Prevalence of endometriosis: A review of literature data

Abstract

Background: Endometriosis is a chronic and often debilitating condition affecting a significant proportion of women worldwide. Despite its impact on quality of life and healthcare systems, the prevalence of endometriosis varies widely across different studies and populations. This variability may be influenced by differences in study design, diagnostic criteria, and population characteristics.

Methodology: This narrative review aims to evaluate and summarize existing literature to determine the prevalence of endometriosis and to identify variability in prevalence rates across different study designs and populations. A comprehensive review of studies was conducted from April 2016 to April 2023 using MEDLINE, ScienceDirect, CINAHL, and PubMed, with a focus on MeSH terms such as ‘endometriosis,’ ‘prevalence,’ ‘incidence,’ and ‘epidemiology.’ The search strategy involved eliminating duplicates and applying strict inclusion criteria, resulting in the analysis of 19 selected articles.

Results: The review encompassed studies based on health insurance data, clinical trials, and surveys. Health insurance data revealed an overall prevalence of endometriosis of 0.76% (95% CI 0.17%–1.35%). Clinical trials demonstrated a wide range of prevalence rates from 0.05% to 37.1%, with a pooled prevalence of 6.82% (95% CI 4.41%–9.24%). Surveys showed varied results, with endometriosis being reported as a cause of infertility in 0.76% of respondents in Scotland and 18.3% in Turkey. Additionally, women with endometriosis reported higher rates of gastrointestinal, neurological, and urinary disorders, as well as significant impacts on their social and financial well-being.

Conclusion: This review highlights substantial variability in the reported prevalence of endometriosis and underscores the need for standardized diagnostic and reporting practices to better understand and address this condition.

Keywords: Endometriosis prevalence, incidence, diagnosis, uterine leiomyomas, endometriosis risk factors

1. Introduction

Endometriosis is asystematic inflammatory disease that is dependent on estrogen(1). It can manifest both within the genital tract and in extragenital locations. (2). Endometriosis affects a substantial portion of the global population, with estimates exceeding one billion individuals.(3).

In fact, a study examined the prevalence, incidence, and duration of disability for 354 causes across 195 countries and territories from 1990 to 2017. Based on this study, it has been found that the global prevalence of endometriosis is estimated at 44,656.0 per 1000 individuals, with a range of 37,289.1 to 52,852(4). Additionally, the number of years lived with disability due to endometriosis is estimated at 4121.5, with a range of 2752.3 to 5940(5).

Regarding diagnosis, a combinationof hysteroscopic andlaparoscopic techniques is utilized to identify endometriosis and other possible abnormalities within the abdomen and uterus(7). A large number of patients are affected by this condition, including up to 80% of those who experience pelvic pain(8). In addition, it is worth noting that endometriosis has a significant impact on nearly half of the patients who seek gynecological care(9, 10). Patients with endometriosis also experience a higher incidence of obstetrical complications(11). Endometriosis is commonly found in a large percentage of patients who experience symptoms related to uterine leiomyomas(12). Furthermore, it is worth noting that endometriosis can undergo malignant transformations(13). Endometriosis has been found to have strong connections to dyslipidemia, hypertension, and cardiovascular disease (14). It has been found that individuals with endometriosis have a higher risk of developing ischemic heart disease (40%) and cerebrovascular disease (19%)(15). There are several conditions that are more frequently observed in patients with endometriosis when compared to the general US population(15). These conditions include hypothyroidism, fibromyalgia, chronic fatigue syndrome, autoimmune diseases, allergies, and asthma(16). This literature review aims to evaluate and summarize existing literature data to determine the true prevalence of endometriosis, identifying variability in prevalence rates across different study designs and populations.

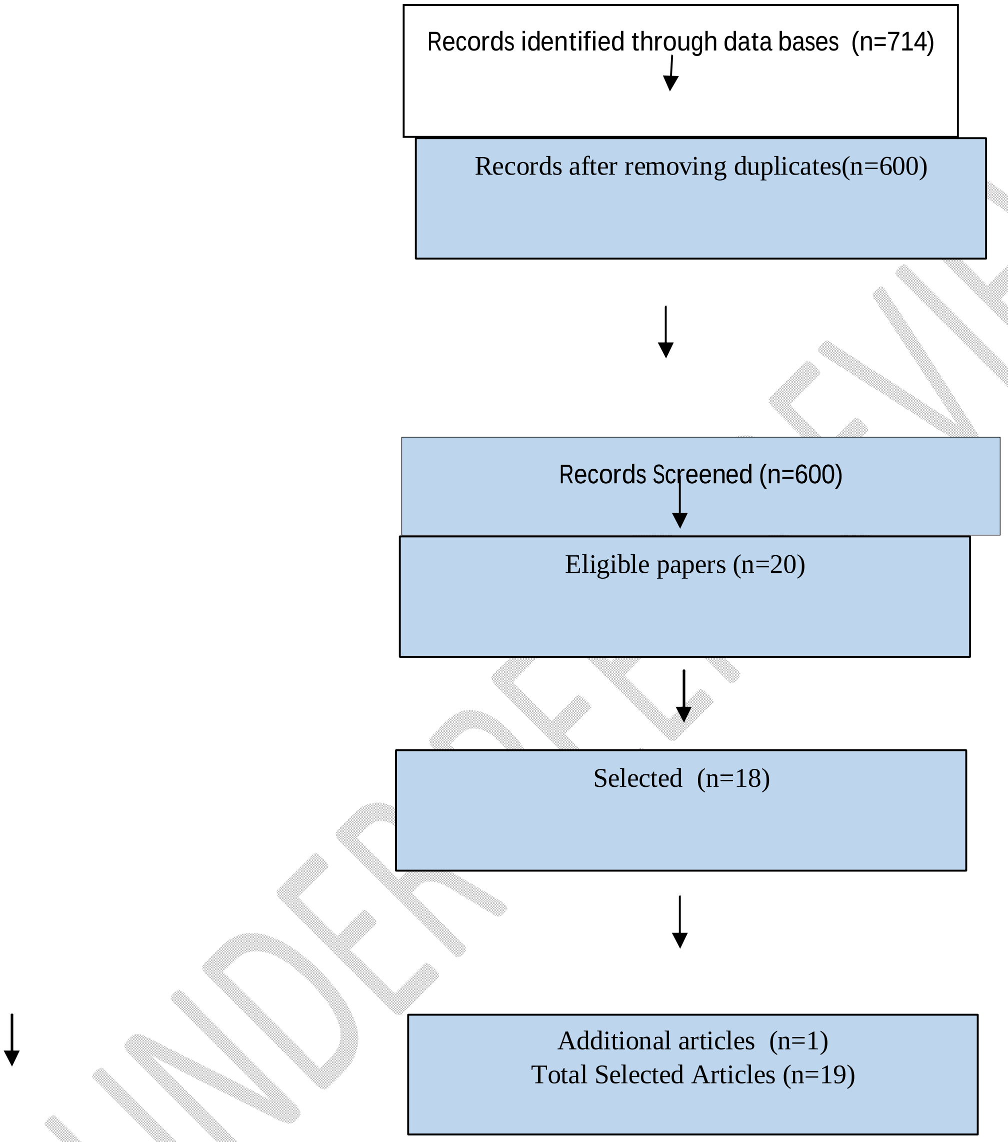
2. Methodology

In this narrative review of literature data assessing the true prevalence of endometriosis, we conducted a comprehensive narrative analysis incorporating studies of varying complexity and design(17). Our search, performed between April 2016 and April 2023, utilized the databases MEDLINE, ScienceDirect, CINAHL, and PubMed. We specifically used the MeSH terms 'endometriosis,' 'prevalence,' 'incidence,' and 'epidemiology' for our search. We selected MeSH terms over author-provided keywords as MeSH terms are curated by database specialists and provide more precise content identifiers.

A total of 714 articles were obtained through different databases. After removing duplicates, 600 articles remained. Based on the titles and abstracts, 582 articles were rejected. From that search, 18 papers were selected for review. One additional article was identified through a manual search of the reference lists and was included in the review. Finally, 19 papers from three countries were deemed eligible for inclusion in this narrative review.

Although MEDLINE is a subset of PubMed, we included searches from both databases due to the earlier inception of MEDLINE (1946) compared to PubMed (1996). This approach resulted in a significant number of duplicate records, which were removed in the fourth step of our search process. Our inclusion criteria required articles to be in English, and consist of Health Insurance data, clinical trials, and cross-sectional studies. Articles with exclusionary medical content and review articles were not included.

Flow Chart



3. Results

3.1 Characteristics of Included Studies

3.1.1 Studies Analyzing Health Insurance Data

Rowlands et al. conducted a study to investigate the administrative prevalence of endometriosis(6). Their study utilized data from a statutory health insurance fund in Germany, with a specific emphasis on outpatient and inpatient information. The research team analyzed a group of 62,323 women between the ages of 54 and 15 who had consistent insurance coverage in 2007. Their goal was to determine the prevalence of endometriosis. After standardizing the data to match the age distribution in Germany, it was discovered that a small percentage of women, specifically 0.81%, were affected by this condition. Women aged 35–44 years had the highest prevalence rate, which was 1.28%.This study aims to evaluate and summarize existing literature data to determine the true prevalence of endometriosis, identifying variability in prevalence rates across different study designs and populations, and highlighting factors that influence these estimates.

Almost the entire population of Hungary, around 98% to 99%, is covered by the National Health Insurance Fund Administration (NHIFA)(18). This is a compulsory health insurance system that ensures everyone has access to healthcare. Healthcare providers, regardless of ownership, have the opportunity to collaborate with the NHIFA by establishing a financing contract. Providers regularly submit monthly data on the services and care they offer, as well as the patient population they cater to. This data is utilized for calculating reimbursement. Based on the data analyzed by Csákvári et al., it was discovered that there was a significant number of 10,058 women (197.3 per 100,000) receiving outpatient care(19). The prevalence in acute inpatient care was significantly lower, with a rate of 23.5 per 100,000.

Eisenberg et al. sought to portray the true epidemiology of endometriosis in a diverse, low-risk population in Israel(20). In order to accomplish this, they utilized the digital databases of Maccabi Healthcare Services, a healthcare provider that serves 2 million members. According to the study, it was discovered that the occurrence of endometriosis in this particular group was 1.08%. Interestingly, women between the ages of 40 and 44 had the highest prevalence, with a rate of 1.86%. In addition, it was found that 37% of patients experienced infertility. The study involved a total of 6045 patients who were recently diagnosed with endometriosis. This resulted in an average annual incidence rate of 7.2 per 10,000, with a 95% confidence interval of 6.50-8.00.

A study conducted by Kim et al.investigated the prevalence of endometriosis using data from the Korean NHIS, which included approximately 1 million Korean individuals from 2002 to 2013(21). The study focused on patients aged 15 to 54 and discovered that the age-adjusted prevalence of endometriosis was 0.35%.

Through the regional centralized data linkage system, Morassutto's group conducted a study to determine the prevalence of adenomyosis and endometriosis in the female population of the Friuli Venezia Giulia region in Italy from 2011 to 2013(22). Diagnoses from hospital discharge records were determined as cases, using procedures that involved direct visualization for endometriosis and adenomyosis, with or without histologic confirmation. The prevalence, calculated based on the incidence, was 2.00%. Adenomyosis is a condition that becomes more common after the age of 50, accounting for 28% of all diagnoses.

In studies based on health insurance data, the overall prevalence of endometriosis was found to be 0.76% (95% CI 0.17%–1.35%).

3.1.2 Clinical Trials Evaluating the true prevalence of endometriosis

Ten included clinical trials found a wide range of prevalence rates for endometriosis, ranging from 0.05% to 37.1%. Based on clinical data, the pooled prevalence of endometriosis was found to be 6.82% (95% CI 4.41%–9.24%)(23-32).

Through a comprehensive review and analysis of various studies, the researchers discovered the lowest recorded prevalence of endometriosis among women in the general population, which was 0.05%. A total of twenty-seven papers were analyzed, with a staggering number of 28,660,652 women included in the study. These papers were carefully categorized based on their design and sources of information. Based on the data provided, the prevalence estimates were 0.05 (95% CI 0.03–0.06) for self-reported data, 0.01 (95% CI 0.01–0.02) for population-based integrated information systems, and 0.04 (95% CI 0.04–0.05) for studies using other designs(33).

Understanding the population's needs in order to effectively plan measures for reducing emergency department visits is crucial. In their study, Xholli et al.examined gynecologic visits to the emergency department at the University Hospital of Modena, Italy, and the findings among women of reproductive age. A total of 461 records were analyzed(34). Endometriosis, leiomyoma, and Adenomyosis were the most frequently observed gynecologic findings in the emergency department. In addition, there were very few cases of potentially life-threatening findings (specifically, 0.2% for hemorrhagic ovarian cysts, 0.2% for tube-ovarian abscess, and 0.4% for pelvic inflammatory disease). Chronic pathologies, such as endometriosis, had a notable impact on the utilization of the emergency department in the current study.

3.1.3 Surveys Evaluating the true prevalence of endometriosis

Bhattacharya et al. conducted a postal questionnaire survey in the Grampian region of Scotland, targeting women aged 31 to 50 years(35). The survey collected data on pregnancy history, time to conception, medical consultations, and factors related to infertility. A random sample of 4466 women was surveyed. Of the respondents, 400 (9.0%) had opted not to have children. Among the remaining 4066 women, 3283 (80.7%) reported no difficulties with conception, while 783 (19.3%) experienced infertility, defined as difficulty conceiving for over 12 months and/or seeking medical advice. Endometriosis was identified as a self-reported cause of infertility by 34 women (0.76%).

A study conducted in Turkeyused the EndoCost tool to analyze data from 15,673 women aged 18 to 50 years(36). Of these participants, 2,880 (18.3%) were diagnosed with endometriosis. Women with endometriosis reported significantly higher rates of gastrointestinal, neurological, and urinary disorders compared to those without the condition. Additionally, 80.1% of those with endometriosis experienced persistent fatigue, and 21.2% felt socially isolated due to their condition. A notable 63.2% of respondents with endometriosis felt that others did not believe their pain or symptoms. Financial difficulties related to treatment costs were reported by 77.9% of women with endometriosis. Furthermore, 46.0% experienced relationship problems, 28.3% faced challenges at school or work, and 7.4% were unable to attend class or work due to endometriosis-related symptoms.

Table 1: Characteristics of Included Studies

Study Type	Study	Population	Data Source	Key Findings	Prevalence Rate

Population Based Cohort	Rowlands et al.	62,323 women aged 15-54 in Germany	Statutory Health Insurance Fund	Administrative prevalence of endometriosis	0.81% (35-44 years: 1.28%)
Descriptive Cross Sectional	Csákvári et al.	Population of Hungary (98-99% coverage)	National Health Insurance Fund Administration (NHIFA)	Prevalence in outpatient and inpatient care	Outpatient: 197.3/100,000; Inpatient: 23.5/100,000
Retrospective Cohort	Eisenberg et al.	2 million members in Israel	Maccabi Healthcare Services	Epidemiology of endometriosis in a low-risk population	1.08% (40-44 years: 1.86%)
Retrospective Cohort	Kim et al.	1 million individuals aged 15-54 in Korea	Korean NHIS	Age-adjusted prevalence of endometriosis	0.35%
Cross sectional	Morassutto et al.	Female population in Friuli Venezia Giulia, Italy	Regional Centralized Data Linkage System	Prevalence of adenomyosis and endometriosis	2.00% (adenomyosis common after age 50)
Clinical Trial	Xholli et al.	Women of reproductive age in Modena, Italy	University Hospital of Modena	Impact of chronic pathologies on emergency department utilization	6.82% (95% CI 4.41%-9.24%)
Cross sectional	Bhattacharya et al.	4466 women aged 31-50 years in Grampian, Scotland	Postal Questionnaire Survey	Endometriosis as a self-reported cause of infertility	0.76%
Cross sectional	Study in Turkey	15,673 women aged 18-50 years	EndoCost Tool	Impact of endometriosis on quality of life and financial burden	18.3%

4. Discussion

This narrative review aims to summaries the current literature regarding the prevalence of endometriosis using different study designs such as health insurance data, clinical trials, and surveys. In comparing the different methodologies, marked variation in the prevalence rates was evident, underpinning the challenge of establishing the true epidemiology of endometriosis.

Research conducted using health insurance data helps to estimate the administrative burden of endometriosis in various populations. For instance, Rowlands et al. conducted a study in Germany and found that the overall prevalence rate was 0. 81%, with the highest rates being reported among women aged 35-44 years(6). Likewise, the NHIFA data of Hungary showed the outpatient prevalence rate of 197. 3 per 100,000, however inpatient care data was much lower at 23 per 100,000. 5 per 100,000(18). Such disparities between outpatient and inpatient settings may be due to differences in diagnostic practices and access to care, as endometriosis is often under- or mis- diagnosed, especially in primary care(37).

In addition, Kim et al. ‘s study conducted in Korea showed a lower age-adjusted prevalence of 0. 35%, while Morassutto et al. ‘s work in Italy reported a prevalence of 2. 00% using hospital discharge data(21, 22). The wide range of estimates, from 0.35% to 2.00%, highlights the effect of study methodology, sample characteristics, and data collection procedures on the prevalence estimates. Specifically, the health insurance-based studies reported an average prevalence of 0. However, this estimate may not accurately reflect the actual prevalence of the disease as there is underreporting, problems with coding, and disparities in health care access.

As our review indicates, clinical trials provided a wider range of prevalence estimates, from 0.05% to 37.1%, with a pooled prevalence of 6.82%. This huge disparity might be attributed to the dissimilar study subjects, diagnostic standards, and the number of participants included in the studies(38). Some of the clinical trials involve certain patient populations like patients with infertility or pelvic pain and this may result in higher prevalence rates than population-based studies(39).

In the same way, surveys, especially those based on women’s own opinions and feelings, provide helpful information into the ways in which women with endometriosis understand their own situation(40). Bhattacharya et al. in their study in Scotland revealed that 0. 76% of women claimed endometriosis to be the reason for their infertility while a bigger survey conducted in Turkey showed that 18% of women had endometriosis(35).The higher prevalence in the Turkish study might be due to the more inclusive criteria used in the diagnosis of the condition or increased awareness of the participants about the disease.

Self-reported data also present some concerns regarding the underdiagnosis of endometriosis, since women might not even consult a doctor for these issues or might not be officially diagnosed. Also, the studies that use self-reported questionnaires show the psychosocial consequences of the disease. In the Turkish survey, women with endometriosis had more often gastrointestinal, neurological and urinary symptoms, fatigue and social isolation. These results therefore show that endometriosis has a significant impact on quality of life, beyond its role in reproductive health.

5. Conclusion

This literature review reveals substantial variability in the reported prevalence of endometriosis, reflecting differences in study designs, diagnostic criteria, and population characteristics. While health insurance data suggest a lower prevalence of 0.76% (95% CI 0.17%–1.35%), clinical trials indicate a broader range, with a pooled prevalence of 6.82% (95% CI 4.41%–9.24%). Surveys also demonstrate significant variation, from 0.76% in Scotland to 18.3% in Turkey. These discrepancies highlight the challenges in establishing a definitive prevalence rate for endometriosis.

The review underscores the need for standardized diagnostic and reporting practices to improve the accuracy and comparability of prevalence estimates. Addressing these inconsistencies is crucial for developing effective public health strategies, allocating resources, and enhancing support for individuals affected by endometriosis. Improved data collection and reporting methodologies will contribute to a clearer understanding of the true prevalence and impact of this condition.

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