



BY JILLIAN MCKOY

# **RACISM, SEXISM, AND THE CRISIS OF BLACK WOMEN'S HEALTH**

BU leads the largest and longest-running study of Black women's health, shining a light on tragic disparities and showing women their lives matter



## Charlene Coyne often thinks back to how her mother, Donna, struggled with severe hypertension for most of her life, battling complications that led to a heart attack and stroke by the time Donna was in her thirties.

She also recalls the dismissive response from a doctor when her mother voiced concerns about the severe side effects—blurry vision, severe headaches, dizziness, nausea, fatigue—of her blood pressure medications.

“I noticed a physical transformation and could see how toxic the drugs were for her,” says Coyne, now a New York-based biopharmaceutical executive. When Donna mentioned her symptoms to her doctor, he refused to change her treatment plan. “He insisted that he knew what he was doing, and that she just needed to give the medication time to work. But she had already done that.”

At age 43, Coyne’s mother passed away from hypertension complications. “She suffered unnecessarily,” Coyne says, “and it breaks my heart to this day.”

Her family’s health history—her father would later suffer a fatal heart attack—and inadequate healthcare experiences are in part what motivated Coyne to join Boston University’s Black Women’s Health Study (BWHS) 28 years ago and become part of a group of 59,000 women in the largest and longest-running study in the United States focused entirely on the health of Black women.

Founded in 1995 at BU’s Slone Epidemiology Center, BWHS aims to understand the underlying causes of poor health—and good health—among Black women, and, with this



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knowledge, raise awareness and spur action to reduce the long-standing racial disparities and inequities in health. Black women are more likely than other racial and ethnic groups to die from cardiovascular disease, hypertension, stroke, lupus, and several cancers. They are twice as likely than white women to develop diabetes over age 55 or have uncontrolled blood pressure. Black women also face greater challenges in accessing affordable and quality healthcare, including a lack of health insurance, higher medical debt, and longer travel times to hospitals.

In the past 25-plus years, BWHS has published more than 350 papers, often in collaboration with external researchers from other cohort studies, such as the BU-based Framingham Heart Study, the longest-running heart

disease study in the US. The heaviest emphasis has been on breast cancer, but the findings span diabetes, obesity, autoimmune diseases, insomnia, and other conditions.

Many of these papers mark the first time these relationships were evaluated among a scientifically meaningful—in other words, large—population of Black women. These studies, often published in prestigious journals, not only fill a significant void in research, but also serve as long-sought acknowledgment that these stark racial disparities exist—and that Black women and their health matter.

“I’m really proud to be part of a study that has prioritized the health of Black women,” says Julie Palmer (SON’80, SPH’85), a BU Chobanian & Avedisian School of Medicine

professor of medicine and director of the Slone Epidemiology Center. Palmer cofounded BWHS, and is one of three lead investigators. “There are behavior changes that individuals can make to improve their health, but to dismantle racial disparities in health, we also need institutional change.”

### Tracking Health Trajectories

Despite their disproportionate health burdens, Black women historically have largely been excluded from clinical research, which has focused primarily on white males.

“Women were just starting to be included in studies when I became an epidemiologist, and Black women weren’t included at all,” says Lynn Rosenberg (GRS’65), a School of Public Health professor of epidemiology who cofounded BWHS. She previously co-led the study and remains part of the core research team. “We knew there was a dire need for this research.”

She and her team—which also included Lucile Adams-Campbell, then-director of Howard University Cancer Center and now at Georgetown University’s Lombardi Comprehensive Cancer Center—secured the massive cohort by inviting subscribers of *Essence* magazine to participate. The National Institutes of Health has renewed funding every five years.

The study launched with participants ages 21–69, on average 38, from

all regions of the US. Most are highly educated; only 3 percent of the women have not completed high school. More than half of the women have provided saliva, blood, or cancer tissue samples for genetic research.

Every few years, the participants complete confidential questionnaires about their demographics, health conditions, and lifestyle, as well as the impact of consequential moments in society, such as the COVID-19 pandemic. The team publishes newsletters and holds educational webinars and community events to share findings, engage with participants, and gather feedback on health topics that interest the women. They hope their findings help patients make informed choices about their health, and arm healthcare providers and policymakers with the necessary data and insight to combat long-standing racial inequities in health.

By examining the same group of women over decades, researchers can comprehensively track the health trajectories of thousands of women as they grow older.

“When I first heard about the Black Women’s Health Study, I said, ‘Thank goodness—someone finally cares,’” says Kim Bressant Kibwe, a Jersey City, N.J.–based participant and retired attorney. “We’re not all the same. There are many experiences that differ from one culture to the next.”



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At 69 years old, Kibwe still wonders if the major surgery she received to remove uterine fibroids as a college student was medically necessary. Black women are two to three times more likely than white women to develop fibroids, according to BWHS research, and 14 percent of participants reported they developed fibroids within the study’s first decade.

Kibwe says she never questioned her doctor’s recommendation to remove one ovary and both fallopian tubes, nor his warning that she may become unable to have children.

That possibility turned into reality. “After the third time I tried to have children, at age 29 or 30, I said it just wasn’t meant to be,” she says. “But I wonder if something less drastic could have been done to address my medical issues and preserve my health.”

### The Role of Racism

The overarching question for the researchers is: Why? Why are Black women less likely than white women to get breast cancer, but 40 percent more likely to die if they do develop it? Why are they more likely to be diagnosed with diabetes and high blood pressure? And what role does racism play in Black women’s health?

Some of the study results align with broadly accepted knowledge: obesity increases the risk of type 2 diabetes; exercise improves physical and mental health.

“Some findings may seem like commonsense conclusions, but policymakers need actual evidence to make decisions and inform policies that will improve the health of their constituents,” says Patricia Coogan (SPH’87, ’96), a BWHS investigator and an SPH research professor of epidemiology. She joined the team in 1996.

One observation is becoming increasingly clear: racism and other stressors may be much stronger predictors of poor health than individual choices or genetic differences.

The psychological trauma of racial discrimination may increase cortisol (the body’s stress hormone) and weaken the immune system, potentially leading to elevated blood pressure, memory problems, and other conditions.

The 1997, 2009, and 2019 questionnaires asked participants about their



past experiences with interpersonal racism, including daily, one-off encounters of perceived slights—such as poor service in a store or restaurant—as well as discriminatory treatment at work or in school, healthcare, the court system, housing, and interactions with police.

The researchers are also measuring the impact of structural racism, a relatively new term in public discourse that refers to the ways in which societies foster discrimination in policies or practices—perhaps less overt than “daily” racism, but still a reflection of the historically racist systems that remain embedded within society.

“Structural racism affects where people live, how they can exercise, the foods they eat, and the resources available to them,” says Palmer, who is also an SPH professor of epidemiology. “We didn’t have a name for it 20 years ago, but we have always acknowledged its influence on health, and we are continuing to examine how these racial experiences uniquely affect Black women.”

Experiences of racial discrimination may lead to increased weight gain, for example, as detailed in a 2009 study by Yvette Cozier (SPH’94,’04), SPH’s associate dean for diversity, equity, inclusion, and justice and an associate professor of epidemiology. About 60 percent of Black women experience obesity compared to 40 percent of white women. Cozier says her findings underscore the role of racism in the US obesity epidemic and the need for continued antidiscrimination efforts across the country. The researchers have also linked racism to increased risks of diabetes, hypertension, accelerated aging, asthma, and most recently, heart disease.

### Social Structures Determining Health

A close look at racial disparities reveals another major predictor of poor health among Black women: zip code.

Historically racist policies, such as slavery and redlining, have led to decades of neighborhood disinvestment in Black communities, which translates to fewer parks, fewer supermarkets with fresh and affordable foods, and higher levels of crime and air pollution. Regardless of their income or education level, Black women are still more likely

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to live in disadvantaged neighborhoods compared to white women.

“We’ve come to realize how much one’s neighborhood environment and social structures, rather than genes, prescribe health outcomes,” says Cozier, an early BWHS investigator who now coleads the study. She studies how psychosocial stressors—from divorce and job pressure to assault and natural disasters—influence the development of autoimmune and immune-mediated diseases, such as the difficult-to-diagnose sarcoidosis, which can affect the lungs, skin, kidneys, muscles, nervous system, and other organs.

“We all have the same genes, but those genes are expressed differently across different groups of people, particularly in hyperstressful or low-resource environments,” Cozier says.

Participant Simona L. Brickers, who lives in Trenton, N.J., observes this disparity in housing time and time again as an organizational leadership and development consultant who has guided government and nonprofit organizations in developing antiracist community initiatives.

“When I travel to other states, I can tell automatically which areas are deemed less desirable, and they are the Black communities,” Brickers says. Participating in BWHS has made her “more aware, more vigilant, and more proactive” about her health.

Black women who live in low-socioeconomic status neighborhoods are more likely to develop a number of conditions, including an aggressive subtype of breast cancer called estrogen receptor-negative (ER–), which has been the focus of some of BWHS’ most prominent research.

In 2014, Palmer led a landmark study that revealed Black women who have more than one child, but who

never breastfed, were more likely to develop ER– breast cancer, and this risk increased with each additional birth.

The findings debunk the common belief that only women who do not have children are at increased risk of developing breast cancer. This risk is only true for ER+ (estrogen receptor-positive) diagnoses, which are seen at higher rates in white women compared to Black women.

Kimberly Bertrand (SPH’05), a BWHS leader and a Chobanian & Avedisian School of Medicine associate professor of medicine, led a subsequent study that reinforced these results and showed a similar increase in risk for women who had their first child at older ages and had greater abdominal fat.

“We still don’t know why having babies without breastfeeding may cause this increased risk of breast cancer, but we can rule out genetics as the main cause,” Palmer says. “It is likely a combination of stressors that raise inflammation in the body, as well as some biological differences.”

And not everyone has the same opportunities to breastfeed, Bertrand notes. From lack of maternity leave to insufficient time or space to pump breast milk at work, she says, “it’s not always an individual choice of whether a woman can breastfeed.”

### Breast Cancer Risk Prediction

When breast cancer is identified quickly, treatment can be very effective. So, knowing an individual’s risk can inform appropriate screening plans. But traditional breast cancer risk prediction tools were only designed based on data from white women.

That changed in 2021, when Palmer led another pivotal study that developed and evaluated a breast cancer risk prediction model specifically geared toward Black women.

“So many young Black women are dying of breast cancer in their thirties and forties, in part because they didn’t know about it until it was too late for the treatments to be successful,” Palmer says.

The newer tool, designed as a questionnaire, is more effective than previous models, and it works best for women under 40. Clinicians and individuals can input information about a woman’s personal and family medical and reproductive history to calculate



The studies published by BWHS fill a significant void in research. The lead investigators are Kimberly Bertrand (far left), Julie Palmer (second from left), and Yvette Cozier (far right). Palmer and Lynn Rosenberg (second from right) are cofounders of the study.

the five-year risk for developing breast cancer. The tool is accessible on the Slone website ([bu.edu/slone](http://bu.edu/slone)).

Bertrand hopes to enhance the tool with data from a major study in progress to examine whether mammographic density (dense breast tissue) and other features on mammograms are useful predictors of breast cancer.

“There is well-established evidence that having denser tissue is a predictor of future breast cancer risk,” she says. “If we can more precisely quantify these associations in the Black population, we can help women make well-informed decisions about how frequently they want to screen, whether they need supplemental screening, or whether they’re eligible for clinical trial enrollment.”

### The Work Continues

Nearly 30 years after the launch of the study, the team’s work is far from over. Researchers are continuing to assess the short- and long-term effects of the COVID-19 pandemic on Black women. Early analyses suggest that vitamin D insufficiency in Black women may increase their risk of severe COVID infection and mortality. But there is

much more to learn about the health and economic burdens of the pandemic on Black women, who are more likely than other groups to be frontline workers, and lack paid sick leave and adequate healthcare.

BWHS is also focusing more heavily on aging and cancer survivorship, as well as the role of faith and spirituality on health. The average age of participants is now 65, so the researchers expect more participants to develop cancers, heart disease, and cognitive decline.

Rosenberg has launched a study to investigate the effects of structural racism on Alzheimer’s disease and related dementias, building upon a

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2020 analysis that she and Coogan published indicating that racial discrimination may spur cognitive decline in Black women.

“Statistics show that Black women have a higher rate than white women of developing this disease, but we don’t know why,” Rosenberg says. “We hope to gain a better understanding of the factors that can lead to healthier aging.”

The team is also turning more attention to stroke and cardiovascular disease in research led by BWHS investigator Shanshan Sheehy, a Chobanian & Avedisian School of Medicine assistant professor of medicine. Sheehy has observed an elevated risk of stroke among participants who had a history of preeclampsia, a common and severe hypertension-related pregnancy complication, particularly in Black women.

“These findings show that we need to increase awareness of pregnancy complications as a risk factor for stroke,” says Sheehy, who is also exploring whether moderately common genetic mutations only observed among individuals of recent African ancestry increase the risk of preeclampsia among Black women. “Even 20 years after delivery, the risk of stroke may still be high.”

The researchers credit the success of BWHS to the dedicated participants who are still involved. Some have passed away or stopped responding, but 40,000 women continue to share updates about their health.

“Our work would not be possible without their contributions,” Cozier says. “I hope they feel more vested and more seen as we work to understand with them the health issues that they experience.”

Coyne says vital time was lost for her mother to receive adequate hypertensive care, but she hopes the study’s persistence will help prevent other Black women and their families from having a similar experience.

“I feel really passionate about this study, and I’m honored to remain a part of it,” she says. “To see people dying in their thirties and forties from preventable deaths—it just shouldn’t happen. I hope people understand the importance of this work and how it will not only help Black women today, but for generations to come.” ■