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COVID-19 Brings Health Disparities Research to the Forefront

Posted on May 14th, 2020 by Dr. Francis Collins

The coronavirus 2019 (COVD-19) pandemic has brought into sharp focus many of the troubling things that we already knew about health disparities in the United States but have failed to address. With the bright light now shining on this important issue, it is time to talk about the role research can play in reducing the disproportionate burden of COVID-19, as well as improving the health of *all* people in our great nation.

In recent weeks, we've seen a growing list of disturbing statistics about how blacks, Hispanics, tribal communities, and some other racial, ethnic, and disadvantaged socioeconomic groups are bearing the brunt of COVID-19. One of the latest studies comes from a research team that analyzed county-by-county data gathered about a month ago. Their findings? The 22 percent of U.S. counties that are disproportionately black accounted for 52 percent of our nation's COVID-19 cases and 58 percent of COVID-19 deaths. In a paper awaiting peer review, the team, led by Emory University, Atlanta, and amfAR, the Foundation for AIDS Research, Washington, DC., noted that neither the size of the county nor whether it was urban or rural mattered [1].

Recently, I had an opportunity to discuss the disparate burden of COVID-19 with Dr. Eliseo Pérez-Stable, Director of NIH's National Institute on Minority Health and Health Disparities (NIMHD). Besides leading an institute, Dr. Pérez-Stable is a widely recognized researcher who studies various factors that contribute to health disparities. Our conversation took place via videoconferencing, with him linking in from his home in Washington, D.C., and me from my home in nearby Maryland. Here's a condensed transcript of our chat:

Collins: Eliseo, you and I recently had a chance to have a pretty intense discussion with the Congressional Black Caucus about health disparities and the COVID-19 pandemic. So, could you start off with a little bit about what populations are being hit hardest?

Pérez-Stable: Collecting data about disease incidence and mortality on the basis of race and ethnicity and other important demographic factors, like socioeconomic status, had really been absent in this pandemic until recently.

Part of that I think is entirely understandable. Hospitals were pressed with a surge of very sick patients, and there was a certain amount of fear and panic in the community. So, people were not completing all these forms that usually get turned in to the health departments and then forwarded to the CDC. If you go back in history, similar things happened in the early 1980s with the HIV epidemic. We weren't collecting data on race and other sociodemographic variables initially. But, with time, we did complete these data and a picture emerged.

With the COVID-19 pandemic, obviously, the outcomes are much faster, with over 60,000 deaths in just a matter of three months. And we started to see reports, initially out of Connecticut, Milwaukee, Chicago, and New Orleans, that African Americans were dying at a disproportionate rate.

Now, the initial—and I think still the most likely—explanation for this higher mortality relates to two factors. The first is a higher rate of co-morbidities. We know that if you have cardiovascular disease, more than mild obesity, or diabetes, you're more likely to get severe COVID-19 and potentially die from it. So, we could have just said, "Aha! It's obvious why this population, and others with higher rates of co-morbidities might be expected to have higher rates of severe disease and higher mortality."

But there is a second factor that relates to getting infected, for which we have much-less clear data. There was recently a map in *The Washington Post* showing the distribution of the rate of COVID-19 infections in Washington, D.C., by ward. The highest rates are in the wards that are east of the Anacostia River, which are about 90 percent African American. So, there is an appearance of a correlation between the proportion of African Americans in the community and the rate of Covid-19 infection. Now why could that be?

Collins: Yes, what explains that?

Pérez-Stable: Well, I think crowding is part of it, certainly in this neighborhood. A second option would be multiple families living under one roof.

Collins: So, you can't exactly practice physical distancing very well in that situation.

Pérez-Stable: Absolutely. You and I can go into our respective rooms, probably have our respective bathrooms, and socially and physically isolate from the rest of the household if need be. Many people can't do that. They have three generations in one small apartment, all using one bathroom, maybe two bedrooms for six or eight people.

So, we do face different conditions by which one casual infection can lead to much more community transmission. But much information still needs to be ascertained and there does seem to be some regional variance. For example, in Chicago, Milwaukee, and Atlanta, the reports, at least initially, are worse than they are in Connecticut or Florida. Also, New York City, which has been the epicenter of the U.S. for this pandemic, has an increased rate of infections and mortality among Latino-Hispanic populations as well. So, it isn't isolated to an African-American issue.

Collins: What about access to healthcare?

Pérez-Stable: Again, we can postulate based on a little bit of anecdote and a little bit of data. I'm a general internist by background, and I can see the enormous impact this pandemic has had on healthcare settings.

First, elective ambulatory visits and elective admissions to the hospital have been postponed, delayed, or cancelled. About 90 percent of ambulatory care is occurring through telemedicine or telephone connections, so in-person visits are occurring only for really urgent matters or suspected COVID-19.

If you have health insurance and can use systems, you can probably, through telephone triage with a nurse, get either approval or nonapproval for being tested [for COVID-19], drive to a place, get tested by someone wearing protective equipment, and never actually have to visit with anyone. And you'll get your result now back as soon as one day, depending on the system. Now, if you're insured, but don't really know how to use systems, navigating all these things can be a huge challenge. So, that could be a factor.

People are also afraid to come to clinic, they're afraid to show up at the emergency room, because they're afraid to get infected. So, they're worried about going in, unless they get very sick. And when they get very sick, they may be coming in with more advanced cases [of COVID-19].

So, telephone triage, advice from clinicians on the phone, is critical. We are seeing some doctors base their decisions on whether a person is able to breathe okay on the phone, able to say a whole sentence without catching their breath. These kinds of basic things that we learned in clinical medicine training are coming into play in a big way now, because we just cannot provide the kind of care, even in the best of circumstances, that people may need.

Of course, uninsured patients will have even more barriers, although everyone in the healthcare system is trying their best to help patients when they need to be helped, rather than depend on insurance triage.

Collins: A big part of trying to keep the disease from spreading has been access to testing so that people, even those with mild symptoms, can find out if they have this virus and, if so, quarantine and enable public health workers to check out their contacts. I'm guessing, from what you said, that testing has been happening a lot less in urban communities that are heavily populated by African Americans and that further propagates the spread of the disease. Am I right?

Pérez-Stable: So far, most testing has been conducted on the basis of symptoms. So, if you have enough symptoms that you may potentially need to be hospitalized, then you get tested. Also, if you're a healthcare worker who had contact with a COVID-19 patient, you might be tested, or if there's someone you've been very close to that was infected, you may be tested. So, I don't think so much it's a matter of disproportionate access to testing by one group or another,

as much as that the overall triage and selection criteria for testing have been rather narrow. Up until now, it has not been a simple process to get tested for COVID-19. As we scale up and get better point-of-care tests and much easier access to getting tested, I think you'll see dissemination across the board.

Collins: It's interesting we're talking about this, because this is an area that Congress recently came to NIH and said, "We want you to do something about the testing by encouraging more technology, particularly technology that can be distributed to the point-of-care, and that is out in the community."

Everyone wants a test that gives you a quick turnaround, an answer within an hour, instead of maybe a day or two. A big part of what NIH is trying to do is to make sure that if we're going to develop these new testing technologies, they get deployed in places that otherwise might not have much access to testing—maybe by working through the community health centers. So, we're hoping we might be able to make a contribution there.

Pérez-Stable: The economic factors in this pandemic are also huge. A significant proportion of the population that we're referring to—the disparity population, the minorities, the poor people—work in service jobs where they're on the front line. They were the restaurant servers and people in the kitchen, they're still the bus drivers and the Uber drivers, and those who are working in pharmacies and supermarkets.

On the one hand, they are at higher risk for getting infected because they're in more contact with people. On the other hand, they're really dependent on this income to maintain their household. So, if they test positive or get exposed to COVID-19, we really do have a challenge when we ask them to quarantine and not go to work. They're not in a position where they have sick leave, and they may be putting themselves at risk for being laid off.

Collins: Eliseo, you've been studying health disparities pretty much your whole research career. You come from a community where health disparities are a reality, having been born in Cuba and being part of the Latino community. Did you expect that COVID-19 would be this dramatic in the ways in which it has so disproportionately affected certain groups?

Pérez-Stable: I can't say that I did. My first thought as a physician was to ask: "Is there any reason to think that an infectious agent like COVID-19 would disproportionally infect or impact any population?" My gut answer was "No." Infectious diseases usually seem to affect all people; sort of equal opportunity invaders. There are some data that would say that influenza and pneumonia are not any worse among African Americans or Latinos than among whites. There are some slight differences in some regions, but not much.

Yet I know this a question that NIH-funded scientists are interested in addressing. We need to make sure that there aren't any particular susceptibility factors, possibly related to genetics or the lung epithelium, that lead to such different COVID-19 outcomes in different individuals. Clearly, something must be going on, but we don't know what that is. Maybe one of those factors tracks through race or ethnicity because of what those social constructs represent.

I recently listened to a presentation by Rob Califf, former FDA Commissioner, who spoke about how the pandemic has created a spotlight on our disparities-creating system. I think much of the time this disparities-creating system is in the background; it doesn't really affect most people's daily lives. Now, we're suddenly hit with a bucket of cold water called COVID-19, and we're saying what is going on and what can we do about it to make a difference. I hope that, once we begin to emerge from this acute crisis, we take the opportunity to address these fundamental issues in our society.

Collins: Indeed. Let's talk about what you're doing at NIMHD to support research to try to dig into both the causes of health disparities and the interventions that might help.

Pérez-Stable: Prompted by your motivation, we started talking about how minority health and health disparities research could respond to this pandemic. In the short-term, we thought along the lines of how can we communicate mitigation interventions, such as physical distancing, in a more effective way to our communities? We also asked what we could do to enhance access to healthcare for our populations, both to manage chronic conditions and for diagnosis and treatment of acute COVID-19.

We also considered in the mid- and long-term effects of economic disruption—this surge of unemployment, loss of jobs, loss of insurance, loss of income—on people's health. Worries include excess use of alcohol and other substances, and worsening of mental and emotional well-being, particularly due to severe depression and chronic mental disorders not being well controlled. Intimate partner violence has already been noted to increase in some countries, including France, Spain, and the United States, that have gone on physical distancing interventions. Similarly, child abuse can be exacerbated under these circumstances. Just think of 24/7 togetherness as a test of how people can hold it together all the time. I think that that can bring out some fragility. So, interventions to address these, that really activate our community networks and community-based organizations, are real strengths. They build on the resilience of the community to highlight how we can get through this difficult period of time.

I feel optimistic that science will bring answers, in the form of both therapies and vaccines. But in the meantime, we have a way to go and we a lot to do.

Collins: You mentioned the promise of vaccines. The NIH is working intensively on this, particularly through a partnership called ACTIV, Accelerating Covid-19 Therapeutic Interventions and Vaccines. We hope that in several more months, we'll be in a position to begin testing these vaccines on a large scale, after having some assurances about their safety and efficacy. From our conversation, it sounds like we should be trying to get early access to those vaccines to people at highest risk, including those in communities with the heaviest burden. But how will that be received? There hasn't always been an easy relationship between researchers, particularly government researchers, and the African-American community.

Pérez-Stable: I think we have learned from our historical experiences that mistrust of the system is real. To try to pretend that it isn't there is a big mistake. Address these concerns upfront, obtain support from thought leaders in the community, and really work hard to be inclusive. In addition to vaccines, we need participation in any clinical trials that are coming up for therapeutics.

We also need research on how optimally to communicate this with all the different segments of the population. This includes not just explaining what it means to be eligible for vaccine trials or therapeutic trials, but also discussing the consequences of, say, getting tested, whether it be a viral or antibody test. What does the information mean for them?

Most people just want to know "Am I clear of the virus or not?" That certainly could be part of the answer, but many may require more nuanced responses. Then there's behavior. If I'm infected and I recover, am I safe to go back out and do things that other people shouldn't do? We'd love to be able to inform the population about that. But, as you know, we don't really have the answers to that just yet.

Collins: Good points. How do we make sure, when we're trying to reach out to populations that have shouldered such a heavy burden, that we're actually providing information in a fashion that is readily understood?

Pérez-Stable: One thing to keep in mind is the issue of language. About 5 to 10 percent of U.S. adults don't speak English well. So, we really have to address the language barrier. I also want to highlight the challenge that some tribal nations are facing. Navajo country has had particular challenges with COVID-19 infections in a setting of minimal medical infrastructure. In fact, there are communities that have to go and get their water for the day at a distant site, so they don't have modern plumbing. How can we recommend frequent hand washing to someone who doesn't even have running water at home? These are just a few examples of the diversity of our country that need to be addressed as we deal with this pandemic.

Collins: Eliseo, you've given us a lot to think about in an obviously very serious situation. Anything you'd like to add?

Pérez-Stable: In analyzing health outcomes, researchers often think about responses related to a metabolic pathway or to a gene or to a response to a particular drug. But as we use the power of science to understand and contain the COVID-19 pandemic, I'd like to re-emphasize the importance of considering race, ethnicity, socioeconomic status, the built environment, the social environment, and systems. Much of the time these factors may only play secondary roles, but, as in all science related to humans, I think they have to be considered. This experience should be a lesson for us to learn more about that.

Collins: Thank you for those wonderful, inspiring words. It was good to have this conversation, Eliseo, because we are the National Institutes of Health, but that has to be health for everybody. With COVID-19, we have an example where that has not turned out to be the case. We need to do everything we can going forward to identify ways to change that.

Reference:

[1] Assessing Differential Impacts of COVID-19 on Black Communities. Millet GA et al. MedRxiv. Preprint posted on May 8, 2020.

Links:

Video: Francis Collins and Eliseo Pérez-Stable on COVID-19 Health Disparities (NIH)

Coronavirus (COVID-19) (NIH)

Director's Corner (National Institute on Minority Health and Disparities/NIH)

COVID-19 and Racial/Ethnic Disparities. Webb Hooper M, Nápoles AM, Pérez-Stable EJ.JAMA. 2020 May 11.

amfAR Study Shows Disproportionate Impact of COVID-19 on Black Americans, amfAR News Release, May 5, 2020.

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7 Comments

Sarah Ricketts **says:**
May 14, 2020 at 9:40 am
It's about time. We have participated in systemic bias–knowingly–for far too long.

Reply

Peter J. Wolczko **says:**
May 14, 2020 at 10:18 am
I was wondering if we are going to be in the same situation next January? A lot of Medical professionals are working extremely hard to find an antidote for the COVID-19. Is anyone looking ahead to January 2021 to see how to avert another pandemic as we have now?

Reply

Jayson Smythe **says:**
May 14, 2020 at 11:36 am
How do we reach out to that 5-10% with English language skill issues and redress that. Would adult or distance learning language class be able to reach that population to aid them in improving language skills?

Reply

Kevin J Waters **says:**
May 14, 2020 at 1:57 pm
Doctors, &, Researcher's, have compared Covid-19 to the Influenza Pandemic of 1918 / 1919 in order to learn about how such Medical Situations Affect Americans, &, How to approach Containment,&, Long range treatment ! I would Suggest that they also look at

the TB. Epidemic of the early 1940's that hit Post Industrial. Large American Cities, with "Poor, inner city, (Urban), multi Generational Housing, and how the Death Rate Affected those Who couldn't manage, (the Cure, Sanatorium's), often Years, of Bed Rest, Fresh Air, Diet ! The Average time for someone who was Financially able to get to "One of These, (ie: Adirondack Mt.), Sanatorium's was 2 yrs. In Bed ! Social Distancing, By Fear, &, Environmental Location, until the advent of Therapeutic drugs like Streptomycin, This Whole Process Took years, Thousands of Slow Painful Deaths, (Consumption), and Also years to overcome The Fear, Coughing In Public, Plus the Stigma of Tuberculosis ! Which Reflects Today's Situation, but Memories Fade !

Reply

John Lipovsky **says:**
May 14, 2020 at 3:33 pm
Cultural differences. Single mothers usually poor. Population density. Poor 75year old and black in nursing home hospice –not looking good.

Reply

Raj Shah **says:**
May 14, 2020 at 3:49 pm
The social distancing as mitigation for COVID-19 spread has also created burden in multigenerational families living together such as I see daily here in Native American tribes in NM. For NAs the social distancing created an unique proximity for the members in a family in such a way that now they are exposed to common behavioral traits of smoking, drinking etc.

Reply

donorcure **says:**
May 17, 2020 at 11:28 pm
Thank you so much for all of these people who are still keeping us posted about health disparities amid this global outbreak!

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