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The two health disparities of uterine fibroids

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What if there was a disease that affected an average of one-in-four reproductive age women in the U.S., and was present in up to 70% of women by the age of menopause? What if this condition significantly increased the likelihood of preterm birth, pregnancy complications, miscarriage, infertility, and even sterility in women? What if the annual cost of the condition to the U.S. health care system was estimated to approach 34 billion dollars, on par with the combined annual costs of breast, colon, and ovarian cancer? What if there were no medical treatments for the condition? What if the condition was a bona fide health disparity, with prevalence much higher in African American women? What if research of the condition was so limited that the prevalence and incidence of the disease was unknown in young women? Of course, there is such a disease: uterine fibroids (1–4). Other than obesity, it is difficult to imagine a more pressing health issue for women in the U.S. The public health and economic burden of the condition is immense.

On a personal level as well, fibroids extract a considerable toll. I just operated on a 42 year old African American woman for fibroids. Her story is not unusual. She underwent a uterine artery embolization for bleeding 3 years ago, but the bleeding recurred. She was seen in the Emergency Department three times in the past 3 years for symptomatic anemia caused by heavy vaginal bleeding; each time a hospital admission was required for blood transfusion. When I first saw her, the uterus was 2 centimeters above the umbilicus—all from fibroids. Her hematocrit was 28 and she was symptomatic from the anemia. She was medically managed with GnRH agonist therapy for 6 months, which stopped the bleeding and reduced the fibroid size. However, because of the considerable toll on her health, she strongly desired hysterectomy at age 42. Would a better understanding of the disease process have saved this patient from suffering for 3 years and ultimately undergoing a surgical procedure? Could surgical management of her uterine fibroids have been prevented by availability of an alternative therapy?

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The manuscript by Marsh et al. (5) in this issue of the journal is important because it fills in a missing piece of the fibroid disease puzzle. Prior studies of uterine fibroids have clearly demonstrated that the condition is a disease of racial disparity, being more prevalent in African American women compared to Caucasian women (3, 4; and references therein). Importantly, not only is the condition more prevalent, but the disease itself is more severe—African American women are more likely to have multiple fibroids, as opposed to a single tumor, resulting in a greater disease burden for this group of women (3), even in pregnancy (4). Furthermore, fibroids in African American women are less likely to regress after menopause (3). As a result of the greater disease burden, severity, and attenuated response to hormones, rates of myomectomies and hysterectomies in African American women are several fold higher than for white women in the U.S. (2; and references therein). Marsh et al. (5) adds information regarding the prevalence and tempo of disease in young black women, which was missing from the literature.

While the sample size is small, 101 patients, the manuscript by Marsh et al. (5) is the first systematic report on the prevalence of disease in African American women under age 25. Interestingly, based on this limited ultrasound surveillance of asymptomatic women, the prevalence of disease was increased in young African American women, 26% compared to 7% in white women. This study needs to be confirmed with a larger sample size, but the information confirms our suspicion that fibroid disease is indeed fundamentally different in African American women: it starts earlier and affects 25% by age 24. This observation is consistent with the tenet that the underlying causative factors that promote the disease differ between races.

In addition to the racial health disparity of the disease, uterine fibroids represent a health disparity on another level: there is a disparity between the immense burden of disease and the resources that have historically been devoted to study of the condition. For all diseases, reduction and ultimate elimination of health disparities is a priority of the National Institutes of Health. This is why NIH requires reporting of race and ethnicity for all clinical research it funds. More specifically, during the past decade, research on uterine fibroids has been promoted by 3 NIH International Congresses on uterine leiomyoma research which have suggested a course of action and identified research needs. Among other advances, in response to the action items, NICHD and the Office of Women's Health Research at NIH established a fibroid tissue bank (<http://clinicaltrials.gov/ct2/show/NCT00710346>). In addition, the Agency for Healthcare Research and Quality (AHRQ) convened a meeting to prioritize the evidence gaps surrounding the treatment and management of uterine fibroids. Specifically, AHRQ identified the need for a multi-center prospective study of the comparative effectiveness of uterine fibroid treatment and management. Also in recognition of the disparity between disease burden and research, the newly formed research institute, Patient-Centered Outcomes Research Institute (PCORI), has planned a targeted funding announcement focusing on the comparative effectiveness of treatment options for uterine fibroids.

Thanks to these initiatives, progress has been made in the past decade, but many unanswered questions remain. Despite the immense burden of the disease, the evidence upon which providers and patients can base clinical decisions regarding treatment remains limited.

Comparative effectiveness studies of new treatments, such as MRI-guided focused ultrasound and uterine artery embolization are needed. Data on surgical outcomes following treatment interventions are limited despite the prevalence of procedures such as myomectomy and hysterectomy, particularly in African American women. Limited evidence is available to guide patients regarding treatment choices. In addition, clinical researchers lack a universally-accepted classification system for fibroid disease, thus comparison between studies and determination of response to treatment is difficult to quantify.

Furthermore, the tumors themselves also remain enigmatic. For instance, it is now clear that within a single uterus some fibroid tumors are growing, some are quiescent, while others may be shrinking (3); but the reasons for the growth and regression remain unknown. To date, molecular studies of fibroid tumors have not investigated whether the tumors were actively growing or regressing. That fact may contribute to variation within the results, but may also obscure important clues to the pathophysiology of disease. Advances have been made regarding the molecular features that accompany common (spontaneous) fibroid development, but a consensus has not been reached regarding the signaling pathways involved in fibroid formation. While the tumors are clonal, the early events that may trigger the disease remain unclear.

In conclusion, fibroids are a health disparity on two levels, one racial; the second a disparity of investment in research funding compared to the prevalence of the condition. The manuscript by Marsh et al. (5) emphasizes that if nothing is done, 26% of young African American women will have fibroids and are destined to suffer under the lifelong burden of the disease. Effective preventative and non-surgical treatment options are urgently needed for young women. More research is needed to fill in these gaps and tackle the immense problem of uterine fibroids. The prevalence of the condition and possible therapeutic targets would seem to make the disease ripe for research and development by pharma. Given the potential to improve the lives of so many women, it is puzzling that more foundations have not engaged in funding of research to help mitigate these two health disparities.

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