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High rate of discontinuation may diminish PrEP coverage among young men who have sex with men

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Abstract

Understanding PrEP discontinuation is key to maximizing its effectiveness at the individual and population levels. Data came from the RADAR cohort study of MSM aged 16–29 years, 2015–2017. Participants included those who reported past six-month PrEP use and discontinued its use by the interview date. Of the 197 participants who had used PrEP in the past six months, 65 discontinued use. Primary reasons for PrEP discontinuation included trouble getting to doctor's appointments (14, 21.5%) and issues related to insurance coverage or loss (13, 20.0%). Few (21%) who discontinued spoke to their doctor first, which has important implications for future long acting formulations.

Resumen

Es importante entender la interrupción en el uso de PrEP para maximizar su efectividad a nivel individual y poblacional. Los datos proceden de RADAR, un estudio de cohorte de hombres que tienen sexo con hombres entre 16-29 años de edad. Se incluyeron participantes que reportaron haber usado PrEP en los últimos seis meses que posteriormente descontinuaron su uso. De los 197 participantes que usaron PrEP en los últimos 6 meses, 65 habían dejado de usar PrEP. Dentro de los motivos principales por los cuales dejaron de usar PrEP se encuentran dificultades para llegar a consultas médicas (14, 21.5%) y otras dificultades relacionadas con la cobertura o pérdida de seguro médico (13, 20.0%). Pocos (21%) indicaron haber consultado la descontinuación de PrEP con su médico, lo cual presenta implicaciones importantes con respecto a futuras formulaciones de acción prolongada.

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Compliance with Ethical Standards

Disclosures: The authors declare that they have no conflicts of interest.

Research Involving Human Participation

Ethical approval: All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed consent: Informed consent was obtained from all individual participants included in the study.

Introduction

Pre-exposure prophylaxis (PrEP) has been shown to be highly effective at preventing acquisition of HIV with up to a 92% reduction in HIV incidence when taken daily.¹ This protective effect is largely dependent on the level of adherence,^{1,2} Past research has found several barriers to adherence including access to and cost of insurance, potential side effects, a preference for a non-daily schedule of taking pills, and an experience of stigma surrounding the use of PrEP.³ In contrast, adherence increased among individuals who received strong support from counselors and among those who expressed a desire to curb the spread of HIV.³

While much emerging research has focused on drivers of PrEP non-adherence, few recent publications have focused on why people stop taking PrEP altogether⁴ (i.e., PrEP discontinuation), particularly among MSM populations. It is important to understand PrEP discontinuation for two reasons. First, high rates of discontinuation will hinder PrEP population coverage and therefore affect its ability to curb new infections. Second, if people discontinue PrEP without re-initiating use of other prevention methods (e.g., condoms, abstinence), they may be at high risk for HIV acquisition. To that end, we analyzed data from a large cohort of young men who have sex with men (YMSM) in order to assess reasons for PrEP discontinuation.

Methods

Study Design & Recruitment

Data come from the RADAR longitudinal cohort study of YMSM living in the Chicago metropolitan area. The primary objective of this cohort study is to apply a multilevel perspective to a syndemic of health issues associated with HIV among diverse YMSM. Methods for participant recruitment have been previously described.^{5,6} Briefly, participants were recruited using venue-based, social media (e.g. Facebook), and incentivized snow ball sampling. All participants were between 16 and 29 years of age, assigned male at birth, spoke English, and had a sexual encounter with a man in the previous year or identified as gay, bisexual or transgender.

The PrEP discontinuation measures included in this analysis were administered to study participants at baseline and each of five follow-up visits occurring every six months between 2015 and 2017. Participants who self-reported being HIV positive were not asked questions about PrEP use.

Measures

We administered several items to assess PrEP usage and discontinuation. At each time point, we assessed past PrEP use with the following item: “In the past six months, have you taken any pre-exposure prophylaxis (PrEP) medication such as Truvada to reduce your risk of HIV transmission?” We also assessed current usage as follows, “Are you currently taking any pre-exposure prophylaxis (PrEP) medication such as Truvada to reduce your risk of HIV transmission?” Among those who had used PrEP in the past six months, but were not

currently taking PrEP, participants were asked to select all: “Reasons why [you] stopped taking PrEP” (response options described below).

Reasons for PrEP discontinuation were initially assessed through an open text response option in order to generate qualitative responses that could be coded into a quantitative measure of reasons for discontinuation. Following a brief period of participants answering the open-ended questions ($n = 42$), we observed saturation in the themes among responses. Two members of the research team classified the open-ended responses into ten different thematic categories (Table 1). We calculated an inter-rater reliability score to assess level of agreement and resolved remaining disagreements by consensus. We achieved a high level of agreement when coding responses ($kappa = 0.85$). Once the range of responses was settled through the qualitative coding we created a quantitative measure that asked participants to select all options that applied as their reason for discontinuation. This checklist also included a free response “other” category (Table 1).

Discontinuation of PrEP use was examined across five time points of available data (data collection is on-going). For this analysis, we restricted the analytic sample to only participants who had used PrEP ($N = 197$) and then subsequently discontinued its use by the time of the interview ($n = 65$). Among those who discontinued PrEP use, 42 answered the open-ended questions and 23 answered the closed-ended thematic questions. Participants only contributed data to the analysis at the first instance of discontinuation, subsequent re-uptake and discontinuation was not assessed in this study. Finally, a subset of participants who discontinued PrEP ($n = 35$ because this item was added to the questionnaire after study launch) were asked about their sexual behaviors (oral, anal, or vaginal intercourse) and condom use following cessation of PrEP, as well as whether they had spoken to a doctor prior to discontinuing the use of PrEP ($n = 29$).

Results

Across all visits, 197 participants reported PrEP use in the past six months. Of these, 65 (33.0%) discontinued medication use by the time of the interview. Twenty-two (33.8%) of those who discontinued PrEP self-identified as non-Hispanic black, 10 (15.4%) as non-Hispanic white, 12 (18.5%) as non-Hispanic multiracial, and 21 (32.3%) as Hispanic. Participants who discontinued PrEP use, compared to PrEP users who did not discontinue at that wave, were significantly more likely to be black or Hispanic ($p=0.026$) vs white MSM. The majority of those who discontinued use had some college education (36, 55.4%), were students (33, 50.8%), and were employed full-time (25, 38.5%). Participants self-identified as gay (48, 73.8%), bisexual (8, 12.3%), or a different category (9, 13.8%). No significant differences were found between those who discontinued PrEP and those who continued its use with regards to age, gender identity, sexual orientation, or education.

Among the 29 participants who received questions regarding PrEP discussions with a medical provider, 23 (79.3%) had not spoken to a doctor before discontinuing PrEP use while 6 (20.7%) had discussed discontinuation with a medical provider. Among participants who received the sexual behavior questions ($n = 35$), the majority of participants continued engaging in anal sex (17, 58.6%) with only seven (24.1%) reporting no sexual contact

following discontinuation. Additionally, among those who continued to engage in anal sex (n = 17), condom use varied: 7 (41.2%) never used a condom following PrEP discontinuation, 6 (35.2%) used a condom 50% of the time, 4 (23.5%) used a condom >50% of the time, and zero always used a condom.

Table 1 provides the participant's stated reason(s) for discontinuation of PrEP. The primary reason given for discontinuation of PrEP use was trouble getting to doctor's appointments (14, 21.5%), followed closely by those whose insurance coverage either lapsed or would no longer cover PrEP (13, 20.0%), and those who felt they were not longer at risk of HIV (12, 18.5%).

Discussion

In a diverse sample of YMSM in Chicago, we utilized a new measure to assess PrEP discontinuation, one which could be applied to other samples. We observed that black and Hispanic MSM, compared to white MSM, were significantly more likely to have discontinued PrEP use. We also found that one-third of participants who reported PrEP use in the past six months had discontinued its use by the time of the interview (65, 33%). The primary reasons given for discontinuation of use were an inability to get to doctor's appointments or issues with insurance coverage of PrEP. Of particular concern, there was also a continued engagement in HIV risk behaviors following PrEP discontinuation.

Black and Hispanic MSM are much more likely to have discontinued PrEP suggesting racial disparities around discontinuation are emerging. These findings are particularly concerning given that black and Hispanic MSM are also those at greatest risk of acquiring HIV.⁷ These emerging racial disparities in discontinuation may be due to structural differences between populations, for example, differences in access to healthcare facilities or access to or cost of insurance. While measures such as these are beyond the scope of this analysis, more research is needed to understand what might factors might be contributing to these increased rates of PrEP discontinuation.

The two most common factors for discontinuation of use – the ability to attend doctor's appointments and lack or loss of insurance coverage – are systemic barriers, indicating that more needs to be done to increase access to PrEP for those who are at high HIV risk. One potential solution may be to enable service providers, such as local health departments, to incorporate proactive services for high-risk HIV-negative individuals. For example, disease intervention specialists (DIS) could link high risk clients, who were identified through partner tracing, with medical providers to ensure they receive PrEP information and a prescription, if warranted. DIS personnel could then follow-up with these individuals to assist with making and keeping future provider appointments (e.g. transportation to/from appointments, appointment reminders, etc.). To address issues of insurance coverage, new governmental policies may need to be introduced to increase cost-sharing measures at the local or federal level aimed at reducing or eliminating the overall cost of the medication. If these cost-sharing measures were implemented, issues surrounding PrEP discontinuation and insurance coverage may be alleviated. Further research and novel intervention

approaches are needed to address issues surrounding PrEP discontinuation among young MSM.

One such novel approach may be the use of “on-demand” PrEP which may reduce the burden of access to medication. In a recent study, participants took PrEP 2–24 hours before and for 48 hours following sexual intercourse.⁸ The researchers found this method to be highly effective at preventing HIV among high-risk MSM and found that this approach may alleviate some of the issues of long-term adherence.⁸ In this manner, the continued use of PrEP would rely less on attending provider appointments to obtain a re-fill prescription and would also allow a single prescription to cover more instances of sexual activity, alleviating some pressure on the individual in the instance of a loss of insurance. However, research has also found that MSM are not good at predicting when they will have sex, which may be necessary for this approach to be effective.⁹ Further, while on-demand PrEP would decrease the need for daily medication, routine medical care should continue to ensure appropriate HIV and STI testing. More studies such as these are needed in order to find novel approaches towards utilizing PrEP to reduce the risk of acquisition of HIV.

There is also evidence that sexual risk is ongoing following discontinuation of PrEP in this sample. The majority of participants did not discuss discontinuation of PrEP with their doctor, continued to participate in anal sex, and either never or infrequently used condoms following discontinuation. Failing to discuss cessation of oral medication with a medical provider, particularly following discontinuation of long-acting medications such as Cabotegravir-LA (CAB),¹⁰ is concerning as this may drive drug resistance to CAB. Additionally, the third most common reason for cessation of PrEP use was, “I didn’t think I was at risk for HIV anymore.” The sample size, however, is small and we cannot be certain that they are truly at continued risk of infection. As more data in this cohort become available, future analyses will examine behavioral changes following PrEP discontinuation as well as how YMSM make decisions about other prevention strategies following discontinuation.

While we have presented several important factors related to the discontinuation of PrEP use, our findings should be considered in the context of their limitations. This is preliminary data and not all participants received questions related to sexual behaviors following PrEP discontinuation. Therefore, the observations presented here are subject to change as more data is collected and analyzed over the course of the study. Additionally, our analysis relies on self-reported PrEP use. Finally, this sample was a community sample rather than a probability sample and, as such, findings may not generalize to the larger population of HIV-negative YMSM.

Even in the context of these limitations, we observed several important factors which must be considered and addressed if PrEP usage is to continue to rise. First, high rates of discontinuation may be hindering the widespread uptake of PrEP and may drive future drug resistance, the reasons of which must be addressed to increase PrEP coverage. Next, continued sexual risk behavior may put people who discontinue the use of PrEP at a renewed risk for HIV, particularly if they do not return to consistent condom use. Finally, research must be conducted to look beyond medication adherence and develop a better understanding

about which other prevention strategies are used following purposeful discontinuation PrEP use.

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Table 1

Participant reasoning for discontinuation of PrEP use, RADAR, Chicago 2015–2017 (n = 65)

	Total	
	n	%
I had trouble getting to doctor's appointments	14	21.5
My insurance would not cover it, or I lost my insurance	13	20.0
I didn't think that I was at risk for HIV anymore	12	18.5
I just didn't feel like taking it anymore	8	12.3
Side effects from the medication	6	9.2
I couldn't afford the medication anymore	6	9.2
I had trouble remembering to take the medication	5	7.7
People reacted negatively when they found out I was taking PrEP (like friends or family)	4	6.2
Other	4	6.2
I was getting it as part of a research study and the study ended	3	4.6