PrEP, a Key HIV Prevention Tool, Isn't Reaching Black Women

Black women face obstacles like lack of awareness about who would benefit from PrEP and medical professionals wary about prescribing it.

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Alexis Perkins thought her OB-GYN's office in Atlanta would be just the place to get a prescription for the type of drug that reduces a person's risk of contracting HIV.

But during a recent visit, the medical assistant who greeted her had not heard of the medicines known as preexposure prophylaxis, or PrEP, and she seemed uncomfortable discussing it, Perkins said. Her provider had heard of it but didn't feel confident prescribing it.

"She was at least honest enough to say that she was interested in it, but she didn't really know that much about it," said Perkins, a 25-year-old nurse, who decided to get on PrEP after participating in a sexual health education class and thinking more about her own risk. She's still trying to find a provider to write her a prescription.

"If I wasn't really confident in myself, this could have been a very discouraging experience," Perkins said.

PrEP is a crucial tool in the fight against the ongoing HIV epidemic and, when taken as prescribed, is highly effective at preventing infection from sexual contact or injection drug use.

But more than a decade after the first PrEP drug was approved for the U.S. market, one of the groups that would benefit most from the medications isn't taking them: Black women, such as Perkins, whose gender identity align with their sex assigned at birth.

Doctors, public health researchers, and those who provide HIV treatment and prevention services say long-standing, systemic factors, such as stigma and racism, are major barriers to PrEP uptake among cisgender Black women. Transgender Black women face obstacles to PrEP uptake as well, especially discrimination related to their gender identity.

But many researchers focus on cisgender Black women, who, they say, are often overlooked by the health care system and face obstacles like: noninclusive marketing leading to a lack of awareness about who would benefit, fewer treatment options for women than for men, and

medical professionals wary to prescribe it. These challenges are even more apparent across the South, which has the highest rates of new HIV diagnoses in the country.

Women had about a fifth of new HIV infections in 2021, according to recent data from the Centers for Disease Control and Prevention. And cisgender Black women made up an outsize share.

“If we don’t figure out how we can change the system, we’re just going to continue to keep failing Black women,” said Tiara Willie, an assistant professor of mental health at the Johns Hopkins Bloomberg School of Public Health.

The FDA has approved three drugs for use as PrEP: the pills Descovy and Truvada, which also has a generic version, and the injectable Apretude. Descovy is newer and comes in a smaller tablet than Truvada, which can make it more desirable. It was approved for men and transgender women who have sex with men, but wasn’t tested on people assigned female at birth.

That decision frustrated HIV researchers and advocates, including Rochelle Walensky, who worked at the Harvard University Center for AIDS Research before later leading the CDC.

In a 2019 editorial, Walensky and her colleague Robert H. Goldstein criticized this “two-tier system,” in which men can get the medication knowing it’s safe for them and with insurance approval, but women can’t.

Gilead Sciences, the company that makes Descovy, later announced it would conduct a trial focused on the drug’s use among cisgender women. The company said that study is ongoing, with data expected in late 2024. The CDC, for its part, earlier this year announced an $8 million grant to fund studies on strategies to increase PrEP uptake among Black cisgender women.

Black women face the same obstacles as other populations when it comes to PrEP, researchers said, but many do so with fewer resources. Recent data from the U.S. Census Bureau shows Black Americans disproportionately live in poverty and women are more likely than men to live in poverty.

Taking PrEP requires regular testing and doctor visits to check for HIV infection, which can present a “tremendous barrier” to access because of cost and logistics, said Michael Fordham, a program manager at the University of Alabama at Birmingham’s 1917 Clinic, the largest HIV care facility in the state.

“We’re actually seeing PrEP patients more frequently than we see our patients living with HIV that are stable,” he said.

The CDC updated its PrEP guidelines in 2021 to reflect the latest science and drug approvals, but the agency has heard complaints from providers that they’re still too onerous, said Robyn Neblett Fanfair, acting director of the agency’s Division of HIV Prevention. She added the CDC is “moving toward” guidelines that are more “timely and nimble.”

Fanfair said her division is also focused on reducing the costs associated with taking PrEP, which can be significant. Just starting on PrEP can cost more than $2,000.

For now, the federal government mandates that private insurance plans cover PrEP, even as that rule faces a legal challenge. Still, in a recent study, CDC scientists found some 50,000 people had uncovered PrEP costs in 2018.

“Policies that increase access to health insurance, such as Medicaid expansion, can improve access to PrEP,” the study said. “This may be especially impactful for the southern US,” where many states have yet to expand the state-federal insurance program for low-income people under the Affordable Care Act.

But paying for PrEP isn’t the only barrier to access, especially in the South.

HIV and other sexually transmitted infections can still be uncomfortable for physicians and nurse practitioners to talk about in the “Bible Belt,” despite their prevalence, said Anitra Walker, the vice president of operations at Mercy Care, an Atlanta-area health clinic that gets federal funding.

Social stigma not only can prevent Black women from talking about PrEP with their friends, neighbors, and doctors, but it can seep into their domestic relationships, said Mauda Monger, an assistant professor at the School of Population Health at the University of Mississippi Medical Center.

“If their partner is the person providing their housing, their food, and resources for their children, saying ‘I’m on PrEP’ openly may actually put her livelihood in jeopardy,” said Monger, noting further that broaching the subject can put women at risk of physical harm.

Increasing PrEP uptake requires expanding access to good jobs, affordable health care, and stable housing, Monger said, to allow Black women to feel more empowered to take control of their health.

Researchers also said messaging about PrEP and how it’s marketed needs to change.

Willie, from Johns Hopkins, conducted focus groups in 2019 in Jackson, Mississippi, with Black cisgender women, who said they felt their experiences weren’t reflected in advertising campaigns for PrEP.

If “it wasn’t just gay men or transgender people who are in the ads,” one participant said, “then it would make everybody feel like … it’s not just for specific people.”

Researchers have to “work upstream” to undo those perceptions once they take hold, said Jessica Sales, an associate professor at Emory University’s Rollins School of Public Health.

Sales is partnering with Atlanta sexual health nonprofit SisterLove to train a small fleet of “influencers” to host informal conversations with community members and study their

effectiveness in increasing PrEP knowledge, interest, and uptake among cisgender women. Perkins, the nurse who was unable to get a PrEP prescription from her OB-GYN, is part of the cohort.

SisterLove's Healthy Love curriculum, backed by the CDC, gives Black women and their social groups the "freedom to hold conversations differently" than they would with medical providers, said the group's founder, Dázon Dixon Diallo.

Failing to ensure cisgender Black women have access to — and are actually interested in taking — PrEP will undermine the fight to bring the HIV epidemic under control, Diallo warned.

There's "damage that has to be undone," she said. "If we're not centering Black women in this epidemic, we are getting nowhere to the end."

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