Desire for Patient-Centered HIV Care Among Inconsistently Engaged Racial and Ethnic Minority People Living With HIV

Jessica Jaiswal, PhD, MPH*
Marybec Griffin-Tomas, MPH, MA
Stuart N. Singer, BFA
Helen-Maria Lekas, PhD

Many low-income people of color living with HIV are not virally suppressed. More research is needed to understand how socially marginalized, disengaged, or inconsistently engaged people living with HIV (PLWH) contend with antiretroviral therapy (ART)-related challenges, particularly in the context of interactions with HIV care providers. Twenty-seven semi-structured interviews were conducted with low-income Black and Hispanic PLWH in the New York City area who were currently, or recently, disengaged from outpatient HIV health care at the time of the interview. Participants valued patient-centered health care in which they felt genuinely heard and cared for by their HIV clinicians. This desire was particularly pronounced in the context of wanting to change one’s ART regimen. Participant emphasis on wanting to manage ART-related challenges with their providers suggests that HIV providers have an instrumental role in helping their patients feel able to manage their HIV.

HIV is now considered a chronic and manageable illness as a result of the advent of highly effective antiretroviral therapy (ART; Mugavero, Norton, & Saag, 2011). Consistent ART adherence is a critical part of the HIV care continuum (also called the HIV treatment cascade), which comprises the stages from first being diagnosed with HIV, becoming linked to care, and then remaining engaged and adherent, ideally culminating in viral suppression (Thompson et al., 2012). Poor adherence to treatment regimens often results in a number of problematic outcomes, including high viral loads, low CD4+ T cell counts, preventable hospitalizations, frequent emergency department usage, excess morbidity and mortality, and an increased likelihood of developing drug resistance (Cheever, 2007; Giordano et al., 2007; Mugavero et al., 2009). Moreover, poorly controlled HIV contributes to the transmission of the virus to sexual and drug-using partners (Skarbinski et al., 2015). Only 28% of people living with HIV (PLWH) are virally suppressed (Cohen et al., 2012), and failed linkage to and retention in care results in
the most significant missed opportunity to achieve viral suppression in the United States (Centers for Disease Control and Prevention, 2015).

Barriers to HIV medication adherence by PLWH have rarely been attributed to one barrier, but rather, overlapping and mutually reinforcing syndemics (Singer & Clair, 2003) make it difficult for individuals to adhere to ART regimens (Friedman et al., 2015). Many PLWH, and especially those who belong to racial, ethnic, and sexual minority groups, have not received ongoing HIV health care (Cunningham et al., 2006; Meyerson, Klinkenberg, Perkins, & Lafoon, 2007). Studies have found that Black participants experienced higher levels of syndemic barriers and poorer medication adherence than White participants (Beer, Mattson, Bradley, & Skarbinski, 2016; Maulsby et al., 2014). A study using data from the Multisite Adherence Collaboration on HIV (MACH14) found that 65% of African American participants and 64% of Hispanic participants were adherent to their ART regimens, whereas 72% of White participants were adherent to treatment (Simoni et al., 2012). Similarly, data from the North American AIDS Cohort Collaboration on Research and Design collected between 2000 and 2010 found that African American males had a higher hazard ratio for ART discontinuation as compared to either their female or White counterparts (Rebeiro et al., 2017) due to myriad barriers. Likewise, socioeconomic groups with lower income also tended to fare worse than higher income groups (McAllister, Beardsworth, Lavie, MacRae, & Carr, 2013).

HIV care providers play instrumental roles in helping their patients contend with ART-related challenges. A study of 255 patients with HIV found that the patient–provider relationship was the only statistically significant relationship that mediated emotional avoidance and ART adherence (Berghoff et al., 2017). Moreover, a qualitative study of 23 patients who were highly adherent to their ART regimens found that early positive experiences with HIV care providers was a critical component of managing the HIV diagnosis and living with HIV (Brion, 2014).

Patient-centered care in particular may provide additional support to PLWH. Patient-centered medicine (PCM) seeks to create an environment in which people are “known as persons in the context of their own social worlds, listened to, informed, respected, and involved in their care—and their wishes are honored (but not mindlessly enacted) during their health care journey” (Epstein & Street, 2011, p. 100). This type of care endeavors to “focus on outcomes from the patient perspective” (Krumholz, 2011, p. 374), and studies have demonstrated that PCM is associated with higher patient satisfaction, more patient-centered communication, and improved health outcomes (Flach et al., 2004; Flickinger et al., 2016; Rathert, Williams, McCaughey, & Ishqaidef, 2015). For example, a study of 1,743 PLWH found that patient-centered care was linked to three improved HIV-related outcomes: initiating ART, adherence to ART, and achieving viral suppression (Beach, Keruly, & Moore, 2006).

Respectful patient–provider relationships are especially important in the provision of HIV care and may help mitigate HIV-related stigma (Flickinger et al., 2016) and medical mistrust among racial and ethnic minority people (Laws et al., 2014). Several studies have documented greater concerns about medication and provider mistrust among Black populations, in particular (Gaston & Alleyne-Green, 2013; Kalichman, Kalichman, & Cherry, 2017). For example, a longitudinal study of African American males living with HIV found that general medical mistrust was a strong predictor of suboptimal medication adherence over time (Dale, Bogart, Wagner, Galvan, & Klein, 2016).

The support offered by HIV care providers is a vital, yet sometimes overlooked, aspect of medication adherence. By recognizing patients who have adhered to medication regimens or encouraging those who are not optimally adherent, HIV care providers create a space for dialogue between patient and provider (Beach et al., 2015). During this dialogue, providers may bolster patient self-efficacy and self-esteem and, ultimately, improve engagement in care and medication adherence (Beach et al., 2015). A robust literature has suggested that self-efficacy is also related to increased medication adherence (Chen et al., 2013; Reif et al., 2013; Tyer-Viola et al., 2014). Data from a clinic-based study found that self-efficacy led to increased medication adherence, which, in turn, led to habit formation (Phillips, Leventhal, & Leventhal, 2013). Furthermore, the stronger the habit formation, the better it became as a predictor of medication adherence.
Habit formation has also been closely linked to self-esteem, a common promoter of health behaviors (Traube, Holloway, & Smith, 2011; Tyer-Viola et al., 2014).

Given how critical ART adherence is to viral suppression, it is important to explore how people contend with ART-related challenges, particularly in the context of their relationships with HIV care providers. Although there is a wealth of extant literature qualitatively exploring patient–provider relationships, there is a lack of qualitative work examining adherence-related challenges (Barroso, Leblanc, & Flores, 2017). Bridging the largely quantitative extant literature on adherence with the rich qualitative literature on PCM will help improve understanding of the unique intersection of ART-related challenges and patient–provider relationships. Moreover, there is also little extant literature exploring the experiences of PLWH who are either disengaged from or inconsistently engaged with HIV care, a population that is difficult to reach, often due to a multitude of socioeconomic and psychosocial barriers, including substance use, housing instability, poverty, and experiences of systemic racism and classism (Rebeiro et al., 2017). Knowing more about this group of people is essential to achieving viral suppression, as they are at higher risk for not being fully retained in care. A qualitative perspective can add to our understanding of these complex phenomena, help contextualize some of the previous findings, and make rhetorical space for patients to articulate, in their own words, their lived experiences (Patton, 2005).

In this paper, we qualitatively explore the intersection between ART regimen challenges and experiences with HIV care providers in a difficult-to-reach sample of socially vulnerable and marginalized low-income, racial and ethnic minority PLWH. Specifically, we (a) explored the life circumstances and HIV care trajectories of people who were either disengaged, had recently re-engaged, or were trying to re-engage in outpatient HIV care at the time of the interview; and (b) examined the desired provider characteristics of this sample, who, due to challenges with HIV medication, had thoughtful ideas about what they needed from their providers in order to successfully manage their health.

Methods

Sample Study Population and Recruitment

From July 2015 to May 2016, participants were recruited from a larger purposive sample used in the parent study that examined disengagement from outpatient HIV care among low-income Black and Hispanic PLWH. For the study presented here, most potential participants were contacted via telephone using contact information provided in the parent study. The parent study recruited participants from a university hospital when individuals were hospitalized overnight or longer for untreated HIV. It is important to note that while the sample of participants, originally recruited in the parent study, were recruited at a single hospital, the participants themselves had histories of attending a wide variety of clinics across all five boroughs of New York City (NYC). Given the multitude of HIV clinics available in NYC, and how each clinic may have several HIV specialists (e.g., the university clinic had 8-10 specialists), the perspectives presented here reflected diverse experiences with providers. Specifically, participant experiences referred to medical providers across the NYC area, and not necessarily the same provider or even the same clinic.

It was difficult to reach potential participants due to their limited contact with the health care system stemming from challenges related to substance use, housing instability, and/or poverty. In order to reach the participants sampled here, the first author employed numerous Health Insurance Portability and Accountability Act-compliant strategies to locate these hard-to-reach individuals, including connecting with social workers and case managers, contacting family and friends using information provided by participants in the parent study, and checking with the hospital’s patient coordinator for new in-patient admissions. Of the 33 individuals for whom follow-up contact information was available and still functional, 27 agreed to participate. Two declined participation, citing lack of time, and one person agreed to participate but was found to be not mentally competent and, therefore, unable to consent to participation; the remaining three were reached via telephone, but their numbers appeared to go out of service before
an interview could be scheduled. Five participants were contacted in person and subsequently inter-viewed when they were hospitalized at the university hospital. The institutional review board of Columbia University Medical Center approved this study, and all participants consented to participate.

**Data Collection**

In-depth qualitative interviews can generate novel insights by enabling participants to express their life experiences and perspectives in their own words (Patton, 2005; Strauss & Corbin, 1998). Given the potentially sensitive nature of the topic of personal health, qualitative interviewing honors participants’ ways of thinking and enables them to articulate experiences in their own words. The first author, who had extensive training in qualitative methods, with a particular focus on eliciting sensitive information about HIV status, mental health, sexuality and sexual behaviors, and other potentially stigmatizing topics, such as substance use, conducted the semi-structured interviews. In order to protect confidentiality, participants were assigned pseudonyms that were similar to their true names and/or reflected their respective cultural backgrounds.

The first and last authors developed a semi-structured interview guide to examine barriers and challenges related to engagement in outpatient HIV care and adherence to ART. Interview guide topics included questions about experiences with outpatient HIV care, ART adherence, and experiences taking ART, and other barriers and facilitators related to engagement in care. Questions were semi-structured and designed to elicit participant experiences and beliefs related to HIV and management of their HIV and overall health. Qualitative interviews ranged from 25 minutes to 2 hours, with an average of 45 minutes. Prior to the in-depth interviews, an interviewer-administered questionnaire was also completed with participants. This 5- to 8-minute survey gathered demographic and health status information.

Preliminary analysis of the data began after the first completed interview, and concluded when saturation was reached at 25 interviews (Creswell, 1998). To confirm that saturation was achieved, two additional interviews were completed.

**Data Analysis**

All interviews were audio recorded for professional transcription. Twenty percent of the transcripts were randomly selected for quality control and to assess accuracy, which was conducted by the first author. Analyzing qualitative data necessitates the development of a rigorous and organized method of managing and analyzing a complex set of data. The method must also ensure that the analysis plan did not compromise the conceptual richness of the data. The first author implemented a multistep method to systematically identify and contextualize the themes present in the data, which included developing a coding scheme and using it to discern patterns, themes, and subcategories. The scheme was a hierarchically organized tool that ranged from general and abstract to more specific concepts. At the top of this hierarchy, the first author identified the analytic foci, which were coded as headings, then the core codes that referred to specific aspects or dimensions of the headings, and finally, sub-codes that referred to specific dimensions of the core codes. An example of a core code was “good patient–provider relationship,” as defined by participants, and examples of sub-codes related to this code were “provider genuinely cares for patient” or “provider listens closely to patient.” After all transcripts were read multiple times and coded, text segments organized by codes/sub-codes were extracted in order to begin discerning higher levels of abstraction and to identify relationships between the various codes. The analyses were closely reviewed by the first and last authors, as well as another senior member of the research team, to confirm themes and address any differences in interpretation. The software Atlas.ti was used to organize the qualitative data. Data from the interviewer-administered questionnaire, analyzed using SPSS (IBM, Armonk, NY), were used to generate a description of the sample of participants.

**Results**

**Quantitative Findings**

The analytic sample consisted of 27 low-income PLWH of color. Table 1 describes the participant
The age range of the sample was 28 to 55 years of age. The sample was 59% female (n = 16) and 41% male (n = 11). The majority of participants identified as non-Hispanic Black (78%, n = 21), and 22% (n = 6) identified as Hispanic. All participants in the sample had Medicaid. The majority of the sample (89%, n = 24) reported being unemployed at the time of the interview; 11% (n = 3) were employed part-time or full-time. Ninety-three percent reported that they lived in New York City-funded HIV/AIDS Services Administration housing, other public assistance-funded apartments, or single-room-occupancy housing. The remaining participants reported that they lived in a nursing home or hospice (11%), had no financial housing assistance (7%), or were homeless (30%). See Table 1.

### Qualitative Findings

Participants recognized, and greatly appreciated, providers who practiced PCM, and the overarching theme that emerged from the data was titled: Role of providers in conveying genuine concern, and supporting ART use and adherence.

Two subthemes emerged as characteristics participants desired in their relationships with HIV care providers: (a) genuine concern, and (b) feeling heard (respected, included in treatment decisions, and being given treatment options). The subthemes reflected the core features of PCM. Participants desired these characteristics in their relationships and interactions with providers, and providers who conveyed these attributes appeared to contribute to participants feeling comfortable and confident, particularly related to taking ART.

In discussing these interactions, participants described many of the tenets of PCM. Having a provider that embodied these characteristics appeared to facilitate engagement in care and, more specifically, retention in care and adherence to ART. It is important to note here that participants referred to their respective clinicians as “doctors,” which, for this sample, could include physicians (MDs or DOs), nurse practitioners, doctors of nursing practice, and physician assistants. Participants were not necessarily aware of these nuances, and often did not know whether or not their “doctors” were internal medicine providers, or HIV/infectious disease specialists. This was made clear during the screening process in which participants filled out information about their HIV care, including provider data, as well as during the qualitative portion of the interview in which the interviewer and the participant discussed the latter’s experiences with providers in detail.

#### Subtheme 1. The value of provider genuine concern

Participants reported various types of interactions with HIV care providers. Some had been with the same provider for 10 or more years, but were not on ART, while others had only recently engaged with an HIV provider on a consistent basis and were on ART. Regardless of whether their relationships with providers were long term or newly established, participants highlighted the importance of feeling that providers were genuinely concerned about them. For example, Jay, a 31-year-old Black man, was largely disengaged from outpatient HIV care and not on ART at the time of the interview. He was interviewed at his bedside while hospitalized for fatigue, shortness of breath, and “probably a little pneumonia,” in his own words. At the time of the interview, Jay had been hospitalized for similar reasons...
twice in the preceding 2 months. Although he expressed appreciation for the way in which his HIV provider interacted with him whenever he visited her, he continued to struggle with accepting his status, “I don’t even wanna think about it … it makes me angry, so I really don’t wanna talk about it.” This lack of acceptance appeared to largely account for his frequently scheduled but missed appointments, although he stated that he planned to make a clinic appointment to see his provider after his hospital discharge. He remarked,

[Dr. S is] my best doctor … She did everything for me. She lets me know what’s gonna happen if I don’t do this and don’t do that. She just talks to me where I don’t have to talk back … She’s smart. She always helps me out. Just looking after me.

CeeCee, a 48-year-old Black woman, was diagnosed in 2006. Her viral load was undetectable and she reported having been on ART consistently for 1 year at the time of the interview. She reported having struggled with alcohol and cocaine use, which had contributed to her difficulty staying consistently engaged in care, as she reported that she had sometimes sold her HIV medications to pay for cocaine. She explained why she was confident that her HIV provider was genuinely concerned about her well-being:

My doctor … She’s very—she’s into your health. She called me late at night, gave me her cell number. She made me go the hospital … my protein level was high, and my potassium was high. This was about 2 weeks ago, or 3—2 or 3 weeks ago, I was in the hospital. They kept me overnight. Then, they brought me back home cuz of the swellin’. I still get edema or whatever in my limbs … She thought I was going through a—she thought my kidneys were gonna stop workin’. She made me go. She’s very concerned.

Similarly, Sandra, a 43-year-old Black woman who had lived with HIV for 25 years, was one of the few participants (like CeeCee above) who was undetectable, engaged in outpatient HIV care, and consistently taking ART at the time of the interview. After many years of struggling to accept her status and overcome internalized stigma and the stigma she experienced from her family, Sandra was finally able to manage her health. She described how her HIV provider’s concern for her health conveyed genuine caring:

I was sick one day, and she, my doctor, just wanted to just wheel me down the emergency room. I was like, “No. I’m okay. I’m okay. I’m okay. I just need some rest. I need to go home and rest.” She’s like, “It’s up to you, now. I’m your doctor, but I really can’t force you.” I had a little abdominal pain, but it went away. She was so concerned. When I got home that day, she called me, asked me was I all right. That’s what also keeps me goin’ because there are people out there that really care. They’re not people out there just wanna get in your business. There are people that really care, and I think that she’s one of the doctors that do care.

Subtheme 2. The value of feeling heard by one’s provider, particularly in the context of wishing to change an ART regimen. Related to the value placed on feeling genuinely cared for, participants also emphasized the importance of feeling heard by their providers. Feeling heard entailed feeling included in decisions about their care, especially ART-related decisions such as being given a choice or presented with options in terms of their regimens or discussing together how to select a regimen. These interactions made participants feel respected and promoted a sense of agency, a core feature of PCM. Tina, a 53-year-old Black woman, was diagnosed in 1995 and, like many participants, had experienced struggles with pill fatigue, and forgetting to take her medication. She noted:

We talk about everything, so I like her … Meds, my health, and what—how my viral loads go down and what makes ‘em go up and things I should do and shouldn’t do. She’s nice … I feel like she’s honest. I don’t know if she is, but she’s honest with me … She told me certain things, and I believe her. I have no reason not to. She’s my doctor. She talks to me. Most doctors don’t talk to you … none of them other doctors I
had didn’t talk to me. They just give me my meds and send me home, or take my pressure and stuff and send me home. They don’t sit and listen to me.

In addition to feeling listened to, feeling heard, as experienced through being given the opportunity to co-construct care, particularly in relation to HIV medication, was also valued. Tanya, a 40-year-old Black woman diagnosed in 1993, had been sober for 8 months and had not relapsed due to her participation in a drug treatment program for her crack use. She remarked:

“[My provider]’s helpin’ me. He changed my meds when I asked him to change my meds. I don’t have no problem with my doctor.”

Janae, a 43-year-old Black woman, had been taking ART consistently for 1 month prior to the interview. She had recently switched to a new medication due to side effects, after an extended period of feeling that her ART concerns were being ignored by her provider. She highlighted how coming to a point where they could “work together” on managing her ART issues was essential to establishing a good relationship:

I kept goin’ [to the doctors], “I’m not takin’ it,” because it give me night sweats, it make me have bumps and chills and everything. They said, “Oh, it’s part of the side effects.” … I’m not gonna keep takin’ somethin’ that’s gonna make me sick. I’m not gonna take it, you know? I’d just rather leave it, leave it as is. Sometimes I just felt like givin’ up ‘cause I’m like, “If y’all not gonna gimme no pills then just leave it.” Just let it go, ‘cause I’m not gonna keep takin’ somethin’ and I’m gettin’ sick, throwin’ up all the time, not eating, not lookin’ like—not care for my children, not carin’ for myself or the household or anything. This [new] pill is workin’ … At first I didn’t [trust my doctor], because she didn’t give me the right meds. Now she find me the right one, because, I felt that you ain’t wanna help me. I had that attitude that you did not want to help me … [The clinic] told me she was a good doctor … I’m not gonna down her. She’s damn good … When I come at you—I’m comin’ at you because somethin’ is not workin’. Somethin’ is bothering me. Don’t look at me and say, “Hmm, well maybe you’re not takin’ it right.” I’m like, “You downin’ me? You think I’m not takin’ my meds? Okay, if you don’t trust me, I won’t trust you.” That’s how I felt until we had that communication. I’m like, “Okay, calm the attitude down,” and just tell her, “Well, okay. This is how it is.” I told her how it is and we was workin’ together. Ever since then I ain’t got no problems, no problems.

For Janae, perceiving her provider as not trusting her or viewing her as a competent patient was initially extremely frustrating, but finally achieving “that communication” enabled Janae to trust her provider and facilitated her adherence. Janae’s use of the term “downing” to describe feeling disrespected also reflected her desire to share the power and to co-construct a collaborative, mutually respectful relationship with her provider. This collaborative relationship reflected one of the core tenets of PCM, which is for providers to respect and respond to patient concerns. Specifically, her provider’s recognition that Janae was having a difficult time living her life as a mother suggested a patient-centered relationship.

Terrence, a 39-year-old Black man, was diagnosed in 1989 as a teenager, but had only sought care in his early 30s, having remained relatively healthy until 2007, when he was diagnosed with AIDS and began ART for the first time. He reported having gone to clinic infrequently, and not being able to continue his ART consistently. He attributed his lack of adherence to the regimented nature of having to take his medication every day to avoid becoming resistant, and his lack of consistent clinic visits to his good health that lasted from his early teen years to his early 30s. Terrence contrasted his current situation with his past negative experience with a provider. Again, this was expressed in terms of ART options, suggesting that choice, agency, and an atmosphere of collaboration were highly valued. He contrasted his past provider to his current as follows:

My [current] doctor, she’ll give you the [HIV medication] options and say, “Look. I think this,” and get insight from me, and see what my thinking is. “How do you feel about that? What’s gonna work for you and the dogs?”
It’s more in depth. It’s more personable, if you will … It’s not, “We’re pushing these meds. Forget [specific drug], don’t take that.” Well, tell me why I don’t need to take it. Give me a valid reason. Don’t just tell me because you guys are pushing [a specific drug company] or this one … It was about, “We’re gonna see what works for you.” For me, that was huge, seeing that actually happen … she gave me my options and went over my labs with me. When something’s good, she—not like makes you feel more good than you need to, but you can hear the genuine, “Okay. We got this. We’re on the right path. Keep it up. You’re doing good,” sort of a thing. That kind of encouragement kinda pushes me to wanna stay on my meds.

Here, Terrence’s provider demonstrated to him that she was interested in his insight, and was genuinely thinking about the significant role of his dogs in his life. This participant’s main source of strength and support were his two small dogs. Terrence almost had to give his dogs up due to housing instability, and his provider was clearly attuned to the importance of the dogs in his life. This reflected how Terrence’s provider saw him as a person not just a patient, which is another feature of PCM.

In contrast to Terrence’s provider, who was highly responsive to the most salient aspects of her patient’s life, Pablo explained how some providers failed to convey a feeling of genuine concern by appearing inaccessible, or failing to work with the patient to jointly arrive at a solution. Pablo, a 46-year-old Latino man, was diagnosed in 2001 and had been enrolled in an outpatient methadone clinic for 1 week at the time of the interview. He “got into drugs] at 12 years old,” and had been struggling with staying sober since then. At the time of the interview, he thought he was “dying” and needed to immediately start taking care of his health, which required him to begin to manage his substance use. Like many of the participants, Pablo had multiple comorbidities, including hepatitis C-related cirrhosis and diabetes. He had not been on ART for at least the prior 7 months, but had expressed a determination to re-start ART. Pablo described the characteristics he appreciated in a provider, as well as expressed frustration at providers who appeared to not genuinely care or listen to their patients:

… You got [to have a] doctor that take the time to talk to you. You got doctors that not … You see some doctors, they’re not worried about you. They don’t really want to work. They no worry about you. They don’t have time to ask the questions about it. They gonna tell you whatever he want to say. They’re not looking for some solution that you really want … They respond, [but] you can’t say, “Okay, I’m positive. I can’t do this. I can’t do that.”

In Pablo’s experience, a provider who is, “gonna tell you whatever he want to say” as opposed to opening a dialogue with the patient suggested that s/he was not committed to working with the patient and, more specifically, to hearing the patient’s concerns and opinions, and co-constructing care.

Aliyah, a 28-year-old Black woman, also reported that she was interacting with a provider who did not appear to be interested in hearing her concerns. Aliyah, born with HIV, had been adherent to her HIV medication (1 pill a day for the last year), but had been avoiding her HIV care provider around the time of the interview. She had been recently transferred from the pediatric HIV clinic to the adult clinic, and explained that she felt that she was forcefully transitioned against her wishes. Aliyah largely attributed her inconsistent, precarious care engagement (i.e., not attending regularly scheduled appointments and only going to see her HIV provider if she had a non-HIV-related problem) to the way in which her care was transferred from pediatric to adult care, as well as her provider’s apparent lack of concern about her drastic weight loss, which she attributed to her ART:

My doctor that I have now doesn’t—like he tells me that it’s the medicine. Basically, if I take the medicine I’ll gain weight. That’s what I’ve been doing. I’ve been doing the medicine but I’m still losing weight, and he doesn’t want to do anything about that … Personally, I feel like he’s just telling me what the—I guess what the doctor books say, you know, “Just take your medicine and you’ll be okay,” but it’s not—I’m still losing weight and no matter how much I eat …
That’s why I really don’t like him too much. Any times I do go to him, like I’m in extreme pain or like … I’ll have an ear infection, which I did have and I went to him. I really don’t go to him for my other stuff that’s going on. I don’t do it. It’s something physically wrong with me, like my foot hurts or my back is aching, I might go to him to try to fix it. Dealing with the HIV, I don’t go to him for that.

Overall, the value participants placed on feeling heard, which entailed not only being listened to, but having their opinions solicited and taken into consideration, was largely expressed in the context of ART and making ART-related decisions. In addition to ART decisions, participants also discerned and desired the following features of PCM: (a) being seen as a person, not as just a patient; (b) providers engaging in communication; and (c) behavior that would allow a more equitable distribution of power, and establishing a therapeutic alliance. Underlying these subthemes was the value participants placed on feeling genuinely cared for by their HIV care providers, which was underscored by being included in important decisions about their care, a process that engendered patient agency.

Discussion

Participant experiences with and reasons for disenagement were varied, but developing collaborative relationships with their providers were revealed to be highly salient aspects of the re-engagement trajectories. Specifically, participant narratives revealed a desire and appreciation for HIV care providers who practiced PCM care. In particular, this appreciation was expressed in the context of needing to change ART regimens due to side effects or other adherence-related difficulties.

It has been well documented in the literature that patient-centered care improves patient–provider communication, people’s feelings of self-efficacy, and clinical outcomes (Barry & Edgman-Levitan, 2012; Flickinger et al., 2016; Rocco, Cher, Basberg, Yalamanchi, & Baker-Genaw, 2011). The findings of our study emphasized the critical role of HIV care providers in practicing this type of health care, specifically in relationship to patient requests for ART regimen changes. As explored above, regimen changes have the potential to dramatically improve a person’s quality of life, as well as strengthen a sense of agency in managing personal health. A strengthened sense of individual agency can build trust with providers, thus increasing the likelihood for continued retention or improved engagement in care (Johnson, Gamarel, & Rose, 2006). For PLWH who are facing multiple forms of social inequality, strengthening of agency is particularly meaningful.

Participants also discussed the importance of having a provider who made them feel genuinely cared for and respected, which was often expressed as feeling heard and making joint decisions regarding ART regimens and other aspects of health care. Our findings affirmed studies that emphasized the importance of PCM in the context of HIV care (Beach et al., 2006; Flickinger, Saha, Moore, & Beach, 2013). For example, Flickinger and colleagues (2013) found that feeling known as a person by a provider was a facilitating factor in engagement and retention for urban PLWH in Baltimore, MD, in a study that was similar to the context and data presented here and that emphasized the importance of patients feeling heard by their providers.

It was meaningful that our participants recognized who engaged in PCM, and that providers practicing this type of medicine were able to engage and adhere more consistently. In particular, the issue of jointly choosing a regimen, or being offered treatment options and being invited to choose a regimen with one’s provider, was highly valued as a signifier of respect and collaborative care, the kind of care that bestowed dignity to the patient and bolstered her or his agency. This shared decision-making, “the pinnacle of patient-centered care” (Barry & Edgman-Levitan, 2012, p. 780), was particularly meaningful because, although participants reported having access to social workers, case managers, and other social service support staff, participants largely emphasized the importance of their HIV care clinician when talking about adherence. This emphasis underlined the importance of the HIV care clinician in the context of team-based care. Patients perceived the HIV care clinician to be the
team leader with the most power and influence; HIV care clinicians then had the unique potential to leverage that perception and share power with their patients.

**Limitations**

It is important to note that this study had several limitations. First, five interviews were shorter than the 45-minute average due to the participants’ poor health and fatigue. These individuals were hospitalized at the time of their interviews, whereas the majority of participants were able to come into the research center to be interviewed. However, the bedside interviews were important because they represented the experiences of the subset of participants that were otherwise not reachable at all due to disengagement from outpatient care. Moreover, while our research provided much-needed perspectives from PLWH who had experienced social and economic exclusion, we did not interview HIV care providers. It would be helpful to include the perspectives of clinicians to more fully understand the nature of the patient–provider relationship. Finally, as this study sampled only participants who were low-income and thus eligible for the city’s extensive network of HIV-related medical and social services, it would be helpful to explore how populations in underresourced areas, including nonurban communities, interact with and think about their HIV care providers.

**Recommendations and Conclusions**

Given nursing’s longstanding emphasis on patient-centered care, nurse clinicians are particularly well suited to provide meaningful and effective counseling about HIV medication. In particular, our findings can help inform clinical practice and public health interventions seeking to improve adherence, particularly for people who experience social marginalization and who may be inconsistently engaged in care and/or ART adherent. HIV care providers, most often serving as primary care clinicians for their patients and playing supportive roles beyond the clinical, are uniquely situated to work closely with patients to effectively face engagement challenges together. Participant emphasis on wanting to manage ART-related challenges with their providers suggests that the HIV provider has an instrumental role in not only increasing CD4+ T cell counts and achieving viral suppression, but also in helping patients feel empowered to remain engaged and adherent to ART.

It is important that HIV care providers help people feel worthy of care and welcomed to contribute to that care in order to enhance people’s abilities and desires to manage their HIV. For PLWH who are disengaged or inconsistently engaged, visits to HIV care providers may happen infrequently. Clinicians who communicate genuine care, concern, and respect for their patients, and who strive to involve patients in care, have the potential to reverse some of the negative emotions that undermine consistent engagement in care. Thus, it is critical that providers working with patients who are inconsistently engaged and/or socially marginalized, practice PCM, especially in the context of ART regimen-related challenges.

PCM aims to effect change at both the individual and population levels. For individuals, particularly those who are socially and economically marginalized and/or struggling with engagement, positive interactions with care providers who strengthen a sense of individual agency and increase trust in HIV care providers can increase the likelihood of continued engagement in care. On a population level, successfully linking this vulnerable population to care has the potential to increase the likelihood of achieving viral suppression.

**Conclusions**

Given the salience of the various ART-related challenges faced by our participants, the experience of being given choices, and being perceived as a partner in care, appeared transformative in helping people feel confident and optimistic about their abilities to manage HIV. Overall, our findings suggested that the presence of interpersonal facilitators engendered agency, provider trust, and the motivation to remain more consistently engaged in care and adherent to ART.
Key Considerations

- Patient-centered medicine (PCM) encourages providers to cultivate an environment in which patients feel genuinely heard, respected, and collaborative in their health care. This model of care may facilitate improved retention in outpatient HIV care and antiretroviral (ART) adherence.
- Although patients may have access to team-based care, including social workers, case managers, and patient navigators, the relationship with their main HIV care provider appears to be particularly meaningful, especially in the context of challenges around ART regimens.
- PCM can be particularly powerful for people living with HIV who experience social and economic marginalization and are inconsistently engaged or ART adherent.

Disclosures

The authors report no real or perceived vested interests that relate to this article that could be construed as a conflict of interest.

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References


care. Medical Care, 44, 1038-1047. https://doi.org/10.1097/01.mlr.0000242942.17968.69
HIV .
JANAC
12
550-553. https://doi.org/10.1080/09540120500241439


