

“I Don’t Feel Judged, I Don’t Feel Less of a Person” - Engaged and Supportive Providers in the HIV Care Experiences of Black Sexual Minority Men Living with HIV

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Background: Black sexual minority men (BSMM) in the Southern region of the United States experience a disproportionate burden of HIV. Research findings suggest that having supportive patient-provider relationships are critical for sustained HIV care engagement. The present study explores the role of supportive healthcare providers in the care engagement among BSMM living with HIV (BSMM+) in the US South.

Methods: Semi-structured qualitative interviews were conducted with BSMM+ in Texas (n=27) to explore perceived barriers and facilitators of sustained care engagement. Interviews lasted 60 minutes on average, were transcribed, coded, and analyzed using applied thematic analysis.

Findings: Participants described how important having relationships with engaged and supportive HIV care and service providers is to sustained engagement in care and positive HIV clinical outcomes. Supportive providers were characterized as non-judgmental, meeting patients’ needs, and making patients feel “seen”. Less supportive providers were described as making their patients “feel like a number” and having lack of follow through on proposed support and resources. Supportive providers were associated with increased care engagement of their patients while less supportive providers often led to patients switching providers, losing touch with services, and getting off track with their care.

Discussion: We found that among BSMM+ an important facilitator of sustained care engagement was having positive, affirming, and knowledgeable healthcare providers, while negative and dismissive experiences with providers was a notable barrier to care engagement. This work highlights the need for a scale up of comprehensive, ongoing trainings in patient-centered and person-first communication for providers. Further, manageable provider caseloads can facilitate more thorough patient interactions where tailored HIV care and education can be provided in a safe and non-judgmental environment.

Plain Language Summary:

- Black sexual minority men in the Southern region of the United States experience a disproportionate burden of HIV. While the role of patient-provider relationships for HIV care engagement has been shown in some contexts, less is known about the specific role of supportive healthcare providers in the care engagement among Black sexual minority men living with HIV in the United States South.
- Semi-structured qualitative interviews were conducted among Black sexual minority men living with HIV in Texas (n=27) to explore perceived barriers and facilitators of sustained care engagement.
- We found that supportive providers were associated with increased care engagement of their patients while less supportive providers often led to patients switching providers, losing touch with services, and getting off track with their care. Our findings suggest the need for a scale up of comprehensive, ongoing trainings in patient-centered and person-first communication for providers.

Keywords: HIV, black sexual minority men, care engagement, patient-provider relationship

Introduction

In 2021, Black sexual minority men (BSMM) had the highest rate of new HIV diagnoses in the United States (US), and in the South specifically, the region of the US with the highest number of people living with HIV.¹ Among BSMM living with HIV (BSMM+), only an estimated 62% are virally suppressed, and only 48% report being adherent to antiretroviral treatment (ART) during the past 30 days.² HIV clinical outcomes among BSMM+ are, in part, driven by psychosocial (eg, mental health, substance use) and structural (eg, unemployment, housing insecurity) syndemic factors.^{3,4} In the US South, complex structural factors, including racial segregation and inequality, poverty, and HIV-related stigma, as well as laws and social practices that further HIV-related stigma, contribute to the disproportionate HIV incidence and suboptimal clinical outcomes.^{5–9}

For people living with HIV (PLWH), supportive patient-provider relationships are associated with patient outcomes like higher adherence, greater self-efficacy, increased care engagement, increased self-esteem, and better quality of life.^{10–12} Supportive patient-provider relationships have proven effective in many contexts. For example, among youth of all genders who are living with HIV, having a case manager who is a consistent presence helps them stay connected to care.¹³ Such supportive relationships with providers have also proven critical for men living with HIV who are incarcerated or those engaged in substance use, with intensive case management being shown to enhance access to both medical and social support services and help prevent substance relapse.¹⁴ The patient-provider relationship, when viewed negatively by the patient, is associated with poor health outcomes. A study among women in Kenya found that even a single negative patient-provider experience was associated with immediate disengagement in care.¹⁰

Although the power of patient-provider relationships has been well established in the literature in many contexts, much less is known about the effectiveness of supportive patient-provider relationships for BSMM+. The small amount of evidence we have to date indicates that patient-provider relationship could play an important role for BSMM+. For example, a recent study in Maryland described how, for BSMM+, a positive patient-provider interaction can be a facilitator of care engagement, while having low rapport with providers who engage in unprofessional behavior can be a barrier to care.¹⁵ Importantly, the authors note that some structural facilitators, such as having co-located services with medical care can overcome less than positive patient clinician relationships. Additionally, two studies with BSMM in the South, one focused on PrEP uptake in Atlanta, Georgia, and one exploring socio-ecological influences on HIV care engagement among BSMM+ in Kentucky, identified provider support as an important factor shaping PrEP use and HIV care.^{16,17} Each of these qualitative studies offer insights into the experiences of BSMM and BSMM+. However, given the complex interactions between cultural and structural factors in the US South, including stigma and discrimination that BSMM+ experience from clinicians and others in the healthcare system, it is important to further elucidate patient-provider interactions to identify, specifically, how relationships with care providers serve to promote positive or negative health outcomes among the most disproportionately affected communities.

Medication adherence is incredibly important for PLWH. When taken as prescribed, ART reduces one's viral load, which leads to better health outcomes and can prevent the onset of AIDS.¹⁸ Further, PLWH who achieve and maintain viral suppression do not transmit HIV to a sexual partner.^{19–21} Both preventing new HIV infections and increasing the rates of viral suppression among those with HIV are enormously important to the global health agenda and are two of the United Nation's Sustainable Development Goals (SDGs), which aim to transform the world by ensuring all people enjoy health, justice, and prosperity.²² The HIV-related goals work toward SDG3, to ensure healthy lives, which includes a specific promise to end AIDS by 2030.²² The United States has an "End the HIV Epidemic" initiative, which includes 4 pillars, one of them being, "treat HIV infection rapidly and effectively to achieve sustained viral suppression", emphasizing the importance of this field.²³

There is currently a lack of research focusing specifically on factors related to the patient-provider relationship and the impact of those factors on HIV care engagement among BSMM+ in the Southern US. The present study begins to fill this gap by exploring the role of HIV care and service providers in sustained care engagement, from the perspectives of BSMM+.

Methods

Study Design and Recruitment

Participants were recruited from a community-based, longitudinal cohort study of BSMM+ in the US South. Participants in the parent cohort were recruited using long-chain referral methods in Dallas and Houston, TX between 2015–2016.^{24–26} An initial group of “seed” participants were identified and asked to recruit BSMM+ in their social networks; most participants were recruited this way. In addition, flyers, social media, and recruitment at venues was used to recruit participants. Eligible participants were assigned male at birth, Black/African American, residents of the Houston or Dallas Metropolitan Areas, and HIV-positive, confirmed by serostatus testing. Additional details of recruitment and study methods of the parent study are reported elsewhere in greater detail.²⁴

Data Collection

Interviews were conducted with a subsample of participants from the fourth wave of quantitative survey collection, administered in 2022. Participants were purposively sampled to include: those who reported less than optimal care engagement or medication adherence, such as those who had a detectable or unknown viral load, reported missing doses of ART in the past 12 months, or who were not currently taking ART; or who reported having experienced intimate partner violence (IPV), or high levels of substance use. A member of the study team sent an invitation to participate in the qualitative interview. In line with a reflexive thematic approach, we did not use the concept of saturation to determine sample size.²⁷ Instead we discontinued data collection at 27, once we felt we had reached appropriate “information power”, a process through which the researcher determines that the data are sufficient for the intended analysis.²⁸ All interviews began with obtaining informed consent, which included publication of anonymized responses. One research team member (CKC, who selfidentifies as a Black gay man) conducted all interviews in English via Zoom from June 2022 to August 2023. Interview domains included the participants’ experiences with their HIV diagnosis, barriers and facilitators to HIV care, the effects of COVID-19 on their lives and the continuum of care, substance use, HIV stigma, and experiences with IPV ([supplementary materials](#)). Interviewees were compensated \$75 for their time. The Institutional Review Board at San Diego State University approved all study procedures.

Data Analysis

Three members of the team (CKC, HER, KK) conducted all qualitative analyses using a codebook thematic analysis approach.^{29,30} Interviews were audio recorded and transcribed verbatim. The qualitative analysts read all interviews to audit and de-identify the data. Paradigmatically, codebook thematic analysis falls between positivist and constructionist approaches, and allows flexibility while eliciting rich and detailed data.³¹ The analysts first read each of the transcripts to become deeply familiar with the data, while taking notes on salient narratives and potential codes (ie, memoing). The team independently conducted open coding on one transcript, then discussed to identify coding agreement among the team, reconcile differences, and develop an initial codebook. This process was repeated with two additional transcripts, resolving coding disagreements, and making needed edits before a final codebook was agreed upon. The analysts then independently coded all transcripts using Dedoose Version 9.0.86 (Los Angeles, CA: SocioCultural Research Consultants, LLC; www.dedoose.com). In line with codebook thematic analysis, the analysts met biweekly to discuss the process and to modify the codebook, as needed, throughout the coding process.^{32,33} Decision trails were maintained throughout the analysis process in order to track codebook development and revisions, as well as team discussions. For the current analysis, the first author extracted text segments labeled with the following codes: “HIV care”, “provider types”, “care experiences”, “care engagement”, “barriers to care”, “access”, “living with HIV”, and “diagnosis experience”, then analyzed those data to construct themes regarding participant experiences with their care providers.

Results

Among the 27 participants in the study, the average age was 30.8 years old (med: 31, range: 26–35), and the majority (78%) identified as gay or same gender-loving, while 22% identified as bisexual ([Table 1](#)). Employment status among participants was varied with 44% being employed full time, 15% employed part time, and 41% unemployed. Approximately half (52%)

Table 1 Participant Demographics

Age			Insurance Status		
Mean	30.81		Yes	19	70%
Median	31		No	7	26%
Range	26–35		Unknown	1	4%
Time Since HIV Diagnosis (Years)			Employment		
Mean	10.85		Full Time	12	44%
Median	10		Part-Time	4	15%
Range	6–17		Unemployed	11	41%
	n	%	HIV Viral Load		
Education			Undetectable	21	78%
High school diploma or GED	7	26%	Detectable	5	19%
Some college, Associate's degree	14	52%	Do not Know	1	4%
Bachelor's degree	4	15%	Currently On Art?		
Any graduate studies	2	7%	Yes	23	85%
Sexual Identity			No	4	15%
Gay	21	78%	On ART for past 60 days	22	81%
Bisexual	6	22%	# Of Days Missed Art Dose - Past 60 Days*		
Gender Identity			Never	6	22%
Man	27	100%	Less than once a week	4	15%
Income			Once a week	2	7%
Less than \$10,000	6	22%	2–3 days a week	6	22%
\$10,000 –19,999	4	15%	4–6 days a week	1	4%
\$20,000–39,999	6	22%	Every day	3	11%
\$40,000–59,999	6	22%	Missed ART 7 Or More Consecutive Days in the Past 12 months?*		
\$60,000–79,999	2	7%	Yes	6	26%
Decline to Answer	1	4%	No	17	74%
Do not know	2	7%			

Notes: *Of those on ART for past 60 days (n=22). **Of those currently on ART (n=23).

of participants reported “some college/technical degree”, while roughly a quarter (26%) reported earning a GED/high school education, 15% a bachelor’s degree, and 7% having completed some graduate studies.

The average interview time was 54 (range: 30–75) minutes. Throughout the interviews, most participants at some point discussed their relationships and interactions with medical and non-medical providers. In the results that follow, we discuss participants’ narratives, organized into four primary themes: 1) Describing Supportive Providers, 2) Impacts of Supportive Providers on Healthcare Engagement, 3) Describing Less-Supportive Providers, and 4) Impacts of Less-Supportive Providers on Healthcare Engagement. Each quote is followed by a pseudonym and participant age.

Describing Supportive Providers

Providers’ explanations of HIV have lasting and important impacts on their patients, encouraging their acknowledgment of a seropositive status and readiness to engage in treatment, and impacting their self-esteem. Some participants specifically recalled providers explaining what it means to have HIV and the emotional support they felt. As Brandon described:

I only been to two facilities, but the two health facilities that I've been to, have been great. I don't feel judged, I don't feel less of a person, and especially now, the provider that I have now, she's wonderful. She instills in me that I'm fine. Like I'm a good person. There's nothing wrong with me, I'm going to be fine, and so, I love it. (Brandon, 29)

For Brandon, his provider was able to help him to maintain a positive self-image and a positive outlook on his life. Darius shared about the most recent doctor he had:

My relationship with my doctor, it was amazing. It was cool. She always understood me, and she taught me how to laugh and joke some things off to show it's not as serious as it seems. These things that we're dealing with are just words with weight. It's like the word HIV, it just sounds really strong. Or depression, it's just a weighted word. But if we start to eat better, find better relationships, we can get through it. And I made it through it. (Darius, 32)

Similar to Darius, others described wanting to be "understood" by their providers, with participants indicating that when they felt understood, they did not feel so alone or overwhelmed, which helped them through difficult times and processes.

Some participants expressed a desire to have one single provider who is more familiar with their lives both inside and outside of the clinical setting – a more holistic approach – and that can help them with all their clinical needs. Wes described that he needs "somebody who knows what's going on with me. Because having to start with a whole new doctor, they have to learn you, learn everything". (Wes, 30) Similarly, Aaron noted, "I want to go to one person, and get everything I want from that one person". (Aaron, 26) For many, HIV care and the experience of living with HIV touches, and is touched by, many aspects of life, so having one provider who really knows and understands them improves their experience.

Other participants described feeling cared for by staff and providers that were committed to meeting their needs. As Mason described,

I think the attitude of showing that you actually care about this person, this new patient coming in, giving a patient basically a home without a home when they go and handle their business and stuff like that because everywhere I went, I've met people that just love what they're doing. Some of these girls that work in the clinic, they make less, and they still come there. They just say they love to see people get help. If we have more people like that, that makes it feel a lot better. (Mason, 31)

Patients also described how some providers were persistent in making sure they were cared for. Jesse described that, "my doctor, oh, man, my doctor stays on my tail. Let me tell you. He will call me personally, if he needs to". (Jesse, 38) The most persistent of providers kept patients engaged by checking in on them often, working their hardest to not let their patients fall out of care. This persistent outreach from providers was favorably received by interviewees and left them feeling valued and supported.

Impact of Supportive Providers on Healthcare Engagement

Importantly, the supportive care described above was important to participants' sustained engagement in care. Paul was going through a particularly difficult emotional time in his life and felt that "relocating probably would help a lot, but the only thing about it is, I wouldn't want to change my doctors". (Paul, 26) For him, moving out of his current environment may have been helpful in improving his mental health. However, his concerns about disrupting his relationship with his providers left him hesitant to relocate.

Many of the participants who described their care as being comprehensive and accessible also shared that they take their HIV medication consistently and did not have as many challenges relating to their HIV care. Many of the interviewees indicated that those positive interactions with supportive providers impacted their willingness and eagerness to go to appointments and stay engaged in their care. One participant claimed:

Back in the day, if I didn't take one [HIV pill], I just stopped. And then I would fall out of care with my organization where I get care from. And then go back, and then stop, and then go back, and stop. But now, I love my doctors and nurses at my clinic that I go to. They're very helpful, and the case managers as well. They're pretty awesome people. (Chris, 33)

Chris' experience illustrates how positive interactions with providers can have a direct, positive influence on one's own personal care engagement.

Describing Less Supportive Providers

Participants described how case workers, doctors, or offices with large numbers of patients made them feel more like a number than a person. One participant described such experiences in a system in a dehumanizing way:

I had went through [a local community health] system. Their system, I do not... I did not like it at all. I felt like a cow, standing in the line with other cows, being ready to be cut up. But the only thing is, it takes a million years for you to get cut up because it just takes that long to see a doctor, or this, or this, or that. (Chris, 33)

Other participants who had experiences in systems with both manageable and unmanageable caseloads were able to explicitly describe the differences between those experiences:

When I was getting private care, I would say the load on the doctor was a little less. So, I don't know. Just, the network was smaller, so I prefer probably a smaller network. Didn't have to be in a big network with so many people and you're just pretty much a number. (Gerald, 32)

Other participants shared frustration with providers who would discuss additional services (eg, housing, medical treatments) though there was no follow through on supporting the participant to obtain these services:

There's programs that she could sign me up for that she don't want to sign— I don't know what she's doing, but she's supposed to sign me up for the housing program. Because they have houses everywhere. But you're [the provider] supposed to sign us up for the one in Dallas, and you don't want to do it. (Jason, 35)

This participant described his case worker as not following through on connecting him to resources, reflecting the experiences of a number of other participants who described feeling like they were not being cared for when there was a lack of provider follow through for their services.

Some described the difference between providers who took a more active role in completing referrals or connections to other services, versus providers who only documented the need. For example, Stephen shared:

The last doctor helped me with my eye appointment in no time. This one, she's still talking about there's a waiting list for dental. She keeps just saying, "I keep marking it. I keep marking it". She'll be like, "Nobody called you yet?" And I'm just like, "No, nobody called me". She just says, "It's in the chart. I wrote it in the charts". But I feel like my last doctor would be like, "Okay, let me see. Let me call". If she was like that, more – but maybe that's the bond or something. That's what I'm still trying to understand. (Stephen, 31)

Stephen was able to clearly articulate a common narrative expressed in our interviews by offering a clear example of what an engaged provider, compared to a less engaged provider, looked like to him. Poor communication from providers was also perceived as a reflection of how much a provider cared about the individual. Aaron learned from his case manager that his HIV diagnosis had progressed to AIDS, instead of learning it from his doctor. He wondered, "as a provider, are you not caring about my health enough to tell me that? Or did you assume that I knew? So that kind of hurt me". (Aaron, 26) Having his doctor not communicate this important information to him made him feel "hurt" and less cared for by his doctor.

Impacts of Less-Supportive Providers on Healthcare Engagement

Some participants described how negative experiences led them to switch doctors. One participant shared, "I ended up switching my doctors because I noticed that my doctor that I had previously, he wasn't really caring for all the needs that I had". (Jamar, 26) Similarly, Phillip described that "they switched up my doctor because the one doctor I was going to, she wasn't trying to hear shit I was trying to say". (Phillip, 35) In these quotes participants cite specific characteristics of a less supportive provider as the reasons they changed providers. The changes in doctors were often explained as long processes which sometimes involved interruptions in patients' care. The impacts of less-supportive providers were also mentioned when it came to the large caseloads with one participant saying:

I told you my experience with my first social worker where it was very, like, one on one and she was really there for me – moving from that experience, moving out to Dallas, it was, like, you're one of a thousand and, like, I just lost touch with services at that point in time. (Jamal, 35)

Participants were very explicit in telling us that they switched providers or fell out of care because they did not “feel seen” or “felt like a number”, drawing direct associations between engagement levels of providers and patient’s own level of care continuum engagement.

Discussion

Overwhelmingly, participant narratives indicated the vital role of engaged and supportive providers to their sustained engagement in HIV care. Supportive patient-provider interactions were described as non-judgmental, making patients feel cared for, and having a strong patient-provider bond. These experiences helped participants cope with their diagnosis, improve their outlook, maintain a positive sense of self-worth, and increase their desire to stay engaged with care. Less supportive patient-provider interactions were characterized by providers who had poor communication, large caseloads, and inconsistent follow through in referring them to additional services for health-related needs. In these cases, participants described wanting to change providers because they felt a lack of care and investment. These descriptions of supportive and less-supportive providers are in line with other research emphasizing the importance of trust and nonjudgmental communication in patient-provider relationships.³⁴

This study contributes important insights regarding the pivotal role of providers in influencing BSMM+ care outcomes. Recently, a quantitative analysis in the South highlighted the importance of promoting affirming environments for BSMM,³⁵ and a qualitative study in Baltimore and Los Angeles described how supportive clinical relationships could be key to improving treatment adherence and viral suppression among BSMM+.³⁶ Given that the highest incidence of AIDS diagnoses and deaths are in the South,³⁷ increasing supportive care for BSMM is particularly important to reduce new infections and improve HIV clinical outcomes. The present study findings are supported by previous research which described supportive patient-provider interactions as being comprehensive, a “one stop shop” HIV care, having effective communication, and reducing stigma by providing patients with a non-judgmental environment.^{38,39}

Recommendations for Policies and Programs

The present study emphasizes the importance of both medical and non-medical provider relationships as a determinant of HIV outcomes. Our findings can inform efforts at the institutional level to improve engagement in care among those groups most impacted by the HIV epidemic. The Centers for Disease Control and Prevention (CDC) recommends that HIV providers engage in communication styles that do not stigmatize people living with HIV.⁴⁰ Related key activities include a scale up of comprehensive, ongoing trainings in patient-centered and person-first communication. The CDC also encourages providers to participate in comprehensive networks and collaborate with community organizations in order to adequately provide comprehensive HIV services. The importance of comprehensive care as recommended by the CDC is supported by the present study. They also suggest that medical providers discuss possible facilitators and barriers to HIV care with patients.⁴⁰ To supplement medical provider interactions the expansion of patient-navigation services are also warranted.

The World Health Organization (WHO) has their five C’s for HIV care, which are principles that apply to HIV services in all settings. One “C” stands for connection. This is based on the idea that providers should assist in patient linkage to care; it also claims the importance of provider interactions being positive to increase care engagement.⁴¹ This is consistent with our findings that supportive care requires that providers be very engaged with their patients. This means that providers need to be persistent and make each encounter with patients positive and thorough in order to keep them connected to care.

Importantly, providers also face structural barriers, some of which are the same barriers affecting patients. It has been well-documented that HIV care providers face inequitable burdens of stress and burnout with factors such as discrimination, overwork, complexity of cases, and increased stress from COVID-19 each playing a role.^{42,43} As HIV focused organizations often hire BSMM to connect with their communities, a study found that many of the workers faced similar challenges relating to discrimination and socioeconomic status as their patients, but that workers ultimately sacrificed

their own well-being for their communities, contributing to burnout.⁴⁴ Other studies have documented the lack of guidance on how to adapt recommended interventions into specific contexts to be another challenging barrier for organizations.⁴⁵ With these notable structural barriers for HIV organizations and providers, we recommend structural changes such as policies in which the HIV epidemic is prioritized in a non-stigmatizing manner⁴⁶ and CDC-recommended approaches to mitigating provider burnout.⁴⁷

Strengths and Limitations

Our study has limitations worth noting. First, this qualitative sample included BSMM+ in two large metropolitan areas in the South, each of which has large populations of Black/African Americans and LGBT-identified persons and are relatively liberal politically and socially compared to the rest of Texas. Thus, these results should be understood in that context and may not be generalizable to other demographic groups or in other geographic regions. However, the study also had notable strengths. First, our findings are consistent with research of other populations and makes a substantial contribution to the existing knowledge base around patient-provider relationships and HIV outcomes. Second, the initial study, from which we recruited this sample, was community-based, not clinic-based. Hence, this study involved men who were obtaining care at a variety of healthcare organizations (or not seeking care at all). Third, we purposively sampled men for interview invitations based on survey responses indicating less than optimal care engagement (eg, missed appointments, lower reported adherence). Further, more than a third reported less than \$20,000 in yearly income, less than half had full-time employment, and 30% did not have health insurance (Texas has not adopted the Affordable Care Act and has not expanded Medicaid to cover low-income people). Thus, patient-provider relationships and their impact on care engagement may differ among men who are already optimally engaged in care and among those who are more economically advantaged.

Conclusion

In this qualitative study of BSMM+ in the Southern US, positive provider relationships and interactions were associated with sustained patient care engagement. These findings highlight the importance of a competent, adequately resourced HIV care provider workforce that can provide engaged and person-centered care. Interventions are needed to support and improve BSMM+ HIV outcomes, including more providers to help thin the caseloads, patient navigators who work closely with both patients and medical providers, and comprehensive stigma trainings for HIV providers.

Data Sharing Statement

The data by which these findings are supported can be requested from the corresponding author. The investigators will meet to review and respond to each request. The data are not publicly available due to concerns about participant privacy around some of the most sensitive domains of the interviews.

Ethics Approval and Informed Consent

The study was conducted according to the guidelines of the Declaration of Helsinki, and approved by the Institutional Review Board of San Diego State University (protocol number HS-2021-0114; approval date: 01/05/2022). Informed consent was obtained from all participants in this study.

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