Health equity: What it means and why it matters

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A visual representation of health equity, as described by Onyema Ogbuagu, MBBCh, an infectious diseases specialist who is leading Yale's clinical studies around COVID-19. "Imagine there's a fence, and the goal is to look over it. A tall adult can see easily, a shorter adult may need a boost, and a child will need to be lifted up to see over it," he says. "Each needs a block of the appropriate size. Equity means that people have to get what they need to achieve the same results." Credit: Yale University

The pandemic has been relentless for everyone, but it's hitting some of us harder. For instance, there is the man whose grocery store job puts him at higher risk for exposure to COVID-19; if he gets the virus, his diabetes could lead to complications. Working at home is not an option for him, and his family depends on his income. A pregnant woman is missing her prenatal visits because going to the doctor means taking two buses to the clinic and bringing along her two other children. She is worried that would mean exposing the whole family to COVID-19—especially concerning since she lives with and cares for her elderly mother, who has dementia.

There are many stories like this that illustrate why health equity matters. When it comes to health, many factors affect how the odds are stacked. If you've noticed that the phrase "health equity" is in the news much more of late, you're right. It's because the events of last year—not only COVID-19, but also issues around systemic racism and social justice—have highlighted the fact that some people face more struggles in life due to their background, culture, race, financial status, type of employment, whether or not they live with a disability, or other distinguishing factors.

As the topic of health equity gains traction in national conversations, Yale School of Medicine is emerging as a leader in the area. Marcella Nunez-Smith, MD, MHS, associate professor of internal medicine, public health, and management at Yale, has been an advisor to President Biden since the campaign, and she was then tapped to co-chair the Biden-Harris Transition COVID-19 Advisory Board to ensure that the response to (and treatment for) COVID-19 is distributed equitably.

In December, it was announced that she will serve as a senior advisor in the Biden-Harris White House as the inaugural chair of a federal COVID-19 Health Equity Task Force. Already a national leader in the field, Dr. Nunez-Smith occupies multiple roles at Yale, including serving

as director of the Center for Community Engagement and Health Equity, the inaugural associate dean for Health Equity Research, and founding director of the Equity Research and Innovation Center (ERIC), which will be incorporated as a center within a newly formed trans-institutional Office for Health Equity Research that aligns resources and programs focused on health equity across Yale School of Medicine.

In addition to her professional work, Dr. Nunez-Smith has shared some of her personal experiences with health inequities. In the U.S. Virgin Islands, where she grew up, "people too often died too young from preventable conditions," she says. "My own father had his first stroke in his 40s and was left paralyzed. I learned there was a term for what we were: an underserved community, marginalized by place and by race."

What is health equity?

As a term, health equity is broad. According to the Centers for Disease Control and Prevention (CDC), as a society we'll achieve health equity "when everyone has the opportunity to be as healthy as possible." Focusing on the pandemic, the CDC notes that "longstanding systemic health and social inequities have put many racial and ethnic minority groups at increased risk of getting sick and dying." Black and Latinx Americans, for example, are roughly four times more likely to be hospitalized with complications from COVID-19 than non-Hispanic white people. In response, the CDC calls for addressing the situation by making sure everyone can maintain and manage physical and mental health, which requires easy access to information, affordable testing, and medical and mental health care.

Health equity is a complex challenge, says Kristen Nwanyanwu, MD, MBA, MHS, a Yale Medicine ophthalmologist and a member of ERIC. "It's bigger than a roster of things to check off a to-do list," she says. "It's a good development that conversations are happening in many different

settings on this topic, as simply raising awareness is a key step toward serving the needs of people who have traditionally been underserved."

Onyema Ogbuagu, MBBCh, an infectious diseases specialist who is leading Yale's clinical studies around COVID-19, says there is an important distinction between "equality" and "equity." "Imagine there's a high fence, and the goal is to look over the fence," he says. "A tall adult can see easily, a shorter adult may need a boost, and a child will need to be lifted up to see over it."

If given three blocks of equal height to stand on, the shorter adult would still need to stretch to see, and the child wouldn't see at all—each needs a block of the appropriate size, he says. "So, equity means that people have to get what they need to achieve the same results. It's less about the quantity of what to do and more about the end result in outcomes."

Which groups face the greatest pandemic challenges?

Health equity issues have hit Black and Latinx communities especially hard in the pandemic. Data from the CDC shows that, in the U.S., people in these two groups who contract COVID-19 are roughly three times more likely to die from it than non-Hispanic white people. Asian Americans and Native Americans are at higher risk as well.

This statistic for Black and Latinx Americans may reflect the broad pattern across the country, but in some places it's even worse. "In some pockets of the U.S., it's four times greater mortality than for their white counterparts and in other parts, it's less than one," Dr. Ogbuagu says. "Sometimes, when we aggregate data, we fail to realize that it's not uniformly distributed, that some parts of the country face even greater disparities in health outcomes for racial and ethnic minorities."

How does 'structural marginalization' play out in real life?

A phrase like "structurally marginalized" (sometimes referred to as "underserved" or "disadvantaged") refers directly to the connection between social and economic factors (such as education, employment, and housing) and health. It's well-documented that many people in structurally marginalized situations have underlying health conditions that are influenced by their socioeconomic status, and that these conditions put them at a higher risk for complications from a number of diseases, including COVID-19. This explains why, as Dr. Ogbuagu points out, the death rate for Black Americans is generally higher than whites for heart disease, stroke, cancer, asthma, influenza, pneumonia, diabetes, and HIV/AIDS; Puerto Ricans suffer disproportionately from asthma and HIV/AIDS; and Mexican Americans from diabetes.

These figures are influenced by factors that, at first, might seem unrelated to health and medicine but, in fact, are closely intertwined. In the case of COVID-19, Dr. Nwanyanwu notes that many people of color live together with several generations of family members; when you live in a crowded house, isolation is difficult. "We're always telling people they need to quarantine and what that should look like," she says. "But if you have a family in a one-bedroom apartment in a city as opposed to a five-bedroom house in a suburban town, that might not be possible. If someone in your house gets COVID-19, everyone else could get it, because there is no place to quarantine."

Other factors fueling the discrepancies in health outcomes include racial discrimination, difficulty accessing health care, and gaps in education and income. Workers whose jobs can't be performed at home—such as those who work in factories, nursing homes, and grocery stores—are far likelier to be exposed to COVID-19 and other infectious diseases.

These issues affect health in more ways than one might guess, including—for example—vision. As an ophthalmologist, Dr. Nwanyanwu sees this play out in her practice. Diabetic retinopathy, for instance, is preventable if diagnosed and treated early, but it remains the leading cause of blindness in adults. Here in the U.S., this condition affects more than one-third of Black and Mexican Americans, because, says Dr. Nwanyanwu, "we aren't screening some patients at the appropriate time."

Even those with loved ones who have lost their sight because of the disease haven't seen an ophthalmologist, she says. To figure out why, she enlisted a team to go into the community and ask questions. Housing, transportation, and challenging life circumstances turned out to be major factors. "Health care lives among a list of one's priorities. If there are barriers to health care in someone's life, it is going to be more difficult to practice preventive care, like getting an eye exam for diabetes," says Dr. Nwanyanwu. "These issues, compounded by systemic racism, become insurmountable for some of our community members."

Telehealth, which should make it easier to see a doctor, turns out to be another roadblock for some people. Many don't have the technology to access telehealth—or knowledge about how to use it, Dr. Nwanyanwu says. "If they had the proper technology, they could stay home, which is probably better for their safety, but instead they have to come into the office."

And others can't afford to pay for the care they need. For example, Dr. Nwanyanwu has learned to make sure patients get their eye drops on the day of surgery so they will avoid developing eye irritation when they go home. Even though insurance pays the majority of the cost for the drops, there is still an out-of-pocket cost barrier, she says. "It's the difference between eye drops being given to a patient on the day of surgery—with the costs bundled into the procedure—and the barriers that come with

having to get to the pharmacy and pay the co-pay necessary to purchase the medication," says Dr. Nwanyanwu.

Fear and mistrust play a role

Mistrust of the medical establishment is well-earned among people of color, given the extensive legacy of unfair treatment and abuse documented in the U.S. An example that is often cited is the Tuskegee syphilis study, a 40-year experiment carried out in Macon County, Alabama, from 1932 to 1972. Public Health Service officials followed 600 Black men (399 with syphilis and 201 who did not have it at the time) throughout their lives without giving them an accurate diagnosis of their disease (or information about the real purpose of the study). They also withheld treatment, even though it became available. Instead of receiving penicillin, which was established as the treatment of choice for syphilis in 1945, participants were given placebos, including aspirin and mineral supplements. Many of the men developed severe health complications of syphilis and died, and a number of their wives and children contracted the disease.

Dr. Nwanyanwu says she has seen patients who avoid seeking care for diabetic retinopathy partly because of stories like this. "Fear is an emotion that can affect people in different ways. Some don't want to come for an exam because they are afraid we would find something," she says. "But in marginalized communities, it can be hard to parse the effects of years of racism from general fear. I've heard people say, 'I don't want to be a guinea pig.' They aren't wrong. We have to address the legacy of racism in research and prove to historically abused communities that we are doing a better job."

Still others have different reasons for their attitudes toward medical advice. Early on during the pandemic, the message was to avoid the emergency room, if possible, Dr. Nwanyanwu says. "I have a patient who

had a really bad eye problem, but he waited because he didn't want to go to the ER," she says. "So, we're looking at rules, and how rules are followed by different communities. For his health, it would have been better if he went to the emergency room."

How can we move things forward?

All these stories give some insight into what Dr. Nunez-Smith will be addressing on a national level with the health equity task force, the doctors say. Work she has done at Yale may provide some clues about how she will do that.

For instance, ERIC, the organization she heads at Yale, promotes population health and health equity through research, much of which has been funded through National Institutes of Health (NIH) research grants. "ERIC is the true North that is really trying to use science to move our population to be healthier," says Dr. Nwanyanwu.

For example, a study published in the *Journal of General Internal Medicine* and cited on the ERIC website highlights the importance of including marginalized populations in health-related data. According to the study, only 28 states and New York City reported on race and ethnicity-stratified COVID-19 death rates. "The availability of high-quality and comprehensive race and ethnicity data is necessary to address factors contributing to inequity in COVID-19 mortality," wrote the study's authors, who include Yale Medicine internist Cary Gross, MD, as well as Dr. Nunez-Smith.

Meanwhile, Dr. Ogbuagu highlights the work of a Yale Center for Clinical Investigation program in New Haven called Cultural Ambassadors. The group partners with the community-based organization Junta for Progressive Action and the African Methodist Episcopal Zion (AME Zion) Church to encourage people to enroll in

clinical trials so that diverse groups will be represented. "We worked together for our COVID-19 vaccine trial," he says. Cultural Ambassadors helped develop recruitment materials and messaging within the communities, and participated in research themselves. "It's been an effective model," Dr. Ogbuagu says. "And it's not just about COVID-19 research. They've used this model for cancer and other forms of research. That's at least one way to do this."

But there is much more be done, he adds. A priority is to reassure people that decades of efforts have been directed toward ensuring that situations like Tuskegee never happen again. Clinical trials are now heavily monitored, the research is safe, and the risks are minimized. Unfortunately, "even in the backdrop of movements like Black Lives Matter, people of color feel that if something bad happens to them, no one will care as much as they would for the person who is not of color," he says, noting that the result is that they won't participate in a trial. "We had to work extra hard to be able to achieve minority recruitment goals with regard to the Pfizer vaccine."

Similar challenges are emerging now that the COVID-19 vaccination program is underway. In early December, 60% of all American adults said they would definitely or probably get the vaccine when it becomes available, while only 42% of Black adults said they would do the same, according to the PEW Research Center. The government is examining how to support minority acceptance of the vaccine, with efforts such as a special ad campaign to encourage people of color to take the vaccine.

What do people need to know?

In addition to the work taking place in the government and community, individuals can also help shape change by advocating among their friends and family members. Participating in clinical research helps ensure the needs of all kinds of people are met. "We are dying more, we

are being affected more, and if we don't get the care we need—if we don't participate in either research or in the outcomes of research—we will never truly know or experience the impact these opportunities can have in our communities," Dr. Ogbuagu says.

More information: Cary P. Gross et al. Racial and Ethnic Disparities in Population-Level Covid-19 Mortality, *Journal of General Internal Medicine* (2020). DOI: 10.1007/s11606-020-06081-w

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