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Structural, dosing, and risk change factors affecting discontinuation of pre-exposure prophylaxis (PrEP) in a large urban clinic

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Abstract

Introduction: Understanding the reasons why clients stop taking pre-exposure prophylaxis (PrEP) is critical to improving PrEP delivery and ultimately reducing HIV incidence.

Methods: We analyzed data from a programmatic evaluation conducted at the Los Angeles LGBT Center (the Center) from February-May 2018. In the evaluation, an online structured questionnaire was emailed to inactive PrEP clients.

Results: Of 180 survey respondents, 91 had stopped taking PrEP and 11 had never started. Most who stopped using PrEP did so for reasons spanning multiple categories. Among former PrEP users, the most common reasons for stopping were entering a monogamous relationship (43%) and side effects (40%). Ten of 11 who never started PrEP reported access barriers (e.g., cost was too high, problems with insurance). An unexpected finding was that the survey led 25% of inactive clients to re-engage with PrEP services at the Center and 15% to restart PrEP by October 2018.

Conclusion: The findings show that improving PrEP retention may require multifaceted interventions – e.g., tailored discussions about stopping and restarting PrEP safely as HIV risk changes, ensuring consistent access to affordable PrEP, and alternative dosing strategies. An emailed survey appears to be a simple yet effective strategy to reengage some clients in PrEP care.

INTRODUCTION

Daily oral tenofovir disoproxil fumarate and emtricitabine (TDF/FTC) is efficacious in preventing HIV transmission when taken as pre-exposure prophylaxis (PrEP).(Baeten et al., 2012; Grant et al., 2010) A continuum outlines stages of engagement with PrEP: 1)

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awareness of PrEP, 2) PrEP access and uptake, 3) adherence to PrEP regimen, and 4) retention in PrEP care.(Kelley et al., 2015; Nunn et al., 2017) Studies of the PrEP continuum in community settings around the United States reveal retention is a major challenge. (Blackstock, Patel, Felsen, Park, & Jain, 2017; Chan et al., 2016; Hojilla et al., 2018; Rusie et al., 2018; Shover et al., 2019) High discontinuation rates were observed in patients receiving PrEP through community clinics in San Francisco (n=344) and Chicago (n=3,451), where only 47% and 43%, respectively, were still retained in care within about a year after starting PrEP. (Hojilla et al., 2018; Rusie et al., 2018) Similarly, a study in Rhode Island, Mississippi, and Missouri (n=267) found only 57% of PrEP clients were retained at six months.(Chan et al., 2016) Retention has been higher in demonstration projects, research cohorts, and integrated care settings. (Hosek et al., 2017a; Landovitz et al., 2017a; Marcus et al., 2016b) Higher retention may be attributable to increased resources in these specialty settings, including telemedicine adherence support, compensation for follow-up visit attendance, onsite treatment of sexually transmitted infections (STIs), and counseling interventions for individuals struggling with adherence (such as Integrated Next Step Counseling (iNSC).(Amico, Mansoor, Corneli, Torjesen, & van der Straten, 2013; Hosek et al., 2017b; Landovitz et al., 2017b; Marcus et al., 2016a)

While poor PrEP retention has been well-documented, few studies have explicitly explored drivers of PrEP discontinuation. In a national survey of gay and bisexual men, Whitfield et. al found that those who discontinued PrEP did so due to lower perceived HIV risk (reducing number of sexual partners or drug/alcohol usage), cost/insurance issues, medication side effects, and difficulties with adherence/maintenance (frequency of lab work, regular HIV/STI testing).(Whitfield, John, Rendina, Grov, & Parsons, 2018) In a survey of young men who have sex with other men (YMSM) in Chicago, participants who discontinued PrEP indicated an inability to get to provider appointments and issues with insurance coverage as their primary reasons for discontinuation.

A quantitative study in a Los Angeles community clinic found that a substantial portion of PrEP clients discontinued within six months (Shover et al., 2019). Clients who accessed PrEP through government assistance programs with no co-payment were more likely to continue PrEP services compared to those with no insurance or those with private insurance. Those aged 18–24 as well as those unstably housed were more likely to discontinue PrEP. Following these findings, a programmatic evaluation was conducted at the clinic to understand reasons for discontinuation and identify potential targets for interventions to improve retention.

In this study we used the data from that programmatic evaluation, which used electronic health record data to identify and survey patients who had discontinued PrEP. We hypothesized that common reasons for PrEP discontinuation would include structural or access barriers (e.g., cost of medication and medical care, insurance problems), change in HIV risk (e.g., entering a monogamous relationship, a period of celibacy), and factors related to the medication itself (e.g., side effects, not wanting to take a daily pill). We also report post-survey PrEP re-engagement.

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METHODS

This analysis uses secondary data that was originally collected in a programmatic evaluation at the Los Angeles LGBT Center (the Center). The Center, a large federally-qualified health center that primarily serves lesbian, gay, bisexual, and transgender patients, has offered PrEP since 2014. Patients who were aged 18 and older at first PrEP intake, had their first PrEP intake between January 2016 and June 2017, and provided an email address and consent to be contacted were invited by email in February through May 2018 to take a ten-minute survey if they had a current gap in PrEP care (>120 days since they last received a three-month PrEP prescription). Two screening questions at the start of the survey confirmed eligibility (1) "Have you ever visited the Los Angeles LGBT Center?" and (2) "Have you ever had an appointment for PrEP (pre-exposure prophylaxis, where you take a pill every day to prevent HIV) at the Los Angeles LGBT Center?" Those who answered "no" or "refuse to answer" to either were ineligible.

The structured 49-item questionnaire (Appendix A) was administered in English and Spanish on Qualtrics, an online survey platform. To encourage early participation in the evaluation, the Center's outreach team offered a $10 gift card to the first 120 people to respond to the survey. After the initial round of emailed invitations prompted many survey responses in the first day, an additional 50 incentives were added for a total of 170. Email reminders (including the text that gift cards were still available) were sent periodically to clients who had not responded until all incentives were allocated. Qualtrics' "prevent ballot box stuffing" option was used, and duplicate responses from the same IP address were discarded. All multiple-choice questions were required and included a "refuse to answer" option; all text-response questions could be left blank.

PrEP use status was classified as current, former, or never started. The first question to determine PrEP status was "When did you take your most recent PrEP dose?" Respondents who answered they took their most recent dose "Today" or "Not today, but in the past 7 days" were classified as current PrEP users. Respondents who chose "More than 30 days ago" were classified as former PrEP users. Those who chose "I have never taken PrEP" were classified as never-starters. If a client declined to answer the question about most recent dose (n=4) or reported they took their last dose "More than 7 days ago but in the past 30 days" (n=6), the follow-up question, "In the past 30 days, how often did you take PrEP?" was used to determine current PrEP status. Those who answered "I do not take PrEP anymore" were classified as former users. Respondents whose current pattern of PrEP use could not be determined based on these questions (n=5) were excluded from analyses.

The primary outcome measured in this study was why an individual stopped taking PrEP or missed PrEP doses. Those who reported never starting PrEP were asked "What were the reasons you did not take PrEP?" followed by the questions on specific reasons. Current and former PrEP users were asked, "Since you first got your PrEP prescription, how many times have you missed more than two doses of PrEP in a week?" Those who reported ever missing two or more doses in a week were then asked the questions on specific reasons. Survey questions were chosen by committee and included questions written by clinicians, PrEP navigation counselors, and other Center staff, along with questions adapted from the "PrEP

in the Wild" survey (Galea, Cook, Pickett, & Gorbach, 2016). Some had follow-up text-response questions (e.g. "What were the reason(s) you did not need to take PrEP?").

At the survey's end, participants were asked "Would you like to be contacted to schedule another PrEP appointment at the Center?" Those who answered yes were prompted to enter their name and phone number so a linkage counselor could follow up. Re-engagement in PrEP following the survey was determined from the subset of patients who requested this follow-up, with appointment data available through October 31, 2018.

Ethics

The programmatic evaluation was reviewed and approved by the Center's compliance officer, medical director, and a committee of clinicians and staff. Use of the resulting data for this study was reviewed and approved by the Institutional Review Board at the University of California Los Angeles (IRB Protocol #17–001731).

Statistical Methods

Descriptive statistics were calculated. Reasons for stopping PrEP, never starting, or missing PrEP doses were tabulated by PrEP status. Proportion of inactive respondents requesting follow-up was calculated, along with proportion who were relinked to PrEP. All analyses were performed using SAS 9.4 (Cary, N.C.)

RESULTS

Invitations were emailed to 799 clients. Of these, 185 (23%) completed the survey. Demographically, respondents resembled invited clients (χ^2, p>0.1 (gender, race, orientation); one-sample, two-tailed t-test p=0.4 (age)) (Table 1). Respondents were classified as current (n=78, 43%), former (n=91, 51%), or never (n=11, 6%) PrEP users. PrEP use status could not be determined for five (3%) respondents. All respondents who never started PrEP (n=11) provided reasons for not taking PrEP, as did 69% (n=63) of former PrEP users and 64% (n-50) of current users. Responding to the question, "In the past 30 days, how often did you take PrEP?" four clients indicated they were taking PrEP "Intermittently, or only when I plan to have sex."

Most former PrEP users (and those who were prescribed PrEP but never started) endorsed at least one reason for stopping PrEP or missing doses (Table 2). Among former users, 71% (n=45) reported dosing-related reasons, while 67% reported change in risk (n=42), and 54% (n=34) reported structural or access barriers. Twenty-seven percent (n=17) reported reasons across all three domains (Figure 1). Among former users, most common reasons for missing doses and/or discontinuing were entering a monogamous relationship (43%, n=27) and side effects (40%, n=25). Twenty indicated they missed or stopped PrEP because they thought they didn't need PrEP. Most who answered follow-up questions wrote that they were not having sex, were less sexually active, or had entered a monogamous relationship (Table 3). Ninety-one percent of never-starters (n=10) reported structural reasons for not taking PrEP, while 45% (n=5) reported change in risk, and 36% (n=4) reported reasons related to dosing or regimen.

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Of the 78 current PrEP users, 45% (n=35) had most recently been prescribed PrEP by a provider not affiliated with the Center, indicating that they had not discontinued but transferred care. Sixty-four percent of current PrEP users (n=50) reported they had ever missed two or more doses in a week; forgetting was the most common reason (n=28, 56%) (Table 1). Three-quarters of current PrEP users reported using at least one method to remind themselves to take PrEP, with most using a pillbox or container (n=25, 32%) or taking PrEP the same time every day (n=23, 29%).

Twenty-five (25%) of 102 inactive PrEP clients requested a call to schedule an appointment for PrEP. The linkage team called all 25 patients, leaving a message when possible. Fourteen patients were relinked to PrEP and one was linked to HIV care, for a total relinkage of 56% of those who requested to be contacted and 15% of all inactive clients.

DISCUSSION

An emailed survey about PrEP discontinuation found about half of the respondents had stopped taking PrEP, while a smaller group had never started. Most respondents who discontinued PrEP endorsed multiple reasons for doing so. This suggests that interventions to improve PrEP retention will need to address the multiple domains that influence continued PrEP use. Unexpectedly, the survey led a quarter of inactive respondents to re-engage with PrEP services, and 15% to get a new PrEP prescription. This unexpected finding suggests that PrEP providers in any setting where clients have regular access to email can use this approach to assess specific factors that influence PrEP adherence and retention among their own client population and to re-engage clients in PrEP care. When clients have consented to be contacted by email, this can be an inexpensive first step so more intensive follow-up resources can be allocated directly to reaching patients who do not respond to the first outreach. Among those who had discontinued PrEP, we found changes in HIV risk, cost of medication, and side-effects were among the most common reasons for stopping PrEP. Stopping PrEP was rarely attributed to one reason; usually there were multiple factors influencing discontinuation. Though each of these reasons have been separately documented in other studies, this study is among the first to describe their co-occurrence among PrEP users.(Arnold et al., 2017; Hojilla et al., 2018; Morgan, Ryan, Newcomb, & Mustanski, 2018; Whitfield et al., 2018) Engaging PrEP users in discussions about stopping and restarting PrEP safely as HIV risk changes, ensuring consistent access to affordable PrEP, and continuing to develop new formulations or dosing strategies may improve overall retention in PrEP programs.

Structural barriers were common, and near universal among clients who never started taking PrEP. Yet the finding that two-thirds of clients reported stopping PrEP because they entered a monogamous relationship or otherwise had reductions in their potential exposure to HIV suggests that stopping PrEP for these individuals was at least partly a deliberated decision versus entirely due to unintentional non-persistence or change in access to PrEP. These two findings highlight the need for flexibility in understanding retention in PrEP. PrEP differs from other preventive medications in that need may wax and wane according to “seasons of risk” (Elsesser et al., 2016).

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Clinics may be best able to provide comprehensive and continuous PrEP care if, at PrEP intake, providers discuss circumstances that may lead to stopping PrEP, and how the clinic could help guide that decision. For example, for a new monogamous relationship, the clinic protocol could suggest simultaneous HIV testing for both partners followed by another testing visit based on individual risk assessment. During the interval between testing the recommendation could be for continued PrEP. This communicates that the provider is a nonjudgmental consultant, fostering informed decision-making regarding PrEP. It also allows a new couple to continue to protect each other during window periods where early infection may yield a negative HIV test result. Such conversations should also cover safely restarting PrEP if the need arises. Without clear plans for what to do if or when a PrEP user would like to stop PrEP, patients may be more likely to simply stop coming in to the clinic; this limits chances to discuss what to do with "left-over" medication or how to safely re-start PrEP if desired. Furthermore, the finding that most clients who stopped taking PrEP reported a dosing-related barrier highlights the potential of long-acting PrEP to improve consistent use. Including peri-coital PrEP as an option for patients may address dosing concerns, while also lowering cost by necessitating fewer pills. The International AIDS Society's recent endorsement of peri-coital PrEP (also called event-based or on-demand PrEP) is another reason this option should be introduced into conversations about PrEP.(Saag, Benson, Gandhi, & et al., 2018)

By contacting PrEP patients who appeared to be inactive, based on their visit records, we were able to assess in-depth reasons for stopping PrEP or missing doses among patients who were known to have been previously prescribed PrEP. Studying PrEP usage in a clinical setting, rather than a research cohort, may increase generalizability to other routine care settings, particularly urban federally qualified health centers.

Limitations

The sample represents those reachable by email and willing to take a survey and may not represent PrEP clients broadly. Though we asked about event-based PrEP, social desirability bias may have led to underreporting, as the clinic's official recommendation was daily PrEP. We removed duplicate responses from the same IP address, but a respondent could have used multiple devices to submit multiple responses. Using self-reported data rather than biomarkers of PrEP adherence may be less accurate but also reflects constraints for most community clinics. Additionally, the survey did not distinguish between reasons for missing doses or temporarily stopping PrEP versus reasons for stopping PrEP permanently – future studies might examine how these differ. Finally, our taxonomy may misclassify the roots of some reasons. For example, if someone loses their pills because they have no stable living place in which to store them, then what we call a dosing reason is a proxy for a structural reason as well, and neither the data collection nor the reported results would have captured that.

Despite these limitations, this study of a programmatic evaluation at the Los Angeles LGBT Center provides important insight into why patients stop taking PrEP, particularly regarding co-occurring factors that may inform interventions. Future studies should examine these questions in larger samples, ideally including more cisgender women and transgender

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people. Clinics offering PrEP may use email to re-engage patients who have stopped returning to care (Arnold et al., 2017). Strategies to support long-term PrEP use must address access and dosing issues while fostering tailored discussions about changing needs.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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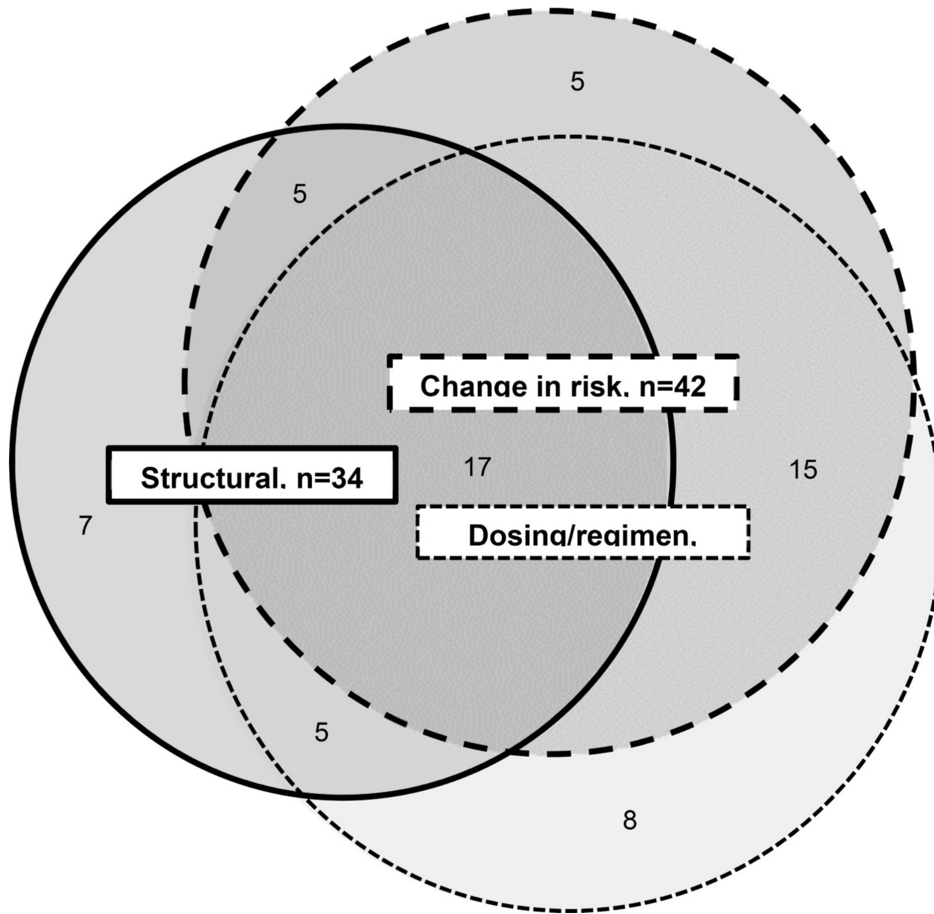

Figure 1.
Overlap of reasons for stopping PrEP or missing doses among former PrEP clients of the Los Angeles LGBT Center who completed discontinuation survey, (n=62)

Note: Structural reasons included cost was too high, problem with insurance, problem with prescription, problem with appointments or clinic, transportation problem, lost pills. Change in need reasons include entered a monogamous relationship, "didn't think I needed PrEP", not having anal sex. Dosing and regimen reasons included side effects, forgot, did not want to take a daily pill, concerned PrEP would interfere with other medications, hormones, or supplements, saving pills for later, sharing pills with someone else.

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Table 1.

Characteristics of PrEP survey respondents, n=180, compared to invited clients (n=799) who received PrEP at the Los Angeles LGBT Center

	Total		Current PrEP User		Former PrEP User		PrEP Never-user		Invited***	
	n	% *	n	% **	n	% **	n	% **	n	% **
Gender										
Cis man	168	93%	72	92%	85	93%	11	100%	756	95%
Cis woman	5	3%	3	4%	2	2%	0	0%	10	1%
Genderqueer/Genderfluid	3	2%	2	3%	1	1%	0	0%	4	1%
Trans man	2	1%	1	1%	1	1%	0	0%	4	1%
Trans woman	1	1%	0	0%	1	1%	0	0%	22	3%
Unreported	1	1%	0	0%	1	1%	0	0%	1	0%
Age (Range: 18–65)	31.6	8.6	32.3	8.4	31	8.5	31.1	10.8	31.1	8.3
Age group										
18–24	29	16%	5	6%	20	22%	4	36%	189	24%
25–30	66	37%	34	44%	30	33%	2	18%	295	37%
31–40	60	33%	27	35%	30	33%	3	27%	224	28%
41–50	15	8%	9	12%	5	5%	1	9%	65	8%
51–65	9	5%	3	4%	5	5%	1	9%	25	3%
Unreported	1	1%	0	0%	1	1%	0	0%	0	0%
Race/ethnicity										
Asian/Pacific Islander	14	8%	5	6%	9	10%	0	0%	63	8%
Black	17	9%	5	6%	12	13%	0	0%	72	9%
Hispanic/Latino	46	26%	21	27%	23	25%	2	18%	227	28%
Middle Eastern	10	6%	6	8%	3	3%	1	9%	N/A	N/A
More than one race	14	8%	5	6%	9	10%	0	0%	N/A	N/A
White	71	39%	32	41%	31	34%	8	73%	348	44%
Unreported	8	4%	4	5%	4	4%	0	0%	35	4%
Other (only in electronic health record)	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	54	7%
Sexual orientation										
Gay	143	79%	62	79%	71	78%	10	91%	662	83%
Bisexual	24	13%	10	13%	14	15%	0	0%	89	11%
Queer	7	4%	4	5%	3	3%	0	0%	N/A	N/A
Another orientation	4	2%	2	3%	2	2%	0	0%	28	4%
Unreported	1		0	0%	1	1%	1	9%	20	3%
Education level										
High school or less	17	9%	11	14%	5	5%	1	9%	85	11%
Some college	41	23%	16	21%	21	23%	4	36%	171	21%
College degree	85	47%	36	46%	45	49%	4	36%	280	35%
Post graduate study/degree	36	20%	15	19%	19	21%	2	18%	97	12%
Unreported	1	1%	0	0%	1	1%	0	0%	166	21%

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	Total		Current PrEP User		Former PrEP User		PrEP Never-user		Invited***	
	n	% *	n	% **	n	% **	n	% **	n	% **
Location of first PrEP appointment										
Hollywood	66	37%	34	44%	29	32%	3	27%	N/A	N/A
West Hollywood	108	60%	43	55%	58	64%	1	9%	N/A	N/A
Don't Remember	6	3%	1	1%	4	4%	7	64%	N/A	N/A
Distance from home to clinic										
< 3 miles	42	23%	21	27%	19	21%	2	18%	N/A	N/A
3->7 miles	49	27%	21	27%	25	27%	3	27%	N/A	N/A
7->12 miles	38	21%	13	17%	22	24%	3	27%	N/A	N/A
12+ miles	43	24%	22	28%	19	21%	2	18%	N/A	N/A
Missing	8	4%	1	1%	6	7%	1	9%	N/A	N/A
Transferred to another clinic	44	24%	35	45%	9	10%	0	0%	N/A	N/A
Request contact for PrEP appointment	37	21%	12	15%	23	21%	2	18%	N/A	N/A
Total	180	100%	78	100%	91	100%	11	100%	799	100%

*Row percentages (of category total)

**Column percentage

***Available demographics from electronic health record

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Table 2.

Reasons for missing doses or stopping PrEP among patients who provided reasons (n=124), by PrEP use status.

	Former[a]		Never[b]		Current[c]	
	n	**%**	**n**	**%**	**n**	**%**
Number of reasons endorsed (range = 0–11)						
Zero	1	2%	0	0%	8	16%
One	12	19%	2	18%	14	28%
Two	18	29%	2	18%	5	10%
Three to four	17	27%	3	27%	14	28%
More than four	15	24%	4	36%	9	18%
Reasons for not taking PrEP (not mutually exclusive)						
Structual/Access						
Cost was too high	18	29%	7	64%	11	22%
Problem with insurance	14	22%	9	82%	12	24%
Problem with prescription	11	17%	6	55%	15	30%
Problem with appointments or clinic	14	22%	1	9%	14	28%
Transportation problem	5	8%	1	9%	1	2%
Lost pills	1	2%	0	0%	5	10%
Change in Need						
Entered monogamous relationship	27	43%	4	36%	6	12%
Didn't think I needed PrEP	20	29%	4	64%	2	4%
Not having anal sex	18	29%	3	27%	10	20%
Regimen and Dosing related						
Side effects	25	40%	1	9%	3	6%
Forgot	21	33%	0	0%	28	56%
Did not want to take a daily pill	14	22%	2	18%	5	10%
Concerned PrEP would interfere with other medications, hormones, or supplements	8	13%	3	27%	2	4%
Saving pills for later	7	11%	1	9%	5	10%
Sharing pills with someone else	1	2%	0	0%	0	0%
Total	63	100%	11	100%	50	100%

[a] Either a) reported they last took PrEP "More than 30 days ago" (n=57) or b) declined to report when they last took PrEP (n=4) reported that they last took PrEP "More than 7 days ago but in the past 30 days" (n=2) and also reported "I do not take PrEP anymore."

[b] Reported they never started taking PrEP.

[c] Reported they took PrEP within the last 7 days.

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Table 3.

Reasons clients who were no longer taking PrEP (former and never) stopped taking PrEP, never started, or missed doses (write-in responses)

Question: What were the reason(s) you did not need to take PrEP?
"No sex" (x2)
"I wasn't sexually active" (x2)
"Wasn't having sex and it made me depressed"
"Not as sexually active"
"No more sex"
"Because I have not had sex in a year"
"not having sex without condom"
"No longer needed in a committed married relationship"
"Relationship, sole sexual partner"
"Monogamous relationship" "LTR" (long-term relationship)
"I'm in a monogamous relationship."
"Wasn't having sex and it made me depressed"
"Nausea"
"I didnt like taking a pill every day. Also there are no known long term side effects of the drug."
"Insurance issues"

Question: If you mentioned that you've ever forgotten to take PrEP, can you think of any reasons why you typically forget to take PrEP?
"Busy schedule or forgot my pill at home"
"No longer having sex"
"Too drunk"
"Cause I ran out of my pills and had to get on a free program" "Have never taken it — but would use morning as a reminder"
"Busy schedule"
"Traveling"
"Was in a rush in the mornings but it was just twice that I forgot."

Question: Were there any other reasons that you missed taking PrEP that we didn't already talk about?
"Reports from friends of feeling paralysis"
"Just forgot if I took it or not and didn't want to double dosage. My own flaw."
"I did not want to be on a pill anymore."
"I became positive"
"I was being irresponsible because of substance use"
"Misinformed at the center, they told me my insurance would cover. However, I was shocked I have been asked to pay $ 1000 after deduction. Bummer, I left the pills over there."

"I lost my insurance and haven't gotten around to getting a new prescription"

"Kidney issues"

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