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Author manuscript

AIDS Care. Author manuscript; available in PMC 2020 May 01.

Published in final edited form as:

AIDS Care. 2019 May ; 31(5): 536–544. doi:10.1080/09540121.2018.1533238.

Barriers to Preexposure Prophylaxis Use Among Individuals with Recently Acquired HIV Infection in Northern California

Julia L. Marcus, PhD, MPH[1], **Leo B. Hurley, MPH**[2], **Dennis Dentoni-Lasofsky, RN, BSN**[3], **Courtney G. Ellis, MBA, MS**[2], **Michael J. Silverberg, PhD, MPH**[2], **Sally Slome, MD**[3], **Jonathan M. Snowden, PhD**[4], and **Jonathan E. Volk, MD, MPH**[5]

[1]Harvard Medical School and Harvard Pilgrim Health Care Institute, Boston, MA, USA

[2]Kaiser Permanente Division of Research, Oakland, CA, USA

[3]Kaiser Permanente Oakland Medical Center, Oakland, CA, USA

[4]Oregon Health & Science University-Portland State University, Portland, OR, USA

[5]Kaiser Permanente San Francisco Medical Center, San Francisco, CA, USA

Abstract

Barriers to HIV preexposure prophylaxis (PrEP) use have not been well-characterized in people who became HIV-infected, all of whom could have benefited from PrEP. We invited members of Kaiser Permanente Northern California with an HIV diagnosis during 2014–2016, following a negative HIV test in the year prior to diagnosis, to complete a survey assessing barriers to PrEP use prior to HIV diagnosis. We used chi-square tests to identify factors associated with specific barriers, and Cochran-Armitage tests to assess trends in barriers by year of HIV diagnosis. Of 268 patients surveyed, 122 (46%) responded. Median age of respondents was 36, most (84%) were men who have sex with men, and 64% were of minority racial/ethnic background. Thirty-six (30%) had discussed PrEP with a provider, of whom 10 were diagnosed with HIV at PrEP intake. Overall, only 5 (4.1%) had used PrEP, and all 5 discontinued before diagnosis. Among all respondents, the most common barrier to PrEP use was lack of PrEP awareness (51%). Among those aware of PrEP, the most common barriers were cost/insurance concerns (36%) and perceived low risk for HIV (24%). Lack of PrEP awareness ranged from 39% among those aged 25–34 to 88% among those aged <25 (P=0.011), and from 33% among Hispanics to 69% among Blacks (P=0.055). Lack of PrEP awareness decreased from 61% of those diagnosed in 2014 to 37% in 2016 (P=0.032). Increasing awareness and affordability of PrEP, and facilitating accurate assessment of HIV risk, are critical to reducing missed opportunities for PrEP.

Keywords

human immunodeficiency virus (HIV); preexposure prophylaxis (PrEP); implementation; awareness; cost

Corresponding author: Julia L. Marcus, PhD, MPH, 401 Park Dr, Ste 401 East, Boston, MA 02215, Tel: 617-867-4557; Fax: 617-867-4276, julia_marcus@harvardpilgrim.org.

Previously presented: This work will be presented at the HIV Research for Prevention Conference in Madrid, October 21–25, 2018.

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INTRODUCTION

Once-daily preexposure prophylaxis (PrEP) using emtricitabine/tenofovir disoproxil fumarate (FTC/TDF) is highly effective in preventing HIV infection and has the potential to end the HIV epidemic (Baeten et al., 2012; Grant et al., 2010; Thigpen et al., 2012; Volk et al., 2015). Although uptake of PrEP has increased since its approval by the U.S. Food and Drug Administration (FDA) in 2012, only 10 percent of the estimated 1.2 million Americans at risk of HIV infection have initiated PrEP as of 2015 (Mera Giler et al., 2016; Smith et al., 2015; Wu et al., 2017). With the National HIV/AIDS Strategy targeting a 25% reduction in HIV diagnoses by 2020, interventions to increase PrEP uptake are now a national priority ("National HIV/AIDS Strategy for the United States: Updated to 2020. The White House.," 2015). To be successful, these interventions must mitigate barriers to PrEP use in people at high risk of HIV infection. Barriers to PrEP use, such as lack of PrEP awareness, cost and insurance concerns, stigma, and concerns about side effects, have been described in recent studies of various populations at risk of HIV infection, including men who have sex with men (MSM) and transgender women (Cahill et al., 2017; Holloway et al., 2017; Hubach et al., 2017; Rael et al., 2018). However, data are limited on barriers to PrEP use in people who actually became HIV-infected, all of whom could have benefited from HIV-prevention strategies such as PrEP. Barriers to PrEP use in people who have acquired HIV infection may differ from those reported by individuals at theoretical risk for HIV infection more generally, many of whom may not actually need PrEP. Furthermore, few studies have assessed trends over time in barriers to PrEP use in high-risk individuals.

We conducted a survey of people who acquired HIV infection after PrEP became widely available to identify barriers to PrEP use prior to HIV diagnosis. We also aimed to identify factors associated with barriers to PrEP use, and temporal trends in commonly reported barriers, with the goal of informing interventions to increase PrEP uptake among individuals who could benefit most.

MATERIALS AND METHODS

Study setting and population

Our study setting was Kaiser Permanente Northern California (KPNC), a large integrated healthcare system that provides comprehensive medical services to 4.1 million members, corresponding to 30% of insured individuals in the surrounding area (Gordon, 2015). We used the KPNC HIV registry to identify individuals with recently acquired HIV infection who were members of the health plan at the time we conducted the survey (January 2018). The KPNC HIV registry includes all known cases of HIV/AIDS since the early 1980s, with confirmation by review of medical charts. We defined recently acquired HIV infections as those among members who had incident HIV diagnoses or sought care for HIV infection in the health plan during 2014–2016, with a negative HIV test in the year prior to HIV diagnosis or seeking care for HIV infection. Prior negative HIV tests were documented at KPNC, supported by records from outside clinics, or reported by the patient. We chose this study period to ensure that all HIV infections occurred after PrEP was approved by the FDA in 2012.

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The institutional review board at KPNC approved this study with a waiver of written informed consent.

Data sources

Survey.—We developed a survey to assess experiences with PrEP and barriers to PrEP use prior to HIV diagnosis. We piloted the survey in 10 KPNC members who were first diagnosed with HIV infection during 2013, and therefore not eligible for study participation. We then identified the eligible survey sample of current KPNC members with recently acquired HIV infection, excluding those who did not have a personal email address on file at KPNC. We queried primary care providers for permission to contact their patients for the study, given the sensitive nature of a survey about recent HIV diagnosis, and excluded individuals when providers preferred they not be contacted.

A PrEP clinician (author JEV) sent eligible members a secure email message through the KPNC electronic health record to notify them that their primary care providers had given us permission to invite them to complete a survey, and that they would receive the survey invitation at their personal email address. We then emailed a link to a password-protected, online survey to these members' personal email addresses, with up to five email reminders over the course of five weeks. The survey included questions about gender, education, and income; awareness of, referrals for, and use of PrEP prior to HIV diagnosis; reasons for not starting or for discontinuing PrEP (respondents could indicate more than one reason); sexually transmitted infection (STI) diagnoses in the year prior to HIV diagnosis; prior substance use; and prior mental health diagnoses. Respondents received a $20 gift card by mail after completing the survey.

KPNC HIV registry.—In addition to dates of first lifetime HIV diagnosis and last negative HIV test, we extracted data from the KPNC HIV registry on race/ethnicity, gender identity, and HIV-transmission risk factor (men who have sex with men [MSM], heterosexual sex, injection drug use).

Electronic health record.—We extracted additional data from the clinical and administrative databases constituting KPNC's electronic health record, including sex and age at the time of the initial survey invitation.

Statistical analysis

We used chi-square and Fisher's exact tests to compare the demographic characteristics of eligible KPNC members who did and did not respond to the survey, and to identify factors associated with common barriers to PrEP use among respondents. We then used Cochran-Armitage tests to assess trends in common barriers to PrEP use by year of HIV diagnosis. Analyses were conducted in SAS 9.4 (Cary, North Carolina). Statistical tests were two-sided, and $P<0.05$ indicated statistical significance.

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RESULTS

Study population

We identified 1213 KPNC members who were first diagnosed with HIV infection during 2014–2016, of whom 394 had a negative HIV test in the year prior to diagnosis. Of the 394 patients with recently acquired HIV infection, 277 were still members of the health plan at the time of survey administration. Of those, four were excluded because they did not have a personal email address on file at KPNC and five were excluded because their primary care provider preferred they not be contacted. Of the 268 eligible members who were invited to complete the survey, 122 (46%) responded. There were no statistically significant differences between those who did and did not respond with respect to age, gender identity, race/ethnicity, year of HIV diagnosis, or HIV-transmission risk factor (data not shown).

The median age of the 122 survey respondents was 36 (range 21–74), most were male (93%) and men who have sex with men (84%), and 64% were of minority racial/ethnic background (Table 1). Most (87%) had at least some college education and 31% had an annual individual income of $80,000 or higher. Nearly half (48%) reported being diagnosed with an STI in the year prior to HIV diagnosis, one-third (34%) had ever been diagnosed with depression, and 3.3% reported ever sharing needles.

Barriers to PrEP use prior to HIV diagnosis

Of the 122 respondents, 36 (30%) had discussed PrEP with a provider prior to HIV diagnosis. Overall, only 5 (4.1%) respondents reported having used PrEP, and all 5 discontinued PrEP prior to HIV diagnosis; reasons for discontinuation included cost/insurance concerns, not wanting people to think poorly of them for taking PrEP, and being too busy to do the laboratory testing required. Of the 122 respondents, the most common barrier to PrEP use was lack of PrEP awareness (51%). In the subset of 59 respondents who were aware of PrEP prior to HIV diagnosis, the most common barriers to PrEP use were cost/insurance concerns (36%), perceived low risk for HIV acquisition (24%), not wanting people to think poorly of them for taking PrEP (15%), the PrEP referral process being too lengthy or difficult (14%), not understanding what PrEP was (12%), and concerns about potential side effects (10%; Figure 1). Among those who were aware of PrEP, there were 10 (17%) respondents who did not initiate PrEP because they were diagnosed with HIV infection at PrEP intake.

Factors associated with common barriers to PrEP use

Factors associated with common barriers to PrEP use are shown in Table 2. Among all respondents, lack of PrEP awareness varied by age, ranging from 39% among those aged 25–34 to 88% among those aged <25 (P=0.011). Lack of PrEP awareness was also more common among females compared with males (88% vs. 48%, P=0.045), and among respondents without an STI in the year prior to HIV diagnosis compared with those with an STI (62% vs. 40%, P=0.014). There was a borderline association between race/ethnicity and lack of PrEP awareness, with lack of PrEP awareness most common among Black (69%) and Asian respondents (67%) and least common among Hispanic respondents (33%; P=0.055). Among respondents who were aware of PrEP, cost/insurance concerns were more

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commonly reported by respondents with annual individual incomes <$80,000 compared with those with higher incomes (45% vs. 11%, *P*=0.016), but were not associated with age, gender, HIV-transmission risk factor, race/ethnicity, education, or recent STI diagnosis. Among respondents who were aware of PrEP, perceived low risk for HIV acquisition varied by HIV-transmission risk factor, ranging from 18% among MSM to 67% among heterosexuals (*P*=0.027), but was not associated with any other factor evaluated.

Trends in common barriers to PrEP use

Changes in the prevalence of common barriers to PrEP use by year of HIV diagnosis are shown in Figure 2. Among all respondents, lack of PrEP awareness decreased from 61% of those diagnosed in 2014 to 37% of those diagnosed in 2016 (*P*=0.032). Among respondents who were aware of PrEP, the proportion reporting cost/insurance concerns and low perceived risk for HIV acquisition did not change over time (*P*=0.38 and *P*=0.86, respectively).

DISCUSSION

In this survey of members of a large healthcare system with recently acquired HIV infection who were asked, after their HIV diagnosis, to reflect on reasons they had not previously used PrEP, lack of PrEP awareness and cost/insurance concerns were the most commonly cited barriers to PrEP use prior to HIV diagnosis. Notably, perceived low risk for HIV acquisition was a common barrier to PrEP use among those who were aware of PrEP, even in this study population in which everyone ultimately acquired HIV infection. We identified several factors associated with common barriers to PrEP use. Lack of PrEP awareness was most commonly reported by younger, female, and Black individuals, and by those without an STI in the year prior to HIV diagnosis. Individuals with lower incomes most commonly reported cost/insurance concerns, while perceived low risk for HIV acquisition was more common among heterosexuals and people with a history of injection drug use than among MSM. Finally, we found that awareness of PrEP increased over time, but remained a barrier to PrEP use for over one-third of respondents diagnosed in 2016. Our results suggest that efforts are still needed to increase PrEP awareness in the highest-risk individuals. As awareness of PrEP improves, interventions to increase perceived and actual affordability of PrEP, and to facilitate accurate assessment of HIV risk by patients and providers, will also be critical to reducing missed opportunities for PrEP.

Although we found that PrEP awareness improved over time, consistent with prior studies of MSM in Canada and the U.S. (Mosley et al., 2018; Patrick et al., 2017), lack of PrEP awareness remained the primary barrier to PrEP use in people diagnosed with HIV infection in 2016, suggesting that efforts are still needed to increase PrEP awareness in key populations. The proportion of at-risk individuals reportedly aware of PrEP has ranged widely in prior studies, with variation likely attributable to differences in study setting, period, and population (Eaton et al., 2017; Garnett et al., 2018; Goedel, Halkitis, Greene, & Duncan, 2016; Misra and Udeagu, 2017; Ojikutu et al., 2018; Walters, Reilly, Neaigus, & Braunstein, 2017). Garnett et al. found that only 18% of Black, substance-using MSM and transgender women in New York City were aware of PrEP in a study conducted during

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2012–2015 (Garnett, et al., 2018). Similarly, Ojikutu et al. found that 20% of high-risk Black Americans were aware of PrEP in a population-based survey conducted in 2016 (Ojikutu, et al., 2018). Higher proportions aware of PrEP have been reported in studies conducted in other at-risk populations during 2015–2017, including 31% among women who inject drugs (Walters, et al., 2017), 44% among notified partners of HIV-infected individuals (Misra and Udeagu, 2017), and 85% among MSM using geosocial-networking smartphone applications (Goedel, et al., 2016), all in New York City. In our study, lack of PrEP awareness was more common in younger, female, and Black and Asian individuals, consistent with the age and racial/ethnic disparities we previously observed among PrEP users in our study setting (Marcus, Hurley, Hare, Silverberg, & Volk, 2016). Interventions are in development to improve awareness of PrEP in high-priority populations, such as mobile health applications and patient navigation through the PrEP continuum of care for young MSM. Lack of familiarity with PrEP among primary care providers may also partly explain why some of the high-risk patients in our study were not prescribed PrEP (Petroll et al., 2017). Strategies to increase familiarity with PrEP among providers are currently being evaluated, including training and electronic support systems to facilitate PrEP prescribing and panel management.

In addition to lack of PrEP awareness, we found that cost/insurance concerns were a primary barrier to PrEP use prior to HIV diagnosis, and the most common barrier in the subset aware of PrEP. This finding is consistent with prior studies that have identified high cost as a commonly reported reason for not initiating or for discontinuing PrEP (Arnold et al., 2017; Goparaju et al., 2017; Rolle et al., 2017; Whitfield, John, Rendina, Grov, & Parsons, 2018; Wood, Lee, Barg, Castillo, & Dowshen, 2017). Notably, cost is a barrier to PrEP use even in insured settings such as KPNC. We previously found that higher copayments were associated with reduced adherence to PrEP among KPNC members, and observed two seroconversions that occurred following PrEP discontinuation during gaps in insurance coverage (Marcus et al., 2016). Efforts may be needed to improve awareness and navigation, for both patients and providers, of state- and pharmaceutical-sponsored medication assistance programs that can help cover the cost of PrEP. However, not all patients are eligible for these programs; moreover, many of the programs do not cover the cost of laboratory monitoring or clinic visits during PrEP use, which may become an even greater burden for patients with the increasing prevalence of high-deductible health plans (Cohen, Martinez, & Zammitti, 2017). Thus, cost is likely to remain a barrier to PrEP use even when a generic version of FTC/TDF becomes widely available. As awareness of PrEP improves, it will become increasingly important to develop strategies to increase both perceived and actual affordability of PrEP, and that of PrEP-associated clinic visits and laboratory monitoring. To inform these strategies, future studies should determine the specific aspects of PrEP care and features of health insurance design that pose the greatest barriers to PrEP affordability. Nevertheless, HIV incidence remains high in a cohort of young Black MSM in Atlanta despite universal awareness of and access to PrEP (Serota et al., 2018), suggesting that removing awareness and cost/insurance barriers alone will not be sufficient to realize the population-level benefits of PrEP across all at-risk populations.

We found that another common barrier to PrEP use was perceived low risk for HIV infection, despite the universal acquisition of HIV infection in our study population.

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Perceived low risk for HIV acquisition was a more common barrier to PrEP use among heterosexuals and people with a history of injection drug use compared with MSM in our study, suggesting that non-MSM populations may be in particular need of efforts to improve self-assessment of HIV risk. Although others have similarly found that perceived low risk of HIV acquisition is a barrier to PrEP use in at-risk individuals (Chan et al., 2016; Kesler et al., 2016; Ojikutu, et al., 2018), with those at the highest risk being most likely to underestimate their risk (Hall et al., 2017), a recent preliminary report by Blumenthal et al. found that providing an HIV risk score to improve accurate self-assessment of HIV risk had no effect on PrEP uptake among MSM (Blumenthal et al., 2018). Providing HIV risk scores to clinicians, instead of or in addition to patients, may help facilitate identification of potential PrEP candidates; indeed, this approach has been used to support clinical decision making in other areas of medicine (Wiens and Shenoy, 2018). In a preliminary report by Krakower et al., a machine learning algorithm using electronic health record data successfully identified patients at risk for HIV acquisition (Krakower et al., 2016), a tool that could be evaluated prospectively as an automated approach to identifying potential candidates for PrEP in primary care settings. Further research is needed to identify strategies to improve assessment of HIV risk, both by patients and their providers, and to evaluate the impact of such strategies on PrEP uptake in at-risk populations.

There are several limitations to our study. First, of the eligible KPNC members who were invited to complete the survey, only 45% responded. This could have introduced selection bias if respondents and non-respondents differed in key ways that affected their reported barriers to PrEP use. However, we found no statistically significant differences in demographic characteristics between eligible members who did and did not respond, suggesting that respondents were likely to be representative of the overall population of KPNC members with recently acquired HIV infection. Second, selection bias could also have been introduced by the exclusion of patients whose primary care providers prefer they not be contacted for this study and those who did not have a personal email address on file at KPNC; however, only nine (3.2%) of the 277 eligible patients were excluded for these reasons. Third, barriers to PrEP use may differ outside of the KPNC health plan; in particular, cost may be an even greater barrier to PrEP use for people who are uninsured. Fourth, the small sample size did not allow for multivariable analysis to identify factors independently associated with barriers to PrEP use, and we were only able to assess bivariable associations for the three most commonly reported barriers to PrEP use. Finally, survey respondents may have misremembered their awareness of or experiences with PrEP prior to HIV diagnosis, and recall may have been poorer for those diagnosed in earlier years.

Our study also has several strengths. First, to our knowledge, this is the first study to systematically assess barriers to PrEP use in a study population with recently acquired HIV infection, thereby informing interventions to increase PrEP uptake in those who could benefit the most. In addition, because we recruited for our survey from a large integrated healthcare system, we were able to collect additional data on eligible members from the electronic health record, allowing us to compare demographic characteristics between members who did and did not respond.

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In summary, although awareness of PrEP is improving over time, lack of PrEP awareness remains the most common barrier to PrEP use prior to HIV diagnosis in people with recently acquired HIV infection. Younger, female, and Black and Asian individuals may benefit most from interventions to increase PrEP awareness. Cost/insurance concerns and perceived low risk for HIV acquisition are commonly reported barriers to PrEP use that will need to be mitigated as part of interventions to increase PrEP uptake. As awareness of PrEP improves, interventions to increase perceived and actual affordability of PrEP, and to facilitate accurate assessment of HIV risk by patients and providers, will be critical to reducing missed opportunities for PrEP.

ACKNOWLEDGMENTS

Potential conflicts of interest: JLM has received research grant support outside the submitted work from Merck. MJS has received research grant support outside the submitted work from Merck and Gilead. All other authors report no conflicts. *Source of funding:* This work was supported by a grant from the Kaiser Permanente Northern California Community Benefit Program and by the National Institute of Allergy and Infectious Diseases [K01 AI122853 to JLM].

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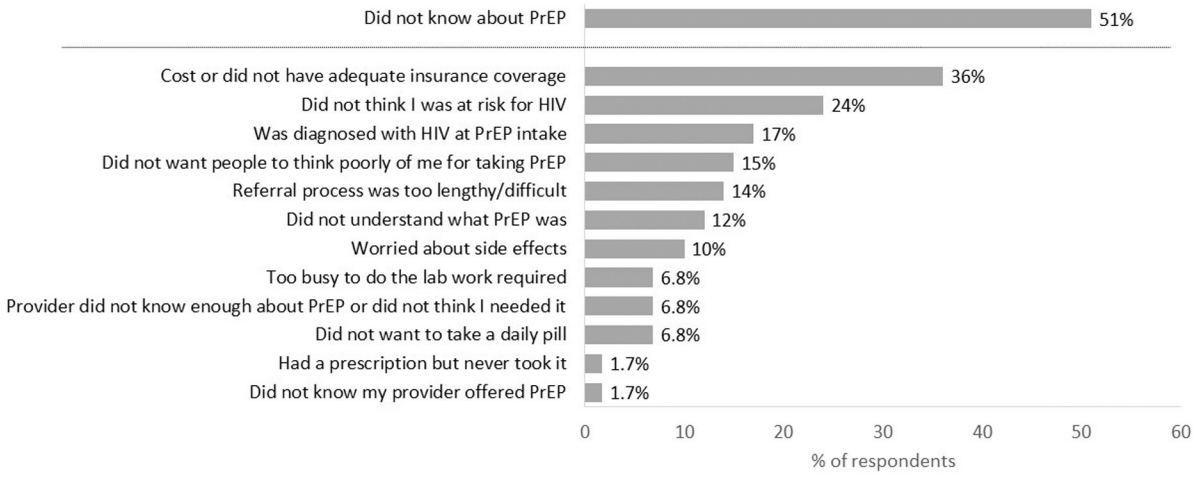

Figure 1. Barriers to PrEP use prior to HIV diagnosis.

PrEP, preexposure prophylaxis; HIV, human immunodeficiency virus. The proportion unaware of PrEP was among all respondents (n=122). All other proportions were among the subset of respondents who were aware of PrEP (n=59). Respondents could indicate more than one reason for not initiating or for discontinuing PrEP.

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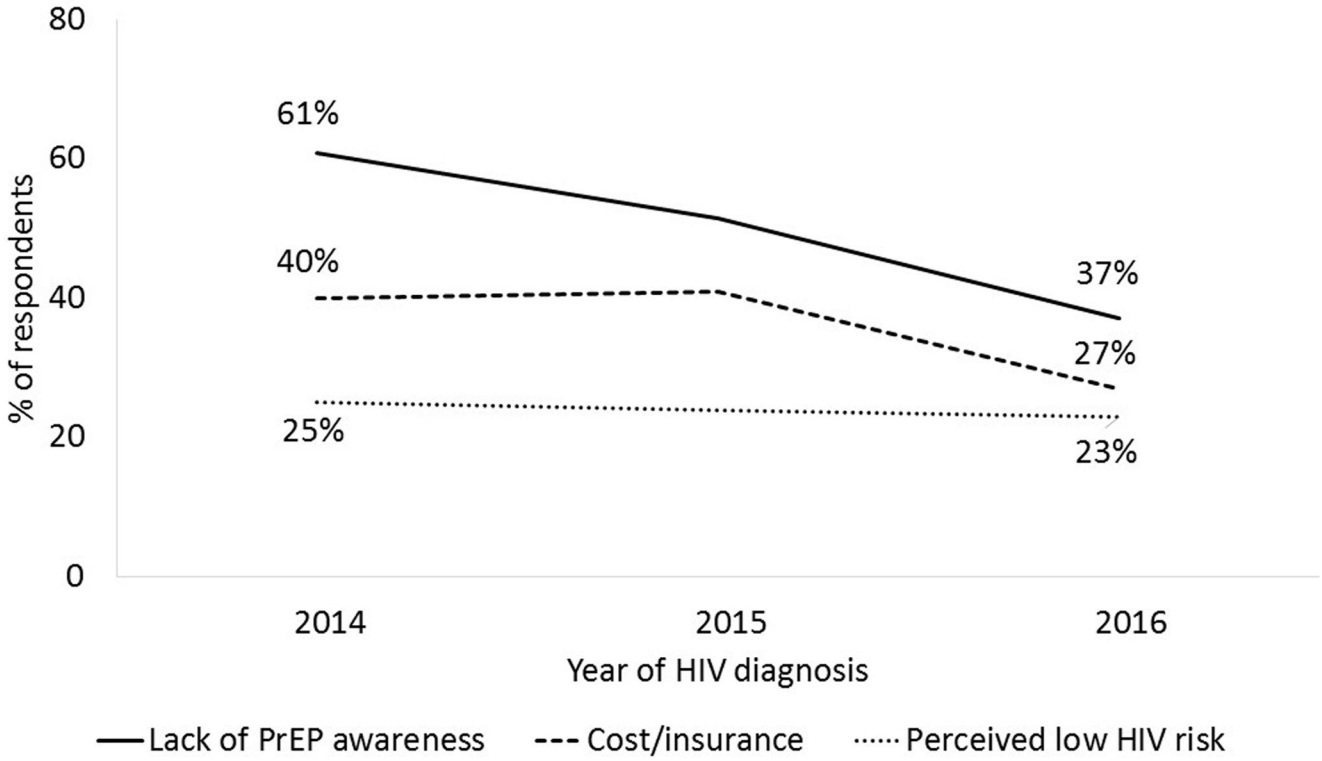

Figure 2. Trends in common barriers to PrEP use by year of HIV diagnosis.

PrEP, preexposure prophylaxis; HIV, human immunodeficiency virus. *P*-values were obtained from Cochran-Armitage tests for trend. Among all respondents (n=122), the proportion reporting lack of PrEP awareness decreased with year of HIV diagnosis (*P*=0.032). Among respondents who were aware of PrEP (n=59), the proportion reporting cost/insurance concerns and perceived low HIV risk as barriers to PrEP use did not change with year of HIV diagnosis (*P*=0.38 and *P*=0.86, respectively).

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Table 1.

Characteristics of survey respondents with recently acquired HIV infection

Total	122 (100)
Year of HIV diagnosis, n (%)	
2014	51 (42)
2015	36 (30)
2016	35 (29)
Age at time of survey, median (interquartile range)	36 (29–47)
Gender identity, n (%)	
Male	113 (93)
Female	8 (6.6)
Non-conforming/fluid	1 (0.8)
HIV-transmission risk factor, n (%)	
Men who have sex with men	103 (84)
Heterosexual	9 (7.4)
Injection drug use	8 (6.6)
Unknown	2 (1.6)
Race/ethnicity, n (%)	
Non-Hispanic White	44 (36)
Hispanic	41 (34)
Non-Hispanic Black	16 (13)
Asian	12 (9.9)
Other	8 (6.6)
Unknown	1 (0.8)
Highest level of education, n (%)	
High school or trade school	16 (13)
Some college	43 (35)
College graduate	41 (34)
Graduate school or higher	22 (18)
Annual individual income, n (%)	
<$20,000	13 (11)
$20,000-$39,999	25 (21)
$40,000-$59,999	23 (19)
$60,000-$79,999	15 (12)
≥$80,000	38 (31)
Did not answer	8 (6.6)
STI in year prior to HIV diagnosis, n (%)	58 (48)
Ever mental health diagnoses, n (%)	
Depression	41 (34)
Anxiety	26 (22)
Attention deficit hyperactivity disorder	8 (6.6)
Bipolar disorder	6 (5.0)

Other	5 (4.1)
Ever needle sharing	4 (3.3)

PrEP, preexposure prophylaxis; HIV, human immunodeficiency virus; STI, sexually transmitted infection. Denominators for percentages were <122 when respondents skipped questions.

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Table 2.

Factors associated with common barriers to PrEP use prior to HIV diagnosis

	Among all respondents (n=122)		Among respondents aware of PrEP (n=59)			
	Lack of PrEP awareness, row %	P^*	Cost/insurance concerns, row %	$P^\dagger$	Perceived low HIV risk, row %	$P^\ddagger$
Overall	51		36		24	
Age at time of survey		0.011		0.30		0.25
<25	88		0		0	
25–34	39		48		19	
35–44	50		31		15	
≥45	51		24		41	
Gender identity		0.045		1.0		0.24
Male	48		36		22	
Female	88		0		100	
Non-conforming/fluid	100		-		-	
HIV-transmission risk factor		0.47		0.84		0.027
Men who have sex with men	50		37		18	
Heterosexual	67		33		67	
Injection drug use	38		20		60	
Race/ethnicity		0.055		0.83		0.81
White	57		32		21	
Hispanic	33		37		22	
Black	69		20		20	
Asian	67		50		50	
Other	50		50		25	
Education		0.23		0.23		0.34
Less than college graduate	57		57		43	
College graduate or higher	46		33		21	
Annual income		0.60		0.016		0.74
<$80,000	47		45		23	
≥$80,000	53		11		28	
STI in year prior to HIV diagnosis		0.014		0.58		0.54

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	Among all respondents (n=122)		Among respondents aware of PrEP (n=59)			
	Lack of PrEP awareness, row %	P^*	Cost/insurance concerns, row %	$P^\dagger$	Perceived low HIV risk, row %	$P^\ddagger$
No	62		42		29	
Yes	40		31		20	
Ever diagnosed with depression		0.25		0.57		1.0
No	48		33		24	
Yes	59		41		24	

PrEP, preexposure prophylaxis; HIV, human immunodeficiency virus; STI, sexually transmitted infection. *P*-values were obtained from chi-square or Fisher's exact tests.

[*] *P*-values compare participants unaware of PrEP to those aware of PrEP.

[†] Among participants aware of PrEP, *P*-values compare participants who reported cost/insurance concerns to those who did not report cost/insurance concerns.

[‡] Among participants aware of PrEP, *P*-values compare participants who reported perceived low HIV risk to those who did not report perceived low HIV risk.