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Building Trust and Addressing Structural Barriers in HIV Care

Announcer:
You're listening to *On the Frontlines of HIV* on ReachMD. Here's your host, Dr. Shelina Ramnarine.

Dr. Ramnarine:
This is *On the Frontlines of HIV* on ReachMD. I'm Dr. Shelina Ramnarine, and joining me to discuss how medical mistrust and structural barriers can impact HIV care is Dr. Aliza Norwood. She's the Chief of the Division of General Internal Medicine and an Associate Professor in the Department of Family Medicine at the University of Texas at Austin Dell Medical School.

Dr. Norwood, thanks for being here today.

Dr. Norwood:
Thanks for having me.

Dr. Ramnarine:
So Dr. Norwood, we know medical mistrust can stem from historical and ongoing experiences of discrimination, stigma, and inequalities within the healthcare system. How can these experiences shape the way patients with HIV approach their care and interact with healthcare providers?

Dr. Norwood:
People living with HIV, or those affected by HIV in any way, including those who are eligible for PrEP, are also most likely to have experienced discrimination, historical medical harm, personal medical harm, stigma, or health inequity—all of the things that erode trust. And we're asking patients living with HIV to trust us with very serious medical decisions and a lot of unknown. The greater the unknown and the greater the risk, the more trust you need.

So when we talk about the health of people living with HIV, especially those who have lived through the trauma of the '90s, when we talk about changes with their antiretroviral therapy or when we talk about HIV-related mortality, we can understand why someone may hesitate before trying a new regimen with a doctor that they don't know well yet or become upset when they're misgendered by a clinician or medical staff. When expectations of the healthcare system have not been consistently met, it's easy for any little negative interaction to cause a break in trust. So I would say the way that these negative experiences shape the way patients show up is that they're almost expecting to be mistreated if they have been mistreated in the past.

Conversely, when somebody knows, "My doctor will be there when I need them, the healthcare system will be there, I will be treated with respect, and my expectations will be consistently met," that's what builds trust. Unfortunately, that doesn't happen as often as it should in our system, and marginalized communities and patients often don't get that consistent positive response. So when trust is broken over and over again, mistrust is actually pretty rational and a protective reflex.

Dr. Ramnarine:
So how do you recognize mistrust in the clinic if a patient doesn't mention it directly?

Dr. Norwood:
That's a great question. So while there are research tools that proactively assess trust in a kind of standardized way, we really don't have any clinically validated tools that are commonly used in clinic to assess trust.

So when I first meet a patient, I spend the first visit, again, with that assumption that trust has been lost somewhere along the way, and I lay the groundwork for trust building by asking three questions and making one statement.

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So first, I ask if they have any pressing needs that we should make sure to address today. I'm letting them know that I care about their concerns over my agenda. I'm intentionally aligning with them and letting them have the power to set the agenda. And if there's more than a couple of concerns, I let them know what we can address today and when I can bring them back to tackle the other things so they have clear expectations.

The second question I ask is more global. It's, "What are your most important goals for your health or even your life that you want me to know about?" Sometimes I'll say, "In the next year or the next couple of years." That helps me understand what's most important to them, and it generally opens up the conversation to be a little bit more human for us to talk about their concerns as a whole person rather than the transactional medical problems.

The third question after that is: “How do you think I, as your doctor, can be most helpful to you? What's worked and what hasn't worked with doctors in the past?” That's the most direct question about mistrust that I use because it opens the door for patients to be able to say, "I had this bad experience in the past, and this is what happened." And then I can be proactive about saying, "I'm so sorry. I'm going to make sure that doesn't happen to you again," or, "I'm going to do everything I can to mitigate that." But it also allows me to learn what did work for them well in the past.

And then finally, I take a page from trauma-informed care and recognize that autonomy and control help people feel safe and less vulnerable. So the more control a person feels, the less vulnerable they're going to feel around me. That translates into more trust, and it's more likely that they're going to make that trust leap with me. I say, "I want to share with you my philosophy as a primary care doctor. Is that okay?" And I say, "My philosophy is that my job is really to be your personal consultant, to give you medical information, to tailor it to those goals that you shared with me, and to give you the information so that you can make the best decision for yourself. It's not to tell you what to do with your body, and you are always going to be in control of your health plan." Many patients have had a top-down paternalistic experience where they haven't really been given the opportunity to say no to a doctor. So I'll say, "If I give you information and even make a recommendation, if you decide that's not what you want to do, that's okay. I just want you to have all the information." And I usually see shoulders come down after that.

Dr. Ramnarine:
And beyond medical mistrust, what are some of the most significant structural barriers that people living with HIV face, and how can these challenges affect their ability to access and engage in care?

Dr. Norwood:
So I think about barriers to engagement and care in three buckets: individual barriers; another bucket is relational, so how does this patient feel like they relate to the healthcare system or to their doctor; and then the third is the structural bucket, which you just asked about. So that structural bucket includes insurance, transportation, housing, and competing priorities like work or childcare—those social determinants of health. But it also includes the way that we've set up our healthcare system: the 15- or 20-minute primary care appointments and an inadequate investment in case management and social work. Those also present barriers to being able to address a patient's needs and retain them in care.

Our healthcare system is largely passive. We wait for these busy, sick people to find the means and the ability to come to us. We aren't very proactive in reaching out for the most part, and that can be really hard for people, especially those most at risk for poor health. I would frame that as a really large structural barrier that we do have the power to change if we can rethink how we deliver healthcare.

Dr. Ramnarine:
For those just joining us, this is *On the Frontlines of HIV* on ReachMD. I'm Dr. Shelina Ramnarine, and I'm speaking with Dr. Aliza Norwood about navigating medical mistrust and structural inequities in HIV care.

So Dr. Norwood, could you tell us about a patient with a low level of trust and explain how you approached their care?

Dr. Norwood:
I once had a patient who told me he didn't like taking medication because it reminded him of his diagnosis, and he had a lot of internalized stigma and shame, so he often missed his pills. So sometimes he would be suppressed, and then sometimes he just couldn't really bear to take the pills, and his viral load would go back up. I counseled him about newer medications that we could change him to and all of the evidence-based reasons that it would benefit his health to switch to a newer single-tablet regimen.

But we were early on in our relationship, and he did not want to make a change. Even though he hated the big pill and all that it reminded him of, it was a known quantity, and that new smaller pill was unknown. And I was basically this stranger asking him to take that trust leap with me to that unknown. And he was scared. The stakes are really high. What if I'm wrong and this medication I'm recommending doesn't actually work? What if he ends up with resistance? What if he develops AIDS again? And we just had not

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developed the trust necessary for him to take that leap.

So I recognized that the problem wasn't education; the problem was trust. So what I did in that case was I saw him regularly. I learned about him. We shared laughs. We talked about his other health issues. I connected him to our case managers for his social needs, and we developed a rapport. And about a year, maybe a year and a half later, one day, he said, "Do you really think I'll be better with this newer medicine?" And I said, "Yes, I do, and I'm recommending it because I care about you, and I think it will help." And he said, "Okay", and then almost immediately after that change, his viral load was undetectable. And he was elated because this new smaller pill was so much easier for him to take, and he said, "I don't feel like a sick person taking this." And that was such a positive experience that it built trust for the next leap that we would have to do.

So COVID hit, and when the COVID vaccine came out, he was definitely in a high-risk category where he would benefit from getting the vaccine. But he really didn't want to get it, and he had heard a lot of misinformation. And I remember sitting in the exam room with him, and he pulled up a video of an influencer on his phone, and it just didn't have any basis and real evidence. I didn't lecture or counter the points that this podcaster was making. I just spoke from my heart and was honest in that moment. I said something like, "I feel angry that this person is lying to you, and you know that I care about you, and I wouldn't be recommending this if I thought it would hurt you. I got it. My whole family got it. I'm recommending it to you because I want you to be safe and healthy. But this is your body, and you get to decide what you want to do." And I give that as an example not to say that's what every clinician should say. I was a little emotional because that felt true to me in the moment. But I think this demonstrates the general recipe of trust building with the understanding that it has to be adapted to individual styles. And in this case, in the end, he got the vaccine, and given his initial views on it, I think that showed me how much he trusted me.

So I think of mistrust as a vital sign, just as important as the blood pressure we take. But unfortunately, we're not taught the skills we need to recognize, measure, and address it. So I think it's just important to be curious about what barriers a patient is facing and to really build the relational capital so that when somebody is unsure or uncertain or feels scared, they listen to your recommendation and know that you're coming from a place of caring.

Dr. Ramnarine:
And while building trust is essential, many barriers extend beyond the patient-provider relationship. What steps can clinicians take to address these broader challenges and create more accessible, supportive environments for HIV care?

Dr. Norwood:
I think this is a great question, because I do think that we can look to our own structures to figure out what we're doing that undermines trust building, and promotes engagement and care. I think most fundamentally, the way that we define engagement and care and measure it should improve trust and should be responsive to what the patient thinks is important.

I'll give you an example. The Ryan White engagement and care definition is defined by regular participation in HIV medical services. So that means documented clinic visits or viral loads and CD4 counts to achieve and maintain viral suppression. So the engagement and care definition is all about medical visits, lab testing, and viral suppression. And don't get me wrong, I'm an HIV primary care doc, and I know that HIV viral suppression is very important, but it's not the only thing that patients care about. And if we don't embed measures of whether or not patients' overall lives are improving, then we're going to lose them in engagement and care.

Researchers from the Women's HIV Program at UCSF found that women living with HIV in their clinic were actually more likely to die from trauma than from HIV, trauma being addiction, violence, or depression. This is just one example of how if we just focus on these measures of a particular clinical state and use that as our corollary for engagement and care, we're going to lose patients, because we may not then be creating clinical incentives for us to address their trauma or to address their addiction, when actually, addressing that is what would keep them in their HIV care. So although it seems a little bit outside of scope, it is all related to trust building and keeping patients engaged in care.

Dr. Ramnarine:
That's a great way to round out our discussion on this topic. I'd like to thank my guest, Dr. Aliza Norwood, for joining me to discuss how we can address medical mistrust and structural barriers in HIV care.

Dr. Norwood, it was great having you on the program.

Dr. Norwood:
Thanks for having me.

Announcer:
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