Racism in Medical Settings May Reduce Willingness to Take HIV Meds

HIV stigma and worries about disclosure were also associated with lower odds of taking treatment as prescribed.

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People living with HIV who experienced racism at clinic visits were two times less likely to take their antiretroviral medications as directed, according to data published in AIDS and Behavior. Other types of stigma and concerns about unwanted disclosure of HIV status also played a role.

The results won't surprise many Black, Latino and other people of color living with HIV. Medical racism has long been a factor affecting engagement in HIV care, which has been linked to a higher likelihood of an undetectable viral load and its health benefits.

Kaylee Crockett, PhD, of the Center for AIDS Research of the University of Alabama at Birmingham, and colleagues surveyed people living with HIV and the health care workers who serve them—from front desk staff to physicians to pharmacists—at seven HIV clinics in Alabama and Tennessee between June 2018 and May 2019.

The surveys asked people living with HIV to describe their experience of HIV stigma, other types of stigma, willingness to disclose their HIV status and how often they took their antiretrovirals. Clinic staff were asked about what they had observed.

In addition, 44 people living with HIV (out of 762 surveyed) and 56 clinic staff members (out of 192 surveyed) went on to participate in 14 focus groups to talk about their experiences or their observations in more detail.

The researchers found that HIV clinics were generally perceived to be nonjudgmental spaces. For instance, the surveys showed that people living with HIV and their providers rated HIV stigma in the clinic as happening nearly never. Mean scores were 1.3 for people with HIV and 1.2 for clinic staff. (A score of 1 meant that respondents had never seen it happen while 4 meant they saw it most of the time.) What's more, clinic staff reported that they provided extra support for people who were or might be living with HIV (2.9), and people with HIV noticed it too (2.1).

But some stigma and other negative experiences did remain. For instance, 17% of people living with HIV said that a healthcare worker had disclosed their HIV status without their permission in the last year, and 9% of healthcare workers said they had witnessed this. And one clinic staff member described overhearing nurses telling each other that they didn't want to go into an exam room where a person with HIV was sitting, because that particular person wasn't on treatment and was using drugs.

More often, however, medical stigma came when people went outside the HIV clinic for care—to dentists or even to the emergency room. One person described being taken to the ER for a blood infection, and the doctor insisting on finding out how they acquired HIV before treating them.

There was also a lot of everyday discrimination. While many people reported no discrimination, nearly half reported experiencing six types of discrimination. Most common was racism: People with HIV reported around 275 instances of racism in medical care. This was followed by queer-phobia (discrimination based on sexual orientation or gender identity), sexism, discrimination based on income and discrimination related to substance use.

And while the researchers couldn't say for sure that difficulty remembering to take HIV medications was the direct result of experiencing discrimination, they certainly were associated. Most significantly, experiences of racism at the clinic were associated with a two-fold decrease in the odds of taking antiretrovirals as directed. In addition, people who'd experienced any kind of stigma in a healthcare setting were 38% less likely to take their meds as directed, and people who worried about HIV status disclosure adhered to treatment 29% less often.

"Even a rare occurrence of stigma in this type of setting—where a client has come to receive help and support—can be highly memorable and damaging," wrote Crocket and colleagues. "Addressing HIV stigma alone will be insufficient based on measures of everyday discrimination. Other forms of discrimination that people with HIV face, such as homophobia, racism, sexism, economic situation and substance use stigma, must necessarily be addressed to create safer spaces for people living with HIV to receive care."

Click here to read the study abstract.

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