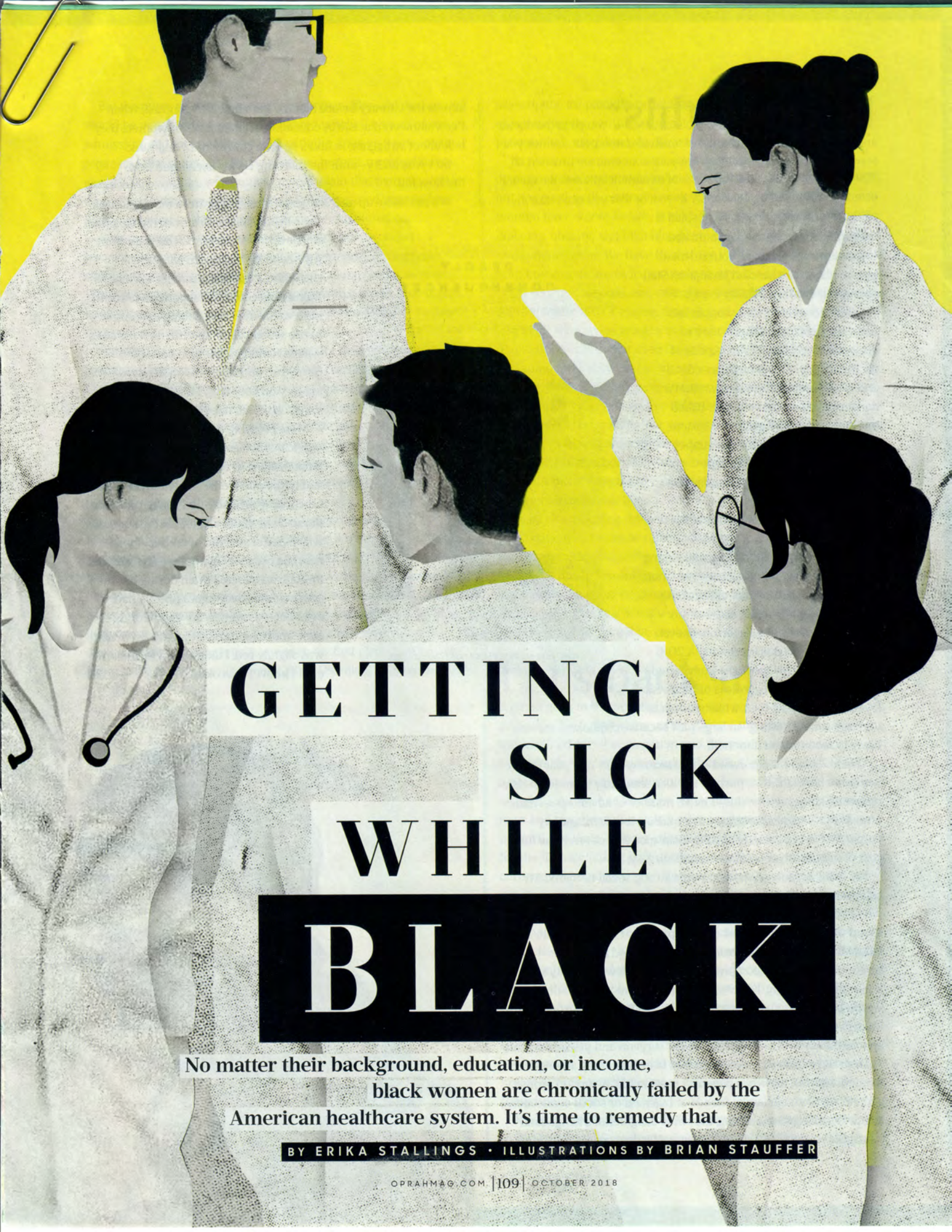


GETTING SICK WHILE BLACK

No matter their background, education, or income, black women are chronically failed by the American healthcare system. It's time to remedy that.

BY ERIKA STALLINGS • ILLUSTRATIONS BY BRIAN STAUFFER

Imagine this: You go to the doctor and routinely feel unseen, unheard, misunderstood. Sometimes you fear you've been misdiagnosed. But your concerns are brushed off. You aren't apprised of the full range of treatment options—the doctor seems to assume they don't apply to you, or that you can't take in all the information. Your local hospital is underfunded, the equipment outdated, frequently nonfunctional. You're denied pain meds. You're handled brusquely. Staff openly question your ability to pay.

While not every black woman has had experiences like these, they're disappointingly familiar to legions of us. Indeed, there is enough anecdotal and factual evidence to suggest that a dangerous color-based bias is baked into the American healthcare system, affecting even well-educated, upper-middle-class patients—the type you might expect to be immune from such inequity.

Several years ago, I was one of those patients. In June 2014, at age 29, I underwent genetic counseling and testing and learned I had a BRCA2 gene mutation, an inherited condition that elevates the risk of developing breast and ovarian cancer. It turns out I was fortunate even to have access to this screening: A 2016 *Journal of Clinical Oncology* study found that black women, regardless of their risk level, are less likely than white women to undergo genetic testing—in large part because physicians are less likely to recommend it to them.

When I opted for a preventive mastectomy later that year (black women who test BRCA-positive are also less likely to undergo risk-reduction surgeries like this), I had a number of advantages. At the time, I was a litigation attorney at a midsize law firm, and my employer offered excellent health insurance that covered the full cost of my pre-op appointments and surgery.

My main advantage, though, was a strong social network. My college roommate happened to be married to a cancer researcher, who had given me a list of questions to bring to appointments. A friend who sits on the board of a nonprofit had referred me to a fellow board member, who, fortuitously, headed the cancer screening and prevention program at one of New York City's top hospitals. Amazingly, I'd gotten an appointment with this doctor within one week of emailing her to ask about genetic testing. Once I received my diagnosis, she helped me identify, and schedule appointments with, a respected breast surgeon and plastic surgeon.

This kind of access, I would come to learn, is a rarity among black women. Many of the white patients I meet in BRCA support groups got referrals through family friends or business or social connections; at one support-group meeting, the white daughter of a hedge fund manager recounted interviewing several leading oncologists from across the country before making her choice. In contrast, when I've volunteered at BRCA education events for black women, they talk about struggling to find a genetic counselor of *any* rank.

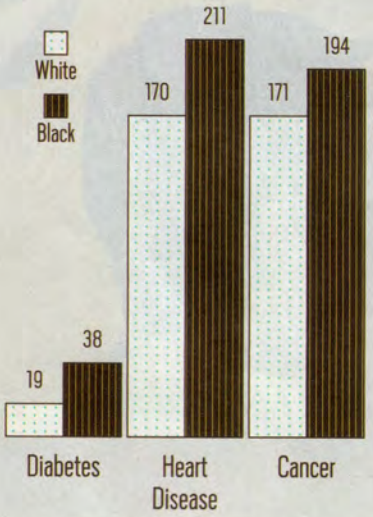
So I was lucky—until the morning I was discharged from the hospital.

When I woke up after surgery, I was groggy from the anesthesia and slightly disoriented from the weight of my new breast implants. The walk from my bed to the bathroom felt like a marathon. I asked my mother to call a friend who could accompany us home in case we needed help getting up the stairs to my second-floor apartment. A nurse—a white woman probably in her 40s—overheard and said, "You didn't have surgery on your legs. I don't understand why you would need assistance."

More pressing was the matter of my surgical drains, installed postmastectomy on both sides of my chest to collect blood and lymphatic fluids. The left drain wasn't functioning properly, so I asked the same nurse if she could call one of the surgeons who'd performed the operation. I was nervous because my mother had suffered through an infected drain during her own mastectomy seven years prior; it had even been written in my chart during early-morning rounds that my left breast was slightly red. I didn't want to go home until I knew I was okay.

DEADLY CONSEQUENCES

Age-adjusted mortality rates (per 100,000) for three leading killers in the U.S.



YEAR: 2014. SOURCE: KAISER FAMILY FOUNDATION.

But the nurse refused to contact the surgeon. She said the hospital would be penalized if I wasn't discharged within 24 hours of my admission, and that I'd have to deal with the drain as it was. Again, I requested that someone call my surgeon. Instead, a second nurse, also a white woman, was brought in to explain that there was no time—I needed to be out of the room. Which seemed strange for a highly regarded facility known for its patient-centered care.

After an extended back-and-forth involving the two nurses, a hospital administrator, my mother, and two friends I'd summoned for support, one of the nurses finally agreed to call my plastic surgeon. When she came to inspect the drain, she saw that the incision wasn't large enough to create a proper flow. After a five-minute fix, I was on my way with two functioning drains.

Although I can't prove that the treatment I received was racially motivated, I can say that the experience is consistent with what I hear from other black women. And it is markedly different from what I see on Facebook support groups for those dealing with BRCA mutations—an overwhelmingly white cohort. For instance: "I've met so many amazing nurses. I plan to track down the nurse who was there for me the first day after my mastectomy.... I want to send her flowers." I have never come across a white woman posting a story anything like mine.

In the past year, we've learned how dangerous it can be to give birth in this country if you're black: how we are three to four times more likely to die from pregnancy- or childbirth-related causes than white women, how black babies are twice as likely to die as white babies. In fact, from cradle to grave, a black woman in the U.S. can expect to have worse health outcomes than a white woman. She is 40 percent more likely to die from breast cancer—even though she's less likely to have breast cancer in the first place. She's more likely to die from cancer in general. She's less likely to receive a prescription for painkillers from an ER physician, even when experiencing the same level of pain and symptoms as a white patient. She's more likely to die at a younger age of heart disease.

To make matters more dire, and far more complicated, the disparities don't exist only in health outcomes—in how things turn out, for good or ill, once you seek medical treatment. Black women have worse *health*, period. We're more likely to live with diabetes, obesity, and high blood pressure. More likely to live with major depression. We have double the risk for stroke and, along with black men, are twice as likely to develop Alzheimer's.

Do genetics, income, and education level play a role in these stark differences? Of course. Does it matter that black women are less likely than white women to have health insurance? Without a doubt. But consider that even these factors are highly influenced and compounded by (and in some cases due to) racial injustices. And consider that black women fare worse not just when it comes to a few particular diseases or disorders, but across a wide spectrum. Then consider that the mortality rate for babies born to black women with a doctorate or professional degree is *higher* than the rate for babies born to white women who never finished high school. A picture begins to emerge of forces at once bigger, deeper, and more insidious at play.

To be clear: Getting the best results out of the American healthcare system can be difficult for anyone. Between byzantine insurance rules, the profits-over-people M.O. of corporatized care, and variations in resources and access depending on where you live, all patients must be proactive, informed, assertive, at times aggressive. If you're a black woman, you'd just better be more so. And even that might not be enough.

Let's back up, to before a woman goes to the hospital, before she even gets sick. Let's go back 60, 80, 100 years, to the days of Jim Crow. The laws that codified racial segregation and discrimination took a measurable toll on black people's health. Nancy Krieger, PhD, a professor of social epidemiology at Harvard T.H. Chan School of Public Health, has found an association between Jim Crow laws and premature mortality rates for African Americans born under those laws. Krieger cites a variety of potential reasons for the link, including lack of access to adequate medical care, excess exposure to environmental hazards, economic deprivation, and the psychological toll of dealing with racism as a part of daily life.

Though Jim Crow laws were abolished in the mid-1960s, their effects endure. Krieger says, "My research shows they're still being reckoned with in the bodies of people who lived through that time." She's not speaking metaphorically. On the contrary, America's version of apartheid appears to have left its mark on a cellular level: Black women born before 1965 in Jim Crow states are to this day more likely than those born at the same time in other states to have estrogen-receptor negative breast tumors, which are more aggressive and less responsive to traditional chemotherapy.

Krieger's findings align with the theory of "weathering," proposed in 1992 by Arline Geronimus, now a research professor at the

University of Michigan's Population Studies Center. The idea is that over time, the toxic stress of dealing with discrimination (stress that has been found to result in increased cortisol levels and inflammation) leads to poorer health outcomes—as well as premature aging, since it can literally shorten our telomeres, the protective caps at the end of each of our chromosomes. In a study published in 2010 by Geronimus and others, black women between the ages of 49 and 55 were an estimated *seven and a half years older,* biologically, than their white counterparts. In other words, just as a house continually battered by storms will eventually list, sag, and crumble, the health of black people in America is corroded by the relentless assaults of racism.

Location, location, location.

That's the mantra of David R. Williams, PhD, a Harvard professor of public health, sociology, and African and African American Studies, whose research focuses on social determinants of health. Williams is convinced that de facto segregation—today some 48 percent of African Americans live in neighborhoods that are primarily black—is a key driver of health inequities. "In the United States, your zip code is a stronger predictor of your health than your genetic code," Williams says.

Why? For starters, communities of color are more likely to be located in areas with higher levels of air pollution, which means the people who live in those communities are regularly breathing in higher levels of particulate matter, dangerous particles that can lead to respiratory issues, lung cancer, and heart disease. In addition, research shows that black neighborhoods—defined as including 60 percent or more black residents—have the fewest supermarkets, and therefore less access to fresh produce and lean proteins. Black neighborhoods are also more likely to lack a local primary care physician (the odds of a shortage of such doctors are 67 percent higher) and may have a dearth of medical specialists (a 2009 study showed that more African Americans living in a county correlated with fewer colorectal surgeons, gastroenterologists, and radiation oncologists).

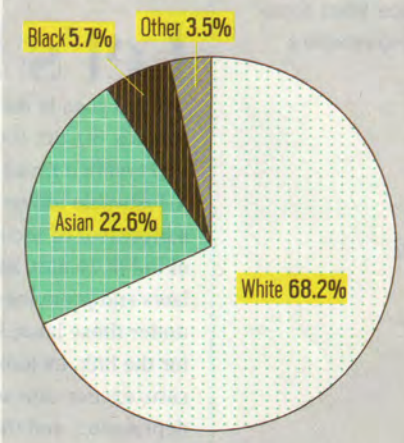
Researchers have also identified a connection between racial segregation and the quality of care a patient receives: A black person who lives in a segregated community and undergoes surgery is more likely to do so at a hospital with higher mortality rates; facilities in such communities are often lacking in resources compared with those in primarily white areas.

LaToya Williams, 41, lives in a Brooklyn neighborhood where roughly 60 percent of residents are African American. "I like living here," she says. "I own my home. And the neighborhood has a suburban feel that's hard to find in the city." Williams, now a senior manager for primary care systems at the American Cancer Society, found a pea-size lump in her breast in January 2007. The local surgeon she visited ordered a sonogram, but then, Williams says, dismissed the lump as fatty tissue. Seven months later, it was the size of a walnut. Alarmed, Williams pushed for a lumpectomy, which led to a diagnosis of stage III invasive ductal carcinoma.

Williams was to start chemotherapy immediately, which meant she needed a port implanted below her collarbone to receive medications and IV fluids and have blood drawn for tests. The procedure was done at a Brooklyn hospital, by her surgeon. Williams recalls waking up afterward and telling her doctor she couldn't breathe. "He said that was a normal reaction after surgery," she recalls. Thirty minutes later, she was still gasping for air. Her mother was able to flag down a different doctor, who immediately inserted an emergency chest tube to help Williams draw breath. An X-ray revealed that her lung had been punctured during the port installation. This meant two weeks in the hospital for what is normally an outpatient procedure, as well as a frightening delay in starting chemo. When Williams finally did begin treatment, it was revealed that the port had been installed incorrectly, and a new one had to be put in her arm.

DOC, DOC, WHO'S THERE?

Breaking down the race and ethnicity of U.S. physicians and surgeons.



YEAR: 2016. SOURCE: DATA USA.

Williams's treatment plan also included radiation. The hospital where she was getting chemo didn't accept her insurance for the treatment, so she turned to another one nearby (one that was recently given a D rating by the Leapfrog Group, a nonprofit that analyzes hospital performance). There was no direct subway line between her office and the hospital, so Monday through Friday, Williams had to make the 35- to 40-minute drive after work. However, on several occasions she arrived at the hospital only to learn that the radiation machine was broken and she wouldn't be able to get treatment that day. As a result, Williams says, her radiation regimen, which was supposed to be completed in eight weeks, took closer to ten. "That's the last thing you need when you're already scared for your life," she says.

In 2010, Williams shared her story at an alumnae meeting of her college sorority (Alpha Kappa Alpha, America's first black Greek-letter organization for women). Afterward, another member, Kathie-Ann Joseph, MD, a breast surgeon affiliated with NYU Langone Health, introduced herself and told Williams about her work. (Joseph also co-heads the Beatrice W. Welters Health Outreach and Navigation Program at NYU Langone's Perlmutter Cancer Center, which provides access to breast cancer screening, treatment, and support for women in medically underserved communities.)

Over time, the two women became friendly, and Williams warmed to the idea of meeting with a colleague of Joseph's to talk about breast reconstruction, which she underwent in 2012. On her first visit to NYU Langone's midtown Manhattan hospital, the contrast was dramatic: a lobby with the lush-plants-and-sparkling-glass vibe of a posh corporate office, cafés with healthy food choices, helpful security guards "who didn't treat you like a criminal for simply asking questions," nurses who tended to Williams courteously and promptly, and "much nicer gowns." She resolved that the next time she sought medical treatment, it wouldn't be in Brooklyn. "I'll probably never go to a hospital near me again," she says. "Which is a shame. Everyone deserves to have good medical care in their own community."

The personal touch matters.

But because research, new lifesaving therapies, and affordable coverage grab headlines, the *care* in healthcare is often discounted. "People discussing health disparities typically focus on access to insurance, but even in Massachusetts, a state that has universal coverage, African Americans still have poorer health outcomes—which shows that access to insurance isn't enough," says Karen Winkfield, MD, PhD, a radiation oncologist and associate director for Cancer Health Equity at Wake Forest Baptist Health in Winston-Salem, North Carolina. "The question is whether people feel welcome and listened to." If a black patient, who may already have some skepticism about the medical system, encounters a rude receptionist or a dismissive nurse, Winkfield explains, she is less likely to want to engage.

Yet behavior needn't be overtly hostile to be harmful. In a 2016 study, researchers videotaped interactions between nonblack oncologists and their black patients at cancer hospitals in Detroit, then asked each doctor to complete the Implicit Association Test, the most widely used measure of implicit bias. The findings: Oncologists whose tests showed greater bias had shorter interactions with their black patients, and their patients rated the interactions as less supportive and had less confidence in the recommended treatments.

Even more troubling is when physicians make judgment calls rooted in racial stereotypes. When researchers at the University of Virginia investigated why so many black Americans are undertreated for pain, they found that a significant number of medical students and residents held wildly erroneous beliefs about biological differences between black and white people (e.g., that black people's nerve endings are less sensitive, or that their skin is literally thicker).

"With any doctor, there's already an imbalance of power because you're vulnerable, and you have to trust this person," says Holly Spurlock Martin, a developmental psychologist in Upper Marlborough, Maryland. "But if you're black and your doctor isn't, there's an extra layer of concern. So when you find a good black doctor, you think, *I found gold.*" That's just how precious, and rare, it can be: Only 5.7 percent of all physicians practicing in the U.S. are African American, out of a population that is over 13 percent black.

"I definitely trust white male doctors less—and to be honest, I trust white female doctors less, as well—unless they come recommended by a person of color," says Lisa, 35, a vice president and senior counsel at a major financial services firm. "I'm also very active in my care and push back on doctors. I make them explain everything, and then I throw in my two cents. That always surprises them. I feel like I then get put in the 'educated' category, at which point either they start to respect me and take the time to explain things to me, or they get pissed off because they think I'm challenging their intelligence."

Many black women are experts in broadcasting the signs and signifiers of education and success in the interest of receiving better medical care. "From an early age, my mother always made me 'dress up' to go to the doctor," says Chelsie White, 29, who works as a senior technical associate at a social science research firm and

holds a master's degree in health policy and administration. "I'm almost 30 years old, and I still wear business casual to doctor appointments. I also go out of my way to mention something about my education and professional achievements. I've found that when I'm seen as being accomplished, I get more time, attention, and detailed information."

But the perception of being accomplished can be a double-edged sword, as Diamond Sharp, 29, discovered nearly a decade ago. In her senior year at a Seven Sisters college, Sharp started to feel that something wasn't right: She no longer had the desire or energy to hang out with friends, and started canceling plans and holing up in her room. "I was spending a lot of time in the dorm crying myself to sleep, which I knew wasn't normal," she says. After a few weeks, worried that she might have clinical depression, Sharp made an appointment with a school-provided counselor. In their initial session, Sharp brought up the crying, the loneliness, the stress of her "pressure cooker" school. The counselor, a nonblack person of color, sat back, asked about Sharp's academic life and campus activities, and pronounced that there was no way she could be suffering from depression. "She told me I got good grades, I was in student government, I was well dressed and put together—so I couldn't be depressed."

It would take two years, another therapist, a prescription for Prozac, and a psychiatric hospitalization before Sharp learned what was actually going on: She had bipolar II disorder. Two years after the diagnosis, she checked herself in to a hospital again. It was a different hospital this time. Which meant starting over with different doctors. And so, as she packed a small bag before going, she took care to place her college sweatshirt just so, with the logo clearly visible, in the hope that the new attending physician would take her seriously and treat her well.

It should be noted that Sharp was exceptionally proactive about her health: Between 2008 and 2012, only 8.6 percent of black Americans saw a therapist, took prescription psychiatric medication, or used another kind of mental health service, compared with 16.6 percent of white Americans, according to the most recent findings from the federal Substance Abuse and Mental Health Services Administration. Many factors are involved here, including cultural stigma about airing private problems outside the family, the tradition of turning to religion to cope, lack of access and insurance—and also, importantly, wariness of being treated by a white mental health professional. (Only about 5 percent of practicing psychologists in America are black.)

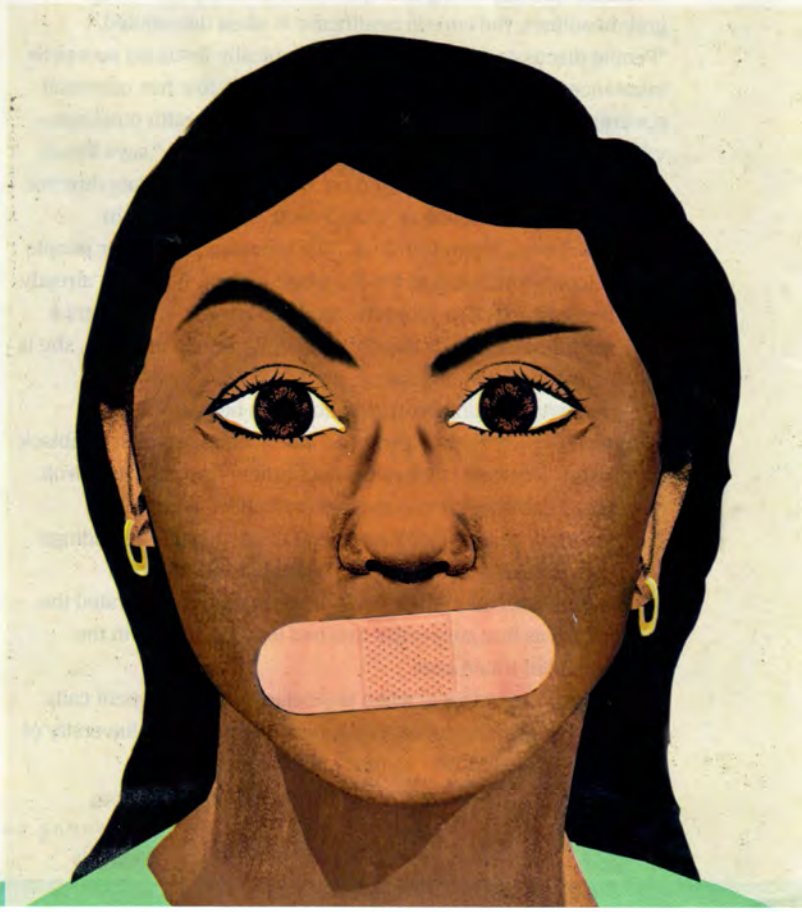
"Research shows that African Americans are more reluctant to use mental health services due to skepticism about what might happen during the appointment," says Suzette L. Speight, PhD, an associate professor of psychology at the University of Akron in Ohio, who studies mental health and African American women. "They're wondering, *Will I be treated well? Will I be able to talk about race? Will I be understood?*" (Meanwhile, any delay in seeking treatment, says Speight, may compound the original mental health issue.)

"A psychologist treating black patients has to have a world view that recognizes sociocultural causes of distress and mental illness," says Speight. For example, she explains, with a black woman who works in upper management at a large corporation and presents with anxiety symptoms such as self-consciousness, shakiness, headaches, or difficulty falling or staying asleep, "it would probably be important to ask how her race and gender 'show up' at her job: 'What's it like being a black woman in your workplace?' A psychologist who doesn't understand how gendered racism works, especially in its subtle forms, could easily minimize this woman's concerns or attribute them to low self-esteem or a lack of self-confidence—internal explanations for psychological distress that do not account for external or environmental factors." Adds Speight, "The psychologist must be willing to raise the question of racism and sexism because the client might not bring it up."

Black women were dying

from childbirth: That was the story in the news in early 2017, when Whitney, a PhD candidate at an elite university, was newly pregnant with her first child. But she reassured herself that Massachusetts, where she lived, had one of the lowest maternal mortality rates in the U.S.

In her last trimester, however, Whitney grew worried when she experienced severe acid reflux and an elevated heart rate. The staff at her group medical practice waved away her concerns and told her to focus on managing her high blood pressure, but when she eventually went into labor, her heart rate shot up still higher and didn't return to normal even after she gave birth. As Whitney lay in the recovery room, she had trouble breathing. The medical staff, believing she might have a blood clot, ordered two CT scans. Both came back negative, so though she remained short of breath, Whitney was discharged.



The following day, she went to her primary care physician and requested a full cardiac workup; she also asked whether she might have peripartum cardiomyopathy (PPCM), a form of heart failure associated with pregnancy (being of African American descent is a known risk factor). Upon seeing the results of the EKG and blood work, the doctor said her heart wasn't the problem. A nurse practitioner said it seemed like anxiety and suggested that Whitney take Zoloft. But the next evening, Whitney's blood pressure spiked to 170/102. At the ER, tests revealed an enlarged heart. Again she asked: Could it be PPCM? No, said the cardiologist, who diagnosed postpartum preeclampsia (a very serious condition, to be sure, but not one that rules out PPCM; in fact, the conditions often overlap) and prescribed beta-blockers. At her six-week postdelivery checkup, the nurse practitioner repeated that her persistent symptoms and chest pain could be due to anxiety.

Around the same time, Whitney's cardiologist reduced her beta-blocker dosage by half; Whitney felt intense pain almost immediately. An echogram showed that her heart, though no longer enlarged, still wasn't pumping properly. She asked her doctor whether the pain could be related to the change in medication. "He told me, 'I don't understand why you're still asking questions,'" she says. "'You should be happy your heart is back to normal size. The reality is you're a female black, so you probably just have hypertension.'"

Whitney panicked. "I was starting to think I might not be around to raise my daughter," she says. Finally, she discovered a PPCM Facebook group, through which she connected with James Fett, MD, a cardiologist and leading PPCM researcher, who referred her to a nearby colleague. Whitney contacted the doctor using her university email; he responded right away. Roughly 12 weeks after her initial inquiry, tests confirmed that yes, she had PPCM.

Whitney's attentive new cardiologist effectively treated her condition. And when the dust settled, she began seeing a therapist to help her process the experience. "The way the doctors and nurses brushed off my concerns made me feel so degraded," she says. "My husband and I would like to have more children, but I don't know if I would risk my body again like that. I really don't feel like healthcare institutions are set up to protect women of color."

"You were brave,"

people say when I tell the story of my surgery discharge and what I had to do to stand up for myself. But I didn't feel brave in the moment, and I still don't. I was simply trying to survive. That's the reality of being a black woman dealing with this country's healthcare system. Too often, we have to go an extra mile—*many* extra miles—just to ensure we get the baseline level of treatment to which everyone is entitled. And all the while, we have to ask ourselves: *Was I mistreated because of my race?*

It's an exhausting business—and scary, considering that our health is at stake. I think about the Toni Morrison quote: "The function, the very serious function of racism...is distraction. It keeps you from doing your work." After an illness or a medical condition lands us in a doctor's office or a hospital, our work, our focus, should be healing. Not fighting the systemic mistreatment that threatens our very lives.

DOING BETTER

Three promising initiatives are pointing the way to healthier healthcare.

EVERY BODY COUNTS

Historically, health research has focused on white men. To build a more representative database, the National Institutes of Health recently launched the All of Us research program (joinallofus.org). Born out of Barack Obama's 2015 Precision Medicine Initiative, the project aims to gather lifestyle and health information from at least a million Americans, especially those from underrepresented communities. As of May 2018, more than 25,000 people had enrolled, and their data could inform thousands of future studies. For protection and privacy, the information All of Us shares with researchers is stripped of identifiers like names and Social Security numbers; researchers must also complete ethics training and sign a contract pledging responsible data use. Says Dara Richardson-Heron, MD, chief engagement officer of All of Us: "The only way we can have a better understanding of how to best serve underrepresented groups is for those groups to participate in research." *—Katherine Pittman*

WINNING HEARTS AND MINDS

Although 65 percent of white women in a 2012 survey knew that cardiovascular disease (CVD) was their most serious health threat, only 36 percent of black women did—even though the prevalence of CVD is significantly higher among African American women (about 48 percent) than non-Hispanic white women (about 35 percent). In response, the American Heart Association (AHA) stepped up its efforts to reach black women: It enlisted Star Jones and other women of color to discuss in the media and at events how CVD has affected them; joined forces with faith-based groups (for example, creating a heart-healthy litany that can be included in religious services); and partnered with black sororities to raise awareness. To leverage the power of word of mouth, the AHA also provides volunteer ambassadors with info on lowering risk factors to share with their communities. The goal is to decrease deaths of *all* women from heart disease and stroke by 20 percent by 2020. Key to reaching this goal, the organization knows, is speaking directly to women of color. *—Corrie Pikul*

PHYSICIAN, HEAL THYSELF

At UC San Francisco School of Medicine, students are learning that being an excellent doctor also means being a socially just one. All first-year students attend two full-day workshops about unconscious bias, microaggressions, and privilege. Through role playing and small-group discussions, they find ways to mitigate stereotypes that disadvantage women, people of color, and LGBTQ patients. As part of the school's Differences Matter Initiative, there are also voluntary workshops for faculty and staff. "It's one thing to talk about what one *should* do and another to have faculty members actively working alongside students to eliminate disparities in healthcare," says Catherine Lucey, MD, the school's vice dean for education. The momentum has spread to the rest of the University of California system, which is considering implementing UCSF's inclusion programs at its other med schools. "Racial disparity in healthcare is a silent epidemic," says Lucey. "We need to educate the next generation of physicians to treat it." *—C.P.*