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In Focus: Reducing Racial Disparities in Health Care by Confronting Racism

September 27, 2018 | **Martha Hostetter** and **Sarah Klein**

Compared with whites, members of racial and ethnic minorities are less likely to receive preventive health services and often receive lower-quality care. They also have worse health outcomes for certain conditions. To combat these disparities, advocates say health care professionals must explicitly acknowledge that race and racism factor into health care. This issue of Transforming Care offers examples of health systems that are making efforts to identify implicit bias and structural racism in their organizations, and developing customized approaches to engaging and supporting patients to ameliorate their effects.

It's been 15 years since the publication of the Institute of Medicine's **Unequal Treatment** report, which synthesized a wide body of research demonstrating that U.S. racial and ethnic minorities are less likely to receive preventive medical treatments than whites and often receive lower-quality care. Most startling, the analysis found that even after taking into account income, neighborhood, comorbid illnesses, and health insurance type — factors typically invoked to explain racial disparities — health outcomes among blacks, in particular, were still worse than whites.

This research prompted the Institute of Medicine to add equity to a list of **aims for the U.S. health care system**, but efforts to ensure all Americans have equal opportunity to live long and healthy lives have been given less attention than have efforts to improve

health care quality or reduce costs. A recent Institute for Healthcare Improvement **white paper** called equity “the forgotten aim,” noting as did the 2010 Institute of Medicine report, **How Far Have We Come in Reducing Health Disparities?** how little progress has been made.

To reduce racial and ethnic health disparities, advocates say health care professionals must explicitly acknowledge that race and racism factor into health care. Less directed efforts to improve health outcomes, ones for instance that fail to consider the particular factors that may lead to worse outcomes for blacks, Hispanics, or other patients of color, may not lead to equal gains across groups — and in some cases may exacerbate racial health disparities.

Addressing social factors like unstable housing that can lead to poor health is important, but it’s also necessary to acknowledge past and present policies — redlining, eviction procedures, and disinvestment in low-income communities for example — that fuel housing instability. “As health care organizations, payers, and others focus on social determinants and population health, we have a responsibility to ask: To what degree are our approaches grounded in a framework that addresses structural racism and equity?” says Rishi Manchanda, M.D., president and CEO of Health Begins, a nonprofit that helps health care and community organizations address social determinants of health.¹ “If we can’t answer that question with rigor and candor, even our most innovative solutions might perpetuate inequity and illness, not prevent it.”

In this issue of *Transforming Care*, we consider the roles of implicit bias and structural racism in creating and perpetuating racial health disparities. **Implicit bias** refers to learned stereotypes and prejudices that operate automatically and unconsciously, while **structural racism** takes into account the many ways societies foster racial discrimination through housing, education, employment, media, health care, criminal justice, and other systems. We focus on these factors more than **interpersonal racism**, or negative feelings or prejudices that play out between individuals, because while the latter is important the former are more likely to be undetected or unacknowledged factors. We offer examples of health systems that are making deliberate efforts to

identify how implicit bias and structural racism play a role in their work, and developing customized approaches to engaging and supporting patients to ameliorate their effects. Many are taking part in the Institute for Healthcare Improvement's **Pursuing Equity Initiative** or have been recognized by the American Hospital Association's **Equity of Care Awards**. Most of our examples relate to health disparities among black patients; we'll delve into health disparities among Hispanics in a future issue.

Addressing Racial Disparities in Cancer Treatment

Greensboro, N.C., is remembered as the site of one of the first "sit-ins" of the Civil Rights movement. In 1960, a group of black college students refused to leave a whites-only Woolworth's lunch counter, coming back day after day. The incident garnered widespread attention and prompted similar protests across the South. The city's role in desegregating health care is less well known. In 1962, George Simkins, Jr., a Greensboro dentist, and other black dentists, physicians, and patients filed a lawsuit claiming that federal support for the Moses H. Cone Memorial Hospital and Wesley Long Hospital, local institutions that served only white patients, was unconstitutional. (One of **Simkins' patients had an abscessed tooth** and needed surgery; Greensboro's black hospital didn't have space for him and the whites-only hospitals refused to treat him.) While the plaintiffs initially lost, they appealed, resulting in the Supreme Court decision, **Simkins v. Moses H. Cone Hospital**, that set in motion the desegregation of hospitals throughout the South.



Cone Health CEO Terry Akin shakes the hand of Alvin Blount, M.D., one of the plaintiffs in

the 1963 *Simkins v. Moses H. Cone Hospital* Supreme Court decision that — along with Medicare regulations, the Civil Rights Act, and other policies — desegregated hospitals in the South.

In 2003, a group of Greensboro community organizers invited researchers from the University of North Carolina School of Public Health to form the **Greensboro Health Disparities Collaborative**, an effort to understand and address the lingering effects of segregation. One of the group's first activities was to conduct focus groups among black and white members about their health care experiences. Many said they had experienced discrimination in a health care setting, with several stories relating to women's experiences with breast cancer treatment.

The group then conducted a study exploring how widespread such experiences were, and whether they affected breast cancer treatment outcomes. Community members helped develop the research questions, conduct interviews, and analyze the results. "This was an important piece of the collaborative," says Christina Yongue, M.P.H., coordinator of the **Greensboro Cancer Care and Racial Equity** study. "We made sure the community had full participation in every step of the research process. This was because of historical distrust among black Greensboro residents for Cone hospital, and because of more general distrust of clinical research going back to **Tuskegee**."

After this initial research, the collaborative sought to test whether customized supports could improve the experiences of black women undergoing treatment for early-stage breast cancer. They also examined the experiences of black men or women with early-stage lung cancer, in part to see whether black women's experiences with breast cancer treatment were related to their gender as much as race. The Greensboro Health Disparities Collaborative partnered with Cone Health's Wesley Long Cancer Center and the University of Pittsburgh Medical Center's Hillman Cancer Center in a project known as ACCURE (Accountability for Cancer Care Through Undoing Racism and Equity). Patients were randomly selected and invited to join the ACCURE study and then randomized into intervention and control groups. They found that at both cancer centers, black men and women with early-stage breast or lung cancer were less likely to

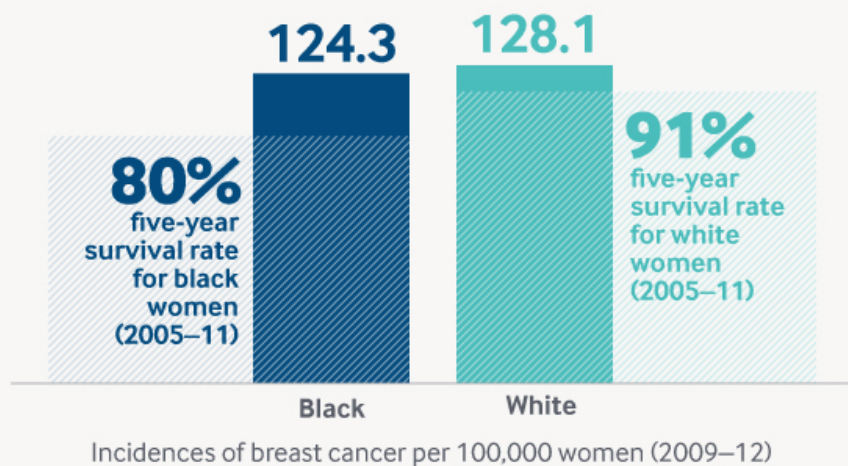
complete treatment than white patients (81% of black patients completed treatment, compared with 87% of white patients), even after taking into account patients' age, comorbid illnesses, health insurance, income, and marital status.

Disparities in the incidence of breast cancer mortality

The incidence of breast cancer is slightly lower among African American women than white women but mortality rates are worse.

During 2009–12, the incidence of breast cancer in black woman was 124.3 cases per 100,000 women compared to 128.1 for white women.

The five-year survival rate for breast cancer diagnosed in 2005–11 was 80% for black women and 91% for white women. The difference was attributed to both later stage detection and poorer stage-specific survival among black women.



Data: American Cancer Society, *Cancer Facts & Figures for African Americans 2016–2018* (ACS, 2016).

As a first step in addressing these disparities, all staff members at the two cancer centers were offered training from the **Racial Equity Institute**, which included sessions on racial disparities documented in the national cancer registry and the roles of racial bias and gatekeeping in health care. Staff and members of the collaborative also mapped out the steps of cancer treatment, from diagnosis through treatment and recovery, and then interviewed patients to understand points of breakdown. Several black women who had survived breast cancer said they had experienced poor treatment, including instances when physicians didn't take time to explain their diagnoses and options, front-desk staff who treated them with disrespect, and lack of support in dealing with complications. A real-time patient registry, including data stratified by patients' race, was created to track missed appointments and treatment milestones, and a physician champion shared clinical outcomes with his colleagues.

Specially trained ACCURE nurse navigators worked with patients to ensure they understood their treatment options and had financial and social supports. When a patient missed an appointment or treatment milestone (e.g., their first chemotherapy infusion), the navigator received an alert and reached out to investigate the reason and offer help with common problems, including financial concerns related to insurance approvals, juggling family schedules, or handling pain and other symptoms. Prior to this intervention, navigators would offer patients a notebook of resources, but typically not follow up unless patients made a request. “Someone would have to have a lot of health literacy to understand all of the things in the notebook and feel empowered enough to reach out,” says Yongue. “The model did not make it easy for a patient going through a traumatic experience.” The navigators worked with patients for up to three years, from diagnosis through treatment and recovery.

In some cases, the ACCURE navigator worked to overcome patients’ distrust, says Beth Smith, R.N., who serves as Cone Health Cancer Center’s patient navigation program manager. “I had a patient tell me that she heard there is a cure for cancer and they are keeping it from patients,” Smith says. “I talked with her about how her care team did not want to see her or any patient suffer and we’re here to do whatever is needed to care for her.”

After the ACCURE study, treatment completion rates increased among all patients, but they increased more among the intervention group, with 91 percent of black patients and 89 percent of white patients finishing their cancer treatment.

Promoting Cancer Screening Among Racial and Ethnic Minorities

Cone Health and other cancer care providers also have worked to address racial disparities in cancer outcomes by encouraging patients of color to obtain regular screenings. Minneapolis-based HealthPartners, which has been stratifying data on its patients’ experiences and outcomes by race and ethnicity for more than a dozen years,

found that rates of screening for colorectal cancer among minority patients lagged rates among white patients (in 2009, 43% of patients of color who were candidates for screening completed it vs. 69.2% of white patients).

Focus group research uncovered concerns among many minority patients about the invasiveness and inconvenience of the traditional colonoscopy. Over the years, HealthPartners has leveraged several different tools to try to decrease the gap, including adding decision support and proactively reaching out to patients. In August 2017, the health system sent a home colon cancer screen, known as FIT (fecal immunochemical test), to more than 3,000 patients of color.² They also encouraged physicians to avoid describing the traditional colonoscopy as the “gold standard” of screening because it implied FIT was inferior when the U.S. Preventive Services Task Force made no distinction. By the end of 2017, three months after this intervention began, an additional 757 more patients of color had been screened. Altogether, the gap in screening rates between white patients and patients of color narrowed significantly, from 77.7 percent for white patients to 70.1 percent for patients of color. HealthPartners hopes to continue building on this momentum and has plans for continued FIT mailings.

Kaiser Permanente has taken a similar approach to encouraging more patients of color to get screened for colorectal cancer; in 2009, screening rates among Latino members, in particular, lagged white members by 5 percentage points. After doing ethnographic research that suggested some racial and ethnic minorities were concerned about taking time off work for a colonoscopy and were more likely to respond to a message about treating cancer rather than finding it, Kaiser Permanente created **photo novellas** (animated comics using photographs) depicting Latino family members trying to convince their loved one to use FIT. This and other initiatives led to an increase in colorectal cancer screening among Latino patients from 65.7 percent in 2009 to 77.3 percent in 2018 (compared to 80% among whites).



Kaiser Permanente photo novella depicting Latino family members trying to convince their loved one to use FIT.

Improving Control of Chronic Conditions

Kaiser Permanente also has sought to improve control of chronic conditions among minority patients, which required a different approach, according to Winston Wong, M.D., the health system's medical director of community benefit and director of disparities improvement and quality initiatives. While something like cancer screening happens once every few years, chronic care management "requires a continuous care relationship that builds around issues of trust," he says.

Kaiser Permanente also has focused on disparities that have a high cost in terms of illness and death. For example, it has reduced the gap between white and black patients with controlled hypertension. “That was really important to us because it represents real morbidity, real mortality — people dying of strokes and heart attacks that could have been prevented if their blood pressure were controlled,” Wong says.

As part of the effort, which spanned eight regions, Kaiser Permanente’s clinicians sought to counter misconceptions reported by some black patients that dying from high blood pressure is “natural” by encouraging clinicians to be clear about the risks and dogged in their efforts to encourage patients to come in for treatment. It also has partnered with the American Heart Association on the national **Check. Change. Control.** campaign, which seeks to reduce disparities in blood pressure control by empowering people to monitor their own blood pressure and encouraging others in their networks to do so. In San Diego, for example, parishioners in 20 predominantly black churches were trained in how to monitor their blood pressure and coach others.

Between 2009 and 2017, Kaiser increased the percentage of African Americans whose hypertension was controlled from 75.3 percent to 89.6 percent, bringing the rate within 2.2 percentage points of the rate among white members.

Targeting Maternal Morbidity and Mortality

Serena Williams’s **postpartum complications** and the story of **Shalon Irving**, an epidemiologist at the Centers for Disease Control and Prevention who studied racial disparities in health care and died three weeks after giving birth from complications of high blood pressure, have focused attention on racial disparities in maternal mortality and morbidity (e.g., deaths or complications related to pregnancy and childbirth). Black mothers die from pregnancy-related complications at **three to four times the rate** of white women. And while maternal mortality has been dropping in Sub-Saharan Africa, rates **actually increased** in the United States from 2000 to 2014. **Socioeconomic status, education, and other factors** do not appear to protect black women from this risk, while factors including smoking, drug abuse, and obesity do not explain the differences.

A black woman is 22% more likely to die from heart disease than a white woman, 71% more likely to perish from cervical cancer, and 243% more likely to die from pregnancy- or childbirth-related causes.

**22%****71%****243%**

Data: Nina Martin and Renee Montagne, "Nothing Protects Black Women from Dying in Pregnancy and Childbirth," ProPublica, Dec. 17, 2017.

These findings have led some health care researchers to suggest that the experience of being a black woman in America is, itself, a risk factor — and that attention must be paid both to black women's **level of stress** throughout their lives and how they are treated by health care professionals. "There's often an assumption in the medical world that racial disparities are due to something genetic, when in fact it might be racism," says Neel Shah, M.D., assistant professor of obstetrics, gynecology, and reproductive biology at Harvard Medical School. "We're taught that racism is evil so it's hard to recognize that in ourselves. But the studies suggest, for example, that we believe black women less when they express symptoms, and we tend to undervalue their pain."

Some health systems and departments of health are working to address these disparities, often by offering women of color the support of doulas or more closely monitoring them after delivery, a point of vulnerability evident in a [report on maternal mortality reviews](#) in nine states that found pregnancy-related deaths occurred more commonly within 42 days of giving birth than during pregnancy.

In 2013, marriage and family therapist and midwife Aza Nedhari, M.S., founded [Mamatoto Village](#) (Mamatoto means “the connection between mother and baby” in Swahili) in Washington, D.C. Her goal was to create a custom model of support for women of color during their pregnancy, childbirth, and postpartum periods. Nedhari believes that typical doula training — a matter of a few days — is insufficient to address black women’s cultural needs or their comprehensive health needs. Instead, Mamatoto has adopted the community health worker (CHW) model, recruiting mothers from the neighborhoods Mamatoto serves and offering them two years of training, mentorship, and field work. The CHWs then specialize in one of three paths: 1) helping women with social problems (e.g., domestic violence or housing instability), 2) helping them initiate and sustain breastfeeding, or 3) helping them manage their health and wellness.

So far, four managed care organizations pay for their members to receive Mamatoto’s services. Last year, among 462 women served by the organization, 74 percent gave birth vaginally (compared with 69 percent of women nationally) and there were no infant or maternal losses. Ninety-two percent of women who received labor support attended their six-week postpartum appointment, and 89 percent were able to initiate breastfeeding (compared with 79 percent of women nationally). The average weight for newborns of mothers who received prenatal and labor support was 6.98 lbs. in 2017, compared with 6.07 lbs. for newborns of mothers who entered the program after giving birth. For more information about Mamatoto Village, [read our interview](#) with Nedhari.

The first obstacle we find is that organizations don’t have a shared definition of racism, so it is hard to even talk about it. If you think that racism is merely people saying mean things to each other and I think it is a system of advantage based on race it will be impossible to co-design any solutions together.

Abigail Ortiz, M.S.W., M.P.H.

director of community health programs, Southern Jamaica Plain Health Center

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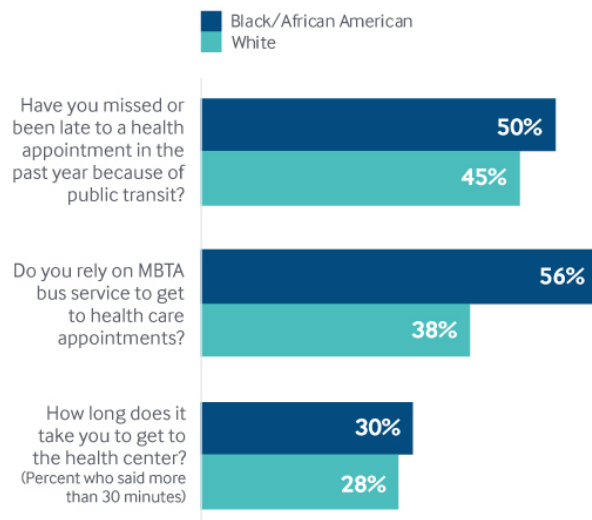
Liberation in the Exam Room

Ten years ago, Southern Jamaica Plain Health Center, a Boston primary care clinic associated with Brigham and Women's Hospital, launched an effort to understand why there were such stark health inequities between white youth and youth of color in their neighborhood. They noted how the obvious divisions — gentrified blocks with nice cafes and rehabbed housing occupied by mostly white, middle-class residents, and weedy blocks with deteriorated housing occupied by mostly black and Latino poor residents — affected their patients' health. This exploration, which included convening a group of white and black teens in a racial justice leadership project, led to a number of initiatives, including: offering training for its 100 staff, others at Brigham and Women's hospital, and community partners to understand the history and current impacts of racism; creating a shared glossary of terms related to racism and other forms of injustice; partnering with nonprofits; and advocating for policy changes to address the root causes of racial health inequities.

As described in the clinic's **Liberation in the Exam Room** toolkit, some clinicians at Southern Jamaica Plain and elsewhere in Boston are now piloting ways to ask patients about their racial and cultural identities, instead of making assumptions, and whether they have experienced racism in health care. "One of the techniques that we learned about early on from one of the residents is to say many of my patients have experienced the effects of racism in health care. Do you have any experiences to share along those lines?" says Juan Jaime De Zengotita, M.D., Southern Jamaica Plain's medical director. "Framing it as something that happened to other people might make others feel like they can speak up." As word spread to patients and other staff about this pilot, they began requesting visits with doctors who were participating. "I got a flood of e-mails from people of color asking for a list of the doctors," says Abigail Ortiz, M.S.W., M.P.H., director of community health programs.

Structural Racism, Transportation, and Missed Appointments

- 1** Many of Southern Jamaica Plain Health Center's patients who arrive late or miss appointments rely on the bus system to travel to the clinic. African-American patients face more challenges with transportation than others.



- 2** Compared with the better-funded commuter rail or subway system, Boston's buses are more crowded and less reliable.



Corbis Commuter Rail Coach



Red Line Park Street Station



Upham's Corner bus stop

- 3** The same Boston neighborhoods that were redlined in 1938 — where residents were denied home mortgages — are today served by buses.



- 4** How is Southern Jamaica Plain Health Center responding to help patients with transportation problems?

Building alliances with patients to let them know providers understand the transportation system is inadequate and unfair.



Finding temporary solutions -- e.g., hiring cabs or Lyft and helping patients apply to Medicaid for transportation benefits.



Advocating for policy changes to improve public transportation, using data showing the impact of unequal transportation on patients.



Linking patients to advocacy groups



Lessons

These examples illustrate the benefits of studying racial and ethnic differences in health care treatment and outcomes, conducting ethnographic research to get at the root causes, educating staff about the impacts of bias and structural racism, and making deliberate efforts to earn patients' trust. They also offer lessons about what it may take to go beyond these nascent steps and make the pursuit of health equity a common practice. These include:

Prioritizing the measurement of health disparities within institutions and among providers. Minnesota, which requires health care providers to track racial and ethnic disparities in treatment for a wide range of conditions, has encouraged this by publicly reporting performance on these metrics. The ***Health of Boston*** report, published by Boston Public Health Commission, highlights racial and ethnic disparities by neighborhood, an approach that offers actionable insights to providers interested in responding to local needs. But thus far many local and state governments, and the federal government, have not collected, published, or leveraged data on racial health disparities in ways that could prompt action.

Even without public reports, health systems can get a sense of disparities from their existing data. In a review, Moffitt Cancer Center in Tampa, Fla., discovered minorities were unrepresented not only in their clinical trials — a ***national phenomenon*** — but as patients. Interviews with Tampa residents revealed many hadn't realized they could call and ask for appointments. "They thought they had to be referred," says B. Lee Green, Ph.D., vice president of diversity, public relations, and strategic communications. "We have done a lot of community education since," leading to a mix of patients that is more representative of the community.

Building partnerships to enable patients to play a meaningful role in developing solutions. Many health care organizations partner with community advisory boards or collect patient-reported experiences and outcome measures to identify potential problems. Southern Jamaica Plain Health Center convened teen workshops to gain insights about the struggles they face, while Cone Health tapped cancer survivors' expertise to identify ways the health system didn't serve them. This work may lead to customized interventions rather than standardized protocols. "When we see disparities, particularly around clinical performance, we tend to think about amplifying methodologies that we use for the mainstream population and thinking that is going to produce better results," Wong says. "But what we are learning is to take some responsibility for understanding the differences among various groups in terms of their attitudes, their access to care, and relevant cultural issues and factor those in when we design quality initiatives."

Making racial equity a strategic priority. Efforts to reduce racial disparities must go beyond cultural competency or workforce diversity initiatives. At HealthPartners, “key equity measures are built into our scorecards, our health equity sponsor group meets regularly, and equity is a standing topic at every board of directors’ quality committee meeting. That has helped keep us on track,” say Brian Lloyd, who oversees HealthPartners’ equity initiatives. The health system has trained more than 170 “equitable care champions,” employees who go through training on implicit bias and cultural humility and then take responsibility for explaining the rationale for equity initiatives to colleagues. The health system also takes advantage of opportunities to facilitate open discussions about racial bias, as it did in July 2016 after Philando Castile, a local African American man, was shot by a police officer during a traffic stop.

In the end, advocates say, it’s important to realize that while racism is a large and multifaceted problem, there are concrete steps health care providers can and should take. “Because we are talking about structural racism — something that is such a broad and deep force in our society — it is tempting to say we are a small organization, what are we going to do about this? We don’t have the power to control national policy or address all these big forces,” says Tom Kieffer, executive director of Southern Jamaica Plain Health Clinic. “For us, it was important just to recognize that we can start small and be explicit about what we are trying to address.”

Next Article

¹ Health Begins recently hosted a webinar on “**Equity and Structural Racism: Challenges and Opportunities for Healthcare.**”

² Patients identified as speakers of Hmong, Oromo, Somali, Spanish, or Vietnamese received instructions and follow-up calls in their first language.

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Experts



**Martha
Hostetter**

Consulting Writer and

Editor



Sarah Klein

Consulting Writer and
Editor



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