtypes: disbelieving reported symptoms and normalizing reported symptoms [31].

Symptom disbelief is rooted in suspicions that it is "all in [the patient's] head" [31] or that the patient is "overreacting" [5]. One study of British and Irish women with endometriosis found that 89% of participants thought that their HCPs did not believe their pain levels [39]. Another qualitative study found that respondents felt they had not been taken seriously by HCPs with one reporting being told that her pain was "in her head" [32]. Without symptom recognition, endometriosis will not be suspected, and thus, its diagnosis will be delayed.

Symptom normalization does not deny the experience of symptoms, yet it also does not accept them as signs of pathology. It is rooted in the belief that painful cramps and other irregularities with menstrual cycles are normal experiences for menstruating women [34, 40]. One participant of a qualitative study on living with endometriosis recounted being told by an HCP that she "was unlucky" and that she just had a "painful menstrual cycle"

[41]. This failure to recognize symptom complaints as signs of endometriosis further prolongs its diagnosis.

Lack of Knowledge and Technical Competence

The shortcomings in recognizing the signs of endometriosis and using the appropriate diagnostic tools have been acknowledged by both patients and HCPs [26, 29, 33]. Most HCPs are concerned with treating the symptoms and finding an "easy explanation" rather than determining its cause [40]. Therefore, considering that most presenting symptoms are pain and menstruation abnormalities, many patients are prescribed analgesics and hormonal contraceptives and preventing an actual diagnosis from being made [42]. Furthermore, a Dutch study found that many GPs are unfamiliar with the true prevalence rate of endometriosis and believe it to be quite rare [26]. This at least partly explains the high misdiagnosis rates, with symptoms commonly misattributed to chronic pelvic pain syndrome, bleeding disorders, and irritable colon syndrome among others [18].

Unfortunately, even when endometriosis is considered, HCPs do not necessarily take the appropriate steps to diagnose the underlying pathology. While GPs are more likely to dismiss symptoms or misdiagnose endometriosis, they have also been noted to refrain from giving gynaecological referrals based on personal beliefs [26]. For example, GP participants in a Dutch study reported that they were less likely to provide a referral to younger patients due to the invasive diagnostic procedure and their opinion that the diagnosis would negatively impact the patients' lives [26]. Similarly, gynaecologists have been reported not to use all diagnostic tools available to them [36]. For instance, one participant in a global study explained that her gynaecologist failed to diagnose her with endometriosis due to not performing a biopsy despite the laparoscopy discovering scar tissue [34]. As previously mentioned, confirmation via biopsy is considered the gold standard of endometriosis diagnosis [12]. Therefore, even when patients gain access to specialists, insufficient technical proficiency can delay diagnosis and proper treatment.

Power Imbalance

HCPs who participated in an endometriosis study indicated that patients' reluctance to disclose specifics of their symptoms contributes to diagnostic delay [33]. However, many failed to recognize their intimidating status, contributing to patients' hesitancy to discuss such sensitive topics. In a study conducted by Young and company, Australian women described going into consultations feeling "nervous," "scared", and "confronted" due to HCPs' demeanour [26]. This fear also interfered with asking questions to avoid appearing ignorant [39]. As mentioned previously, self-advocacy is an important contributor to diagnosis [34]. However, this factor is contingent on HCPs' empathy, respect, and receptiveness [29]. The significance of this attitude is highlighted in a study which found that

patients who had positive experiences with their HCPs and described them as “understanding,” “empathetic,” and “transparent” not only had shorter diagnostic delays, but also experienced less distress [29]. Thus, HCPs’ demeanour can play a role in patient disclosure and influence diagnostic delay.

Discussion

This literature review resulted in the identification of social determinants that contribute to the diagnostic delay of endometriosis. Findings were grouped into patient-related factors and HCP-related factors.

Although unique social factors emerged within each group, there was also significant overlap between the groups. Specifically, the patient and HCP lacked awareness and knowledge of endometriosis, limiting their ability to identify and treat the condition [26, 28]. Patients frequently had to turn to alternate resources to learn about endometriosis due to the incompetence of HCPs, the healthcare system, and the lack of societal awareness in general [35]. This lack of knowledge functioned in tandem with the normalization of pain and the stigma surrounding female health in preventing patients from receiving a diagnosis. Beliefs that severe pain during menstruation is normal, unwillingness to discuss reproductive organs, and general shame all contributed to women suffering in silence [18, 28, 33]. These beliefs about women’s health also influenced HCPs in how they perceived their patients, viewing them as neurotic and attention-seeking [31]. These perceptions resulted in dismissive and disrespectful attitudes, further discouraging patients from seeking diagnosis and treatment [5, 33]. The power imbalance between HCPs and their patients also hindered communication and limited the patients’ abilities to advocate for themselves [25].

Overall, these findings suggest that larger societal beliefs related to women’s health influence both patients and HCPs and prevent women from receiving effective healthcare. Female patients face stereotypes and are often mischaracterized as being hysterical, resulting in HCPs questioning the legitimacy of their claims and not valuing their input [43]. This incredulity can be internalized by patients and cause them to mistrust themselves. Societal attitudes towards menstruation and women’s reproductive health, in general, are rampant with misinformation, further obstructing women’s ability to receive well-informed treatment [40, 44]. This lack of knowledge is partly due to women and women’s health issues being heavily underrepresented in medical research [45]. Endometriosis is underfunded and under researched, especially within younger age groups partly because of reluctance to perform pelvic examinations on sexually inactive, underaged patients [46, 47]. Educating the general population, expanding research on women’s reproductive health, and modifying attitudes towards female patients are crucial to reducing diagnostic delays and improving women’s experiences in the healthcare system.

Conclusions

This literature review aimed to identify health inequities and social determinants that influence delays in the diagnosis of endometriosis. The analysis of the current literature determined that diagnostic delays occur among both patients and HCPs. Taken together, these findings provide insights into larger issues within the global healthcare system, specifically in relation to the treatment of female patients. Future research should aim to examine potential solutions and interventions to reduce these delays and improve the quality of care received by patients with endometriosis.

List of Abbreviations Used

HCP: healthcare professional
GP: general practitioner

Conflicts of Interest

The authors declare that they have no conflict of interest.

Ethics Approval and/or Participant Consent

No ethics approval or participant consent was needed to conduct this literature review.

Authors' Contributions

KD: Conducted a literature review on PsycInfo, analyzed collected articles, made contributions to the introduction and methods, drafted the discussion and conclusion, revised the manuscript, and gave final approval of the version to be published.

HF: Conducted a literature review on Web of Science, analyzed collected articles, made contributions to the introduction, methods, and results, formatted the references, revised the manuscript, and gave final approval of the version to be published.

KT: Conducted a literature review on PubMed, analyzed collected articles, made contributions to the introduction and results, drafted the abstract, revised the manuscript, and gave final approval of the version to be published.

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