


A Young Black MSM on PrEP Is Lost to Follow-Up and Acquires HIV Infection: A Case to Call for Improved Strategies to Support Youth Adherence and Engagement in HIV Prevention

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Abstract

Young men who have sex with men (YMSM) are disproportionately affected by HIV in the United States. High-risk sexual behaviors are difficult to modify; thus, HIV pre-exposure prophylaxis (PrEP) with a daily pill is a promising prevention tool for this vulnerable population. We present a case of a young black MSM who was able to successfully access PrEP with the help of a community program but was not able to adhere to the regimen or engage in care. He ultimately acquired HIV infection. We review the existing literature and advocate for increased services and research to support youth's adherence to PrEP and engagement in HIV prevention programs, with a focus on YMSM of color.

Keywords

YMSM, YBMSM, adolescent HIV, PrEP, HIV prevention

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What Do We Already Know About This Topic?

PrEP is safe and effective for youth when they are adherent to once-daily administration.

How Does Your Research Contribute to the Field?

This case illustrates the importance of not only increasing uptake of PrEP but of also supporting PrEP adherence and engagement, especially for YMSM of color.

What Are Your Research's Implications toward Theory, Practice, or Policy?

We call for more comprehensive youth-targeted programming that includes support of adherence and engagement to PrEP, as well as for future research to determine optimal methods and tools to provide this support.

Introduction

The Centers for Disease Control and Prevention reports that in 2015, 22% of new human immunodeficiency virus (HIV) infections in the United States were in youth, defined as individuals aged 13 to 24 years.¹ Young men who have sex with men (YMSM) accounted for 81% of these new infections, and there were clear racial and ethnic disparities; 55% of cases in YMSM occurred in black individuals, 24% in Hispanic/Latinos, and 16% in whites.² Therefore, YMSM of color are a key population to target for HIV prevention services.

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Tenofovir disoproxil/emtricitabine (TDF/FTC) once daily by mouth was approved by the Food and Drug Administration (FDA) in 2012 for pre-exposure prophylaxis (PrEP) for HIV infection in adults aged 18 years and older.³ Since approval, PrEP uptake was initially slow but started to increase in 2014.⁴ Still, the majority of the increase in prescriptions were for older white males. One study reported 74% of prescriptions were in whites, 12% in Hispanics/Latinos, and 10% in blacks.⁵ Less than 10% of prescriptions were given to young people <25 years of age. In May 2018, the FDA approved a revision to the TDF/FTC labeling to expand the PrEP indication to include adolescents weighing at least 35 kg. Still, to date, PrEP is not widely accessible to youth or to individuals of color, nor is it a typical component of youth-centered HIV prevention programs.

Results from a PrEP demonstration project in YMSM conducted through the Adolescent Trials Network (ATN) were recently published.^{6,7} The paired studies of ATN 110 (aged 18-22) and ATN 113 (aged 15-17) demonstrated that PrEP is safe and effective in these age groups, when individuals are adherent. Drug levels were measured by dried blood spot testing at each study visit, and overall, the levels decreased substantially once visits became less frequent (every 3 months), and 40% of the participants in the ATN 113 study dropped out before the study was complete. These results suggest that YMSM need more services to support retention and engagement in a PrEP program, but little is known to date about what services would be most helpful.

The individual described in the case report participated in a focus group research project that was approved by the institutional review board (IRB) of University of Minnesota. He provided written consent before participating in the focus group. The following case is a description of what followed after the focus group. The same IRB of University of Minnesota waived the need for ethics approval and the need to obtain consent for the publication of this case report, as it represents anonymous data and is a noninterventional study.

Case Report

An 18-year-old young black MSM (YBMSM) presented to the Infectious Disease (ID) clinic at the University of Minnesota. He learned about PrEP from a local organization that provides HIV treatment and prevention services to youth and made the appointment seeking a PrEP prescription. The patient identified as “gay” and only had sexual intercourse with male partners. His first sexual encounter was at the age of 13 or 14 years. He had since engaged in mainly receptive anal sex, as well as both receptive and insertive oral sex. He denied any history of coerced or forced sex, no exchange of sex for money or drugs, and no sexual encounters where he felt unsafe. He reported mainly anonymous or one-time sexual encounters and had not had any long-term partners. He estimated approximately 10 sexual partners in his lifetime. He also estimated approximately 30% condom use with anal sex and less with oral sex.

Past medical history was significant for attention-deficit/hyperactivity disorder. He was prescribed methylphenidate in the past but was no longer taking it due to side effects of nausea. The patient rarely smoked cigarettes (roughly 3 per month), reported minimal alcohol use, and smoked marijuana socially at parties or when it was available, although he often went weeks without using marijuana. He tried recreational oxycodone/acetaminophen once and did not enjoy it. He denied any use of cocaine, recreational methamphetamine, or heroin and denied ever using intravenous drugs. The patient lived in special housing for homeless youth, attended high school, and worked a part-time job at a fast-food chain restaurant.

Examination was unremarkable. Standard PrEP laboratory evaluation revealed a normal creatinine and negative tests for hepatitis B, hepatitis C, and sexually transmitted bacterial infections. The HIV-1, -2 antibody antigen fourth-generation combination assay was negative.

The ID provider determined that the patient was a candidate for PrEP, and a prescription for once-daily TDF/FTC was sent electronically to the clinic pharmacy. An appointment was made the same day for a 3-month follow-up. The patient did pick up the first 30-day supply of TDF/FTC; however, he did not call for a refill. Subsequently, he did not return to the clinic for the scheduled follow-up, and he did not contact the clinic. There were no pharmacy or clinic procedures in place at the time to directly contact the patient.

Seven months later, the young man participated in a focus group comprised of youth who were HIV vulnerable (high-risk HIV uninfected). In the session, they discussed their knowledge, attitudes, and perceived barriers to PrEP. The case patient had knowledge of PrEP and disclosed to the group and facilitator that he had taken PrEP in the past. He had an overall positive attitude about biomedical HIV prevention but voiced that he wished it was easier to take. He lamented the need to take a pill every day and asked if there was a liquid formulation or another way he could take the medicine.

After the focus group concluded, all participants were offered free HIV testing. The case patient had a rapid third-generation HIV antibody test performed, and the result was reactive. He received immediate counseling, and plans were made for confirmatory testing at the University of Minnesota laboratory. Two days later, an HIV-1, -2 antibody antigen fourth-generation combination assay was performed and was reactive. A supplementary HIV-1, -2 antibody assay was performed and was positive for HIV-1 and negative for HIV-2. HIV RNA polymerase chain reaction (PCR) demonstrated detectable virus at 9306 copies/mL. The absolute CD4 count was 617 cells/mm³ (36%). HIV genotype and phenotype were performed, and no evidence of antiretroviral resistance was identified.

The patient returned to the ID clinic at the University of Minnesota to establish HIV care. He reported that he had picked up the initial PrEP prescription but found it very difficult to swallow the large tablet. He tried every day for 1 week but felt the tablet would get stuck in his throat, and he could not get it down. After the first week, he gave up and did not try

again. He continued his prior high-risk sexual behaviors and had multiple anonymous sexual encounters without using condoms. He reported, "I don't really like condoms, I have to admit." He did not know the HIV serostatus of any of his partners. He did not recall any febrile episodes or acute illnesses in the interim.

The patient was counseled about his antiretroviral therapy options and about the importance of adherence. Along with his provider, he chose a regimen of tenofovir alafenamide/FTC and dolutegravir, which were the smallest tablets that were offered. He received a cup from the pharmacy that was designed to help facilitate easier swallowing.

The patient was able to swallow all pills in his antiretroviral regimen, and he achieved an HIV viral load of <20 copies/mL within 6 weeks of initiating therapy. He has remained in care and maintains regular follow-up visits.

Discussion

There were several missed opportunities to support the case patient's adherence to PrEP and engagement in care. The community program that assisted the patient in accessing PrEP did not follow-up with him after his initial appointment with a health-care provider. The patient did not reach out to the pharmacy, clinic, or ordering provider to discuss his difficulties. When he did not refill the TDF/FTC or make a return appointment, he was not contacted by the pharmacy or the clinic. Perhaps something as simple as a pill cutter would have changed the outcome for this patient, although we suspect that he may have needed more comprehensive support to remain on daily PrEP.

Unfortunately, there are very few published reports that address interventions to support youth in PrEP adherence or engagement in HIV prevention programs that include PrEP. The research team from the ATN 110 and ATN 113 studies uses their experience to suggest that a more frequent health-care provider visit schedule or an option for additional visits might be best for youth on PrEP.^{6,7} They also suggest using mobile technology for medication reminders or check-ins and providing adherence support through peer groups. One other PrEP program for YMSM of color in Philadelphia described their methodology to support adherence over 28 weeks in 2013.⁸ Their small cohort of 23 YMSM of color were asked to come in weekly for medication pickup and adherence counseling, with monthly rapid HIV testing and quarterly sexually transmitted infection and creatinine testing. Their clinic was located in the same site as a community organization that catered to high-risk youth and was open only in the evening hours. A social worker offered weekly workshops that most of the cohort chose to attend. They reported a median adherence of 82% for participants who had taken PrEP for at least 1 month, measured by who returned for weekly medication pickup.

Pre-exposure prophylaxis adherence and engagement among YBMSM, YMSM, and youth in general is an emerging field of inquiry, with multiple new studies either ongoing or planned. Recently, presented data include results from a study of a

youth-tailored short message service (SMS)-based intervention. This intervention was shown to increase PrEP retention and adherence among diverse YMSM and transgender women aged 18 to 29.⁹ In addition, the iPrEx (from Spanish: iniciativa profilaxis pre-exposicion) open-label extension study conducted a 12-week pilot study of a mobile health intervention with a convenience sample of their PrEP users, a quarter of whom were less than 30 years of age. The intervention included weekly SMS or e-mail support messages and was found to be feasible and acceptable, particularly among the younger PrEP users and participants of color.¹⁰ An ongoing trial in South Africa referred to as CHAMPS Pluspills includes both male and female HIV-negative adolescents aged 16 to 19 years. This study is using SMS, adherence clubs, trained youth-friendly counselors, and real-time feedback on drug levels. A baseline and early data analysis was performed using initial plasma TDF levels and suggested a promising uptake and use of PrEP in these participants.¹¹

There are published interventions that study HIV prevention services overall for youth and YMSM that include targets of modifying risk behaviors, increasing condom use, and improving safer sex attitudes. A comprehensive review of such HIV prevention intervention studies for YMSM identified a total of 15 studies, of which only 4 were focused on YMSM of color.¹² The review was not able to identify specific efficacious modalities, as the studies were not uniform enough to lead to clear conclusions. The authors advocated for standardized measures and criteria for sustained behavior change to strengthen methodology and generalizability. Their opinion was that future behavioral interventions should include mobile technology and differentiate between adolescent groups (aged 13-18) and young adults (aged 19-24).

Young men who have sex with men of color may face additional psychosocial barriers to adherence such as those related to age, race, or sexual orientation. The ongoing psychological development of youth may impede their adherence capacity. Therefore, PrEP support interventions that include psychological or mental health support with youth-tailored counseling and/or peer support groups may be beneficial. Adolescent Trials Network 082 demonstrated the feasibility of combining a behavioral intervention that included counseling with PrEP and found a reduction in risky sexual behaviors over time.¹³ Findings from a national summit on YMSM services in 2015 highlighted 4 strategies as key to engaging YMSM of color in HIV prevention services based on expert opinion: utilizing peers, providing holistic care, making services fun, and utilizing technology.¹⁴

Conclusion

The disproportionate rates of HIV infection in YMSM of color in the United States make them a key target population for HIV prevention services. Pre-exposure prophylaxis is a biomedical intervention that is safe and effective when individuals are adherent to TDF/FTC, but uptake has been slow for youth, and for YMSM of color in particular. Therefore, emphasis has been placed on increasing access to PrEP for this vulnerable population. Our case highlights the additional importance of

supporting youth after they are prescribed PrEP. Further research should focus on strategies to improve adherence to TDF/FTC and engagement in HIV prevention programs that include PrEP for YMSM of color.

Authors' Note

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