



Unmuting Fibroids: Meaningful Action Toward Equity for Black Women



The Impact Of Uterine Fibroids On Black Women

Uterine fibroids (U.F.) are benign growths on the wall of the uterus that impact 26 million women in the U.S. between the ages of 15 and 50.ⁱ Symptoms can include severe menstrual bleeding, anemia, fatigue, pain, bladder or bowel dysfunction, impaired fertility, pregnancy complications and loss.ⁱⁱ However, many symptoms may be unrecognized or attributed to other conditions.ⁱⁱⁱ Given this and the limited widespread knowledge of fibroid symptoms and treatment options^{iv}, many live with symptoms of fibroids for years before seeking treatment.^v

The impact of uterine fibroids on work and quality of life is staggering. It is estimated that \$34.4 billion is spent annually in the U.S. on fibroids, with \$4.1-9.4 billion spent on fibroid-related care such as surgery, hospital admissions, outpatient visits, and medication each year.^{vi} Additionally, more than in four women attribute fibroids to lost workdays, leading to one-fifth of those women feeling concerned about losing their job.^{vii}



The Statistics Are Dire: A Pressing Public Health Crisis

While millions of women experience uterine fibroids, Black women are disproportionately impacted. Nearly 80 percent of Black women will develop fibroids by 50^{viii}, three times more frequently than other racial groups.^{ix} Black women also typically experience an earlier onset of uterine fibroids compared to white women – even in their 30s,^x 74 percent of Black women will have multiple fibroids compared to 31 percent of white women.^{xi} Further, disparities in diagnosis and care of fibroids result in Black women waiting longer than white women before seeking treatment for their fibroids – typically four years or more.^{xii}



Where We've Been: Black Women's Treatment Journey With Uterine Fibroids

Despite minimal awareness and good intentions, Black women are still not getting the care they need for their fibroids. The burden of uterine fibroids is compounded by profound disparities in diagnosis and care. Unfortunately, gaps in healthcare and specific vulnerabilities of Black and brown women are sadly unresolved, and many women's health issues remain chronically underserved. In fact, despite the prevalence and severe health and quality of life implications, uterine fibroids are in the bottom 50 conditions funded by the NIH.^{xiii}

Black women are more than twice as likely to undergo a hysterectomy for fibroids,^{xiv} and have an almost seven-fold increased risk of undergoing a myomectomy; despite studies that show increased morbidity with both procedures.^{xv} Black women are also twice as likely to be hospitalized for fibroid-related issues as white women.^{xvi} Compared to white women, Black women who undergo hysterectomies are four times as likely to develop complications and nearly three times as likely to be hospitalized, with a higher rate of mortality.^{xvii}

While research shows disparities in fibroid diagnosis, treatment, and symptom severity exist among Black, Hispanic, Asian, and Native American women,^{xviii} little has been done to better serve these marginalized communities. Improving care for women with this condition, especially in underserved populations, requires increased education and awareness for both patients and providers and increased support and funding for research from the federal government.



UNmuting Fibroids: Getting Loud For Equal Care

For too long, Black women have suffered with fibroids, often in silence. We need to move beyond simply raising awareness for fibroids and begin to address the barriers that stand in the way of improved outcomes for Black women, and other historically underrepresented patients, living with fibroids.

To address this public health crisis, a multidisciplinary group of experts convened during *UNmuting Fibroids*, a roundtable organized by the [Black Women's Health Imperative](#) (BWHI) in partnership with Hologic's [Project Health Equality](#), a multifaceted, multiyear initiative that uniquely combines research, education, and access to address the structural and cultural barriers that prevent Black and Hispanic women from receiving the same quality of healthcare as white women.

The goal of the roundtable was to identify and discuss those factors and the inequities that hamper the ability for Black women to receive adequate care.

The roundtable was moderated by Tiffany Cross, host of MSNBC's "The Cross Connection," who shared her personal experience with fibroids. Participants included health, policy, and cultural leaders, including:



- Christopher Cox, Chief of Staff, Office of Congresswoman Yvette Clarke (D-NY)
- Cindy Duke, MD, Ph.D. FACOG, Medical Director, Nevada Fertility Institute
- Cynthia Bailey, American Model, Reality Television personality, and Actress
- Donald Cravins, Executive Vice President and Chief Operating Officer, National Urban League
- Kim Miller-Tolbert, Deputy Legislative Director & Policy Advisor, Office of US Senator Cory Booker (D-NJ)
- Kimberly Wilson, Founder and CEO, HUED
- Lauren Powell, MD, Board-Certified Family Medicine Physician, "The Culinary Doctor"
- Mervyn Jones, Son of late Stephanie Tubbs Jones, Principal, MLJ Strategies
- Nischelle Turner, Co-Host, Entertainment Tonight
- Rachel Villanueva, MD, FACOG, Clinical Assistant Professor of Obstetrics/Gynecology, NYU Grossman School of Medicine
- Shawna Watley, Co-founder, Women Investing in Leadership Development (WiiLD), Lobbyist for Holland & Knight, and First Lady of Kingdom Fellowship AME Church in Silver Spring, MD
- Sophie Maeter, Legislative Aide, Office of US Senator Shelley Moore Capito (R-WV)
- Soyini Hawkins, MD, Gynecologic Surgeon, Fibroid and Pelvic Wellness Center of Georgia
- Tamar Braxton, Grammy Nominated Singer, Emmy Nominated TV Host and Executive Producer
- Wanda Durant, Founder, The Wanda Durant Real MVP Foundation
- Yvonne Orji, Actress, Comedian, and Author



Where We Are Today: Four Key Topics That Emerged

Four key topics emerged during the roundtable discussion.

A. Health providers don't prioritize periods in conversations with patients

Black women do not feel encouraged to talk freely with their providers about their monthly period. Women who experience painful or heavy periods often feel they must suffer silently or do not realize their symptoms could be uterine fibroids or another serious condition like anemia. Additionally, not enough emphasis is placed on what a "healthy" period cycle is for patients, especially those who are more likely to experience uterine fibroids. Unlike monthly breast exams, women are not taking stock of their periods and seeking help when they notice something is "off" so that they can get a diagnosis.

B. Uterine fibroids are not given enough attention in medical school

A common experience among Black women is they do not receive quality care from healthcare providers who are not Black and that their providers do not know enough about uterine fibroids. Only five percent of U.S. physicians are black, and only two percent are black women.^{xix} A lack of culturally competent providers may impact Black women's outlook on fibroid treatment or their willingness to seek treatment. Physicians should be educated about how uterine fibroids affect Black women in medical school, as well as being offered additional instruction thereafter that covers a culturally competent curriculum.

C. Research and education for uterine fibroids is limited

Despite costing the healthcare system billions of dollars, in 2019, fibroid research only received about \$17 million in funding.^{xx} This puts uterine fibroids in the bottom 50 conditions funded by the NIH.^{xxi} Research and education are essential to eliminate disparities and provide more treatment options for Black women with fibroids.

D. Uterine fibroids are stigmatized in the Black community

A common thread woven throughout the roundtable discussion was the urgency to normalize the conversation about symptoms of fibroids, and in doing so, helping to reduce the stigma that plagues talking about the disease. Black women do not feel supported, encouraged, or secure in openly discussing their uterine fibroids journeys. Currently, Black women either deal with fibroids in silence or if it is discussed, it is not with a sense of urgency, and the issue is often masked or minimized. "I had a procedure" is a common way Black women may discuss their UF with family and friends. Many Black women with uterine fibroids experience fear, pain, and feelings of being alone as if no one understands what they're going through. Participants discussed how women should feel more encouraged to talk freely about their monthly period and that periods need to be framed as a primary indicator of health, with mindfulness around periods leading to solutions that can benefit patients long before more extreme symptoms arise.



Necessary Steps To Enable Equality Today And In The Future: Critical Actions Identified By Participants

A. Designating periods as a vital sign

During this discussion, Cindy Duke, M.D., Ph.D., FACOG of the Nevada Fertility Institute linked the warning signs of anemia such as hair loss, heart disease, fatigue, low sex drive, and fertility issues to heavy periods. A common point of the discussion was that many of the women on the panel were told by direct family members that an extremely heavy period was normal and that they did not receive encouragement to talk about this issue. Having shared this common experience, the panelists agreed that periods need to be discussed as a vital sign of health. Far too often, a period and menstrual health are discussed during conversations of sexual health, but not general wellness, and that is something this panel would like to see changed. Women should be encouraged to talk about their periods with each other and with their healthcare provider, who in turn might be able to uncover a larger issue that is driving a heavy period. In talking more broadly about period health, both patients and physicians can move into conversations about uterine fibroids and how they can be managed from early on.

B. Enable more culturally competent care by ensuring that medical education includes more info about uterine fibroids and Black women's experience.

Almost every participant who spoke about their experience navigating the healthcare system to find a physician that would fit their needs expressed extreme frustration in how challenging it was to find a provider that would understand their specific experience. However, while thirteen percent of the US population is Black, only four percent are active physicians in the workforce, and two percent are Black women.^{xxii} While one side of this challenge is adding more Black women physicians to the workforce, the more pressing issue is to ensure that all physicians, regardless of race, are educated in culturally competent care, relieving the patient of the burden of finding a provider who understands their care needs. Culturally competent care refers to care that respects diversity in the patient population and cultural factors that can affect health and healthcare, such as language, communication styles, beliefs, attitudes, and behaviors.^{xxiii} In order to provide the appropriate care to every patient, it is essential for our healthcare providers to be knowledgeable about the experiences patients may be facing.

C. Increase funding for research, education and awareness for providers and patients

[The Stephanie Tubbs Jones Uterine Fibroid Research and Education Act of 2021](#) is a nonpartisan issue, yet still requires support to be passed by Congress. Policymakers are encouraged to support this piece of legislation that seeks to increase research funding, improve awareness, training, and seek data to measure outcomes and cost. This includes establishing new research funding through NIH, totaling \$150 million over five years, and a public education program through the CDC to ensure women today, and those of future generations, will have access to necessary resources needed to make informed decisions about their fibroid health.

D. Talk openly without shame about uterine fibroids

All the panelists agreed that the most important first step that everyone can take in reducing the disparities in this disease space is to start having open and candid conversations about one's experiences. *Entertainment Tonight* host, Nischelle Turner, spoke about the importance of using her platform to bring this conversation into more homes and communities in the hope that it will open the door for more women to discuss their journeys. More open conversations give other women a chance to say, "tell me about that" and would encourage them to get more information about uterine fibroids. In having these conversations with healthcare providers, friends, family, and community, more women will be motivated to get the care they deserve.

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