Episode 71: Understanding mistrust of flu and COVID-19 vaccines.

Featuring Dr. Sandra Crouse Quinn.

The relatively low uptake of flu vaccinations in Black and Hispanic communities is a longstanding health disparity and a public health concern. What if this pattern is repeated for the coronavirus, which is already having a disparate impact? Dr Sandra Crouse Quinn has researched in depth the underlying causes of vaccine uptake disparities, and here she shares her findings with podcast host Dr Mary O'Connor. Dr. Quinn's research points to the need for better community-based health education, including acknowledgement of historical factors, and the importance of increasing minority participation in medical research. Posted on November 4, 2020.

Dr. O'Connor: Hello and welcome, you are listening to the Health Disparities Podcast, a program of the Movement Is Life Caucus. I'm Dr. Mary O'Connor, Chair of the Movement Is Life Caucus and Professor of Orthopedics and Rehabilitation at the Yale School of Medicine. Health equity is my passion, and I am delighted to host this very important podcast today in which we take a closer look at vaccines and vaccination through a health equity lens. Our guest is a distinguished expert in the field of vaccinations, Dr. Sandra Crouse Quinn. Dr. Quinn is Professor and Chair, Department of Family Science and Senior Associate Director at the Maryland Center for Health Equity and the University of Maryland School of Public Health. We also understand that Dr. Quinn is closely, involved with the current full court press to develop a safe and effective vaccine for COVID-19 in the shortest time possible. Welcome, Dr. Quinn.

Dr. Quinn: Thank you, Dr. O'Connor. I'm happy to be here.

Dr. O'Connor: I'd like to talk about vaccines and underserved patients, particularly, individuals of color. You have researched and written about lower vaccination rates in African

Americans for all types of vaccines. For example, the flu vaccine. What are the factors, which contribute to this lower rate of vaccination in the black community?

Dr. Quinn: It's a complex question, but we do have some answers and some of them rest with individuals in the black community themselves, some of them rest with our systems and how we approach getting vaccine out. So, let me first talk, for a moment, about African American communities based on my research. And so, we know a couple of things and I'm going to focus a lot on flu vaccine, which is, actually, really pertinent today given the need for increased flu vaccine uptick. So, consistently, over time, if you look back, year after year, African Americans get vaccinated for the flu at lower rates than whites. Latinos, also, as another group, get vaccinated at lower rates, as well. And so, there are a couple of things. We know that perceived risk of flu is important, but we also know that African Americans are more likely to perceive the risk of side effects, and think of them as serious, and if the risk of side effects goes up, that perceived risk, and I say perceived because most side effects for the flu are quite mild, a sore arm, feeling achy for a day or headachy. If the perceived risk both goes up and is thought of as serious, then, the likelihood of getting the flu vaccine goes down. We also know that trust, and by that I mean trust in the vaccine itself, trust in the process, we actually tested to what extent people understood the process from the time the strains of the flu are decided upon for the flu vaccine that year, down to the provider that injects them in the arm. What we found is that African Americans had lower trust and sort of everyone in that pipeline from CDC, FDA, pharmaceutical company, healthcare organizations, down to providers. So, trust is a really, critical issue but there are also a couple of other things we don't normally think about and this is where the link to the system becomes important in the healthcare system. So, what we did was we, actually, examined also people's experience of being an African American in a healthcare setting did they perceive they were being

treated fairly? How conscious were they of their race when they were in a healthcare provider's office and whether they had been discriminated against? So, what we found was that when their perception of racial fairness was high, they were more likely to trust the vaccine, more likely to take the vaccine. Now, imagine for a moment, you're African American, you're sitting in a provider's office and everyone is white except you. So, your consciousness of sort of your race, as it would be, Dr. O'Connor for you or for me, sitting in a provider's office predominately of people of color would be different. The higher consciousness of race, being conscious of race in the setting meant that it decreased trust in the vaccine and it also increased perception of perceived side effects. So, same thing, experiences of discrimination in the healthcare system. We weren't talking about the overall society, also made a difference in terms of trust in the vaccine and willingness to be vaccinated.

But there are a few other things and I just have to say this because I think this is something, there's something providers can do that makes a difference and that is when we look at the literature, what we find is that even when African American patients come in during the season for a visit, they're less likely to receive a recommendation and an offer of the vaccine that day, at the same visit. What we know is when you get those things combined, when you, Dr. O'Connor, say, "I strongly recommend that you take this vaccine. With your Type 2 diabetes, you're going to be at high risk for complications. We know side effects are mild and this is safe. I can give it to you today during this visit." So, it's both community fears and distrust but it's also some things on the provider side that they can do differently.

Dr. O'Connor: Dr. Quinn, there are several points that you made that I want to follow-up on and just for our audience, who is listening, because they can't see us, we are both Caucasian women, just for people to understand the context of your comments. So, the issue of

African American patients and I am assuming that it would be the same for Latina patients, Latinos going to the physician, to a healthcare provider's office and not receiving the same opportunity to have a vaccination that same day is so disturbing. It's incredulous. I didn't know that, and I really shouldn't be surprised because I do a lot of reading and studying about health disparities, but this is such a basic system process. If someone comes in why would it be more likely if your skin color is white that you're going to be given a recommendation, an offer to get the vaccine that very same day, at that moment, which, of course, would be more convenient for me, as a patient, and I would be more likely, I'm assuming that you would say from a research perspective, it's more likely that I would be vaccinated if it all happens in that moment. Correct?

Dr. Quinn: That is correct and so, I think there are a couple of things, Dr. O'Connor and so, I raise this just because you know there's a lot of literature that certainly documents ongoing bias in the healthcare system and, you know, fortunately, I think healthcare organizations and medical schools and nursing schools are really starting to tackle that in a serious way. So, I mean, we know that, often, whites will get offered one standard of care for a condition, but non-whites may be offered something different. So, I think this is something that can be tackled and addressed. I think why that's really important is that when any community doesn't take the flu vaccine, as African Americans haven't, and other adult vaccinations, as well, we can't place it all on them and say, if they'd only learn to comply. We have to say, what do we have to do to help, number one, address concerns like vaccine side effects, address trust and indeed, to be more trustworthy, so that people believe, yes, you, as my provider, have my best interest at heart and we know that African Americans and pretty much everyone, when you say who is your biggest source, who do you trust most with your health, they say their doctor. So, I think for doctors that's a position that they can use

effectively, particularly, if they're willing to talk. If they're willing to talk, you know, about questions about vaccine safety, questions about the side effects. If they're willing to, also, be a role model. I get vaccinated and I get my family vaccinated. Those are some of the things, particularly, if the provider is African American, to be able to say that is really, useful.

Dr. O'Connor: So, from your research, is it more likely that a patient of color would be more willing to be vaccinated, to receive a vaccine, if they're in an environment where there are more individuals of color, whether that's patients in a waiting room or the provider, and is there a difference between if the provider looks more like them in terms of race/ethnicity or can other patients in the practice, so to speak, the patients in the waiting room mitigate that? If I am a white physician, but I happen to care for a lot of patients of various race and ethnicities, does that help my patients have a greater perception of fairness?

Dr. Quinn: So, it's interesting to ask that and that's a complex question and I would say in my other research, we found that the race per se wasn't that important. What was important, we didn't ask the question in the context of the flu vaccine, but we did ask as you said about fairness and consciousness. I think what's most important is the ability to listen, to communicate and to be a trusted provider for that patient. I don't think race, by itself, will do it. Does it help? Yes, it's very likely to help and I always do this little sort of informal interview. I live in the Washington DC area, when I go into my provider, my primary care or even if I go in for another check-up, at that time, and many of the nursing assistants, some of the physicians are African American and I'll say, "How are your patients doing? Are they taking the flu vaccine?" Their response is often, no. Every now and then I'll say, "Do you take the vaccine?" I'm surprised when I get a no because our own research also says norms about

vaccinations are important. So, the more people that are important to you, your doctor, your family, who you believe want you to get the vaccine, get the vaccine themselves, that's important and that can increase vaccine uptake.

Dr. O'Connor: I think that is an excellent point, Dr. Quinn, and as we look at people's acceptance of the vaccine, if the people in their communities that they know and respect are saying, "Yes, I received the flu vaccine," and we'll get into the COVID vaccine in a minute, "I received the flu vaccine and I think everyone should, too," because we know that even pre-COVID, the flu kills people every year and the people that are at risk, can be at risk because of someone in their household who is younger who is going to get the flu but not die from it or not get as sick, they can get the virus from that household member. So, it's really, important because we are all essentially one family, one community that we're trying to protect each other.

Dr. Quinn: You know you hit the nail on the head and we actually ask a question in our work about whether people have a moral obligation to take the vaccine to help protect others. We found for our African American responders that was a predictor of taking the vaccine. So, I think for providers being able to say, you've got a new baby in your household, also has grandma living there and grandma has diabetes, that sense of collective concern for one's family is a value and for one's community is a value in many African American communities. Let me just say, African Americans, when I say communities, we're not a monolith. Just like there's no group that's a monolith and there are differences, but, you know, there is a collective sense of concern for each other and I think that is something that we can use in talking to patients. This is not just about you, it's also about the people you love.

Dr. O'Connor: As we've been talking about trust and distrust with the system, has that been changing over time? Are there factors that contribute to trust that have changed, let's say, in the last ten years?

Dr. Quinn: We can spend a lot of time talking about that. I think there are a couple of things happening. In our qualitative work, when we ask people, when we're exploring trust, many people brought up, and I'll never forget in the first focus group, somebody said and this was in 2014, I guess, said, "How can you talk about the flu vaccine without talking about the Tuskegee syphilis study, which they have done a lot of work on the legacy of the Tuskegee study. So, we got into it. Over time what played out in some of these groups and interviews was certainly there is ongoing concern for those historical, really, critical, cultural sort of markers of research abuse by medical and public health researchers. That's still there and any provider, any researcher for vaccine clinical trials who is not ready to address that could be in trouble. On the other hand, what we also heard from people was, "You know, maybe it's time to set aside some of that distrust and kind of actively step out there," and what we heard and what we surmised when we listened to our white participants and then, in separate, our African American participants, except for our African American participants it was often a much more sort of deliberative process. Am I going to make a decision to trust? So, what has happened in our world in the last few years? Certainly, we've seen the advent of social media and I have a grant that studies that. It is a challenging world in terms of exacerbating conspiracy and myths and misinformation, but I'll also give you an example of something that I think is important and that is, a couple of months ago, not long after Weiss went on our stay-at-home orders in March in Maryland, one of the barbers, an African American barber that we work with sent a photo to us of a flier that was sort of stuck in the door of the barbershop and the flier went through black and white, 8½" by 11" piece of paper,

nothing fancy, "*COVID is a hoax. Don't take the vaccine. It's caused by 5G. The vaccine will insert some sort of device to track you and don't be a guinea pig*." So, I said all of that to say those fears have been there long before social media, but there it was in just, plain old black and white stuck in the door of the shop. So, distrust is an issue and we also found that African Americans were more sensitive and concerned about the motives of government when it came to things like vaccine programs. Not as much the competence but the motives. So, we can't divorce any of these things, particularly, now, from the cultural, political and social context in which we operate. All of those things have an impact.

Dr. O'Connor: You wrote a fascinating article in 2018 about users of Twitter or Facebook being more likely to receive vaccines. I just think that's fascinating. Why do you think that is?

Dr. Quinn: Like any good researcher, I'm going to give you the caveats. That was a different world just five years ago, then we're in right now. So, you know, certainly, and I don't know if that were to hold true today. I really don't. That said, what I do know from our social media research is this, is that the anti-vaccine movement on social media punches above its weight. It looks bigger. It looks more, scary. It's not to say it's not scary. It is. But there are a lot of people who also are not going to refuse vaccines, but they just have questions that a good provider, listening and engaging them can answer. Would it be true today? I guess that's a testable hypothesis that it's really a complex world in terms of the information, some of our COVID research looking at what is perceived as misinformation in COVID, they're finding it really complex. So, I think it's a testable and important hypothesis.

Dr. O'Connor: Let's turn to COVID, right now, and I'm interested in your thoughts on are there differences, do you see, fundamentally, in terms of people's openness to taking the COVID vaccine versus, for example, the flu vaccine because we have a lot of experience with the flu vaccine and, of course, COVID is new and there's been, unfortunately, I think a lot of, I'm looking for the right term, a lot of politics that may have been interjected into what should be a very medical and scientific matter. I think our listeners would be very interested in your thoughts on is willingness to get the COVID vaccine when we have one, do you see it as fundamentally different than willingness of people to have the flu vaccine?

Dr. Quinn: That's a really interesting question. So, I think, first thing, one of the things we know from our research because we ask about people taking flu vaccine, not just the season we did the survey, but, also, for the previous five years. So, we know, when we learn this also on our H1N1 pandemic work in 2009/2010, previously getting the flu vaccine predicts future, getting the flu vaccine. So, if we look, right now, at African Americans being high 30's, low 40's in terms of flu vaccine uptick for adults that's going to give us a clue, but I think there are a couple of other things here that are challenges for us. Number one, just what you said the insertion of political rhetoric around the vaccine has been an enormous challenge. The conversation, the term Operation Warp Speed because most of the public, not just African Americans, but most of the public really doesn't know much about the vaccine clinical trial, the research and development process. They'd have no reason to. So, I think the Operation Warp Speed somehow was interpreted by many as this is taking shortcuts and yet, when you look at these trials and the protocols, it's not taking shortcuts, it's doing more collapsing so the trials are Phase 1 and Phase 2 trials, for example, are done almost simultaneously, as soon as they've got strong data to suggest safety, then, they may move to the next trial. So, I think the politicization, the Operation

Warp Speed, I think there's one more piece that is going to be an issue for us. That is that one of the options is that these vaccine companies could request an emergency use authorization, which is a different mechanism than a standard flu vaccine approval process biologics license approval. It is really it allows you to request approval based on data that doesn't require the completion of the study, which most of these are 18 to 24-month studies, and it's done because it can only be used in emergencies. We're in a desperate emergency. Right? I think that that terminology and often the language we use around things like that will also, potentially, sow further distrust or skepticism. So, I think we've got some challenges ahead of us that are not insignificant. One of the things I'm happy to see is that I think many of these companies are stepping up and saying, "Here's our process." Letting other scientists look at this and sort of interpret it for the public. Reporting on what's happening and I think those things will help. This is going to be a huge problem.

Dr. O'Connor: Sometimes, I've thought about this challenge and in my own mind thought about what would motivate people that might be resistant to the vaccine to consider getting it, and I'm making the assumption that we have a safe vaccine. One thing that I thought might be helpful would be to get some patients who have been sick, the so-called long haulers, patients who continue to have symptoms of illness months and months after the acute phase because there's so much about this virus that we don't understand and these patients may suffer for years or maybe they're going to suffer their entire lives. We just don't know. If their infection could have been prevented and they could be messengers to the larger public to say, it's really important that you don't get sick. This is what happened to me. Whether that would be effective at showing people the other side of this disease. It is not just the flu. It is not just the flu. So, I welcome your thoughts on it. I mean if you were the Queen of the Universe and

you could create a public service campaign that would help engage patients in being vaccinated, once we have a safe and effective vaccine and, in particular, engage our communities of color and communities that traditionally underutilize vaccinations what would you do?

Dr. Quinn: Even today in the context of vaccine trials, we're seeing some prominent and often just regular people, African Americans, stepping forward and saying, "I'm volunteering for this trial," and that's critically important. Your point, I think, about having messengers that come from communities, being able to say, "Here's my experience. You don't want to go there. You don't want to have this experience, and you can prevent it," I think is going to be essential and I think that's part of why local health departments, healthcare systems have got to be reaching out to community organizations, to faith communities, to federally-qualified health centers, to local media, you know, black radio stations or Latinx and begin to talk to them about the vaccine, also to have some of the very people that you're talking about, I mean, I know people who had mild disease in March and in October still have symptoms. They were not hospitalized, they were not suffering severe disease, but they are not back at work because they still have symptoms, young people. So, I think that's vitally important. I also think that what the country has done and rightly so, has invested enormous sums in this because we need this to save lives and begin to recover whatever the new normal will look like. That said, what we have not invested in is the social and behavioral science research to really help build the communication strategies, test those strategies because, ideally, it doesn't strike the day one of these vaccines is approved, it starts, now. These are different platforms. They have different dosages. It's a complex picture we're facing and we're going to have to explain that to everyone and why some are two vaccines, and some are one vaccine, and what does it mean. If you get one of vaccine A and one of vaccine B.

We have a lot to share with the public and I don't think we wait until it's ready for you at Yale or for us at Maryland to start giving it out.

Dr. O'Connor: No, no, I agree and the other thing I thought about is the tremendous loss of life. So, it's not just people having residual symptoms, it's the loss of our loved ones. People who have suffered that loss reaching out to say, "You can help prevent this happening in your family. You can get the vaccine and have less, dramatically less risk of becoming ill." I'm almost concerned that we're just getting fatigued from the pandemic and we are now seeing lower death rates because, quite honestly, we in the medical community know how to take care of these patients better, now and there are other treatments that have come out. And so, we are seeing a lower mortality rate, but we still have patients dying of this illness and we still have individuals, as you just mentioned, suffering longer term consequences. So, it truly is a public health crisis for us.

Dr. Quinn: It absolutely is and I think your point, Dr. O'Connor, is well taken because, you know, you may remember the start of the HIV and AIDS crisis and one of the things that really made a difference in beginning to turnaround HIV infections, particularly, among me who has sex with men, was they were seeing their loved ones die. They were seeing their friends die. These were horrific deaths, and I don't think we're hearing some of the stories from families, as much as we need to hear. I think those are vitally important. The other thing is for African Americans and there's also, for many people, they're working in front-facing positions. They may be in the hospital, they may be a provider, they may be in the housekeeping staff, they may be in the cafeteria, they may be the receptionist in the ER, as well as in other workplaces where they don't have the luxury of working at home, and so, I think recognizing that risk and the horrific consequences we've seen is just something we need to be

talking about more and more with people. We've kind of got caught a lot talking about fatigue and political debates on the steps we need to take to mitigate our risk and not talking about this is having long-term effects on families, affecting them for their whole lives.

Dr. O'Connor: Absolutely. I wonder if the way that patients have died in this pandemic, isolated from their families and, in general, the social isolation that we're going through in this pandemic is part of the reason why we're not understanding this loss better. This general kind of isolation that we're feeling, I'm interested in whether you believe, I don't know if there's any data on this, but whether you believe that further fuels people's sense of, "I don't need the vaccine. I'm kind of isolated." Whether that contributes to people being resistant to having the vaccine. I think the whole country's kind of a little on the depressed side. So, if we look at that and say we're all tired of the pandemic and I haven't been out to a restaurant to have a fine meal since March. And so, my quality of life is different, now, and I say that flippantly and I know that there are far greater issues than whether my husband and I go to a restaurant to have dinner, but, nonetheless, there just is a time, for example, on a weekend evening, when normally we would go out to dinner, that I recognize that I miss it. And so, I wonder if this kind of global sense of loss, if you think that's going to impact people's willingness to have a vaccine?

Dr. Quinn: Yes, I think there is a part of this where many of us around the country are sort of low level of depression and certainly anxiety. I think for many of the people who have suffered far more than you and me because they've lost jobs, I mean for them it's an enormous crisis but we're all experiencing this and I do think that sometimes that sort of for some people, because we don't have a unified message that says to the American public, much as we've seen presidents like President Roosevelt during the

Depression say, we are in this for the long haul. This is going to be difficult. This is going to be painful and I feel for you and we need to look out for each other. So, acknowledging to everyone this is going to be really, hard, just like he had to do during the Depression and at the start of World War II. “This is going to be hard. We’re asking sacrifices of you and I know it will be hard,” and be empathetic. We have not had that on a large scale, and I do think, right now, we need here some of the people saying to us, “We know this tough. We know it’s hard what we’re asking you to do, by-and-large, stay at home, wear your mask, get a vaccine that you’re anxious about. On the other hand, this is what we’re going to have to do collectively. I’m going to do it with you. We’re going to do this together. We know some of us are at greater risk and have suffered more than others, and we’re also going to be here to support them. So, I think there’s not just the scientific part of this, the emotional part of it. There’s also, I think the need for, sort of, a public front-facing, we can do this together, mask and vaccines and looking out for each other are the ways we’re going to do it. Even if we had these vaccines tomorrow, as you well know, as a physician, they will be a scarce medical resource. We won’t have enough for ourselves, much less the world. Initially, it will take time. The other thing is we will have priority groups, based on who is at risk and I think many of us would say those people out in the hospital providing that care, whether they’re cleaning the room or literally providing that care, we’ve got to get them vaccinated. They have to be protected. But we’re going to have to help the people understand that in order to help them be patient, and then, have those early people be speaking about I’ve got it. I’ve got the confidence to get it. I’m still wearing my mask because we’re still going to have to do those things.

Dr. O’Connor: Absolutely. I know. I received an upsetting call today. My husband’s cousin who is an ICU nurse has just contracted COVID and I am praying for her and she’s young and

strong and healthy, so she should recover, but it's still scary and when I go in and take care of COVID patients who have hip fractures because, in my world, we're not doing elective surgeries on patients who have COVID but, obviously, we're doing emergency surgeries on patients who have COVID. So, that's primarily people in an accident or people who break their hip. My family has a lot of angst about me getting sick, of course, when I go in to take care of them, and I know that I have my faith. I'm not concerned about me but it is still an issue about the people that are caring for other people and how we are all in this together, and we're all linked together and that is one thing that I really hope we will learn or have a deeper appreciation of in this pandemic is how much impact each of us have on each other and how much we can support each other when we have a safe and effective vaccine and we all get vaccinated.

Dr. Quinn: Yes. I think, you know, we're all in this together and yet, we always have to remember we don't have the same risk of exposure and the same risk of bad outcomes. So, being able to support people, be they African American or Latinx or native communities who don't have the resources to stay home if they're exposed, we need to say this is important. It's important for these families and it's important for all of us if we make sure that people have what they need.

Dr. O'Connor: Dr. Quinn, I just want to ask you if you have any closing thoughts or closing comments for our listeners today?

Dr. Quinn: As I said this is going to be the long haul. This is not going to be over tomorrow or next month or the beginning of 2021. So, I think it's a call to a couple of things. It is a call to our common humanity. It is a call for us to rededicate ourselves to health equity and addressing the disparities that put so many people at risk. I also think it is

a call because we know enough now about this disease for all of us who can to be cognizant and devoted to improving our health aside from COVID. So, being physically active, reducing weight, if we can, taking care of our mental health and really, doing the self-care and management necessary if we have any of these chronic diseases. This is a wakeup call that we need to be doing those things whether we ever catch COVID or not, for our own health, long-term. So, those are some of the thoughts that I'll leave you with and I really, appreciate the conversation.

Dr. O'Connor: Dr. Quinn thank you so much and I particularly appreciate your comment at the end because this is the Movement Is Life Health Disparities Podcast and, of course, we are passionate about the importance of movement to health. The healthier you are the less likely you are to get sick and we are passionate about the importance of movement to health and, particularly, the importance of movement and health equity. So, I do thank you for that. I want to thank our listeners for joining us today. Remember, you can find and subscribe to the podcast on leading platforms such as iTunes. So, everyone, please stay safe, stay well, and join us, again, soon. Until then, good-bye.

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