

Interview with **Michael Chancley, Part 2**

In Part 2 of this series, Dr. Wood continues the discussion with Michael Chancley around HIV PrEP and stigma. This portion of the discussion dives deeper into the specific role that medical providers and organizations can play in ensuring that patients feel comfortable, well-informed, and empowered to make decisions around their sexual health care.

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Brian Wood: This is part two of the interview with Michael Chancley from PrEP4All on stigma as a barrier to HIV PrEP. We will pick up with Michael's answer to the question of what providers and clinics can do to help individuals feel welcome and comfortable discussing HIV PrEP.

Michael Chancley: Earlier, I said part of that spectrum, almost like the stages of change is realizing like, "Okay, PrEP is for me. I've gotten the awareness, I've gotten the misinformation corrected." And you find out about the medication and copay assistance programs and everything's a go. And then you get in the clinic, you get in front of a provider, and you're ashamed because of inconsistent condom usage. You are ashamed because of your number of partners. You are told PrEP isn't for you because you're in a monogamous relationship or you're a cisgender woman. So I think that becomes like sometimes people are convinced. We talk about the times when people don't know about PrEP and trying to convince people to get on PrEP. But I think we also have to realize that some people are ready to make that step. They're ready to get on PrEP.

And I can speak from firsthand experience, as well as talking to some of my own clients who have... They decided not to get on PrEP at another clinic and either came to us or acquired HIV and had to get into care. Even though they initially wanted to get on PrEP because they were met with stigma. I've had people shame me. I've had medical providers, medical assistants shame me for not using condoms 100% of the time. And as someone with tough skin, as someone who's very knowledgeable about that work, that is still today almost... I've been on PrEP for eight years. And when you're met with that from a provider, no matter how confident you are, no matter how far you've gotten in your advocacy, that is a sharp blow to come and get a medical service and be shamed about your own medical choices.

And so I think if I have tough skin and I'm well-informed and I'm doing all of this advocacy work and I'm sex positive and that still hits me right in the chest. Think about a 19-year-old who is coming to you to talk about PrEP and you're shaming them because of their number of partners. Shaming them because of the inconsistent condom usage, shaming them because they engage in sex work. That person isn't going to want to continue to come and see you every three months to get their prescriptions. That person is going to avoid you. And by avoiding you, that means they're not going to get their labs done. They're not going to answer those calls for a reminder appointment. They're not going to continue to stay on PrEP.

Brian Wood: Absolutely. Mike, I just want to tell you again how much I appreciate you sharing your experience because that really is such an important message. And so learners, especially providers, really, I want them to hear that and take that message home. I will certainly take that message with me. And I'm hearing about the importance of initiating the conversation of building trust, of remaining open, of not shaming, of remaining nonjudgmental. And I'm wondering, I want to ask you for providers who are newer to PrEP and starting to learn about PrEP. I am wondering if you have advice on where to start or if you've ever engaged with a provider who was not as informed, not as knowledgeable about PrEP yet. They are still in the learning process. What did that look like for you and how would you advise providers who are newer to the field to start having these conversations?

Michael Chancley: I think the biggest misinformation I have received about PrEP, and again, I know it's not isolated because a lot of it... I almost feel like any story I can tell, I've had clients who have had the same situations. And it's not the tough questions that people ask that providers get wrong. It's the most basic questions that I've had. I've had providers tell me, "If you miss a single dose, PrEP is no longer effective." And I know that is not true. I've had providers tell me that it takes anywhere from

two weeks to a month of daily PrEP use for it to actually start working. I've had providers exaggerate the failure rate of PrEP to... If they believe I should be using condoms consistently it's like, "Well, I'm going..." Almost like consciously giving misinformation sometimes to... consciously giving misinformation sometimes to fit their own agendas.

But also, sometimes I think I've actually had providers who were not as knowledgeable about PrEP, who were very proactive in trying to learn about PrEP. And again, I think it's sometimes just those basic things. Knowing about dosing, knowing about when PrEP becomes effective, knowing about the on-demand 2-1-1 method. I think, again, we have so much information on the Internet and at our fingertips that when I realize you're giving me wrong information, I don't want to come back to you. Or if I come back, it's strained our relationship. And again, I've experienced that with a dermatologist. So it's not just in the sexual...

Brian Wood: Sure. It's not just with PrEP.

Michael Chancley: ... health field. It's like, "Wait, I've gone on WebMD, and I've found this information and this." And we definitely know there's a lot of misinformation on the internet, but when you find a reliable source like, "Hey, wait, this says this on a CDC website, which is a complete contrast to what you're telling me." So I don't think it takes for a provider to know everything there is about PrEP. We know those guidelines for physicians are very, very, very, very long. But the most basic things, dosing, how frequency, how forgiving it is. I definitely think those things are important, like show you at least know the basic knowledge of how PrEP works. Also, I've actually had providers who rather than give me misinformation, say, "Hey, I'm going to consult with someone in our infectious disease department, or let me go back and reread these guidelines."

And I love that because that shows me that we are working together to give me the best service, not that you are coming as the expert over my health. Almost like we're working together. I don't know all of the answers. My background is in social work, so I'm coming to you because you're a provider. So, I want to, again, going back to that trust issue, I want you to say, "I don't know this answer. Let me get back to you on that."

Brian Wood: No, I really appreciate that point. As a provider that comes up for me in clinic, again, not only in talking about sexual health and PrEP, but with other issues as well. So I feel like I could talk to you all day about this, Michael. And this is such a wealth of experience and wisdom. I do really, really appreciate all of this that you are sharing. And maybe I could ask you on a bigger scale about some of the work that PrEP4All is doing to improve access. And your overall efforts and change you'd like to see in the coming years on a larger scale to help improve the availability and access to PrEP.

Michael Chancley: So the big thing that we have been advocating for is a federally funded national PrEP program, and that's a three-pronged program. So, one of the things that we have been advocating for is obviously addressing coverage barriers for uninsured individuals. So something we've proposed like a PrEP pass, something you can go on your phone and apply for, and just like any medication assistance program, it spits out those insurance numbers. You can bring it to a provider to get your labs done, you can bring it to the pharmacy and get your medication covered. So that's part one of what we've been advocating for in a national PrEP program. Also, provider expansion. Not only does that mean educating more providers, but also making telehealth available. We know that getting sexual health services, being a southerner myself, I love the South. But we know that depending on what region of the South you're in, we know that views around sexual health may not be as

progressive even in a health care setting.

So giving people the option to access telehealth not only through maybe their own phones, but we're partnering with like, the community centers, LGBTQ community centers, intimate partner violence shelters. So having all of these different points of contact where someone can access PrEP services outside of going specifically to a HIV or sexual health clinic. And also, the other part is demand creation. So not only having community-led campaigns to educate and spread awareness about PrEP to fill those gaps where people don't know about PrEP or where people have misinformation. But also, knowing about the programs that exist to help you get on PrEP. Oftentimes, I've had people, they'll go into a clinic, they don't have a PrEP navigator. They just go into their primary care provider and then they get to the pharmacy and realize, "Oh wait, I have this copay or even I'm uninsured. How do I access this service?"

And oftentimes, the information is just right there and like a simple Google search could probably tell you. But again, we can't wait for people to opt in. We have to make sure that these services are... If there's a medication assistance program or if there's a free PrEP program in your city, definitely making sure that there are community-led campaigns where people are learning about those services. That's one of the big things that we've been doing. A big part of the national PrEP program would be having people access affordable generic medications. So, even though definitely, we want to make sure that people have options with which medication they choose, including long-acting injectable PrEP. But for the most part, as we see right now, most people can safely benefit from generic PrEP medication. But there's a lot of misinformation about generic medications in the US where people think that when we hear generic, we think about the cereal that's on the bottom shelf.

And so I've even heard where people are like, "Oh, they're going to force the generic medications on poor Black people while White people get the Truvada." And so letting people know that generic medication is widely used across the globe and for treatment prevention or any other health issues. And that it's effective and it's safe. And a big part of that, again, because money is not finite... It is not infinite. There's definitely only... There's so much that we can put into a federally funded national PrEP program. And to optimize that, we have to be able to take advantage of generic medications as these patents expire on name brand PrEP medications. So definitely, that's been a big part of what we've had to do is just challenge that misinformation and stigma around generic medication as well.

Brian Wood: That's a really interesting corollary to the stigma and mistrust we were talking about earlier. So thank you for bringing that up and making the analogy with the cereal boxes on the bottom shelf.

Michael Chancley: And I've had people reach out to me, both community members and friends, as well as patients when I worked in a clinic like, "Wait, why did they change my medication?" And literally have had people like, "I'm not taking this. I don't know what this is. I've been on Truvada for four years. Why are they giving me..." Yeah. And so having to explain like that's cost savings. Those are the things that keep your insurance premiums down. Those are the things that help you take advantage of these free programs to get on PrEP. That is going to be a key component of a national PrEP program.

So again, I've been on PrEP for eight years. I've been on generic PrEP for about three of those years. So, letting people know it's going to keep you negative, it will likely... I mean, unless you're allergic to one of the inactive ingredients in the medication. Basically, if Truvada had no side effects, I may have only heard of one or two cases where someone switched from Truvada to generic and had a side effect. So just again, challenging that misinformation and letting people know this is a key component to making PrEP widely accessible, not only domestically but across the globe.

Brian Wood: Absolutely. Well, thank you for sharing all of that and doing that work. And there's a lot there about improving coverage, improving access. And then we're coming back to the importance of education and information, engaging in conversations, helping people understand why their medication might be changing. For example, helping individuals understand why the generic might be right for them, might be just as effective, might be important to make that switch or worth making that switch.

Michael Chancley: And being proactive about it because I can only speak to the community members, friends, and clients who reached out to me about it. I've also heard those stories of where people just don't follow back up if something happens at the pharmacy or they don't understand their lab results, and nobody explained it to them. Those are the little things that can make people fall out of care, so sometimes being proactive. Whenever I had a new patient, I'm like, "Hey, if you don't understand your lab results, give us a call, like don't..." I would also mean to say like, "...wait until somebody calls you with the lab results." Sometimes they upload it to the patient portal faster than we could call. And sometimes that medical jargon can be a little misleading and intimidating.

So again, but that would be me being proactive and saying like, "Hey, I'm not a medical provider and I don't even understand some of these lab results sometimes, so I didn't understand generic medication. So hey, if you go to the pharmacy..." If I've been saying the word Truvada, Truvada, Truvada during this whole session, I have to make sure like, "Hey, if you end up with Teva, that doesn't mean that they gave you the wrong medication. That just means that your insurance provider is only covering the generic." And explain what that means. Not always waiting for them to contact me and tell me that they have a problem. Almost like just putting that into my regular spiel about PrEP with new patients.

Brian Wood: No, absolutely. It's an important point and there's a lot of really important messages here. And as a provider, I'm going to take a lot of this with me as a provider who's trying to learn, to grow, to do these things better. So thank you for all of that, and we've certainly talked longer than I intended. I appreciate this. Again, I feel like I have a lot more questions and perhaps at some point we can do a follow-up. But before we wrap up, perhaps we can come back to some of the key points you made and come back to the issues of stigma. And I wonder if there's maybe one or two final just take-home messages you would like to emphasize for providers who are trying to help to disseminate PrEP to individuals who need it or to clinics trying to get set up for this. What would you like to highlight as the key take-home points?

Michael Chancley: I always like the drive home personal choice. It can be very... When you're passionate about the work you're doing, of course I'm not a provider, but I am a social worker who's linked patients to different services. And it can be discouraging when you feel like you were about to get somebody on PrEP and they made the personal decision not to. When you see statistics that one in two Black gay men in their lifetime will acquire HIV. When you see those CDC statistics, it could be jarring to have someone walk out of the office and decide that it's not for them. It could be even more hurtful when that person comes back and tests positive for HIV. And so I always look at it as my goal is not to get people on PrEP. My goal is to empower people to stay healthy.

You know what? If PrEP isn't for you, if consistent condom usage isn't for you, if multiple partners is for you, if sex work is for you and you come back to my clinic one day and you test positive, now the goal is still the same. To keep you healthy. So, instead of trying to convince you to get on PrEP, now we've just moved to making sure we're knocking down any barriers to get you access to HIV treatment. So I think once I started... Because it can be very, very discouraging. And I think once I mentally got to the point where it's like my goal is not to get people on PrEP. My goal is to empower people to make their own sexual health decisions and provide them with the correct information and the correct resources

to stay healthy. Rather than that, "You know what, if you are symptomatic, let's talk to the provider about getting you treatment today and not waiting two weeks for those STI results to come in."

Again, so looking at it more holistically and how we can get people to be empowered around their sexual health, not just this very narrow goal of how can we get patients on PrEP. When you are sincere, we may not think of it as an agenda, per se. When you think of an agenda, you think of big pharma. But we come in with our own preconceived notions. And so again, meeting patients where they are, not coming in with our own agenda, because if my goal is to get you on PrEP, then I'm focused on my goal, not your goal of staying healthy. So again, just learning when to back off, learning when to keep an open ear.

If that person is making a decision based on misinformation or misunderstanding, I always ask, "Hey, if I just explain these labs, hey, could you explain it back to me?" Because if they can explain it back to me, I know they've captured everything that I was trying to say. And I can correct those pieces of misinformation or miscommunication. So again, just making sure that I'm focusing on empowering patients to make their own health decisions, and not to get them to do what I want them to do.

Brian Wood: A really important message. And that brings me back to what you said before about meeting people where they are at. Engaging, building trust, focusing on education, empowerment. I'm glad you brought up that at the end. Empowering people and helping them know that no matter what they decide, no matter what happens, you'll be there for them in a nonjudgmental way. And be there to help them get what they need.

Michael, thank you. We really appreciate your time and for sharing all of your experience with us. So again, this is Brian Wood for the National PrEP Curriculum. Michael, thank you very much.

Michael Chancley: Thank you.

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