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Barriers to HIV Care and Treatment Among Participants in a Public Health HIV Care Relinkage Program

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Abstract

Improving patient retention in HIV care and use of antiretroviral therapy (ART) are key steps to improving the HIV care continuum in the US. However, contemporary quantitative data on barriers to care and treatment from population-based samples of persons poorly engaged in care are sparse. We analyzed the prevalence of barriers to clinic visits, ART initiation, and ART continuation reported by 247 participants in a public health HIV care relinkage program in King County, WA. We identified participants using HIV surveillance data ($N = 188$) and referrals from HIV/STD clinics and partner services ($N = 59$). Participants most commonly reported insurance (50%), practical (26–34%), and financial (30%) barriers to care, despite residing in a state with essentially universal access to HIV care. Perceived lack of need for medical care was uncommon ($<20\%$), but many participants (58%) endorsed a perceived lack of need for medication as a reason for not initiating ART. Depression and substance abuse were both highly prevalent (69% and 54%, respectively), and methamphetamine was the most commonly abused substance. Barriers to HIV care and treatment may be amenable to intervention by health department outreach in coordination with existing HIV medical and support services.

Introduction

Inadequate patient engagement in HIV care limits the potential of antiretroviral therapy (ART) to improve the health of persons living with HIV/AIDS (PLWHA) and to prevent HIV transmission.[1] Few evidence-based interventions are available to improve retention in HIV care.[2–4] Numerous factors have been identified as barriers to HIV care and treatment since the beginning of the epidemic, and several reports have provided important qualitative information on barriers to care and treatment in the current ART era.[5–8] However, contemporary population-based data on the relative prevalence of patient-perceived barriers to HIV care and treatment are sparse.[9]

For more than a decade, state and federal funding has assured that Washington State residents have near universal access to HIV treatment. The percentage of persons who link to HIV care within 3 months after HIV diagnosis is among the highest reported in the US (92% in 2011).[10] Nonetheless, many PLWHA in Washington are not consistently engaged in care and are not virologically suppressed.[10,11] We began a health department-based intervention to promote HIV care relinkage and ART use among PLWHA in King County, WA in 2011. As part of this program, we systematically collected data from patients about their perceived barriers to HIV care and ART initiation and reasons for ART discontinuation, which we present in this article. Our findings highlight the barriers that are likely to persist even after care expansion under the Patient Protection and Affordable Care Act (ACA).

Methods

Surveillance-based outreach to promote HIV care re-engagement

The Care and Antiretroviral Promotion Program (CAPP) is a population-based program to promote care engagement and ART among PLWHA in King County, WA.[12,13] Most CAPP participants are identified by use of public health HIV laboratory surveillance data. During the period of this study, persons were eligible if they were diagnosed with HIV for ≥ 6 months and met one of two criteria: (1) no CD4 count or plasma HIV RNA [viral load (VL)] results reported for ≥ 12 months, or (2) a VL >500 copies/mL and CD4 ≤ 500 cells/mm^3 at the time of last report in the preceding 12 months. (Since the period of the study, we have expanded the second criterion to include all persons with a VL >500 copies/mL.)

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All persons reported to have HIV infection in King County are potentially eligible for the program; eligibility is not restricted by site of clinical care or diagnosis. Persons who did not speak English or Spanish were not eligible for outreach during the study period because we did not have translation resources. Prior to launching CAPP, we consulted HIV medical and social service providers, community representatives, relevant government entities, and individual PLWHA identified through surveillance to inform the development of the intervention.[12,14,15]

Intervention components

The CAPP intervention consists of case investigation, medical provider contact, patient contact, and structured one-on-one counseling. CAPP counselors are disease intervention specialists experienced in working with PLWHA. The case investigations are conducted according to a protocol described in more detail elsewhere.[16] Briefly, it includes investigation of death records, matching with surveillance systems in other jurisdictions, medical records review, and inquiry of Accurint®, a Lexis Nexis database that collates public records. If the investigation does not reveal that the person has died or moved out of jurisdiction, CAPP counselors contact the medical provider associated with the last reported CD4 or VL result. Staff contact providers once every 6–12 months with a single list of all of their patients who are eligible for CAPP. Providers have the opportunity to opt out of contact for individual patients on a case-by-case basis. Initially, our rationale for this was to increase provider acceptability of the program in response to information we gathered during our formative work. Furthermore, we conceived provider notification as a part of the intervention because it could prompt providers to contact patients or otherwise attempt to engage them with care. In addition to surveillance-based identification, PLWHA are referred to CAPP through partner services investigations for bacterial STDs, the STD Clinic, or HIV clinics.

CAPP counselors attempt to contact eligible individuals by phone and offer a face-to-face counseling session (the ''individual component'' of the intervention), which takes approximately 45 min and for which the participant is compensated $50. The goal of the individual component is for the counselor and participant to jointly identify barriers to HIV care and treatment and to develop a concrete plan to address the barriers. This may include the counselor helping the participant to schedule and complete a medical appointment and actively connecting the participant with case management, health insurance assistance, and ancillary support services. Counseling sessions are conducted at the Public Health–Seattle and King County STD Clinic, which is located adjacent to the largest Ryan White-funded HIV clinic in Seattle. With participants' consent, the CAPP counselors send letters summarizing the encounter to the participants' medical providers and case managers. CAPP counselors do not follow-up with medical providers and case managers, but do contact all participants one month after the appointment to assess relinkage and ART use and offer additional assistance.

Assessment of barriers to care and treatment

Participants in the individual intervention complete a computer-assisted self-interview (CASI) that includes questions about demographics, education and income, past experience with HIV care and case management, ART experience, sexual behavior, drug use, and depression screening. We use a modified AUDIT-C to assess alcohol use[17] and the two questions validated by Whooley and colleagues for brief depression screening in primary care settings.[18]

To assess barriers to care and ART initiation and reasons for ART discontinuation, we modified questions from the medication adherence instruments of the Adherence Working group of the Outcomes Committee of the Adult AIDS Clinical Trials Group (AACTG) adherence instruments.[19] We asked participants about barriers to care as follows: ''Below are several reasons why people sometimes don't have HIV doctors or don't see them as often as they might. For each reason, please indicate if it has been important in preventing you from getting medical care.'' The factors listed in Table 3 were included with ''important'' and ''not important'' response options. Participants could report multiple barriers as ''important,'' and we did not ask questions to distinguish the relative importance of barriers. Participants who were ART-naïve or had discontinued ART were asked about barriers to ART continuation or reasons for discontinuation in the same format. Participants were also given the option to enter text about barriers other than those listed. CAPP is conducted as a public health program, not a research activity, and thus is not under the jurisdiction of an Institutional Review Board.

Analysis

We assessed uptake of the individual component of the CAPP intervention as of April 30, 2014, defining ''participants'' as those persons who completed the individual component of CAPP. Using HIV case surveillance data, we examined demographic, clinical, and behavioral factors among (1) CAPP participants compared to the entire population of HIV-diagnosed persons in King County, and (2) surveillance-identified CAPP participants compared to participants referred from STD partner services, the STD Clinic, or HIV clinics. We used Pearson's chi-squared tests for these comparisons. By source of identification, we quantified the percentage of participants who reported ever having completed an HIV medical appointment after HIV diagnosis (linked to care), a case manager, initiated ART, or discontinued ART; and the percentage who reported having a medical provider, case manager, and taking ART at the time of the interview. We categorized substance use as described and validated by Tegger and colleages[20] into the following hierarchical, mutual exclusive categories: (1) opiates with or without other drugs; (2) amphetamine with or without other drugs; (3) cocaine with or without alcohol; (4) alcohol only; or (5) no substance use.

We quantified the proportion of participants who reported each factor as a barrier to (1) HIV medical care, among all participants who completed a survey; (2) ART initiation, among ART-naïve participants; and (3) ART discontinuation, among participants who reported having discontinued treatment. The lead author reviewed participants' text responses in the ''other'' field and, when possible, coded them into categories, consulting the CAPP counselors if the appropriate category was unclear. Separately, we categorized barriers to care into four mutually exclusive groups: (1) factors related to the organization and delivery of health care (lack of insurance, costs not covered by insurance too high, forgetting appointments, trouble getting appointments, not knowing how to find a doctor, poor relationship with doctor); (2) co-morbid health conditions (depression and substance use); (3) social circumstances (homelessness and lack of transportation); and (4) health beliefs and knowledge (medical care not needed or helpful). We compared barrier categories by participant demographic and behavioral characteristics, all of which we selected as potential correlates a priori. We used Poisson regression to obtain estimated relative risks for reporting each group of barriers by patient subgroup. All analyses were performed in STATA 10.1 (Statacorp, TX).

Results

Investigation of surveillance-identified cases and individual intervention uptake

At the end of April 2014, 257 persons had completed the individual component; 195 were surveillance-identified, and 62 were referred to the program. The surveillance-identified participants were recruited from a pool of 1461 cases initially identified for investigation in July 2012. Of these, 1046 (72%) were eligible for potential participation in CAPP. The ineligible persons had either moved out of King County ($n=179$); had an undetectable VL not reported to surveillance ($n=97$); died ($n=45$); were incarcerated ($n=14$); or were ineligible for miscellaneous other reasons (e.g., non-English or Spanish-speaking) ($n=80$). Additionally, 266 persons who were eligible for CAPP in July 2012 subsequently had an undetectable VL reported to surveillance prior to the time that CAPP counselors attempted to contact them. Of the 780 remaining eligible persons, HIV providers opted out of CAPP participation (refused patient contact) for 141, most often because the patient had recently achieved viral suppression, recently started ART or no longer had viral suppression as a clinical goal due to terminal illness or extensive resistance (data not shown). No locating information was available for 65 persons. Thus, CAPP counselors attempted to contact 574 persons and successfully contacted 278 (48%). The majority of contacted persons (77%; $N=215$) agreed to participate in the individual component, but 20 did not complete the session, leading to the final 195 surveillance-identified participants. In sum, we completed CAPP interviews with 34% (195/574) of surveillance-identified persons we attempted to contact and 25% (195/780) of all eligible, surveillance-identified persons.

Participant characteristics

Compared to the overall population of HIV-diagnosed persons in King County, CAPP participants were younger (12% vs. 7% under age 30; $p<0.001$); more likely to be injection drug users [(IDU), including men who have sex with men IDU (MSM-IDU)] (31% vs. 14%; $p<0.001$); and more likely to have been diagnosed with HIV recently or remotely [< 2 years: 27% vs. 8%; > 20 years: 25% vs. 14% ($p<0.001$)] (Table 1). Among all CAPP-eligible cases in surveillance, participants were more likely than non-participants to be IDU (31% vs. 11%; $p<0.001$) and more likely to meet VL instead of missing lab criteria (75% vs. 60%; $p<0.001$). Of 257 participants, 247 (96%) completed a survey by CASI (85%) or with the assistance of the interviewer (15%). Ten participants did not complete a survey due to language barriers or inability to meaningfully respond to questions due to mental status at the time of the interview.

Table 2 summarizes the care status of participants who completed a survey. Almost all (92%) had disengaged from HIV care after successful linkage (i.e., completion of the first HIV medical care appointment); only 4% reported never having linked to care. Most participants (77%) reported having an HIV medical provider, at the time of the interview, but only about half (54%) reported having a case manager. Respondents with a medical provider were more likely to report having a case manager (67%) than those without a medical provider (9%; $p<0.001$). Most participants had started ART previously (73%), but the majority of those (76%) had discontinued ART at some time; 109 (44%) reported having a current ART prescription at the time of the interview. Compared to surveillance-identified participants, referred participants were less likely to report having linked to care (90% vs. 93%; $p=0.02$), having a medical provider at the time of the interview (63% vs. 81%; $p=0.008$), having a current prescription for ART (29% vs. 49%; $p=0.02$), or having current health insurance (47% vs. 70%; $p=0.01$). Approximately two-thirds (69%) of participants screened positive for depression and about half (54%) reported current illicit substance or hazardous alcohol use. Methamphetamine was the most commonly reported substance (32%), and was substantially more common among referred participants compared to surveillance-identified participants (56% vs. 24%; $p<0.001$)

Reported barriers to care and ART

The prevalence of reported barriers to HIV care and ART was not significantly different between surveillance-identified and referred CAPP participants (comparisons not shown). Thus, we report barriers for the combined groups (Table 3). Lack of insurance was the most commonly reported important barrier to care (50%). Although we did not specifically query patients about cost barriers besides lack of insurance, 75 participants volunteered this as an important barrier to care. Although 79 (32%) participants cited trouble getting appointments as an important barrier, most of these (63%; $N=50$) nonetheless indicated that they would prefer to have one main doctor than a team of doctors with open-access scheduling. A minority of participants endorsed a perceived lack of need for HIV care (‘‘Don’t need a doctor’’: 19%).

Among 60 ART-naïve participants, most cited their concerns about side effects (77%) and adherence (55%) as important reasons for not initiating ART. In contrast to barriers to care, many participants cited perceived lack of need for treatment as a barrier to ART (‘‘I can control HIV with a healthy attitude, at least for now’’: 58%). Similarly, many of the 138 participants who had initiated but discontinued ART reported side effects and incomplete adherence as reasons for discontinuing ART (41% reported each factor). Concerns about medical side effects and adherence were not associated with age or time since HIV diagnosis (data not shown). Depression was the most commonly endorsed reason for discontinuing ART ($N=62$; 45%). Among 114 participants who did not have an active ART prescription and reported having previously talked with their HIV medical provider about starting or restarting ART, 72 (63%) said their doctors

Table 1. Demographic Characteristics of CAPP Participants, By Referral Source, Compared to Surveillance-Identified Non-Participants and All HIV-Diagnosed Persons in King County

	Persons living with HIVAIDS in King County, end of 2012 (N=7104) N (%)	*All CAPP participants* (N=257) N (%)	*Surveillance-identified as eligible*		*Referred participants* (N=62) N (%)
			Non-participants (N=851) N (%)	*Participants* (N=195) N (%)	
Sex at birth[b]					
Male	6353 (89)	230 (89)	736 (86)	170 (87)	60 (96)
Female	751 (11)	27 (11)	115 (14)	25 (13)	2 (4)
Race/ethnicity					
Non-Hispanic white	4709 (66)	168 (65)	487 (57)	126 (65)	42 (68)
Non-Hispanic black	1201 (17)	40 (21)	178 (21)	40 (21)	13 (21)
Hispanic	758 (11)	23 (9)	105 (12)	21 (11)	2 (3)
Other, multiple & missing	436 (6)	13 (5)	81 (10)	8 (4)	5 (8)
Mode of transmission[a,b]					
MSM	4904 (69)	154 (60)	548 (64)	116 (59)	38 (61)
MSM-IDU	612 (9)	61 (24)	77 (9)	42 (22)	19 (31)
IDU	326 (5)	19 (7)	32 (4)	17 (9)	2 (3)
Heterosexual	694 (10)	17 (7)	112 (13)	16 (8)	1 (2)
Other/missing	568 (8)	6 (2)	82 (10)	4 (2)	2 (3)
Age, years[a,b]					
<30	462 (7)	31 (12)	80 (9)	22 (11)	9 (15)
30–39	1206 (17)	64 (25)	191 (22)	41 (21)	23 (37)
40–49	2530 (36)	91 (35)	327 (38)	72 (37)	19 (31)
≥50	2906 (41)	69 (27)	247 (29)	60 (31)	9 (15)
Missing	0 (0)	2 (1)	6 (1)	0 (0)	2 (3)
Years since HIV diagnosis[a,b]					
<2	564 (8)	9 (4)	34 (4)	5 (3)	4 (6)
2–5	1208 (17)	43 (17)	206 (24)	36 (18)	7 (11)
6–10	1526 (21)	58 (23)	227 (27)	51 (26)	7 (11)
11–20	2806 (39)	70 (27)	252 (30)	68 (35)	2 (3)
>20	1000 (14)	17 (7)	49 (6)	15 (8)	2 (3)
Missing	–	60 (23)	83 (10)	20 (10)	40 (65)
Eligibility criterion for CAPP[b]	NA				
CD4 <500 & VL >500	–	154 (60)	513 (60)	146 (75)	8 (13)
No labs 12 months	–	57 (22)	335 (40)	47 (24)	10 (16)
No visits ≥6 mo.[c]	–	34 (13)	NA	NA	34 (55)
Missing	–	12 (5)	3 (<1)	2 (1)	10 (16)

CAPP, The Care and Antiretroviral Promotion Program; MSM, men who have sex with men; MSM-IDU, men who have sex with men injection drug users; VL, viral load; NA, not applicable.

[a]$p<0.05$ for chi-square test comparing CAPP participants to overall King County PLWHA; [b]$p<0.05$ for chi-square test comparing surveillance identified to referred CAPP participants; [c]and no visits scheduled in the next 2 months. This criterion was only used to identify eligible participants who were not surveillance-identified, and is not necessarily exclusive of the categories used to identify eligible participants through surveillance.

advised them to start medications, 33 (29%) said their doctors did not advise them to take medications, and the remaining 9 (8%) were unsure about or did not remember what their doctors recommended. Participants less frequently reported factors reflecting HIV stigma (''people might find out about HIV'': 27%) and lack of readiness for treatment (''need more time to adjust to being HIV-positive'': 18%) as barriers to ART initiation.

Barriers to care by category and participant subgroups

Factors related to healthcare organization and delivery were by far the most commonly reported barriers to care (74%), while about a third of participants cited each of the other three categories as significant barriers (Table 4). Social factors were more often reported among non-Hispanic blacks compared to non-Hispanic whites (57% vs. 35%; $p=0.03$), persons who screened positive for depression (47% vs. 26%; $p=0.04$) or substance use (47% vs. 30%; $p=0.03$), and persons aged 30–39 compared to age ≥50 (54% vs. 28%; $p=0.02$). Participants who reported social barriers to care were more likely to report having case managers (67% vs. 45%; $p=0.006$).

The majority of participants who screened positive for depression identified depression as an important reason for never starting ART (62%) and for discontinuing ART (57%). Among the 162 persons who screened positive for depression, 91 (56%) reported depression as a barrier to clinic visits or ART use; 8 (12%) of 66 with a negative depression screen reported depression as a barrier. Similarly many substance users, though not the majority, reported substance use as an important barrier to care (31%), starting ART (27%) or a reason for discontinuing ART (42%). A poor relationship with the medical provider was more commonly cited as a

Table 2. HIV Care Engagement, Antiretroviral Therapy, Substance Use, and Depression Among CAPP Participants Who Completed Baseline Surveys

	All participants (N=*247*) *N* (%)	*Surveillance-identified* (N=*188*) *N* (%)	*Referred* (N=*59*) No.
Ever linked to HIV care[a]			
Yes	228 (92)	175 (93)	53 (90)
No	11 (4)	5 (3)	6 (10)
Missing	8 (3)	8 (4)	0 (0)
Has a medical provider[a]			
Yes	187 (77)	150 (81)	37 (63)
No	57 (23)	35 (22)	22 (37)
Has a case manager[a]			
Yes	132 (54)	101 (55)	31 (53)
No	99 (40)	73 (26)	26 (44)
Unsure	16 (6)	14 (8)	2 (3)
Ever on ART			
Yes	181 (73)	141 (75)	40 (68)
No	60 (24)	42 (22)	18 (31)
Unsure/refused to answer	6 (2)	5 (3)	1 (2)
Discontinued ART (*N*=181)			
Yes	138 (76)	106 (75)	32 (80)
No	39 (22)	32 (23)	7 (18)
Unsure/refused to answer	4 (2)	2 (1)	1 (3)
Current ART prescription[a]			
Yes	109 (44)	92 (49)	17 (29)
No	134 (54)	92 (49)	42 (71)
Unsure/refused to answer	4 (2)	4 (3)	0 (0)
Current health insurance[a]			
Yes	159 (64)	131 (70)	28 (47)
No	77 (31)	49 (26)	28 (47)
Unsure/refused to answer	11 (5)	8 (4)	3 (5)
Depression screen			
Positive	171 (69)	127 (68)	44 (75)
Negative	72 (29)	59 (31)	13 (22)
Refused	4 (2)	2 (1)	2 (3)
Current substance use[a,b]			
Heroin	16 (6)	12 (6)	4 (7)
Methamphetamine	64 (26)	35 (19)	29 (49)
Cocaine or crack-cocaine	16 (6)	13 (7)	3 (5)
Hazardous alcohol	37 (15)	31 (16)	6 (10)
None of the above	114 (46)	97 (52)	17 (29)

CAPP, The Care and Antiretroviral Promotion Program; ART, antiretroviral therapy.

[a] $p < 0.05$ for chi-square test comparing surveillance identified to referred CAPP participants. [b] Categories are mutually exclusive and hierarchical in the order listed.

barrier to care among participants who were currently using heroin (50%), methamphetamines (33%), or cocaine (38%) compared to participants who did not report current substance use (22%; $p < 0.05$ for all comparisons).

Discussion

In this analysis of self-reported barriers to HIV care and treatment among persons participating in a public health care relinkage program, we found that lack of insurance was the most commonly reported barrier to care, even in a state that has had essentially universal access to HIV care for over a decade. Furthermore, the cost of care and treatment borne by the patient, or at least the perception of those costs, remains a substantial barrier even among insured PLWHA. Participants identified practical difficulties related to the organization and delivery of healthcare as barriers to care much more often than social factors, substance use, or lack of perceived need for HIV care. In contrast, participants often identified their own health beliefs and depression as reasons for not initiating ART or for discontinuing ART.

Our finding that practical aspects of healthcare organization and delivery were the most prevalent barriers to care is, in some aspects, an encouraging one. Many of these barriers are amenable to outreach and intervention. At least in Washington, most persons without insurance can be linked to Ryan White funded care and case management. The CAPP counselors inquired about the reasons for lack of insurance during individual interviews and helped patients enroll in state assistance programs. Notably, many uninsured participants were simply unaware of the assistance available to uninsured PLWHA because they had employer-based

Table 3. Factors Identified as "Important" Barriers to HIV Care and ART Use (Not Mutually Exclusive) Among CAPP Participants Who Completed a Survey

Barriers to HIV care (N=*247*)		*Reasons for never starting ART* (N=*60*)		*Reasons for discontinuing ART* (N=*138*)	
At least one "important" barrier reported	219 (89%)	At least one "important" barrier reported	57 (95%)	At least one "important" barrier reported	133 (96%)
No insurance	124 (50%)	Side effect concerns	46 (77%)	Depressed	62 (45%)
Forget appointments	83 (34%)	Can control HIV with a healthy attitude, at least for now	35 (58%)	Wanted a break	57 (41%)
Trouble getting appointments	79 (32%)	Adherence concerns	33 (55%)	Side effects	57 (41%)
Costs not covered by insurance are too high[a]	75 (30%)	Depressed	28 (47%)	Non-adherent, worried about resistance	56 (41%)
No transportation	70 (28%)	Doctor said I don't currently need ART	28 (47%)	Couldn't afford med	43 (31%)
Don't know how to find doctor	64 (26%)	CD4 count high	27 (45%)	Couldn't get med due to reason other than cost	38 (28%)
Poor relationship with doctor	65 (26%)	People might find out about HIV	16 (27%)	Using drugs	36 (26%)
Homelessness	59 (24%)	Using drugs	10 (17%)	Health problems interfered with taking meds	31 (22%)
Using drugs	56 (23%)	Need more time to adjust to being HIV+	11 (18%)	Homelessness	29 (21%)
Don't need a doctor	48 (19%)	Prefer alternative therapy	13 (22%)	Didn't need meds	28 (20%)
Doctor wasn't helpful in the past	49 (19%)	Other things in life more important right now	11 (18%)	Meds weren't helping	24 (17%)
Prefer alternative therapies	43 (17%)	God is helping me with HIV and that's enough	10 (17%)		
Depression or other mental health issues[a]	7 (3%)	Homelessness	10 (17%)		

CAPP, The Care and Antiretroviral Promotion Program; ART, antiretroviral therapy.

[a] These factors were not systematically assessed as barriers. Only who described these factors in the open ended question about "other" significant barriers are included.

insurance when they were diagnosed with HIV and subsequently lost insurance coverage. This highlights the need for outreach programs such as CAPP and community education about Medicaid eligibility. Forgetting appointments, trouble getting appointments, and trouble finding a doctor can be addressed with interventions at the patient, clinic, and health department levels. These are the primary barriers that case management and patient navigation are designed to address. We found that many participants did not have a case manager, and many never had. This, too, presents a possible opportunity for improvement of our public health and HIV care system. The lower levels of linkage to care, case management, and insurance among patients referred from the STD Clinic suggest that STD Clinics are an important part of the infrastructure necessary to improve the HIV care continuum.

Nearly half of ART-naïve participants indicated that their doctors said ART was not necessary. This finding may reflect, at least in part, the changes in HIV treatment guidelines and provider acceptance of earlier ART initiation that occurred during the study period. However, it also demonstrates an opportunity for intervention and emphasizes the role of health departments in ensuring that all PLWHA have the opportunity to make an informed decision about ART initiation. When participants indicated that their provider had said ART was unnecessary, the CAPP counselors reviewed current HIV treatment guidelines and encouraged patients to talk to their providers again about ART initiation.

In contrast to the barriers that are clearly amenable to intervention, our finding that methamphetamine was the most commonly used substance among participants is concerning. Methamphetamine abuse is an extremely challenging problem for public health and healthcare systems to address.[21,22] Most studies of interventions to decrease methamphetamine use have had modest or short-term effects. Studies of medication-assisted therapy to reduce methamphetamine use have, to date, mostly been negative, apart from one study of mirtazapine.[23] The proportionately greater methamphetamine use among referred participants, who were identified primarily through the STD Clinic and STD partner services, likely reflects the higher HIV/STD transmission risk among methamphetamine-using MSM[24,25] and further highlights the public health challenge of addressing methamphetamine as a barrier to HIV care and treatment and as a facilitator of HIV transmission. Many substance users did not identify their substance use as an important barrier to care. The extent to which this reflects participants' incomplete recognition of the impact of substance use on their lives versus an accurate reflection of the greater importance of practical barriers to care is unclear. Substance use is clearly associated with worse HIV-associated health outcomes.[26] Creative, evidence-based, effective solutions to improve HIV care outcomes for

Table 4. Self-Reported Barriers by Group

	N	*Healthcare organization and delivery N (%)*	*Co-morbidities (% reporting)*	*Social factors (% reporting)*	*Health beliefs and/or knowledge (% reporting)*
Overall	247	184 (74)	61 (25)	97 (39)	89 (36)
Sex at birth					
Male	221	163 (74)	55 (25)	82 (37)	77 (35)
Female	25	21 (84)	6 (24)	14 (56)	11 (44)
Race/ethnicity[b]					
Non-Hispanic white	161	119 (74)	40 (25)	56 (35)	53 (33)
Non-Hispanic black	51	40 (78)	13 (25)	29 (57)[a]	25 (49)
Hispanic	23	15 (65)	4 (17)	8 (35)	6 (26)
Age, years[b]					
<30	29	23 (79)	4 (14)	11 (38)	10 (34)
30–39	63	48 (76)	22 (35)[a]	34 (54)[a]	22 (35)
40–49	86	70 (81)[a]	25 (29)[a]	33 (38)	32 (37)
≥ 50	69	43 (62)	10 (15)	19 (28)	25 (36)
Years since HIV diagnosis[b]					
<2	8	7 (88)	2 (25)	0 (0)	5 (63)
2–5	42	32 (76)	12 (29)	18 (43)	18 (43)
6–10	56	46 (82)	15 (27)	21 (38)	22 (39)
11–20	66	43 (65)	12 (18)	24 (36)	21 (32)
>20	17	12 (71)	5 (29)	5 (29)	7 (41)
Depressed					
Yes	158	126 (80)	48 (30)	74 (47)[a]	63 (40)
No/missing	89	58 (65)	13 (15)	23 (26)	26 (29)
Substance use					
Heroin	16	15 (94)	14 (88)[a]	11 (69)[a]	9 (56)
Methamphetamine	64	55 (86)	30 (47)[a]	29 (45)	26 (41)
Cocaine/crack-cocaine	16	11 (69)	6 (38)[a]	9 (56)	7 (44)
Hazardous alcohol	37	26 (70)	3 (8)	14 (38)	7 (44)
None of the above	114	77 (68)	8 (7)	34 (30)	40 (35)
Have a case manager					
Yes	132	103 (78)	42 (32)[a]	65 (49)[a]	50 (38)
No/missing	115	81 (70)	19 (17)	32 (28)	39 (34)

[a] $p<0.05$ in Poisson regression compared to the following reference groups: non-Hispanic white, age ≥ 50, not depressed, not substance using, no case manager.

[b] Subgroups do not sum to $N=247$ due to omission of other categories and cases missing data for the indicated categories.

persons who use methamphetamine and other substances are undoubtedly needed.

Depression, while more challenging to address than practical barriers to care and treatment, can be successfully addressed with the primary HIV care setting. For persons who identify depression as a barrier to care and treatment or who screen positive for depression, the goal of public health intervention should be to actively assist the patient with reengaging in HIV primary care. Outreach workers can assist participants with returning to medical care and facilitate communication between patients, medical providers, and case managers. Health department relinkage programs should attempt to leverage, coordinate, and help the patient navigate existing resources in the community rather than duplicating them.

Our finding that medical providers opted out of contact on behalf of many potential participants prompts the question of the appropriate role of providers in a health department relinkage program. In our experience, theoretical concerns about allowing providers to opt-out on behalf of individual patients have been outweighed by the practical benefits of involving providers in the outreach and relinkage process. Providers have current information on patients' treatment statuses and contact information, and relationships between health department and medical office staff members facilitate appointment-making and relinkage to care for patients. The majority of provider refusals were for reasons in alignment with public health priorities. Providers in King County have generally been supportive of the intervention, and our experience is that this has improved with time, similar to the pattern we have observed with implementation of other public health programs like HIV partner services, Nonetheless, our results demonstrate the need to systematically track reasons for provider refusals and to analyze the outcomes of patients for whom providers refuse contact.

The major strength of our study is that it provides contemporary data on the prevalence of perceived barriers to care and treatment among a population-based sample of PLWHA, most of whom could not be captured in a clinic-based study. A key limitation of our study is that it was limited to one geographic site. The prevalence of some of the barriers we examined, particularly those that reflect certain health beliefs (''God is helping me with HIV'') or stigma (''people might find out about my HIV''), may vary substantially throughout the US. Only a minority of persons we attempted to contact participated in the intervention, however, many of the persons we were unable to contact had likely moved away.[16,27] We did not specifically query patients about costs not covered by insurance as a barrier to care. Our finding that many participants volunteered out-of-pocket cost barriers in a free text section suggests that it would have been much more commonly reported if we had systematically queried patients about it. Similarly, we asked about depression as a barrier to ART use, but we did not systematically ask about it as a barrier to care. We have revised the questionnaire we use in CAPP accordingly.

Our analysis of barriers to care and treatment does not allow us to determine the relative importance of each factor. The results of the survey were used as a starting point for a one-on-one, in-depth discussion of barriers. Our approach was not that of a research study, but one of integration into a health department program with ongoing monitoring. We are currently studying the effect of the CAPP intervention on virologic suppression.

In summary, we found in a population-based sample identified by HIV surveillance that practical and perceived financial factors are the most common barriers to care, even in a setting with essentially universal access to HIV care. Perceived lack of need for medical care was an uncommon barrier to clinic visits, but perceived lack of need for ART was a common barrier to ART initiation. Depression and substance use are both prevalent and commonly perceived as barriers to HIV care and treatment among persons poorly engaged in care. Barriers to HIV care and treatment may be amenable to intervention by health department outreach workers in coordination with existing HIV medical and support services.

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