People Who Obtain PrEP Without a Prescription May Not Use It Correctly

Informal PrEP users were more likely to take it intermittently and skip recommended medical tests.

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People who obtain PrEP online, from friends or through other channels outside the medical system are less likely to follow recommendations for correct use and may therefore be at greater risk for HIV infection or medical problems, according to a poster presented at the Conference on Retroviruses and Opportunistic Infections (CROI) last month in Seattle.

Although these results are from a survey conducted in Germany, they may have implications for people in the United States who seek to obtain PrEP anonymously or more cheaply through informal channels.

Currently, once-daily Truvada (tenofovir disoproxil fumarate/emtricitabine) is the only HIV prevention regimen approved by the Food and Drug Administration. However, studies have shown that on-demand Truvada taken according to a set schedule before and after sex is also highly effective, as is daily use of the newer Descovy (tenofovir alafenamide/emtricitabine) pill.

Guidelines from the Centers for Disease Control and Prevention recommend that people get tested for HIV, hepatitis B virus (HBV) and sexually transmitted infections (STIs) before starting PrEP. The tenofovir in Truvada is active against HBV as well as HIV, and stopping it could trigger HBV reactivation. While taking PrEP, repeated HIV and STI testing is recommended every three months. Tenofovir can cause kidney problems in susceptible people, so kidney function tests should be done before starting PrEP and repeated every six months while using it.

Uwe Koppe, PhD, of the Robert Koch Institute in Berlin and colleagues conducted a survey to estimate how many people are using informal PrEP in Germany and to identify possible risk factors associated with nonprescription use.

Generic versions of the drugs in Truvada have been available in German pharmacies for those with private prescriptions since October 2017, the researchers noted as background. Before that, many people obtained PrEP through informal sources. While the cost of PrEP has fallen from the equivalent of $900 to around $50 per month in Germany, the associated HIV, STI and kidney function tests are not covered by health insurance. (By comparison, Truvada for PrEP retails for

around $1,600 to $2,000 per month in the U.S.; Gilead Science has a patient assistance program and co-pay card that limit out-of-pocket costs for many users.)

From July 24 to September 3, 2018, Koppe's team recruited 2,005 PrEP users (median age 38) through dating apps for gay and bisexual men, community-based HIV testing sites and a community website. Participants were asked to take an anonymous online survey about their PrEP use; 78.7 percent completed the survey.

A large majority of participants—80.4 percent—obtained PrEP by prescription through German pharmacies or clinical trials. The rest got it from informal sources including ordering online (9.9 percent), buying drugs in another country (3.2 percent), getting it from friends (2.8 percent), using medication obtained for post-exposure prophylaxis, or PEP, (1.0 percent) and buying it from dealers or obtaining it at sex parties (both 0.8 percent).

On average, nearly three quarters (73.1 percent) took PrEP at least 26 days per months, 10.5 percent took it 12 to 25 days per month and 16.4 percent took it one to 11 days per month.

Almost all participants—95.4 percent—reported that they obtained medical tests before starting PrEP and 86.9 percent said they did so while using PrEP. These figures indicate that some people who obtained PrEP through nonprescription channels nonetheless managed to receive the recommended testing.

PrEP users who reported nonprescription use had been on PrEP longer, on average, than prescription PrEP users (median seven to 12 months versus three to six months, respectively). Nonprescription users were twice as likely to use PrEP intermittently or on demand around the time of sex and more likely to take it fewer than 26 days per month.

Not surprisingly, nonprescription users were three times more likely to say they had not obtained medical tests before starting PrEP or that they did not receive follow-up testing while using it.

"Nonprescription PrEP users were less likely to use PrEP according to current guidelines," the researchers cautioned. "This could increase the risk for undetected HIV and STI infections in this group. Our findings highlight the need for patients to access PrEP through health care systems in order to allow safe use."

Click here to read the CROI study abstract.

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