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“It’s almost like a crab-in-a-barrel situation”: Stigma, social support, and engagement in care among Black men living with HIV

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Abstract

Social support is associated with improved health outcomes for people living with HIV (PLWH), including initiation and engagement in HIV care and antiretroviral therapy (ART) adherence. Yet, stigma may negatively affect the availability and utilization of social support networks, especially among African American PLWH, subsequently impacting HIV care and health outcomes. This qualitative study examines the relationship between stigma and social support relationships among African American PLWH. We conducted 23 interviews with Black men living with HIV who reported being out of care or non-adherent to ART. Thematic content analysis revealed three primary themes including variation in social support, experiences of stigma and discrimination, and coping mechanisms used to deal with stigma. Findings reveal that although social support may be protective for some men, many African American PLWH face challenges in harnessing and sustaining needed social support, partly due to stigma surrounding HIV and homosexuality.

Keywords

Stigma; social support; African American men; engagement in care

Introduction

In the United States, only two-thirds of persons living with HIV (PLWH) are linked to care, and even fewer are retained in care (37%) and achieve viral suppression (25%; Hall et al., 2013). Poor engagement in care and low adherence to antiretroviral therapy (ART) is particularly evident among Black Americans, who have lower rates of ART adherence (Lazo et al., 2007; Oh et al., 2009; Sullivan et al., 2007) and are less likely to be retained in HIV medical care than White Americans (Giordano, Hartman, Gifford, Backus, & Morgan, 2009).

A growing body of literature has examined the role of social support in facilitating engagement in care and ART adherence, suggesting that social support may facilitate

increased engagement in care and be an essential component of HIV treatment. Often conceptualized as quality and quantity of social connections, social support is thought to have compensatory and protective factors reducing the negative effects of stress and risk environments (Wills & Ainette, 2001) by enhancing effective coping, improving self-esteem, and through engagement in health promotion (Lazarus & Folkman, 1984). Furthermore, social support may offer protection against some of the socio-structural barriers that can impede positive health behavior. Individuals with a strong network of support are more likely to be socially engaged, happier (Kawachi & Berkman, 2001; Uchino, Cacioppo, & Kiecolt-Glaser, 1996), and have increased psychological well-being, improved physical health, and greater health-promoting behaviors (Cohen, 2004).

Supportive social relationships have also demonstrated effectiveness at protecting against HIV and improving health outcomes for PLWH (Lauby et al., 2012). For example, among PLWH, social support is directly and indirectly associated with greater treatment adherence (DiIorio et al., 2009; Kelly, Hartman, Graham, Kallen, & Giordano, 2014; Woodward & Pantalone, 2012). Greater social support (perceived and received social support) is associated with lower viral load and greater viral suppression among PLWH (Amberbir, Woldemichael, Getachew, Girma, & Deribe, 2008; Friedman et al., 2017; Simoni, Frick, & Huang, 2006). Furthermore, at the time of HIV diagnosis, social support may be a critical factor in facilitating initiation and engagement in HIV care (Lauby et al., 2012), facilitating ART adherence (Latkin et al., 2013), and improving coping with HIV-related stressors (Lam, Naar-King, & Wright, 2007; Power et al., 2003).

Yet, research has indicated that the availability of social support may be limited for some African Americans (Friedman et al., 2017), who are more likely to report smaller social networks compared with White men (Kapadia et al., 2013). This may stem, in part, from stigma, a pervasive social process which is negatively associated with social support among PLWH (Farber, Lamis, Shahane, & Campos, 2014; Mak et al., 2007; Simbayi et al., 2007; Simbayi et al., 2007). There are several pathways by which stigma can influence social support. As a result of stigma, PLWH may experience discrimination, alienation, and social exclusion (enacted stigma) or anticipate such consequences as a result of their HIV status (anticipated stigma; Earnshaw, Smith, Chaudoir, Amico, & Copenhaver, 2013). Anticipated or experienced HIV stigma can lead to social isolation (Courtenay-Quirk, Wolitski, Parsons, & Gomez, 2006; Davison, Pennebaker, & Dickerson, 2000), subsequently inhibiting PLWH from acquiring social support (Dowshen, Binns, & Garofalo, 2009). PLWH may fear negative repercussions of others knowing of their HIV status, including social rejection (Jeffries IV et al., 2015; Rao, Kekwaletswe, Hosek, Martinez, & Rodriguez, 2007), which may preclude them from disclosing HIV status. Furthermore, individuals may internalize such stigmas, believing or accepting the negative perceptions of PLWH perpetuated within society (Turan et al., 2017). Shame about one's HIV status can make HIV status disclosure difficult (Chaudoir, Fisher, & Simoni, 2011) and can influence decisions to seek out social support (Chesney, 1999). Internalized stigma is also associated with less frequent disclosure of HIV status to sexual partners (Overstreet, Earnshaw, Kalichman, & Quinn, 2013), increasing risk of HIV transmission. There are also established relationships between stigma and poor HIV outcomes. Persons who perceive higher levels of HIV stigma have decreased access to medical care, poor ART adherence, and lower rates of HIV care utilization (Katz et

al., 2013; Rueda et al., 2016). Experiencing stigma from health care providers is associated with delays and gaps in HIV care (Eaton et al., 2015) and HIV stigma is negatively associated with engagement in HIV care (Kinsler, Wong, Sayles, Davis, & Cunningham, 2007) and viral suppression (Quinn et al., 2017).

For Black Americans in particular, HIV stigma can occur alongside other social stigmas including racism and homonegativity, which can exacerbate the consequences of HIV stigma, contribute to internalized stigma, and further limit social support. For example, Black gay and bisexual men may face rejection and homonegativity from within the Black community due to their sexuality (Malebranche, 2003), and HIV-positive men can also face discrimination and alienation from the broader, HIV-negative gay community (Courtenay-Quirk et al., 2006). Similarly, Black men living with HIV may experience racism outside the Black community (Hirschfield & Piquero, 2010), which can be associated with ART nonadherence among Black PLWH (Bogart et al., 2015). Black gay, bisexual, and other MSM may experience social isolation and lack of social support from Black communities and consistently report the absence of organized communities and opportunities to connect with one another (Fields, Morgan, & Sanders, 2016; P. A. Wilson et al., 2016b). Lack of community connectedness can contribute to deleterious effects on identity development and self-esteem (Cohen, 2004), lead to internalized homonegativity and identity concealment, (Stokes & Peterson, 1998) and increase risk behaviors (Ayala, Bingham, Kim, Wheeler, & Millett, 2012). Given the stigma surrounding HIV, Black PLWH often have a small number of friends and confidants who are aware of their HIV status and can offer support, for fears of intolerance and discrimination (Bogart et al., 2017). Avoidance and isolation, although potentially useful coping mechanisms, can contribute to poor health and social outcomes (Bogart et al., 2017).

Researchers have called for a greater focus on how social support may buffer PLWH from associations between stigma and poor health outcomes (Earnshaw, Bogart, Dovidio, & Williams, 2013; Earnshaw, Lang, Lippitt, Jin, & Chaudoir, 2015). For example, social support may enhance resilience to stigma, helping PLWH respond to stigma in a healthy manner (Earnshaw et al., 2013; Pascoe & Smart Richman, 2009). Furthermore, instrumental social support has been found to be an effective resource for PLWH experiencing stigma; individuals who perceive greater instrumental social support report lower levels of stress in response to anticipated stigma, which may protect them from worse HIV health outcomes (Earnshaw et al., 2015). This study seeks to contribute to this developing body of literature and qualitatively examine experiences of stigma and social support among Black PLWH who are not engaged in HIV care or non-adherent to ART. We aim to provide a more nuanced understanding of social support and experiences of stigma among Black PLWH to inform interventions to improve engagement in retention in care.

Methods

This study took place in Milwaukee, Wisconsin, a city that, like much of the United States, has significant racial disparities in HIV. In 2016, the HIV diagnosis rate for Black males was fourfold higher than White men and the median age at HIV diagnosis was 28. Estimates indicate approximately 70% of individuals diagnosed and living with HIV in Milwaukee had

at least one medical visit in 2016 and 56% were retained in care (defined as two or more medical visits at least 3 months apart; Wisconsin Department of Health Services, 2017).

In 2014, we recruited 23 Black men living with HIV who were either not currently receiving HIV care or were non-adherent to ART to complete in-depth interviews. Research assistants trained in qualitative and community-based participatory research methods conducted direct outreach at LGBT organizations, HIV/STI clinics, coffee shops, bars, homeless shelters, and other community organizations. We partnered with various organizations to educate staff and case workers on the purpose of the study and provided recruitment flyers and cards to make available to any clients or persons in the organization. Online outreach was done through Craigslist and LGBT newspapers. Prospective participants were screened by phone to determine if they met the study's eligibility criteria of identifying as Black or African American, being 18 years or older, and HIV-positive. Race is a social construct, yet given racial disparities in HIV, it is an important construct to consider. Thus, we situate the experiences of the men in this study within the context of institutionalized inequality and historical and political patterns of power inequity and racism. Additionally, participants had to be out-of-care (not receiving HIV care in the previous 6 months) or ART non-adherent (less than 90% adherence in the previous 30 days).

The research assistants responsible for recruitment also conducted the interviews and participants provided their written informed consent immediately prior to the interview. A semi-structured interview guide was created to attain in-depth narratives about participants' experiences in and out of HIV care. Interview topics covered experiences with HIV testing, history of HIV care, treatment barriers, ART use and adherence, and social and family relationships, and provided opportunities for men to tell their stories and direct the focus of the interview. Medication adherence was measured using the Visual Analog Scale (VAS; Giordano, Guzman, Clark, Charlebois, & Bangsberg, 2004). Participants indicated on a visual scale of 0 to 100, the percentage of the time when they took their medications as prescribed in the previous month. Upon completion of the interview, participants received \$30 and a resource guide, which provided resources for mental health, substance use, and HIV treatment. Interviews (45-75 minutes) were audio-recorded and transcribed verbatim. The research protocol was approved by the Institutional Review Board at the Medical College of Wisconsin.

Transcripts were uploaded to MAXQDA qualitative analysis software. Data analysis was grounded in thematic content analysis and utilized a three-stage analytic coding strategy including open, axial, and selective coding, as described by Corbin and Strauss (2015). Interviews were initially coded by demographic variables (e.g., age, sex at birth, years since HIV diagnosis, and adherence) to allow for comparative analysis based on participant characteristics. We then took an inductive approach to analysis to develop and refine codes. Five members of the research team independently read two interviews and constructed a list of themes that emerged from the interviews, which were used to develop an initial codebook. An additional list of deductive codes was added based on the interview guide and existing literature about stigma, social support, and engagement in care among Black men. The codebook was then applied to two additional interviews and the research team continued to refine the codebook (e.g. combine or split codes, enhance code definitions, etc.) until

consensus on codes and definitions was reached. Four members of the research team applied the finalized codebook to all interviews. The final codes included HIV attitudes (e.g. stigma, gossip), HIV diagnosis (e.g. time since diagnosis), medical care, general health, and antiretrovirals (e.g. reasons for nonadherence).

Results

Analysis was based on in-depth interviews with 23 Black men living with HIV who reported being out of care or having suboptimal medication adherence. Participant characteristics are presented in Table I. It is important to note that medication adherence and engagement in care are not synonymous. Some participants reported high levels of ART adherence but had not seen a physician in the previous 6 months (n=5). Similarly, some participants were engaged in care but not taking their medications as prescribed (n=3). Most commonly, participants were neither engaged in care nor adherent to ART (n=15).

We examined experiences, sources, and challenges to receiving social support among HIV-positive Black men, with a specific focus on how enacted, perceived, and internalized stigma affected social relationships, engagement in care, and medication adherence. Below we describe the major themes that emerged from analysis: 1) the variation in social support men received, 2) experiences of stigma and discrimination from family and friends, and 3) the coping mechanisms men used to deal with stigma including engagement with the gay community, non-disclosure of HIV status, and cultivating the support of other HIV-positive individuals. Pseudonyms are used throughout.

“My social circle got real small”: The effects of stigma on social support

The narratives of participants in this study were simultaneously filled with experiences of extensive, loving social support networks, and rejection, stigma, and social isolation. For many, the extent of support they received varied by support system (e.g. family vs. peers) and fluctuated over time. Yet, nearly all recognized the importance of social support in their physical and mental well-being. Most notably, several individuals described the importance of social support immediately following diagnosis.

I come to terms with my situation I want to say maybe 6 or 7 months afterwards. I think it took the support of my family – the ones I had decided to let know of my situation – to get me a little more comfortable with it. My friends were super supportive. Like, they would go to doctor appointments with me, they would take off work, they just made me more comfortable and as time went by. Just being around that atmosphere and just the fact that they respected that I didn't want to be held back from anything. I didn't want to be like “oh, are you ok?” They kind of treated me still the same and made me feel like it's ok. – *Derek, 29 year-old, ART non-adherent but engaged in care*

Although Derek eventually received the support he needed, it took several months before he was comfortable disclosing his HIV status to select family members and friends and seeking out care. Furthermore, despite initiating care with the support of friends and family, at the time of his interview, Derek was not taking ART, citing loss of health insurance and the high

cost of his medication. Thus, although his social support network helped to facilitate engagement in care, he faced more significant obstacles to ART adherence. Others similarly described how social support, especially from family, helped facilitate periods of engagement in care over time, even if other factors (e.g. loss of insurance, substance use), eventually contributed to disruptions in care.

I: Has anybody outside of yourself impacted your decision about taking or not taking medication?

P: My mother, my family. The more I learn to like myself and to love myself, the more I want to live... I realized when I started to like myself and realized that others did love me and cared about me that's when I wanted to live. For the first 45 years of my life I didn't like myself. – *Geoffrey, 55 year-old, ART non-adherent and out of care*

In the over 30 years since his diagnosis, Geoffrey cycled in and out of HIV treatment, often coinciding with substance use relapses, poor mental health, and economic challenges. He credits his family, however, for ultimately motivating him to receive medical treatment, although, like Derek, he continued to struggle with adherence due to financial difficulties.

HIV-related stigma, whether experienced, anticipated, or internalized, was woven throughout men's narratives and was frequently attributed to a lack or loss of social support. Despite the recognized importance of support, many participants described rejection, shame, and isolation associated with their HIV diagnosis. For some, this led to depression and isolation and limited their ability to tap into their social support networks. Others saw friends and family pull away and treat them differently upon learning of their HIV status. For example, Eric described the slow break down of his social circle after his friends found out he was HIV-positive.

My social circle got real small. I had a lot of friends and, I mean, most of them were really actually close friends. But once they found out, they pretty much knew about the homosexuality, but once they found out about the HIV, it was kind of like they strayed away. Not right away, but slowly but surely pulled away and stopped calling or coming by or stuff like that. – *Eric, 37 year-old, ART non-adherent and out of care*

Likewise, Jeremy described the initial loss of peer support following his diagnosis. He noted having two friends, both of whom were also HIV-positive, which may be partly why he was able to maintain their support.

I only have 2 friends. Back when I was younger and I was popular, I thought I had a million and one friends and when it [HIV status] leaked out to them... I was up there socially and known, and you know. Looked up to and all these things. And they used that [HIV status] to tear me down. So, trust became the biggest issue to conquer with people. So out of all those so called friends I found out that I only had 2. Those are the ones that are still with me today. – *Jeremy, 23 year-old, ART non-adherent and out of care*

Jeremy's experience of involuntary disclosure was not unique. Several participants described how friends or family inadvertently found out about their HIV status through gossip, rumors, or invasion of privacy (e.g. reading text messages or mail, finding prescription bottles). Fear of involuntary disclosure led others to limit to whom they disclosed their status in an attempt to control anticipated gossip, discrimination, and stigma.

These experiences of shame, rejection, and the loss of social support following an HIV diagnosis were rooted in deeply seated stigmas around sexuality, masculinity, and HIV. This was especially notable among men for whom disclosure of HIV status coincided with disclosure of sexual orientation or behavior. They often had not previously disclosed their sexuality, anticipating negative and unsupportive reactions. As Eric (37 years old) noted, *"My mother and father –I think it was hard to find out that I was homosexual. I don't think it was the HIV."* These men frequently experienced HIV stigma and homonegativity simultaneously, particularly from family members. Whether implicit or explicit, participants described how this intersection of stigmas limited the support they received from friends and family.

P: Some of my friends, I know they probably judge me. HIV is considered like a dirty disease... I know a lot of them are Christians and they have strong feelings for gay people... they feel like being gay is a sin and I know what they are probably thinking, that this is God giving me this.

I: Are there others who you decided that you would not disclose to?

P: Family, even though my mother knows. That's because she's nosy. But if I had a choice, I wouldn't tell her... I don't think that they would be very helpful they would also pass judgment they would probably tell me that I need to stop being gay because they are very, very religious, more religious than my friends. –*Marcus, 22 year-old, ART non-adherent but engaged in care*

Although for a few individuals, religion was cited as a source of support and comfort during difficult times, others, like Marcus, noted how conservative religious ideologies around homosexuality contributed to homonegativity, HIV stigma, and limited social support.

Engagement in care: the influence of stigma and social isolation

As evidenced above, anticipated or experienced stigma and discrimination from family and friends was a frequent barrier to social support. In turn, both limited social support and HIV stigma were described as impediments to HIV care. As noted earlier, some men reported strong social and familial support and credited that support in facilitating periods of engagement in care and medication adherence. Yet, overwhelmingly, men in this study described how experienced or anticipated loss of social support contributed to disengagement in care. For example, Jeremy (age 23), whose social support network was primarily comprised of two HIV-positive friends, described how stigma contributed to a loss of familial support and subsequently, a lack of motivation to receive treatment. He was diagnosed with HIV when he was 15 and has been in and out of medical care for the last 8 years. He recalled how he "went through a lot. Family throwing away cups and plates after I eat and the word got out and it was just like my whole image was just thrown in the dirt."

Not only do such experiences reflect antiquated fears around HIV transmission and continuing HIV stigma, such experiences made it difficult for men to care about their health and engage in care. As Jeremy explained, such experiences also contributed to depression, anxiety, and social isolation.

Peter, who cycled in and out of care since his diagnosis nearly 20 years ago, similarly described his experiences of stigma from his social network.

People who are HIV/AIDS, they have a lot of pressure, and not just being sick wise. It's like more being judged... When you tell people that you are HIV, which I have been known to do, all of a sudden they don't want to be around you and they just shut you out. You know, just 'you are gay' or stuff like that. It's like mainly people who are family members. Or like, you know, I told my church that I was HIV ... they think that they are going to catch it and this and that, 'don't put your hands on me and stuff like that.' That's what I get a lot. –*Peter, 52 year-old, ART non-adherent but engaged in care*

He went on to say, “*I think that is the hardest thing. In your community, you know a lot of people who don't educate themselves. I mean, my community needs to be educated so much.*” The ‘community’ he was referring to is the African American community in Milwaukee, which he believed perpetuates stigma and gossip. As a coping mechanism for anticipated gossip and stigma, men attempted to distance themselves from HIV by not disclosing their status, staying out of care, and socially isolating themselves.

Other participants similarly described how the intersecting stigmas surrounding HIV and homosexuality could influence engagement in care, particularly for Black men. One participant, when asked what would have to change in his life in order for him to start seeing a healthcare provider described how stigma made it difficult to access needed help and social support in the African American community.

There is such a stigma around it... You already got a stigma for being a minority then you got a stigma for being gay within your minority, then you got a stigma for being positive within your minority... in our community it kind of it's almost like a crab in a barrel type of situation where everybody wants to be on top but we can't be on top together. So, since it's crab in a barrel you get shot down, you can't turn for specific help. Or, if you do want to turn to someone for help, you can't because you don't know how that stigma is gonna affect the relationship. So people tend to kind of feel like they can do it on their own. Or hey, I'll just save up money and leave town and no one has to know. –*Daniel, 31 year-old, ART non-adherent and out of care*

Daniel highlights one of the challenges associated with intersectional stigma; each additional stigma limits the perceived availability of social support. Furthermore, the stigmas he is contending with make it difficult for others in his community to provide social support. The ‘crab-in-a-barrel’ mentality refers to people in one’s community (who, in this case, may also be stigmatized due to race or sexuality) limiting support in an attempt to protect or improve their own social situation and prevent others from getting ahead or achieving success.

Stigma management techniques

The men in this study described a variety of adaptive and maladaptive coping mechanisms in response to anticipated and experienced stigma from social support circles. Most notably, men described strengthening ties or distancing themselves from the gay community, selective disclosure of HIV status, and building relationships with HIV-positive peers.

Disengagement from the gay community

Experiences of stigma and discrimination, or the anticipation of future discrimination, often precipitated decisions to avoid opportunities to establish social connections or utilize existing social support networks. This was especially evident among men who explicitly noted not wanting or being able to establish connections with other Black MSM and those who reported experiencing HIV stigma within the gay community. For example, when asked why he hadn't disclosed his HIV status to his friends, Derek noted a lack of trust within the gay community:

I not really big on the gay community. The gay community in this day, the majority of it is very like messy, dirty. Spread this and this, talk, rumors, and I just don't want to be a part of that category. I hear people say all the time 'oh, that's why they're sick.' No, I'm not going to give you that opportunity to throw something like that in my face. I feel like anybody who is connected with that group in any way, whether I feel like you're that kind of person or not, I just don't want to tell you. I don't want you to have the opportunity to let it slip out of your mouth or anything to the wrong person. -Derek, 29 year-old, ART non-adherent but engaged in care

As noted earlier, several participants perceived a stigma surrounding HIV within the gay community, and feared disclosing their HIV status to other gay friends would result in rumors, gossip, and negative treatment and discrimination. Gossip is often rooted in stigma and reflects social norms and expectations within the broader community. For example, an HIV diagnosis can be seen as an indication of promiscuity or sexual irresponsibility, labels that many men were trying to avoid. Thus, disassociation from the gay community or other social support systems was used as a coping mechanism to avoid anticipated gossip, discrimination, and stigma. Others similarly described the gay community as perpetuating HIV stigma and discriminating against gay men with HIV.

I: Why do you think that people drop out of HIV treatment?

P: Majority of this is because of their peers. They don't want most people to know because a lot of people out in Milwaukee, Wisconsin, in our gay community, are judgmental ... It's people that you're hanging around with because they don't feel that you should have it [HIV] because you did this or that. So that will bring you down. Talking about you, going to make you feel so much insecure about yourself that you just shield yourself again. -Patrick, 26 year-old, Out of care but adherent to ART

As Patrick explained, not only could judgments from peers contribute to dropping out of care, but it could also lead to further isolation, insecurity, and the desire to ‘shield’ oneself from the potential judgments.

Selective disclosure of HIV status

Among PLWH, an important step in recruiting social support is the disclosure of one’s HIV status, which for some, may also reveal sexual behaviors (McFadden, Bouris, Voisin, Glick, & Schneider, 2014). Nondisclosure is often driven by anticipation of stigma or rejection. For several men in this study, the prospect of disclosure evoked significant anxiety, and for some men, disclosure of HIV status, even to others who were HIV positive, was not seen as an option. When asked whether any of his friends knew of his HIV status, Derek explained how the stigma surrounding HIV within the gay community prevented him from disclosing his HIV status to most of his gay friends. Not only did he generally not want to disclose his own status, he noted that although he had one friend whom he knew to be HIV-positive, it was likely that he has additional HIV-positive friends who also had not disclosed to him because of the stigma.

I feel like there are other friends of mine that feel the same way I feel. They won’t tell. In fact, there was one that honestly, something was going on with him. But close friends, I only have one that I know for a fact he is. He finally decided to tell me last year. I haven’t told him my situation. It’s like, I would have felt like when he told me I could tell him, but it didn’t make me open up anymore. I was just, “Oh, sorry to hear that. I’m here for you.” I still won’t even tell him. –*Derek, 29 year-old, ART non-adherent and out of care*

Lack of disclosure to trusted peer, family, and other support persons was often a response to anticipated judgment or anxiety about rumors and gossip. Another participant, David, who was diagnosed within a year of his interview, had not initiated any HIV care, and explained that he had not disclosed his HIV status to anyone other than healthcare workers.

I: Have you disclosed to anyone your HIV status?

P: Not besides the care workers.

I: What are the reasons you have chosen not to tell people about your HIV status?

P: Stigmas around it. Maintaining value, relationships. Like, it’s hard to explain it ‘cause I do have friends that have disclosed to me but then I just sat back like ‘oh.’

I: And you never disclosed to them?

P: Exactly ... I’m pretty sure that it goes back to stigmas. And also when you looking for support system, you don’t want nobody to tell you that you are wrong when you already know that you are wrong. When you get the HIV status, I was already told that, ‘shame on me.’ I don’t need you to also say ‘shame on me.’ –
David, 40 year-old, ART non-adherent and out of care

Although his lack of disclosure to family and other HIV-positive friends potentially limited the support he needed, he perceived his lack of disclosure as necessary to maintaining his support system and avoiding the stigma he believed would inevitably accompany disclosure.

This passage also highlights the effects of internalized stigma and shame and the acceptance of societal narratives about HIV as a reflection of promiscuity or sexual irresponsibility.

Connection to HIV-positive peers

In contrast to those men who described HIV non-disclosure, including to their HIV-positive peers, several other men described the unique support system they were able to establish by disclosing and connecting with others who were HIV-positive.

P: Its good because I can, you know, I am relieved, because they know what I'm going through and they know what is happening because they are struggling with themselves you know and even then I need help or they need help, we can help each other and bounce it out of each other and that is a good thing you know.

I: Yeah would you say of your friends that are positive, what percent would you say are in care, taking their meds, doing their thing?

P: The majority, I would say, half of my friends. You know, those are the ones that I stay around with because they're keeping me motivated you know. If they can do it, I can do it too you know. –*Peter, 52 year-old, ART non-adherent but engaged in care*

Peter explained that he spent most of his time with just half his friends, those who were adherent to ART. Yet, although he credited them for keeping him motivated, he reported taking his medications only about 35% of the time. All participants in this study were either non-adherent or out of care at the time of their interview, yet several individuals similarly attributed periods of ART adherence and engagement in care to having the necessary social support, especially from HIV-positive peers. One participant described how it was an HIV-positive friend, rather than medical professionals, who was able to convince him to start taking his medication.

I: Was there any advice to you? Like, the doctors telling you to try something different or maybe like you felt that you were struggling with these things?

P: It wasn't the doctor. It was actually a friend that's positive who told me that they believe, 'cause they went through something similar. They told me that I need to switch the time period for when I taking [ART] and make sure I'm eating properly... speaking to a friend who, they've been positive since 18, they pretty much were able to guide me in the right way. 'Cause, if anyone asked me if I've been taking my meds, I told them the truth, no I haven't. We pretty much had a heart to heart talk and he was just telling me that he's been living with it for so long and he's so healthy and he wants the same for me. – *Randall, 29 year-old, ART non-adherent and out of care*

Similar to others described earlier, Randall was initially hesitant to disclose his HIV status, even to his HIV-positive, long-time friend. Prior to receiving his friend's support, he was not receiving HIV care and had yet to initiate ART. Yet, his narrative exemplifies how support from HIV-positive peers can be critical in fostering adherence and engagement in care.

Finally, social support from HIV-positive peers could also be a source of empowerment, especially among younger MSM. This participant, for example, had seven close friends, and although he also expressed hesitation about disclosing his status to them, he described this peer group as an important part of his physical and mental health.

When I told them, I was still scared. I was still skeptical on how people would react no matter if it would cheerful or negative vibes. But when I told my peers, the seven that I told, they open their arms for me. And they told me about their situation, what was going on in their lives, and how as team we going to make sure that we better the youth and our friends and our peers around us. That it's not a death life situation. We can, as a team, we can create a vaccine that can cure this. We all are HIV promoters and at the same time, I have some of my peers are going into that field, so they open their arms with so much joy for me. But at the same time, me be me still in the back of my head, like 'yea I'm just waiting for you to give this negativity that I never received it.' So I thank my friends for giving me that encouragement to actually come out and tell them that. – *Patrick, 26 year-old, Out of care but adherent to ART*

Discussion

This study examined the intersection of stigma, social support, and engagement in care among HIV-positive Black men who were non-adherent to ART or not engaged in HIV medical care. Our findings support previous research that has demonstrated that strong social support networks may buffer against some of the structural and social barriers that can impede positive health behaviors (Scott et al., 2014). Yet, our findings also reveal the complexity of social support and illustrate the challenges Black men living with HIV face in harnessing and sustaining needed support systems. Men in this study described experiencing enacted, anticipated, and internalized stigma surrounding HIV status and sexual orientation, which subsequently influenced their ability to seek out or maintain social support.

Harnessing social support is a documented coping mechanism for HIV-positive Black men (Bogart et al., 2017). Previous work has indicated that strong social and family connectedness may help Black MSM avoid syndemics (Reed & Miller, 2016) and may be an important component to Treatment as Prevention, given the relationship between social support and viral load suppression (Simoni et al., 2006). Social support may also buffer the effects of stigma. For example, strong social support networks can moderate the effects of HIV stigma on ART nonadherence over time (Bogart et al., 2015). Yet, our findings illustrate how stigma can also limit the availability of social support for some Black men living with HIV. Although several men described how strong social support networks were essential in facilitating periods of adherence and engagement in care, social and environmental barriers (e.g. loss of health insurance, financial barriers, and stigma) regularly interrupted care. Furthermore, experienced, anticipated, and internalized stigma made it difficult for some men to leverage existing social support networks or establish new support systems to combat that stigma.

Several men in this study disassociated from the gay community in order to avoid anticipated stigma. Although this tactic may provide some immediate protection, it was clear that this also contributed to weakened social ties and limited social support. Leveraging gay community connections and social support is protective against poor mental health (Doty, Willoughby, Lindahl, & Malik, 2010), yet our findings make clear that engaging social support from the gay community is a coping mechanism only available to those who already had or were able to disclose their sexual orientation. For several men in this study, previous experiences of homonegativity and anticipated stigma surrounding their sexuality limited opportunities for disclosure of sexual orientation and subsequently limited some men's ability to garner social support to cope with these experiences. Importantly, Black gay and bisexual men are less likely, compared to their white peers, to benefit from connectedness to sexual minority communities, partially due to experiences of racism (Haile, Rowell-Cunsolo, Parker, Padilla, & Hansen, 2014; Raymond & McFarland, 2009). Thus, the protective effects of social support may not be as realized among Black PLWH.

Selective or nondisclosure of sexual identity or HIV status is another widely recognized coping mechanism among people living with HIV and sexual minorities (Asakura & Craig, 2014; McDavitt et al., 2008) and may be protective and adaptive, allowing men to preserve important social connections and networks (Frale, Platt, & Hoey, 1998). Yet, disclosing sexual identity is not uniformly adaptive. Men in this study described their complex decision-making around selective disclosure, often believing disclosure would jeopardize relationships, support, and their reputation in the community. Although nondisclosure may allow some individuals to avoid discrimination (Choi, Han, Paul, & Ayala, 2011), concealment of sexual orientation or HIV serostatus can lead to internal distress and social isolation (Pachankis, 2007). The burden of concealing a stigmatized identity or attribute can contribute to poor physical health and psychological health outcomes (D. M. Quinn et al., 2014) and reduce social support (Chaudoir & Fisher, 2010; Weisz, Quinn, & Williams, 2016). Furthermore, nondisclosure of HIV status to others at the time of first seeking HIV care is associated with poor retention in care (Elopre et al., 2015) and Black MSM who disclose their HIV status early and to more social contacts may have more stable social networks post-diagnosis (McFadden et al., 2014).

Broad disclosure of HIV status may demonstrate confidence in one's networks to sustain support in spite of their HIV status (McFadden et al., 2014) and may reflect trust in social ties to withhold judgment and stigma. Most men in this study had disclosed their status to at least one person, but disclosure, especially immediately following diagnosis, was typically limited to people deemed safe, which only occasionally included other PLWH. Selective affiliation, or limiting social interactions to others who are similarly marginalized, can also serve as an opportunity of self-preservation and may be useful in coping with discrimination and stigma (Bogart et al., 2017). Establishing a community or social support system of others living with HIV can help shield men from discrimination by limiting social interactions to others who have similar experiences. Yet, even those who credited their engagement in care or ART adherence to support received from their HIV-positive peers noted discomfort, hesitation, and anxiety associated with disclosing to other PLWH. Furthermore, several PLWH noted not disclosing their HIV status to other PLWH, despite the potential benefits, which may reflect internalized stigma, shame, and embarrassment.

Our findings offer several opportunities for intervention. First, it is clear that large-scale efforts are needed to alter social norms targeting societal stigma and discrimination and improving opportunities for social support. Structural interventions should be designed to provide safe spaces and strengthen social support, especially for Black PLWH (Garcia et al., 2015; Hull, Gasiorowicz, Hollander, & Short, 2013). Although social support can enhance engagement in medical care, our findings indicate that intersecting stigmas (e.g. homophobia and HIV stigma) uniquely affect Black PLWH's ability to harness needed support. As such, interventions targeting engagement in care should consider the unique experiences and barriers of Black PLWH, including the effects of stigma.

Second, enlisting endogenous support persons and networks may help build sustainable, supportive environments, improving long-term care engagement and overall well-being (Lauby et al., 2012; Serovich, Grafsky, & Craft, 2011). Future interventions should seek to bolster existing support networks as well as cultivate new supportive relationships. Such interventions should also seek to improve HIV disclosure for PLWH, as garnering social support to enhance HIV care is facilitated by disclosure of one's HIV serostatus. However, this may be more difficult for some Black PLWH, whose disclosure of HIV status or sexual behaviors may result in a loss of social support or enhanced stigma. Helping these individuals identify one or two potential support persons may be especially useful. Similarly, for those without endogenous support persons, interventions should seek to build support and mentorship from other Black PLWH.

This study has limitations. Data were obtained via a small convenience sample in one Midwestern city and may not be generalizable to all Black men living with HIV. Our sample consisted of 23 individuals; it was difficult to identify and recruit people who are out of care. Participants in this study spanned a large age range (20-55). Analyses did not reveal any differences by age, which may be due to a small sample size. Future work should explore these differences further. Additionally, individuals who are out of care may be more socially isolated, less likely to disclose HIV status, and less willing to discuss lack of HIV care with researchers. As such, future studies should seek out new opportunities to engage out-of-care individuals and explore the role of stigma and social support among a larger sample. Additionally, social support is just one of several resilience domains (Wilson et al., 2016a), and research should continue to explore resilience as a multidimensional construct to better understand factors, in addition to social support, that may buffer against or be influenced by stigma. Finally, data were collected in 2014–2015 and there continue to be advances in biomedical science that improve engagement in care and adherence among persons living with HIV. As the science continues to advance, the needs and experiences of individuals living with HIV will likely change and researchers should be mindful of how those advances interact with stigma and social support.

Our findings illustrate that despite the documented benefits of social support, especially on engagement in care (Lauby et al., 2012), stigma may inhibit cultivating or maintaining the support needed among Black PLWH. PLWH in this study utilized several stigma coping mechanisms to self-protect against social ostracization and stigma. Although perhaps immediately protective, such efforts limited social support.

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Table I

Participant Characteristics (n=23)

Age (mean, range)	36.1 (20-55)
Length of HIV diagnosis	
<i>Less than 5 years ago</i>	14 (60%)
<i>6-10 years ago</i>	3 (13%)
<i>11-20 years ago</i>	3 (13%)
<i>20+ years ago</i>	3 (13%)
Sexual Orientation	
<i>Gay/Bisexual</i>	19 (83%)
<i>Heterosexual</i>	4 (17%)
ART Adherence rates (based on the VAS) (mean, range)	43% (0-99%)
ART Adherence and Engagement in Care	
<i>Adherent to ART but not engaged in care</i>	5 (22%)
<i>Non-adherent to ART but engaged in care</i>	3 (13%)
<i>Non-adherent to ART and not engaged in care</i>	15 (65%)