People Seeking PrEP Face Numerous Nonfinancial Roadblocks

An analysis of veterans seeking PrEP found that they often had to be extraordinarily persistent in their efforts to receive a prescription.

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Given how doggedly persistent individuals seeking to obtain a pre-exposure prophylaxis (PrEP) prescription often must be, it should come as little surprise that many people at high risk for HIV fall through the cracks of a health care system poorly equipped to provide them access to a highly effective form of prevention.

This is the concerning top-line finding of a largely qualitative new study of veterans seeking PrEP through the Veterans Health Administration (VHA) that was published in the Journal of General Internal Medicine.

PrEP seekers, the study concluded, invariably must initiate conversations with health care providers about the HIV prevention pill. They are frequently met with clinicians' ignorance about or refusal to prescribe PrEP as well as stigmatizing attitudes toward homosexuality and sexual behaviors associated with HIV risk. And they frequently endure delays—in some cases of more than a year—before finally obtaining their first monthly supply.

The study was led by Avy A. Skolnik, PhD, of the Center for Healthcare Organization and Implementation Research and the Edith Nourse Rogers Memorial Veterans Affairs Medical Center in Bedford, Massachusetts. He and his coauthors focused on the VHA health care setting in particular because they wanted to assess non–cost-related barriers to PrEP uptake, and there are fewer cost barriers to obtaining PrEP through the VHA than through commercial insurance.

PrEP is typically covered by insurance, and Gilead Sciences offers a co-pay card

that covers up to $7,200 in out-of-pocket costs annually for Truvada (tenofovir disoproxil fumarate/emtricitabine) or Descovy (tenofovir alafenamide/emtricitabine), the two approved forms of PrEP. Nevertheless, some individuals have reported experiencing financial barriers to PrEP access—for example, if their insurance company places restrictions on the use of co-pay cards.

Even for insured individuals, any out-of-pocket costs related to the quarterly clinic visits and lab tests required to maintain a PrEP prescription may serve as barriers to access.

Given the fact that the U.S. Preventive Services Task Force recently gave PrEP an A rating, all insurers will be required to cover the HIV prevention pill with no cost sharing starting in January 2021. For those who are uninsured, Descovy's manufacturer, Gilead, in partnership with the federal government, will soon begin rolling out a donation of enough bottles of Descovy to cover 200,000 people annually.

Gilead's patient assistance program already provides PrEP for free to low-income people lacking insurance, so the new donation is essentially a broadening of that existing program.

The new study's authors conducted a retrospective structured chart review of 825 veterans from 90 VHA sites who sought PrEP, poring over medical records including notes, referrals and communications. They conducted a closer analysis of a subset of 161 people.

In the overall study cohort, 56% of the members were white, 20% were Black and 15% were Latino. Ninety-seven percent were men, 2% were women and 1% were transgender. The average age was 41 years old. Ninety-seven percent were men who have sex with men (MSM).

The demographics of the members of the overall cohort were similar to those of the smaller cohort whose charts received the more detailed analysis.

Of the 90 VHA sites, 54% were in urban areas, and 45% were in rural areas. Forty-two percent of the sites had what the study authors deemed a low rate of PrEP prescribing, while 58% had a medium or high rate of prescription. The sites served between 11 and more than 700 HIV-positive patients. Fifty-three percent of the charts sampled came from VHA facilities that served fewer than 300 HIV-positive people.

For 55% of the 161 charts that were closely analyzed, access to PrEP was relatively straightforward. So the study authors focused on the barriers to PrEP access affecting the remaining 45% of the individuals, breaking them down into four categories.

The VHA health care providers could be woefully misinformed about PrEP. Clinicians' notes from the charts included:

> "Vet has been tested for HIV, was neg. I informed him this medication is not provided for preventive measures, needs to protect himself by practicing safe sex and avoiding risky behaviors."

> "Informed him that PrEP is effective only 50% of the time, maybe less."

In fact, daily use of Truvada by HIV-negative individuals reduces their risk of the virus by more than 99%. A recent two-year study comparing Truvada with Descovy as PrEP found they had comparable efficacy.

Clinicians could also have knowledge gaps about VHA policy and procedures with regard to prescribing PrEP:

“[PrEP] is not part of standard practice at the VA at this time as a ‘necessary medical care’ and I would recommend veteran go to the health department.”

“I called pharm and they could not tell me whether Prep [sic] was available. I placed [infectious disease] consult, but suspect it is not available.”

There were examples of health care providers expressing judgmental, stigmatizing and antigay attitudes toward PrEP seekers’ sexual behaviors. This could include a reluctance to write a prescription when an individual reported multiple sexual partners, despite the fact that doing so is actually an indication that the person is a good candidate for PrEP, according to the Centers for Disease Control and Prevention (CDC). Statements included:

> “I suggested a monogamous relationship.”
>
> “Multiple sexual partners, unable to maintain same sexual partner.”
>
> “I am not comfortable prescribing for this purpose.”

There were also barriers to uptake when the VHA clinics apparently could not sort out which departments were responsible or most appropriate for prescribing PrEP:

> “Patient called upset about receiving a letter from an infectious disease clinic.”
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> “[Infectious disease] consult was [discontinued] because [patient] is HIV neg. Please reschedule with primary care.”

These four types of barriers occurred in both urban and rural settings and in primary care and infectious disease clinics irrespective of the prevalence of HIV in the larger surrounding community. In some cases, the barriers arose even before someone seeking PrEP saw a physician, such as through an initial interaction with a nurse or clinic office clerk.

Eighty-eight percent of the charts had clear documentation that the patient initiated the conversation about PrEP, while in just 6% of the cases the health care provider initiated the conversation. This finding held despite the fact that at least 16% of the veterans who sought PrEP had documented evidence in their medical chart of being at high risk for HIV, including having been diagnosed with a sexually transmitted infection, having been prescribed post-exposure prophylaxis (PEP), having requested multiple HIV tests, having disclosed sharing needles for drug injection or having had an HIV-positive sexual partner.

In 35% of the charts, the PrEP seekers experienced delays obtaining their prescription, which ranged between five weeks and 16 months. During these delays, some of the individuals made follow-up requests.

The long delays in receiving a PrEP prescription, the study authors note, not only leave individuals vulnerable to HIV “but may also sour the patient experience of their health care. This burden on

patients also deviates from other forms of preventative care (e.g., immunizations, cancer screenings) in which patients are not expected to request. Placing the majority of the onus on the patient to request this service may be contributing to the modest uptake of PrEP in VHA and other settings."

While some of the VHA clinicians may have been poorly educated about PrEP, it was typical for people seeking a prescription to arrive at their clinic visit armed with knowledge about the HIV prevention pill. Charts noted that one patient "has been reading CDC guidelines," while another "brought in a [medical] journal article."

A major theme coursing through the medical charts was the persistence, including "the ability and willingness to keep trying even after being turned away," of these individuals who wanted to take PrEP and wouldn't take no for an answer.

Twenty-three percent of those who made an initial inquiry about PrEP had a second documented request. Eight percent of the charts had records of three or more requests for PrEP before an individual obtained a prescription.

"Patients not only made multiple requests," the study authors wrote, "but they also made multiple clinic visits, requested appointments even when they were told PrEP was unavailable, utilized different strategies when requesting PrEP and sought PrEP at VHA after being unable to obtain it elsewhere."

The study's findings, the authors wrote, "[raise] the question of what happens when patients lack the time, energy, money, education, mental health, ability or self-assurance to be such an advocate" for themselves in the quest to obtain PrEP.

The investigators recommended that primary care clinics increase their capacity for prescribing PrEP; that both infectious disease and primary care clinicians receive educational initiatives that address bias against people seeking PrEP; and that health care systems improve their capacity for identifying good candidates for PrEP.

To read the study abstract, click here.
