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Observational “go-alongs” of follow-up HIV care visits of two virally suppressed Black sexual minority men

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Abstract

Purpose: This study explored potentially underreported healthcare contexts, clinical experiences, and motivations for adherence in care among virally suppressed Black sexual minority men (BSMM) living with HIV in Baltimore, MD.

Methods: Go-alongs with two virally suppressed BSMM living with HIV supplemented 27 in-depth interviews of a larger qualitative study guided by Positive Deviance and Life Course Theory. The go-alongs involved accompanying participants’ follow-up HIV care visit to obtain a better account of contextual healthcare factors. Observations focused on 1) clinic location and resources, 2) sources of HIV and sexuality stigma or support in the clinic, and 3) patient-provider interactions.

Results: We found facilitators and barriers to viral suppression for BSMM living with HIV including structural factors (i.e., healthcare setting, facility, and services), quality of patient-provider interactions, and personal motivations to achieve viral suppression.

Conclusion: Clinic accessibility, co-located clinical services, and rapport with clinicians and healthcare staff could be key contextual conditions that facilitate retention in care among BSMM living with HIV.

Keywords

viral suppression; adherence; nursing; medicine; retention in care

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1. Introduction

Persistent U.S. racial disparities in retention in HIV care inhibit 90-90-90 global targets (Anderson et al., 2020; Jeffries IV et al., 2020; United Nations Programme on HIV/AIDS (UNAIDS), 2017). Specifically, Black sexual minority men (BSMM) living with HIV (LWHIV) are less likely to maintain healthcare and viral suppression than other racial/ethnic groups of sexual minority men, even after accounting for differences in education, income, and health insurance coverage (Hoots et al., 2017). Only 59% of BSMM LWHIV maintain care and 57% are virally suppressed (CDC, 2017). BSMM under the age of 35 are less likely to maintain care and viral suppression than BSMM over age 35 (Singh et al., 2017). HIV care provides STI screening, evaluation for treatment adherence and drug resistance, and ultimately supports viral suppression (Mizuno et al., 2014; Tripathi et al., 2010). However, it is well-established that structural factors such as HIV and sexuality stigma, racial discrimination, and having limited resources prevent healthcare maintenance, treatment adherence, and viral suppression for BSMM (Arnold et al., 2014; Hightow-Weidman et al., 2017; Quinn, Dickson-Gomez, Zarwell, et al., 2018).

Some BSMM LWHIV do not access or maintain care due to anticipated stigma and mistreatment based on their race and sexuality, which is compounded by experiencing racial discrimination and homonegativity from society, family members, and healthcare staff (Arnold et al., 2014; Quinn, Dickson-Gomez, Zarwell, et al., 2018; Turan et al., 2017). For BSMM of different ages and life phases, HIV treatment improvements and increased social acceptance of same-sex relationships could also impact healthcare maintenance (Dangerfield II, Cooper, et al., 2020; Dangerfield II, Heidari, et al., 2020). Older BSMM (i.e., over age 35) possibly have greater investment in maintaining HIV care due to their exposure to the AIDS epidemic and its deadly consequences in the early 1990's (Dangerfield II et al., 2017; Dangerfield II, Heidari, et al., 2020). Younger BSMM LWHIV could have competing priorities in survival due to being low-resourced youth who might have been recently rejected by family (Dangerfield II et al., 2017; Dayton et al., 2020). Different historical contexts of HIV treatment and outcomes could create varied attitudes toward maintaining HIV care for BSMM of different ages and resources. However, little is known about the motivations and contexts of healthcare maintenance among BSMM LWHIV who have achieved viral suppression.

Despite the fact that a large proportion of BSMM LWHIV do not maintain care, successfully achieve long-term viral suppression. While apparent factors such as having healthcare coverage, financial resources, and “good” relationships with clinicians have been identified (Brion, 2014; Carey et al., 2018; Jemmott et al., 2019; Turan et al., 2017), more data regarding the social and structural factors that support BSMM LWHIV are needed. Little is known regarding factors such as clinical services, policies, and workflow or the components of positive interactions with clinicians and clinic staff that could influence retention in care for BSMM. The underlying motivations in navigating clinical settings among BSMM who experience additional intersectional challenges of being low-income, stigmatized, and LWHIV are also less known.

Guided by Positive Deviance (Marsh, 2004; Ober et al., 2017) and Life Course Theory (LCT; Elder, 1998; Jones et al., 2019), the goal of this study is to identify potentially underreported healthcare contexts, clinical experiences, and motivations for retention in HIV care among virally suppressed BSMM. Positive deviance refers to examining how some individuals within a community experience better outcomes than their peers despite having comparable high-risk trajectories (Friedman et al., 2008; Marsh, 2004; Ober et al., 2017). In HIV care, an exemplar “positive deviant” can refer to BSMM LWHIV who maintain their follow-up care and successfully achieve viral suppression, since a substantial proportion do not. LCT guides the examination of generational differences in exposures to HIV treatment and age-related development on healthcare maintenance (Dangerfield II et al., 2017; Dangerfield II, Heidari, et al., 2020). Together, these frameworks can be used to explore healthcare experiences among virally suppressed BSMM of different ages. Virally suppressed BSMM could have different (or uncommon) healthcare experiences than those who are not virally suppressed. Age could also contribute to differences in motivations and experiences in healthcare among BSMM LWHIV (Dangerfield et al., 2020; Dangerfield II, Cooper, et al., 2020). Uncovering these factors could contribute to structural interventions that increase retention in care and viral suppression among BSMM LWHIV (Brown et al., 2019).

2. Methods

2.1 The observational “go-along”

The go-along method includes a researcher being “walked through” participants’ social contexts to obtain a more detailed account of nuanced ecological factors (Carpiano, 2009; Kusenbach, 2003; McDonald, 2005). The go-along is advantageous for this study because BSMM could overlook pertinent details in an in-depth interview and fail to describe factors that are not prominent or that they do not perceive as outstanding (Carpiano, 2009; Kusenbach, 2003). Therefore, participants were asked if they were willing to be shadowed in their next HIV care appointment to provide the researcher with more context about their healthcare experiences. Observing the experiences of two BSMM enables the exploration of similarities and differences between cases (Baxter & Jack, 2008; Kusenbach, 2003).

2.2 Study sample

Participants come from a larger qualitative study of in-depth interviews that explored HIV treatment adherence strategies among 26 BSMM LWHIV in Baltimore City and Los Angeles, CA. Participants were recruited using a combination of active and passive strategies (White et al., 2019), including contacting individuals from existing studies who expressed interest in future research and posting fliers at clinics. Eligibility included the following criteria: (1) 18 years of age, (2) self-reporting LWHIV, (3) self-identify as Black or African American, (4) virally suppressed with viral load < 200 copies/mL, and (5) virally suppressed for one year. Viral load was confirmed by reviewing standard of care labs from patient records after participants signed a release of health information form. All participants who completed in-depth interviews were asked during in the informed consent document if they were interested in being contacted for future participation in a go-along to provide the researcher more information about their healthcare experiences and interview responses.

After immediately completing in-depth interviews for the parent study, participants were asked to confirm their interest in being contacted in the future to participate in the go-along, the focus of this study. Go-along participants were selected based upon their age and length of diagnosis to compare younger and older BSMM LWHIV for different lengths of time in addition to the timing of their upcoming appointment for scheduling and feasibility, resulting in two participants for study.

2.3 Data Collection

The first author conducted the go-along as a silent observer during follow-up HIV care visits to actively explore participants' experiences and practices (Carpiano, 2009; Kusenbach, 2003). The go-along included a pre-observation interview along participants' clinic route to further discuss their habits, typical experiences, and expectations from clinicians and clinic staff. During the go-along, participants introduced clinicians to the researcher, who remained silent and seated behind participants during their visit. The researcher was not introduced to other clinic staff or familiar acquaintances. Data collection included field notes, jottings, and mental notes of the healthcare location, facilities, and services along with patient-clinician interactions. Data collection also included participant conversations with clinicians and clinic staff prior to, during, and after healthcare visits. After visiting the clinician, go-alongs ended in a post-observation interview outside of the clinic to debrief and identify how typical the visit was for participants and whether presence of a researcher influenced their visit. Go-alongs lasted between 90 and 120 minutes, in addition to the 20-minute post-observation interview. Participants were compensated \$40 for completing in-depth interviews in the parent study and an additional \$40 for the go-along. Participants provided written informed consent for in-depth interviews and ethnographic go-alongs separately. The Johns Hopkins School of Medicine Institutional Review Board approved all study procedures.

2.3 Data Analysis

Guided by Positive Deviance and LCT, analysis focused on the following domains: clinic location and resources, sources of HIV and sexuality stigma or support in the clinic, and patient-provider interactions. Since these are well-established factors that impact retention in HIV care among BSMM (Carey et al., 2018; Jemmott et al., 2019; Quinn & Voisin, 2020), our framework helps identify potentially protective factors within these domains for BSMM of different ages. Field notes, jottings, and mental notes of the go-along and debriefing were documented in detail within two hours of the visit and analyzed for important and insightful observations within and between cases (Kusenbach, 2003; Winder, 2015). Data were also triangulated from descriptions in the parent in-depth interviews to explore potential inconsistencies between how participants reported their clinical experience and their actions and attitudes during the go-along. Specifically, in-depth interviews from the parent study were reviewed to explore similarities and differences in themes from the 26 participants and the observations from the two go-alongs. Additionally, targeted analysis on the first in-depth interviews of the two participants was conducted to identify similarities and difference in their attitudes toward healthcare facilities, clinicians, and staff compared to field notes, jottings, and mental notes of the go-along. Both participants have pseudonyms to protect their identities.

3. Results

3.1 Devin

Devin is 36 years old and was diagnosed with HIV infection two and a half years prior to the go-along (when he was 33) and maintained an undetectable viral load for two consecutive years despite occasional crack cocaine and methamphetamine use. He reported using drugs prior to seroconverting and shared that his drug use does not interfere with his ability to maintain follow-up appointments. He was unemployed and had been receiving disability benefits and publicly subsidized housing since his diagnosis. He had not disclosed his HIV status to his boyfriend and was estranged from his family. When asked during the in-depth interview if he had challenges communicating with his HIV care clinician, he said,

I don't at all. I can talk to her about any and everything. Anything I need or anything I need to know I can call her or they'll email her and she'll call me back a couple of days later. The only thing I don't like is the social work team. The social worker I have, some days this man is not heard from. Some days he's spaced out, and I just don't get it. Like, if I'm your client, you're my social worker. And you give me a list to call? You give me that list you should already have called around to certain places before I do it.

Overall, Devin's visit showed how having multiple, co-located relevant services could help support retention in care when patient-clinician rapport is ordinary. However, the go-along revealed nuanced information regarding the true nature of his experience and communication with clinicians.

3.1.1 Clinic location and resources—Devin attends a well-established HIV care clinic affiliated with a university hospital in Baltimore. The clinic is located within walking distance from a subway station and has a bus stop, which Devin uses to attend visits. His healthcare team includes a HIV physician, a social worker, and a nutritionist. The nutritionist recommended healthy meals and orders them for delivery directly to his home through a social service voucher. There was also an on-site pharmacy. His go-along included appointments with all three clinicians.

3.1.2 Sources of clinic support combating stigma—Devin checked in for his appointment at a check-in desk, which had partitions to maintain patient privacy. Because he is a familiar patient, receptionists and clerical staff recognized and greeted him when he and the researcher entered the clinic. After checking in, other nurses and staff greeted him while he and the researcher sat in the lobby. In the lobby, there was a banner that read "Pronouns matter," referring to respect for personal preferences like "he" or "them," despite the fact that the facility is not focused on LGBTQ patients. The waiting area also had a bulletin board with spiritual messages such as, "Stay Prayed Up" and "Trust God."

3.1.3 Patient-clinician interactions—Devin's first appointment with his HIV specialist was 15 minutes late due to an extended appointment with a prior patient. When the appointment began, his physician (a white woman in her mid-30s) began by asking about his lifestyle, "*What's going on in your life right now?*" She also asked targeted questions

regarding potential changes in lifestyle, housing, and employment status. Devin described challenges living with his new boyfriend and being at risk for eviction since his boyfriend was not paying rent and he could not work due to his disability status. The physician listened and asked about future housing plans. He said that he didn't have the money to move or pay the rent, and the physician reminded him that their social work team could help him obtain affordable housing. She confirmed if he was still working with them then asked, "*How often are you missing a dose?*" He responded, "*Only like once a week, if that.*" She praised him and proceeded to ask if he has been "*Top, bottom or verse?*" and encouraged him to screen for extragenital STIs based upon his response. When she asked him about drug and alcohol use, he denied using drugs, although he had described crack cocaine and methamphetamine use during the in-depth interview in the parent study. At the end she asked, "*What else do you need today?*" She wrote his prescription for HIV medications, and he went to the restroom to provide samples for STI testing. The visit lasted approximately 15 minutes. Overall, their rapport appeared to be mutually respectful but not overly close given his short, 1–4-word responses.

After his HIV care visit, he waited for his next appointment to meet with his social worker and explore housing options. After about five minutes of waiting, Devin used the public phone in the lobby to call his social worker and inquire about the delay. Shortly after he talked with the social worker, he was prompted to proceed upstairs for the appointment. The social worker, a middle-aged white man, apologized for the delay and tried to calm aggravated Devin down. He asked about his housing needs, and Devin shared his concerns with the possibility of needing affordable housing. The social worker mentioned that he was missing a necessary form to process Devin's earlier request, and Devin emphasized that he already submitted the form, increasing in aggravation. The social worker proceeded to look through a junk pile of mail and maintained that he was missing the document. He showed the social worker email correspondence on his phone confirming that he sent the requested document. Soon after, the social worker found the document and proceeded to process the housing request. The visit lasted about 15 minutes, and Devin left the appointment frustrated.

The last appointment was with a nutritionist sponsored by Ryan White in collaboration with a large supermarket in Baltimore. The nutritionist on staff was a substitute for his normal provider, who was on vacation. She opened a program on her computer, identified his case, outlined his budget, and then shared her screen showing a list of groceries he could purchase for the month. The two collaborated on the types of meats, vegetables, and fruits that he liked and discussed general health benefits of the foods he chose, all of which could be seen within the program she was using as she clicked on different food items. Occasionally the meeting was disrupted by the nutritionist's personal cell phone calls, which she answered during the appointment. She discussed her personal concerns about her home life with Devin as the research sat in the background, further agitating him and making him eager to complete the visit. Once they decided on food items, they continued collaborating to optimize his budget and obtain as many food items as possible, rearranging the cart to search for cheaper items or reducing the quantity of items. Once the grocery list was finalized, they scheduled a time for delivery to his home. This visit lasted almost 30 minutes.

3.1.4 Post-observation interview—During debriefing, Devin shared that this visit was typical despite the presence of a researcher. When asked about his short responses with his provider, he mentioned that his primary objective with his HIV provider is always to refill his HIV medication prescriptions. He also mentioned that “*she didn’t need to know*” about his drug use. When asked about racial or cultural preference for clinicians, especially for one at the facility who is a Black, gay-identified man, he mentioned preferring a culturally incongruent team because “*He out here just like I am, so he can’t tell me anything. I don’t want him knowing my business.*” When asked if he was upset with his visit, he said, “*Yeah, at least everything is here though.*”

3.2 Dominic

Dominic is 59 years old and at the time of the go-along had been LWHIV for more than 20 years. He reported living with an undetectable viral load for almost the same amount of time. He shared that he was also receiving disability services and residing in subsidized housing. His drug use included occasional crack cocaine use, which he said did not affect his ability to maintain follow-up appointments. He attended a different HIV care facility that is also affiliated with a major hospital with multiple specialty departments. During the in-depth interview, he mentioned his family did not know that he is gay or LWHIV. In the interview he was asked to discuss his relationship with his HIV provider since he had not disclosed his sexuality or HIV status to family. He said,

I think we have one of the better relationships that I have, so as to how it could be better, I’m not sure how because I have a strong relationship with my doctor. I really do. Just like I’m looking you in your face it’s like we’re man to man and that’s the way I carry on with him. And he knows when I come walking in that door, “Okay, I got to sit my ass down, listen to this man and talk to him, answer all his questions, and whatever he want, I have to apply myself.”

Overall, Dominic’s case demonstrates how social support within the clinic and positive rapport with clinicians could circumvent other experiences of stigma. His clinical experience was more congruent with the description he provided in the in-depth interview than Devin’s.

3.2.1 Clinic location and resources—Dominic caught the bus to the clinic, which has a stop directly in front of the building in addition to a subway station in case patients need an alternative route. He mentioned that he has a bus stop on the street where he lives so it is manageable to get to and from the clinic. In the clinic, there is an automated kiosk where he can check-in and notify the healthcare team that he has arrived. During the in-depth interview and go-along, he mentioned that he attended a community social support group held at the clinic that has members of different races, sexual orientations, and HIV serostatuses.

3.2.2 Patient-clinician interactions—While waiting in the lobby, nurses and other clinic staff who recognized him greeted him and talked casually about current events in his life and events in the city. When the physician was ready, a nurse escorted him to his room for the visit. The physician was a middle-aged, South Indian-American man. He began the visit with a hug. Dominic asked about his wife. The physician responded joyfully then

asked Dominic about the current events in his life. They talked casually about the quality of his sleep, his eating habits, and whether or not he was still smoking cigarettes, which the physician encouraged him to “*cut down on.*” Quickly into the visit, the physician noticed a scar on Dominic’s hand and mentioned “*that wasn’t there during your last visit,*” which was three months ago. Dominic mentioned hitting his hand on something sharp at home. His physician also mentioned noticing weight loss since their last meeting. They transitioned to talk about Dominic’s cholesterol along with the neuropathy that resulted from the statins the prescribed at the last visit. His physician apologized for the treatment recommendation and outlined alternatives for the neuropathy. He outlined all pros and cons, including the costs and copays for each prescription, then explored Dominic’s treatment interests. Dominic chose one and they both agreed to try it and assess his progress during the next visit. Neither Dominic nor the physician ever mentioned HIV status, viral load, or medication adherence. Drug use also was not discussed. Only at the end of the visit when the provider asked if a refill was needed was HIV referenced. They planned to meet again in six months. At the end of the appointment, Dominic said, “*Doctor, I say this all the time, next to my family, you’re the most important man in my life.*” The visit lasted approximately 30 minutes.

3.2.3 Sources of clinic support combating stigma—After the appointment, Dominic went to the clinic’s in-house pharmacy to obtain his prescriptions. At the entrance, there was a sign that read, “*What name do you go by?*” There was also an indication on the floor for where to stand in line to give others space and privacy to talk with the pharmacy technicians. The prescription was quickly filled, and Dominic checked out using the automated kiosk where he checked in.

3.2.4. Post-observation interview—During debriefing, Dominic mentioned that his visit was typical despite the presence of a researcher and that occasionally he talks with his provider for up to one hour about a variety of personal issues that affect him and always looks forward to working with him. This go-along suggested that having a supportive clinician and familial support groups in the clinic could supplement non-disclosure to family and support HIV care maintenance.

4. Discussion

This study detailed the observations of a follow-up visit among two BSMM of different age groups who have continued their HIV care and maintained viral suppression despite facing many of the same challenges as those who did not. Data revealed nuanced details regarding structural factors such as clinic setting, facilities, and services in addition to interpersonal factors such as patient-clinician interactions. Accessible public transportation, inclusive language in the clinic, and co-located services were identified in both cases and could contribute to successful HIV care maintenance for BSMM of different ages. Positive rapport with clinicians could also contribute to HIV care maintenance for these men. Personal motivations that contributed to HIV care maintenance and viral load suppression were also identified. These factors are consistent with previous studies detailing elements that support HIV care maintenance for marginalized groups (Brion, 2014; Carey et al., 2018; Jemmott et al., 2019).

Although some structural factors were similar between the two cases, personal motivations for specific goals for follow-up and viral suppression differed. In Devin's case, the convenience of having co-located medical and social services could outweigh consistent frustrations from unprofessionalism and low rapport with clinicians because he is low-resourced and might not obtain as many benefits otherwise. In Dominic's case, positive social interactions and deeper rapport with clinicians, staff, and other community members could strengthen motivations to follow-up despite having to catch two buses to maintain healthcare and not disclosing sexuality or status to family. Social support is important for BSMM LWHIV (Dangerfield II et al., 2018; Quinn, Dickson-Gomez, Broaddus, et al., 2018). For some, receiving social support from healthcare facilities and medical providers could be the only support they receive. BSMM of different ages could have different support needs due to differing lengths of exposure to stigma, rejection, resource instability, and HIV infection (Dangerfield II et al., 2020). Therefore, younger men might prioritize immediate tangible resources and older men may prioritize more caring environments.

While research shows that some BSMM prefer culturally congruent clinicians (Cooper et al., 2003; Dangerfield II, Cooper, et al., 2020), our data suggests that providers who are not Black or sexual minorities can build rapport and support retention in care for BSMM. Having open and personalized dialogue could build trust and support retention in care for BSMM (Dangerfield II, Cooper, et al., 2020). Clinicians who can discuss the costs and side-effects of different treatment recommendations could address social determinants of health and barriers to treatment adherence (Dangerfield II et al., 2020; CDC 2019). By outlining costs and side-effects of treatment recommendations, clinicians can create an environment of shared decision-making that can build trust among BSMM. However, neither patient disclosed their illicit drug use to their providers, suggesting lack of full trust in the provider. Motivations for illicit drug use were also not discussed. Drug use could be an additional source of stigma for BSMM (Dangerfield II, Cooper, et al., 2020; Dangerfield II et al., 2018) and despite good rapport with providers, BSMM may be reluctant to discuss it. Moreover, training in substance use disorders is limited in nursing and medical education and providers may not be comfortable screening for drug use or providing substance use treatment recommendations.

In both cases, other HIV comorbidities such as depression, anger, and medication fatigue were not discussed between patients and providers. The more general health-related discussions could in part be due to both men's overall adherence. However, it is well-established that BSMM LWHIV experience psychosomatic challenges due to their serostatus (Arnold et al., 2014; Bird & Voisin, 2013; Overstreet et al., 2013), which could disrupt their treatment adherence and follow-up. Participants in the present study revealed that few individuals in their family and community knew they were gay and LWHIV. Providers should screen for psychological challenges associated with long-term treatment adherence and inquire about interest in mental health referrals among BSMM LWHIV, since feelings of isolation and stress are salient for this group.

Future intervention research studies should explore these factors among a larger sample of BSMM LWHIV and among BSMM living in other U.S. contexts. Intervention activities focused on patient-provider interactions could improve retention in care among BSMM

LWHIV. Most interventions to increase viral suppression involve behavioral interventions to improve HIV treatment adherence (Mannheimer & Hirsch-Moverman, 2015; World Health Organization, 2013), which have largely been unsuccessful among BSMM as evidenced by the persistent low prevalence of viral suppression for this group. Many interventions to improve retention in care include smartphone apps, intensive outreach, and peer navigators to support care coordination (Cao et al., 2017; Morgan et al., 2019; Tanner et al., 2016; Thompson et al., 2012).

4.1 Limitations

Generalizations cannot be made from a sample of two individuals. The researcher's presence could have influenced clinicians' interactions with patients due to being observed. This is another reason why multiple go-alongs would be useful. However, triangulation with interview data from the parent study suggests that researcher impact on clinician interactions was likely limited, since participant descriptions of rapport and interactions with clinicians and staff in the interviews was congruent with the observations. Limiting data collection to a single go-along not only precluded data saturation or generalizability, but limited inferences that can be made about these participants' overall relationships and interactions with clinicians. Ethnographic research typically includes longer periods of cultural immersion within the study population (Winder, 2015). However, other research has documented shorter ethnographic go-alongs, and triangulating experiences with responses from in-depth interviews could strengthen the validity of findings (Murray et al., 2009).

4.2 Conclusion

Go-alongs expanded upon in-depth interview data and provided more detailed information regarding multi-level factors and clinical experiences that could support retention in care and viral suppression among BSMM LWHIV. These factors would have been missed in in-depth interviews without the supplemental contextual data of the go-along. Contextual factors and underlying motivations for seeking care could contribute to HIV care maintenance and viral load suppression among BSMM.

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Research data are not shared.

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