Generation PrEP?

Pre-exposure prophylaxis has an uncertain future among youth under 25.

April 2, 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 (PrEP) to prevent HIV.

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 has 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 that consists of the meds tenofovir disoproxil fumarate and emtricitabine and that—if he takes it daily—has the power to reduce his risk of contracting the virus by an estimated 99 percent or more.

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 can cost over $1,000 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.

As a young Black MSM, Alexis belongs to the demographic experiencing the nation's highest rate

of new HIV cases. When, as an undergraduate, he learned about Truvada's use as HIV prevention through a young Black leadership group, he was living in Atlanta, a city where, according to a recent estimate, a staggering 11 percent of his peers contract the virus every year.

This astonishing statistic turned personal for Alexis during his junior year at Georgia State when a fellow young Black man he had been involved with disclosed that he'd tested positive for HIV.

"I felt like I was him," Alexis recalls of the emotional impact of the news. "I could've been him. It really put me on alert. I learned how harmful that is—that sense of panic."

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 although it's too early for public health investigators to gain a firm handle on how Truvada is affecting the rate of HIV transmission among MSM across the United States, encouraging signs indicate that the daily drug regimen is already having a significant impact.

Whether PrEP is a sweeping solution to the high rate of HIV transmission among young MSM, and those who are Black in particular, is another question.

Kareem AlexisCourtesy of Kareem Alexis

According to Gilead Sciences, which manufactures Truvada, by the end of 2017, the estimated number of U.S. residents taking the tablet for HIV prevention had jumped fivefold in three years, to 153,000. (Truvada was approved as PrEP in July 2012.) When the company 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—presumably almost all of them were MSM—of whom just 11 percent were younger than 25.

These demographic figures bode well for the future of the HIV transmission rate among older white MSM. But 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 is that between 2008 and 2014, the estimated annual HIV transmission rate among 13- to 24-year-old MSM dropped by 18 percent, from 9,400 to 7,700 new cases. But this still leaves considerable room for improvement in 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 target PrEP among African-American MSM, advocates face an added challenge given 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. About one in six new diagnoses occur among white MSM, and nearly half of new cases among Black MSM occur among individuals in this age range.

The fact that PrEP isn't approved for those under age 18 has complicated very young MSM's access to the HIV prevention tool, since insurance companies may be unwilling to cover off-label prescriptions for Truvada. Fortunately, this impediment might be eliminated in mid-May 2018, when the Food and Drug Administration (FDA) is expected to decide whether to lower the minimum age for PrEP prescriptions, possibly to as low as 15.

Whether a significant population of high-school age MSM would 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 and 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. However, it is arguable that neither study kept these young participants on a schedule of monthly clinic visits over a long enough period to strongly support such a presumption. And a key question remains unanswered: Is asking teenagers to visit the doctor every month a recipe for success over the long term, or does this amount to yet another blockade?

Daniel Chiarilli, PhD, the associate director of the Gay Health Advocacy Project (GHAP) at Columbia University's student health center, says some undergraduates who receive PrEP there "will put up holy hell" over having to stop by the campus health center even every three months for monitoring—despite the fact that most of them live and attend classes no farther than a block or two from the site.

A litany of variables, both internal and logistical, can keep MSM of any age from accessing PrEP. These factors are often magnified by adolescence, a period during which individuals are less certain of their sexual orientation, less engaged in the health care system and less likely to adhere to a daily drug regimen.

The first step for young guys is simply to identify that they are at risk for the virus. Next, they have to know that PrEP 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.

Andrew PerryCourtesy of Andrew Perry/Andrew Humphrey

“It was much more of a community education, rather than a formal education from anywhere,” says Andrew Perry, 23, of how he came to seek out PrEP. His public high school in Peachtree City, Georgia, provided only the most cursory sex education, which never addressed sex between men. So he says he learned about HIV and prevention of the virus through pop culture, Google searches and conversations with friends.

Similarly, 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 prevention.)

Those 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, this administrative problem can often be worked around.)

“There’s a real concern among youth about confidentiality and privacy if they’re trying to access PrEP and their parents either assume that they’re HIV positive or they’re gay if they haven’t come out,” says Jeffrey Burack, MD, MPP, the co–medical director of the East Bay AIDS Center in Oakland, California.

Perry, who recently graduated from the Georgia Institute of Technology and has relocated to Washington, DC, for a job in software engineering, is one of the fortunate ones in this regard. Not only did his conversation with his mother (who holds his insurance policy) about his desire to go on PrEP go smoothly, but one of the reasons she so readily supported him was that even his 30-year-old brother, who is straight, knew about PrEP and was adamant that Perry should arm himself with a Truvada prescription.

Once young people have successfully navigated the murky waters of insurance and gotten their hands on regular 30-day supplies of Truvada, then comes the task of sticking to the daily regimen.

“For a lot of youths—young adults and adolescents—taking a pill a day is not something that is part of their routine,” says Burack.

“I can barely take my daily medicine right now,” reflects Perry as he prepares to access PrEP for the first time.

Alex MangusCourtesy of Alex Mangus/Christopher Mccann

As they await the results of more studies investigating PrEP use among young MSM—not to mention greater anecdotal experience—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 participants 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.

One of that study's lead researchers, Darrell Wheeler, PhD, MPH, who is vice provost for public engagement and dean of the School of Social Welfare at the State University of New York at Albany, stresses that for young Black MSM in particular, "PrEP the pill is only one of the many modes of disruption that we should be using to break the cycle" of HIV transmission. "And if we get too complacent in thinking PrEP is the solution, then we're not paying attention to things like abstinence, condom use, [HIV] treatment as prevention, behavioral interventions," and, he adds, risk factors related to substance use.

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."

Benjamin Ryan is POZ's editor at large, responsible for HIV science reporting. His work has also appeared in The New York Times, New York, The Nation, The Atlantic and The Marshall Project. Follow him on Facebook, Twitter and on his website, benryan.net.

© 2026 Smart + Strong All Rights Reserved.