

Racial disparities in uterine fibroids and endometriosis: a systematic review and application of social, structural, and political context

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Importance: Uterine fibroids and endometriosis are 2 of the leading causes of morbidity among reproductive-aged women. There are significant racial disparities in disease prevalence, incidence, age of onset, and treatment profile in fibroids. The data on endometriosis are less clear.

Objective: To conduct a systematic review of racial disparities in prevalence of uterine fibroids and endometriosis in the United States and summarize the literature on these 2 highly prevalent benign gynecologic conditions using a framework that explicitly incorporates and acknowledges the social, structural, and political contexts as a root cause of racial disparities between Black and White women.

Evidence Review: A systematic review regarding racial disparities in prevalence of fibroids and endometriosis was conducted separately. Two separate searches were conducted in PubMed to identify relevant original research manuscripts and prior systematic reviews regarding racial disparities in uterine fibroids and endometriosis using standardized search terms. In addition, we conducted a structured literature search to provide social, structural, and political context of the disparities.

Findings: A systematic review of the literature indicated that the prevalence of uterine fibroids was consistently higher in Black than in White women with the magnitude of the difference varying depending on population and case definition. Prevalence of endometriosis varied considerably depending on the base population and case definition, but was the same or lower among Black vs. White women. As a result of the social, structural, and political context in the United States, Black women disproportionately experience a range of exposures across the life course that may contribute to their increased uterine fibroid incidence, prevalence, and severity of uterine fibroids. However, data suggest no racial difference in the incidence of endometriosis. Nevertheless, Black women with fibroids or endometriosis experience worse clinical and surgical outcomes than their White counterparts.

Conclusion and relevance: Racial disparities in uterine fibroids and endometriosis can be linked with differential exposures to suspected etiologic agents, lack of adequate access to health care, including highly skilled gynecologic surgeons, and bias and discrimination within the health care system. Eliminating these racial disparities will require solutions that address root causes of health disparities through policy, education and programs to ensure that all patients receive culturally- and structurally-competent care. (Fertil Steril® 2023;119:355–63. ©2023 by American Society for Reproductive Medicine.)

Key Words: Fibroids, endometriosis, racial disparities, racism, structural determinants, allostatic load

Healthy People 2030 defines health disparities as “a particular type of health difference

that is linked closely with economic, social, or environmental disadvantage,” which are the result of the social, struc-

tural, and political context (1–6). Specifically, the social, structural, and political contexts in combination with an individual’s identities shape the exposures they experience across the life course, which in turn influence their disease characteristics and experiences with the health care system (Fig. 1) (1–6). Historically, health disparities were discussed in the context of “health equality”. Although health equality is an idealized goal, it presumes that individuals from different groups are starting from the same place, ignoring the role of the social, structural, and

Received January 12, 2023; accepted January 17, 2023; published online January 20, 2023.

This material is the result of work supported with resources and the use of facilities at the VA HSR&D Center for the Study of Healthcare Innovation, Implementation and Policy, VA Greater Los Angeles (J.G.K.). T.C. Plowden has nothing to disclose. E.E.M. has served as a consultant for Myovant Sciences and Pfizer. The views expressed herein are those of the author(s) and do not necessarily reflect the official policy of the Department of the Army, Department of Defense, Department of Veterans Affairs, or the US Government. The authors have no other disclosures.

Supported in part by National Institutes of Health grant R01MD011570 (E.E.M.).

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Fertility and Sterility® Vol. 119, No. 3, March 2023 0015-0282/\$36.00

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<https://doi.org/10.1016/j.fertnstert.2023.01.022>

political context, and emphasizing genetics, and individual behaviors and risk factors. In contrast, health equity scholarship recognizes the important contextual factors that shape individual's lives, choices, and opportunities in ways that privilege some groups while disadvantaging others (1–6). These inequities in lived experience result in health disparities across the life course through embodiment, or the biologic manifestation of the social conditions in which an individual or population lives (7, 8). Embodiment is a multilevel process that can take many forms, including alterations in gene expression or physical characteristics, which contribute to an individual's disease risk. A key mechanism for embodiment is allostatic load, defined as the interaction of body systems with the cumulative burden of chronic stress and events across the life course (9, 10). One way in which allostatic load may manifest with respect to health is through a process termed “weathering,” which refers to the early deterioration of health due to cumulative socioeconomic disadvantage (11, 12). Health equity frameworks illuminate the need for interventions that move beyond the individual level and address institutional and structural factors to change the context that shapes people's health and health outcomes through embodiment.

Measuring and more importantly addressing health disparities can provide a means of assessing progress toward health equity (5). Although there are many types of health disparities, racial disparities are among the most documented in the United States, including persistent disparities in reproductive health outcomes, particularly between Black and White women (13). Within the scope of reproductive health, Black/White disparities in pregnancy and cancers are researched most significantly, yet disparities in benign gynecologic

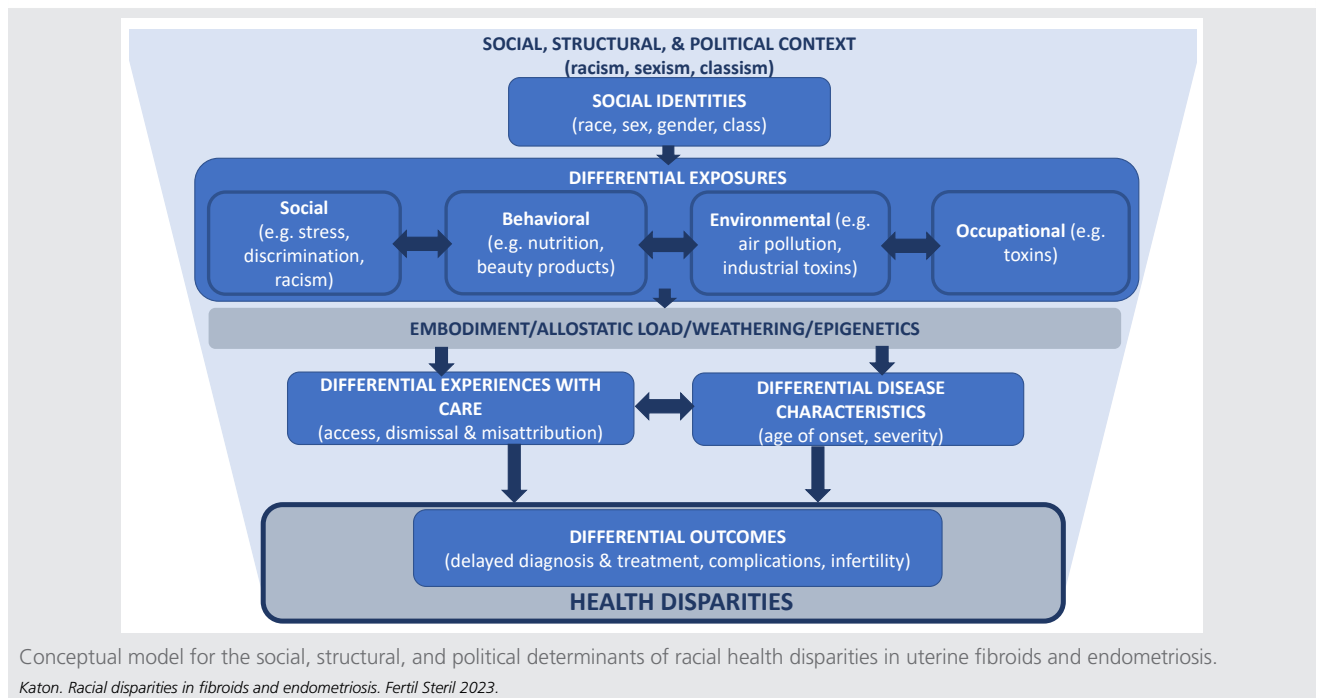
conditions are relatively understudied (13–15). The purpose of this review is to summarize the literature regarding Black/White health disparities in 2 prevalent benign gynecologic conditions: uterine fibroids and endometriosis. Using a framework that explicitly incorporates and acknowledges social, structural, and political determinants of health, we will review key drivers of disparities in these 2 common gynecologic conditions.

METHODS

To systematically review racial disparities in prevalence of uterine fibroids and endometriosis we conducted 2 separate searches of PubMed using the search terms: “(fibroids) AND (race) AND (prevalence) AND (United States)” and “(endometriosis) AND (race) AND (prevalence) AND (United States)” on January 12, 2023. These searches were limited to articles published between January 1, 1995, and October 1, 2022. We used the PubMed filters to limit the search to articles dealing with human species and female sex, and that were in English. Articles from the resulting lists were retained if they summarized findings from a United States population, were original research, and included estimates of population prevalence for uterine fibroids or endometriosis among Black and White, and were not limited by a specific other condition or disease. We also reviewed reference lists of included articles and identified reviews.

To summarize the literature regarding disparities in uterine fibroids and endometriosis and the role of social, structural, and political context we conducted 2 separate searches in PubMed to identify relevant original research manuscripts and prior systematic reviews regarding racial

FIGURE 1



disparities in uterine fibroids and endometriosis using standardized search terms for articles published between January 1, 1995, and October 1, 2022 (search conducted on October 4, 2022). The search terms for uterine fibroids were “(uterine fibroids) AND (disparities)” “(uterine fibroids) AND (race)” “(uterine fibroids) AND (ethnicity).” Similarly, search terms for endometriosis were “(endometriosis) AND (disparities)” “(endometriosis) AND (race)” “(endometriosis) AND (ethnicity).” The resulting article lists were scanned for relevance based on title and abstract. Reference lists of review articles also were searched for additional relevant manuscripts.

RESULTS

Uterine Fibroids

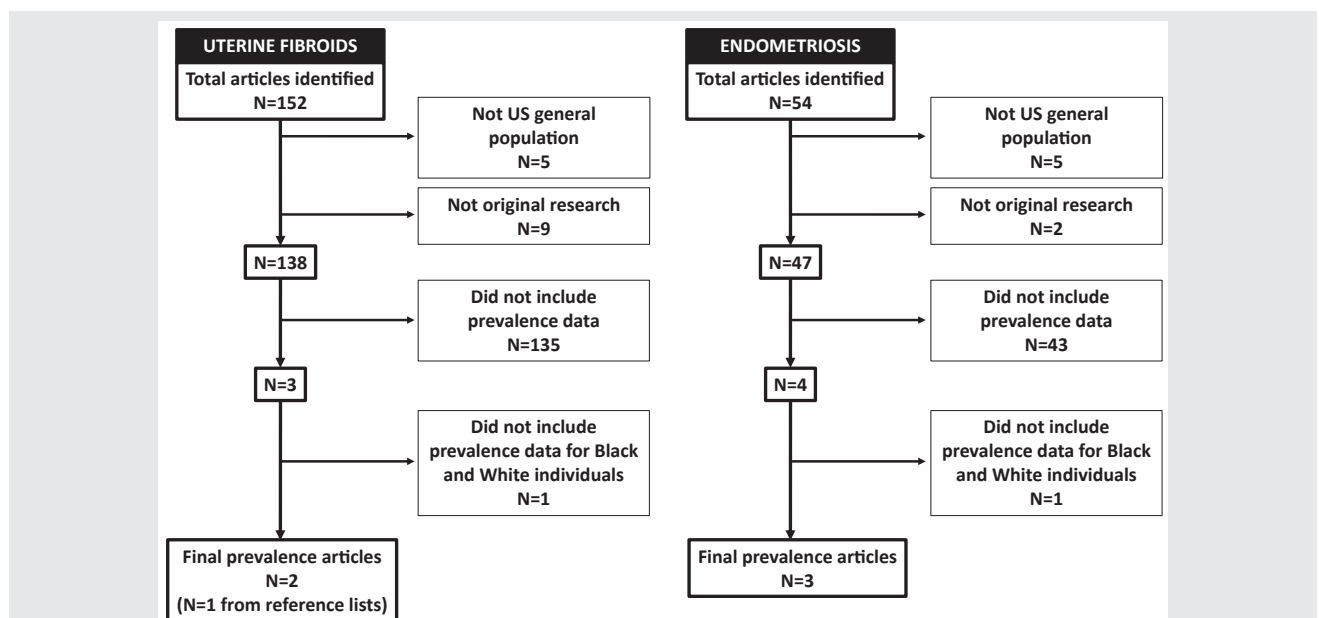
Uterine leiomyomata (commonly called uterine fibroids) are noncancerous smooth muscle tumors of clonal origin that are common among individuals with a uterus. Approximately 70% of individuals with a uterus will have uterine fibroids by age 50 (16). Although uterine fibroids can be asymptomatic, 25%–50% of those with uterine fibroids experience symptoms, such as heavy bleeding, bulk symptoms, or pain, which can negatively impact quality of life (17, 18). Uterine fibroids also have been linked to increased risk of infertility and recurrent pregnancy loss, preterm birth, placenta previa, placental abruption, and cesarean section (19). While the number of conservative options for treatment have increased over time, hysterectomy remains the only definitive treatment for uterine fibroids and continues to be one of the most common treatments (20). When surgery is deemed necessary, minimally-invasive approaches are preferred because of

shorter recovery time and lower risk of complications compared with an open abdominal approach (21, 22). Current estimates indicate that in the United States costs associated with uterine fibroids are approximately \$34.4 billion per year (23). Compared with White women, Black women are disproportionately impacted by uterine fibroids (16, 24–26). While other racial disparities in uterine fibroids may exist, the majority of the literature focuses exclusively on Black/White disparities and these will be the focus of this review (27).

Our systematic review of the literature regarding racial disparities in prevalence identified 3 manuscripts meeting our criteria (Fig. 2). Two involved ultrasound determination of presence of uterine fibroids, 1 of these was limited to younger asymptomatic women and 1 included a random sample of women regardless of age or symptom status (16, 28). A third study relied on electronic medical records and ICD-9 codes to identify uterine fibroid cases (29). In all studies, Black women had a higher prevalence of uterine fibroids than White women, although the difference in prevalence varied depending on the population and case definition (16, 28, 29). Among those 18–30 years old with no fibroids symptoms, 26% of Black women and 7% of White women had ultrasound evidence of uterine fibroids (28). Among those 35–49 years old sampled regardless of symptoms or clinical diagnosis, approximately 80% of Black women and 70% of White women had evidence of uterine fibroids by ultrasound (16). Using electronic records, the prevalence of diagnosed uterine fibroids among Black and White women 18–65 years old was 18.5% and 10.3%, respectively (29).

Myometrial mass and morphology of smooth muscle cells are altered in uterine fibroids, and it is well established that

FIGURE 2



Flow chart for sequential article exclusion for the systematic review of racial disparities in prevalence of uterine fibroids and endometriosis.

Katon. Racial disparities in fibroids and endometriosis. *Fertil Steril* 2023.

estrogen and progesterone have key roles in promoting fibroid growth (30). Notably, racial differences are reported at the gene expression level among those with fibroids. This includes the expression and intensities of several proteins compared between fibroids from African Americans and other racial groups (31). Pan et al. (32) found that of 1470 genes identified that were expressed differentially in fibroids, 177 genes were overexpressed, and 91 genes were underexpressed among fibroids from African Americans vs. those from White individuals. There also is some evidence of differences in micro-RNA expression in fibroid tissue obtained from African American vs. White individuals (33, 34). Other potential pathways that are implicated in fibroid etiology and might provide some insight into racial disparities in uterine fibroids include polymorphisms of genes involved in estrogen synthesis, variation in the expression of retinoic acid nuclear receptors, and aromatase inhibitors (30).

The differences in gene expression, as well as racial disparities in prevalence, may reflect that Black women disproportionately experience a wide range of exposures that also are associated with increased risk for uterine fibroids across the life course reflecting their positionality at the intersection of racism and sexism (Fig. 1) (35–37). These include social exposures, such as stress and interpersonal racism (10, 15); behavioral factors, such as poor diet, lower levels of physical activity, vitamin D deficiency, and use of certain beauty products (e.g. hair straighteners) (38–41); and a wide range of environmental and occupational exposures, including persistent organic pollutants, endocrine-disrupting compounds, and air pollution (42, 43).

In terms of social exposures, a 2019 meta-analysis of observational studies concluded that chronic psychologic stress was associated with risk of uterine fibroids (highest vs. lowest category of chronic stress: odds ratio [OR]_{pooled}, 1.24; 95% confidence interval [CI] 1.15, 1.34) (44). Similarly, moderate daily stress and anger squelching are reported to be associated with increased risk of fibroids among Black women (45). Another study that followed a cohort of more than 22,000 Black women found that higher exposure to perceived racism was associated with an increased risk of fibroids among United States-born Black women (highest vs. lowest quartile of everyday racism (Oare, 1.27; 95% CI, 1.14, 1.43) (46). Increased risk of fibroids and more severe fibroid symptoms also are associated with adverse childhood experiences, which may be more prevalent among Black vs. White women depending on the instrument used and population sampled (47–52).

While stress and childhood adversity may influence fibroid risk through activation of inflammatory and other biologic pathways, it also may increase fibroid risk indirectly by leading to behavioral coping mechanisms, such as alcohol use, poor diet, and lack of physical activity (47, 53–58). The Black Women's Health Study found that increased consumption of beer was associated with increased risk of uterine fibroids in a dose-dependent manner (55). Additionally, various indicators of poor diet are reported to increase risk of fibroids, including increased intake of fatty acids of animal origin and lower intake of fruits and vegetables (54, 59). Lower levels of physical activity also were associated

with increased risk of fibroids with Baird et al. (58) reporting that relative to those in the lowest category of physical activity those in the highest had 40% lower odds of uterine fibroids developing (OR, 0.6; 95% CI, 0.4–0.9). Findings regarding tobacco use and caffeine intake are inconsistent (55, 60, 61). Historically, pelvic infection was thought to have a role in fibroid incidence, but recent evidence does not support this. Non-Hispanic Black women have a higher incidence and prevalence of sexually transmitted infections than non-Hispanic White women in the United States, although this is explained largely by partner networks and concurrency rather than individual behaviors (62). Importantly, multiple studies failed to find any association between infection with bacterial vaginosis, herpes simplex virus type 2, or chlamydia trachomatis and increased risk of fibroid development or growth (63–65).

Pressure to conform to predominantly White standards of beauty has increased the likelihood of Black women using products, such as hair straighteners and relaxers, that contain chemicals that are associated with increased risk of uterine fibroids (4, 66–68). Black consumers in the United States purchase hair relaxers and straighteners at much higher rates than White consumers, and compared with White women, Black women are more likely to use a greater number and variety of products (41, 69). Use of these products frequently begins at ages as young as 4–8 years old (70). Notably, Wise et al. (66) found that ever vs. never use of hair relaxers among Black women was associated with a 17% higher incidence of uterine fibroids (OR, 1.17; 95% CI, 1.06, 1.30), with positive trends identified for association of fibroid risk with frequency and duration of use.

In addition to toxins contained within beauty products, Black women are disproportionately exposed to a wide range of environmental and occupational exposures across the life course, including heavy metals, persistent organic pollutants, and endocrine-disrupting chemicals, which are associated with increased risk of fibroids (42, 43). Several studies have noted a relationship between fibroids and environmental contaminant exposures. Diethylstilbestrol (DES), which is classified as an endocrine-disrupting chemical, exposure in the prenatal period has been associated with development of fibroids, with Baird et al. (71) reporting that those exposed to DES prenatally had >2-fold increased odds of fibroids and Mahalingaiah et al. (72) reporting a 12% higher incidence associated with DES exposure. Additionally, exposure to phthalates has been associated with fibroid development (42). One study found that exposure to phthalates was universal in a cohort of premenopausal women who had fibroids; however, Black women with fibroids had significantly higher levels of specific phthalates than White and Hispanic women (73). Due to historical and current racial segregation and discriminatory patterns of zoning, Black women are more likely than White women to be exposed to high levels of air pollution (74, 75). Multiple studies suggest that chronic exposure to air pollution is associated with a higher risk of fibroids (76, 77). For example, Lin et al. (76) reported an 11% increase in odds of fibroids associated with a 10 µg/m³ increase in PM_{2.5} (OR, 1.11; 95% CI, 1.07, 1.14), and an 8% increase in

odds of fibroids per 10 ppb increase in O₃ (OR, 1.08; 95% CI, 1.04, 1.11).

A potential consequence of the cumulative disproportionate exposures to childhood adversity, stress, and certain environmental exposures may be the greater likelihood of early menarche among Black vs. White women (78–81). Early menarche is thought potentially to increase the risk of uterine fibroids through increased exposure to menstrual cycles across the life course (61). Indeed, Edwards et al. (82) found that not only was there an inverse relationship between age at menarche with each 1 year increase in age at menarche associated with a 13% lower risk of fibroids (relative risk [RR], 0.87; 95% CI, 0.82, 0.91), but that early menarche was associated with increased likelihood of multiple fibroids. These findings were consistent with earlier findings by Wise et al. (83).

The same structural determinants that may lead to higher prevalence and severity of fibroids among Black women also influence their ability to access high-quality, patient-centered fibroid care as demonstrated by a small but growing number of qualitative studies. Black women frequently experience biased and discriminatory treatment in the context of seeking care for fibroids. One qualitative study conducted semi-structured interviews with 37 Black women who were planning surgical management of their fibroids. Several themes emerged, including poor patient-provider interactions that left women feeling unsatisfied with their care (84). Patients often felt that their concerns were dismissed, leading to delayed diagnosis of fibroids, and that they did not receive empathy/compassion from their health care providers, further compromising the therapeutic relationship (84). Another qualitative study found that women of color with fibroids reported negative interactions with health care providers related to racism. These experiences led to feelings of distrust and skepticism, negatively impacting their care (85).

Negative experiences with care seeking, combined with health care system and societal access barriers may result in greater likelihood of delayed or foregone care for Black women with uterine fibroids and worse clinical outcomes (86, 87). Despite higher overall population rates of hysterectomy, recent evidence highlights the fact that Black women with uterine fibroids are more interested in and more likely than White women to schedule a uterine-preserving surgery (e.g., myomectomy) when more conservative care is presented as an option (27, 88–91). This preference for uterine-preserving treatments may reflect a combination of cultural values, delayed childbearing, and/or mistrust of the medical system because of the historical and present-day mistreatment and coercive reproductive health care practices toward Black women, including forced sterilization (15, 84, 85, 92–94). Therefore, if not offered treatment options that are uterine-preserving, or if they believe that they will not be offered such treatments, Black women may be more likely than White women to delay or forego treatment and the sequelae thereof (84). Additionally, evidence indicates that newer surgical techniques, including minimally-invasive approaches, such as robotic-assisted surgeries, may diffuse more slowly among Black patient populations due to the under-resourcing of predominantly Black serving hospitals, greater

reliance on Medicaid or Medicare, and limited access to high-volume surgeons (87, 95–99). Thus, if Black women ultimately do undergo hysterectomy, they may have larger fibroids than White women, a greater number of prior surgeries, and be less likely to have their surgery in a hospital with capacity for minimally-invasive hysterectomy (87, 100). These factors may explain at least partially why Black women are reported to have twice the odds of White women of having an open abdominal vs. minimally-invasive hysterectomy (101, 102). The Black/White disparity in minimally-invasive hysterectomy persists even in the context of an enhanced access system, such as the Veterans Health Administration supporting the idea that access alone cannot create health equity (103, 104). Regardless of surgical route, Black women undergoing surgery for uterine fibroids have higher rates of surgical complications, longer surgery times, and greater likelihood of hospital readmission compared with White women (101, 102).

Endometriosis

Endometriosis is a chronic inflammatory gynecologic disease that is characterized by the growth of endometrial glands and stroma in areas outside of the uterus (105, 106). The gold standard for diagnosis historically has been tissue pathology that requires surgery. Women with endometriosis exhibit a range of symptoms, including pelvic pain, dyspareunia, dyschezia, and infertility (105). Many women with endometriosis have been shown to experience negative effects on quality of life in a variety of domains, including sexual functioning, ability to participate in daily and social activities, work and educational productivity, and mental wellbeing. On an individual level, endometriosis is associated with 6.3-hour per week productivity loss and higher annual health care costs of approximately \$16,753 per patient (107, 108). The annual economic cost of endometriosis was estimated at \$69.4 billion in a 2009 study (109).

Our systematic review of the literature regarding racial disparities in prevalence of endometriosis among Black and White individuals in the United States included 3 manuscripts, all of which used different study populations and case definitions, including an electronic health record-based study that relied on ICD-9s, a patient survey that used self-reported prior diagnosis, and a surgical population-based study that used postoperative notes and pathology (Fig. 2) (110–112). In the 2 nonsurgical-based population studies, Black individuals had similar to slightly lower prevalence of endometriosis (Black 0.7%–4% vs. White 0.9%–7%) (110, 111). In the single study that used a surgical population (e.g., those undergoing laparoscopy or laparotomy), the overall prevalence of endometriosis was higher and the difference in diagnosis was substantially larger (Black 12.5% vs. White 67%) (112).

Given the racialized disparities in access to health care in the United States, and the need for surgical diagnosis of endometriosis, it is difficult to establish prevalence and incidence rates and determine if there are racial disparities in these through reliance on administrative data or population-based surveys. Additionally, the recognition and diagnostic

description of endometriosis in 1921 as a gynecologic condition was heavily influenced by sex, class, racial biases, and cultural politics of the time. Early theories of the etiology of endometriosis suggested that it was a consequence of contraceptive use and delayed childbearing (113, 114). Thus, it frequently was assumed to be a disease predominantly of middle-class White women and this idea was popularized in many medical texts and popular culture leading to misattribution of symptoms and misdiagnosis or delayed diagnosis among Black women (115, 116). This meant that clinicians were less likely to consider endometriosis in their differential diagnosis for Black women experiencing pelvic pain and other symptoms consistent with the condition. For example, Chatman et al. (117) found that 20% of Black women who had a laparoscopy as part of a diagnostic workup for pelvic pain had endometriosis, and approximately 38% of these had been diagnosed inaccurately with pelvic inflammatory disease preoperatively. Therefore, despite evidence from the 1950s, 1960s, and 1970s indicating no difference in incidence of endometriosis among White and Black women among private patients, prevalence studies continue to find that White women are more likely than Black women to be diagnosed with endometriosis (117–120).

Although the etiology of endometriosis remains poorly understood, some of the same factors that are known to be associated with increased risk of fibroids also are putatively associated with increased risk of endometriosis. As described in the previous section, Black women experience these exposures at greater frequency and severity than their White peers. For example, relative to White women, Black women have a higher likelihood of exposure to air pollution, endocrine-disrupting chemicals, and heavy metals, all of which are associated with an increased risk of endometriosis (42, 121). Additionally, earlier menarche is associated with increased risk of endometriosis and occurs more frequently among Black women, possibly because of differential exposures to environmental factors (81, 106). Nevertheless, studies report that Black women appear to have a similar incidence of endometriosis, if not lower, than White women (118, 119). This inconsistency may be due to a combination of diagnostic bias and disparities in access to health care, as well as potential differences in disease presentation as endometriosis is a heterogeneous condition with a multiple and complex etiologies (118). At least 1 study suggests that Black women may be more likely than White women to have uterine implants, which otherwise are considered rare (122). However, it is unclear how or if this difference in disease would impact diagnosis and more recent findings indicate no difference in location of endometriosis lesions by race or ethnicity among patients undergoing surgery for endometriosis (123, 124). Current qualitative research efforts seek to understand how access to health care as well as bias and discrimination shape experiences of endometriosis and result in different pathways to diagnosis and treatment among racially and ethnically diverse samples (125). This is important not just because of persistent diagnostic bias on the part of clinicians, but also because the sentinel symptom of endometriosis is pelvic pain and presentation of pelvic pain, and its components are influenced heavily by psychosocial context.

Ultimately, differential experiences with seeking care and diagnosis and limited access to quality health care also may lead to racial disparities in treatment and treatment outcomes. At least 2 recent studies indicate that relative to White women, Black women undergoing surgery for endometriosis are more likely to have surgical complications even after adjusting for surgical approach and individual patient factors. Movilla et al. (124) estimated that Black women had 64% higher odds (95% CI, 1.10–2.45) of major complications from hysterectomy for endometriosis relative to White women. Similarly, Orlando et al. (123) found that among those having any surgery for endometriosis relative to White women, Black women had 71% higher odds of any complications in the 30 days postoperatively (95% CI, 1.39–2.10). Both studies included adjustment for surgical route (e.g., open abdominal vs. minimally invasive) as Black patients undergoing gynecologic surgery for benign conditions are less likely than White patients to have a minimally-invasive route, which is associated with increased risk of surgical complications (25, 126).

CONCLUSIONS

Black/White racial disparities in uterine fibroids and endometriosis exist and persist. For uterine fibroids, there are ongoing racial disparities in prevalence, symptom severity, treatment, and outcomes. In the case of endometriosis, it is unclear whether racial disparities in incidence or prevalence exist. However, consistent findings indicate that Black/White racial disparities in diagnosis, treatment and outcomes for endometriosis still occur. Although the limited racial disparity research in uterine fibroids and endometriosis is focused largely on differences in tumor biology, symptom presentation, and treatment choice, we know that root causes of racial health disparities are much more complex than genes, individual health behaviors, and access to care. For example, gene expression is impacted by allostatic load, which is driven by the chronic daily stressors of racism, sexism, classism, homophobia, and many other marginalizing harmful factors. Additionally, health behaviors and health decisions are not simply individual choices, but are driven by our jobs, incomes, where we live, what language we speak, and how safe we feel, all of which are shaped similarly by the interaction of our identities within a specific social, structural, and political context. We propose a model, informed by scholarship on health equity, Black feminism, and social epidemiology, that incorporates these contextual factors as root causes and determinants of racial disparities in uterine fibroids and endometriosis. This model suggests that findings regarding racial disparities in these gynecologic conditions, must be interpreted within the context of these root causes and determinants if we are to make meaningful strides toward health equity. Further, our findings highlight the need to address structural causes of health disparities through policy, education and programs, ensuring that all patients receive culturally- and structurally-competent care (127), and investing in development of novel diagnostics and treatments and equitable access to these technologies.

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