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Barriers and Facilitators for Clinical Care Engagement Among HIV-Positive African American and Latino Men Who Have Sex with Men

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Abstract

Achieving optimal health among people living with HIV (PLWH) requires linkage to clinical care upon diagnosis, followed by ongoing engagement in HIV clinical care. A disproportionate number of black/African American and Hispanic/Latino men who have sex with men (MSM) living with HIV do not, however, achieve ongoing care. We conducted semistructured interviews in 2014 with 84 urban black/African American and Hispanic/Latino MSM living with HIV to understand their barriers and facilitators to engagement. We classified men as care-engaged or not at the time of the interview, and conducted content analysis of the interview transcripts to identify barriers and facilitators to engagement. Respondent mean age was 42.4 years (range, 20–59). Over half (59.5%, n = 50) were black/African American. Slightly more than a third (38.1%, n = 32) reported not being continuously care-engaged since diagnosis, and 17.9% (n = 15) delayed entry, although they have subsequently entered and remained in care. Sustained engagement began with overcoming denial after diagnosis and having treatment plans, as well as having conveniently located care facilities. Engagement also was facilitated by services tailored to meet multiple patient needs, effective patient-provider communication, and providers who show empathy and respect for their patients. Respondents were less likely to be care-engaged when these factors were absent. It can be difficult for racial and ethnic minority MSM living with HIV to begin and

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sustain care engagement. To optimize care engagement, our findings underscore the value of (1) convenient multipurpose HIV care facilities that meet patient needs; (2) excellent provider-patient communication that reinforces respect, trust, and HIV treatment literacy; and (3) assisting PLWH to create personalized treatment plans and overcome possible challenges such as diagnosis denial.

Keywords

HIV care continuum; black/African American men who have sex with men; Hispanic/Latino men who have sex with men; healthcare engagement; content analysis; HIV/AIDS

Introduction

Following an HIV diagnosis, it is critical for persons living with HIV (PLWH) to begin and sustain engagement in clinical care.^{1,2} To prevent disease progression, clinical care engagement should begin at diagnosis and continue throughout the PLWH's life. Being retained in care remains key for primary, secondary, and tertiary HIV prevention and treatment success. PLWH who achieve ongoing engagement can benefit from antiretroviral treatment (ART) prescribed and monitored by their physician. This supports optimal patient health outcomes because ART facilitates viral suppression, and viral suppression helps the patient's immune system remain intact. Regarding primary prevention, patients who sustain suppressed viral load have effectively no chance of transmitting the disease.¹⁻⁵ PLWH viral suppression thereby lowers new infection rates within and between sexual networks, especially when infections are diagnosed and treated early.⁶⁻¹⁰ Models suggest that if 90% of all diagnosed PLWH were linked and retained in HIV care, the number of new HIV infections would decrease by 52.3% (or 274,000 new infections averted) in the United States.¹¹

However, some PLWH do not become care-engaged after learning their diagnosis, or they move in and out of care over time.^{12,13} Many reasons for why PLWH have care engagement challenges are shared with individuals living with other chronic illnesses. For example, emotional burdens related to diagnosis with a serious disease, anxiety related to potential loss of health or life expectancy, difficulties with visits to healthcare facilities or care providers, side effects of treatments, adverse impact on sexual or family relationships, and impact on the patient's economic and social life are factors that can disrupt clinical care for cancer patients.¹⁴ Among US publicly insured patients seeking care, barriers related to family and work, suboptimal interactions with providers, perceived discrimination, and healthcare coverage, financial, and access difficulties increased the odds of patients having delayed, foregone, or no clinical care.¹⁵ Additional factors may inhibit engagement. For example, PLWH may not perceive signs of illness for long periods, and a lack of noticeable symptoms may result in detachment from care. Attaining and sustaining viral suppression sometimes may not be an individual's primary personal goal; rather, their top priority for managing HIV infection might be to feel healthy and live a routine life. If such a patient feels healthy, they may have little motivation to engage in ongoing HIV clinical care. For instance, in 2014, 21.2% of US PLWH surveyed, said they never started ART because they felt healthy or they believed their HIV laboratory results were "good."¹⁶

HIV-positive black/African American and Hispanic/Latino men who have sex with men (MSM) (hereafter referred to as “MSM of color”) have substantial challenges getting HIV care.^{17,18} Prior studies suggest that the social and personal circumstances of black/African American MSM living with HIV may affect their ability to begin and stay in HIV care.^{7,19–21} In a sample drawn from 33 US jurisdictions, only 53.2% of black/African American MSM diagnosed with HIV and alive at the end of 2013 were in ongoing care.²² Based on another sample of HIV-positive black/African American MSM alive at the end of 2010 and residing in any of 19 jurisdictions, an estimated 71.6% were linked to care and 46.3% were retained in HIV care.²³ In addition, HIV-positive Hispanic/Latino MSM alive at the end of 2010 and residing in these same 19 jurisdictions had 80.3% linkage and 54.1% retention in care rates.²⁴ For US urban MSM in 2014, linkage to care rates were 88.8% for black/African Americans, 85.1% for Hispanic/Latinos, and 89.3% for whites.²⁵ Among PLWH aged 13 years or older at the end of 2014, 40.1% of black/ African Americans and 48.1% of Hispanic/Latinos were estimated to have durable viral suppression, compared with 56.4% of whites.²⁶ The number of MSM of color living with diagnosed HIV are projected to substantially increase by 2045, unless there is a significant improvement in HIV clinical care engagement.²⁷

Additional information is needed to pinpoint why specific PLWH populations, including MSM of color, do or do not attain sustained care engagement. Therefore, the purpose of this article is to identify some of the key reasons why HIV diagnosed, MSM of color experience varying degrees of HIV care engagement. While we acknowledge that many other important factors, including complex sets of psychological, structural, and cultural conditions, can play roles in care engagement, in this article, we focus attention on identifying factors derived from men’s personal experiences and statements.²⁸ Identifying factors affecting health or social service efforts—in this case, HIV healthcare services for MSM of color living with HIV—can influence whether HIV care programs achieve or fail to attain sustained care engagement. Specifically, this study presents men’s self-reported descriptions of their personal successes and struggles to manage their HIV care. We contend that understanding men’s perceptions of factors that have facilitated or impeded their personal care engagement can provide essential information useful for improving health outcomes, achieving national HIV prevention, care, and treatment objectives, and can assist healthcare providers to tailor services to meet patient needs.^{7,10,12,29–31}

Methods

We used a cross-sectional, qualitative research design. Study sites were five US cities: Atlanta, GA; Baltimore, MD; Chicago, IL; Los Angeles, CA; and Washington, DC. These cities have elevated HIV prevalence and large populations of MSM of color.³² The Emory University Institutional Review Board approved the protocol. Respondent recruitment was achieved through medical provider and case manager referrals, listserv postings, and flyers distributed at events or locations frequented by MSM of color. Eligibility criteria for the purposively selected respondents included the following: self-reported HIV diagnosis; identified as a cisgender male; being 18 years or older; identified as black/African American and/or Hispanic/Latino; reported having had oral or anal sex with another man at least once

in the past 6 months; and ability to be interviewed in either English or Spanish. Respondents were screened by phone or in person.

Eligible men were invited to complete face-to-face interviews. At the time of data collection, early to mid-2014, US HIV treatment guidelines recommended ART should begin at a CD4 count of 500 or less, or when the patient had at least one opportunistic infection. Shortly after data collection finished, these guidelines were updated to prescribe ART for all PLWH.³³ This change may partially explain why some men said they followed their doctor's treatment advice, but were not taking ART. However, as described in the Results, the sample also included men who likely were qualified for ART under the old guidelines but were not care-engaged and not taking ART. In sum, and in keeping with our study purpose to identify factors that MSM of color perceive to facilitate or impede their HIV care engagement, the sample included men with a broad range of clinical care experiences.

Respondents provided sociodemographic characteristics using structured response questions, including age, race/ ethnicity, sexual identity, education, and health insurance coverage. These data were analyzed using SPSS. The questionnaire also included a series of open-ended questions asked of each respondent pertaining to respondents' experiences with treatment, including ART; understanding of HIV laboratory and diagnostic tests; experiences with medical and social service providers and facilities; perceived barriers and facilitators to care engagement and treatment adherence; and HIV status disclosure to their interpersonal social support networks. Interviews were recorded digitally and transcribed verbatim. Senior project staff reviewed transcripts for quality assurance. Personal identifying information was redacted. Spanish interviews were translated into English during transcription.

Multiple methods were used to analyze data from the openended questions.^{34–37} As our first step, we conducted a content analysis of the transcripts to identify potential barriers and facilitators. Content analysis has been used since the 1940s for systematically analyzing text-based data; it typically includes combinations of both qualitative and quantitative techniques.^{38–41} Content analysis studies commonly report frequencies and descriptive statistics computed for common themes; to examine co-occurrences or associations between themes, various bivariate and multivariate statistics often are used.^{36,38,40,41} In our data, barriers and facilitators included an array of personal beliefs, behaviors, experiences, circumstances, or other factors that potentially hindered or helped the men get HIV clinical care. We developed a codebook that listed and defined each possible barrier or facilitator.^{42,43} Each transcript was classified as either containing or not containing statements that corresponded to each specific barrier or facilitator. We used the final codebook to code each man's transcript using NVivo. We assessed inter-coder agreement using Cohen's kappa.⁴³ The coders' average kappa scores were between 0.6 and 0.7 across all codes, with 70% of codes having a kappa of 0.8 or higher, indicating substantial inter-coder agreement. Any remaining coding disagreements were resolved through discussion among the coders. Final codes assigned to each respondent were used in subsequent analysis steps.

After coding potential barriers and facilitators to care, our second step was to create a classification typology based on how respondents described their HIV care engagement. In

this article, we compare respondents who were engaged in clinical care, versus men who were not care-engaged at the time of the interview. Men classified as “engaged” included two respondent subgroups: men who said they had been continuously care-engaged since diagnosis, plus men who became engaged following a period of delay after learning their HIV diagnosis. Men classified as “not engaged” at the time of the interview comprised two other subgroups: men who were care-inconsistent (i.e., sporadically sought HIV clinical care) since learning their diagnosis, along with those who reported being HIV care-detached entirely since learning their HIV diagnosis.

Our third step was to determine if co-occurrences existed between each potential barrier and facilitator and whether the respondent was care-engaged or not. To do this, we used crosstab tables and chi-square statistics; this method commonly is used in many content analyses.^{36,37,40,41} For our purposes, this step allowed us to identify and focus on those themes associated with our engagement classification variable ($p < 0.05$).

As our final step, we selected illustrative case studies typifying respondents who experienced different types of barriers or facilitators associated with care engagement. The illustrative quotes add contextual explanatory details not provided through the statistical results. We present the findings from all four analytic steps in the Results.

Results

The sample included 84 MSM of color living with HIV. Table 1 shows descriptive characteristics. Slightly more than a quarter were from Atlanta (28.6%, $n = 24$), and nearly the same number from Chicago (27.4%, $n = 23$). Slightly less than a quarter were from Los Angeles (23.8%, $n = 20$) or Baltimore/Washington, DC (20.2%, $n = 17$). Only 14 of the 84 interviews were conducted in Spanish and transcribed into English for analysis. Table 1 also shows the mean age was 42.4 (SD = 10.3; range, 20–59) years. The men were predominantly black/African American (59.5%, $n = 50$). Hispanic/Latinos comprised 36.9% ($n = 31$) of the sample. Over two-thirds identified as gay or homosexual (69.0%, $n = 58$), with 20.2% ($n = 17$) identifying as bisexual. Over half (58.3%, $n = 49$) had some college education or were college graduates, and 58.3% ($n = 49$) said they had comprehensive health insurance coverage (via Medicaid, Medicare, or private insurance). Another 17.9% ($n = 15$) indicated they had at least partial coverage (through Ryan White). In addition, 66.7% ($n = 56$) reported their HIV diagnosis occurred after 1996, thus, after ART became commonly available for PLWH.³³ Seven respondents (8.3%) said they were diagnosed within an 18-month period before their interview. In sum, nearly a third of the sample were long-term HIV survivors diagnosed in the 1980s and 1990s, and the others were diagnosed after ART became commonly used and standard care (Table 1).

Fifty-two of the men (61.9%) were classified as engaged in HIV clinical care at the time of the interview (Table 1). Of these 52 respondents, 37 (71.2%) described that they entered care shortly after learning their HIV diagnosis, and have remained in care since (data not shown in Table 1). The other 15 respondents (28.8% of the care-engaged) reported a period of postdiagnosis delay before starting clinical care, with some waiting for many years. These men subsequently initiated care, and have remained in care. Thirty-two respondents

(38.1%) reported they were not consistently care-engaged at the time of the interview. Not care-engaged was distinguished by having missed (and not rescheduled) at least two of their last five appointments, or reported not having an ongoing consistent relationship with a medical provider. Four of the 32 not care-engaged were detached from care altogether, thus reported not seeing a provider for HIV care since diagnosis.

With the exception of education, the city and other variables listed in Table 1 were not associated with care engagement (based off chi-square statistics; $p > 0.05$; details not in Table 1). Men with “some college” (78.1%) and “college graduates” (70.6%) tended to be more likely to be care-engaged than “high school diploma/GED” (31.6%) and “less than high school diploma” (56.3%) respondents ($p = 0.008$). We therefore checked to see if education acted as a confounder in subsequent analysis steps described below. Multiple interviewers were used, but interviewer ID was not associated with the care engagement variable ($p > 0.05$; details not in Table 1). This indicates that interviewers did not introduce systematic bias that affected whether a respondent was classified as careengaged or not.

Although our coding process involved multiple HIV care-related themes, only some (7 out of 23 codes) were statistically related to care engagement. Table 2 lists these seven factors associated with engagement, based on chi-square statistics ($p = 0.05$). In addition to being unrelated to engagement, interviewer ID was not associated with how the men were classified for any of these seven factors ($p > 0.05$; details not in Table 2). As previously noted, education was the only variable from Table 1 related to engagement, but education also was not associated with the seven themes listed in Table 2 ($p > 0.05$; details not in Table 2), and therefore did not act as a confounder.^{44,45} We discuss these seven factors in greater detail below. The men’s narratives help explain how and why these factors relate to engagement.

Period of diagnosis denial

Many men, regardless of their degree of engagement, experienced a period of denial after learning their HIV status (Table 2). Surprisingly, engaged men were more likely than the men not engaged to report prior periods of denial (32.7% vs. 12.5%; $p = 0.0379$). Clearly, engaged men overcame their denial; some even embraced the diagnosis in functional ways. Indeed, as seen in the following, some men overcame their denial with strengthened personal resolve regarding their HIV disease, or they gained hope by learning about the utility of treatment and sustained care.

The first three years I was in denial. I was scared.and I prayed about it. I’m sitting at graduation.and I’m thinking I’m going to die in two years. But then I said, “Lord no, we going to do this together.” So I just got a positive outlook on it. My attitude was like, “no, you are going survive this.” - Care-engaged (delayed), 49, black/African American, diagnosed pre-ART

I got diagnosed in 1993. The first time I got tested, they told me I was HIV. So, I was like, “Ok I got to go back and get a second opinion.” I went back, and did it through the formal thing that they do it through. They told me, “Yes,” I was HIV. It took me a while to grasp it. It was like a year or maybe two later. I went and started getting treatment through the center, which was helpful. Then I started trying to

deal with it. I started coping with it and stuff. I been coping pretty good since then.
- Care-engaged (delayed), 52, black/African American, diagnosed pre-ART

I lost my mind. It was like it was total devastation. It was just, first, really denial. I was in so much denial, not wanting to accept it. This couldn't be happening, but then I just going through a lot of things. I went through a lot of drug abuse because I was wanting anything to just drown all that out, then after going through it for so long, it was like, "Ok, I can't keep doing this." I wasn't on any meds, then I saw my health start to deteriorate. Then, they, the doctors, were telling me what was happening, so I knew. That made me realize, "Ok, this is really actually happening." So I stopped all that garbage, got into treatment, got into the program and everything. Got myself clean, got sober, then started taking meds, and everything started to swing around the other way. - Care-engaged (delayed), 52, black/African American, diagnosed pre-ART

While many experienced initial denial, they frequently found a way to accept their diagnosis. Yet the process for overcoming denial was a substantial personal hurdle that could hinder a man's willingness to seek HIV treatment, as exemplified by this respondent.

My doctors talked to me about it [managing his HIV], and they said there's ways of being treated. "You can live with it. It's not something that can be cured; it can only be eased." It was kind of hard for me to deal with it, so I kind of just stopped. I just put it in the back of my mind. Actually, I even forgot about it. [Interviewer: "You were in denial."] Yes. I went into a type of a depression mode. I didn't want to be bothered with anyone. I stayed to myself. I felt that I was going to die now. I just couldn't accept it. I wanted to find out who I had got it from. Who to blame, right. I was angry, very angry. - Not care-engaged (inconsistent), 45, black/African American, diagnosed post-ART

As seen in the following, another potential dynamic of denial and its impact on care regard the subjective feelings of not being "sick." The following respondent sums his detachment from care as,

I was diagnosed in 2006. I basically didn't after that receive treatment because I just wasn't feeling sick. I don't feel like I'm just sick enough to get treatment. I've already been on disability for something else but that came up so I just felt like while my health is like it is why bother it. - Not care-engaged (detached), 47, black/African American, diagnosed post-ART

While we cannot explicitly state this respondent is in denial, this narrative suggests his feeling of not being sick may involve a degree of denial, if not lack of knowledge regarding HIV's impact during the asymptomatic stage of infection.

HIV care and treatment pla

Once care-engaged respondents overcame denial, they took a step toward on-going engagement. Subsequently, they began focusing on their disease management. For example, having a treatment plan, formal or informal, differentiated respondents' degree of care engagement. Respondents who specifically described having a treatment plan were more

likely to be care-engaged than men who did not mention having a treatment plan (p 0.0041; Table 2). Some plans were informal self-care practices, while others resulted from discussions with medical providers.

I put my agenda book and I write the things that I need to do during the week, like every week, every week, every week. I have my pills, [and] my plastic pill box. Every Sunday I separate by day, day by day, day by day. I'm trying, I change also my food regimen. I eat more like vegetarians, yogurts, vegetables, fruits. This is you know from my side, right, but with the medical treatment, I always get an agenda and I write in the agenda my appointments. I never, never skip any appointment. I try to be very, very sharp with the appointments and I respect the decisions of the doctors. - Care-engaged (continuous), 51, Hispanic/Latino, diagnosed pre-ART

Yes, I have a plan. My plan consists of the basics of going to the doctor, getting the labs, all that, the medication and that's it. Every two months, or every month, I think. It depends on how the doctor sees you, how often he sees you. The doctor decides looking at your seeing your quantities. he decides if you are doing well. - Care-engaged (continuous), 31, Hispanic/Latino, diagnosed post-ART

I was going to her [his provider] every three months, and then every four months and now it's every six months because I'm doing well. And, you know, it's just every six months I visit, and labs and, you know, the pharmacist sees me, the social worker sees me, and the doctor sees me every time. I'm on Atripla, and then I take the vitamins—fish oil, D, and multi. I've never cancelled a visit. - Care-engaged (delayed), 37, Hispanic/Latino, diagnosed post-ART

Having a specific plan, regardless of what that plan includes or whether it is implicit or explicit, was not the case for many who were not engaged consistently in care, or were detached from care. The following two narratives show this:

[Interviewer: "Do you have a treatment plan?"] I don't know. I'm one of those people I can't even take aspirin. It makes me gag. I don't do needles, they hurt. - Not care-engaged (detached), 54, black/African American, diagnosed pre-ART

Well, sometime I'm not being responsible with myself, not paying so much attention to what is really important. Many times, I put other things before that thinking probably that I'm still here. I'm alive. I'm not dying, so what's the problem? -Not care-engaged (inconsistent), 42, Hispanic/Latino, diagnosed pre-ART

For a few men, their lack of a treatment plan reflects their belief they do not need one.

Like I said, I don't get sick. So I mean, I be good. I'm good. - Not care-engaged (inconsistent), 45, black/African American, diagnosed pre-ART

General facilitators to HIV care and treatment

Care-engaged men described various factors that helped them stay in care (p 0.0133; Table 2). Specific examples included having strong personal resolve to remain healthy, receiving

incentives or appointment reminders from care facilities, or receiving support from friends. Care-unengaged men did not mention these advantages.

If I refuse to take the medication, refuse to be involved with my health, I'll die. If I'm consistent on what I should be doing as far as the medication is concerned, as far as eating right, being healthy—I'll live long. It's simple. it's not rocket science, if you want to live do this, if you want to die do that; simple. - Care-engaged (delayed), 48, black/African American, diagnosed post-ART

I have to admit the [name's program] makes it easy, because they give you incentives. Cash incentives if you comply. I mean it's sad but for some people that has to be a reminder you know because they do like a text messaging thing every day. And just that text message survey on a daily basis pays you two dollars. But it reminds you about your medicine. It reminds you- it asks you questions about your lifestyle, how are you living. - Care-engaged (continuous), 48, black/African American, diagnosed post-ART

Favorable aspects of HIV care and medical facilities

Many care-engaged respondents explicitly described positive experiences with medical facilities and staff. These experiences contribute to ongoing retention and care engagement p 0.0183; Table 2).

You know, I mean all of them care for me. You know, they don't go around saying, "Oh, you poison." You know they don't do anything like that. They treat me just fine in- in you know the doctor's office and in the waiting room is great, where I go. They're friendly, they're respectable, you know, it's a good environment for me. - Care-engaged (continuous), 45, black/African American, diagnosed post-ART

They just comfortable. They make you feel at home, you ain't gotta worry about discussing nothing, you can discuss what you want. Sometimes it's hard to discuss a lot of things with people, but with them they make you feel at home. - Care-engaged (continuous), 33, black/African American, diagnosed post-ART

Unfortunately, these experiences were not universal. Indeed, several of inconsistent and detached from care respondents mentioned bad experiences with medical facilities and staff.

I like to argue that that's what has kept me from going to the doctor when I did have insurance is, they're judging me; they're mean. - Not care-engaged (inconsistent), 33, black/African American, diagnosed post-ART

The last time I was just there [his medical clinic], I was 20 minutes late for my appointment, and they, and I told them I had been off meds for at least three or four months. "Well, I'm sorry, you're gonna have to come back." You aren't supposed to turn away an HIV patient from someone, there was some doctor there that could have spent 10, 20 more minutes just to write me a prescription or something. So they turned me around. That's what raised the red flag. for me. I said, I need to find a better doctor's office to go to. - Not care-engaged (inconsistent), 24, black/African American, diagnosed, post-ART

Some not care-engaged men had concerns with ancillary services, such as medical transportation. In the following, a respondent describes his negative experiences with Medicaid's transport.

You have to call in a week before, and all this and that, and then that's another problem because most of the time they're not on their job. I've seen on certain occasions where they come late, then they blame the people. "It's not really their fault," and then- oh I've heard some horror stories as far as their driving and then their smoking, and just being careless. So that's why I never really, really dealt with the Medicaid transportation because it's horrible. - Not care-engaged (inconsistent), 50, black/African American, diagnosed pre-ART

These narratives, both facilitating and obstructing care engagement, affirm that having personable staff and caring providers with friendly "bedside manner" fosters retention in care. When the facility and/or the means to access care is staffed by people who appear not to be empathetic or seem more interested in their own convenience, the result drives patients away. Another area respondents mentioned was clinic location.

Convenient care facility location

The perceived location convenience of the respondent's care facility was associated with the likelihood of respondents' being care-engaged ($p = 0.0218$; Table 2). Respondents especially liked facilities that only took a short time to get to, or did not require unpleasant transportation. As seen in Table 2, 20.1% of the care-engaged men cited having a convenient facility, versus only 3.1% of care-unengaged men.

It's [his clinic] close; it's maybe twenty minute, twenty minute ride by vehicle. [Interviewer: "And do they pick you up and take you there?"] Yes they do. They do pick me up at my door step and drop me off at my doorstep. - Care-engaged (continuous), 48, black/African American, diagnosed post-ART

It's right downtown. It's not in a bad neighborhood or anything. Easy to get to. - Care-engaged (continuous), 29, black/African American, diagnosed post-ART

What do I like about where I go now? It's conveniently located. It's within walking distance. I'm very familiar with the staff itself. I can easily get in and get an appointment, and I can get in early in the morning. - Care-engaged (delayed), 57, black/African American, diagnosed post-ART

However, for unengaged participants, concerns with the lack of convenience served as a barrier to care.

[Interviewer: "How easy or hard it is to make your visits to the doctor?"] It's hard. It's hard sometimes, like, to just go there and then get—it's not hard, but it's a little bit, it just too much to be going on a bus and then the bus be packed and. I can't deal with big crowd. When the bus gets crowded, I sweat like, I think I have anxiety. I don't know. I don't like crowds. [Interviewer: "If you could get it at a time that was better for you when the bus wouldn't be so crowded, would you go more regularly to your appointments?"] Mm hmm. - Not care-engaged (inconsistent), 21, black/African American, diagnosed post-ART

“One-stop shop” care facilities

In addition to care location, respondents strongly appreciated facilities offering a wide array of services beyond HIV clinical care. Study participants who had these types of multifunction care facilities tended to be much more likely to be care-engaged compared with men who did not report having this type of care facility ($p = 0.0005$; Table 2). Having a “one-stop shop” care facility was the factor most strongly related to HIV care engagement in our sample: half of the care-engaged men described having a “one-stop shop” type of care facility, whereas only a small number of the men who were not fully engaged at the time of the interview mentioned having “one-stop shop” facilities (Table 2). Respondents For personal use only. unequivocally supported this pattern, as seen in the following quotes:

Well I’m in treatment at [name of clinic] and anyone who is familiar with [name of clinic] it’s like the one-stop shop. There’s everything there. - Care-engaged (delayed), 48, black/African American, diagnosed post-ART

[Interviewer: “What do you like about where you go now?”] One-stop shop. Everything is in there. Dental, psychiatry, primary doctor, get my medicine there, it’s cool. I have no complaints. It’s all good. - Care-engaged (delayed), 45, black/African American, diagnosed post-ART

It’s copacetic. It’s a one-stop shop. Everything you need is right there in that place. - Care-engaged (delayed), 53, black/African American, diagnosed pre-ART

I’m very happy with [name of clinic], because they have everything there, you know, the dentist, the mental health, blah blah blah, you know, all the, the pharmacy. In other clinics in DC, they don’t have these components, and sometimes it’s very difficult, like referrals too. Like right now, my doctor, two weeks ago, she make me a referral for the orthopedic. [She] made me very easy. I have difficulties with the mobility; they help me to do that. I like also the fact that everybody’s bilingual in [name of clinic], so they make facility for everybody to understand. - Care-engaged (continuous), 51, Hispanic/Latino, diagnosed pre-ART

Physician communication and empathy

In keeping with many prior healthcare studies, our respondents supported the essential role of the patient-provider relationship as fundamental to being and remaining care-engaged ($p = 0.0183$; Table 2). By definition, care-engaged men see their providers more often than care-unengaged respondents; this means care-engaged men have had more opportunities to recall patient-provider communication interactions. However, care-engaged respondents tended to be more likely to view their communication interactions favorably, as seen in the following examples:

He [his provider] understands me real well, because I am my own advocate.

[Interviewer: “Do you ever feel like your background or your race has an impact on the care that you receive or could receive?”] Uh no, I don’t think so. I think that if you have a problem with your race and the doctor’s there to see you, you got a problem with yourself because he’s there to help, you know, or she. You know, to me, I believe that if you not you’re supposed to be your own advocate because the

doctors are not psychic. - Care-engaged (continuous), 45, black/African American, diagnosed post-ART

I understand well, because she's [his provider] good with telling me what's going on. She breaks it down to laymen's terms. If I don't understand it, I'm like, "Wait, hold on doc. Let's do this one more time, explain to me what you just said," yes. We have good rapport. - Care-engaged (delayed), 48, black/African American, diagnosed post-ART

Now, I was fortunate. I was a military brat and my doctor, my private physician was with the military. He was very good. He detected early on that I was bi-curious. Early on he taught me that, you know, "You need to, if you're sexually active." He actually caught me at a party that I should not have been at. And he said, "We'll have to talk," and he was gay. And he called me. He said, "You need to come in for an appointment," and he sat me down had a long conversation. "I don't mean to get into your business, but we need to talk about how we want to treat you." So he began to tell me how to take care of myself. - Care-engaged (delayed), 51, black/African American, diagnosed post-ART

Oh, I'm really delighted with my doctor. I can see he really cares about me. He acts in, on my behalf. If I have a question, I can ask. I'm very happy. - Care-engaged (continuous), 50, Hispanic/Latino, diagnosed post-ART

You know, she's a really good doctor. I'm really thankful to have her. You know, she sits down, and she cares, genuinely cares about my well-being. She asks about how I'm doing, any vacations coming up, anything going, anything going on. [That] allows me to be comfortable with her and to then say anything that I need to say, you know, and I don't feel bad about it or I won't feel judged. - Care-engaged (delayed), 37, Hispanic/Latino, diagnosed post-ART

However, respondents who were not fully care-engaged often described poor quality patient-provider relationships.

I used to see another doctor on the Northside, but I really didn't like her. She was really like, she would like scold me. She goes, "Well, I can't deal with you no more," and she sent me over here [his current clinic]. "I'm recommending you over there." And I'm like, "What?" I was scared to go to her. That's why I used to lie to her. - Not care-engaged (inconsistent), 55, Hispanic/Latino, diagnosed pre-ART

They [the clinic staff, including providers] could treat you a little better; they could worry about you. They don't remember you. Or sometimes, when you go to the clinic, they are very like rude or they don't give you it's like you don't feel good. They have a certain kind of treatment that. [Interviewer: "Like you are one more number."] Yes. "Oh, there's another one." And it's like everything is just fast. They don't give you a certain attention, or it's they are cold people. - Not care-engaged (inconsistent), 35, Hispanic/Latino, diagnosed post-ART

Some not engaged respondents discussed incidents when their provider scolded them. Feeling scolded reinforced the respondent's low interest to seek care. For example, a 55- year-old, Hispanic/Latino diagnosed before ART became standard of care responded,

“because he [his provider] was going to scold me” when asked why he had missed four of his last five appointments.

Finally, among the Hispanic/Latino Spanish-speaking men, we examined whether they had language difficulties when they sought care. This very rarely appeared to be a barrier to patient-provider communication in our sample, because the respondent was bilingual, their medical providers spoke Spanish, or they had translators during their appointments.

Discussion

A prerequisite to successful HIV treatment is that PLWH become linked to clinical care as quickly as possible upon diagnosis (aka, a “test-to-treat” approach), and they subsequently remain in care. However, not all PLWH are linked after diagnosis, while others undergo prolonged delays before becoming care-engaged. Even among PLWH successfully linked to care, some later drop out or sporadically go in and out of care over time. Moreover, not all subpopulations of PLWH have similar care engagement experiences. Black/ African American and Hispanic/Latino MSM living with HIV often face greater challenges in achieving sustained clinical care. To improve HIV care and treatment, it is crucial to understand factors that affect successful HIV care engagement.

We identified factors related to engagement based on MSM of color’s personal reports of their own HIV care and treatment successes and challenges. A key advantage to our approach is that it allowed the men to describe—in their own words—their first-hand personal experiences. Based on the men’s statements, we saw variation in the degree to which they were care-engaged at the time of their interview, as well as a general idea of how soon they became engaged after their HIV diagnosis. Men’s personal experiences likely add to other broad structural and cultural conditions that affect clinical care and care access in communities where MSM of color reside. Some men in our study were linked to and stayed in care soon after learning their HIV test results, but some waited many months or years. Others described patterns where they go into and out of care over time. Also, a few never have been in any type of HIV clinical care. The men’s explanations regarding why they were or were not care-engaged yield useful clues on how care providers and public health personnel can better address the needs of black/African American and Hispanic/Latino MSM living with HIV. Spanish language issues did not appear to be a major barrier when our Hispanic/Latino respondents sought HIV clinical care. Although race/ethnicity was not associated with engagement in our specific sample, providers should offer services that are culturally, socially, and linguistically well tailored to meet their clients’ multiple needs.

An unexpected finding was that care-engaged men often were more likely than care unengaged men to describe explicitly how they went through previous periods of denial after diagnosis. Those care-engaged men had found ways to get past their earlier denial, and commonly explained how they developed personal resolve for managing their disease. HIV care providers should recognize that denial may be a frequent response by PLWH who recently have learned their diagnosis. During a period of denial, providers can take the opportunity to begin building trust and rapport with the patient as a foundation for encouraging future care engagement.³¹ Offering support and encouragement may help

PLWH overcome denial. Some patients in denial may find it helpful to learn that others have successfully found ways to overcome the challenge. HIV care providers need better ways to help PLWH overcome denial or other barriers to entry into sustained care.

Our findings highlight other factors that can facilitate care engagement, and hinder engagement when absent. For example, after overcoming any denial, men with treatment plans were more likely to be care-engaged. We cannot know which came first—care engagement or a treatment plan— because of the cross-sectional nature of our study design. However, PLWH should work with their providers to create personalized treatment plans as a means to promote successful medication adherence.^{46,47} Linkage to care specialists, including peer navigators, can assist PLWH navigate complex medical care systems, provide encouragement and emotional support, and help patients develop skills needed to manage their illness and remain in care over the long term.⁴⁸ Likewise, providers can promote other factors that help men become and stay engaged. These include development of strong personal resolve to stay healthy; receipt of appropriate incentives to overcome economic challenges to care seeking; appointment reminders; seamless access to a host of services; and encouraging patients to seek constructive support from friends.

Our results reinforce the importance of how HIV care services are delivered. Providers themselves recognize the key role this plays in engagement.³¹ Improvements to care delivery can be addressed through facility planning, administration, financial support, and staff selection, supervision, and training. Respondents clearly endorsed the importance of attending facilities where they felt welcome and were respected, and where staff did not negatively judge or scold them. Care-engaged men also emphasized the value of conveniently located facilities. When needed, transportation assistance helps overcome difficulties attending less convenient facilities. Our respondents unequivocally endorsed the utility of having “one-stop shop” facilities that provided additional services beyond just HIV clinical care. Some of our care-engaged respondents and many of our not engaged respondents described poor communication experiences with their providers and inconvenient care facility location as challenges; clearly, these are areas that need further improvement. Finally, our results underscore the crucial importance for PLWH to have physicians with high levels of empathy and excellent patient-provider communication skills.

Successful HIV medical care facilities should use a comprehensive model for addressing these factors, rather than merely focusing on single issues in isolation. For example, in one recent description of services at a Ryan White clinic in Pittsburgh, a multidisciplinary team of staff offers HIV and STI testing and referral; HIV medical treatment; a broad array of mental health, substance use, social work, and transportation assistance services; as well as on-site pharmaceutical services and payment and billing assistance.⁴⁹ Social workers assist new patients during intake to familiarize the patient with the clinic. Subsequently, panels comprised physicians, nurses, and social workers review on-going care and retention needs, and individualized treatment plans are created with each patient. The entire provider team consciously attempts to maximize effective patient-provider communication, build trust, foster harm reduction, and improve health literacy. Patients themselves reported that they felt welcomed, valued, and respected at this facility, which in turn encourages long-term

retention. Overall, the success of this program's comprehensive approach to HIV care has helped more than 86% of its PLWH patients becoming virally suppressed.⁴⁹

Our study has a variety of limitations. First, the purposive sampling design ensured we recruited MSM of color living with HIV from the five cities and two racial/ethnic groups. However, there are likely sampling biases; our findings should not be interpreted as reflective of all MSM of color living with HIV, or other PLWH populations. The cross-sectional nature of the study does not reveal how the men's care engagement evolves over time and relied on recalled, self-reports. The interviews occurred before there was a change in recommended ART treatment policy for PLWH; MSM diagnosed after this time may have different engagement patterns.³³ The data rely on self-report, which could not be evaluated against other sources (e.g., clinic records).

We checked to see if interviewers introduced systematic bias. In doing so, we determined that interviewer ID was not associated with care engagement, and was not associated with any of the seven themes discussed as factors related to care engagement. Interviewer ID therefore is not a confounder and cannot account for the co-occurrences in our findings.^{44,45} However, differences in the way interviewers worked may have introduced nonsystematic misclassification errors into how we coded the respondents. Vague respondents or recall difficulties may further complicate transcript quality and coding. We minimized these errors through training and transcript quality assurance reviews, and we ensured strong inter-coder reliability. When nonsystematic errors like these independently occur and affect either or both variables in cross-tabulation tables, prior methods' research shows the net effect can be to bias the magnitude of associations toward the null.^{44,45} Thus, to the extent that nonsystematic misclassification errors remained and affected our transcripts or coding for any reason, our chi-square statistics may be artificially low estimates. Stated otherwise, this means that the relationships between care engagement and any one of the seven themes—such as if the respondent has a “one-stop shop” HIV care facility—might actually be stronger than what we presented.

Taking all these considerations into account, the apparent existence of the co-occurrences between engagement and the seven themes highlighted in our analysis likely are conservative. As readily seen from the illustrative quotes, the men consciously recognize that getting beyond denial of their initial HIV diagnosis, having treatment plans that work for their personal situations, or being able to access convenient care facilities staffed by providers who communicated effectively and treated them with respect were key ingredients to helping them enter and stay in HIV clinical care. The men themselves provided personal, self-reflective statements that agree with and help validate our findings. This is an important strength, because it allowed the men candidly to explain why they were or were not utilizing HIV clinical care services. Future studies might consider how factors derived from self-reports compare with broad contextual conditions, such as community-level or structural conditions, which influence the lives and healthcare services of MSM of color living with HIV. Further progress in reducing HIV incidence in the United States must address the needs of MSM because they currently experience the majority of HIV transmissions.^{32,50} Our findings reinforce HIV treatment guidelines.^{33,51,52} Some interventions, like offering comprehensive medical homes where patients have a “one-stop shop” for receiving multiple

services, or reducing logistical barriers, are likely to be helpful for all patient populations. As our findings show, some MSM living with HIV may have particular needs. Regardless of the details, HIV care providers and facilities should offer an array of services optimally matched to meet patient needs, which in turn will help them begin and sustain effective HIV clinical care. Carefully listening to PLWH describe, in their own words, what helps or hinders managing their disease is an essential step toward improving the effectiveness of HIV prevention, care, and treatment services in the United States.

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Disclaimer:

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Table 1.

Respondent Sociodemographic Characteristics for Racial/Ethnic Men Who Have Sex with Men Who Are Living with HIV (Sample n = 84)

Characteristic	Percent (number)
City of residence	
Atlanta	28.6 (24)
Baltimore/Washington, DC	20.2 (17)
Chicago	27.4 (23)
Los Angeles	23.8 (20)
Age in years ^a	
Mean (standard deviation)	42.4 (10.3)
Race/ethnicity	
Black/African American	59.5 (50)
Hispanic/Latino	36.9 (31)
Mixed	3.6 (3)
Sexuality ^b	
Gay/homosexual	69.0 (58)
Bisexual	20.2 (17)
“Something else” or other response	10.7 (9)
Level of education	
< High school diploma	19.0 (16)
High school diploma/GED	22.6 (19)
Some college	38.1 (32)
College graduate	20.2 (17)
Health coverage	
No coverage	23.8 (20)
Partial coverage, for example, ADAP/Ryan White	17.9 (15)
Full coverage, for example, Medicaid, Medicare, private insurance	58.3 (49)
HIV diagnosis pre- or post-ART availability	
1980–1996	32.1 (27)
1997–2014	66.7 (56)
Unknown	1.2 (1)
HIV care-engaged at time of the interview	
Yes	61.9 (52)
No	38.1 (32)

Percent totals may not equal 100% due to rounding.

^a n = 80 for Age.

^b Screened eligibility criteria included having had sex with another man in the prior 6 months.

ADAP, AIDS Drug Assistance Program; ART, antiretroviral therapy.

Table 2. Interview Response Themes Associated with Care Engagement at the Time of the Interview (Sample n = 84)

Themes coded in interview transcripts	Percent engaged (n = 52)	Percent not engaged (n = 32)	Chi-square value (df = 1)	p
In denial after learning HIV diagnosis	32.7	12.5	4.31	0.0379
Describes having HIV treatment plan	42.3	12.5	8.24	0.0041
Describes facilitators to staying in HIV care and treatment	78.8	53.1	6.11	0.0133
Describes favorable aspects of their HIV care or care facilities	82.7	59.4	5.57	0.0183
Mentions convenient location of their HIV care facility	21.2	3.1	5.26	0.0218
Has “one-stop shop” care facility that provides all key services on site	50.0	12.5	12.13	0.0005
Describes communication issues with their physician	82.7	59.4	5.57	0.0183