CONNECTING CARE PODCAST // EPISODE #5 // TRANSCRIPT

Understanding Structural Racism within HIV and OUD Care

Alex Walley:

For many patients of color with HIV and opioid use disorder, structural racism is interwoven throughout, playing a role in their access to care, their patient experience, and their ability to stay in care.

Bisola Ojikutu:

When we look at issues of policy, we can think about them on a bigger level, so residential housing, segregation, and all the policies that have sort of led to that. But then sort of trickle it down to what's happening within individual people's lives. And I think that's really a good way to think about structural racism so that people kind of understand it.

Alex Walley:

You are listening to Connecting Care. I'm Alex Walley, an HIV, primary care doctor and addiction medicine specialist in Boston, Massachusetts. I'm joined again by my colleagues, Dr. Jessica Taylor and Dr. Sim Kimmel. On today's podcast, we are joined by Dr. Bisola Ojikutu to talk about the impacts of systemic racism in healthcare and our responsibilities as public health professionals and providers to address it on a policy and individual level.

Welcome back to Connecting Care. In today's podcast, we are going to build on our previous four podcasts, which have addressed the intersection of HIV and opioid use disorder in the time of COVID. We had three podcasts on pre-exposure prophylaxis for people who inject drugs, where we covered a case that went well, a case that did not go well, and then our most recent podcast where we featured a program on the front lines that is offering prep and antiretroviral treatment directly to people who inject drugs and who are homeless. In each of these podcasts, race, racism and the structural challenges faced by people who have opioid use disorder and either have HIV or are at risk for HIV have been key to our discussion. Today I'm excited that we are going to focus head-on on the structural racism and discrimination faced by our patients and what can be done about it.

I'm both excited and grateful that we have just the expert guest star to help and guide us through this topic. Dr. Bisola Ojikutu is an expert in addressing racial and ethnic inequities experienced by people living with or at risk for HIV, both internationally and here in the United States. Dr. Ojikutu provides HIV and ID specialty care at Mass General in Brigham and Women's Hospitals. She's an assistant professor of medicine and global and social medicine at Harvard Medical School, and an associate physician within the Division of Global Health Equity at Brigham and Women's. Her research explores the impact of structural factors and norms including racism, discrimination, immigration, medical mistrust, and homo negativity on HIV transmission and the use of biomedical HIV prevention. Dr. Ojikutu co-edited the comprehensive textbook on the HIV epidemic with black and Latinx communities titled HIV in US Communities of Color, the newest edition just out in 2020. Again today, I am joined also by my co-hosts and good friends, Jess Taylor and Sim Kimmel. Jess and Sim, please introduce yourselves.

Jessica Taylor:

Hi, everyone. Really, really thrilled to be here today. Jessica Taylor. I'm a primary care and addiction doc at Boston Medical Center, where I also do HIV care and HIV prevention work. And I'm the medical director of Faster Pass, which is our low barrier substance use disorder bridge clinic.

Sim Kimmel:

I'm Sim Kimmel. I'm an infectious disease and addiction specialist. I take care of patients with HIV in the ID clinic at Boston Medical Center, and I'm also the medical director of a drop-in site for people who use drugs.

Alex Walley:

Bisola, thanks again for joining us today. I hit on some of the selected highlights from your extensive expertise and experience. Please share, if you don't mind, what drives you to focus your clinical care, your research, and your advocacy on the crucial area of racial and ethnic inequities among people with and at risk for HIV.

Bisola Ojikutu:

Thanks, Alex. And also thanks to Sim and Jessica for having me join you today. You know, the honest reason why I focus on HIV is because inequity by race and ethnicity remains such a pervasive aspect of this epidemic. I like a challenge, and certainly the challenge is still there. If you look at the most recent period that's available in terms of data, 2014 to 2018, and solely focus on race and ethnicity, the rate of new diagnosis for black, Latinx and white individuals decreased. However, the diagnosis rate was still more than eight times higher among black individuals and more than twice as high among Latinx individuals compared to white. And among women, these data are even more stark. The rate of new HIV infection for black women was more than 13 times higher than for white women, and the rate for Latinx women is four times higher.

So, as I said, the challenge is still there, and my worry is that as we attempt to end the HIV epidemic and funding is distributed, if we don't approach this work equitably, we'll be leaving the most disproportionately impacted groups behind. So I will continue to focus my research, advocacy and clinical work here because the challenge is still there.

Alex Walley:

Thank you. Can you talk to us specifically about racism and structural racism that you've seen within the health and public health systems that's driving these inequities that you just described?

Bisola Ojikutu:

I think it helps to start with definitions, and the way that I define structural racism is probably a little bit simple, but I think it's helpful to remember. It's basically the totality of ways, both historical and contemporary, so today, that reinforce a system of hierarchy, privilege, and power, that includes white people and excludes non-white individuals. It's, we all are probably aware, not a feature of any one individual, but it's a feature of our world and of the social, economic and political systems in which we exist.

I think it also helps to kind of look at this in terms of examples. So let me pose an example for you to think about, and then we can kind of talk through what this has to do with HIV. A number of studies have noted that issues like neighborhood disorder or neighborhood disadvantage, which really result from centuries of structurally racist policies leading to things like residential housing segregation,

they've looked at this issue and they've found that these issues, residential housing segregation specifically, are associated with worse health outcomes amongst people living with HIV and in higher rates of HIV infection, so higher HIV risk. There have been policies that have been put in place to sort of mitigate that, to address those issues and change our neighborhoods. But the reality is that these situations continue to exist. And as we look around our urban centers, Boston for example, we certainly see that there are areas that are quite segregated and that have suffered from historic and long-term disinvestment.

So, if you look at that and you say to yourself, "What does that have to do with health?" Well, if you think about it just in terms of the resources that are available in those communities, those different neighborhoods may have lower quality healthcare. There may be longer distance to access healthcare services. And in terms of HIV, you're looking at a situation where these individuals in these neighborhoods, who are living with HIV, may have detectable viral loads. So you have a higher community viral load, and you may have a higher risk of sort of drug use network and sexual transmission risk networks. So I think that when we look at issues of policy, we can think about them on a bigger level, as I mentioned, so residential housing segregation and all the policies that have sort of led to that, but then sort of trickle it down to what's happening within individual people's lives. And I think that's really a good way to think about structural racism so that people kind of understand it.

And I'll also add that currently I'm a clinical advisor at the Multicultural AIDS Coalition, which is a local community-based organization. And one of the challenges that we've been facing is that the clients or the patients who are sort of trying to link to health services, particularly the female clients who have substance use disorder, who may be engaging in transactional sex, actually exist and work informally in certain areas of the city. And these are historically lower income areas, but there's gentrification that's occurring, right? And when you have gentrification, you also have hyper policing. You also have disbursement or displacement of people who live there. And it's harder to find these women. They're transient.

Bisola Ojikutu:

... of people who live there. It's harder to find these women, they're transient, and they were naturally transient, but now they're even more transient. So it's been very difficult to locate some of our longer term clients, because they've moved away from the areas that we would normally find them in. So it's these types of issues, these bigger issues, that truly do affect the work that we do. I think that's how you can look at structural racism in a way that makes it very tangible to clinical services as well as within public health.

Alex Walley:

The four of us today on the podcast are all physicians, we're creatures of a health system, and, to some degree, we all participate in public health. You mentioned housing as a example of structural racism, specifically segregated housing and neighborhoods, as well as income disparity. Can you reflect a little bit on, as a healthcare provider and somebody who also advises and works with community-based organizations, how the health system that we're part of also has structural racism as part of what patients face?

Bisola Ojikutu:

Well, I think part of it I mentioned briefly, alluded to, in my previous answer in that oftentimes healthcare services are removed or are separated from the people who are most vulnerable and may need the most. And there hasn't been enough investment in engagement in communities where there needs to be more of these services. Sometimes, and I shouldn't say all the time, I was actually going to

say all of us, but no, I think that there has been some effort, but I think what happens is that there's investment often in the academic center or the hospital or the location where it's the static location, and less actually going into, going out, making the partnerships and collaborations, both with communities and with people who actually need the services.

Because if you're talking about things that are structural, they really do have to have structural solutions. So there has to be something that's happening on the policy level in terms of housing and infrastructure development, that sort of thing. But on the institutional level, we can mitigate the problem by reaching into those communities, by offering more services, by funding paid professional community health workers who are out tracking folks down.

For example, in the example that I gave, working with the Multicultural AIDS Coalition, we do have peers who are out there looking for folks, using their social networks to find people, but we don't have enough of them. We're probably going to lose them eventually to other opportunities. So the same type of investment that we put into services at the hospital or at the static location need to be put into how we are truly engaging and really creating more of community of health beyond the health institution.

Alex Walley:

That point about peer outreach workers and the workforce capacity is crucial, and I hope we'll come back to that. I want to go to Jessica and have her talk about her experience as a leader and provider in a low barrier access clinic that cares for patients who've been stigmatized because of their substance use and because of their race and their reticence to engaging in care, despite a low barrier clinic in a traditional healthcare setting.

Jessica Taylor:

Sure. Thanks Alex and Visol. I think the point about disbursement and access barriers really strongly resonated, because we know that getting into the medical center has become even more challenging when faced with things like hyper policing, disbursement from one's own neighborhood, intersecting stigma related to substance use disorder, race, ethnicity, gender. These are all tremendous barriers.

I can say that sometimes the way I feel as a provider, if I'm caring for a patient who faces all of these barriers and is not able to come in, sometimes for me that emotion is fear, because I might be taking care of someone with a high risk medical condition where I'm not able to easily get in touch or support them or connect to do the care that we need to do.

But unfortunately, I think sometimes the way that plays out is blame on the patient and it becomes a bit of a self-fulfilling cycle, where the first problem that we had was racism and stigma, and then next thing we know, a patient has been labeled as non-adherent or non-compliant because of missed visits, when in fact there were structural barriers that prevented the patient from coming in. And then the next time they interact with the health system, they're walking in to see providers that have a already set expectation about what the interaction will be like that becomes a negative interaction and a stigmatizing one.

I really worry that one of the systemic racism issues that we need to tackle as a health system is making sure that we don't assign individual blame for systems issues. And this is something that we come across quite a bit while serving the same clients that Visol is talking about.

Alex Walley:

So blaming the patient is really a symptom of structural factors in many cases, specifically structural racism. Sim, you work in a program for people who use drugs that's directly across the street from a full

service hospital. From your perspective and your colleagues and the patients you see, how does racism play into preventing them from engaging in care?

Sim Kimmel:

I think a lot of what we do is help people navigate the risks of entering into care or not entering into care from across the street. People come in with high risk conditions needing emergency care, and what does it look like for them to actually go into the hospital? If they have to go to the pharmacy, they have to walk right past the security guards, they feel like they'll be stigmatized, they'll be asked questions. If they're going to go to the emergency room, sometimes people feel like they've had negative experiences in the past and they're traumatized from those experiences and they really want to avoid those settings. I think the patients that we take care of that have experienced racism, that it's even more pronounced than patients who are stigmatized just from using drugs.

Alex Walley:

What are some of the bad experiences that people might have in the emergency department specifically or experiences that your patients have had?

Sim Kimmel:

There's a lot of different kinds of experiences people have in the hospital. If you're using drugs and you want to get medical care, you may not want to stop using drugs in order to get your medical care. And so people sometimes will use before they go to the emergency room expecting that they'll start having withdrawal, or they'll bring drugs into the emergency room, which sets up this kind of guilty... The security guards are looking for people who maybe are bringing drugs in, and then there's these searches in the emergency department, and then escalation and conflict and people leave. In other settings people are actually restrained if there's concerns that there's mental health issues. And these experiences really scar people.

Alex Walley:

I want to spend a minute, I'm not sure when the podcast is going to come out, but this is the week when the Derek Chauvin trial for the murder of George Floyd, the guilty verdict was announced. And so public safety or law enforcement or the war on drugs, I think it's in my mind every week, but it's particularly in the mind of the national consciousness right now. And so this feeling in a hospital where you have security that is there to keep this hospital safe, that experience is going to be very different for some people of color.

I know that my patients have talked about that and I've heard them tell me stories about how they are treated differently because of the color of their skin by the hospital security. And that, of course, echoes from their experience in the community and their experience with law enforcement. So that's another, I think, institution that we actually partner with in healthcare in order to so-called keep our space safe, which I think is another element of the structural racism that our patients are facing be.

Visol, how do you feel about that? Do you have anything to add to the role of law enforcement?

Bisola Ojikutu:

I think that everything that you just stated is critically important to understanding structural racism within our country. This issue of policing, of the criminalization of drug use, of the fear that's built into the training of our police within the criminal justice system, and biases and fear of people of color, people who are...

Bisola Ojikutu:

... and biases and fear of people of color, people who are engaging in substance use. I think that all of that is certainly, I think, in our minds, as people who do this work on a regular basis, but I do appreciate that it's becoming a part of the national discussion around what we should do to change.

There's been a lot in the media, and I'm certainly amongst advocates about defunding the police. And I think that what we need to focus in on is shifting funding away from some of these very hyper criminal, hyper policing systems and moving them into services that people need and that people trust and that people can utilize to improve their access to care and treatment and mental health services as well as substance use services. So I think that if we try to reframe that narrative a bit in how we sort of look at policy, that we're really talking about shifting funding into better systems to keep us safe in a sustainable way as opposed to creating this cycle of mass incarceration that this country is sort of mired in currently.

But I totally agree with everything you said, but just to add into the specifics of what we can do to change policy is think about it in a very concrete way about where funding will go, where will it be shifted to, what is it that we really think will help this process? I think that's important. And I think a lot of that is built into what we should be doing in terms of physician advocacy. And I do think that all four of us on this call are very much so involved in that arena, but being very specific in how we frame our discussions around what we should do about policing in this country and how it might help with our very vulnerable patients, I think, would be advantageous.

Alex Walley:

Jessica, do you want to talk a little bit about your specific interactions in your clinic with security when issues arise with your patients?

Jessica Taylor:

One thing we've reflected on a lot, because we care for a lot of patients that have had negative interactions with public safety, with police, with houses of corrections, with law enforcement, is thinking about our own role and our own contribution to this problem is physicians and providers, in the case of my program, in an interdisciplinary team. It's one thing to say that our patients have had negative interactions with public safety, which is valid and true in many cases, but I think we also need to say, "What are we doing that is starting the chain reaction that leads there?" And really be reflective about when we're activating public safety, and when and how bias becomes a part of that decision.

And so I work in a program that tries very proactively and very deliberately to not activate public safety. And we do so very rarely, a handful of times per year in a program that sees 650 patients per year. We try to be really explicit that we only involve public safety for physical violence risk situations. But we've also made a commitment together as a team team that anytime we do call public safety, we'll do an interdisciplinary team debrief and actually really specifically ask ourselves, "Why did we call? What could we have done differently to deescalate the situation or to have an outcome that didn't involve pulling in public safety? And how did or could race and ethnicity of the patient and race and ethnicity of the provider, of the team members involved, play a role in the decision to call public safety or not public safety? And basically, would the situation have played out differently if instead of, for example, a black patient, if we'd been serving a white patient, would public safety have been involved?"

So thinking about just being comfortable asking those challenging questions and creating a team dynamic where it's not about finger pointing, it's about saying, "Listen, we all have implicit bias. We know that we're working with a population that has had very, very stigmatizing and very damaging, harming interactions with our public safety colleagues who are really, at this point, with everything

they're facing in terms of amphetamine use, in terms of symptoms of psychosis often, they're really faced with a lot. And so we need to take responsibility for our part of starting a chain of events that can result in a bad interaction that impacts our patients.

Alex Walley:

Because there's a structural issue that a lot of money and power go to law enforcement and public safety agencies. That's, I think, a long historical legacy through multiple institutions, and changing that requires the advocacy that Basola is talking about as well as these concrete, specific things that Jessica's mentioning. When our communities are in crisis and we've invested so much in law enforcement, it's no wonder that we go to law enforcement to try to fix the problems. And they're, in I think some cases, not the right institutions to help with that. And so we need to develop other power systems. We have to invest and fund in other institutions and build them up so that they have the capacity to actually better address these issues.

So, Basola, the challenges faced by our patients and facing structural racism are daunting at multiple levels. What can we do at a systems level to address what our patients are facing?

Bisola Ojikutu:

So, I think that's a great question, and I don't think there's any one answer. I don't think that any one system per se, or even if you look at all of our systems together, there is no one answer. What I've seen, or I should say I've not seen, is what I would call cross-sector alignment. So what I'm saying there is really looking at all the different systems and how they should be intersecting to provide the right kind of care for our patients who have substance use disorder, particularly given what we're talking about now looking at structural racism, our patients of color. So what that might look like might be something where our response teams are really built around the fact that we have a multi-sectoral, diverse community partnership between our hospitals or our academic institutions, and we have people out in the community, faith-based organizations as well as community-based organizations, that are well funded to not only just be there to act as first responders, but to really be spreading the message and to decrease the stigma around substance use.

Because I feel like when you're talking about substance use, particularly to my patients of color, the first response is a stigmatizing one. Either it's internal stigma that they're experiencing, stigma that they faced in the healthcare system, stigma within their own communities, and the second one tends to be fear. So they're afraid of the criminal aspect of it or the fact that police are involved. It's also, on top of that, we were just talking about not wanting to go get help because they've been treated so poorly within the known systems. So a way to sort of avoid all that would be to better create systems that they do know and better inform those systems and better fund them so that we have people who are available and who are accessible to folks who may not want to access traditional pathways or who can't access traditional pathways.

Alex Walley:

So well said, Basola. I'd like to take a little time to explore this topic that came up earlier around peer outreach workers really investing more in the community that we're trying to reach and specifically investing through building the workforce capacity from that community. And in my experience, more recently, there have been moves in those areas, but there is more to be done. So I'll go to Sim. You can talk from your experience with your street level outreach program. To develop the workforce capacity for these types of needed workers, what do you see as the opportunities and what are the challenges?

Sim Kimmel:

Yeah. I think it's a really good question. In our setting, we have peer outreach workers who have lived experience, many of them, with substance use. And one of the things that we've tried to figure out is, people who are utilizing our services are entering into early recovery, who are trying to make their way in the world, often don't have...

Sim Kimmel:

Who are trying to make their way in the world often don't have many job opportunities. And so one of the things that we've tried to do is actually try to provide job opportunities for people and actually hiring former clients to work as outreach staff and to pay them and to recognize that their lived experience is in fact valuable work experience and should be compensated for that knowledge. That's one small way, but it obviously needs to be done in a much, much grander scale.

Alex Walley:

[inaudible 00:24:29], do you see a promise in the community-based organizations that you're working with with this approach?

Bisola Ojikutu:

Absolutely. I think the most effective systems that I've seen have been ones that have incorporated peers with their own personal experiences with the patients or the clients that they're working with. Sim made an important point, and we have to pay people appropriately to do the work, otherwise the job doesn't become sustainable. They end up leaving after you've sort of prepared them and done some training. But I think that not only paying them, but there has to be sort of a professionalization, if you will, of this idea of peer engagement and community health worker sort of strategies. And I think people do this and they do it well and it's certainly done globally. It's done locally. But in my opinion, I don't see it done sort of uniformly well in terms of professionalizing them, really training them and certifying them to do their work and making them truly part of the team so that you're shifting power away from those of us who have multiple degrees after our names into the people who have their own lived experience.

As well as, like I said, providing them with the right certification to work in different populations and to develop a real professional skillset. So I do think that we need to think more critically about how to do this in the setting of individuals with substance use disorder as well as other individuals who are marginalized for other reasons. It's certainly being done on a smaller scale, but I really would like to see that done on a broader scale. And let me just emphasize again, this idea of shifting power, because what I oftentimes see is that there'll be somebody, a doctor, a nurse, or somebody else who's sort of in charge of the community health workers, and you don't often see the same sort of level playing field when it's time to make decisions and to determine exactly what it is you're going to do and how you're going to approach problems.

So as we're thinking as teams in our clinics or in our public health departments or settings, we really need to put our sort of standard feelings, our egos or whatever aside, and think about how it is that we can be sort of truly anti-racist. So really address structural racism and shift power to other people who are actually probably better prepared to do the work.

Alex Walley:

It really resonates with my own experience. I'm personally rewarded from taking care of patients who have substance use, many of my patients are people of color and they face racism. There's no way I can do it alone. I always worked in a interdisciplinary team and that team includes people who have lived

experience, have been lucky enough to work on those teams. The way the current structure of the system is, I definitely have the power, as the physician working at a medical center at a hospital, but that doesn't need to be that way. And I think if there was more capacity in community-based organizations to provide these career pathways for people that were really empowered to make decisions and to organize care, that we'd be able to engage a lot more people in healthier care, both for HIV and opioid use disorder. Jessica, what are your reflections on this issue?

Jessica Taylor:

Just listening to everyone. I actually had a patient in mind who I met in 2016 and only came to my office, only not partially because of literally only came into my office, because one of the outreach workers from Project Trust walked her there, sat in the waiting room with her, and then came into the visit and said at least a half dozen times, "No, this doctor's okay." And so it took that intensity of community-based support and peer support to even get in the door of a physician visit. And I still take care of that patient. And she faces many of the barriers that we've talked about today, including displacement, including sex work, including violence and trauma. And she comes back to see me. And the only reason that she was willing to talk to me was that I had a partner in someone with lived experience and who was working as a peer.

So I think as providers, we have to be really humble that of course we have clinical scientific expertise on the medicine piece, but on the art of what's best for a patient in a given moment. On the connection piece, on the environment piece, on the harm reduction front, we really need to be humble that that is not really the strength of our training when we look at the traditional medical school or residency approach. And really make sure that we are giving people not only a seat at the table, but a voice in designing our programs and making our care as accessible as possible.

Alex Walley:

[inaudible 00:29:16], we're so grateful that you are able to join us today and help us with the really important topic. I want to give you the last word and opportunity to pass on your wisdom to our audience and to us.

Bisola Ojikutu:

So thank you so much, Alex. I really enjoyed the discussion. I think the last word is what I would say should be the first word. I think that it's important to have discussions like this that acknowledge that there's a problem, acknowledge that structural racism truly exists and understand what it is, how it impacts our patients. Particularly those who are vulnerable and marginalized and those with substance use disorder, as well as living with HIV or at risk for HIV. But taking it one step further and really looking at where we can have an impact. There's this larger issue of structural racism that doesn't involve individuals, it's really about systems, but we can also have an impact. And I appreciated this discussion because I think that's what we touched upon.

Alex Walley:

Thank you so much. I hope we can have you back sometime and I wish everybody the best.

Bisola Ojikutu:

Thank you.

Alex Walley:

You're listening to Connecting Care. Our program was produced today by JSI and Boston Medical Center. Connecting Care is supported by the HRSA funded project, strengthening systems of care for people with HIV and opioid use disorder. The project aims to enhance system level coordination and networks of care among Ryan White, HIV/AIDS program recipients and other federal, state and local entities. You can learn more about the project and find resources at www.ssc.jsi.com.