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Unmet needs and barriers to services among people who inject drugs with HIV in the United States

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Abstract

Data on use of and barriers to HIV ancillary care services among people who inject drugs (PWID) with HIV can inform interventions intended to improve access to care, but national estimates are lacking. We analyzed data on PWID with HIV from the CDC Medical Monitoring Project. Overall, 79% had an unmet need for ≥1 service. Services with the highest unmet need included: dental care (38%), drug/alcohol treatment (20%), transportation assistance (20%), and HIV peer group support (20%). Unmet needs for mental health services (13% vs. 23%) and HIV peer group support (15% vs. 29%) were lower among persons attending Ryan White HIV/AIDS Program (RWHAP)-funded facilities for HIV care. Barriers to care services varied by service type. Modeling components of the RWHAP structure in non-RWHAP funded facilities, including integration of support services and use of patient navigation services in the HIV medical care setting, may improve outcomes among PWID with HIV.

Keywords

People who inject drugs; HIV; unmet needs; barriers to care

Introduction

Overall, 9% of HIV infections are attributed to injection drug use (IDU) or male-to-male sexual contact and IDU (Centers for Disease Control and Prevention, 2019a). A large HIV outbreak in Scott County, Indiana demonstrated how quickly HIV can spread in a setting

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with high prevalence of IDU and injection equipment sharing (Peters et al., 2016). Other IDU-related outbreaks have been observed around the United States recently (Alpren et al., 2020; Golden et al., 2019), and have not only highlighted the importance of implementing programs to limit transmission risk among persons who inject drugs (PWID), but also engaging PWID with diagnosed HIV in care to ensure they receive the services they need and are virally suppressed.

Among people with HIV, PWID have worse clinical outcomes than other persons (Centers for Disease Control and Prevention, 2019b; Genberg et al., 2019; Palepu et al., 2003). PWID experience high levels of homelessness, incarceration, and poverty, and limited healthcare coverage (Nandi et al., 2010; Strathdee et al., 1997), which are associated with insufficient access to medical care services (Adler & Newman, 2002). Limited access to services that address these challenges is strongly associated with lower HIV care engagement and increased viral load (Dandachi et al., 2019).

Health equity is a primary focus of the HIV National Strategic Plan (HIV Plan) (Department of Health and Human Services, 2021). Given that PWID are disproportionately affected by HIV, the HIV Plan aims to prioritize efforts to reduce disparities and improve outcomes among this priority population. The Ryan White HIV/AIDS Program (RWHAP) provides comprehensive care services, including HIV medical care, support services, and antiretroviral therapy (ART) medications, to underserved populations with HIV. RWHAP plays an essential role in reducing HIV-related disparities and achieving health equity by engaging people who are disproportionately affected by HIV in medical care and increasing levels of viral suppression (Health Resources and Services Administration, 2020; Department of Health and Human Services, 2021).

Estimates of unmet needs for ancillary care services among people with HIV have been published using recent, nationally representative data (Centers for Disease Control and Prevention, 2020a; Dasgupta et al., 2021a). Previous reports have also described unmet needs for HIV ancillary care services among selected populations, including men who have sex with men and Hispanics/Latinos (DeGroote et al., 2016; Korhonen et al., 2016). However, estimates on use of, and barriers to, ancillary care services by healthcare setting among PWID with HIV are lacking, but are essential for informing interventions intended to improve access to care. Thus, we reported nationally representative estimates on use of and need for ancillary care services among PWID with HIV, overall and by receipt of care at a RWHAP-funded facility. Among persons who reported having unmet needs for care services, we reported barriers to ancillary care services.

Materials and methods

Population

The CDC Medical Monitoring Project (MMP) is an annual, cross-sectional survey that reports nationally representative estimates of behavioral and clinical characteristics among adults with diagnosed HIV. MMP uses a two-stage sampling methodology. During the first stage, 16 states and Puerto Rico were sampled from all U.S. states, the District of Columbia, and Puerto Rico. In the second stage, simple random samples of adults with diagnosed HIV

were sampled for each participating jurisdiction from the National HIV Surveillance System, a census of all people with diagnosed HIV in the U.S.

During the 2015–2017 data cycles, data were collected annually from June to May of the following year. Data on demographic, behavioral, and clinical characteristics were collected through face-to-face or phone interviews. Medical records were abstracted for interviewed participants who received HIV care during the 2 years prior to interview. MMP is conducted as a part of routine public health surveillance and is considered non-research. Participating jurisdictions obtained institutional review board approval as needed for data collection; informed consent was obtained from all participants.

All sampled jurisdictions participated in MMP, and included California (including the separately funded jurisdictions of Los Angeles County and San Francisco), Delaware, Florida, Georgia, Illinois (including Chicago), Indiana, Michigan, Mississippi, New Jersey, New York (including New York City), North Carolina, Oregon, Pennsylvania (including Philadelphia), Puerto Rico, Texas (including Houston), Virginia, and Washington. These participating jurisdictions represented >70% of persons with diagnosed HIV during 2016 (Beer et al., 2019). Response rates for sampled persons by cycle year ranged from 40% to 46%.

Measures

Interviewers asked participants about IDU in the past 12 months. Participants were also asked to identify their most frequent source of HIV medical care, and RWHAP funding status of the HIV provider was ascertained during medical record abstraction. Information was obtained about HIV ancillary care services received and needed by participants in the past 12 months, including for HIV case management, dental care, mental health services, and drug or alcohol counseling or treatment. An unmet need was defined as needing, but not receiving, an ancillary care service. Among those who reported having unmet needs for specific services, people were asked about reasons for not receiving services. Participants could report more than one barrier for each service.

Analysis

We combined data from the 2015, 2016, and 2017 cycles for this analysis. Among people who reported injecting drugs in the past 12 months ($n = 340$), we reported the percentage who received and needed, but did not receive, specific ancillary care services using weighted percentages and 95% confidence intervals (CIs). We examined differences in unmet needs for ancillary care services by attendance at a RWHAP-funded facility for HIV medical care using Rao-Scott chi-square tests ($p < .05$). Finally, we examined barriers to ancillary care services among persons who reported unmet needs. To ensure reliability of estimates, barriers to care were only reported for care services with ≥15% unmet need. Estimates with coefficient of variation ≥ 0.30 may be unreliable and are denoted with an asterisk; associated statistical testing results were suppressed.

Data were weighted based on known probabilities of selection, adjusted for non-response, and post-stratified to NHSS population totals by age, race/ethnicity, and sex at birth. All analyses were conducted using SAS 9.4 (Cary, NC).

Results

Overall, 3% (95% CI: 2–3%) of adults with diagnosed HIV injected drugs during the past 12 months (PWID with HIV) [not shown in table or figures]. A majority of PWID with HIV were male (92%; 95% CI: 89–95%) and non-Hispanic/Latino White (57%; 95% CI: 49–65%). Over half had public insurance (excluding RWHAP/AIDS Drug Assistance Program [ADAP] only) (60%; 95% CI: 53–67%) and 13% (95% CI: 6–20%) relied on RWHAP/ADAP coverage only or had no coverage. More details on the demographics of this population have been described elsewhere (Dasgupta et al., 2021b).

Overall, 79% (95% CI: 73–85%) of PWID with HIV had at least one unmet need for an ancillary care service; over half (52%; 95% CI: 46–59%) had unmet needs for at least two services, and 39% (95% CI: 32–45%) had unmet needs for at least three services (not shown in table or figures). The most prevalent unmet needs were dental care (38%), drug or alcohol counseling or treatment (20%), transportation assistance (20%), and HIV peer group support (20%) (Figure 1). Unmet needs for food assistance through the Supplemental Nutrition Assistance Program (SNAP) or Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) (19%), shelter or housing services (18%), and mental health services (16%) were also substantial. Unmet needs for mental health services (13% vs. 23%) and HIV peer group support (15% vs. 29%) were lower among persons who received HIV care at RWHAP-funded facilities compared with those who did not (Table 1).

Among persons with unmet needs, barriers to ancillary care services varied by service type (Figure 2). The most substantial barrier to dental care was not having enough money or insurance coverage (46%). The most common barrier to receiving SNAP/WIC benefits (70%) and shelter/housing services (51%) was that the service did not meet the person's need or the person was not eligible for the service. Among persons with unmet needs for HIV peer group support, common barriers included both not being able to find the service or not knowing it existed (56%) and personal reasons, such as fear or embarrassment or having other things going on that made it difficult to receive the service (57%). The most prevalent barrier to drug or alcohol counseling or treatment (79%) and mental health services (59%) was personal reasons, such as fear or embarrassment or having other things going on which made it difficult to receive services.

Discussion

To our knowledge, this was the first analysis of unmet needs for ancillary care services among PWID with HIV using nationally representative data. We found that nearly 4 in 5 PWID with HIV had at least one unmet need for HIV care services, which was substantially higher than the overall percentage of adults with HIV who experienced unmet needs (Dasgupta et al., 2021a). The most prevalent needs were for dental care, drug or alcohol counseling or treatment, transportation assistance, and HIV peer support. People attending RWHAP-funded facilities for HIV care were less likely to have unmet needs for mental health services and HIV peer group support. Barriers to care services varied by service type and were often multifactorial. Personal reasons, such as fear or embarrassment or having

things going on which made it difficult to receive services, were a substantial barrier to receiving drug or alcohol counseling or treatment and mental health services.

In addition to experiencing challenges in accessing healthcare services, PWID often have co-occurring medical issues that may complicate HIV management and treatment and potentially worsen outcomes, especially among those with limited healthcare access. For instance, a large percentage of PWID experience mental illness, which if untreated could not only result in adverse clinical outcomes among PWID with HIV but also drug overdose (Pabayo et al., 2013; Perdue et al., 2003; Pence et al., 2018). Providing support for these patients through HIV peer support interventions, particularly in non-RWHAP-funded facilities where there is greater unmet need for HIV peer support, may be effective in improving retention in care (Cabral et al., 2018).

Prevalence of unmet needs for several services among PWID with HIV was quite high; in particular, one in five PWID with HIV had unmet needs for drug or alcohol counseling or treatment. Generally, integration of substance use disorder treatment services with other care services is an essential strategy for delivery of comprehensive care services for PWID with HIV. Co-location of these services ensures that patients can address a multitude of health issues at a single location, if needed (National Academies of Sciences Engineering Medicine, 2020). In addition, inclusion of other preventive services in the medical care setting—including pre-exposure prophylaxis and post-exposure prophylaxis for sexual and injection partners of PWID with HIV, and sterile syringes and other injection equipment through a syringe services program (SSP)—could be helpful in reducing HIV transmission risk. SSPs provide a comprehensive, integrated approach to HIV prevention and are key partners in reaching PWID with HIV for services, including HIV care and treatment, substance use disorder treatment and other health and social services (Wejnert et al., 2016). SSPs should be considered for integration, where possible, into strategies to improve access to care services for PWID with HIV. Availability of patient navigation services in a facility with co-located HIV care services may also be helpful in assessing needs and identifying resources for patients.

We showed that unmet needs for ancillary care services are equivalent or lower among PWID with HIV attending RWHAP-funded facilities. Because the structure of RWHAP-funded healthcare providers facilitates co-location of healthcare services, HIV patients attending RWHAP-funded facilities may have access to a broader range of available ancillary care services (Beane et al., 2014). Our findings were contrary to those of a recent national analysis which found that people with HIV attending RWHAP-funded facilities for HIV care may have greater unmet needs for some services than those receiving HIV care elsewhere (Weiser et al., 2015). The findings from the present study suggest the RWHAP model may be effective in providing care services to PWID with HIV, a population that may experience numerous challenges in engaging in care, including poverty, limited healthcare coverage and access to services, and incarceration (Centers for Disease Control and Prevention, 2020b; Kamarulzaman and Altice, 2015). Therefore, modeling certain components of the RWHAP structure in non-RWHAP funded facilities, such as integration of support services into the HIV medical care setting and use of patient navigation services

and case management services, may improve medical care engagement and health outcomes among PWID with HIV.

Given that PWID with HIV are much less likely to be virally suppressed than other people with HIV (Dasgupta et al., 2019), addressing barriers to care engagement and viral suppression is essential for ensuring positive health outcomes among PWID and limiting HIV transmission risk to others. However, we found that barriers to receiving care can be complex and vary by service type. For instance, the predominant barriers to SNAP or WIC services and shelter or housing services were structural, as barriers were related to eligibility or the extent to which the service met the person's needs. With growing socioeconomic challenges related to the COVID-19 pandemic (Center of Budget and Policy Priorities, 2021; Congressional Research service, 2021), demand for subsistence services among PWID with HIV could rise over time; resources should be expanded to continue meeting needs of PWID with HIV, who may be particularly vulnerable to housing instability.

As opioid overdose deaths continue trending upward (Centers for Disease Control and Prevention, 2021), it is important to remain cognizant of ways to deliver substance use disorder (SUD) treatment. The COVID-19 pandemic has impacted delivery of and access to services, with substantial barriers to receiving treatment, even with expanded availability of telehealth visits (Mellis et al., 2021). In addition, due to financial challenges following the pandemic, staff working in settings that provide SUD treatment may be laid off or furloughed, leading to shortage of workers and increasing chance of provider burnout and low workforce retention (Pagano et al., 2021). Further, the general supply of physicians with buprenorphine waivers that allow them to prescribe medications for opioid use disorder (MOUD) is low in the U.S.; only 2% had waivers, and even among those who did have waivers, nearly half had five or fewer patients (Rosenblatt et al., 2015; Sigmon, 2015; Substance Abuse and Mental Health Services Administration, 2021). Further, a majority of U.S. counties, representing more than 30 million people, have no physicians with waivers (Rosenblatt et al., 2015). This could leave a mismatch in available prescribers with respect to people who may need and want MOUD to address addiction. Local assessments of needs for SUD treatment, as well as barriers to receiving treatment, may help improve access to services and ensure that people receive essential services they need. For areas with a dearth of available MOUD prescribers, local public health partners could encourage providers to obtain waivers to better serve local patients. Providers with waivers could be encouraged to have conversations with their HIV patients to routinely assess SUD and provide treatment options for those who do have SUD.

This analysis demonstrated that the most common barrier to drug/alcohol counseling or treatment and mental health services was personal reasons, such as fear or embarrassment or having things going on which made it difficult to receive services. Although not directly assessed, this barrier could have been related to stigma experienced by PWID related to drug use, HIV infection, the need for mental health services, or any combination of these. Other studies have also demonstrated high levels of stigma and discrimination experienced by PWID with HIV (Paquette et al., 2018; Stringer et al., 2019). Because stigma can prevent people with HIV from seeking care and treatment, and is associated with adverse HIV outcomes among PWID (Stringer et al., 2019), reducing HIV-related stigma is a national

priority (Department of Health and Human Services, 2021). Stigma and discrimination occurring in the healthcare setting can cause PWID to distrust healthcare providers and prevent people from engaging with the healthcare system. Incorporating trainings and policies in HIV care facilities highlighting the negative effects of stigma and encouraging inclusivity of patients in the healthcare setting could help reduce stigma. Barriers to some services were clearly multifactorial, such as dental care and HIV peer group support. Allocating resources to identify and address HIV care barriers may be needed at the local level to improve medical care engagement and health outcomes among PWID with HIV.

This analysis is subject to limitations. Data on IDU, receipt and need for ancillary care services, and barriers to care were self-reported, and thus, may be subject to information bias. For instance, IDU may have been underreported due to social desirability bias. Person-level response rates were suboptimal; however, results were adjusted for nonresponse and post-stratified to known population totals by age, race/ethnicity, and sex from the National HIV Surveillance System using standard methodology (Beer et al., 2019). Due to a limited sample size, we were unable to examine unmet needs or barriers to care services by demographic characteristics among PWID with HIV. There could also be geographic variation in estimates of unmet needs and barriers to care, which we could not examine in this study. Finally, because PWID represent a small proportion of adults with diagnosed HIV, our sample size of persons who inject drugs with HIV was limited, resulting in some unreliable estimates.

An overwhelming majority of PWID with HIV had at least one unmet need for HIV care services, and over half had unmet needs for more than one service. Unmet needs for mental health services and HIV peer support were less prevalent among people attending RWHAP-funded facilities. Barriers to care services were substantial, varied by service, and were often multifactorial. These data demonstrate that information on unmet needs for HIV ancillary care and barriers to care services should be assessed locally, as service accessibility and care barriers could vary geographically; subsequently, interventions to address needs should be tailored to the local PWID population. This is especially important now, given that the COVID-19 pandemic has impacted delivery of and access to healthcare services. In addition, modeling certain components of the RWHAP structure in other non-RWHAP funded facilities—including integration of support services in the HIV medical care setting and use of patient navigation and case management services—may also be effective in improving healthcare utilization and clinical outcomes among PWID with HIV.

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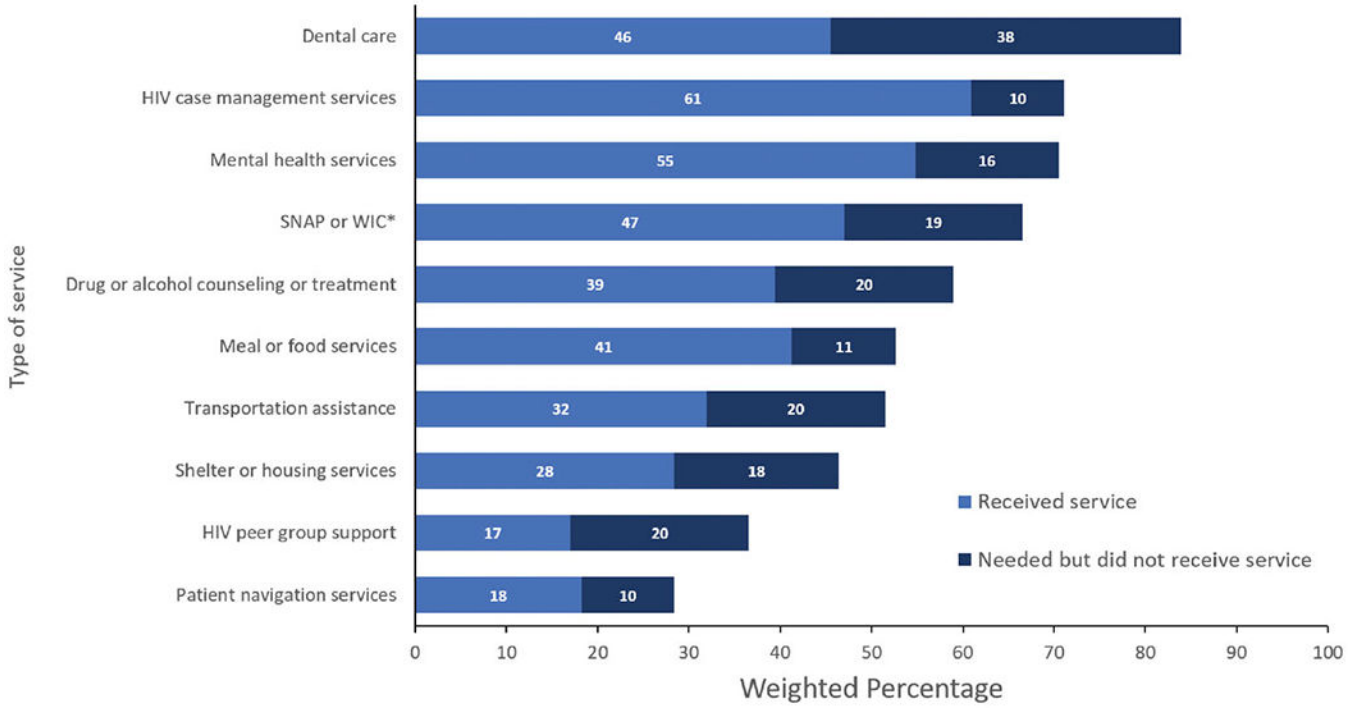
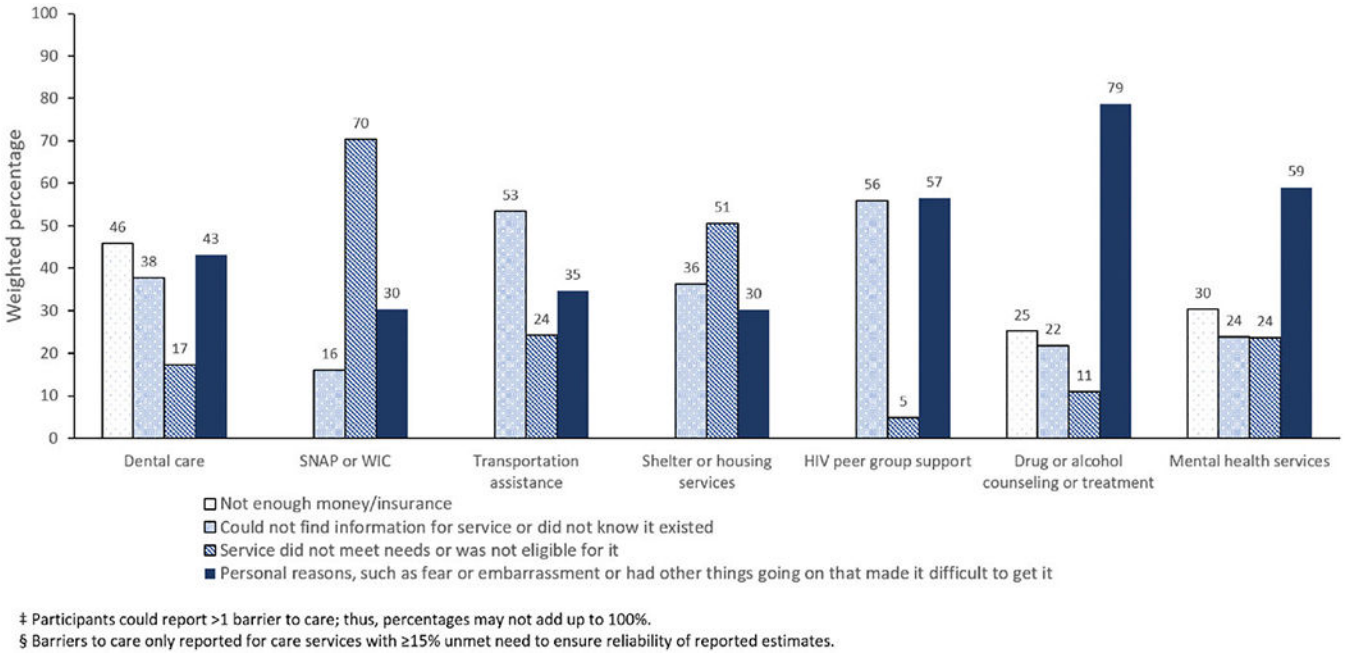


Figure 1.

Receipt of and need for ancillary care services among people who inject drugs with HIV—United States, 2015–2018.



‡ Participants could report >1 barrier to care; thus, percentages may not add up to 100%.
§ Barriers to care only reported for care services with ≥15% unmet need to ensure reliability of reported estimates.

Figure 2.
Barriers to ancillary care services among people who inject drugs with HIV—United States, 2015–2018.[†§].

TABLE 1.

Unmet needs for ancillary care services by attendance at a Ryan White HIV/AIDS Program (RWHAP)-funded facility among people who inject drugs with HIV—United States, 2015–2018.

	Attended RWHAP-funded facility		Did not attend a RWHAP-funded facility		
	n	**Weighted col % (95% CI)**	***n***	**Weighted col % (95% CI)**	***p***
Total	**224**		**108**		
Dental care					0.625
Yes	78	37 (30–45)	41	41 (29–53)	
No	146	63 (56–70)	67	59 (47–72)	
HIV case management services					
Yes	12	9 (2–16) *	14	12 (2–21) *	
No	212	91 (84–98)	93	88 (79–98)	
Mental health services					0.025
Yes	31	13 (8–18)	22	23 (15–32)	
No	193	87 (82–92)	86	77 (68–86)	
SNAP or WIC					–
Yes	45	20 (13–27)	26	18 (7–29) *	
No	179	80 (74–87)	82	82 (71–93)	
Drug or alcohol counseling or treatment					0.682
Yes	40	21 (14–28)	18	19 (11–27)	
No	184	79 (72–86)	89	81 (74–89)	
Meal or food services					–
Yes	31	14 (9–19)	11	6 (1–11) *	
No	193	86 (81–91)	97	94 (89–99)	
Transportation assistance					0.752
Yes	39	20 (13–28)	24	19 (10–28)	
No	185	80 (72–87)	84	81 (73–90)	
Shelter or housing services					0.594
Yes	42	17 (10–24)	19	20 (8–32)	
No	182	83 (77–90)	89	80 (68–92)	
HIV peer group support					0.001
Yes	33	15 (10–20)	25	29 (18–40)	
No	191	85 (80–91)	82	71 (60–82)	
Patient navigation services					–
Yes	20	11 (5–18) *	9	8 (1–16) *	
No	202	89 (83–96)	98	92 (84–100)	

* Denotes estimates that have a coefficient of variation ≥ 0.30 and should be interpreted with caution. Associated statistical testing results may have questionable reliability and thus are suppressed.