

# EPIDEMIOLOGY AND PREVALENCE OF ENDOMETRIOSIS

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Endometriosis is one of the most common diagnoses made at laparoscopy of the infertile woman. Many women over the last 25 years have undergone surgical treatment, via laparoscopy and laparotomy, of but a few spots of endometriosis in the hopes of improving their fertility potential. Whereas the association between endometriosis and primary or secondary infertility remains to be more precisely defined,<sup>10, 12, 13</sup> the epidemiology of endometriosis as a disease has been better described over the last decade by several investigators.<sup>1, 8</sup> This article summarizes current knowledge of the prevalence of endometriosis, as well as the characteristics of women harboring this disease.

## PREVALENCE ESTIMATES

The *commonness* of a disease may be expressed as *incidence* (the number of new cases diagnosed per unit time) or *prevalence* (the number of known cases at any instant of time). In diseases in which there may be a prolonged course of either its natural history or diagnosis and treatment, prevalence is thought to provide a more accurate description of its commonness. Prevalence may be estimated from incidence by multiplying by the duration of the disease, if known.

The prevalence of endometriosis in the literature to date varies widely from 1% to 50%, based on surgical series.<sup>13</sup> As long as the diagnosis of endometriosis requires operative diagnosis, prevalence estimates will be biased by the types of women that require operative evaluation (Table 1). This selection bias is the single greatest problem currently in the accurate estimation of the prevalence of endometriosis in women at large. Table 2 presents the varying prevalence of endome-

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**Table 1. RANGE OF PREVALENCE ESTIMATES OF ENDOMETRIOSIS FROM SURGICAL CASE SERIES IN THE EXISTING LITERATURE**

Author (Year)	Included Patients	No. of Patients	Prevalence (%)
Long and Ströcher (1939)	Abdominal surgery	1453	1
Williams (1975)	Gynecologic surgery	5117	6
Duignan et al (1977)	Primary infertility	520	9
Hasson (1976)	Chronic pelvic pain	75	14
Peterson and Behrman (1970)	Unexplained infertility	204	33
Goldstein et al (1980)	Teenagers' pelvic pain	140	53

triosis, depending on the procedure performed by a group of 21 gynecologists practicing at Baylor College of Medicine affiliated hospitals. Clearly, the frequency with which endometriosis was discovered at surgery is directly related to the clinical indication for surgery and which operation is performed.

Cramer<sup>1</sup> reviewed 1980 discharge diagnoses from acute care, nonfederal hospitals in an attempt to bypass the biases inherent in clinical case series. He found that endometriosis was a first-listed diagnosis in 0.5% of hospitalized women and an any-listed diagnosis in 0.6%. Of women admitted with genital disorders other than those associated with pregnancy, endometriosis was the first-listed diagnosis in 5.6% and any-listed in 7.9%. These estimates are not without their biases in that this is a select group of the overall population of women with endometriosis who require hospitalization and treatment.

The least biased prevalence estimate of endometriosis would require a minimally invasive screening technique applied to an appropriately large random sample of reproductive-aged women. Although serum markers such as CA-125 and imaging modes such as transvaginal sonography or magnetic resonance imaging have been evaluated as diagnostic methods, the diagnosis of endometriosis will continue to be largely surgical for at least several more years.

While we wait for a screening test for endometriosis, the overall prevalence of endometriosis may be best estimated from women undergoing surgical evalu-

**Table 2. VARYING PREVALENCE OF ENDOMETRIOSIS FROM A POOLED CLINICAL PRACTICE FROM 1976 TO 1984: IMPACT OF SELECTION BIAS ON OBSERVED PREVALENCE**

Operation Performed	No. of Operations	Endometriosis Prevalence
Tubal anastomosis	1860	13 (1%)
Laparoscopic tubal ligation	3060	49 (2%)
Abdominal hysterectomy	5511	622 (11%)
Operative laparoscopy	2065	619 (31%)

Data from Wheeler JM: Epidemiology of endometriosis-associated infertility. *J Reprod Med* 34:41, 1989.

ation for symptoms other than those attributable to endometriosis. We reviewed the incidence of endometriosis discovered at the time of vaginal hysterectomy done for symptoms not typical of endometriosis from the practices of 21 gynecologists at Baylor over the years 1976 to 1984. We selected vaginal hysterectomy because for this group of doctors, the technique, quantity of tissue submitted for histologic examination, and the detail of pelvic examination were sufficiently standardized to estimate the prevalence of otherwise undiagnosed endometriosis in reproductive-aged women. Patients whose admitting diagnoses included endometriosis, pelvic pain, or pelvic adhesions were excluded from the study. Office records were used to confirm the lack of suspicion of endometriosis reflected in the hospital records in an attempt at deriving as pure a group as possible with undiagnosed endometriosis.

Using these criteria, the 21 gynecologists performed 858 vaginal hysterectomies over the 8-year sampling period; 71 (8.3%) women had histologic diagnoses, the vast majority of which (93%) would be classified as mild-to-moderate severity. The most common sites of involvement were the posterior cul-de-sac and the ovaries. Recognizing that younger women were undersampled in this hysterectomy-based study, it is likely that the prevalence of endometriosis in women aged 15 to 50 years is about 10%.<sup>13</sup> This same prevalence estimate has been achieved independently by other investigators as well.<sup>4</sup>

## DEMOGRAPHY

From the first clinical reports of women with endometriosis, an interest emerged in their demographic characteristics. The reported age at diagnosis ranges from 10 to 83 years (for this author, 13–75 years), with most series placing a median age at about 29 years of age. In older clinical series dominated by hysterectomy as the procedure of choice, the peak occurrence was in women aged 45 to 55 years. Regarding age, it seems clear that most endometriosis occurs within the reproductive-aged group, with important yet small subpopulations who are peripubertal or postmenopausal.

Originally regarded as a disease of Caucasians, endometriosis is diagnosed in similar proportions of African-American, Israeli, Afghani, Iranian, and Japanese women, who have undergone operative evaluation of the pelvis. Again, race seems less a factor than the selection bias that pervades the decision to take an individual woman to the operative suite to evaluate either pelvic pain or infertility. Although the literature would have to be described as confusing regarding the issue of race, there is at least as much evidence to suggest that access to gynecologic care of reasonable technology is at least as important to incidence estimates as race.

Initially characterized as a disease of the upper socioeconomic strata, endometriosis is found in all groups in similar proportions, depending on the clinical indication for surgical evaluation. In comparing relative prevalence estimates between socioeconomic groups, it is again important to realize the issue of access to gynecologic health care of sufficient technologic degree to diagnose endometriosis.

## RISK FACTORS

A family history for endometriosis, especially in its more severe forms, imparts greater risk for the disease. Women with first-degree relatives with

endometriosis have a threefold to tenfold increase in their risk of endometriosis. These familial clusters tend to have a variety of the disease that is biologically aggressive and more severe in its extent. In the lack of a clear inheritance pattern, the genetic contribution to endometriosis risk is thought to be imparted via polygenic/multifactorial inheritance.

Anatomic variants that obstruct the normal outflow of menstrual products predispose women to endometriosis. Typically, these patients are younger, and their endometriosis is often widespread throughout the pelvic peritoneum, but is less invasive in its biologic behavior. Treatment typically includes relief of the obstruction, debridement of endometriosis, and subsequent hormonal endometrial suppression.

The existing literature abounds with the hypothesis that pregnancy prevents endometriosis. Rather, it appears that the tonic levels of sex steroids during pregnancy put endometriosis lesions in a dormant phase of its pathogenesis. Thus, rather than preventing endometriosis (other than by introducing a period of amenorrhea), pregnancy delays its clinical presentation or recurrence if the disease is already under treatment.

The contribution of menstrual factors to endometriosis risk have been reviewed by Goldman and Cramer.<sup>4</sup> Detailed personal interviews were conducted between endometriosis patients and control subjects. Women with endometriosis had greater exposure to menstruation, with shorter cycle lengths, longer duration of flow, and possibly heavier flow. Although seemingly supportive of Sampson's hypothesis of transtubal regurgitation as causative of endometriosis, these menstrual factors may also reflect higher levels and more frequent cycles of sex steroids, which could predispose the pelvic peritoneum or ovaries to the development of endometriosis.

Interestingly, exercise on a regular basis seems to reduce the risk of endometriosis. Perhaps, if regular enough, subsequent anovulation and reduced menstrual flow and sex steroids would explain the reduction in endometriosis risk.

## CLASSIC VERSUS CLINICAL EPIDEMIOLOGY

Endometriosis monographs, meetings, and international symposia all typically include a brief review of the prevalence and risk factors of the disease. These reviews are classifiable as *classic* epidemiology, in the sense of characterizing populations of women with endometriosis. *Clinical* epidemiology is a field of study expanding on classic epidemiologic principles to critically analyze pathophysiology, classification, efficacy of treatment, and prognosis for outcome. The writings of Olive, Guzick, and Cramer often reflect the Feinsteinian<sup>3</sup> roots of clinical epidemiology in the search for truth through the fog of the existing endometriosis literature. Basic science research into the role of various molecules and their genetic codes will no doubt be fundamental to our understanding of the pathogenesis of endometriosis. Until then, an epidemiologic approach is perhaps our best methodology to study "whole organisms," namely, our patients with this unusual disease.

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