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Why I quit pre-exposure prophylaxis (PrEP)? A mixed-method study exploring reasons for PrEP discontinuation and potential re-initiation among gay and bisexual men

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Abstract

Literature concerning pre-exposure prophylaxis (PrEP) among gay and bisexual identifying men (GBM) has explored facilitators and barriers to uptake and adherence. Far less reported are the reasons why GBM discontinue PrEP use. A national sample of 1,071 GBM completed surveys about PrEP use and discontinuation. Participants who were still taking PrEP the 24-month follow up were compared to those that had stopped. Eighteen percent (n=31) of GBM who reported ever using PrEP discontinued use. Younger (AOR=0.96; 95% C.I.=0.92–1.00), and unemployed (AOR=4.58; 95% C.I.=1.43–14.70) GBM were more likely to discontinue PrEP than their counterparts. Those that discontinued provided details on why via a free response question. The most common reasons for discontinuation were lower perceived HIV risk (50%) and cost/insurance (30%). Reasons for potential re-initiation included higher-risk sexual activities and changes to structural related barriers. More research is needed to inform interventions on how GBM can continue taking PrEP during changes to employment that effect insurance coverage and cost.

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The authors declare that they have no conflict of interest.

COMPLIANCE WITH ETHICAL STANDARDS

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.

Keywords

gay and bisexual men; Pre-exposure prophylaxis (PrEP); medication discontinuation; HIV prevention; sexual risk perception

INTRODUCTION

Gay, bisexual, and other men who have sex with men (GBMSM) continue to be disproportionately affected by human immunodeficiency virus (HIV) in the United States (U.S.), making up 84% of new infections among men in 2015 (1). Pre-exposure prophylaxis (PrEP) is a promising biomedical HIV prevention tool that is FDA-approved and shown to be 92–99% effective in the prevention of HIV among GBMSM (2–4). A major focus of the social and behavioral literature on PrEP has focused on facilitators and barriers to PrEP uptake and adherence (5–14). Recently, the Motivational PrEP Cascade (15) was proposed and reported from a national sample of gay and bisexual identifying men (GBM); of those who had ever been on PrEP, 16.6% had discontinued use (16). With an estimated 6.16 million GBM in the U.S. (17, 18) and rates of PrEP uptake continuing to increase, it is likely that the number of those GBM discontinuing a regimen are also going to increase. The majority of literature on GBM and PrEP has focused on uptake and adherence, leaving a gap in the literature about reasons GBM discontinue a PrEP regimen.

One reason for potential discontinuation of PrEP comes from the idea of stopping PrEP during times of decreased risk. “Seasons of risk” is used to refer to the temporary use of PrEP during times of higher amounts of sexual risk, subsequently discontinuing use during decreased risk (19). Elsesser et al. (20) examined this concept by asking a large sample of 7,305 GBM about changes in sexual risk due to being on vacation. Of those that had engaged in condomless anal sex (CAS), 92.6% reported that having to take once-daily PrEP was a barrier to PrEP use while 74.3% reported being interested in PrEP for short periods of increased risk (e.g. vacationing), leading to discontinuation afterwards. Similarly, the term “season of PrEP” addresses small periods of time where individuals may want to begin a PrEP regimen for a finite amount of time (21, 22). Both of these terms suggest not taking PrEP continuously, but just during “seasonal” times of increased need. However, a rise and fall of risk behavior likely does not explain all reasons for stopping a PrEP regimen.

Overall, the literature around other reasons for PrEP discontinuation among GBM is scattered and has not yet been the primary focus of any paper. In a qualitative study of GBM who had used PrEP, researchers reported that some participants who engaged in condomless anal sex (CAS) were simultaneously going through stages of increased substance use triggered by periods of emotional stress. This suggests that for some, PrEP may be an effective prevention technique for HIV risk reduction during periods of increased substance use and emotional stress, but not necessarily perpetual use (23). In another qualitative study, a prominent reason given for discontinuing PrEP reported by GBM was concern of long-term side effects (24).

Some reasons for discontinuation may be similar to previously published barriers to initial PrEP uptake. One major barrier previously reported is cost (e.g., health insurance,

prescription copay, costs of quarterly sexually transmitted infection (STI) and HIV testing) (5, 9, 12, 13, 25–28). After beginning a PrEP regimen, a change in employment or insurance coverage could impede someone from being able to afford the medication and/or the quarterly medical visits. Additionally, risk perception (i.e. does the person view themselves as an appropriate candidate) (8, 27–29) has been identified as a barrier to uptake. As such, if GBM do not see themselves as someone for whom PrEP is intended, they are less likely to start a regimen. A change in risk perception could lead to discontinuation regardless of actual changes in risk behavior. Side effects have also been reported to be of concern for those engaged in PrEP care (5, 7, 9, 10, 12, 14). It is likely that if someone is experiencing adverse side effects they may discontinue use. We simply do not yet know if barriers to continuation of PrEP are similar or different to those that restrict beginning a PrEP regimen. By pinpointing barriers that directly affect discontinuation researchers may be able to create interventions targeted at keeping individuals on PrEP in the presence of HIV transmission risk behavior. However, until research is conducted with participants who are prescribed and discontinue PrEP at their own volition these assumptions will remain hypothetical.

The following exploratory study utilizes qualitative surveys to determine why some GBM stop using PrEP and potential reasons for PrEP re-initiation. Additionally, we explore demographic differences and sexual risk behavior between those currently on PrEP and those who discontinued.

METHODS

Participants and Procedures

One Thousand Strong is a longitudinal cohort study prospectively following a U.S. national sample of 1,071 HIV-negative gay and bisexual identifying men for three years (2014–2017). The goal of recruitment was to obtain a sample which reflected U.S. Census data on same-sex households in terms of race and ethnicity, and geographic distribution. To do so, we enrolled participants identified via Community Marketing and Insights, Inc. (CMI) from a panel of over 45,000 lesbian, gay, bisexual, and transgender (LGBT) adults, of which over 22,000 were GBM currently living in the U.S. In order to maintain a diverse panel of potential participants, CMI recruited their panel of individuals drawn from a variety of over 200 sources including LGBT events, LGBT social media, LGBT e-mail broadcasts, and non-gay identified venues/mediums. Using their panel, CMI identified potential participants, screened them for eligibility via an internet survey, and then shared their responses and contact information with the research team. Participants were then independently enrolled in the longitudinal assessment. In order to be enrolled in the final sample participants had to complete a series of steps including bring screened through CMI as mentioned above, an online completion of a computer-assisted self-interview (CASI) which they were compensated with a $25 Amazon gift card, and at-home STI and HIV testing which they were compensated an additional $25 Amazon gift card. All participants enrolled in the final sample received an HIV-negative test result at baseline. An initial sample of 9,011 men were identified via CMI as potentially eligible if they were 18 or older, identified as a gay or bisexual male, and had regular internet access. In addition to the CMI eligibility of age, sexual identity, and internet access, individuals had to also report currently living in the U.S.

and having a stable residence (i.e. having not moved more than twice in the last six months), having a U.S. mailing address (non P.O. Box), being a minimum of 18-years-old, biologically and identify as male and self-identified as gay or bisexual, report being sexually active with another male in the past 12 months (engagement in either oral or anal sex with another male identifying individual), have the ability to complete internet-based assessments in English, access to a device capable of taking digital photos, and complete at-home rapid HIV antibody and, self-collect rectal and urine samples for STI testing to be included in the final cohort.

Of the 9,011 men who were emailed an invitation to complete the screening survey, 6,371 did not open the email and another 90 emails were unable to be delivered. Of the 2,550 who opened the email, 2,393 (93.8%) completed the screening survey. Of these, 1,375 (57.5%) were deemed eligible, with the most common reasons for ineligibility being an HIV-positive status or not being sexually active with a man. Of the 1,375 eligible men, 1,071 (77.9%) completed all requirements of the assessment and were enrolled into the *One Thousand Strong* cohort. The final sample of 1,071 participants is representative of HIV-negative GBM in the U.S., which resulted in fewer men of color because of the HIV prevalence among men of color.

Participants were reassessed annually (completing a CASI and STI/HIV testing, with $50 in compensation) and asked to complete an additional optional CASI survey at 6 month intervals between annual assessments, for which they were not compensated. All CASI data was collected via Qualtrics survey software (qualtrics.com), which offered the survey via the internet and also mobile device optimization. Data for this manuscript were collected during the 18-month and 24-month surveys. We included a qualitative assessment of why men discontinued PrEP use in their 18-month survey and we continued to monitor PrEP discontinuation over time through the 24-month survey. Additional specifications of both the recruitment and enrollment procedures are detailed elsewhere (30). All procedures were approved by the Institutional Review Board of CUNY.

Quantitative Measures and Analyses

Participants were asked questions about their demographics, including age, race/ethnicity, educational attainment, employment status, and whether or not they had health insurance. Participants also reported current PrEP use at both the 18 and 24-month surveys by responding to the question “Have you ever been prescribed HIV medication (e.g., Truvada) for use as PrEP (HIV pre-exposure prophylaxis)?” Response options were, “Yes, I am currently prescribed PrEP,” “Yes, but I am no longer prescribed PrEP,” and “No, I’ve never been prescribed PrEP”. Additionally, participants indicated if they had any CAS in the past 3 months. We conducted bivariate analyses to compare men who discontinued PrEP use to those who remained on PrEP using chi-squared comparisons and logistic regression for categorical and continuous variables, respectively. We compared men who discontinued PrEP to those still on PrEP using multivariable logistic regression to determine differences by age, race/ethnicity, education, employment status, insurance status, and engagement in CAS in our fully-adjusted model.

Qualitative Measures and Analysis

We asked participants about their reasons for discontinuing PrEP using an open-text response during the 18-month and 24-month self-administered survey: “We are interested in knowing more about the reasons you began taking PrEP and what caused you to stop. Please provide as much information as you’re willing about how/why you came to start and later stop your PrEP regimen.” A thematic content analysis (31) of the free response data was then conducted to identify common themes for why men stopped using PrEP, and we also used them to explore reasons why men might reinitiate PrEP use in the future. This method of free response data analysis is a valid method of ‘safety net’ inquiry (32), allowing us to explore an issue with limited research and quantitative measurement to date.

RESULTS

In total, 891 (83.2%) of the baseline sample completed the 18-month assessment and 985 (92%) completed the 24-month assessment; 36 (3.4%) provided data on PrEP discontinuation during at least one of these assessments. We examined baseline predictors of missing follow-up data and found that completion of at least one of these visits was less common among those without a 4-year college degree (42.5%) compared to those with a degree (57.5%); no differences were observed for race/ethnicity, employment, income, region, or relationship status.

Demographic characteristics of the sample of GBM who had initiated PrEP by 24-month follow-up are reported in Table 1. Immutable characteristics, such as race, were captured at the baseline assessment. Time-varying characteristics such as age, employment, and health insurance were drawn from both the baseline and 24-month data. GBM in the he full *One Thousand Strong* cohort of 1,071 were predominately White (71.2%), had at least some college (92.8), were employed full-time (67.2%), had health insurance (91.3%), and the average age was 40.2 years old. GBM who had initiated PrEP by the end of 2016 were predominately White (68.0%). Nearly two-thirds (64.5%) had a Bachelor’s degree or less of education, and most (88.4%) were employed. Almost all (95.4%) of the men who had initiated PrEP had health insurance, and the average age was 37.67 years old. Forty-two percent of the men had engaged in CAS.

Current Users versus Those that Discontinue

In bivariate comparisons (Table 1), GBM who had initiated PrEP but discontinued use by the 24-month follow-up were significantly more likely to be younger, unemployed, and without health insurance compared to men who were still currently on PrEP. Men who quit using PrEP were less likely to have recently engaged in sexual HIV transmission risk behavior, but this finding was only marginally significant (i.e., $p = 0.095$). In the multivariable logistic regression model, only employment status and age remained significant. Men who were unemployed had 4.58 times the odds of discontinuing PrEP compared to the GBM who were employed, and younger men were significantly more likely to quit PrEP by the 24-month follow-up (AOR = 0.96, $p = 0.034$). No significant differences in race/ethnicity or educational attainment were found in our analyses comparing previous and current PrEP users.

Why Individuals Quit Taking PrEP

Participants were asked “Have you ever been prescribed HIV medication (e.g., Truvada) for use as PrEP (HIV pre-exposure prophylaxis)?” during the 18-month and 24-month survey. Of the 852 that completed the 18-month CASI, 19 (2.23%) selected “Yes, but I am no longer prescribed PrEP”. Of the 985 that completed the 24-month CASI 31 (3.15%) selected “Yes, but I am no longer prescribed PrEP. Of those participants, two were excluded as they had reported discontinuing PrEP because they were part of an effectiveness trial and lost access to PrEP after the trial ended, leaving us with an analytic sample of 36 unique individuals between the two time points. Our goal was to assess reasons for discontinuation that was of the participant’s own volition. The majority of those that discontinued PrEP by the 24-month follow-up were white (61.1%), employed (66.7%), and had health insurance (83.3%).

All 36 participants who reported discontinuing PrEP by the 24-month assessment provided free response data used for analysis. Data about PrEP discontinuation were arranged into four main themes: 1) cost and insurance issues, 2) adherence and maintenance difficulty, 3) medication side effects, and 4) perceived lower HIV risk since starting PrEP. Sub-themes associated with lower perceived HIV risk emerged, including decreasing the number of sexual partners, adjusting their sexual lifestyle by addressing issues associated with drug and alcohol use, and preferring the use of alternative HIV prevention methods. Finally, participants discussed reasons why they might reinitiate PrEP use in the future.

Perceived lower HIV risk—The majority of participants (n=18, 50%) described discontinuing PrEP because of changes in their sexual behavior, which they perceived to reduce their HIV risk. Men mentioned several HIV risk reduction behaviors that prompted an end to PrEP use including decreasing the number of sexual partners, starting drug and alcohol use management/cessation programs, and resuming alternative HIV prevention methods such as condom use, management of partners’ HIV viral load (treatment as prevention), and sexual positioning.

> *I entered into a monogamous relationship where we both tested negative for HIV.*
>
> - 24 y/o, Latino

> *I began attending 12-step meetings (for an alcohol or drug use problem) and it was recommended that I not have sex or relationships in the first 90 days.*
>
> - 44 y/o, white

> *My doctor and I felt it was a good step to take after I had to go on PEP twice due to exposures I had while under the influence of alcohol. Shortly after starting PrEP, I made the decision to live sober. I continued PrEP for a couple months longer until I was sure I was fully committed to my sobriety and no longer concerned about slipping up and having another exposure. Once I knew I was committed to my sobriety, I made the decision to stop taking PrEP because I was only “hooking up” or engaging in high-risk behavior when I was under the influence of alcohol.*
>
> - 22 y/o, Latino

I found out that I had contracted chlamydia. I had been solely focused on just avoiding HIV, and I was reminded about the many other risks. So I decided to … reduce [my number of] sexual partners [and engagement in other] risky behaviors.

- 52 y/o, white

I started taking it because my partner is positive. I stopped taking it because … I [now only] have protected sex with my partner, and his viral load is undetectable.

- 27 y/o, white

I have dramatically reduced my number of partners to two in the last 6 months … [and] I also don't bottom, which according to my doctor has a greater risk associated with it.

- 42 y/o, multiracial

The most frequently repeated reasons for discontinuing PrEP were entering a relationship or purposely reducing the number of sex partners, both of which are associated with lowering sexual risk. However, HIV seroconversions do happen within relationships and it is unclear if quitting PrEP because of perceived monogamy is appropriate for all users. A reduction in the number of sexual partners highlights the possibility that for some, taking PrEP may be a daily reminder of the sexual risk they are engaging in and thus influences their awareness of behavior.

Cost and insurance issues—The cost of PrEP and other associated insurance difficulties was discussed as a reason for discontinuing PrEP by eleven of our participants (30.5%). Others could not afford the cost of PrEP because of high copays required by their insurance, and additional men had PrEP insurance coverage issues.

I decided to save my $50/month copay.

- 52 y/o, white

My insurance would not pay for it … even though I have a prescription, I cannot afford it.

- 22 y/o, Latino

Changed insurance – [I] can't afford [PrEP] now.

- 29 y/o, white

I couldn't afford it and I couldn't get it on my parent's health insurance. I am a student that isn't working to be able to get my own insurance.

- 21 y/o, white

Eight of the twelve participants that reported issues with affording PrEP were in their 20s and all reported their reason for quitting being insurance coverage. The 20's are a period of time where individuals may be on their parent's health insurance, transitioning jobs frequently causing changes in coverage, and according to the CDC the age group of 25–34 year olds are the only age group for which transmission rates are increasing (33). Continued research needs to focus specifically on discontinuation among GBM in their 20s.

Medication side effects—Some men (*n*= 4, 11%) on PrEP experienced side effects, causing them to discontinue PrEP use under advisement from their healthcare provider. Even for men who did not experience any immediate side effects, some implicitly weighed the potential long-term effects of using PrEP with their current behavior described next.

> *The side effects were affecting my health, so I stopped using PrEP.*
>
> - 23 y/o, multiracial

> *I tried taking it on a regular basis, but my kidney functions were not within the norm. My doctor advised me to stop taking it, which I did.*
>
> - 46 y/o, white

> *[I] didn't want to needlessly have such a powerful medication circulating in my bloodstream.*
>
> - 24 y/o, Latino

Two participants reported negative health consequences that they believed to be attributed to PrEP use. One of the participants referred to the drug as a "powerful medication" but did not report experiencing side effects. It is unclear how the side effects of PrEP, if at all, were effecting the participants on a daily basis or if they would reconsider taking PrEP if the formula changed in the future.

Adherence and maintenance difficulty—Although some reported no issues with the PrEP regimen, others (*n*=3, 8.3%) discussed issues associated with the dosing and testing requirements of PrEP. Maintenance of a PrEP prescription requires adherence to the once-daily pill as well as regular laboratory assessment and HIV/STI testing, which some men found problematic.

> *I stopped taking it because I wasn't keeping up with it.*
>
> - 27 y/o, white

> *I needed to go have blood work done to get my prescription renewed, and I got distracted with other things going on.*
>
> - 30 y/o, Latino

The first participant reports not "keeping up with it" but it is unclear what is being referred to as multiple things are required to continue a PrEP regimen. For example, quarterly doctor's visits and testing, along with taking a pill daily. The second participant clearly states the mandatory quarterly tests being an issue to his continued use. For this participant as ease of continued access to PrEP may influence his decision to adhere.

Potential for reinitiating PrEP use—While not explicitly asked in our open-text response to PrEP uptake and discontinuation, men freely provided responses about when and if they would reinitiate PrEP use. Those with PrEP maintenance issues discussed intentions for reinitiating PrEP after ameliorating current barriers. Men who discontinued PrEP based on perceived HIV risk described potentially reinitiating in the future if they decided to engage in higher-risk activities again. Not surprisingly, individuals did not discuss reinitiating PrEP when they had side effects with the current drug formulation. While not

discussed, those with affordability and insurance issues may reconsider PrEP with these barriers removed.

> *If in the future I decide to engage with multiple partners or behavior that is [considered] high risk again, I know PrEP is available and would have no problem starting a regimen again.*
>
> - 22 y/o, Latino

> *When I become more sexually active I will get back on prep.*
>
> -23 y/o, Asian

> *I just went yesterday to get the bloodwork done, and hope to be back on PrEP by the end of next week.*
>
> - 30 y/o, Latino

PrEP reinitiation was observed in the quantitative data between 18- and 24-month follow-up. Thirty-six unique individuals reported stopping PrEP at some point by 24-month follow-up. However, five participants who reported stopping PrEP at the 18-month follow-up had reinitiated PrEP by the 24-month assessment. These individuals' age ranged from 24–38 years old (M=30), three reported being white and two Latino, all were employed, two had a college degree, and four reported being single. The exclusion of these five individuals explains why the quantitative sample of those who stopped taking PrEP compared to those on PrEP at 24-month is equal to 31, even though a total of 36 individuals had stopped PrEP at some point by the 24-month follow-up.

In summary, men who were previously on PrEP but discontinued use provided detailed responses about why they were no longer on PrEP. Responses had themes aligned with structural barriers related to cost and insurance, difficulties managing the adherence and testing requirements for PrEP, side effects of the current drug formulation, and perceived change in HIV risk from when they initiated PrEP. Moreover, reinitiating PrEP was considered for some, and others may reinitiate after structural barriers are removed or they increase their sexual risk behavior.

DISCUSSION

The reasons given for discontinuing a regimen consisted of medication cost, insurance issues, adherence/maintenance issues, adverse side effects, and lower perceived HIV transmission risk behavior. Those that reported possible re-initiation of a regimen stated they would start PrEP again if their perceived risk of HIV increased, and if some of the structural barriers required for PrEP maintenance were removed. However, no participants who reported having adverse side effects to PrEP discussed reinitiating a regimen again. These findings for discontinuation are aligned with previous research that highlights barriers to initial uptake including insurance, cost, and maintenance (5, 9, 12, 13, 15, 25–27), risk perception (8, 27–29), and side effects (5, 7, 9, 10, 12, 14).

Some themes of seasons of risk did emerge within our findings; however, none of our participants reported having an intentional period of use set out when they began a regimen.

Some men stated they would begin PrEP again in the future if they thought their HIV risk increased and would warrant the protective benefits of PrEP. It may be possible that after initiating and stopping a PrEP regimen some GBM may then become cognizant of either planning for or recognizing periods of heightened risk, making them prime candidates for PrEP use. Some GBM may begin and stop a regimen in the future based on their behavior at the time or expected future behavior. Other research has shown that GBM tend to overestimate when they will have sex (34), and thus seasonal PrEP may be a promising mechanism for these individuals who anticipate periods of heightened risk. Nonetheless, further research on the seasons of risk is needed as additional dosing regimens become available. On-demand PrEP dosing (35) might be a good option for individuals engaging in changing levels of risk, and a long-acting injectable might be a good alternative for individuals who experience difficulty maintaining daily-pill adherence. In fact, uptake of PrEP may increase if long-acting injectable PrEP were to become available (36–40), and recent research among PrEP users indicates many GBM taking daily-oral PrEP would actually prefer a long-acting injectable dosing form of PrEP (41). Based on our findings, expanding the use of on-demand PrEP might be a good alternative for some, and discontinuation might decrease marginally if a long-acting injectable form of PrEP were to become available and considered for GBM with daily adherence challenges.

There were significant demographic differences between participants of our sample that were currently on PrEP at the 24-month survey compared to those that had discontinued use. Those no longer on PrEP were likely to be younger, unemployed, and without health insurance compared to those that were currently on PrEP. The CDC reported that youth (between 13 and 24 years-old) are at high risk of HIV acquisition and accounted for 1 in 5 new HIV diagnoses in the U.S. in 2015, 81% of whom are young GBM (42). Although this subgroup is still at heightened risk for HIV transmission, we did find that those who discontinued PrEP also reported engaging in marginally less CAS compared to those that were still on PrEP. Men not taking PrEP may be engaging in less CAS compared to those currently taking PrEP, but less does not mean zero and thus they may still benefit from a PrEP regimen.

Issues around health insurance were uncovered in both qualitative findings and quantitatively comparing groups at the 24-month follow-up. For some GBM, changes in employment and/or health insurance may highly impact their ability to continue taking PrEP. Without insurance PrEP can cost upward of $14,000 a year (43). PrEP may be more affordable for individuals who qualify for Medicaid, however there are restrictions to coverage depending on the state one resides in (44). Furthermore, some research has shown that an expansion of Medicaid may have influenced an increase in PrEP implementation, but changes in Medicaid via a repeal of the Affordable Care Act may set forth an enormous decrease in PrEP utilization (45). Furthermore, GBM who live near major metropolitan areas have more access to both providers and PrEP for free. To what end these participants are aware of their access to PrEP via alternative routes beyond health insurance is unclear. This may be an area where PrEP providers are able to offer education to their patients about different options for continued access should there be a change in their income, employment status, or health insurance.

Limitations

There are limitations to the generalizability of this exploratory study, the largest being the sample size. With a quantitative sample of 31 men who discontinued PrEP use, we had limited power to detect significant differences in our statistical analyses. However, research on discontinuation of PrEP is extremely limited and rates of discontinuation are likely to rise as uptake continues to increase. It is important that research continues to address potential ways to keep at-risk GBM on PrEP when they discontinue so interventions to keep HIV at-risk GBM on PrEP can be developed and implemented. Another limitation to the generalizability of this study is the eligibility criteria. All participants had to report self-identification as gay or bisexual, as opposed to only reporting sex with another man. Some research has shown that differences between men who engage in sex with other men and identify as gay or bisexual versus those that identify as heterosexual can often be attributed to minority stress (46), or high levels of stress faced by individuals of stigmatized groups, usually caused by interpersonal prejudice and discrimination. Men who have sex with men but do not identify as gay or bisexual may avoid some of these stressors as they may not endure the same prejudice and discrimination as those that identify as gay or bisexual. In terms of PrEP use, heterosexually identifying men who engage in high risk sexual behaviors may perceive PrEP to be for gay or bisexual men due to both advertising and PrEP guidelines for use. More research should be conducted with non-gay and bisexual identifying men who have sex with men as additional barriers for this group may include higher levels of HIV related stigma, the possibility of exposure as engaging in same-sex behavior for anyone who may see the medication, and having to speak with a medical provider about their sexual behavior whom may not know they engage in same-sex behaviors. Another consideration for the results of this study is that the participants are predominantly White and making more than $30,000 per year. Similarly, individuals who reported not having a college degree were less likely to complete follow-up surveys, thus this sample's reasons for quitting may be different than those who have differing socioeconomic statuses.

Future Directions

Facilitators and barriers have been explored for uptake and adherence of PrEP, but they have not been explored for the decision to discontinue PrEP and reinitiate. This study highlights multiple reasons for discontinuation that mirror areas previously tied to barriers to PrEP uptake including financial access, risk perception, and side effects. One additional barrier this study highlights is the maintenance of doctor visits for HIV/STI testing after the initial prescribing. At this time, it is unknown what percentage of GBM stop taking PrEP because of the additional doctor's appointments every three months, but this may be a place for potential interventions or alternate testing strategies. For example, this study consists of participants that were able to conduct self-administered rapid HIV and STI testing from home with samples mailed to a testing laboratory. Home-based PrEP persistence activities—such as conducting at-home HIV/STI self-testing with prescription mailing (47)—could be one mechanism to reduce barriers to PrEP maintenance activities such as the frequency of required in person clinical follow-up appointments. Another area which may require intervention or education is how GBM come to conclusions about how they measure their HIV risk (i.e. number of partners, specific encounters, etc.). Multiple participants reported

that an increase of sexual risk behavior may lead to re-initiation but how they measure this risk may be different for individuals, thus making sexual risk a subjective feeling instead of objective fact (i.e. CDC criteria for uptake). This may be a place for future interventions in how prescribing doctors can initiate a conversation about behavioral risk when prescribing PrEP and the potential for discontinuation.

Additionally, our finding that young GBM and those who are currently unemployed had discontinued PrEP is concerning. Future research needs to address needs, wants, and interventions that can help GBM stay on PrEP even when unemployed. PrEP may be more accessible and free in urban areas, but that does not necessarily benefit those that are not within a manageable distance from a PrEP provider. Finding ways to bridge these gaps so that those who would prefer to stay on PrEP but may be strapped financially is imperative. Along with the price of medication, those who are unemployed may also have difficulties making and paying for quarterly appointments and testing.

Lastly, this is merely one study with a relatively small sample size and more research must be done on reasons this at-risk population has for quitting PrEP. It is imperative that when asking individuals about their experience on PrEP we also ask them about why they quit and why they might be considering reinitiating PrEP use so we are able to create interventions to keep individuals who want to stay on PrEP engaged in a regimen.

Conclusions

This research highlights that although some GBM may initiate and discontinue PrEP based on their HIV risk perception, not all individuals who discontinue use are doing so because their risk behavior has decreased. These results suggest that not all GBM who are behaviorally eligible for PrEP will be able to continue a regimen for a variety of reasons. Based on these results, we suggest that when studying discontinuation, researchers need to focus on two areas, those who do not perceive themselves to be at risk, and those who want to continue PrEP but have other barriers (i.e. doctor's appointments, costs, employment status). With PrEP being the most effective bio-medical behavioral prevention strategy currently available it is imperative that research does not conclude entirely with uptake and adherence.

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Table 1

Demographics and sexual HIV transmission risk behavior and their associations with PrEP discontinuation for current PrEP users (n = 172) versus previous PrEP users (n=31) at the 24-month follow-up.

	Current PrEP users		Previous PrEP user		Group Comparisons		
		Column		*Column*			
Categorical Variables	***n***	**%**	***n***	**%**	χ^2	***AOR***	***95% CI***
Race/Ethnicity					0.79		
Non-White	55	32.0	12	38.7		–	–
White	117	68.0	19	61.3		0.71	0.29–1.73
Education					1.54		
Bachelor's degree or less	111	64.5	23	74.2		–	–
More than a Bachelor's degree	61	35.5	8	25.8		0.53	0.20–1.39
Employment Status					7.40***		
Employed	152	88.4	23	74.2		–	–
Unemployed	20	11.6	8	25.8		4.58**	1.43–14.70
Health Insurance Status					5.81**		
No health insurance	8	4.7	4	12.9		–	–
Has health insurance	164	95.4	27	87.1		0.27	0.05–1.41
Sexual HIV Transmission Risk					2.78*		
Engagment[1]							
No	99	57.6	22	61.1		–	–
Yes	73	42.4	9	38.9		0.51	0.21–1.23
Continuous Variables	*M*	*SD*	*OR*	*SE*		*AOR*	*95% CI*
Age (Range: 20–67 years old)	37.67	11.4	0.96**	0.02		0.96**	0.92–1.00

Notes:

[1] any condomless anal sex with an HIV-positive or unknown partner or any casual partner in the past 3 months;

* $p \leq 0.10$;

** $p \leq 0.05$;

*** $p \leq 0.01$.