Hi, my name is Corey O’Hara and I’m Country Director for iDE Nepal. We’re an international nonprofit that creates livelihoods for the rural poor. Currently Nepal is looking pretty good on the COVID-19 front. People don’t mind wearing masks here and the climate’s mild so people can socialize outside. Tests are only showing a few hundred new cases per day now, that’s down from about 5000 a few months ago and for comparison, the country has a population the size of California. And officially fewer than 2000 deaths have been linked to COVID here but unofficially everyone knows our numbers are artificially low. We’re pretty sure that due to social stigma, deaths in rural villages are being reported as heart attacks or something else and testing rates are very low now as well so it’s also unclear what the current spread of the disease is nationally.

We know that we’re better off than most of the world as far as disease spread goes though which is lucky. The bigger problem here has been with our food supply. Most people in Nepal are subsistence farmers with very little land who grow most of the calories they eat. About 2/3 of the national population depends on this kind of small-scale agriculture and the national lockdowns we’ve faced, even more than the disease, has had a devastating impact on these rural communities. Our first case here was in January, a student who returned from Wuhan, and after that we were all on high alert with restrictions on travel from China, then Europe, and on border crossings from India. Then when we saw our second case in March, the entire country locked down.

This was a severe restriction on all movement nationally. Police in many areas took their jobs very seriously. Here in the city I saw people being beaten with canes and arrested for going to the market or being outside at the wrong time. All transportation in the country was stopped except with a medical permit. In some areas, police beat farmers for working in their own fields. That kind of severe response was eventually reigned in but it was well covered in local press and many farmers around the country were understandably terrified because of it. Meanwhile supply chains totally broke down. In the first three months of lockdown we saw produce rotting in some parts of the country where buyers were unable to come pick it up and farmers were unable to deliver it to markets. Many farm supply shops were forced to close or were unable to restock their shelves so farmers didn’t have access to the seeds and basic supplies they needed for the spring planting season.

A lot of the corn or maize that went into the ground this spring was low quality seed leftover on farms from a previous season rather than more trustworthy, high-yield varieties that farmers typically purchase to plant. For some crops that wouldn't matter much but not corn. So we saw yields drop dramatically in those fields. Poor families depend on that crop for the summer months all the way until October’s rice harvest and then the rice harvest should carry them through to the following spring. Instead we saw terrible hunger problems spreading across the country over a period of several months. Just to compound these food supply problems, this year we were invaded by the fall armyworm, a corn pest from the Americas that caused extensive damage at exactly the point when farmers weren’t able to buy supplies to manage it. At iDE we’ve been working with government donors to coordinate the national response to the pest through integrated pest management approaches, which means low toxicity tools like pheromone traps and organic pesticides.
Our surveys during the lockdown showed that our messages were getting out there about how to treat the pest appropriately but because suppliers weren’t open, farmers couldn't get the tools they needed to respond. Then in June we saw another insect plague, the desert locust which came to Nepal for the first time since 1960. It’s been a tough year for Nepal’s farmers. Our summer rice harvest was good though but we’re still seeing the after effects of that first strict lockdown. Prices for all foods here rose by about 25% during those months and they still haven’t stabilized. We’re all paying a lot more for food these days and in rural communities that means people have less to eat and what they’re eating is lower quality and cheap cereal grains. Meanwhile households that depend on remittances from family members working abroad lost their main source of income and the ones hardest hit are landless renters and farm laborers who don’t have land of their own.

Nepal’s situation isn’t really that unusual globally, there are half a billion small farmers around the world who have all been facing these same kinds of issues in the past year. They typically feed or support about half the world’s population. So this isn’t a small problem. These kinds of small family farmers can sometimes be unusually resilient in a crisis because they’ve always had to depend on different coping strategies but in an extended crisis like this and in some areas like Nepal, a crisis after crisis after crisis, we’ve seen that supply chain breakdowns in the agriculture sector mean disruptions to the food supply months down the line. We’ve already seen what happens in the U.S. when there are interruptions in the toilet paper supply, now just imagine what that situation is like for small farmers globally who haven’t been able to harvest enough food to feed their families or to bring to market due both to COVID-19 and to the world’s response to it.

Anonymous

I am a hospital social worker in Oregon which has been relatively less hard hit than other areas of the country and world. It’s still been an incredibly difficult and confusing year, even more so for our hardworking bedside staff like the nurses, respiratory therapists, CNAs. As a social worker I can see every aspect of my patient’s lives has been changed by the pandemic. Most commonly people feel alone, disconnected, and unstable. Any pre-existing problems like depression, housing instability, domestic violence, addiction, COVID makes these problems devastating and sometimes deadly. The hardest situations for me to watch involve family, maybe because I haven’t been able to see my family and friends for so long.

One of my patients in the ICU and his wife who are 40-something, able-bodied, working professionals and their child all had COVID. While dad was in the ICU, mom died of respiratory failure at home in front of her kid who then had to spend two lonely weeks quarantining at a family members house without seeing anyone. Another older gentleman was admitted with COVID only a day or two after two of his adult children had died of COVID. He spoke only a Mayan dialect which we did not have access to in our language bank. His family said goodbye over video call. These stories sadly are common. COVID has disrupted our grieving process in horrifying ways. People die alone with strangers in full protective gear who don’t speak their language, we are isolated, unable to hold each other or gather together. It’s been a really hard year and in some ways a lost year. I’m so angry and sad about how our country has handled COVID. I have moments of hope, like when I got my vaccine doses but I also fear things are gonna get a lot worse before they get better.
Amanda

Hi Erin and Erin, my name's Amanda and I'm a microbiologist with a passion for epidemiology and infectious disease. My sister Megan and I wanted to reach out and tell our dad's story because we feel it's a COVID story that needs to be told. Our father had immigrated from Mexico when he was a little boy and had made his life in the U.S. As he got older he was spending more and more of his time traveling back to Mexico. On many occasions he would fly back to the U.S. when he was unwell from not taking care of himself or treating his various ailments or illnesses and my family would work diligently to get him healthy again only to see him fly back to Mexico. Most recently he'd left an assisted care facility a few months into the pandemic to fly back to Mexico to be with his girlfriend in spite of being asked not to because of the pandemic because it was dangerous for somebody his age with his illnesses to be traveling.

We'd not hear from him for many months and then the day after Thanksgiving things changed. His girlfriend had reached out to us to see if we'd heard from him. She said that he was trying to make his way to the airport when he'd gotten confused and starting driving in circles. He was pulled over by the police and escorted back to the hotel after explaining to the officers he didn't feel well and couldn't breathe. The police dropped him off and said that they would call an ambulance. He had called his girlfriend and said he was confused, couldn't breathe, and felt like he was drowning. That was the last time anyone had spoken to him. The hotel staff found him deceased in his bed the next day. While the outcome might have been the same, we're disappointed that the police didn't do more to get our dad help. Instead of driving him back to the hotel, why didn't they drive him to a hospital to make sure that he was treated for whatever illness he was experiencing?

We can't help but wonder if the police would've done more if he wasn't an older Hispanic man in the southwest United States. Thank you for taking the time to hear our story, we hope that it shed some light on the discrimination that people of color experience daily both as part of this pandemic and the healthcare system in general. Thank you. And remember to wash your hands and wear your masks, you filthy animals.

Erin Allmann Updyke

Thank you so much for sharing your stories with us to all of our firsthand account providers. And thank you also to everyone who has written in to share your story with us, we really appreciate it and we are very grateful that you're willing to share your stories with us.

Erin Welsh

Yeah, we really are. Hi, I'm Erin Welsh.

Erin Allmann Updyke

And I'm Erin Allmann Updyke.

Erin Welsh

And this is This Podcast Will Kill You.

Erin Allmann Updyke

Welcome to the 16th installment-

Erin Welsh

16th!

Erin Allmann Updyke

16 episodes in our Anatomy of a Pandemic series covering COVID-19.

Erin Welsh

That's a lot of episodes. We say this every episode but-

Erin Allmann Updyke

We do. (laughs)
Erin Welsh: (laughs) Well we are very excited for this particular episode because we get to revisit a topic that we covered earlier in the pandemic but from a very different perspective.

Erin Allmann Updyke: Yeah.

Erin Welsh: So this week we are talking about disparities and what kind of disparities that we are seeing in COVID-19, particularly in the U.S. And we are super excited but before we get ahead of ourselves, let's start with the quarantini?

Erin Allmann Updyke: We should start with the quarantini. This week we're drinking Quarantini 16. 16 entire quarantinis.

Erin Welsh: That's a lot of quarantinis.

Erin Allmann Updyke: It is.

Erin Welsh: It's a lot of recipes.

Erin Allmann Updyke: It really is, Erin. You're a boss for coming up with them all. So what is in the Quarantini 16?

Erin Welsh: The Quarantini 16 is rye whiskey, orange juice, lemon juice, and a bit of grenadine.

Erin Allmann Updyke: Yum.

Erin Welsh: And we will post the full recipe for this Quarantini 16 as well as our nonalcoholic placborita on your website thispodcastwillkillyou.com as well as on all of our social media channels.

Erin Allmann Updyke: Yes. Other business items really quick, Erin?

Erin Welsh: The usual stuff. If you head to our website you will find a link to our bookshop.org affiliate account, you will find a link to our Goodreads list, you will find a link to merch, to transcripts, to alcohol-free episodes, and a link where you can submit your firsthand account for COVID-19 for this anatomy of a pandemic series.

Erin Allmann Updyke: Yeah. Basically we're just saying you should check out our website.

Erin Welsh: There's a lot of stuff there.

Erin Allmann Updyke: A lot of stuff there.

Erin Welsh: Yeah.

Erin Allmann Updyke: All right. So this episode, like Erin said, we're very excited to be revisiting disparities. In our earlier episode on disparities we had a really amazing conversation with Dr. Jonathan Whittall from Doctors Without Borders about how vulnerable populations are disproportionately impacted by public health crises. And we discussed how these issues play out on a much more global scale.
But in this episode we’re zooming in a bit to talk about racial disparities in healthcare in the U.S. and particular how the COVID-19 pandemic has profoundly amplified these disparities. Where did these disparities come from? What do they look like especially in the context of COVID-19? How do we measure them? And importantly, what are we doing to reduce or eliminate these disparities to achieve actual health equity in this country?

Erin Welsh: Yeah that’s a big one. To help us answer these questions and so many more, we are thrilled, like so fangirl exited-

Erin Welsh: Oh my gosh, yeah.

Erin Allmann Updyke: Yeah. We got to chat with Harriet Washington, amazing writer, medical ethicist, whose books 'Medical Apartheid', 'Deadly Monopolies', 'Infectious Madness', 'A Terrible Thing to Waste', and most recently, 'Carte Blanche: The Erosion of Medical Consent' have received wide critical acclaim.

Erin Welsh: We recorded this interview on March 10th and we are recording this on March 25th so just keep that in mind when we discuss any numbers and stuff like that. But you know what, let’s just get to the interview.

Erin Allmann Updyke: Yeah.

Erin Welsh: So we will let Harriet introduce herself right after this break.

**Harriet Washington**: My name is Harriet Washington, I'm a writer and I focus on medical ethics, research ethics typically. I've been doing a lot of work lately around informed consent and some of the hidden problems with it such as it disappearing from the landscape without anyone really realizing it. But I also work on other things, I'm very concerned about conspiracy theories and I've been to several international conferences presenting on some aspects of conspiracy theories that kind of elude us, we talk about them in order to dismiss people's fears but sometimes these are real conspiracies, not just conspiracy theories and sometimes the fears are actually, you know, rational. So that makes the situation harder but we need to confront that. And those are some things I'm working on. I'm also interested in the use of art in medicine to promulgate political stances and frankly perpetuate lies. So that's a fascinating topic. I keep busy.

Erin Welsh: (laughs) Well thank you so much for joining us, we are so excited to chat with you today. So can you just start us off by telling us a bit about your new book that just came out and what inspired you to write it.

**Harriet Washington**: Well it's hard to think of inspiration as the right term but the book is entitled 'Carte Blanche' and it focuses on the erosion of informed consent. Informed consent is a very detailed and very informative mode of transmitting information to people who are thinking about engaging in medical research. Before you engage in the research, you oughta know what the risks are, you oughta know what the potential benefits might be, you oughta know the lifestyle effects. Will you be unable to drive? Will you be very tired? You also need to know what your options are. Are there other medications that are not experimental but are tested, tried and true that you might prefer to take? Are there non-medical things that you could do for your condition or do you have the option of not taking any treatment at all? All these things have to be spelled out to you in great detail according to American law and that's largely because of abuses that we vowed would never happen again.
Things like the Holocaust where people were murdered in the name of medicine, pretending to do research, the Nazi doctors actually focused on Jews, Poles, other people but mostly Jews. And they incurred harm, forced them into research, sometimes killed them outright as part of studies. And then in this country we had prison research, the long history of abusing African Americans in the research arena that culminated in people’s horror over Tuskegee. All these things made Americans and American doctors swear that they would never have this done in medicine again. And it’s worth noting it was American doctors and lawyers who went to Nuremberg, Germany to confront the Nazi architects of the Holocaust. So all these things culminated in what we hear everyday one way or another that in this country no one can be forced into medical research without their consent. But it’s actually wrong as I detail in the book. Many people have been escalating, we’re talking about tens of thousands of people forced into medical research without their permission.

Erin Allmann Updyke

Mm-hmm, yeah. This kind of issue of eroding consent that you touch on in the book and how it disproportionately affects people of color, it’s really just one dimension of health disparities both here in the U.S. and abroad. And we know that although health disparities have been around forever, it’s only within the last few decades that that term itself was actually coined and it’s often only vaguely defined. Would you mind describing for us kind of what we mean when we talk about health disparities?

Harriet Washington

Well if you ask 10 people, you get 10 different definitions. But I think the simplest and most useful definition is simply treating any group of people en masse differently than you treat other people. So if for example there are studies done showing that consistently and routinely African Americans are less likely to have their complaints of pain acknowledged and treated, then that’s a very important health disparity. In fact in 2016 a University of Virginia study showed that half of all medical students surveyed thought that African Americans didn’t feel pain the way whites did. And a good number of practicing doctors think that too. That’s a very clear example of a health disparity that has wide ranging effects. Instead of having their pain addressed with appropriate medication or other treatment, African Americans are often dismissed as drug seeking and sent away without any medication and stigmatizing notes in their medical charts.

So that’s a very dramatic example but frankly you’d be hard-pressed to find any area of American medicine where you’re not going to find disparities in the way that black and white people are treated. And that emanates from the 19th century where you had this wave of very prominent doctors and scientists telling the country and telling the world who African Americans were. And one of the things they said about African Americans were that African Americans had very different bodies from white people, they suffered very different diseases, they had immunities to certain diseases, they didn't feel pain the way whites did. These beliefs are not lodged in the past, these beliefs have surfaced today in these studies that consistently show that we don't treat African American pain. But I worry about the things that we're not studying, we're not following. What other beliefs from the 19th century are still held by doctors but we don't interrogate them? I see quite a few.

Erin Welsh

Yeah, absolutely. So in these discussions of health disparities, sometimes the conversation focuses solely on barriers to quality healthcare in the U.S. but in reality those inequalities are only one part of the story. So can you talk a bit about how it's not just being able to go to a doctor or afford a doctor but how things like access to education, chronic stress, and environment racism interact with and compound each other when it comes to these health disparities.
I frankly don’t see any difference between environment exposure and the more traditional barriers you mentioned, it’s simply another barrier. The fact is that we know that African Americans, Native Americans, and Hispanic Americans are much more likely to be forced to live in areas that abut toxic-spewing industrial parks, bus depots, old housing that is rife with interior lead paint. These exposures are strictly racial, in fact they had been characterized for a very long as socioeconomic and people often spoke about vulnerable people being low income people and although poverty is a risk factor, it’s a risk factor that is dwarfed by racism. Studies have shown consistently that your race is what dictates whether you’re exposed to environment toxins or not. In fact one study showed that African Americans with an average income of like $60,000 a year are more exposed to environmental toxicity than very poor whites who only have an income of say $10,000 a year. Very poor. So it’s not poverty, it's race.

And these barriers are of many varieties but they're racial barriers and that's what's really important to me. They can be categorized in many ways but if you’re focusing on the victims and focusing on improving their health, then the most important characteristic to me is how prevalent they are and what effect they have on people's health. Environmental racism has an extremely profound effect on people's health and yet it's not often enough included in initiatives to resolve health issues and address health disparities. I wrote an article for Nature last year showing that environmental racism is a key indicator of susceptibility to coronavirus 19. In fact, the risk factors caused by environmental racism are the same risk factors that make one susceptible to coronavirus 19. So these are all barriers to better health for people of color.

But of course we have to realize that we will indict some of the barriers as if they arose of their own. These barriers arose for a reason and that means that in some sense these barriers were all created by people. It's racist policies that sometimes date from the 1950s and 60s that dictate how African Americans are trapped in areas with a lot of environmental toxicity. So we have to remember that these are human decisions, human actions, and existing policies and laws that need to be changed. It's not just a matter of, 'Hmm, this seems to be standing between African Americans and good health'. We have to take a more holistic view.

Absolutely. What are some of the ways that we actually kind of measure these health disparities?

They’re measured in so many ways. Sometimes people look at the years of life lost, the years of health lost, and depending on what question you’re trying to answer there are a variety of ways you can do it and some measurements are better for certain estimations. But what’s really important is the fact that no matter what measure you use, if it is an accurate measure, you’re gonna find a dramatic difference in the health status people of color and otherwise comparable white people. And that’s because of our healthcare system. We have a healthcare system that is rife with policies and behaviors that may not be encoded in policy but certainly exist. These behaviors are part of the healthcare system.

So one thing that frustrates me is how frequently when we look at healthcare disparities and we see a very pronounced healthcare disparity, the initial response is to look at African American behavior. How can we change it? How can we educate African Americans? How can we get them to come to the doctor more often? How can we remove this fear of medical research? That’s the wrong focus. In fact to focus on African Americans is to imply that there's something pathological about African American behavior when it's not African American behavior, it’s the trustworthiness of the U.S. healthcare system. If you don’t look at both things, not only are you not gonna be successful in changing it, you are unfairly stigmatizing people of color. Some of these measures are not very good measures. I mean one of the things that is illogical is how often people will invoke education. They'll say, 'Well, educated people seem to have better health according to this measure, and better education will improve African American health status.'
Better education is always a good thing for a variety of reasons but this is an error. You have to understand that for African Americans race actually countermands many of the advantages of education, for example African American men who are college graduates earn less money on average than white high school graduates. Dr. David Williams at the Harvard School of Public Health, a brilliant public health scientist, was relating to me how when he went to the reunion of his class at Yale, most of the African American men in the class had already died. The fact is having a Yale degree did not save them from the effects of healthcare disparities. So education is not a good measure and we have to stop using measures that have not been proven because too often, in my view, they are direct mythologies. That's a mythology. It also has a subtle form blaming the victim, you know. If you had done better in school, if you were a smarter, more diligent student then you wouldn't be suffering so. That's not true and that's not fair.

Erin Welsh

Right, yeah. So these health disparities are also often measured as outcomes like the differences in mortality rate or years of life lost, instance of particular diseases. But these outcomes represent the end result of a lifetime or multiple generations worth of inequalities and the narrative too rarely focuses on addressing the root causes of these inequalities. So can you talk about why it's important to understand the context of these disparate outcomes?

Harriet Washington

That is such a brilliant question. Because if you think about it, frankly what good is it to examine this at the end of life? You know what we'd like to do is intervene so that that lifespan can look more like the normal American lifespan. And intervening is something that we have been slow to do quite frankly. One of the ways in which I think my vision has been informed by the research I did, looking at the history of medicine is that I have a different idea of why we have some of these disparate treatment that leads to early death and greater disability. People use a term 'bias', I'm not saying that's not accurate, it's often appropriate. But what I see is not so much bias as mythology. The 19th century scientists that I mentioned earlier on, they had this nucleus of beliefs about African Americans and they basically veiled their beliefs, you know their mythology about who blacks were, they veiled it thinly in scientific data to make it look scientific. Science was beginning to trump other ways of knowledge in the 19th century and that made it more palatable, it made it more impressive.

It didn't make it scientific, though. So these beliefs about who African Americans are, why they die, and why they survive are largely mythological. You know, sort of perpetuated from the 19th century without enough scrutiny. We need to, in this era of evidence-based medicine, we need to go back to the drawing board and start applying scientific analysis to some of our beliefs and policies. We have policies that for example assume that education is going to elevate health status and life expectancy, maybe, I don't think so. We need to look at this, we need to have research that looks more objectively about certain measures. If African Americans are dying early, very often the focus is on biological dimorphism, differences or purported differences between black and white bodies. You see a lot of intense and expensive research going on and find what looked to me as rather modest differences, if they're differences at all. Very modest differences. A lot of investment is made in finding them and the argument that because there seems to be preponderance of some kind of subtle genetic difference, all this effort and resources poured into that.
But sometimes there are screamingly important differences that are not being investigated, like environmental exposure. If we spent the same amount of money on finding ways of separating people of color from a constant environmental assault, I think that would be money better spent. So we need to do the research to find out what’s going on. One of the things that I have found really frustrating and almost comical if it weren’t so sad is the focus on the Tuskegee experiment and their rationale for the supposed reluctance of African Americans to join clinical trials for the COVID vaccine and now to accept the vaccine. You know I get so frustrated when I hear this because having studied this history in great depth and understanding that the history of medicine has aligned in the experience of African Americans, I realize that researchers invoke Tuskegee because that's all they know. They don't know about the history, they don't know about the many extensive, rich, and frankly and flagrantly the violations that have taken place that African Americans know about. It happened to their family, it might've happened to them.

And so they will invoke Tuskegee but where's research to show it? I've looked at it, the research is really poor. It begins with the assumption that Tuskegee is at fault, which is not the way science operates, they should be asking open-ended questions. That research needs to be done, in fact it has been done. Thomas LaVeist at Johns Hopkins did a series of studies and found that it's not Tuskegee, in fact, he found in one of his studies that people who had never hear of Tuskegee, African Americans who had never heard of that study were more fearful of medical research than people who had. So despite all the evidence, we are still clinging to this mythology that black people are afraid of Tuskegee and therefore they're not interacting with the healthcare system appropriately, which is not true. First of all they are interacting appropriately and second of all if they were not, you could not blame Tuskegee for it. But again this is like some very stubborn ignorance that needs to be resolved and public health science should be focused on resolving it.

Erin Allmann Updyke
So of course these health disparities have existed long before the COVID-19 pandemic but in this last year I think they've really become both magnified and deepened in many ways. So can you talk a bit about the disproportioned impact that COVID-19 has had on communities that were already facing significant barriers to healthcare.

Harriet Washington
Well it's devastating. We already know that life expectancy has fallen. The volume of deaths alone is completely devastating and not novel, you know, this is not unique at all. Think of what happened with HIV early on in the 80s and 90s, when we didn't really know what we were dealing with in the 80s, one thing that emerged very quickly was that it was infecting and killing many more African Americans than whites. Hepatitis C, 20% higher rate in African Americans than whites. This is not at all a novel event, it's quite something we frankly should have expected. Infectious disease simply reflects what's already transpiring, the vulnerabilities that already exist due to things like environmental racism, due to things like disparate access to healthcare and poor treatment when you finally do access healthcare. All these things are vulnerabilities that are magnified whenever you have a health crisis and infectious disease is like the perfect agent to magnify these things and it’s happened repeatedly. And frankly coronavirus 19, I would love it if it were the last wave of emerging infectious disease that we face but that's very unlikely.
Look what we've gone through just in the past decade or so, you know. HIV, Hepatitis C, zika, chagas disease, a lot of these have not been well recognized in the media because they're affecting enclaves of people of color. Toxoplasmosis, you know, these diseases are coming in waves and they're coming in regularly. We're gonna be dealing with others after coronavirus 19, so I think it's time to act on what we already know that when you have people that are already marginalized and separated from healthcare access and treated poorly by the healthcare system once they interact with it, of course these people are going to become victims of the infectious disease. And yet where's all the scrutiny, a lot of the scrutiny? The scrutiny's on African American behavior. 'Oh, what are they doing, are they failing to practice social distancing?'

Even the Surgeon General, remember in April last year? Surgeon General got on TV, he did deliver a good message for the most part, but then he began talking about avoiding drug use and alcohol use as if these were special concerns for African Americans. And he's African American and he's the Surgeon General, he certainly knew or should have known that African Americans and Hispanic Americans were less likely to be able to practice social distancing as he urged them to do. It's time to take our heads out of the sand and apply what we already know about the vulnerability of populations who are treated badly by the healthcare system to these infectious diseases including but not limited to coronavirus 19.

Erin Welsh
Mm-hmm. Yeah this mythology that there is a biologic basis for health disparities, this narrative has shown up repeatedly throughout discussions of COVID-19. Can you talk a little bit more about that and what are some of the examples that you have seen in which this race-based medicine has shown up during this specific COVID-19 pandemic?

Harriet Washington
Oh there's so many. The focus on social distancing. Okay so that's behavioral but also plays on an old trope that African Americans cannot be trusted to act in their own best interest medically. They're unable to comprehend the right way to behave. So people began talking about where people choose to live, which is completely absurd. No one chooses to live in a walkup tenement in New York City, you know, where you are crowded around people, where you cannot social distance, where you are forced to share elevators with people, and you're almost certainly to be exposed in this very dense environment to someone who's infected. But then there are other things as well. In France there was a study, I forget exactly what date it came out but I found it staggering. There was a study coming out of France basically saying one of the reasons why we're seeing high rates in black people in the U.S. and in the U.K. and we can expect to see it in France is that black people react differently to infection. Black people are medically more susceptible to infection.

I'm reading this study and I'm thinking I'm not an epidemiologist but this is just not making any sense. They didn't talk about any particular infectious agent, they wrote 'infection' very broadly. So I'll just say I had my strong doubts. And yet the paper was published, I didn't see any retractions, I didn't see criticism of it, it's something that was simply accepted. The belief in bodily differences of course often evolves around genetics and so I've also read about very small genetic differences purportedly found between African American and white and the thing is that it's a bit meaningless. If there was indeed some genetic difference, how do you know it's a difference in African Americans? A lot of the research that uses racial labels never defines how they came by that racial label.
I'm constantly amused to see research in which African Americans and Hispanic Americans and whites are compared and contrasted without ever defining the terms because Hispanic Americans can be people of any race. So some of the Hispanics they're referring to are undoubtedly people who identify as white or as black or as both Hispanic and black. And so it really makes no sense. I think that a lot of the data is not only less than rigorous, that even if there is a small difference you know there's no proof that difference actually has a significant effect on coronavirus infection or effects. Race simply maps very poorly onto genetics and yet people are clinging to this straw in order to support their belief of biological dimorphism.

Meanwhile, again things that we know are impacting one's risk of developing and sickening and dying from coronavirus go unaddressed. Not only environmental exposure although that's very important but also things like your access to a doctor. More African Americans than whites lack a primary care physician. Without a primary care physician, you not only have greatly reduced immediate access to necessary health information, you have no advocate within the healthcare system. And if you're African American, you need an advocate because when you get to the healthcare system you're likely to be treated differently. You know your symptoms are likely to be dismissed, your pain is dismissed, you're sent home very often without appropriate treatment or any treatment. And then when you sicken, worsen, and die and go to the hospital - if you're fortunate enough to have access to the hospital - then you're not going to get the same type of treatment as whites.

So all these things we know exist and we should be focused on quantifying and eliminating these things, instead we're hunting for some mythical genetic difference that is going to explain to us why people of color are more vulnerable when frankly we already know why they're more vulnerable and it has nothing to do with genes.

Erin Allmann Updyke: Mm-hmm, absolutely. I feel like that sums it up. So how can we actually work to increase health equity in this country? What are some things that we could do at an individual level to help and what are, in your mind, some policies at the state or national level that could help narrow this gap?

Harriet Washington: How much time do you have? (laughs)

Erin Allmann Updyke: (laughs)

Erin Welsh: (laughs)

Harriet Washington: I do have some ideas. In the context of coronavirus, discussions about policy are focused on basically, I call it the 'get rich quick syndrome', they're focused on things that can be effected very quickly in hopes that you'll have a rapid change. That's highly unlikely and even if it were going to work, I'm not sure that's the direction we'd wanna go. Remember I said that - and I'm sure you're very well aware - this will not be our last emerging infectious disease. There's gonna be another one. Every time we have a new health challenge we will have to go back to the drawing board and undertake the really quick policies that aim at changing people's behavior very quickly are likely to be temporary as well. I think it makes more sense for us to face the facts and look at long-term changes that will yield long-term solutions. And that means something more intense, something a little bit more comprehensive that's going to take longer time. So if we do that, if we look for meaningful, persistent changes, we have to look at where the problems are.
First of all we've done a lot of studies showing that they exist but fewer studies looking at why they exist and how to address them. For example, lots of studies on pain. We know African American pain is treated very badly, it's not acknowledged, it's not treated appropriately, people are stigmatized as drug-seeking when they're in pain, we know this. So we need to focus now on how to fix it, what's causing this. And you know frankly sometimes it's good to know what causes a problem but sometimes I think it's wasted time and effort that we really can't afford, rather than worry about what exactly is causing the problem because that can be grounds for a lot of let's just say unhelpful nasal gazing. People talk about implicit bias in part because it's more comfortable than talking about explicit bias. What's important is that there's bias and it needs to be ended.

So we often talk about education and training but look at pain. I'm not sure education and training is the route, I'm sure it's not enough because if you look at pain, the studies showing that half of medical students, a good proportion of practicing doctors thinks African Americans don't feel pain and treat them accordingly. So we've established that. If you talk about education and training, where are you gonna do it? How are you gonna direct it? You don't find this information in textbooks, that's not why medical students think this. They think that because this is what they're learning on the clinical floors. They begin on the clinical floors in the latter part of their education and they see consistently African American people who are complaining of pain being turned away as drug-seeking. That's a tacit part of their training. They internalize that, they replicate it, and then they will teach that to their own students in residence. So we need to break that cycle. Instead of education and training I think we need to treat this like we treat other behavioral problems. It's really a quality of services problem.

A medical student would not be allowed to graduate without acquiring certain knowledge and certain skills. A resident would not be allowed to finish his residency if he weren't able to do certain things required of it. These students and these practicing doctors should not be allowed to advance in their profession until they've demonstrated that they are treating all patients equally. And we need to devise structure for assessing that the way we assess whether they can run a central line or do any other tasks required for their profession, we need to assess that. Not on paper and pencil tests, medical students are all smart enough to know to give the right answer, doesn't mean they're doing the right thing. But we need to build that into medical education and make behaving appropriately a prerequisite for graduating, for advancing in your field, for getting a promotion, for becoming chief resident.

It's time to monitor the behavior of not only the individuals but also the systems, hospitals that should be checked, overseen, their data should be scrutinized, and hospitals that show a record of not treating a group of patients appropriately, African Americans or anyone else, should be made to undergo penalties. You know we shy away from penalties for healthcare providers because we have such respect for them, they have such high social status, but I think we need to use these rewards and penalties. Meaningful penalties that will not only encourage compliance but also send the message to healthcare providers that this is important, it's an important hallmark of your ability to practice medicine well. So I think we need a change of perspective here.

I also think we need to have laws that change. The policies and laws reinforce healthcare disparities. One of them in the research arena is the structure of IRBs. IRBs by law only have to have one person who is unrelated to the institution on the IRB board. So what can that person do? You're sitting there and you're facing, what? 5, 10, 15 scientists all of whom want to do a particular study, you are the appointed layperson and you're not comfortable with it but what kind of effect can you have? First of all, you know your intimidated. These are scientists, you don't speak their jargon, you can't understand everything that they're saying, and they certainly don't have any incentive to listen to you. You have to be there, you're allowed to speak, but what influence do you have? You have no influence, you can't.
And so I wrote in 'Medical Apartheid', that was back in 2007, that IRBs should be constituted of half laypersons and half scientists and that way the laypersons on the IRB could have a real voice and some real leverage. If the people from whom you’re gonna draw the subject pool hear about the study you want to conduct and they have questions or concerns, this is a way to make their concerns addressed in a meaningful way. And then I heard from peers who said to me, 'That's not gonna work because laypeople can't understand the scientific nuances and procedures and they're not gonna know what's going on.' And I said, 'But scientists can explain it to them, otherwise how can the scientists explain it to the subjects they enroll in the study as they're required to do by law?' Scientists are very good at explaining even complicated, sensitive issues. It takes some time, you can't do it off the top of your head very often, but I know I've read a lot of studies, I've talked to a lot of researchers and I know how good they are at doing this.

So it's something that needs to be done, we need to involve laypeople in numbers will make their participation meaningful. This will also I think lower resistance in the larger community when they know that people like them are involved in devising these studies, I think they'll have greater confidence, it's not something that's just being enforced on them from above, so to speak. So I think those are really important policy changes.

I have others as well. One of my big recommendations is to get rid of healthcare lobbyists. Lobbyists have no place in healthcare. Essentially what's happening, as I understand it, we're electing lawmakers to enact our will and instead the lawmakers are essentially receiving money via lobbyists to enact the will of corporations that might be very different from what we have in mind. In fact frankly I think they often are. The corporations are focused on the bottom line, not on improved healthcare as their number one policy. Those are two big changes. We need to revoke the laws that encourage patenting by corporations of all universities.

The law was passed in 1980 and the shorthand is the Bayh–Dole Act and there were other lesser laws but this is what actually changed American medical research and changed the agenda setting from the institution that was a public health-centered institution to corporations who again are centered on the bottom line. These corporations are why their focus on maximizing profits is almost, not completely but almost total and that's why we have 20 drugs for erectile dysfunction and only one new drug for malaria in the last couple decades. So I could go on but those are my basics.

Erin Welsh

(laughs) Yeah. So we have on final question for you. So you just went through many different things that we can do to kind of help to increase health equity in this country at a hospital level, at a national level and so on. But in general, how can the medical establishment work to earn the trust of these communities that we have historically disenfranchised and in many ways, as we've talked about during this interview, continue to disenfranchise when it comes to health?

Harriet Washington

The U.S. healthcare system is untrustworthy. If it wants to gain the trust of people it must become trustworthy. And I know it's kind of logical but it's also reflecting the fact that this will not be a fast solution. It's been four centuries of abuse in the healthcare arena, so it's unrealistic to expect to fix a problem in a few months or even in a year. But the healthcare system has things it needs to do desperately. One of them is to become more inclusive and I mean racially inclusive but I mean more than that. I mean right now we have a healthcare system in which there is an interaction between patients and their physicians and perhaps a patient advocate. But the healthcare system has got to give more points of entry for laypersons into the system. There are already some unused avenues for monitoring and oversight within the healthcare system, we need to start using them.
For example, in research there are provisions into the law for government oversight of medical research. Provisions are very important because you have IRBs that are supposed to conform to laws and I don't know how many but I'm sure many of them do. But many of them do not. Many of them have permitted too much research that is clearly in violation of laws and of ethical strictures. But the oversight is not well funded, there's no money for the oversight, it's there in the law but it's not happening so that means that the research generated by an institution is as good as its IRB. You have a conscientious, meticulous patient-centered IRB, you have good research. You have another type of IRB or IRB that is reliant on fast track approval, essentially rubber stamping research, then that's exactly what you're going to get. That's why we need the federal oversight that's already in the law, it needs to be funded and put into operation.

We also have provisions in the law to remedy some of the problems caused by the jealous corporate protection of patents, they're protecting their patents above all else and they often will produce medications that cost the better part of a million dollars a year so that people can't afford it. There's a provision for this in the law that allows the government to step in, take the patent for that company, give it to a company that commits to producing the drug at an affordable price, pay off the first company, something for the use of the patent. And that way the first company gets some money, not the million dollars a year they were looking for of course but people who need the medication will get the medication. That's a great solution. Well it's not a great solution but considering the system which I think is a bad system, that is a solution. But our government refuses to undertake it. They won't use it to give our people affordable drugs, they use it to allow DIRECTV but they don't use it to allow us to have good drugs. (laughs)

So we have to look at things that are already in the law that could afford us some relief and could afford African Americans and other people easier, affordable access into the healthcare system that we're just not using, we're ignoring that. I don't know why we're ignoring it but I will say it's yet another reason why we need to get lobbyists out of healthcare. I'm not saying the lobbyists have anything to do with this but I am saying that it certainly benefits lobbyists if we don't split these laws. So I think we need to make lawmakers free to do the will of the people unencumbered by financial interest from these companies.

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Erin Welsh
Erin Allmann Updyke
Erin Welsh
Erin Allmann Updyke

Thank you so, so much Harriet, it was such a joy to chat with you, it was unbelievable. What a great conversation.
Oh my gosh, yeah. We covered so much information.
Yeah we really did. So as per usual, shall we go over some five learning points?
Let us do that.
All right. Number one. The many barriers to healthcare that exist were put into place by people. Environmental racism is one example where explicitly racist policies like redlining, segregation policies, the Indian Removal Act, and so many more created inequalities in environmental conditions between black, Native American, Hispanic or Latino, and other minorities and white people deliberately. And these policies haven’t disappeared, they exist today in the Dakota Access Pipeline, in the Flint water crisis, and they persist in unequal access to clean water, fresh food, clear air, safe housing, and many other things that a lot of people take for granted. These barriers, created and enforced by racist laws and policies especially within healthcare and behaviors not encoded in policies, these have a direct impact on the health of people today. Despite these systemic inequalities and barriers, much of the focus of health disparities, especially racial disparities, focuses on individual human behavior. Essentially blaming the victims of health disparities for their conditions.

Yeah. Number two. Racial disparities in health are generally reported as outcomes, disproportionate death rates or infection rates, disease prevalence, shorter life expectancies. These disparities don't magically appear in a vacuum, they are the result of a lifetime or generations worth of unequal access to healthcare of racist medical or environmental policies, of excess stress. And of course it’s important that we measure these outcomes and that we’re having these discussions but it does us no good if we don’t also address the root causes of these disparities and how they interact and compound each other to lead to such stark differences. So step one is finding out, okay, what are these disparities?

But step two, which really should be taken alongside step one is how do we increase health equity by addressing the roots of these disparities? These are not something that we can fix by making one simple change, we need to put some of our resources to understanding what it is about the healthcare system, the legal system, the educational system, housing policies, our entire society in general that perpetuates these outcomes that we can measure. Racial disparities are often multi-generational and are always multifaceted. And making any improvements requires us to take a step back to see the bigger picture and put policies in place that address the roots of these inequalities rather than at the branches.

Number three. Speaking of root causes, a lot of attention in medical research has been paid to try to prove biological differences between races, leading to race-based medicine. However, these supposed biological differences are rooted in pure racist mythology perpetuated in the 19th century when self-styled scientists thinly veiled their racist views in scientific language despite the fact that in the decades since, there have been ample studies illustrating that these biological differences in race truly are mythology and have no basis in fact, these racist notions permeate the way medicine is taught and practiced today. Many physicians make decisions based on this mythology. The myth of differences in pain tolerance, lung capacity, predisposition to certain diseases, and there is a tremendous amount of research conducted to find a biological basis for racial disparities in health outcomes.

Instead we need to use those resources to go back to the drawing board and actually apply evidence-based medicine to addressing health disparities rather than relying on this mythology created and perpetuated by eugenicists and racists. We have to shift the focus from these supposed biological differences which truly do not exist and instead focus on the things that are actually different due to systemic racism, like access to healthcare, like environmental conditions, like access to education, clean food, water, I mean the list goes on and on.

Yeah, it really does. Number four. While the disparities that we are seeing with COVID are not unique and infectious diseases often reflect the vulnerabilities that exist in societies, the disparities that we are seeing today due to COVID are bleak.

Mm-hmm.
In the U.S. studies throughout this pandemic have consistently found that black people are at least twice as likely, and some studies have found up to 6-8 times as likely to test positive for COVID than white people. They are hospitalized at at least 3x greater rates and account for significantly higher proportions of deaths due to COVID. And the same is true for other minority groups. Native Americans are almost 4x as likely to be hospitalized due to COVID, Hispanic and Latino people 3x as likely. And the thing is these are national estimates that I’m citing from the CDC, some individual studies in various states have found much higher disparities among racial and ethnic groups. And the thing is it hasn't been limited to COVID disease hospitalization or death. Job losses have also been higher among black and Hispanic/Latino people. COVID has caused increases in food insecurity, housing instability, access to other medical care including routine vaccinations for kids. And we have done a terrible job in ensuring equitable access to vaccinations so far and not just in the U.S.

According to one study in England, elderly black people were half as likely to be vaccinated compared to white people for COVID-19. And in the U.S. a patchwork of vaccine distribution has led to severe inequities by race and ethnicity that vary state by state but overall the stats are pretty grim. Some reports and news outlets seem to tie this inequity all back to vaccine hesitancy but that's really its own form of victim blaming and it's not the root cause of the disparities that we're seeing.

Yeah. So number five. How do we fix it? It is not going to be easy and it's not going to be quick. It has been four centuries of abuses in healthcare in this country so we can't expect to fix the problem overnight and we can't expect that education itself is going to fix the problem. We have to apply meaningful changes in the way clinical medicine is taught and practiced. Individuals and institutions need to be held accountable for disparities that persist and the healthcare system has to do the work to become more inclusive. This might mean having more points of entry into the medical system, it might mean more monitoring and oversight with actual repercussions for noncompliance. And it might mean changes to laws such that there is an incentive to prioritize actual human health and wellbeing instead of corporate interests.

It's gonna be a long road, that's for sure.

Oh yeah. Absolutely.

If you'd like to look in more detail and know exactly where we got some of the data in this episode from, we have links to all of our sources on our website thispodcastwillkillyou.com. Most of the stats came directly from the CDC’s website as well as a couple of peer-reviewed journal articles that we found.

Again, thank you so much Harriet for taking the time to cat with us, I feel like this was a very informative episode.

Yeah. Absolutely. Definitely. And I think a really important one as well.

Mm-hmm. Yeah. And thanks again also to everyone who provided a firsthand account, we really appreciate it.

Yeah, thank you. Thank you to Bloodmobile for providing the music for this episode and all of our episodes.

And thank you to the Exactly Right network of whom we are a very proud member.
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<th>Erin Allmann Updyke</th>
<th>And thank you to you, listeners, for listening through this episode. We hope that you learned something.</th>
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<td>Erin Welsh</td>
<td>Yeah.</td>
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<td>Erin Allmann Updyke</td>
<td>And enjoyed it.</td>
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<tr>
<td>Erin Welsh</td>
<td>Yeah. Well until next time, wash your hands.</td>
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<td>Erin Allmann Updyke</td>
<td>You filthy animals.</td>
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