Untangling Why Young People Don't Take PrEP

Awareness of the HIV prevention pills don't match their use.

July 13, 2021 By Heather Boerner

The Food and Drug Administration (FDA) approved the first medication proven to keep people HIV negative in 2012. Nine years later, awareness of the prevention method is near universal in New York City, but only 23% of gay and bisexual young men and fewer transgender women are using it, according to a survey published in the journal AIDS and Behavior. What's more, 70% of those not on pre-exposure prophylaxis (PrEP) said they'd rather use a long-acting injectable than a pill.

The first medication approved for PrEP was the single-pill combination of tenofovir disoproxil fumarate/emtricitabine (marketed as Truvada but now available as a generic). In 2019, the FDA approved a second prevention pill, Descovy (tenofovir alafenamide/emtricitabine), a close relative of Truvada. And more HIV prevention methods appear to be on their way, including bimonthly injectable cabotegravir, a vaginal ring and potentially an implant.

Back when Truvada for PrEP was first approved, it was more popular among cisgender women than young sexual minority men or transgender women, who have the highest rates of HIV in the country. But over the years, its appeal has spread. Still, young people are less likely to take it than older people, and people with inadequate or no insurance may be dissuaded from trying it because of fears about cost and because many health care providers are not competent to prescribe it.

In this survey, Jessica Jaiswal, PhD MPH, of the University of Alabama at Tuscaloosa, and colleagues at Yale University and Rutgers University School of Public Health invited 202 HIV-negative participants of the longitudinal P18 Cohort Study in New York City to take a survey about their experiences in the health care system, their beliefs about HIV, other sexually transmitted infections (STIs) and PrEP and their trust of the health care system. The survey was conducted from February 2018 to February 2019.

The participants were a median of 25 years old, 9% were transgender women who have sex with men and the rest were cisgender gay and bisexual men; 28% were white, 33% were non-Latino Black, 15% were Latino and the rest identified as some other race. Roughly equal proportions identified as tops (40%) and bottoms (41%), and one in five identified as versatile. Most (85%) had health insurance—including 15% of those on their parents' insurance—while a large minority

received care through Medicare or Medicaid. Still, 30% of participants said they had a hard or extremely hard time affording care. And 4% said their health was “bad or extremely bad.”

Overall, 98% of participants said they knew about PrEP, but only 23% were taking it. And it wasn’t that people not taking PrEP trusted doctors any less than those who were taking it. Participants in both groups were just as likely to trust physicians. Only older age and first hearing about PrEP from their clinician predicted PrEP use.

Just over half (51%) said they’d prefer long-acting injectable PrEP over a daily pill. That proportion increased to 70% for people not currently taking PrEP, compared with 30% of people already on the daily pills. Nine out of 10 people not currently on PrEP said they worried about remembering to take a daily pill, and 88% said they didn’t want to take a pill if they weren’t sick.

Opinions varied among people not taking PrEP too. People not currently on PrEP were more likely to say they thought everyone should be on PrEP (57% versus 43%), but they were also far more likely to say that wasn’t true (82% versus 18%). The good news is that non–PrEP users were more likely to say that if people knew they took PrEP, they would think they care about their sexual partners, are responsible, are HIV negative and get tested for both STIs and HIV often.

PrEP is covered by Medicaid, Gilead Sciences offers a copay assistance card for Truvada and Descovy, and tenofovir disoproxil fumarate/emtricitabine is now available as a generic. But that may not be enough to help people access the HIV prevention pill. While only 22% of all respondents said the cost of PrEP was prohibitive, a full 84% of people not taking PrEP cited cost as a primary barrier.

Interestingly, Black, Latino and mixed-race people in the study were five times more likely to be taking PrEP if their health care provider suggested it, compared with white participants who were more likely to take it only if they were older or were OK with taking daily pills. Meanwhile, participants of color were 54% less likely to take PrEP if they scored high on a medical mistrust scale, 70% less likely to take it if they were concerned about taking a daily pill and 79% less likely to do so if they weren’t sure whether everyone should be on PrEP.

The study does not separate out data for transgender women from that of sexual minority men.

“Broadly, our findings advocate for the development of culturally sensitive, LGBTQ-competent and accessible strategies to assuage the concerns of young sexual minority men and transgender women,” wrote Jaiswal and colleagues.

Click here to read the study abstract.

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