



Special Report

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Race and health

Understanding and confronting the disparities

When Lisa Peyton-Caire's mother died of heart disease at the age of 64, she was devastated. After the wake and funeral, Peyton-Caire started to reflect on her mother's death.

"Left in that quiet period after, just trying to comprehend and adjust to this new reality, it just became very clear to me that it was a pattern of something that I'd experienced my entire life," Peyton-Caire says.

Growing up in the church and in her mother's hair salon, she had known too many women who lived with serious illness or passed away prematurely of heart attacks, strokes and cancer.

"I'd been to so many funerals ... These were women whose hair I'd just shampooed the week before who were 38, 42, 45, 50s, maybe in their 60s," Peyton-Caire says. "Women who had very little education, who were

working blue-collar jobs, all the way up to women who were university professors making six figures, and so many of them were getting sick."

She started making a list of the names of those who had died: Frances. Paulette. Hazel. Eva. Linda. Kimberly.

In total, her list had over 40 names.

"I remember just dropping the pen, I was crying, saying, 'Oh my God. My dear God, this is wrong. This is unacceptable, this can't be, this isn't supposed to be.'"

Peyton-Caire and all the women on her list have something in common: They are Black Americans. As such, they are at higher risk of an array of poor health outcomes.

For example, Black women have the highest heart disease and cancer death rates of women of any race in the U.S. These differences are known as health disparities.



Lisa Peyton-Caire and others celebrate the opening of the Black Women's Wellness Center in Madison, Wisconsin — home of The Foundation for Black Women's Wellness. Peyton-Caire started the organization and serves as CEO and president.

What are disparities?

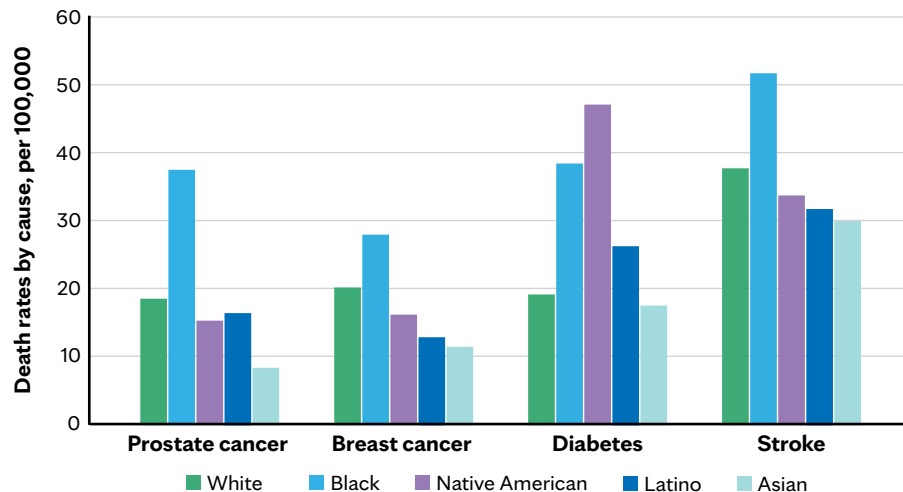
The Centers for Disease Control and Prevention has defined health disparities as differences that are avoidable and affect socially disadvantaged groups. People may be disadvantaged due to their gender, race, sexual orientation, geographic location, age group, disability status or other factors.

This special report will focus on health disparities between racial groups. Racial and ethnicity-related disparities — including those related to health care — are at the forefront of debate, thought and action in the U.S. and around the world. Compassion and problem-solving are needed in many areas of health care today, and highlighting issues related to race is an important part of this conversation.

When discussing disparities, defining them as differences that are avoidable is important to Chyke Doubeni, M.B.B.S., M.P.H., director of the Mayo Clinic Center for Health Equity and Community Engagement Research. This demonstrates that these disparities are due to structural barriers and social circumstances, not biological factors, and can be addressed and prevented.



Chyke Doubeni, M.B.B.S., M.P.H.



Rates of death due to many common diseases vary by racial category.

Source: Centers for Disease Control and Prevention

Peyton-Caire founded The Foundation for Black Women's Wellness in Madison, Wisconsin, for just that purpose. She serves as CEO and president of the nonprofit with a goal to advance the health and well-being of Black women and girls and to prevent others from experiencing the disparities she's witnessed. The organization provides education, advocacy and support services to over 5,000 people each year.

Many other nonprofits, activists, researchers and medical professionals throughout the nation also are combating racial health disparities. Below are just a few examples of these disparities in the U.S.

Diabetes

Black, Latino, Asian and Native Americans all have higher percentages of diagnosed diabetes than whites. Data from 2017 showed that Native Americans and Blacks were over twice as likely to die of diabetes compared with whites. Latino diabetes death rates were 40% higher than whites. Asians have the lowest diabetes death rates of any racial group.

Cancer

Looking at all cancers as a group, whites have the highest rates of cancer diagnoses, but Black Americans have

the highest cancer death rates. A few other disparities of note:

- Black men have the highest rates of new prostate cancers and prostate cancer deaths of any racial group.
- Black and Latina women have higher rates of cervical cancer diagnoses and death compared with white women, while Asian women fare better than white women.
- Alaska Natives have the highest rates of new cases and deaths from colorectal cancer. Both rates are about twice that of Black rates, which are the next highest.

Cardiovascular disease

In measure after measure of heart health, Black Americans fare worse than other racial groups. Blacks have higher rates of hypertension, peripheral arterial disease and death from stroke than whites — and the highest heart disease and death rates of any race. Latino, Asian and Native Americans all die of heart disease at lower rates than whites.

Why do disparities exist?

It's common to look at people with poor health and think, "If only they practiced these better health behaviors, if only they went to the doctor on time, if only they ate better food or were more physically active,

Racial disparities are nothing new, but the COVID-19 pandemic has brought them to the forefront of the public's consciousness.

According to the Centers for Disease Control and Prevention, Black, Latino and Native Americans have higher rates of COVID-19 cases and hospitalizations compared with white Americans, and they have higher death rates. As of October 2020, Native Americans had an age-adjusted hospitalization rate over four times higher than white Americans, and Black Americans had a COVID-19 death rate over twice that of whites.

There are many contributing factors to these disparate outcomes. Black, Latino and Native American people are less likely to have health insurance. Some groups of color are more likely to have various underlying health conditions — such as type 2 diabetes — that increase the risk of severe illness with COVID-19.

Many people of color have jobs that are considered essential and involve interaction with the public. According to 2018 Bureau of Labor Statistics data, almost one-quarter of employed Latino and Black Americans work in the service industry, compared with 16% of white workers. In addition, some groups of color more often live in multigenerational homes. These factors can make social distancing difficult.

Unfortunately, there's also concern that this pandemic is exacerbating existing disparities.

The social determinants of health can lead to health inequities, and COVID-19 illustrates that the opposite is

also true: Health inequities can feed into the social determinants of health. For example, COVID-19 is disproportionately killing Black, Latino and Native Americans. In some cases, this means the death of the family's breadwinner, potentially plummeting a family further into poverty, says Dr. Doubeni.

"We've got a vicious cycle," he says.

Peyton-Caire saw Black women in her community laid off and furloughed due to COVID-19. This led to an immediate increase in stress and economic instability.

"We saw a massive number of women who were contacting us, saying (things like) 'I need help, I lost my job. I'm unemployed. I can't pay my rent this month. I can't pay the light bill. I don't know how I'm going to keep the water on. I'm stressed. I'm going to break under all this pressure,'" Peyton-Caire says.

In an April 2020 national survey by the Pew Research Center, 61% of Latinos, 44% of Black Americans and 38% of white Americans reported a loss of a job or wages in their household as a result of the COVID-19 pandemic.

Dr. Doubeni hopes that health disparities remain in the public consciousness even after COVID-19 has faded away. He argues that the pandemic has shown us that ignoring disparities harms our collective societal interests.

"All of us have seen businesses that closed, communities that are essentially decimated," Dr. Doubeni says. "The health of a neighbor is also our health. And if we don't pay attention to it, ultimately it will come back to affect all of us."

they could have prevented these problems from happening in their lives," Peyton-Caire says.

"But that's a very limited view of what really drives health quality in our country," she says.

Along with your genetics and health behaviors, your health is affected by a wide variety of external factors — such as your job, neighborhood and education — known as the social determinants of health, which can play an important role in health via:

Economics

The following all play into personal financial stability and health:

- **Employment** — This can provide direct access to health insurance and sick leave. The type of work you do can also affect your health; consider manual laborers at risk of

injuring themselves or the difficulty of juggling multiple part-time jobs. According to 2018 U.S. Census data, Blacks, Native Americans and Latinos have higher unemployment rates than whites.

- **Food insecurity** — People who are "food insecure" don't have enough resources to be sure they can access food of sufficient quality or quantity. Black and Latino households experience higher rates of food insecurity. An analysis spanning 195 countries found that a poor diet was the top risk factor for premature death, beating out smoking.
- **Poverty** — Poverty affects your ability to pay for adequate housing, food and health care. A major 2016 U.S. study found that the life expectancy of men at age 40 in the top 1% of income distribution was

14.6 years longer than men in the bottom 1%. The difference was 10.1 years for women. Poverty occurs in all racial and ethnic groups, but Black, Latino and Native Americans have higher poverty rates compared with whites.

Though economic factors play a role in your health, there are also examples of racial disparities that persist at similar economic levels. For example, the pregnancy-related death rates for Black mothers with at least a college degree is more than five times higher than similarly educated white mothers.

Neighborhood and environment
Your immediate surroundings can affect your health through factors such as crime rates, pollution, housing quality and access to healthy foods.

SOCIAL DETERMINANTS OF HEALTH

Economic stability	Education	Health care	Neighborhood and built environment	Social and community context
<ul style="list-style-type: none"> • Poverty • Employment • Food insecurity • Housing instability 	<ul style="list-style-type: none"> • High school graduation • Enrollment in higher education • Language and literacy • Early childhood education and development 	<ul style="list-style-type: none"> • Access to primary care • Access to health services • Health literacy 	<ul style="list-style-type: none"> • Access to healthy foods • Quality of housing • Crime and violence • Environmental conditions 	<ul style="list-style-type: none"> • Social cohesion • Civic participation • Discrimination • Incarceration

Source: Social determinants of health, U.S. Department of Health and Human Services

For example, people affected by crime can be harmed physically and mentally, and those living in high-crime neighborhoods may not feel safe exercising outside. Pollutants and contaminants — such as air pollution and bacteria or pesticides in water — can take a toll on health.

Segregation and racism have historically limited where people who are not white could live. Today, nonwhite people deal with negative neighborhood and environmental factors at disproportionate rates, including these examples:

- Black and Latino Americans experience greater exposure to fine particle pollution in the air compared with whites, according to a 2019 Environmental Protection Agency report. Current evidence also shows that nonwhite populations have a greater risk of negative health effects from this pollution.
- Some Native Americans may face special risks from exposure to toxic or heavy metals, as many Native American communities are near abandoned, potentially toxic mines in the Western states.

Health care

Primary care is important for preventive care, as well as proper care for chronic conditions such as diabetes. If you do not have health insurance or reliable transportation to get to a health care facility — or if you cannot find a provider to accept your insurance — this can prevent or delay care. Telehealth access can be an issue for those without high-speed internet.

When it comes to having health insurance, U.S. Census data from 2018 shows that the percentage of uninsured white people is 6%, but it's 19% for Native Americans, 18% for Latinos and 10% for Black Americans.

Even with proper access, people of color may be hesitant to seek care because they do not trust the medical community, sometimes due to past personal or historical mistreatment.

A flagrant and often-cited example of historical mistreatment is the 40-year Tuskegee Study. The study began in 1932 and recruited Black men in and around Tuskegee, Alabama with and without syphilis. To encourage participation, researchers told the men they were receiving free treatment. But the experiment was designed to examine the course of syphilis — not to treat it — and participants were not offered penicillin when this became the standard treatment. The experiment was not stopped until 1972.

Finally, health care is not always delivered equally. In the area of pain medicine, a study of primary care centers found that physicians more often underestimated pain experienced by Blacks as compared with whites. Studies of emergency medicine have found that nonwhite patients, especially Black patients, were not as likely to receive pain medication. A 2016 study found that some white medical students and residents still incorrectly believe that Black people have less sensitive nerve endings and thicker skin than white people, myths used in the 19th century to argue that Black people were biologically distinct and inferior.

Racism

Racism is a social system based on racial or ethnic appearance that disadvantages or discriminates against certain groups across society, culture and institutional systems.

You can experience racism through a personal interaction — such as being followed around a store because you are suspected of shoplifting — or a system, institution or structure that puts certain groups at a disadvantage — such as residential segregation or disproportionately high rates of incarceration among minorities.

Racism can act as a chronic stressor, and discrimination has been associated with:

- Poor mental health, including depressive symptoms
- Poor physical health, possibly including obesity and hypertension

The total effect: stress

Racism and other negative social determinants of health can add up to an incredible amount of stress.

When you're stressed due to a perceived threat, your body prompts your adrenal glands to release a surge of hormones, including adrenaline and cortisol. These hormones quicken your heart rate, raise your blood pressure and boost energy short term. Your body also curbs functions that would be nonessential or detrimental in a fight-or-flight, high-stress situation.

The long-term activation of the stress response system — and the overexposure to cortisol and other stress hormones that follows — can disrupt many of your body's processes

and may lead to or increase the risk of health issues such as anxiety, depression, heart disease, digestive problems and weight gain.

Addressing disparities

There are many complicated factors contributing to health disparities. But there are also nonprofits, health institutions, research centers and other parties working to tackle these disparities from different angles. Here is what this can look like in action.

Case management

Years ago, The Foundation for Black Women's Wellness saw a woman in need of serious support.

The woman was a single mother working multiple low-wage jobs to try to provide for her three kids. She didn't have significant family support, and her kids were on their own after school while she worked. Child protective services then took away her children, citing neglect.

"Her situation was one where she needed less systemic punishment for what appeared to be neglect — which was really stress and not having enough resources to really build stability in her life for herself and her children," Peyton-Caire says.

The mother didn't have adequate health insurance but had high blood pressure and a heart condition that was undiagnosed at the time.

"Heart disease is the No. 1 killer of all women, and particularly Black women at younger ages," Peyton-Caire says. "So our concern was, as you're shouldering this stress of trying to work, provide for your kids, fight for them in court, how do we hold you up and keep you healthy?"

Over several years, the organization advocated for her in court, and helped her look for better paying jobs and access to workforce training. The woman attended the organization's programming around physical, spiritual and financial wellness.

That woman now has stable housing and living-wage work and has been able to prove her ability to care for her children, Peyton-Caire says. The organization helped her manage and monitor health conditions for herself and her children. Her journey came full circle; she now helps the organization as a wellness ambassador to other women and young mothers.

"We could help her find the solutions for those very tangible, concrete things that she needed answers to: money, jobs, housing. She's on a better path now," Peyton-Caire says. "(She's) now pouring (her energy) into other women, and that's our cycle."

The Foundation for Black Women's Wellness cannot always dedicate so much time to one woman. Thus, they try to influence the whole "ecosystem" around Black women, Peyton-Caire says, acting as advocates and speaking to city, county and state leaders about policies, practices and systems that affect Black women and families.

DO GENETICS MATTER?

Genetics clearly plays a role in your risk of disease, even if that role isn't always well understood.

But does genetics play a role in racial disparity in the risk of disease? The answer is nuanced. One factor is the concept of race. Race is a social construct that is based on your appearance, not your genetic profile. For example, appearing "Asian" could mean having heritage from countries as diverse as Mongolia, Japan or the Philippines. Plus, people of different heritages have been having children together for much of human history.

Another factor is that with many common diseases, it's difficult to assign specific genes as the cause of increased or decreased disease risk. Rather, genetic and environmental interactions across the entire genome come into play. This makes it much more difficult to assign a percentage of genetic or ancestral risk across a larger population, and to identify how much that might contribute to a disparity.

That doesn't mean ancestry and genetics should be ignored. With inherited disease, it's good to know that whites of Northern European heritage are at a higher risk of developing cystic fibrosis, and people of African ancestry are at a higher risk of sickle cell disease. This can help health care professionals narrow down diagnoses or identify a need for screening or closer monitoring for problems.

However, the concept of genetic risk needs to be clearly understood and used properly. In one example, researchers at Mayo Clinic have been studying a genetic link for a disparity with multiple myeloma, a serious blood cancer that is generally known to occur about two to three times more often in Black people than in white people.

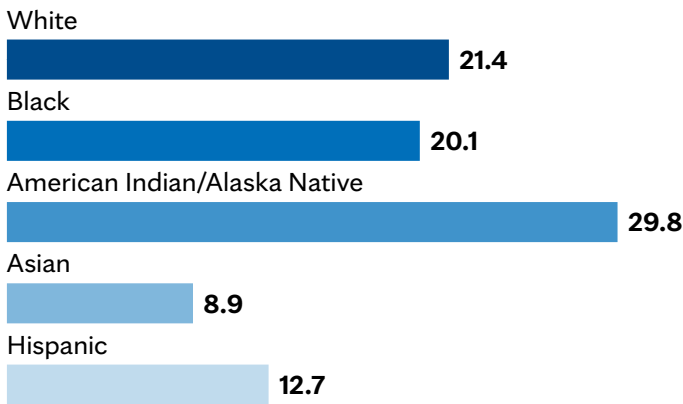
A key to the success of this research was obtaining a DNA profile of study participants to calculate genetic ancestry, rather than relying on racial appearance or self-described race. In addition, researchers were able to identify genetic characteristics of certain myeloma subtypes that drive the increased risk in Black people.

It turns out that not all people who self-identify as Black were at the highest risk of developing these myeloma subtypes. The highest risk group included people with the highest levels of calculated African ancestry. Since response to cancer treatment varies based on the genetic subtype of the cancer, it's hoped that this research will lead to more effective treatment for certain Black people with myeloma — and a better understanding of myeloma in all races.

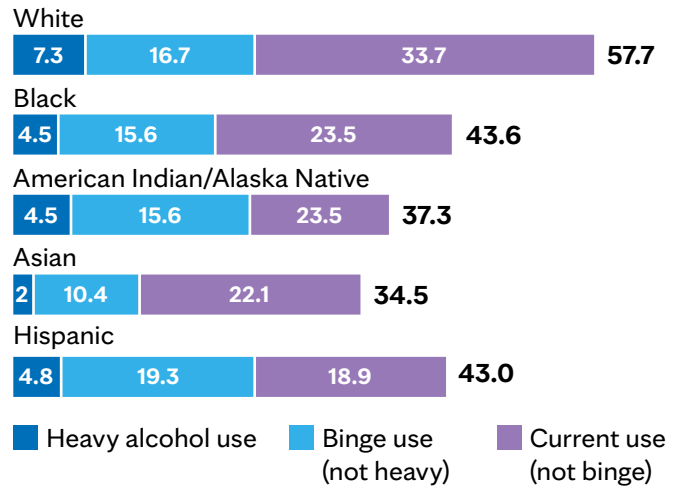
Genetics can be an important factor in disease risk. But given the fact that 99.9% of the genetic code in all human beings is the same, it is far from being the only contributor.

THE ROLE OF HEALTH BEHAVIORS

ANY TOBACCO PRODUCT USE (%)



ALCOHOL USE (%)



When categorized by major racial and ethnic groups, rates of tobacco use and heavy or binge alcohol use — two important, health-harming habits — don't consistently correlate to disparities often seen in health outcomes.

Sources: Centers for Disease Control and Prevention, U.S. Department of Health and Human Services

Clinical research

The goal of clinical research is to advance medicine to help people live longer and healthier lives. But all too often, not enough people of color are included in clinical research trials.

Consider cancer research in 2019: Just 4% of the 3,593 clinical trial participants for 11 new cancer drugs were Black and 5% were Latino, according to the Food and Drug Administration (FDA). To compare, Black people and Latinos are 13% and 19% of the U.S. population, respectively. Another study found that only 13 of over 70,000 participants in 145 cancer drug trials were Native American.

Donald Northfelt, M.D., a Mayo Clinic medical oncologist and Arizona site director of Mayo Clinic's Center for Health Equity and Community Engagement Research, says that this underrepresentation is a problem.

"The purpose of cancer clinical trials is to show us the best way to treat people with cancer," Dr. Northfelt says. "But there is a big difference in the way that people from different backgrounds experience their cancers.

"What works in a group of Caucasian women isn't necessarily going to lead to the same outcome for somebody who lives remotely on a reservation,

or who has trouble understanding directions given by her care team because her care team doesn't speak Spanish, or (a Black woman) with diabetes and high blood pressure that she hasn't been able to get controlled adequately because of unconscious bias and racial disparities in her health care," he says.

Including diverse populations in clinical trials helps researchers get closer to understanding the true value and true harm of a cancer intervention, Dr. Northfelt says. Additionally, it's important that people have equitable access to the innovative approaches offered in clinical trials.

However, minority groups may face unique barriers to participating in clinical trials. They may have less access to or awareness of trials, or face transportation barriers or worries about cost. These are real challenges for Native American tribes near Mayo Clinic in Arizona.

Those living on a remote part of the reservation may not have any cellular service in their homes, or they may have limited means and periodically run out of money for gas, Dr. Northfelt says. These factors can make contacting and coordinating with patients more logistically challenging.

While not insurmountable barriers, these require understanding and workarounds in order to keep people engaged in clinical trials, he says.

Through an existing partnership with the Phoenix Indian Medical Center (PIMC), Mayo Clinic has joined in the work of overcoming these obstacles.

For over a decade, Mayo Clinic has provided weekly in-person oncology and hematology consultative services at PIMC, working in partnership with



Donald Northfelt, M.D.

PIMC doctors providing cancer care. Today, if Mayo doctors identify people at PIMC who are eligible for a clinical trial at Mayo Clinic, they are invited to participate. As a result, Native American participation in Mayo Clinic's Arizona campus clinical trials increased from 0.9% in 2019 to almost 5% in 2020.

These are encouraging results, but Dr. Northfelt and the Center for Health Equity and Community Engagement Research in Arizona want to further strengthen connections between local tribes and Mayo Clinic.

"We see some of their patients, but I think we could do a lot better at opening the doors of Mayo Clinic to patients from these local tribes," he says. "Is there something we could do to make Mayo Clinic in Arizona a more welcoming place for our Native neighbors? That's going to make Mayo a more diverse place than it currently is."

Community education

Black and white women have similar rates of new breast cancer diagnoses, but Black women are 40% more likely to die of breast cancer.

Aware of the disparate breast cancer outcomes for Black women, two Mayo Clinic employees — Marion Kelly, director of community engagement at



Marion Kelly

Mayo Clinic in Arizona, and Michele Halyard, M.D., a radiation oncologist and dean of the Arizona campus of the Mayo Clinic Alix School of Medicine — got to work.

In 2010, the pair formed the Coalition of Blacks Against Breast Cancer (CBBC) as a nonprofit to support breast cancer survivors, family members and caregivers, and to provide breast cancer education to the Black community.

The organization hosts a monthly support group for breast cancer survivors and their loved ones, which is open to people of all races. To reach the community, CBBC teams up with Black churches to host educational workshops. At every event, attendees hear a story from a survivor, learn the facts and figures about breast cancer in the Black community, and are informed about the resources CBBC offers.

"A good day for us is that we got the information out to a group of people that had not received it before," Kelly says. "People who ask us for resources because they don't have them, and our ability to get them to a place where they can be treated, is success for us."

At one community workshop, a woman raised her hand during the question-and-answer session and told the crowd that a mammogram had revealed a lump in her breast. After following up with a physician, she was slated for a biopsy. But she was scared and didn't follow through. It was now two years later, and she had skin lesions on her breast.

"She was in tears saying, 'I'm so scared that I can't do this on my own,'" Kelly says.

Black women may be hesitant to seek care for a number of reasons, Kelly says, including fear of racial discrimination and lack of access to insurance and quality care.

But in this case, the story had a hopeful ending: CBBC connected her with one of its ambassadors, who accompanied her to an appointment. The woman was then subsequently diagnosed with breast cancer and began treatment.



Michele Halyard, M.D.

Clinical care

Properly managing your diabetes can be a lot of work. Now imagine you don't have health insurance or the extra income to buy healthy food options or a membership to a gym for exercise. Perhaps it's difficult to research diabetes management on your own, because you may have only a few years of schooling, or perhaps you can't read or write at all.

That's the situation facing many of the clients of the seven St. Mary's Health Clinics in the St. Paul and Minneapolis metro area in Minnesota.

"It's a very complex disease," says Cristina Flood Urdangarin, community health outreach manager at St. Mary's. "All of those things make it even more complex."

St. Mary's saw about 1,700 patients in its last fiscal year, 99% of whom are Latino. The vast majority speak Spanish as their primary language. They don't have health insurance and live within 200% of the federal poverty guidelines. In 2020, that was an annual income of \$25,520 for an individual or \$52,400 for a family of four.

The clinics, staffed with the help of many volunteers, are a ministry of the Sisters of St. Joseph of Carondelet and run completely on philanthropy, grants and donations.

WHAT YOU CAN DO

Compassion and problem-solving are needed in many areas of society, and the realm of health care fairness and equity is no exception. Below are some starting points if you would like to learn — or do — more:

- *Donate your time, talent or money to a local organization working for health equity* — To find local nonprofits you're passionate about, read your local newspaper or use an online directory such as VolunteerMatch: www.volunteermatch.org.
- *Engage in advocacy* — Education, health care and housing play a big role in health.
- *Examine your own biases* — You can take quick online tests that can help uncover your hidden biases on a range of topics including race, age, weight and sexuality at Project Implicit: www.implicit.harvard.edu.

To learn more about the social determinants of health and health disparities, check out the following resources:

- U.S. Department of Health and Human Services Office of Minority Health: www.minorityhealth.hhs.gov
- Centers for Disease Control and Prevention: www.cdc.gov/socialdeterminants
- World Health Organization: www.who.int/health-topics/social-determinants-of-health

To learn how others approach issues of disparity, community health and research, visit:

- Rochester Healthy Community Partnership: <https://rochesterhealthy.org>
- The Foundation for Black Women's Wellness: <https://ffbww.org>



Cristina Flood Urdangarin

With low levels of health literacy, some people did not take their medication if they felt fine. Others just needed medication adjustments, such as those who felt uncomfortable taking insulin shots during the middle of the workday.

Community health workers also accompany and advocate for patients during their St. Mary's appointments.

"For instance, the doctor will say that the diet should have more fruit and vegetables, and the patient will tell the community health worker, 'I only have one dollar for the rest of the week,'" Urdangarin says. "There are things the patient hears that they cannot do unless we help them connect with food shelves or other resources."

Solution in sight

Peyton-Caire's list of Black women who have died prematurely continues to grow. She regularly gets phone calls from women sharing their grief at the loss of their family members.

"Equity is a life or death issue," she says. "Whether we achieve it or not has very real consequences."

But progress is possible, as organizations like St. Mary's Health Clinics, the Coalition of Blacks Against Breast Cancer, Mayo Clinic and Peyton-Caire's own Foundation for Black Women's Wellness illustrate.

Today, Peyton-Caire has another list of names: women who have said that the organization has inspired them to improve and advocate for their health.

She's encouraged by the progress, but, like Mayo Clinic's Dr. Doubeni, says that ending health disparities will require a larger, systemswide response.

"Disparities are the result of a long history of structural barriers and social injustice. The solutions to them require mobilization of an entire society to change them," Dr. Doubeni says.

Though the task is daunting, Dr. Doubeni is confident it can be done.

"We know what to do; we know the interventions that will work. We know who's affected," he says. "It comes down to our collective willingness as a society to make the investment, stick with it, hold ourselves accountable for the results that we desire. We can do it if we want to." ■

Cover illustration: Original photo by Hedi Rudd Photography Portraits by Jim Rownd

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