Disparity in endometriosis diagnoses between racial/ethnic groups

Citation for published version:

Digital Object Identifier (DOI):
10.1111/1471-0528.15805

Link:
Link to publication record in Edinburgh Research Explorer

Document Version:
Peer reviewed version

Published In:
BJOG: An International Journal of Obstetrics and Gynaecology

General rights
Copyright for the publications made accessible via the Edinburgh Research Explorer is retained by the author(s) and / or other copyright owners and it is a condition of accessing these publications that users recognise and abide by the legal requirements associated with these rights.

Take down policy
The University of Edinburgh has made every reasonable effort to ensure that Edinburgh Research Explorer content complies with UK legislation. If you believe that the public display of this file breaches copyright please contact openaccess@ed.ac.uk providing details, and we will remove access to the work immediately and investigate your claim.
Mini-commentary on BJOG-18-0267.R1: Influence of race/ethnicity on prevalence and presentation of endometriosis: A systematic review and meta-analysis

Disparity in endometriosis diagnoses between racial/ethnic groups

Authors: Leslie V. Farland¹, Andrew W. Horne²

Affiliations:
¹Department of Epidemiology and Biostatistics, Mel and Enid Zuckerman College of Public Health, University of Arizona
²MRC Centre for Reproductive Health, Queen’s Medical Research Institute, University of Edinburgh

Corresponding author email: andrew.horne@ed.ac.uk

Bougie and colleagues systematically reviewed the current literature on the association between race/ethnicity and endometriosis diagnosis (Bougie et al. BJOG 2019 xxxx). Compared to white women, black women were less likely (OR:0.49, 95% CI:0.29-0.83) (studies=16) and Asian women were more likely to be diagnosed with endometriosis (OR:1.63, 95% CI:1.02-2.58) (studies=10). The data suggested that Hispanic women were less likely to be diagnosed with endometriosis compared to white women, with a similar magnitude of effect as black women, but this finding was not statistically significant (OR:0.46, 95% CI: 0.14-1.50) (studies=5). There are many unanswered questions regarding the interpretation of these findings for research and clinical practice. Ultimately, we do not
know whether these associations are artifacts of diagnostic biases or whether there is heterogeneity in endometriosis phenotype or clinical presentation between racial/ethnic groups.

Endometriosis has historically been described as a disease of affluent, high-achieving women with private health insurance who delayed marriage and childbearing (Meigs JV. Obstet Gynecol. 1953;2:46-53). These early descriptions of endometriosis patients implied a rarity of disease in the “non-private patient and, therefore by inference (often stated as such) uncommon in black women” (Chatman DL. Am J Obstet Gynecol. 1976;125:987-9), despite early research showing no difference between black and white women and suggesting that pelvic pain in black women was misdiagnosed (Chatman DL. Am J Obstet Gynecol. 1976;125:987-9.). In 1979, Buttram wrote, “Typically, our patients with endometriosis appear to have an intense desire to excel. They are usually well-dressed and have trim figures” (Buttram VC, Jr. Fertil Steril. 1979;31:117-23). While overtly sexist, classist, and racist descriptions of endometriosis patients are less common today, these not-so-distant views may still consciously or unconsciously influence clinical care leading to disparities in endometriosis diagnoses.

Differences in endometriosis diagnoses between black, Asian, Hispanic, and white women are likely synergistic with larger systemic problems related to the difficulty of receiving an endometriosis diagnosis. Indeed, women globally wait on average seven years between endometriosis symptom onset and disease diagnosis, with some women never receiving a formal diagnosis. There are numerous factors that contribute to this diagnostic delay including inconsistent symptom recognition by both the patient and provider and the lack of a non-invasive diagnostic test. When the results of the present study were restricted to women
presenting with infertility, disparities for black women attenuated and there was no statistically significant difference in endometriosis diagnoses between black, white, and Asian patients, suggesting that once patients establish access to clinical care, disparities in diagnosis diminish.

Bougie et. al. described substantial heterogeneity ($I^2>50\%$) between studies. While the authors stratified by study year and diagnosis modality, differences in health care access across populations also likely contributes to this heterogeneity given the social and economic complexities of diagnosis. Different countries will have different medical referral patterns and insurance systems, as well as different racial and economic biases. Both race and gender have been shown to unconsciously influence referral patterns and clinical care (Schulman KA et. al. NEJM. 1999;340:618-26). While future studies investigating the association between race/ethnicity in relation to endometriosis are warranted, they must be interpreted through the lens of quantifying disparities in access to diagnostic care. We must ensure that women of all racial and ethnic backgrounds are comfortable recognising and describing their symptoms and that health care providers take these symptoms seriously and provide appropriate and timely referral for endometriosis diagnosis and treatment.

**Disclosure of interests:** Andrew Horne receives grant funding from the NIHR, MRC, Chief Scientist’s Office, Wellcome Trust, Wellbeing of Women, Ferring and Roche. He has received honoraria for consultancy for Ferring, Roche and Abbvie. Dr. Farland has nothing to disclose. Completed disclosure of interest forms are available to view online as supporting information.
Funding: Andrew Horne is supported by funding from an MRC Centre Grant (MR/N022556/1).