Troublesome Challenges Persist

Why aren't the very young people whom Truvada as pre-exposure prophylaxis would help the most using this HIV prevention pill?

September 3, 2018 By Benjamin Ryan

Of all people, Kareem Alexis should be able to successfully jump through the numerous hoops required to access Truvada as pre-exposure prophylaxis, aka PrEP. The Georgia State University graduate is highly educated and super savvy about health care. He is midway through his studies to receive a master's degree in public health from Columbia University and a medical degree from Duke University. He assisted with research about PrEP access among young men who have sex with men (MSM). Crucially, he has health insurance and easy access to a campus physician.

And yet, despite his acumen, this 25-year-old gay man has struggled mightily to get his hands on a steady supply of the light-blue HIV prevention pill.

Alexis is up against a daunting behemoth: the health insurance industry. As PrEP use has swelled in the United States, many insurers have erected new barriers that may impede access to the prevention regimen, which costs over $1,500 per month. Alexis reports problem after problem satisfying a Blue Cross Blue Shield requirement that he receive PrEP only through a specialty mail-order pharmacy. His attempts to navigate the bureaucratic maze before him have been further complicated by a need to switch doctors after he moved from North Carolina to New York to conduct his coursework at Columbia.

"I'm embarrassed about it because I know how this works," says Alexis of his difficulty in accessing PrEP, which he had been taking for months before his insurer stopped allowing him to refill his prescription at his local pharmacy. "I needed to admit to myself: I need to ask someone for help." He recently sought counsel from the researcher at Duke under whom he worked, saying to her, "I know I'm helping you publish these papers about how PrEP access is needed. But I need to get it myself, and I don't have it."

"It was so humbling," he says of that phone call.

To Alexis, who remains HIV negative, PrEP was a logical solution to this sort of damaging anxiety and to his own risk of contracting the virus.

Indeed, HIV-negative MSM who have jumped on the PrEP bandwagon report many emotional benefits from taking Truvada, including a greater sense of intimacy with their partners as well as a

greater acceptance of HIV-positive men. “And new research suggests that rising PrEP use in the United States is in fact independently associated with declining HIV diagnosis rates.”

According to Gilead Sciences, which manufactures Truvada, by the middle of 2018, an estimated 180,000 U.S. residents were taking the tablet for HIV prevention, up from 153,000 just nine months prior. Truvada, which consists of the meds tenofovir disoproxil fumarate and emtricitabine, was approved as PrEP in July 2012.

If taken daily, PrEP has the power to reduce the risk of HIV among men who have sex with men by an estimated 99 percent or more. (To be clear, pre-exposure prophylaxis isn’t exclusively for men who have sex with men. PrEP can also help other HIV-negative men—as well as women—lower their chances of acquiring the virus.) When Gilead conducted an in-depth analysis of those who had started PrEP as of the fall of 2016, it found that about three quarters of them were white. Eighty-five percent of the overall group were men. A more recent analysis estimated that just 15 percent of those who have ever tried PrEP are younger than 25.

In light of recent HIV diagnosis trends, the lopsidedness of these PrEP uptake numbers reveals the troubling truth lurking behind all the recent fanfare about the HIV prevention method: It is failing to reach many of those who stand to benefit from it the most.

According to the Centers for Disease Control and Prevention (CDC), of the nearly 40,000 HIV diagnoses in 2016, about 44 percent were among African Americans and 26 percent were among whites. This means that per capita, Blacks had an HIV rate about eight times that of whites. Seventy percent of diagnoses that year were among MSM. Of all U.S. diagnoses in 2016, a respective 26 percent and 19 percent were among Black and white MSM.

The good news on the youth front is that between 2008 and 2015, the estimated annual HIV transmission rate among 13- to 24-year-old MSM dropped by 21 percent, from 9,800 to 7,700 new cases. But this still leaves considerable room for improvement during an era when an increasing number of state and local public health departments are talking about “getting to zero” new infections, or at least something close to it.

In their quest to promote PrEP use among African-American MSM, advocates face the added challenge that in this racial group, new HIV cases are much more concentrated among young people compared with the breakdown among white MSM. About 30 percent of new HIV cases among MSM are among those who are 13 to 24 years old. In this age range, about one in six new diagnoses occur among white MSM, and nearly half of new cases occur among Black MSM.

The fact that PrEP was only approved by the Food and Drug Administration (FDA) for adolescents, including those younger than 18, in May 2018 has complicated very young MSM’s access to the HIV prevention tool. A recent analysis of data from at least 80 percent of U.S. retail pharmacies found that only a few hundred people ages 12 to 17 had a PrEP prescription in either 2016 or 2017.

With PrEP now approved for their age group, whether a significant population of high-school-age

MSM will succeed in both accessing PrEP and sticking to the regimen is up for speculation.

Lacking significant real-world evidence regarding PrEP uptake among young MSM, researchers and clinicians have had to read the tea leaves in the findings from two yearlong PrEP studies—ATN 110 and ATN 113—conducted recently. One was among a cohort of 18- to 22-year-olds; the other focused on 15- to 17-year-olds.

“Those studies were not home runs,” says Kenneth Mayer, MD, medical research director at Fenway Health in Boston and one of the nation’s leading PrEP researchers. He is careful to add: “But I think there are some youths who have their act together and can very much get PrEP as part of an HIV risk-reduction strategy.”

In both studies, rates of adequate adherence to the daily Truvada regimen among the participants, who were at very high risk of contracting HIV, were substantial during the first three months: About 50 to 60 percent took at least four tablets per week. (Truvada’s effectiveness is dependent on consistent use and drops off among MSM if they take fewer than four tablets weekly.) After this point in the study, the participants were no longer required to make monthly clinic visits and instead received such monitoring only every three months, as is standard to maintain a PrEP prescription. Following the scheduling protocol shift, the proportion of participants hitting the four-tablet-per-week adherence threshold plummeted and ultimately fell to between 23 percent and 34 percent.

By the end of the study of the 18- to 22-year-old males, the Black participants had almost entirely stopped taking Truvada.

PrEP advocates have gone to great lengths to tout what they characterize as the silver lining of these studies, claiming that groups of young high-risk MSM can indeed do well on PrEP if monitored monthly.

A litany of variables can keep MSM of any age from accessing PrEP. The first step for young guys is simply to identify that they are at risk for the virus. Next, they have to know that pre-exposure prophylaxis exists, how well it works, what is and isn’t true about any associated risks and side effects, how to get a prescription and how to pay for it; they also need to decide that taking a daily pill is something they want to do and can handle. After that, there’s the potentially daunting task of finding a willing medical provider who offers the care and guidance that make young MSM feel comfortable talking about subjects as sensitive as sex and HIV prevention.

As clinicians await the results of more studies investigating PrEP use among young MSM—not to mention greater anecdotal evidence—those seeking to promote its use in this population are being as creative as possible in their approaches. For example, at Fenway in Boston, researchers are evaluating the use of peer counselors and advocates as a better means of connecting with at-risk youth than, in the words of Fenway’s Kenneth Mayer, “talking to an old fart like me.”

“We expect that with improved outreach to both young adults and health care providers, more people younger than 25 will increase their use of PrEP,” says Dawn K. Smith, MD, MPH, a CDC

epidemiologist. “Additionally, as ongoing research presents new methods to advance adherence among young adults, we expect PrEP adherence among these groups will improve.”

A major research project by investigators from the University of North Carolina and Emory University is examining a cornucopia of smartphone apps designed to address the full spectrum of barriers impeding young people’s access and adherence to PrEP.

Also on the horizon are the much-anticipated in-depth analyses of the major HPTN 073 study, which has tested innovative means of fostering PrEP adherence among Black MSM. The investigators in that study, in which about 40 percent of study members were 25 or younger, emphasized taking care of the participants holistically and addressing not just their risk for HIV but also the other factors that may undermine their use of PrEP, including racism, homophobia, unemployment and unstable housing.

As Kareem Alexis keeps trying to iron out the administrative mess with his insurance company, he advises other young MSM seeking PrEP to stay the course. “Ask for help and keep asking for help,” he says. “Because if things don’t work out for you, it’s not that you’re incapable or it wasn’t meant to be. It’s because there are so many roadblocks intentionally set up for you.”

That said, Alexis acknowledges an unfortunate truth: Others less motivated to get on PrEP may indeed give up in the face of such obstacles.

“If I didn’t care enough about it, I would’ve stopped a long time ago.”

Lessons in PrEP

How two young men got educated about pre-exposure prophylaxis

When Andrew Perry, 23, attended public high school in Peachtree City, Georgia, the institution provided only the most cursory sex education, which didn’t include information about sex between men.

“It was much more of a community education, rather than a formal education from anywhere,” Perry says. He says he learned about HIV and prevention of the virus through pop culture, Google searches and conversations with friends.

Like Perry, Alex Mangus, a 23-year-old who recently received a BFA in fashion design from Pratt Institute in New York City and now lives in the San Francisco Bay Area, says he learned his first big lesson about PrEP from a guy he exchanged messages with on Grindr. (The popular hookup app has been instrumental in normalizing PrEP use since it began providing users a way to indicate on their profiles that they’re HIV negative and taking Truvada for protection.)

Young people wishing to keep their PrEP prescription a secret from family members may run into a wall if they’re on their parents’ health insurance plan, which may send home a report with a line item for Truvada. (However, it may be possible to work around this administrative problem.)

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