

Behind the times: revisiting endometriosis and race

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Historical Perspective

The modern history of endometriosis can be traced back to the work of American gynecologist John A. Sampson,¹⁷ 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.¹⁸⁻²⁰ 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.^{19,21,22}

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 Meigs²³ 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.²⁴ Many of his colleagues agreed; one 1950 article described endometriosis as the scourge of the private patient.²⁵

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.^{26,27} 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.²⁸

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.^{23,24,29,30} 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."³¹

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.³² 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.³³ 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.³³

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.³⁴⁻³⁶ 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.³⁶

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.¹¹ Tellingly,

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

116 More studies that showed near identical rates of incidence
117 in white and black patients followed, but the assumption that
118 endometriosis was a disease of the white and middle-class
119 persisted.^{37,38} In part, the enduring popularity of Meigs'
120 theory can be attributed to his professional prominence as
121 well as his engagement with the popular press.¹⁹ While the
122 media was occasionally critical of the biases evident in Meigs'
123 work, the media depictions of endometriosis as a middle-class
124 or career woman's disease persisted well into the 2000s.^{39,40}

125 In 1976, African-American gynecologist Donald L. Chat-
126 man⁴¹ published a frank critique of the ways in which this
127 racial bias was having a negative impact on patient care.
128 Chatman noted that 1 in 5 of his private African-American
129 patients demonstrated laparoscopic evidence of endometri-
130 osis but that 40% of these women had been wrongly diag-
131 nosed with pelvic inflammatory disease. Chatman argued that
132 these misdiagnoses stemmed from the still pervasive myth
133 that women of color were somehow immune to endometri-
134 osis and the stereotype that African-American women were
135 more promiscuous than their white peers. Only by addressing
136 racial biases regarding endometriosis and pelvic pain would
137 African-American women receive quality reproductive care.

138 Current state of evidence

139 There is a paucity of contemporary literature on the topic of
140 race and endometriosis. Prevalence studies^{5,12,14,15,42-44}
141 provide little world view on the topic, and the most com-
142 mon finding is often a lower prevalence among black vs white
143 women.

144 A consistent limitation of the literature in this realm is the
145 strong potential for selection bias, as well as a primary focus
146 on prevalence, instead of disease experience of endometriosis.
147 For instance, Missmer et al¹² studied the association of pa-
148 tient demographic and anthropometric factors on the inci-
149 dence of endometriosis in the Nurses Health Study II cohort.
150 Although this was a prospective cohort study, with excellent
151 follow-up and control for confounding factors, the fact that
152 endometriosis was surgically diagnosed may lead to biased
153 conclusions. Symptomatology, access to health care, and
154 variations in sociocultural acceptance of surgical intervention
155 may vary among women of different races/ethnicities.⁴⁵

156 Is there still a bias?

157 Looking to several foundational textbooks of gynecology, we
158 see that throughout the 1960s and 1970s, there remained a
159 strong conviction that endometriosis was less common in
160 black women as well as those of low socioeconomic status.^{7,8}
161 Chatman⁴¹ identified textbooks as a primary vehicle for
162 spreading misinformation about race and endometriosis,
163 pointing to medical education as a possible site of reform.

164 During the 1980s, there was a palpable shift toward iden-
165 tifying genetic and environmental factors, and explicit state-
166 ments were made to discredit the notion of racial disparity in

167 the diagnosis of endometriosis.^{46,47} Interestingly, more recent
168 editions of Speroff's textbook^{48,49} have suggested a racial
169 discrepancy in asymptomatic endometriosis, based on limited
170 evidence.^{12,50}

171 Although more recent research has attempted to determine
172 the true prevalence of this endometriosis in women of
173 different ethnicities,¹² implicit bias suggesting that this disease
174 is more common in white women who delay child-bearing is
175 likely still present among the medical community, perpetu-
176 ated by small, subconscious ideas (such as the text included in
177 that by Speroff) at the population level. We believe that the
178 focus on prevalence studies in the medical literature, con-
179 ducted mostly in homogenous populations, is problematic
180 and continues to perpetuate this biased notion through
181 several mechanisms.

182 First, there is little effort made to examine the potentially
183 different presentations of endometriosis in various ethnic
184 groups. Because the primary presenting symptoms of this con-
185 dition includes various components of pelvic pain⁵¹ and this
186 symptom is heavily influenced by psychosocial factors,⁵²⁻⁵⁴
187 women of different ethnic and cultural backgrounds with
188 endometriosis likely have a different clinical presentation.

189 Until we are able to examine the patients' diagnostic
190 journey in an ethnically/culturally sensitive manner, ac-
191 counting for the potential variation in the pattern of seeking
192 medical attention, we will be unable to make relevant con-
193 clusions based on the diagnosis of endometriosis alone.

194 Second, the literature on the prevalence of endometriosis is
195 heavily based on research performed in white women, pub-
196 lished in the English language,^{5,12,13,44,55} which may not be
197 externally valid in an ethnically and culturally diverse popu-
198 lation. There is scarce literature about endometriosis in
199 women of other racial/ethnic minorities (beyond those pre-
200 viously specified), and we suggest that there needs to be an
201 effort made to include these women in future endometriosis
202 research.

203 Third, it is extremely difficult to account for the con-
204 founding factor of socioeconomic status when looking at race
205 as an exposure in a study. Studies looking at the prevalence of
206 endometriosis have not been able to control for this impor-
207 tant factor.^{12,14} Race affects provision of health care at all
208 levels^{45,56} and, in the case of endometriosis, likely influences
209 access to care, specialist referral, diagnosis, and treatment
210 offered.

211 The genetic impact of race on disease pathophysiology is
212 likely overestimated; in fact, some suggest the time has come
213 to remove race out of biological research altogether because
214 this trait is intimately interrelated with social and cultural
215 constructs.⁵⁷ There needs to be a greater focus on these as-
216 pects and the potential barriers to clinical management of
217 endometriosis, beyond determining prevalence by race.

218 From a clinical perspective, perhaps a more important
219 question is whether race has an impact on the provision of
220 care, a question that has not previously been addressed and
221 one that will be difficult to answer, particularly in the context
222 of a potential diagnostic bias. Literature in other medical
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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.⁵⁸

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.¹⁻³ It commonly presents with pelvic pain, painful periods, and infertility and can significantly have an impact on one's quality of life.⁴⁻⁶ Early exploration into the pathophysiology of this condition identified race as a risk factor for endometriosis, with the condition predominantly identified in white women.^{7,8} 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.⁹⁻¹¹ 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.¹²⁻¹⁴ Furthermore, information on diverse populations by race/ethnicity, other than white or black, is quite limited.^{15,16} 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

UNCORRECTED PROOF

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