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Socio-Ecological Influences on HIV Care Engagement: Perspectives of Young Black Men Who Have Sex with Men Living with HIV in the Southern US

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Abstract

Young Black men who have sex with men (MSM) living with HIV evidence the lowest rates of linkage to care and viral suppression of all US MSM. Kentucky, identified by the US Department of Health and Human Services as a “hot spot” state with elevated HIV incidence compared to the rest of the country, exhibits similar racialized outcomes. Structural, interpersonal, and individual drivers of engagement along the HIV care continuum among people living with HIV have been identified, primarily through quantitative designs. However, the mechanisms by which these factors shape HIV care engagement, and the ways they may combine or reinforce each other, as well as from the lived experience of young Black MSM living with HIV, have been studied to a lesser extent. In this study, a purposive sample of $n = 29$ HIV-positive young Black MSM (age $M = 25$ years old; 38% retained in care) residing in Kentucky participated in in-depth interviews. Factors that were most influential on engagement varied along the continuum, with health insurance status and knowledge of HIV being relatively more influential to diagnosis, and housing stability, psychological processes, and interpersonal relationships being more influential on retention. For some participants, barriers to care at multiple levels had a mutually influencing and intensifying impact on care engagement. Additional efforts to center the voices of young Black MSM living with HIV will help illuminate acceptable and sustainable interventions for increasing their care engagement and narrowing persistent racial disparities in HIV morbidity and mortality.

Keywords HIV care engagement · Young Black MSM · Structural · Social support · Mental health

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Introduction

Young Black men who have sex with men (MSM) in the United States (US) ages 18 to 29 evidence disparities in engagement along the HIV care continuum, including diagnosis, linkage to care, retention, and viral suppression [1]. The southern region of the USA is the region with the highest death rate among people living with HIV [2]. In the state of the Kentucky, in the Southern US, even though only 9% of Kentucky’s population is Black, 30% of new HIV cases in 2019 were among Black residents, with Black men being diagnosed at 4.9 times the rates of White men [3]. Among all Kentucky residents diagnosed with HIV, 35% are between the ages 20 and 29 [3]. According to the 2021 Kentucky HIV Continuum of Care Report, among those diagnosed with HIV, 50% of White individuals compared to 42% of Black individuals living with HIV were retained in care, and 57% of White individuals compared to 48% of Black individuals were virally suppressed [4]. Kentucky is also identified

as an HIV “hot-spot” according to the national Ending the HIV Epidemic in the U.S. initiative [5]. Understanding the complex causes of these disparities is critical if efforts to mitigate them are to be effective.

A socio-ecological framework for health outcomes, including HIV-related behaviors, categorizes influences on health conditions based on the societal level at which they exist, including at the structural level (e.g., patient-provider relationship, housing, poverty); community and interpersonal level (e.g., interpersonal relationships, social support); and individual level (e.g., mental health, coping) [6, 7]. Some structural, interpersonal, and individual correlates and predictors of HIV-related behaviors among young Black MSM have been identified, with socio-economic status, stigma, insurance status, and social support having been examined most often [8, 9]. Relatively less focus has been placed on other risk and resilience factors (e.g., positive individual-level factors), and HIV care engagement behaviors specifically as outcomes, or on the ways the effects of such factors, when combined, may reinforce or help counteract the influence of each other on HIV care engagement among young Black MSM.

Structural variables, including food insecurity, financial and housing instability, and negative interactions with healthcare providers, have been linked to lower care engagement among people living with HIV [10]. Lack of stable housing and having no income are associated with lower antiretroviral therapy (ART) adherence and viral suppression among people living with HIV, regardless of sexual orientation, race, or ethnicity [11, 12]. Structural predictors of engagement along the HIV care continuum have been underexplored among young Black MSM compared to other groups. However, positive interactions with healthcare providers, particularly provider behaviors that communicate respect for their patients, are associated with greater ART adherence among Black and Latino MSM [13]. Besides HIV care engagement, distrust in providers and homophobia experienced in healthcare settings, as well as racial discrimination experienced in general, were found to be linked to less HIV testing and greater sexual risk taking in a quantitative study with a large sample of HIV-negative Black and Latino MSM [14].

The influence of interpersonal relationships, particularly social support, increases engagement in care. Having others in one’s life who encourage ART adherence is associated with better adherence among Black and Latino MSM [13]. On the other hand, being in a romantic relationship is inconsistently linked with engagement along the HIV care continuum [15, 16]. Finally, a study using logistic regression to predict likelihood of viral suppression among 92 young Black MSM living with HIV found that higher levels of enacted HIV-related stigma in interpersonal relationships,

such as rejection, were associated with a lower likelihood of being virally suppressed [17].

At the individual level, psychological and psychological processes are linked to lower engagement in HIV care. Mental health symptoms, including depression and anxiety, are associated with lowered retention in care and ART adherence in people living with HIV [18], and have been identified by Black MSM living with HIV as a major concern [19]. Stigma operating at the individual level also affects HIV care engagement. Anticipated stigma, or fear of being rejected due to one’s serostatus, and internalized stigma, or internalization of negative societal attitudes related to one’s stigmatized identity, are barriers to HIV testing, medication adherence, and viral suppression [20, 21]. Resilience factors at the individual level are also beginning to be identified. Beliefs about the benefits of HIV care have been reported by Black MSM as motivators for getting linked to care and ART adherence [21].

Current Study

Overall, systemic, interpersonal, and individual influences on HIV care engagement among people living with HIV have been documented, with varying levels of examination among young Black MSM specifically. However, few studies have examined concurrently multiple socio-ecological influences, at the structural, interpersonal, and individual levels, on engagement along the HIV care continuum among young Black MSM living with HIV in the Southern US, or ways that those influences may amplify, lead to, or help mitigate the effects of each other. Even fewer have examined these multiple drivers from the perspectives of young Black MSM living with HIV. Therefore, this study examined views of structural, interpersonal, and individual facilitators and barriers at points along the HIV care continuum, diagnosis, linkage to care, and retention in care, as well as re-engagement in care, among young Black MSM living with HIV in the southern state of Kentucky. In-depth interviews were employed as they can help contextualize, illustrate, and explain participants’ experiences of a particular phenomenon [22], in this case influences on engagement in HIV care.

Materials and Methods

Sampling

Individual interviews were conducted from December 2019 to June 2021 with $n = 29$ participants in the state of Kentucky, predominantly from urban and suburban areas. Inclusion criteria included (a) between the ages of 18 and 29, (b) identify as Black, (c) identify as a cisgender male, (d) have had sex with another male in the past 12 months, and (e)

diagnosed with HIV. Purposive sampling was conducted to reflect different lengths of time living with the diagnosis and different levels of engagement as defined by the US Centers for Disease Control and Prevention [23]. Participants who had been diagnosed within the past 12 months were categorized as newly diagnosed. Participants who had been diagnosed with HIV for more than 12 months and at some point did not engage in a stage of the HIV care continuum were categorized as sub-optimally engaged. Finally, participants who had been diagnosed with HIV for more than 12 months and reported consistently attending at least two doctor's appointments per year were categorized as retained.

Recruitment

A variety of recruitment strategies were utilized consistent with the purposive sampling framework. Participants were recruited from infectious disease clinics, AIDS Service Organizations (ASO), community events (e.g., "Vogue" nights, drag shows), and social media outlets (e.g., Facebook, Craigslist, Jack'd). From December 2019 to March 2020, study recruitment occurred predominantly in-person. The research team paused participant enrollment from March 2020 (the onset of state-wide COVID-related shelter in place policies) through May 2020 to establish and receive IRB permission for additional virtual recruitment, informed consent, and data collection procedures. A research team member conducted screening to determine eligibility, based on the inclusion criteria and ability to participate in a semi-structured interview in English, and monitor distribution across the purposive categories. All enrolling individuals signed a combined informed consent and HIPAA authorization for research form, either in-person or virtually, through RedCap electronic signature technology. The University of Louisville Institutional Review Board provided approval and oversight of the study.

Data Collection

Trained qualitative interviewers (ESH, CA, RM) collected the data through semi-structured individual interviews. Participants were interviewed in-person prior to the COVID-19 stay at home orders and then subsequently primarily through a secure video-conferencing platform (i.e., Microsoft Teams). The interview guide consisted of questions related to the participants' experience learning about their HIV diagnosis and facilitators and barriers to engagement in care throughout the time they had lived with HIV. Interviews lasted between 60 and 90 min. Demographic characteristics were collected via a self-report questionnaire. At the end of the interview, participants were provided a list of social service resources. Prior to the COVID-19 shelter-in-place orders, participants received

\$40 as compensation for their time. After the shelter-in-place orders, given the additional demands on participants, such as needing to use video-conferencing and electronic signature software that may have been unfamiliar, building rapport and trust with the interviewer virtually, and finding a private place to engage in the interview, the compensation for each interview was increased to \$75. IRB approval was sought and obtained prior to implementing the increased compensation amount. Subsequent to the interview, the medical clinic of each participant was contacted and provided the signed HIPAA research authorization form to collect the most recent CD4 count and viral load results for each participant.

Data Analysis

A professional transcription company transcribed the interviews verbatim, and data were analyzed using framework analysis [24]. Framework analysis allows for the organization and categorization of qualitative data related to a well-defined topic using pre-determined concepts but also allows for researchers to identify and document inductive themes as they emerge. The analysis was guided by socio-ecological theory [6] and the HIV care continuum. Five researchers (ESH, RC, EA, CA, RM) read a subset of transcripts and developed a framework of key issues and themes. This framework was applied to an additional set of three transcripts and then iteratively refined through rounds of team-based coding and discussion of additional transcripts. The final set of themes and full dataset were entered into Dedoose [25], a cloud-based platform for team-based qualitative analysis. All transcripts were coded by two members of the analysis team (ESH, CA, RM), with one coder assigned as primary coder and a secondary coder reviewing code applications. Any coding discrepancies were resolved via discussion at regular analytic team meetings. A priori thematic saturation, in which data is collected to exemplify theory [26], was met; all 29 participants discussed facilitators and barriers at individual, interpersonal, and structural levels, and the number of participants discussing sub-themes or codes (e.g., housing, mental distress) varied from 10 to 29.

Results

The mean age of study participants was 25.24 (SD = 3.02), with participant age ranging from 18 to 29 years. Participants are identified as gay ($n = 20$), bisexual ($n = 6$), pansexual ($n = 1$), and disliking labels ($n = 2$). Other sample demographic information can be found in Table 1.

Table 1 Demographic characteristics of participants (N=29)

	M (SD) or n (%)	Range
Age	25.24 (3.02)	18–29
Sexual identity		
Gay	20 (69.0%)	
Bisexual	6 (20.7%)	
Pansexual	1 (3.4%)	
Dislike labels	2 (6.9%)	
Living situation		
Own home or apartment (alone or with roommate)	10 (34.5%)	
Parent’s home or apartment	9 (31.0%)	
Another family member’s home or apartment	5 (17.2%)	
Couch-surfing	3 (10.3%)	
Shelter	2 (6.9%)	
Education		
Less than high school	1 (3.4%)	
High school degree	8 (27.6%)	
Some college	16 (55.2%)	
College degree	3 (10.3%)	
Graduate degree	1 (3.4%)	
Employment		
Full-time	13 (44.8%)	
Part-time	6 (20.7%)	
Not employed	10 (34.5%)	
Level of HIV care engagement		
Newly diagnosed	9 (31%)	
Sub-optimally engaged	9 (31%)	
Retained	11 (37.9%)	
Virally suppressed at interview	24 (82.7%)	

Socio-Ecological Influences on HIV Care Engagement

Different combinations of structural, interpersonal, and individual factors impacted engagement across the HIV care continuum (see Fig. 1).

Diagnosis

Ten participants were diagnosed due to experiencing HIV-related symptoms, such as night sweats, swollen lymph nodes, and chronic fatigue. An additional 9 participants learned their HIV status through routine testing. Participants

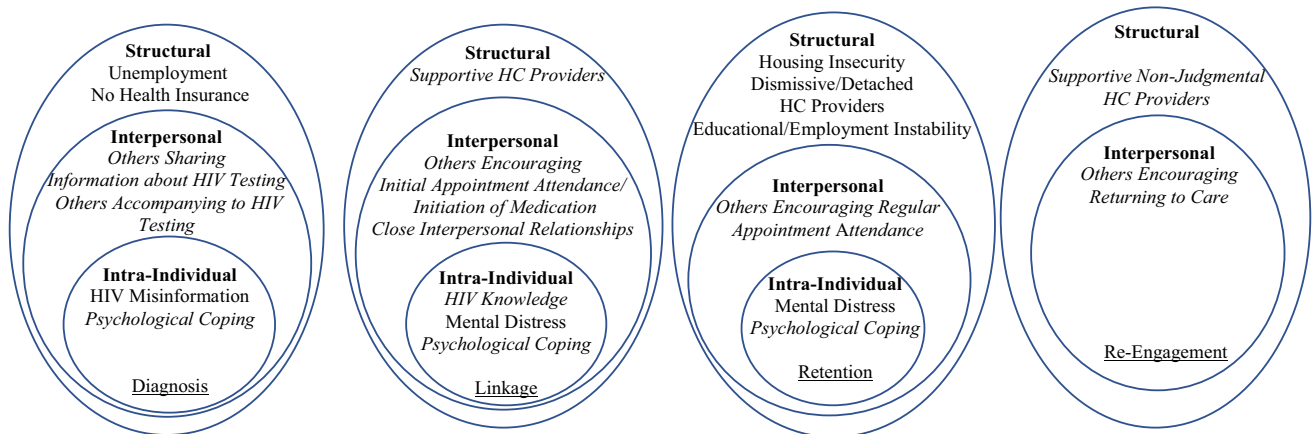


Fig. 1 Socio-ecological influences on engagement in stages along the HIV care continuum among participants. HC = Healthcare, Facilitators are in italics, Barriers are in regular font

who suspected they were HIV-positive, either because they received a preliminary positive test result or were experiencing symptoms, who then delayed confirmatory testing reported that financial concerns, at the structural level, impeded confirmatory diagnosis. At the interpersonal level, social support for testing facilitated receiving a confirmatory diagnosis, and at the individual level, misinformation about the manageability and availability of services for treating HIV hampered timely confirmatory diagnosis, whereas positive psychological coping facilitated diagnosis.

Barriers

Lack of Health Insurance and Unemployment Lack of health insurance and unemployment were identified most commonly as the structural barriers to obtaining a confirmatory HIV diagnosis. Sam explained that he delayed receiving an HIV test for a year after suspecting his symptoms were HIV-related due to financial concerns, “I started feeling... tired a lot, kind of weak... Thinking back on it, I knew I should have gotten the test earlier. At the same time, I didn't have health insurance so I was telling myself, you know, if this really is what you think it is, you're not going to be able to do anything. It's going to kill you” (26 years old, sub-optimally engaged).

Low-income Kentucky residents living with HIV can access insurance for comprehensive HIV care, including medical treatment and ancillary services [27]. However, as Sam was unaware of the existence of such financial assistance prior to being linked to care, he put off obtaining a confirmatory HIV test until he obtained a job with insurance.

HIV Misinformation At the individual level, having misinformation about the survivability of HIV, as well as limited knowledge about the affordability of HIV care, led some participants to delay receiving a confirmatory diagnosis. Jamal described avoiding getting tested for HIV to guard against acknowledging what he believed would be his imminent death. “I didn't know much about HIV at the time... I thought it was a death sentence... I was really feeling the symptoms between those years. I had one experience where I tried to get up and walk to the store one day... it was painful to walk... I was kind of in denial” (26 years old, sub-optimally engaged). Eventually, the worsening of Jamal's symptoms led him to seek treatment, and he was diagnosed with AIDS, although his viral load was undetectable at the time of the interview.

Combined Influence of Barriers at Multiple Levels Structural and individual factors combined to act as a barrier to HIV testing in that many participants were unaware of financial assistance available for people living with HIV. Therefore, those who did not have health insurance described avoiding

testing because they believed they would not be able to afford treatment if they were diagnosed with HIV.

Facilitators

Social Support for Testing Social support for testing, including providing information about the benefits of testing and accompaniment to testing, from support persons helped facilitate diagnosis. Most participants received HIV testing at a clinic or community HIV testing, with one participant reporting testing through a self-testing kit. Ray described him and his new partner getting tested before entering into a committed relationship, “Well, the person that I was with [we were] wanting to get that done for both of us first before we move forward. So, unfortunately he came back negative and I came back positive” (24 years old, sub-optimally engaged).

Psychological Coping Some participants had an individual life management and belief style that tied taking care of physical health to attainment of personal and professional goals. Mark described attending a confirmatory test appointment after systematically analyzing whether he could follow previously set future goals while living with HIV, “I've had a 25-year plan since I was 10 years old... So I had to, in those four days [between initial test and receiving a confirmatory test], determine, all right, does this is change the 25-year plan? It does. But can it still be completed? Yes. And I was able to make a decision [to get a confirmatory test]” (28 years old, retained). For Mark, engaging in an organized decision-making process motivated him to seek a confirmatory test in a timely manner.

Linkage to Care

Subsequent to receiving a confirmatory HIV diagnosis, the factors that participants identified as facilitating linkage to medical care included, at the structural level, positive interactions with healthcare providers; at the interpersonal level, social support for linkage from their personal networks; and at the individual level, accurate knowledge regarding HIV and psychological coping strategies. The one barrier to linkage to care consistently described by participants was mental health symptoms, including depression and anxiety.

Barriers

Mental Distress Some participants described that experiencing depressive and anxiety symptoms led them to delay getting linked to care. Nate explained that he waited a year and a half to engage in care due to depressed mood, partly resulting from internalized stigma:

I was in a really bad place. So it was like, ooh, is it even worth it? Do I honestly just want this to takeover my life and just call it a day or do I want to help myself and get better... I didn't know who I was, so I didn't know how my life was going to be different... Now I'm very comfortable with who I am... I'm not ashamed. (25 years old, sub-optimally engaged)

Once he accepted himself as a person living with HIV, Nate was ready to engage in care. Importantly, while several participants reported experiencing some sort of HIV-related stigma at the individual level, including anticipated and internalized stigma, only two participants described the stigma influencing their linkage to care.

Four participants either attempted suicide or experienced suicidal ideation following their HIV diagnosis. Dion experienced suicidal ideation after a positive diagnosis, "When I first got it, I did think about killing myself a lot... for those few days... [but then] I was like, I can't do that because a lot of stuff is going good for me right now. A lot of positive things are going on. I can't just do that... I need to live" (19 years old, newly diagnosed). Willfully turning his focus to positive aspects of his life allowed Dion to move out of suicidal ideation and seek care for his HIV.

Facilitators

Supportive Healthcare Providers Healthcare provider behaviors described as promoting linkage to care included providing emotional support and information related to the effectiveness of ART, as well as facilitating immediate prescription of medication. For example, Victor described a provider who provided emotional support and inspiration, as well as a referral to an HIV clinic:

[The doctor] told me, "Do you want to hear the good news or the bad news?" ... She said, "Well, the bad news is you have HIV but the good news is we caught it early ..your red blood cells and your CD4 count. Everything looks really good"... She introduced me to the [infectious disease clinic]. She also told me that her mother had lived with it [HIV] for years... She was telling me all the good things that come with it like, "You're not in this alone," and 'It's not a death sentence.'" (23 years old, sub-optimally engaged)

Close Interpersonal relationships Some participants who had multiple close interpersonal relationships, such as with family members, wanted to be healthy to support loved ones. Many also had supportive friends or family who emphasized the manageability of living with HIV through medication, "I was like I'm not getting on medication... I said whatever

happens to me it happens, just let me be.... Then after a month, my boyfriend was like, 'Can you stop being so in denial. You're not going to die.'... Then I got on medication" (Antwon, 24 years old, retained).

HIV-related Knowledge Possessing knowledge that HIV could be controlled by medication facilitated linkage to HIV care. "Knowing that my uncle, he died in 1994 from HIV, from AIDS. Because back then they didn't have the medication they have now and just knowing that if I didn't take my medication I was going to slowly degrade and just poof, die off somewhere. So, wanting to be there for my family. Live a long, healthy life" (Chris, 20 years old, newly diagnosed). For Chris, knowing that HIV is survivable combined with a desire to support his family motivated him to get linked to care.

Psychological Coping Strategies Similar to the decision to receive a diagnosis, some participants described engaging in a thought process that helped them accept an HIV-positive diagnosis and get linked to care. Participants described deciding that HIV was not going to stop them from achieving their goals. "As soon as I heard, I went to go get my second [test]... I was like, 'This isn't the end of the world and as long as you are controlling it then you can live a normal and healthy life, basically'" (Jared, 27 years old, retained).

Retention in Care

Factors at all three socio-ecological levels, that is, structural, interpersonal, and individual, influenced retention in care. Barriers included financial instability, educational changes, housing instability, changes in health insurance, and negative interactions with healthcare provider, at the structural level, as well as mental health difficulties at the individual level. Facilitators of retention in care included social support from friends, partners, and mentors, at the interpersonal level, as well as internal coping at the individual level.

Barriers

Housing Insecurity Housing instability could lead to not having medication on one's person or forgetting to take medication due to stress and mental toll of not having a stable place to live. Victor described the way these factors interacted to impede medication adherence:

I have been down. That has to do with my living situation. Me not having a place of my own and living with people. I feel like if I'm more self-[sufficient], I will be willing to take my medicine more. If I leave my medicine at home and I don't really feel welcomed at home,

or... If I have a really bad argument with my mom or something and I leave and I don't take my medicine with me, I don't really feel comfortable with coming back to come get it.

Educational and/or Employment Instability Both interruptions in education and employment negatively impacted care engagement among participants. For example, some participants attending college left school to emotionally and psychologically process the diagnosis or due to other stressors, such as the COVID-19 pandemic. Often the disruptions had a negative impact on engagement in care such that the change in daily routine made it more difficult to remember to take HIV medication consistently. Wilson described such an impact, “When I was in school, it was good because I was on a schedule, I'm waking up at the same time every day. ...Then when I came back [moved] home... I'll put it in a drawer, and then just say ‘Okay maybe I'll take it today, maybe I'll take it at 3 am after I get done drinking’” (24 years old, sub-optimally engaged).

In addition, some participants lost or changed jobs, which negatively affected their engagement in care. For example, in recounting reasons why he stopped taking his HIV medication, Tyrell relayed a cascade of negative developments, initially triggered by him not being accepted into an educational program, including unemployment, a negative mental state, increased risk-taking behavior, and subsequently falling out of care.

I wasn't accepted [to professional school]...[prior to that] I had several leadership positions and supervisory kind of things [as a paraprofessional in the field]... when I realized I wasn't going to [professional] school...I felt like I had to get out of the career...[but then] I didn't really care anymore about my future because I didn't really know...what I wanted to do...I was just kind of lost...I was doing things that I would not normally be doing...heavy drug use... sex parties and orgies...and then there was a point in time where I didn't take it [medication], just because it was not on my radar, given the drug use. (28 years old, sub-optimally engaged)

For Tyrell, concluding that he had reached a dead-end in his chosen career path led to him feeling aimless and unfocused. To manage those feelings, he engaged in increased sexual risk taking and drug use, and the latter led to him regularly missing doses of his medication.

Dismissive and/or Detached Healthcare Providers The quality of interactions with healthcare providers had a meaningful influence on retention in HIV care. Healthcare professionals who did not make an effort to create a relationship with participants, who dismissed participant concerns, or

who did not provide timely and responsive communication regarding appointments could lead to participants having a gap in care engagement. “When I would have side effects to a certain medication, she [my doctor] would fight me on trying to change it...I would tell her what the hell's going on and she was like ‘You still got to take it.’ Which ended up making me go off of medication for two years” (Jason, 29 years old, sub-optimally engaged). For Jason, the fact that his doctor would not change his prescription to help him experience fewer side effects led to a serious gap in treatment adherence.

A few participants described that White and heterosexual healthcare providers, and society as a whole, can be discriminatory. However, they did not identify discrimination related to race, sexual orientation, or HIV status, per se, as impacting retention in care. In the case of race, some participants resigned themselves to the idea that racism is a persistent reality. “No one's really discriminating about me being positive, but Black, yeah. I've got that nearly my whole life. There's always going to be prejudice and racism in the world, 'til the world ends. That's something that it's kind of... being racist and prejudice is kind of like the disease. It's going to stick around forever” (Omar, 29 years old, newly diagnosed).

Mental Distress Some participants described the onset or worsening of mental health symptoms, triggered by events unrelated to HIV, impeding their retention in care. For example, Corey experienced significant depression and anxiety in the aftermath of being robbed at gunpoint, and shortly thereafter, being evicted from his apartment.

I got robbed at gunpoint. It sent me backwards into a depression state. So I think for a month I stopped taking my medicine. And then that caused even more anxiety, because it was like, “Okay, when you get back on your medicine, are you ...” It just makes it harder...I think that's why I missed my doctor's appointment recently. Because I was scared to let them know. It's been a month long [after the robbery] that I've gone without it... I was petrified to stay in my house. So I would get drunk to kind of ease myself. But I would get overly drunk to where I would pass out...And I wouldn't take my medicine. And then the next day I would be sick. So I'd be like, “Oh, I'm not going to take it.” (Corey, 27 years old, newly diagnosed)

Corey also described the cumulative stress of the robbery, worries about missing doses of medication, being suspended from his job, conflicts with his apartment complex over changes in fees and rent, and the impending eviction, as causing him significant distress. He was hopeful that he would be able to start taking his medication regularly now

that he was in a new home saying, “I think I finally came into peace when we moved here... I feel like now I'm in my prime to do the best I can do now.”

Combined Influence of Barriers at Multiple Levels For some participants, structural barriers to care, including housing instability, unemployment, and community violence, impaired their mental functioning, including subject experiences being unfocused, anxiety, and depression. These mental states could directly influence engagement in care by reducing motivation overall, or through the participant engaging in less than optimal coping strategies, such as substance use, which could lead to medication non-adherence.

Facilitators

Social Support for Retention in Care Support persons, including family members, friends, partners, and mentors, encouraged some participants to stay retained in care. These support persons facilitated HIV care retention through verbally encouraging medical appointment attendance and medication adherence, providing concrete resources to help participants achieve or maintain financial stability, and supporting participants' mental health. For example, Jared described the ongoing support from childhood up through his HIV diagnosis he received from a mentor. “So I was in the Big Brothers/Big Sisters program when I was little and he [my mentor] was my big brother and he's always been there throughout my entire life as someone to look up to.... He was very supportive [when I told him of my diagnosis]... He just told me how it's so easy to manage, making sure I live a healthy life...that was comforting.”

Psychological Coping As was the case for diagnosis and linkage to care, generating thoughts related to future goals or a larger purpose to life helped participants stay retained in care. Brandon described the positive reciprocal influence of his career goals and desire to manage HIV, “It [the HIV diagnosis] pushed me to be better. I want to help people and I want to help myself... I just want to get better and help people and help somebody else be better” (27 years old, retained). Brandon reminds himself that in order to achieve his goal of becoming a teacher, he has to remain healthy by staying engaged in HIV care.

Re-Engagement in Care

Compared to the other HIV care engagement phases, participants who had at some time left HIV care identified fewer factors that facilitated their re-engagement in care. The two facilitators of re-engagement discussed were effective healthcare staff re-engagement strategies and role

modeling from members of social networks. Participants did not identify individual level processes as influencing their decision to re-engage in care.

Facilitators

Supportive Non-judgmental Healthcare Providers Healthcare providers who encouraged participants to re-engage in care without shaming them were most effective. Wilson described supportive interactions with his healthcare team in the following way, “Even if I missed an appointment, they're not shunning me or threatening me in any type of way, it's like ‘What's wrong? How can we help you?’ ...I don't have any people in my life like that. It makes me feel good, every time I come.” A supportive attitude and lack of judgment from clinic staff were crucial in making participants feel welcome in HIV specialty settings after a hiatus from care and were particularly helpful in the context of limited outside social support.

Social Support for Re-engagement Similar to our findings around retention in care, participants who tended to re-engage received encouragement from a support person or witnessed the negative effects of medication non-adherence. Jason described the positive impact that his partner's engagement in care had on his willingness to re-engage, “Now it's easier because of the partner that I'm with. He goes but to a whole different [HIV provider] hospital...Just because of him basically support I get from him. He's like ‘When's your next appointment? You better go. I'll take you if I have to.’”

Discussion

This qualitative study presented perspectives of young Black MSM living with HIV in the Southern US on socio-ecological risk and resilience influences on their engagement along the HIV care continuum. Young Black MSM have been the subject of multiple studies of HIV-related behaviors, but few qualitative studies exploring influences from multiple societal levels on HIV care engagement have been conducted, leading to less opportunity for the field to benefit from the lived experiences and knowledge of this population. This study produced several important findings.

First, the factors that were most critical to influencing engagement varied somewhat depending on the stage of the HIV care continuum. Unemployment and lack of health insurance, as well as misinformation about the survivability of HIV and availability of financial assistance for care, were

described by the young men who delayed seeking a confirmatory diagnosis as reasons they did so. After a confirmed diagnosis, supportive interactions with healthcare providers, acute mental distress, and psychological coping seemed to be uniquely meaningful for linking to care. In terms of retention in care, mental distress co-occurring with or triggered by housing, educational, and employment instability seemed particularly impactful. Healthcare providers who were encouraging and non-judgmental seemed to be especially beneficial for re-engagement in care. Having close and supportive personal relationships was helpful all along the continuum, including facilitating testing, linkage, retention, and for those who left care, re-engagement.

Second, this study helps illustrate some of the mechanisms by which previously identified barriers to care engagement may operate. Although several studies have identified lack of health insurance as a barrier to engagement in HIV care for Black MSM [8, 28], the narratives of participants in our sample suggest it may be more specifically the lack of information available to the general public related to financial assistance, such as federal Ryan White HIV/AIDS Program [29], that can discourage engagement for those who do not have insurance. Guidelines for HIV testing often include instructions for explaining the test procedures and meaning of results [30, 31]. Given the brief window of time in which a person who receives a positive diagnosis may be accessible to the testing professional, it may be important for professionals to also provide verbal and written information about the accessibility and effectiveness of medical treatment for HIV before testing and after delivering results. In addition, after a confirmatory diagnosis, some participants experienced mental distress which made it difficult to link to care. Consequently, screening all patients who receive an HIV + result for the need for evidence-based crisis debriefing and counseling [32] and providing referrals for ongoing mental health services may be beneficial for facilitating care engagement. Finally, while several young men reported experiencing stigma, by and large, stigma was not described as influencing care engagement. In the future, more detailed investigations of the potential impact of discrimination in healthcare, and the ways it may be perceived by young Black MSM across geographic areas, would better elucidate this barrier.

Third, this study highlighted and illustrated important assets for engagement in care that can be capitalized on in interventions. Consistent with previous findings of associations between social support and engagement in the HIV care continuum [33, 34], social support for the range of specific care continuum behaviors was described by participants as facilitating engagement, and as provided by a wide variety of individuals, including friends, partners, informal mentors, and family members. In addition, several young men identified psychological coping strategies in which they focused on future goals, and positive aspects of themselves and their

lives, as facilitators of engagement in care. Individual coping strategies for young Black MSM living with HIV have been studied very little, with strategies for coping with stigma and discrimination being examined most often [16, 35]. Building on existing coping strategies for managing emotional distress holds promise for supporting engagement in care.

Fourth, although quantitative studies have found a combined, or syndemic, effect of negative processes at structural/systemic, interpersonal, and individual on engagement in care among young Black MSM [28, 36], this is one of the first qualitative studies [37] to explore how and ways in which these influences affect each other. For example, for some participants, housing instability and/or taking a break from school led to depression and disruptions in one's daily schedule, both of which led to lowered motivation and capacity to remain engaged in care. Black MSM have been found to be overrepresented among those experiencing housing instability and unemployment [38]. Thus, addressing housing and financial insecurity in ways that are both effective and sustainable may be critical leverage points for interventions aiming to increase HIV care engagement among young Black MSM, through both promoting a regular schedule and reducing mental distress. In addition, YBMSM living with HIV should be screened regularly for mental health difficulties, particularly subsequent to changes in life circumstances, such as unemployment, housing instability, and experiencing traumatic events.

Limitations

The sample for this study consisted only of young Black MSM living in Kentucky. Several participants described having small social networks that did not include any or very few other Black MSM or people living with HIV, thereby limiting generalizability to other areas that have larger and more interconnected networks of Black MSM and people living with HIV. In addition, as the highest rates of HIV diagnoses are currently among those age 25 to 34, future studies examining socio-ecological influences on HIV care engagement among young Black MSM should extend recruitment to participants through age 34 [1]. In addition, all participants, even those currently out of care, had plans to engage in care. Thus, findings might be different for young Black MSM who are out of care and intend to stay out of care for the foreseeable future.

Conclusion

This study demonstrates the complicated nature of the influence of socio-ecological factors on engagement along the HIV care continuum from the lived experience of

HIV-positive young Black MSM. To date, there have only been two multi-level interventions developed and tested for young Black MSM that target structural, interpersonal, and individual influences on HIV, and only one exhibited overall positive results [9]. Thus, development and testing of the feasibility, acceptability, and effectiveness of multi-level interventions are urgently needed to eliminate disparities in HIV care engagement, and consequently HIV morbidity, experienced among young Black MSM. Such interventions should help young men maintain stable housing and living incomes, increase or maintain social support, and facilitate mental well-being through capitalizing on individual psychological strengths and coping strategies, promoting acceptance of oneself, and providing hope by integrating information regarding the accessibility and effectiveness of HIV treatment prior to and after test result communication. Public health campaigns that frame HIV as a chronic and treatable condition, as well as emphasize the accessibility and affordability of HIV medications and care, would also correct misinformation related to HIV services and insurance coverage that leads to delay of confirmatory tests and linkage to care.

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Data Availability The data is not available as it is qualitative and could reveal participant identity of accessed in its entirety.

Code Availability Not applicable.

Declarations

Ethics Approval Research was approved and monitoring by the Institutional Review Board at the University of Louisville.

Consent to Participate All participants provided informed consent prior to study participation.

Consent for Publication Not applicable.

Conflict of Interest The authors declare no competing interests.

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