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Review Article

Is Endometriosis More Common and More Severe Than It Was 30 Years Ago?

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ABSTRACT **Objective:** Current estimates of endometriosis prevalence and incidence are highly variable, leading to uncertainty regarding true endometriosis frequency or validity of quantified changes over time. We present a comprehensive review of the prevalence, incidence, and stage of endometriosis worldwide as reported over the past 30 years.

Data Sources: We conducted a systematic search of observational studies using the PubMed, Web of Science, EMBASE, and CINAHL databases to identify research papers published in English between January 1989 and June 2019. Search terminologies were limited to titles containing endometriosis and prevalence or incidence, or epidemiology, or frequency, or occurrence, or statistics.

Methods of Study Selection: Two independent reviewers screened abstracts for study eligibility, and data from included studies were abstracted.

Tabulation, Integration, and Results: Overall, 69 studies describing the prevalence and/or incidence of endometriosis met the inclusion criteria. Among these, 26 studies involved general population samples, 17 of which were from regional/national hospitals or insurance claims systems. The other 43 studies were conducted in single clinic or hospital settings. Prevalence estimates for endometriosis widely varied from 0.2% to 71.4% depending on the population sampled. The prevalence reported in general population studies ranged from 0.7% to 8.6%, whereas that reported in single clinic- or hospital-based studies ranged from 0.2% to 71.4%. When defined by indications for diagnosis, endometriosis prevalence ranged from 15.4% to 71.4% among women with chronic pelvic pain, 9.0% to 68.0% among women presenting with infertility, and 3.7% to 43.3% among women undergoing tubal sterilization. A meta-regression was conducted with year as the predictor of prevalence. No trend across time was observed among "general population in country/region" studies ($\beta = 0.04$, $p = .12$) or among "single hospital or clinic" studies ($\beta = -0.02$, $p = .34$); however, a decrease over time was observed among general population studies abstracted from health systems or insurance systems ($\beta = -0.10$, $p = .005$).

Conclusion: As with all human studies, population sampling and study design matter. Heterogeneity of inclusion and diagnostic criteria and selection bias overwhelmingly account for variability in endometriosis prevalence estimated across the literature. Thus, it is difficult to conclude if the lack of observed change in frequency and distribution of endometriosis over the past 30 years is valid. Journal of Minimally Invasive Gynecology (2019) 00, 1−10. © 2019 AAGL. All rights reserved.

Keywords: Systematic review; Prevalence; Incidence; Stage

It is commonly stated that endometriosis affects approximately 10% of women of reproductive age worldwide, reaching up to 50% among women who are infertile [1−3]. Endometriosis has a heterogeneous clinical presentation with respect to symptoms, empiric treatment response, and phenotype, which influence diagnosis sensitivity and specificity. Health disparities, including access to experienced surgeons or imaging specialists, impact the likelihood of being evaluated and diagnosed. Although the standard criterion for diagnosis remains surgically visualized lesions, skilled imaging can successfully identify ovarian endometrioma and deep endometriosis but not superficial peritoneal disease [4,5].

Determining the frequency and distribution of chronic diseases such as endometriosis that can severely impact the quality of life is critical for public health and clinical care [2,6−9]. Prevalence quantifies the proportion of patients

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This study has been registered in International Prospective Register of Systematic Reviews (pending ID: 149927).

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with disease in a population at a single point or period in time, whereas incidence is the rate of new disease occurrence or diagnosis in a population across a specified period [10]. Measuring true change in disease frequency over time requires stable definitions and likelihood of detection within the same or similar populations.

Quantifying changes in endometriosis frequency can provide insight into the etiology of the disease that may be attributed to correlated risk factors that in addition change over the same time period. The Global Burden of Disease represents the broadest effort to quantify frequency measures of many diseases, tabulated using a mixture of nation-level morbidity, hospital discharge, and insurance data with the intention to allow countries to recognize their relative health challenges and changes over time [11]. Endometriosis was included in 2017, with documentation reporting available data with a decrease in age-standardized rates of 3.1% (95% confidence interval = −6.3% to 0.5% change) from 1990 to 2007 and of −3.0% (−3.9% to −2.0% change) from 2007 to 2017. An assessment of the sources of these data, heterogeneity among them, or potential biases within the data is not considered. To the best of our knowledge, no comprehensive systematic review has been conducted to examine changes in reported frequency measures in the published literature over time.

The aim of this review was to apply a systematic approach to summarize endometriosis frequency, distribution, and stage estimates since 1989 from all areas of the world and to critically assess the studies' sampling and design when evaluating variations among these estimates.

Materials and Methods

Protocol and Registration

This study was developed in line with Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines and registered with the International Prospective Register of Systematic Reviews.

Search Strategy

A systematic computerized search was performed in 4 databases, including PubMed, Web of Science, EMBASE, and CINAHL, for relevant manuscripts published from January 1, 1989, to June 30, 2019. Search terminologies were limited to titles containing "endometriosis" AND "prevalence" or "incidence" or "epidemiology", or "frequency", or "occurrence", or "statistics." The searches were conducted independently by 2 authors (M.G. and M.T.K.). Endnote X8 was used to retrieve full texts and organize and select studies.

Study Selection, Case Definition, and Eligibility Criteria

Studies were selected for eligibility on the basis of the title and abstract, and any disagreements were resolved by the third author (S.A.M.). The literature of interest included cross-sectional and longitudinal studies in any population anywhere in the world and was restricted to original research articles written in English that reported incidence and/or prevalence of endometriosis. Eligible studies meeting inclusion criteria underwent a full-text review. In addition, a manual search of reference lists was performed to identify other relevant publications. Studies with a case definition of diagnosed endometriosis based on clinical (e.g., physical examination and imaging) and/or surgical visualization with and without histologic confirmation, whether self-reported or abstracted, were included. Studies with a case definition of suspected or possible endometriosis based on symptoms without further imaging or surgical assessment were excluded. We excluded case series and case reports because of the lack of a comparison group and the absence of a denominator population. Manuscripts that did not contain empiric results, such as letters to editors, reviews, opinions/commentaries, expert committee reports, and conference abstracts, were excluded. Because the research objective involved detection in humans, we excluded nonhuman studies.

Data Extraction and Quality Evaluation

Relevant study characteristics and estimates abstracted included study design, publication date, date range of the study data, location and setting of the study, population source, sample population or subpopulation, data source (e.g., insurance claims, medical records, or self-reports), sampling method, age range, sample size, diagnostic or reporting criteria and methods, response rate where relevant, prevalence and/or incidence when reported, and stratification by endometriosis stage when documented (Supplemental Table 1). Beyond stage, few studies reported data regarding symptom profile or quantified symptom severity, and those that did were presented uniquely in a form or detail that could not be harmonized or compared and were therefore not incorporated into the systematic review. Prevalence and incidence estimates were reported with standard errors, when reported. Population source was categorized as single hospital or clinic vs general population samples. General population samples were further subcategorized as those that were drawn from nation/region-wide surveys or surveys in general public places (country/region) vs those drawn from hospital systems and insurance claims systems. Study quality was assessed using a risk-of-bias tool, which is an adaptation of the Grading of Recommendations, Assessment, Development and Evaluations criteria for prevalence studies by Hoy et al [12].

Data Analysis and Synthesis

Studies were stratified by sampled population, and forest plots were generated to visualize the range of estimates. Studies were compared across time to examine any

emerging trends and provide a narrative synthesis. All statistical analyses were conducted in R version 3.6.1 [13], and meta-analyses were performed using the metafor package for R [14]. To quantify interstudy heterogeneity, I^2 was calculated and reported, with I^2 >75% representing high heterogeneity among studies. Estimates of pooled prevalence for various subgroups (by study setting, geographic location, and clinical indication) were reported using both fixed-effects and random-effects models. Under the fixed-effects model, study weighting was conducted using inverse variance with the larger studies receiving more weight. Under the random-effects model, a tau-squared measure for interstudy variation was applied to calculate the inverse variance. The high heterogeneity observed among studies supports the preference for random-effects estimates. The Freeman-Tukey arcsine square root transformed proportion was used to normalize and stabilize the variances of prevalence estimates and calculate random-effects summaries. Where applicable, pooled estimates were calculated after back-transformation using the procedure by DerSimonian and Laird [15]. Meta-regression analyses were performed using mixed-effects models for proportions, examining the univariate association between prevalence and year of publication for all studies and then stratifying by general population vs single hospital/clinic population sources. A multivariable meta-regression model was applied that included the year of publication (1989−2019), location of study (continent), and source population (general population vs single hospital/clinic). To examine directly if the year of publication could explain part of the heterogeneity when stratified by source population, a meta-regression analysis was conducted with year as the predictor of prevalence.

Results

Study Selection

A search of the PubMed, Web of Science, EMBASE, and CINAHL databases with the aforementioned search terms yielded 846 records (Fig. 1). After excluding duplicates, 367 articles were screened. A total of 283 records were excluded on the basis of relevance of the title and abstracts, with 84 full-text manuscripts ultimately being assessed for eligibility. After assessing the 84 full-text articles, 34 were excluded. A search of the bibliographies of the remaining 50 articles yielded an additional 19 studies not captured in the initial search; thus, a total of 69 articles included in the systematic review.

Study Characteristics

A total of 69 cross-sectional and cohort studies were included for qualitative synthesis in the 30-year period under review (1989−2019). Among the included studies, 16 reported the incidence of endometriosis [16−31] and 62 reported the prevalence of endometriosis [16−24,32−84] (Supplemental Table 1). Among these 69 studies, 26 had a sampling frame from the general population, and the remaining 43 were conducted in single hospital or clinic settings (Table 1). The largest proportion of studies was from Europe (38%) and the smallest from Australia (3%). Study sample sizes ranged from n = 13 to n >14 million (Table 1 and Supplemental Table 1). Fourteen studies reported a population sample size of ≥10 000 women. Prevalence estimates were higher in studies with smaller sample sizes (<10 000), whereas the large studies typically reported a prevalence of <5%. However, all these studies were more likely to include the adolescent population (lowest age limit, 12−18 years) (Supplemental Table 1). A total of 54 studies used a mix of case-ascertainment methods; most studies reported using laparoscopy, laparotomy, and other surgical procedures as the primary diagnostic tool or these in association with International Classification of Diseases codes and self-reported questionnaires. Only 27 studies explicitly reported histologic verification. The remaining 15 studies reported relying on imaging findings only (e.g., ultrasound), on the use of diagnostic coding only, or on self-reported questionnaires.

Evaluating the risk of bias within and among the 69 studies suggested moderate risk overall. Of the 10 criteria, 4 (likelihood of nonresponse bias, valid minimum prevalence time period, acceptable case definition, and appropriate numerator and denominator for the parameter of interest) were required for the studies to be 100% present or absent by the inclusion or exclusion criteria, respectively. For the other 6 risk-of-bias criteria, 92.8% of the 69 studies used the same mode of data collection for all participants, and the same high proportion of studies (92.8%) had a sampling scheme that yielded a close representation of the target population. The problem that posed was that the target population represented an unbiased selection of the general population in only 37.7% of the studies, and some form of random selection was applied in only 29.0% of the studies.

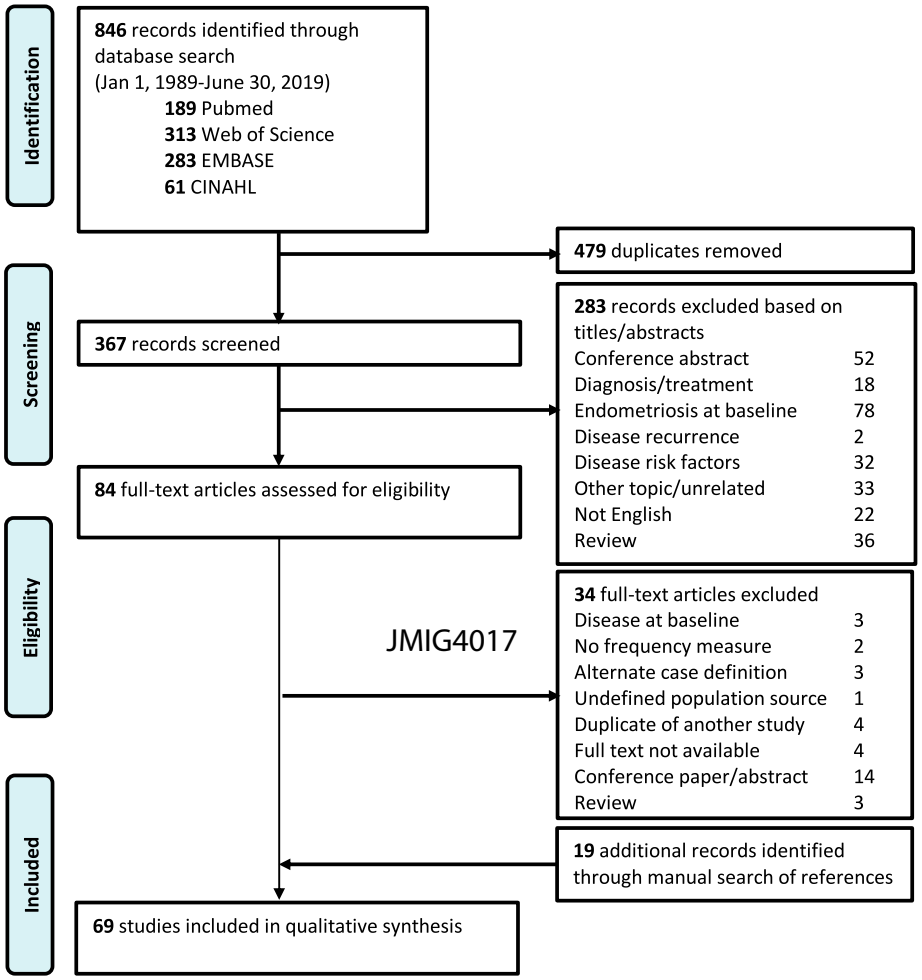
Endometriosis Prevalence by Study Type and across 30 Years

Overall, no clear time trend was observed for endometriosis prevalence across the past 30 years (Fig. 2). The meta-regression analysis revealed that only population source was a statistically significant predictor of prevalence ($p < .001$). No significant trend was observed among the "general population in country/region" studies ($\beta = 0.04$, $p = .12$) or among "single hospital or clinic" studies ($\beta = -0.02$, $p = .34$). A decrease over time (i.e., negative slope) was suggested when analyses were restricted to general population studies abstracted from health system/insurance systems ($\beta = -0.10$, $p = .005$).

Twenty-eight studies reported prevalence using a single gynecologic indication or subdivided a broader population

Fig. 1

Preferred Reporting Items for Systematic Reviews and Meta-Analyses flowchart of search strategy, screening, and study selection process for systematic review.



by gynecologic indication, any of which may impact the likelihood of evaluation for the presence of endometriosis overall or at a specific study site (Table 2). Among these, 17 studies provided prevalence estimates among women with infertility or those presenting for infertility treatment, yielding an overall prevalence of endometriosis of 27%, an estimate using fixed-effects assumption of 25%, and an estimate using random-effects assumption of 34%. Similarly, 11 studies provided prevalence estimates of women with chronic pelvic pain, in whom the overall prevalence of endometriosis was 29%, the estimate using fixed-effects assumptions was 28%, and the estimate using random-effects assumptions was 47%. Hysterectomy was an indication in the smallest number of studies (n = 3) but included the highest number of women (n = 9976), reporting a prevalence among all studies of 16%, an estimate using fixed-effects assumptions of 16%, and an estimate using random-effects assumptions of 22% (Table 2). The overall prevalence by indication across the 30 years of publications did not suggest an increasing or decreasing trend (Fig. 3).

Endometriosis Incidence

Among the 69 studies, 16 provided incidence estimates with heterogeneous results. A total of 7 studies provided information regarding incidence only; another 9 studies included additional information regarding prevalence at baseline or at a specified time period during the study. Among these, 6 studies compared incidences within the sample population during different time periods.

Three studies reported no change in endometriosis incidence observed over time in populations based in Sweden [28], Iceland [29], and the United States [19]. One study based on healthcare services' records of a large population in Israel reported an increase in incident endometriosis of 1.6% annually between 2000 and 2015 [18]. Two studies reported a decrease in endometriosis incidence: one in a

Table 1

Studies published from 1989 to 2019 that reported frequency and/or stage of endometriosis (n = 69) by population source

Population source	Number of studies (%); number reporting prevalence	Range of prevalence estimates, %	Prevalence estimate Fixed effect, % (95% CI)*	Prevalence estimate Random effect, % (95% CI)*	Prevalence estimates, % $I^{2\dagger}$
General population	26 (38); 20		2.4 (2.4−2.4)	4.2 (2.2−7.0)	100.0
Country/region‡	9 (13); 9	0.7−8.6	4.3 (4.2−4.4)	3.4 (1.9−5.4)	99.7
Population included in study <10 000	6; 6		2.4 (2.2−2.7)	3.3 (2.0−5.0)	94.4
Population included in study ≥10 000	3; 3		4.4 (4.4−4.5)	3.5 (1.0−7.3)	99.9
Hospital system/insurance claims	17 (25); 11	0.8−23.2	2.4 (2.4−2.4)	5.0 (2.1−9.1)	100.0
Population enrolled in study <10 000	6; 4		11.4 (11.1−11.8)	12.5 (6.0−21.0)	99.7
Population enrolled in study ≥10 000	11; 7		2.4 (2.4−2.4)	2.2 (0.2−6.1)	100.0
Single hospital or clinic	43 (62); 42	0.2−71.4	15.9 (15.5−16.4)	22.9 (17.1−29.2)	99.1
Patients enrolled in study <100	6; 6		38.0 (32.5−43.6)	42.4 (22.2−64.0)	92.6
Patients enrolled in study 100 to <1000	31; 31		24.5 (23.7−25.3)	22.9 (16.0−30.6)	98.8
Patients enrolled in study ≥1000	6; 5		8.1 (7.6−8.7)	8.0 (2.9−15.3)	99.2
Geographic region					
Africa (data from 1977 to 2017)	7 (10); 7	0.2−48.1	11.0 (10.1−11.9)	10.6 (3.4−21.1)	99.0
Americas (data from 1984 to 2014)§	15 (22); 14	0.7−69.6	10.7 (10.7−10.8)	13.0 (9.6−16.8)	99.9
Asia (data from 1970 to 2015)	19 (27); 18	1.0−71.4	0.09 (0.09−0.09)	20.7 (12.1−31.0)	99.6
Australia (data from 2012 to 2017)	2 (3); 2	3.4−3.7	3.6 (3.2−4.1)	3.6 (3.2−4.1)	—
Europe (data from 1933 to 2018)	26 (38); 21	0.8−70.3	7.7 (7.6−7.7)	11.5 (10.4−12.8)	99.9

CI = confidence interval.

* Fixed-effects model calculated using inverse variance, with larger studies receiving more weight; random-effects model calculated using a tau-squared measure for inter-study variation modified inverse variance (Metafor package for R 3.6.1).

† I^2, measuring percent of variation among studies attributed to heterogeneity and not chance; calculated using Cochran's heterogeneity.

‡ Country/region: general population samples drawn from nation/region-wide surveys or surveys in general public places.

§ n = 14 from North America, n = 1 from South America.

Fig. 2

Prevalence of endometriosis in studies published from 1989 to 2019 (n = 62 studies). Univariate meta-regression plot stratified by (A) prevalence in general population and (B) prevalence in single clinic or hospital studies. Prevalence (%) plotted against Year of Publication. Circles indicate observed prevalence estimates, radius of circles proportional to inverse standard errors. Lines above and below are 95% CI bounds.

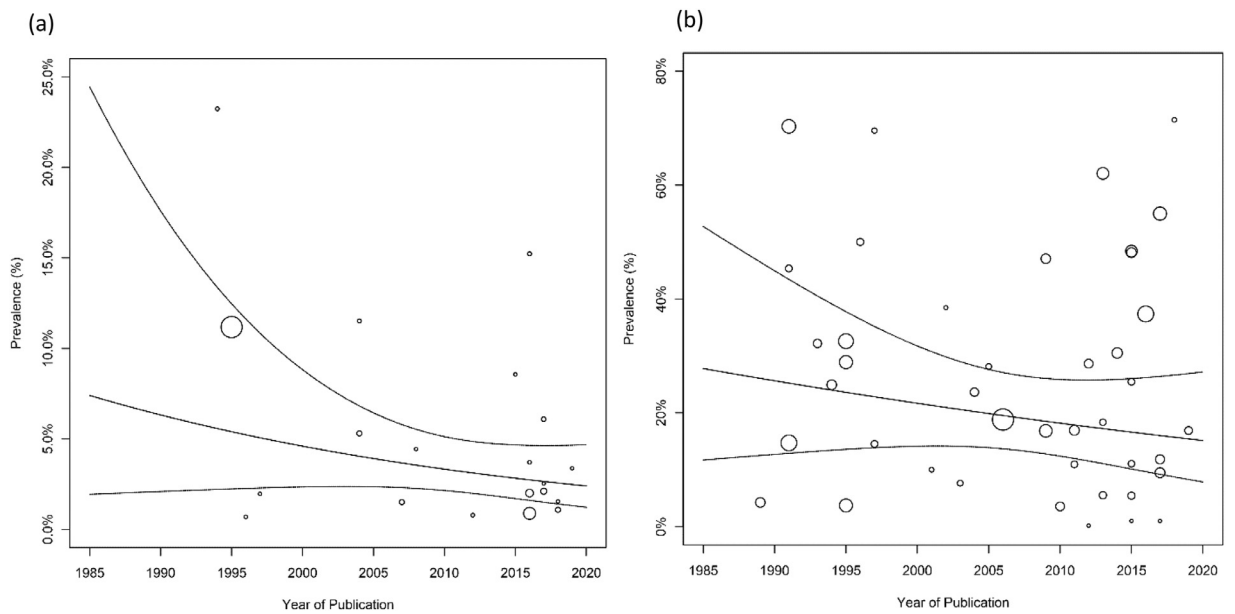


Table 2

Pooled prevalence estimates of endometriosis in subpopulations defined by gynecologic indications that underlie the likelihood of evaluation for the presence of endometriosis among studies published from 1989 to 2019

Gynecologic indication*	Number of studies	Total population	Total endometriosis cases	Endometriosis proportion, % (overall)	Range of prevalence estimates, %	Prevalence estimate fixed effect (95% CI)†	Prevalence estimate random effect (95% CI)†	Prevalence estimate, I^2%‡
Infertility	17	8172	2193	26.8	9.0–68.0	24.8 (23.9–25.8)	34.4 (24.3–45.1)	98.9
Chronic pelvic pain	11	5104	1487	29.1	15.4–71.4	28.1 (26.9–29.4)	46.6 (31.1–62.3)	98.4
Tubal sterilization	4	4477	231	5.2	3.7%–43.3%	4.4 (3.8–5.1)	10.6 (4.9–18.1)	96.0
Hysterectomy	3	9976	1561	15.6	15.2–28.6	15.5 (14.8–16.2)	22.2 (13.0–33.0)	93.5
Ovarian cancer	5	1171	117	10.0	5.4–25.5	9.3 (7.7–11.1)	11.7 (6.4–18.4)	89.5

CI = confidence interval.

* References: Infertility [32,37,38,40,52,54,58–64,70,80,83,84], chronic pelvic pain [32,35,37,40,54,56,58,65,70,79,80], tubal sterilization [37,58,76,81], hysterectomy [58,65,66], ovarian cancer [33,41,51,57,68]

† Fixed-effects model calculated using inverse variance, with larger studies receiving more weight; random-effects model calculated using a tau-squared measure for inter-study variation modified inverse variance (Metafor package for R 3.6.1).

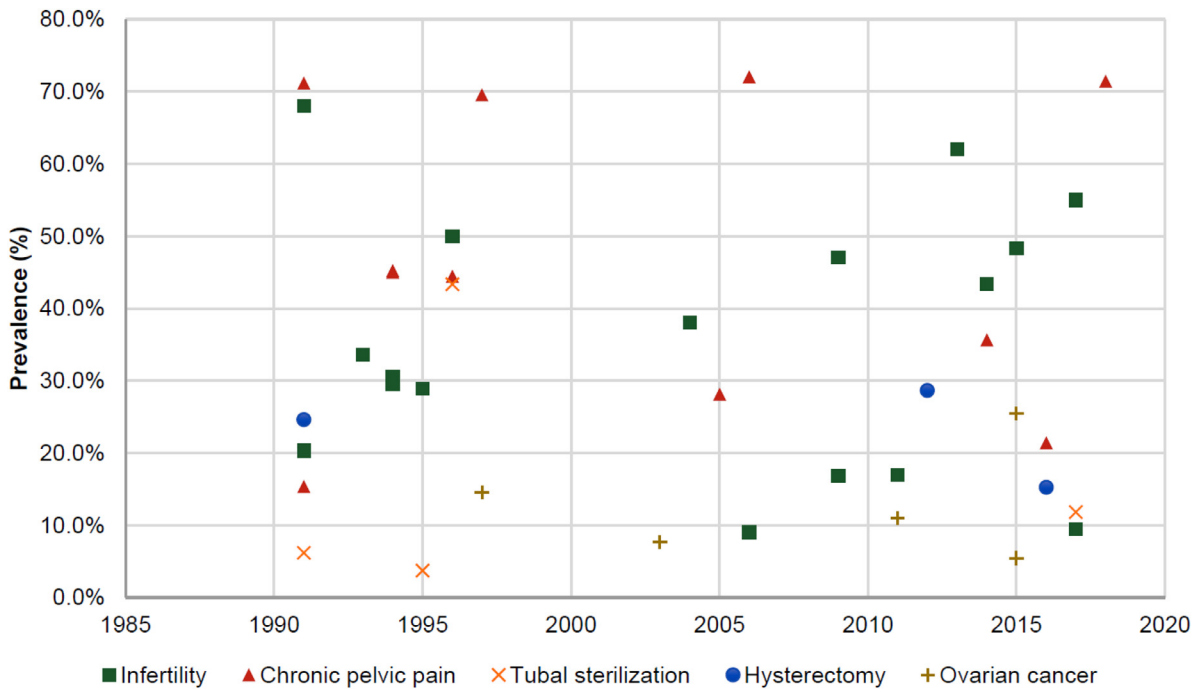
‡ I^2, measuring percent of variation among studies attributed to heterogeneity and not chance; calculated using Cochran's heterogeneity statistic (Q) and degrees of freedom (df): $I^2 = 100\% \times (Q - df)/Q$.

hospital-based population of orthodox Jewish women undergoing hysterectomies from 1970 to 1989 in Israel [25] and the other inclusive of the Finnish Hospital Discharge Register, in which the age-standardized incidence rate of surgically verified endometriosis decreased from 116 per 100 000 women in 1987 to 45 per 100 000 women in 2012 [30].

Two studies, one by Leibson et al [19] in the United States from 1987 to 1999 and other by Gylfason et al [29] in Iceland from 1981 to 2000, noted a marked increase in

Fig. 3

Prevalence of endometriosis in subpopulations defined by gynecologic indications (infertility, chronic pelvic pain, tubal sterilization, hysterectomy, and ovarian cancer) that underlie the likelihood of evaluation for the presence of endometriosis (n = 28 studies published during 1989–2019) organized by year of publication.



the use of laparoscopy over their study time period. Leibson et al [19] further noted that although the surgical diagnoses of endometriosis increased from 65% in 1970 to 1979 to 88% in 1987 to 1999, histologically verified diagnoses did not increase [29].

Endometriosis Stage at Diagnosis

Endometriosis was staged during surgical visualization according to the revised American Fertility Society (rAFS) [85] or revised American Society for Reproductive Medicine (rASRM) [86] and was reported in 26 studies (Supplemental Table 1). A total of 19 studies provided staging details based on the rAFS system [32,37,39,49,50,52,54,56,58−63,70,72,76,81,83], and 7 studies were staged by the rASRM [26,29,34,38,40,64,67] system. A total of 20 studies (77%) were either based in a single hospital or clinic or used data from a hospital or insurance system. There was considerable heterogeneity among studies by geographic region and sample population, including age ranges, mean ages at the time of staging, case definition for endometriosis, and indication for surgery (Supplemental Table 1). In addition, the rAFS- and rASRM-documented stage is reflective of 1 point in time and may vary over the natural history of endometriosis within each individual.

The endometriosis stage, although often conflated with "severity" terminology, is predictive of surgical complexity but is not correlated with patient's symptom profile, symptom severity, or treatment prognosis [87]. No data are available across the past 30 years to attempt to document changes in presenting symptom severity, life impact, or short- or long-term prognosis among women with endometriosis.

Discussion

As reported previously [2,88], there continue to be large variations in prevalence estimates among studies that are driven by heterogeneity in study populations, sampling scheme, endometriosis case definition, and indications for evaluation for the presence of endometriosis. In addition, all studies of endometriosis frequency document only those women who successfully achieve an evaluation and diagnosis; the true frequency of undiagnosed endometriosis and its proportion among all women with endometriosis are unknown. General population studies yield an underestimate of the true prevalence of endometriosis owing to diagnostic bias, whereas single hospital/clinic populations yield an overestimate owing to selection bias.

Overall, 69 studies describing the prevalence and/or incidence of endometriosis met the inclusion criteria, of which 62 reported prevalence and 16 reported incidence or incidence rates, whereas 26 studies included details of endometriosis staging at the time of surgical diagnosis using the rAFS or rASRM criteria. There was no evidence of change in prevalence over time among all women with endometriosis or when stratified by gynecologic indication for evaluation of the presence of endometriosis. Among 6 studies examining the incidence of endometriosis across time in well-defined populations, data were highly inconsistent, with 1 study suggesting an increase in incidence [18], 2 studies reporting a decrease [25,30], and 3 studies reporting no change [19,28,29].

This comprehensive review of the literature indicated that there have been very few high-quality, broadly representative cross-sectional or longitudinal studies for useful comparison among populations or across time periods. Fewer studies have examined the distribution of endometriosis by stage at surgical diagnosis. This critical limitation in research and publications suggests that the individual or meta-analyzed estimates or plotted prevalence estimates across time cannot be used to rule in or rule out true changes in endometriosis prevalence or incidence.

Beyond the limitations of the existing literature, there are fundamental issues with endometriosis diagnosis that must be overcome before a true population prevalence can be defined [2]. The lack of a noninvasive diagnostic modality creates insurmountable diagnostic biases driven by characteristics of those who can and those who cannot access a definitive surgical or imaging diagnosis. Women with ovarian endometrioma or deep endometriosis can be diagnosed through imaging if they are geographically, economically, and socially able to achieve referral to and evaluation from an experienced imaging specialist [5]. For those with superficial peritoneal disease, definitive diagnosis by means of surgical evaluation is limited by the severity of symptoms and response to empiric treatment because of the invasive nature and inherent risks of surgery. Even among those with adequately life-impacting symptoms enough to warrant referral for a surgical evaluation, geographic and economic barriers to accessing endometriosis-focused surgeons remain. Beyond access to an appropriate, skilled physician, the wide range of symptoms associated with endometriosis—many of which are stigmatized or normalized [6,7]—reduces the likelihood of referral and increases time to referral to appropriate specialists [2,7,89,90].

Social and cultural factors play a role in diagnostic bias as well. Black women within the United States have been found to have lower odds of being diagnosed with endometriosis than white women despite having the disease [91]. The bias in diagnosis itself may be influenced by variations in clinical symptoms among different populations not adequately captured or appreciated by standard clinical definitions or may represent implicit bias in healthcare, leading to an alternate interpretation of the same symptoms affecting the likelihood of diagnosis [91]. Moreover, there is considerable underrepresentation of studies from African and Asian countries compared with European and North American countries (Table 1). High-quality studies from these regions might alter existing global prevalence

and incidence estimates, leading to more accurate overall estimates and improved public health focus.

In addition, diagnostic methods and definitions change over time, which will impact longitudinal measurements. The potential for detection bias must be considered because of changing awareness of endometriosis, improved access to minimally invasive gynecologic surgery, and advances in imaging. It is extremely important to consider changes in likelihood of diagnosis when attempting to determine the true change in endometriosis incidence across time. Furthermore, it is important to consider the thoroughness of evaluations even among surgical populations. For example, endometriotic lesions may be missed during tubal ligation but would have been observed and documented during a surgery for chronic pelvic pain. Studies estimating the prevalence of endometriosis among highly selected populations, such as those at infertility centers or tertiary care hospitals, cannot be generalized more broadly. The estimates from these populations are an overestimate of the true proportion of women with endometriosis in the general population.

Studies that follow large numbers of diverse girls and women and that collect data about demographic characteristics as well as gynecologic and other medical symptoms and experiences, including access to and interaction with the healthcare system, are needed. Several environmental and sociologic risk factors have been associated with endometriosis risk [2], and the changes over time in exposure frequency and distribution could plausibly drive true changes in endometriosis incidence and in symptom and phenotypic presentations. In addition, these may underlie true differences among populations with respect to endometriosis prevalence. As increasing knowledge of and investment in endometriosis is made, it is essential to prioritize improved and unbiased quantifications of endometriosis prevalence and incidence.

Supplementary materials

Supplementary material associated with this article can be found in the online version at https://doi.org/10.1016/j.jmig.2019.11.018.

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