# Behind the times: revisiting endometriosis and race

Olga Bougie, MD, FRCSC, MPH; Jenna Healey, PhD, MA; Sukhbir S. Singh, MD, FRCSC

## Historical Perspective

The modern history of endometriosis can be traced back to the work of American gynecologist John A. Sampson,[1] who published his first article on the condition in 1921. While reports of aberrant endometrial tissue appear as early as 1860, it was Sampson who first coined the term endometriosis to describe the growth of endometrial tissue outside the uterus.[2–4] His research was part of a broader trend toward the study of sterility, driven by both the discovery of hormones and social panic about the decline of birth rates among upper-class women in the United States.[3,5,6]

Throughout the 1920s and 1930s, Sampson and his colleagues proposed several new etiological explanations for endometriosis, including retrograde menstruation, coelomic metaplasia, and lymphatic or vascular transplantation. In 1938, Boston-based gynecologist Joseph Vincent Meigs[7] wrote an editorial linking endometriosis to contraceptive use and delayed child-bearing, a fertility pattern that was more common among the well-to-do.

Meigs theorized that long periods of uninterrupted menstruation could lead to pathological changes in the coelomic epithelium. Meigs' depiction of endometriosis as a lifestyle disease proved to be enormously influential, creating a lasting association between endometriosis, class, and delayed child-bearing.

Central to Meigs' theory was his claim that the incidence of endometriosis was higher among his private patients than those he encountered in the hospital ward.[8] Many of his colleagues agreed; one 1950 article described endometriosis as the scourge of the private patient.[9]

In the United States, the labels of private or ward patient carried both racial and socioeconomic connotations, conflating race and class in the medical literature.[10,11] If endometriosis was a disease of white, middle-class women who had put off child-bearing, as Meigs claimed, it followed that endometriosis would be rare among nonwhite women. Implicit in this formulation was the racist assumption that women of color were less civilized than their white counterparts and therefore less susceptible to the stress of modern life.[12]

This interpretation was bolstered by Meigs' own fondness for contrasting the pathological childlessness of well-to-do women with the natural fertility of the monkey, a racially charged analogy he would repeat many times over the course of his career.[7,8,13,14] By 1956, a gynecologist reviewing the literature declared it was now obvious that "endometriosis is a disease of white women in the higher income brackets."[15]

For his part, Meigs rarely addressed the issue of race directly, an omission that might be explained by the fact that his patients at Massachusetts General Hospital were almost exclusively white.[16] But the racial implications of Meigs' theory were not lost on his colleagues. In one 1951 study, for example, gynecologists at Harlem Hospital in New York declared that endometriosis was almost nonexistent among their African-American charity patients.[17] Following Meigs' theory, this was precisely the result the authors expected. The authors suggested that, given the extent of the racial disparity, a constitutional racial factor might be also at play.[17]

These early theories about the relationship between endometriosis and race look strikingly similar to racialized theories of cancer during the same time period. In the 1920s and 1930s, cancer, like endometriosis, was widely considered to be a disease of civilization, most common among white women who were susceptible to the stresses of modern life.[18–20] Conversely, physicians hypothesized that African Americans rarely developed cancer because of their slow-paced, agrarian lifestyles. The mass migration of African-Americans to Northern cities threatened to disrupt this epidemiological pattern by exposing African Americans to the habits and higher cancer mortality of white Americans.[20]

In the postwar period, improved cancer statistics undermined arguments of racial immunity, but epidemiologists continued to organize cancer data into undifferentiated white and nonwhite categories. These simplistic dichotomies, primitive vs modern, white vs nonwhite, obscured more nuanced questions about the relationship between race, class, and disease.

The belief that endometriosis was an exclusively white disease did not go unchallenged. As early as 1951, a study directly refuted Meigs' theory by showing that private and ward patients had similar rates of endometriosis.[21] Tellingly,

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From the Departments of Obstetrics and Gynaecology (Drs Bougie and Healey) and History (Dr Healey), Queen's University, Kingston, Canada; and Ottawa Hospital Research Institute (Dr Singh) and Department of Obstetrics and Gynecology (Dr Singh), University of Ottawa, Ottawa, Canada.

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Corresponding author: Olga Bougie, MD, FRCSC, MPH. bougieo@kgh.kari.net

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this study divided patients into 3 groups: private patient, white ward patient, and Negro ward patient, laying bare the assumption that the private patient would always be white.

More studies that showed near identical rates of incidence in white and black patients followed, but the assumption that endometriosis was a disease of the white and middle-class persisted.[22,23] In part, the enduring popularity of Meigs' theory can be attributed to his professional prominence as well as his engagement with the popular press.[3] While the media was occasionally critical of the biases evident in Meigs' work, the media depictions of endometriosis as a middle-class or career woman's disease persisted well into the 2000s.[24,25]

In 1976, African-American gynecologist Donald L. Chatman[26] published a frank critique of the ways in which this racial bias was having a negative impact on patient care. Chatman noted that 1 in 5 of his private African-American patients demonstrated laparoscopic evidence of endometriosis but that 40% of these women had been wrongly diagnosed with pelvic inflammatory disease. Chatman argued that these misdiagnoses stemmed from the still pervasive myth that women of color were somehow immune to endometriosis and the stereotype that African-American women were more promiscuous than their white peers. Only by addressing racial biases regarding endometriosis and pelvic pain would African-American women receive quality reproductive care.

## Current state of evidence

There is a paucity of contemporary literature on the topic of race and endometriosis. Prevalence studies[27–33] provide little world view on the topic, and the most common finding is often a lower prevalence among black vs white women.

A consistent limitation of the literature in this realm is the strong potential for selection bias, as well as a primary focus on prevalence, instead of disease experience of endometriosis. For instance, Missmer et al[28] studied the association of patient demographic and anthropometric factors on the incidence of endometriosis in the Nurses Health Study II cohort. Although this was a prospective cohort study, with excellent follow-up and control for confounding factors, the fact that endometriosis was surgically diagnosed may lead to biased conclusions. Symptomatology, access to health care, and variations in sociocultural acceptance of surgical intervention may vary among women of different races/ethnicities.[34]

## Is there still a bias?

Looking to several foundational textbooks of gynecology, we see that throughout the 1960s and 1970s, there remained a strong conviction that endometriosis was less common in black women as well as those of low socioeconomic status.[35,36] Chatman[41] identified textbooks as a primary vehicle for spreading misinformation about race and endometriosis, pointing to medical education as a possible site of reform.

During the 1980s, there was a palpable shift toward identifying genetic and environmental factors, and explicit statements were made to discredit the notion of racial disparity in the diagnosis of endometriosis.[37,38] Interestingly, more recent editions of Speroff's textbook[39,40] have suggested a racial discrepancy in asymptomatic endometriosis, based on limited evidence.[28,41]

Although more recent research has attempted to determine the true prevalence of this endometriosis in women of different ethnicities,[28] implicit bias suggesting that this disease is more common in white women who delay child-bearing is likely still present among the medical community, perpetuated by small, subconscious ideas (such as the text included in that by Speroff) at the population level. We believe that the focus on prevalence studies in the medical literature, conducted mostly in homogenous populations, is problematic and continues to perpetuate this biased notion through several mechanisms.

First, there is little effort made to examine the potentially different presentations of endometriosis in various ethnic groups. Because the primary presenting symptoms of this condition includes various components of pelvic pain[42] and this symptom is heavily influenced by psychosocial factors,[43–45] women of different ethnic and cultural backgrounds with endometriosis likely have a different clinical presentation.

Until we are able to examine the patients' diagnostic journey in an ethnically/culturally sensitive manner, accounting for the potential variation in the pattern of seeking medical attention, we will be unable to make relevant conclusions based on the diagnosis of endometriosis alone.

Second, the literature on the prevalence of endometriosis is heavily based on research performed in white women, published in the English language,[27,28,32,46,47] which may not be externally valid in an ethnically and culturally diverse population. There is scarce literature about endometriosis in women of other racial/ethnic minorities (beyond those previously specified), and we suggest that there needs to be an effort made to include these women in future endometriosis research.

Third, it is extremely difficult to account for the confounding factor of socioeconomic status when looking at race as an exposure in a study. Studies looking at the prevalence of endometriosis have not been able to control for this important factor.[28,33] Race affects provision of health care at all levels[34,48] and, in the case of endometriosis, likely influences access to care, specialist referral, diagnosis, and treatment offered.

The genetic impact of race on disease pathophysiology is likely overestimated; in fact, some suggest the time has come to remove race out of biological research altogether because this trait is intimately interrelated with social and cultural constructs.[49] There needs to be a greater focus on these aspects and the potential barriers to clinical management of endometriosis, beyond determining prevalence by race.

From a clinical perspective, perhaps a more important question is whether race has an impact on the provision of care, a question that has not previously been addressed and one that will be difficult to answer, particularly in the context of a potential diagnostic bias. Literature in other medical conditions (ie, myocardial infarction) has demonstrated that an implicit bias regarding the prevalence of disease in different racial categories may have an impact on treatment decisions.[50]

## Moving forward

As we strive to improve patient care, we want to acknowledge the lesson we have learned from history of endometriosis to date. Early etiological theories posited that the incidence of endometriosis was highest among white women, an assumption that was bolstered by stereotypes about race and class. Even though this literature has been shown to be methodologically flawed, the biases already created are problematic because they are difficult to resolve and may hinder the quality of care that women receive.

In working to find a solution to resolve such biases, we need to recognize the following: (1) endometriosis can occur in women of any race and (2) women of various ethnicities may have different presenting symptoms of endometriosis and express different treatment preferences.

We propose that research in endometriosis should shift focus from prevalence studies to looking for patient symptomatology and disease experience, using validated and culturally sensitive patient outcome measures. We advocate for adaptation of an individualized and patient-centered approach to the management of endometriosis to achieve more accurate and timely diagnosis and improve patient management. ■

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## ABSTRACT

# Behind the times: revisiting endometriosis and race

Endometriosis is a common gynecologic condition, affecting approximately 10% of reproductive-aged women. It commonly presents with pelvic pain, painful periods, and infertility and can significantly have an impact on one's quality of life. Early exploration into the pathophysiology of this condition identified race as a risk factor for endometriosis, with the condition predominantly identified in white women. It is still unclear whether there is a biological basis for this conviction or whether it can be explained by methodological and social bias that existed in the literature at that time. Although there is more recent literature exploring the association between endometriosis and race/ethnicity, studies have continued to focus on the prevalence of disease and have not taken into account possible variation in disease presentation among women of different ethnicities. Furthermore, information on diverse populations by race/ethnicity, other than white or black, is quite limited. This paper explores the history of how the association between endometriosis and whiteness was established and whether we still ascribe to a certain stereotype of a typical endometriosis patient today. Furthermore, we discuss the potential implications of such a racial bias on patient care and suggest areas of focus to achieve a personalized and patient focused approach in endometriosis care.

**Key words:** endometriosis, ethnicity, history, race