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The Boundary of HIV Care: Barriers and Facilitators to Care Engagement Among People with HIV in the United States

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Abstract

Treating people with HIV (PWH) quickly and effectively to achieve viral suppression is a key strategy for Ending the HIV Epidemic. Understanding barriers and facilitators to HIV care engagement could improve outcomes among PWH and reduce HIV infections. We sampled PWH who participated in the Medical Monitoring Project from June 2018 to May 2019 and were not engaged in HIV care to participate in 60-min semistructured telephone interviews on barriers and facilitators to HIV care engagement. We used applied thematic analysis and placed codes into themes based on their frequency and salience. Participants reported various intrapersonal, health system, and structural barriers to care. We conceptualize the boundary of care as the space between the stages of the HIV care continuum, where PWH may find themselves when they lack intrapersonal, health system, and structural support. Research and interventions tackling these barriers are needed to improve outcomes among PWH and reduce HIV infections.

Keywords

HIV; qualitative research; HIV care engagement; HIV care continuum; barriers to HIV care; facilitators of HIV care

Introduction

THE HIV CARE continuum depicts the stages that help people with HIV (PWH) achieve and maintain viral suppression. PWH who are not retained in care or are unaware of their

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HIV diagnosis transmit ~80% of annual HIV infections.[1] In the United States, among people with diagnosed HIV, only 74% have ever received care and 58% have been retained in care, steps that precede viral suppression.[2] One key strategy of the Ending the HIV Epidemic (EHE) in the US initiative is to treat PWH quickly and effectively to achieve viral suppression. Understanding barriers and facilitators to HIV care engagement is therefore vital.[3]

Qualitative research has shown that barriers and facilitators to HIV care are multifaceted and complex. Barriers include fatalistic beliefs about HIV, mental illness, low social support, stigma, poor patient-provider relationships, housing instability, limited access to transportation, and no employee benefits (e.g., sick leave, daycare).[4–16] Facilitators of HIV care engagement include social support, HIV status accepance, positive patient-provider relationships, the colocation of needed services; and access to housing, transportation, employment, and health insurance.[4,6,7,9–12,16–19]

Previous qualitative studies tend to focus on one socio-demographic group, are conducted locally, or recruit people from infectious disease clinics or service organizations, thereby excluding people who are not engaged in the health care system. While people who are not engaged in HIV care may experience barriers similar to people in HIV care, PWH who are not engaged in HIV care may experience these barriers to greater degree, may experience more barriers relating to structural and health system factors, and have not overcome barriers to HIV engagement. We seek to fill these gaps by exploring the barriers and facilitators to HIV care engagement among PWH who are not engaged in HIV care across the United States.

Methods

The Medical Monitoring Project (MMP) is an annual cross-sectional survey designed to produce nationally representative estimates of the sociodemographic, behavioral, and clinical characteristics of adults with diagnosed HIV in the United States. Sociodemographic and behavioral data are collected through structured interviews conducted across 23 jurisdictions.[20] The MMP Qualitative (MMP-Qual) Project collected qualitative data from PWH not engaged in HIV care that complemented quantitative MMP data.

We sampled people who participated in MMP from June 2018 to May 2019 for the MMP-Qual project. Eligibility criteria included having an HIV diagnosis, being 18 ≥ years, living in an MMP jurisdiction, and self-reporting being out of HIV care for ≥12 months (based on their response to the question, “What month and year was your most recent visit to a doctor, nurse, or other healthcare worker for HIV care?”) or having never received HIV care (based on their response to the question, “Since testing positive for HIV in [diagnosis date], have you ever seen a doctor, nurse, or other healthcare worker for HIV care?”). In addition, participants must have spoken English and not have been incarcerated. Informed consent was obtained for all participants. The Centers for Disease Control and Prevention (CDC) determined that this project was public health surveillance; thus, Institutional Review Board was not obtained.

We conducted semistructured 60-min telephone interviews with 34 participants. Data collection lasted from August 2018 to May 2019. The interview guide contained questions about various topics; however, for this analysis, we only analyzed questions about barriers and facilitators to HIV care engagement. All interviews were audio recorded and transcribed verbatim by trained staff. Data quality checks were performed on all transcripts.

Five team members independently read two interview transcripts and created preliminary codes for the initial codebook. The team continued to refine the codebook until reaching consensus. During round one of coding, two team members coded all transcripts. We performed intercoder reliability on seven transcripts, reviewing, and discussing codes until reaching agreement. During round two of coding, five codes were added and applied to all transcripts. We performed intercoder reliability on six transcripts during round two. We used applied thematic analysis, looking at the most frequently applied codes and placing codes into themes. We also conducted word searches and used keyword-in-context techniques. We obtained demographic data from the MMP quantitative interview.

Results

We interviewed 34 PWH. Seventy-six percent of participants were male, 65% were Black or African American (hereafter referred to as Black), 70% were ≥40 years, and 34% lived in the South (Table 1). The three broad themes were intrapersonal, health system, and structural factors.

Intrapersonal barriers

Intrapersonal barriers were related to someone’s mental health, cognition, emotion, and behavior. We considered stigma to be intrapersonal because it affects a person’s emotion, cognition, and behavior; however, we understand that stigma is also interpersonal and structural (Table 2). Participants often discussed not wanting to be seen going into a facility or sitting in a waiting room. For some, walking into a health care facility was triggering, especially for those who had not accepted their HIV diagnosis. One participant described this distress, saying, “…first and foremost, for me anyway, is… the internal stigma of just being reminded of okay, you have seroconverted and just the… the emotional messiness of that. And really having to come to terms with it in a very real way.” (Black male, 30s, West)

Stigma also affected HIV disclosure. By not disclosing their diagnosis, participants were attempting to protect themselves from social isolation and judgment. One participant said, “That’s the worst part about it…we lie about it…People know I’m sick, but they think I have multiple sclerosis. They don’t’ know I have HIV, because if I tell them HIV…. I won’t have a family, I won’t have friends, I won’t have anyone.” (Black female, 50s, Northeast)

One participant, who was deemed ineligible for financial assistance for HIV treatment, felt embarrassed after seeking help and being rejected. Afterward, he thought, “I got it from a poor decision that I made, and it’s not their [/financial assistance provider] fault, so should they have to compensate me because I made a poor decision? No.” This participant—feeling undeserving of help—noted, “I’ll start taking medicine when I start feeling sick or end up in the hospital.” (Black male, 30s, South).

Participants also experienced a range of mental health issues (e.g., depression, anxiety, bipolar disorder) that affected their decisions to seek medical care. For some, mental health issues were consequences of an HIV diagnosis. For others, alleviating symptoms of mental health issues was more pressing than seeking HIV care. Some participants sought HIV care in the past hoping to receive mental health care.

Health system barriers

Health system barriers were related to the organizations, people, institutions, and resources that deliver health care. Patient-provider relationships were one of the most salient themes. Participants discussed negative experiences with health care providers and other clinic staff, which deterred them from seeking care (Table 2).

One participant described receiving his HIV diagnosis over the phone, which he interpreted as an uncaring and inappropriate means of delivering a life-changing diagnosis. Several participants discussed feeling as though their provider did not take the time to listen to them or treat their health needs. Some participants expressed that their health care was limited to being told what to do.

> …it's a rare thing when you find those doctors or nurse practitioners that cater towards you as an individual… Every time I would go to the doctor it's like, okay, I'm an individual, but you want to pop pills in my mouth when I come in…You want me to do this. But what about me? (Multiracial male, 50s, South)

Additionally, some participants were made to feel that their diagnosis reflected irresponsibility and poor decision-making.

> …the people didn't actually treat you like a person… the providers, they kinda made me feel uncomfortable… They like talk down to you like you were stupid or this was my fault. (Black male, 50s, South)

Participants expressed other health system barriers, including difficulty getting a timely appointment, substantial time spent during an appointment, bureaucratic hurdles to obtaining a prescription, and a fragmented approach to delivering care (e.g., being unable to get labs done in their provider's office).

Structural barriers

Structural barriers related to the economic and social conditions affecting health like employment, housing, and health insurance access.[21,22] Participants discussed responsibilities and needs—often substantial stressors—that took precedence over seeking care. Structural barriers meant that prioritizing other needs and responsibilities over HIV treatment was necessary (Table 2).

Participants discussed prioritizing work over seeking health care, which was associated with additional costs and was time spent away from work. For employed participants, the nature of their work (e.g., self-employed, temporarily employed, traveling for work) made it difficult to seek care either because they had no sick leave or consistent schedules. Other participants noted that obtaining an income was their most pressing need: "I need income, not a doctor." (White male, 60s, Northeast).

Several participants put aside their own medical needs to serve as primary caregivers to family members with disabilities or medical conditions. As one participant noted, “I bathe her [spouse], take her to appointments, feed her, wash her clothes and I can barely walk.” (White male, 60s, Northeast)

Some participants described experiencing housing instability, including homelessness. One participant who was previously receiving HIV care noted that homelessness “carries with it” a “whole subset of additional problems” and has affected “all facets” of his life. For him, finding a place to sleep was a greater priority than accessing HIV care (White male, 40s, West).

Some participants described being uninsured or experiencing lapses in health insurance in the past, leading them to stop seeking care. For one participant, being uninsured meant living in fear if an unexpected medical event occurred: “There’s like a shared fear that I have with the friends of mine that don’t have health insurance…you’re always slightly on edge because you don’t have a cushion to fall onto, in case something does happen… financially anyway.” (Black male, 30s, West) Some participants who were underinsured or uninsured described accessing HIV care in the limited ways available to them, including doing blood tests without seeing a provider or through clinical trials.

Some participants described the high cost of HIV medications, including being unable to afford prescribed medications or that prescribed medications were not covered by their health insurance. One participant described being ineligible for financial assistance for medication because of his income and also described experiencing food insecurity.

Health system facilitators

Participants described positive interactions with providers in the past and the qualities they prefer in a provider (Table 3). Several participants noted that their best experiences seeking medical care in the past—for HIV or other health conditions—were those in which the provider engaged them in a conversation, spoke to them with empathy, and took the time to listen. Participants perceived such providers as “caring” and “helpful.” Participants did not want to feel like their provider was judging or talking down to them. Some wanted their providers to reassure them that living healthily with HIV was possible. Other health system facilitators included appointments soon after scheduling, more appointment times outside of traditional work hours (e.g., before 7 am, after 4:30 pm), and being able to receive care for other health concerns, especially mental health.

Structural facilitator

Access to transportation was the most salient HIV care facilitator. Several participants depended on public transportation. For some, there were few if no public transportation routes near where they live, the health care facility was inconveniently located to bus routes, or the cost was a barrier (Table 3).

Some participants noted that having health insurance would facilitate their entry into HIV care. Others noted that if they did not have to worry about health care costs, they might get care. Some participants had health insurance or Ryan White HIV/AIDS Program coverage.

Knowing that affording medical bills would not be a barrier should they seek care put some of these participants at ease. Some participants also discussed needing financial assistance or employment, as securing income was a necessary precursor to seeking HIV care.

Discussion

Our findings highlight the complex ways in which intrapersonal, health system, and structural factors affect HIV care engagement. We posit that these barriers may place people at the boundary of care, or the space between the stages of the HIV care continuum. PWH exist at the boundary of care when intrapersonal, health system, and structural factors impede entrance into and progression through the stages to achieve and maintain viral suppression. This new conceptualization expands the HIV care continuum model, a traditionally biomedical paradigm, to include intrapersonal and structural factors.

Stigma was a substantial barrier to HIV care engagement, which aligns with other qualitative studies.[8–13,18] For some participants, entering an HIV facility was triggering and a difficult reminder of their diagnosis. Taylor et al similarly found that entering an HIV clinic waiting room was one of the more profound stigma experiences expressed by participants in their study. Participants also described not disclosing their HIV status to protect themselves against rejection, social isolation, or judgment. Previous research has shown that PWH do not disclose their HIV status as a self-protective strategy.[23] Participants have also internalized assumptions and stereotypes of HIV as an illness that reflects deviance, irresponsibility, or a moral failure. For some, interactions within the health care system reinforced this internalized stigma, leading some to believe that they were undeserving of help and many to stop seeking care.

Addressing stigma is key to achieving the goals of the EHE initiative; however, more evidence-informed/based interventions to reduce HIV stigma are needed. Stigma is intrapersonal and interpersonal and structural—it is both created and perpetuated by interpersonal processes and society. Therefore, stigma interventions should occur at the individual-, interpersonal- and community-level. Furthermore, providers play a vital role in guiding PWH through the HIV care continuum but might impede this process through stigmatizing attitudes, behaviors, and beliefs about PWH. Studies have shown that providers have less HIV stigma when they work in settings where HIV stigma policies are reinforced or where they recently completed HIV stigma training.[24]

In addition, stigmatizing attitudes toward PWH were mostly found among White, male, and primary care physicians.[24] HIV stigma training—which can focus on cultural competency and how racism, transphobia, homophobia, and so on perpetuate stigma—for providers is essential. Our participants experienced mental health issues that affected their decision to seek HIV care, which aligns with other qualitative findings.[5,6,9,12] For some, alleviating mental health symptoms was more imperative than seeking HIV care. Integrating mental health care with HIV care is key. Providers can support PWH by screening for mental and behavioral problems and ensuring that PWH receive facilitated or active referrals to mental health services.

Participants described negative experiences with providers who did not listen to them, treat their individual health needs, engage them in a conversation, or make them feel worthy of their time. Other researchers have documented the importance of the patient-provider relationship. Participants in other qualitative studies are also dissatisfied when providers do not engage them in a conversation and simply tell them what to do. Participants in these studies felt that HIV care was limited to being told to take HIV medications.[16,19,25] Our participants also described positive interactions with providers in the past and the qualities they prefer in a provider. They wanted their provider to engage them in a conversation about their health, speak to them with empathy, treat them as an individual with unique needs, and reassure them that living healthily with HIV was possible.

Other studies have similarly found that providers who demonstrate caring, compassion, and responsiveness deliver individualized care; relate optimism about the effectiveness of HIV treatment; value shared decision-making; and empower patients to remain engaged in HIV care.[4,6,7,9,11,17,25]

Community health workers can also play an integral role in helping PWH engage in HIV care. Community health workers help PWH overcome barriers to care engagement by providing education, coaching, and social and emotional support. One study found that community health workers embodied qualities that PWH value such as persistence, commitment, and a nonjudgmental attitude. In this study, participants appreciated that community health workers helped them access ancillary services like mental health, met them where they were, and empowered them to engage with HIV care.[26]

Participants expressed health system barriers, including long wait times, difficulty getting an appointment soon, and a fragmented approach to delivering care. Other qualitative studies have similarly found that such health system barriers were challenges to care engagement.[4,6,7,9,11,,25] Participants in these studies valued when HIV care was colocated with other needed services (e.g., pharmacy, social work). The colocation of services—meant to facilitate access by removing some structural barriers—can improve linkage to care and antiretroviral (ART) uptake. However, more research is needed to determine whether colocation of services improves retention in HIV care.[27]

Participants experienced substantial stressors related to work, caregiving, housing, and income. For many, managing these stressors took precedence over seeking HIV care. Our findings align with other qualitative findings, in which care-giving responsibilities and work —including requesting time off and finding a flexible work schedule—were obstacles to HIV care engagement.[6,8,9,14] We found that seeking care was difficult because employed participants had no sick leave or consistent work schedules. In addition, caregiving was a significant stressor. Informal caregiving, or unpaid care provided to family members or friends, frequently leads to chronic stress and has negative physical and mental health effects.[28] Health care or social service providers can facilitate access to care coordination programs, which connect care-givers to local resources and services, or individual-level programs, which typically involve skills building, social support, or stress management.[29] Participants also expressed that having transportation would facilitate their (re)entry into care.

Other qualitative studies have similarly shown that expensive, limited, and unreliable transportation are barriers to care engagement.[6,9,10,14,15] In addition, participants prioritized basic needs over seeking HIV care. Some participants had inadequate or no health insurance, and expressed concerns about health care costs, which has also been found in other qualitative studies.[6,15,18] Financial incentives such as cash-equivalent gift cards for blood draws, clinic visits, or viral suppression have been shown to improve retention in care and viral suppression.[17,30,31] Financial incentives may reduce the weight of structural barriers such as no income, transportation, and inadequate health insurance.

Some of our participants had several substantial barriers to care, including housing instability, unemployment, and severe mental health issues. People with substantial and complex barriers may need more intensive interventions. The Max Clinic is one example of a program that successfully reengaged patients who had previously failed to engage in traditional HIV medical care by providing high-intensity support, low-threshold access, and incentives.[31]

The HIV Care Continuum is a widely used model depicting the stages that help PWH achieve and maintain viral suppression. Our findings support the bidirectionality (people may transition in and out of treatment) and permeability (there are re-entry and exit points) of the HIV care continuum.[32] We also add to current understandings of the HIV care continuum by positing that intrapersonal, health system, and structural factors place PWH at the boundary of care or the space between the stages.

Participants' experiences and stories informed this concept. For some, being at the boundary of care meant interacting with the health care system in limited ways available to them (e.g., through a clinical trial, intermittent laboratory tests done without the consultation of a provider). For others, being at the boundary of care meant understanding the benefits of HIV care but being unable to engage because of caregiving responsibilities or more basic needs such as housing and income. These participants have exited the continuum of HIV care and entered the boundary of care, a space that relies on social and economic interventions.

This concept places PWH's perspectives at its center since it is informed by their experiences and considers the many factors that affect people's ability to navigate the HIV care continuum. Therefore, it expands the traditionally biomedical lens of the HIV care continuum. A visual representation of the boundary of care highlights where some people who have not been linked to care, remained engaged in care, or achieved viral suppression may lie, the different entry and exit points, and the boundary as a barrier that includes intrapersonal, health system, and structural factors. To be within the boundary, people must have engaged with the health system at some point (Fig. 1).

Treating PWH quickly and effectively to achieve sustained viral suppression is one key strategy of the EHE initiative. For PWH who are at the boundary of care, effective treatment to achieve viral suppression will require a multipronged approach that addresses barriers such as stigma, mental health issues, health systems issues, housing instability, and unemployment. Despite being crucial for optimal health outcomes, linkage to care and re-engagement in care interventions and research studies are few.[33] Furthermore, few evidence-informed and evidence-based interventions tackle the intrapersonal and structural barriers we outline.[30] Thus, future research and interventions that address these stages and barriers are needed.

We examined barriers and facilitators to HIV care engagement among people who were not engaged in HIV care. Our findings show the unique barriers and facilitators that people who are not engaged in HIV care face and how they are dissimilar to those experienced by people engaged in HIV care. While other studies have noted that lack of employment benefits serve as barriers to HIV care engagement, we found that the nature of employment (e.g., self-employed, temporarily employed, traveling for work) was also part of the issue. For example, it is difficult to maintain an appointment when work schedules are subject to daily change, or when work requires traveling across the country. Caregiving was also a barrier to HIV care engagement that was salient among our participants, but which has not been a major finding in other studies.

We also found that participants attempted to access care in the limited ways available to them. In a systematic mixed studies review, Arora et al. similarly found that enrolling in clinical trials was one of the only ways to obtain treatment for migrants living with HIV.[34] However, to our knowledge, no study in the United States among nonmigrants has found a similar finding. Finally, we did not find social support to be a facilitator, although it appears as one in many qualitative studies. While social support is an important facilitator, it may be the case that structural and health system facilitators are a priority among people who are out of care. This is in line with findings from Carey et al., where men who were not engaged in HIV care did not mention social support as a strong facilitator of HIV care engagement, whereas it was a salient facilitator among people engaged in care.[7]

Our analysis was subject to some limitations. Our sample was derived from people who self-reported no HIV care engagement; thus, the data are subject to response bias. In addition, we only analyzed responses to questions about barriers and facilitators to HIV care; however, participants discussed barriers and facilitators throughout the interviews, which we expected. To address this, we conducted keyword-in-context techniques to identify other times when the participants discussed barriers and facilitators. Although participants were demographically comparable to the population of PWH in the United States, we had few female, young, and Hispanic/Latino participants, and no transgender participants. Thus, we might be missing important perspectives. However, unlike many qualitative studies, we did not restrict our analysis to specific sociodemographic groups or geographic regions; thus, incorporating many perspectives. Although our findings are not generalizable to a larger population, they may be transferable to other settings.

Our findings show that people who are not engaged in HIV care report many intrapersonal, health system, and structural barriers to HIV care engagement. Our data show how these barriers manifest in people’s lives beyond what is possible with quantitative data. Moreover, we posit that these barriers place people at the boundary of care, which is the space between the stages of the HIV care continuum. This concept acknowledges the key role that nonclinical factors play in a person’s position on, and ability to progress through, the HIV care continuum.

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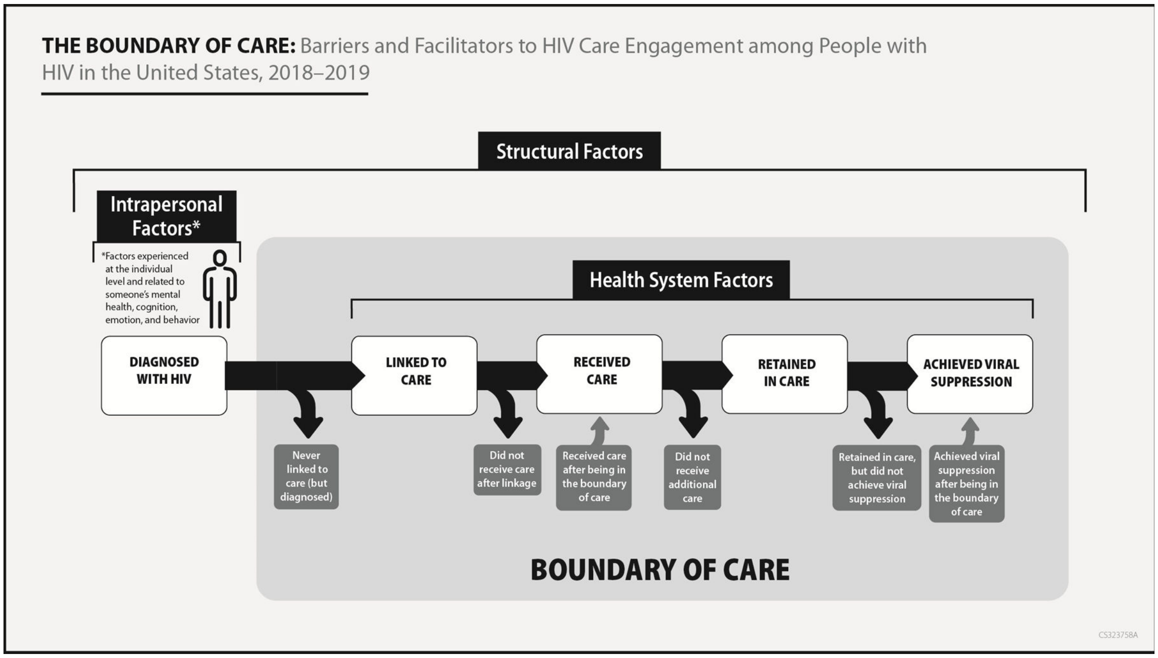

FIG. 1.

The Boundary of Care: Barriers and facilitators to HIV care engagement among people with HIV in the United States. The figure depicts how intrapersonal, health system, and structural factors may place people with HIV at the boundary of care or the space between the stages of the traditional HIV care continuum. Intrapersonal factors are those experienced at the individual level and are related to someone’s mental health, cognition, emotional, and behavior. Health system factors are those that exist within the health care system, which is composed of the organizations, people, institutions, and resources that deliver health care. Structural factors are those that relate to the economic and social conditions affecting health. People with HIV can exit the continuum of HIV care and enter the boundary of care when they have experienced any intrapersonal, health system, or structural barriers. The boundary of care relies on social and economic interventions in addition to health system interventions. This visual representation of the boundary of care highlights where some people who have not been linked to care, remained engaged in care, or achieved viral suppression may lie, the different entry and exit points, and the boundary as a barrier that includes intrapersonal, health system, and structural factors. To be within the boundary, people must have engaged with the health system at some point.

TABLE 1.

Demographic characteristics of study participants ($N = 34$)

Participants demographic characteristics [a]	**N *(%)***
Age group (years)	
18–39	10 (30%)
40–49	9 (26%)
≥50	15 (44%)
Gender	
Male	26 (76%)
Female	7 (21%)
Transgender	0 (0)
Missing[b]	1 (3%)
Race and ethnicity[c]	
Non-Hispanic Black/African American	22 (65%)
Hispanic/Latino[d]	2 (6%)
Non-Hispanic White	7 (21%)
Other race/ethnicity[c]	3 (8%)
Current US region of residence[e]	
West	7 (21%)
Midwest	8 (24%)
Northeast	7 (21%)
South	12 (34%)

[a] Participant demographic data were obtained from the MMP quantitative survey.

[b] Data were coded as missing because participant refused to answer.

[c] Hispanics or Latinos might be of any race. Persons are classified in only one race/ethnicity category.

[d] Includes American Indian/Alaska Native, Asian, Native Hawaiian/Other Pacific Islander, or multiple races.

[e] Regions based on classification by United States Census Bureau: West (CA, OR, WA), Midwest (IN, IL, MI), Northeast (NJ, NY, PA), South (DE, FL, GA, NC, VA, TX).

MMP, Medical Monitoring Project.

TABLE 2.

THEMES AND SUBTHEMES RELATING TO BARRIERS TO HIV CARE ENGAGEMENT AMONG PEOPLE WITH HIV WHO WERE NOT ENGAGED IN CARE

Theme	***Theme definition***	***Subtheme***	***Illustrative quotes*** [a]
Intrapersonal barriers	Experienced at the individual level and related to someone’s mental health, cognition, emotion, and behavior	Stigma	“I mean I think first and foremost, for me anyway, is like the, the internal stigma of just being reminded of okay, you have seroconverted and just the… the emotional messiness of that. And really having to come to terms with it in a very real way.” (Black male in his 30s living in the West) “And I’ve had it [/HIV] all these years and it affects people differently, but usually when I go there [/HIV care facility], it’s like a trigger, like you know, it just brings up stuff” and “I’d rather just go on with my life, and not have it in my face.” (White male in his 40s living in the West) “That’s the worst part about it, you know, we lie about it. You know that? We lie about it. People know I’m sick, but they think I have multiple sclerosis. They don’t’ know I have HIV, because if I tell them HIV, you know, I won’t have a family, I won’t have friends, I won’t have anyone.” (Black female in her 50s living in the Northeast) “I got it from a poor decision that I made, and it’s not their [/whoever is providing the financial assistance] fault, so should they have to compensate me because I made a poor decision? No.” (Black male in his 30s living in the South)
		Mental and emotional health	“I’m not a hundred, I’m not mentally…stable to go, to start a doctor’s thing right now. I have to straighten my life out.” (White male in his 60s living in the Northeast)
Health system barriers	Existed within the health care system, which is composed of the organizations, people, institutions, and resources that deliver health care	Patient-provider relationships	“He was cold, and it was business. It didn’t matter if you were sick, it didn’t matter if you were having what you thought was a side effect or there were issues, didn’t matter. This is the appointment; this is the days he’s off and that’s that…I didn’t like that at all.” (multiracial male in his 20s living in the Midwest) “…to me it’s a rare thing when you find those doctors or nurse practitioners that cater towards you as an individual instead of, ‘okay, this is what you get. Okay, let’s do this.’ Cause you’re out the door…. Every time I would go to the doctor it’s like, okay, I’m an individual, but you want to pop pills in my mouth when I come in. You want me to do this. You want me to do this. But what about me?” (multiracial male in his 50s living in the South) “…I didn’t feel comfortable with the way they… talked to me…I think I didn’t like the, the impression that, you know, you’re promiscuous or you’re always running around doing something just because you’ve contracted the disease or that you’re gay. They immediately assume that.” (White male in his 50s living in the West) “…my experience were the people didn’t actually treat you like a person… the providers, they kinda made me feel uncomfortable especially when I was at, when I was going to the health department. They like talk down to you like you were stupid or… this was my fault.” (Black male in his 50s living in the South)
		Other health system barriers	“The system’s so backed up it’s, you know, there’s this, these incredible waiting lists …I’ve reached out but again, things get hard… Things get very difficult and just… reaching appointments or going into, can become a complicated issue.” (White male in his 40s living in the West) “…having an appointment, I still have to wait up to an hour and a half. So, I quit that part of it, I’m like really? I don’t tink [/think/] so.” (White male in his 50s living in the West) “… I had tried calling multiple doctors and they were either booked full for like four months out before you could get a new patient in. And I was like ‘Jesus,’ and you can’t make an appointment with a specialist, even for like an emergency situation, like you were out of medication, you cannot get a prescription without an appointment from a general practitioner first, and then a referral to a specialist.” (Multiracial male in his 20s living in the Midwest)
Structural barriers	Related to the economic and social conditions affected health	Employment and income	“I need income, not a doctor.” (White male in his 60s living in the Northeast)
		Caregiving	“I bathe her [/spouse], take her to appointments, feed her, wash her clothes and I can barely walk.” (White male in his 60s living in the Northeast)
		Housing	Homelessness “carries with it” a “whole subset of additional problems” and has affected “all facets” of life. (White male in his 40s living in the West).
		Health insurance	“There’s like a shared fear that I have with the friends of mine that don’t have health insurance. And it’s like, you’re always slightly on edge because you don’t have a cushion to fall onto, in case something does happen, I mean financially anyway.” (Black male in

Theme	***Theme definition***	***Subtheme***	***Illustrative quotes*** [a]
			his 30s living in the West) “where I work at, they don’t supply insurance so that also, also makes it [accessing care] difficult. And I’ve been at my job for about twenty-two years… I’m in a situation right now where I’m tryna get it and I’m having a hard time.” (Black Hispanic/Latina female in her 40s living in the Northeast)

[a] Quotes were modified slightly to remove superfluous language (e.g., “like,”).

TABLE 3.

THEMES AND SUBTHEMES RELATING TO FACILITATORS TO HIV CARE ENGAGEMENT AMONG PEOPLE WITH HIV WHO WERE NOT ENGAGED IN CARE

Theme	***Theme definition***	***Subtheme***	***Illustrative quotes*** [a]
Health system facilitators	Existed within the health care system, which is composed of the organizations, people, institutions, and resources that deliver health care	Patient-provider relationships	“I had my regular doctor and I had a specialist, and I ended up going to my specialist more than my regular doctor just for general medical just cus he was very open, very friendly and was much more personal. Like he was invested in how I was doing. He really cared” (Multiracial male in his 20s living in the Midwest) When explaining treatment for another medical condition: “…it was just like, more care, you know what I’m saying? He just didn’t stop, he ain’t stop, when they were trying to find out what was triggering the seizures. He went beyond on his own” (Black male in his 40s living in the Midwest) “And when you go into the… healthcare office, that’s what are the people are, they’re just as positive. They’re almost giddy, and you just absorb that, and you do feel good when you leave. You can conquer anything. Especially this.” (Black male in his 60s living in the South)
		Other health system facilitators	“Convenient hours. That, that would be the, the determining factor, the main factor …6 AM to 7 AM or 4:30 to 7 PM.” (Black male in his 50s living in the South)
Structural facilitators	Related to the economic and social conditions affected health	Access to transportation	“Long as I have transportation, I would go.” (Black male in his 20s living in the Northeast)
		Health insurance	“Well, I mean it [/having health insurance] doesn’t really have a role other than setting my mind at ease that these crazy, astronomical costs that you see are, I don’t have to bear it all…I wouldn’t do those tests…I’d just live with the pain or whatever because I wouldn’t pay those kind of amounts on my own. I—I wouldn’t have the money.” (White male in his 50s living in the Midwest)

[a] Quotes were modified slightly to remove superfluous language (e.g., “like,”).