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Building Trust and Relationships Between Patients and Providers: An Essential Complement to Health Literacy in HIV Care

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Abstract

Health literacy is important for access to and quality of HIV care. While most models of health literacy acknowledge the importance of the patient–provider relationship to disease management, a more nuanced understanding of this relationship is needed. Thematic analysis from 28 focus groups with HIV-experienced patients (n = 135) and providers (n = 71) identified a long-term and trusting relationship as an essential part of HIV treatment over the continuum of HIV care. We found that trust and relationship building over time were important for patients with HIV as well as for their providers. An expanded definition of health literacy that includes gaining a patient's trust and engaging in a process of health education and information sharing over time could improve HIV care. Expanding clinical perspectives to include trust and the importance of the patient–provider relationship to a shared understanding of health literacy may improve patient experiences and engagement in care.

Keywords

health literacy; HIV; HIV self-management; patient; provider relationship

The ability of individuals to find, understand, and follow health-related information, known as health literacy, can have a substantial impact on health outcomes (Institute of Medicine Committee on Health Literacy, 2004). This may be particularly true for complex and chronic health conditions such as HIV. The U.S. Centers for Disease Control and Prevention has estimated that only 86% of people living with HIV (PLWH) in the United States have been diagnosed and know that they have the disease, and even fewer are linked to care, engaged in care, and prescribed life-saving antiretroviral therapy (Gardner & Young, 2014). They further estimated that only 30% of PLWH have achieved viral suppression, the main marker of controlled disease. Although many factors contribute to this situation, it is likely that health literacy plays an important role that is not yet fully understood.

The notion of health literacy has been defined in various ways, with early conceptualizations seeing it as a set of individual capabilities within the social context of a health care encounter. In 2004, the Institute of Medicine Committee on Health Literacy defined health literacy as, “the degree to which individuals can obtain, process, and understand the basic health information and services they need to make appropriate health decisions” (2004, p. 32). Implementation of this clinical conceptualization of health literacy (Pleasant & Kuruvilla, 2008) focused largely on patients’ deficiencies in capabilities to direct their own health, seeing the lack of health literacy as a risk for poor health. More recent public health models of health literacy have examined health literacy as an asset, and as an outcome of health-related education and communication efforts (Nutbeam, 2008), but the exact relationship has not been empirically demonstrated. Although health literacy is clearly an important factor in health outcomes, neither the clinical nor the public health definitions fully acknowledge the relational aspects of the concept.

For most people, health literacy is closely interconnected with socioeconomic status, education levels, age, and race/ethnicity (Kutner, Greenberg, & Baer, 2006; Paasche-Orlow & Wolf, 2007; Wawrzyniak, Ownby, McCoy, & Waldrop-Valverde, 2013). Many individuals with low health literacy are marginalized within society based on these characteristics, and may also be ashamed of their lack of literacy (von Wagner, Steptoe, Wolf, & Wardle, 2009). Because of the stigma associated with HIV, PLWH may be doubly concerned about revealing their lack of health literacy within the clinical setting. In one recent study, investigators found that a high perception of social stigma was a significant independent predictor of poor medication adherence for those individuals with low literacy (Waite, Paasche-Orlow, Rintamaki, Davis, & Wolf, 2008). And, for people of color, historical events may be another barrier to accessing health care. Relevant patient and provider communication varies with levels of health literacy as the person with low health literacy may not know what questions to ask or may not fully comprehend what providers are explaining to them. For this reason, the patient–provider relationship (Paasche-Orlow & Wolf, 2007) may be particularly important to ensuring that patients receive the information and care that they need; an open relationship and a provider’s true knowledge of a patient’s understanding may help compensate for lower levels of health literacy.

We conducted a multisite qualitative study, the objective of which was to gain a more nuanced understanding of HIV health literacy and its relationship components, from the perspective of PLWH, providers, and other professional care team members. We suggest

that, within the overarching concept of health literacy, social and relational components are an essential complement to more capacity-based elements such as literacy and numeracy.

Methods

An international network of nurse researchers conducted this multisite qualitative study, the aim of which was to gain a more in-depth understanding of the meaning of health literacy for PLWH. Data were collected from 2013–2014 through a series of 28 focus group discussions at six sites in the United States, one site in Puerto Rico, and one site in Botswana.

Three types of participants were recruited from HIV clinics and service organizations: PLWH; health care providers (HCP), including nurse practitioners and physicians; and professional care team members (PCTM), including social workers, nurses, and physician assistants. Flyers were posted in clinics and AIDS service organizations; people who were interested in participating called the study telephone number or e-mailed the study address for more information. In addition, letters and flyers were sent to clinic leaders to distribute to clinic staff, including HCP and PCTM. Again, interested individuals contacted study staff for more information.

PLWH who were interested in participating were screened for eligibility, which included being 18 years of age or older, having the ability to provide informed consent, being fluent in the local language, being infected with HIV by self-report, and being available on the date of the focus group. Participants who were eligible then went through an informed consent process, including receiving information about the purpose of the study and participant requirements. They then signed informed consent forms.

Following the informed consent process, PLWH participants completed a brief survey, which included demographic, health, and HIV-related data. The survey also included a staff-administered Mini Mental State Exam (MMSE; Folstein, Folstein, & McHugh, 1975) to ensure cognitive ability to participate in the focus group discussion. Based on scoring norms, a score of 20 or less on the MMSE was considered an indicator of moderate to severe cognitive impairment (Folstein et al., 1975); for the purposes of this study we elected not to include patients with such cognitive impairment, as we were concerned they would not be able to contribute to the conversation and might, in fact, be a barrier to others participating fully. Therefore, these individuals were given a small monetary token of appreciation (\$10 USD). Three individuals were excluded from study inclusion due to low MMSE scores.

HCP and PCTM who were interested in the study contacted the investigators via phone or e-mail. Each person was screened briefly over the phone to determine eligibility criteria: 18 years of age or older, able to provide informed consent, fluent in the local language of the study, and available on the date of the focus group. Additional HCP criteria included being a provider of direct patient care (currently working with PLWH to direct their medical treatment plans) and being a nurse practitioner or physician. Additional PCTM criteria included working in a professional capacity to provide support to PLWH (e.g., registered nurse, social worker).

Nurse investigators experienced in HIV research conducted the focus groups. All investigators followed focus group guides that included questions related to how and where PLWH learned about their HIV. Additional probes were used to elicit information about the meaning of HIV health literacy and about how participants understood the need for treatment and for maintaining treatment. All focus group discussions took 60–90 minutes and were audio-recorded and transcribed. Transcriptions from Puerto Rico and Botswana were also translated into English. No names were disclosed during interviews.

Ethical Approval

Our study received ethical approval from each site, and from Rutgers University and the University of California, San Francisco, as coordinating centers. All participants in the focus group discussions received a monetary token of appreciation (\$20–\$50 USD).

Data Analysis

The investigative team used ATLAS.ti qualitative analysis software (ATLAS.ti., 2011, Version 6.2.0; ATLAS.ti Scientific Software Development GmbH, Berlin, Germany) to manage the coding and analysis process. The team first worked through each transcript to develop a codebook, and 15% of the transcripts were double-coded to ensure an intercoder reliability of 90%. Once a codebook was developed, a single coder, who was an expert in qualitative methods and who participated in developing the codebook, completed all coding to ensure consistency. Finally, content analysis was used to reduce the data and allowed investigators to focus on identifying major themes (Charmaz, 2004).

Results

In all, we conducted 28 focus group discussions with a total of 206 individuals, including 135 women and men living with HIV, 32 primary care providers, and 39 professional care team members. PLWH participants were equally female and male, and women made up the majority of both HCP participants (64.7%) and PCTM participants (72.7%). Of the PLWH participants, 68.1% had at least a high school education, and most were people of color who had inadequate or barely adequate incomes. Further demographics are shown in Table 1. Because comments from HCP did not differ significantly from those of PCTM, HCP and PCTM are referred to as “providers” or “HCP” in the results presented below.

Within the overarching discussions of the concept of health literacy, participants consistently identified having an ongoing and trusting patient–provider relationship as one of the most important contributors to the health of PLWH. While PLWH learned a great deal about managing HIV from each other, our data demonstrated that both participants and their providers felt that a long-term relationship was an essential part of HIV treatment over the entire course of having HIV infection, starting with initial diagnosis, to entering treatment for HIV, adhering to medication regimens, and staying connected to care. PLWH and HCP consistently emphasized that this relationship was critical to patients’ health outcomes. Building this trust was described as an iterative, dynamic, and mutual process that occurred over time. Not only did patients need to trust providers, but providers also needed to trust their patients. Some patients described an inherent level of trust in their providers:

I have to trust my MD to give me the right information. I know she has been studying medication and HIV for a very long time now. I see her as a professional who is not going to hurt me and I take whatever advice that she has to give me.

Other participants, however, felt that they had no other choice but to follow providers' instructions in order to receive care: "Most people have to trust them because they don't know any better. I mean they don't know anything about medical stuff. Most people have to trust their medical provider." Another PLWH said,

So I came here because I ain't know what else to do. I had nowhere else to go. I had no information and I was scared to death, and that's how I wound up here ... I'm just trusting in what she's telling me at this point and trying to learn as much as I can.

As one provider noted, however, many HCP were aware of their patients' distrust in the health care system. Understanding this feeling can help providers work with patients in more effective ways, with the goal of establishing a trusting relationship that results in improved health outcomes: "I see that ... they don't really trust what we say anyway, but they know they have to come here ... So you kind of have to work with the fact that they may doubt everything you offer ..." Another HCP added,

And I think, at least our patients ... have had some marked unsuccessful events with the medical system and so they're just like, you know, don't want to go near it ... [T]hey don't trust it, probably feel like they been screwed by it and so they're not going to even begin to think about how to care for a particular condition until there is some trust or some understanding.

Patient doubt about HCP may negatively affect a provider's ability to educate a patient about her/his illness and the ability to treat the illness. In addition, as these HCP suggested, some patients will not fully engage in or participate in care until they trust their providers, and a patient who trusts a provider may be more likely to follow recommended treatment plans. Providers need to be able to assess trust and build it over time. These are special skills that may be even more important for a population that is marginalized in multiple ways.

Further breakdown of study data indicated that the theme of trust in the provision or experience of HIV care encompassed three important subthemes: (a) respect, (b) partnership, and (c) a dynamic and continuous process of building and re-building trust over time.

Respect

Although patients may or may not trust HCP when they are first diagnosed or enter HIV care, a number of factors can help build this trust over time. For PLWH, a crucial element was respect:

When you can get that level of respect that you're not just, "Oh god, I've got to see this person. It's another day, another dollar," but when they respect you and respect your concerns and your feelings, that's basically when you can get into trusting and listening and doing.

Before patients will listen to providers' information or advice about HIV, they need to feel respected. Only then can the patient and provider move to actively manage HIV. This suggested that a lack of respect was a barrier to care, and could lead to poorer health outcomes. A number of participants also emphasized the importance of having HCP who listened to them and who engaged in conversations, rather than just telling them what to do. Spending time with patients and taking the time to call them personally to discuss test results or other issues was also important to our PLWH participants.

Respect may be particularly important for patients who have been marginalized or stigmatized because of their HIV status or for other reasons. As one provider explained:

[H]ow can we expect them to remain open and trusting and want to hear what we have to say, if we make them feel bad about themselves or disrespected or not listened to? Then why would they listen to us? Or share things with us that will help them be assessed? They won't even want to come back to us. And they won't.

Many PLWH are marginalized by society, not only because of their HIV status, but for a number of other reasons, including race/ethnicity, sexuality, poverty, and/or substance use. HCP who have these biases may not respect their patients, and thus may have a difficult time establishing a trusting and effective relationship with their patients. This provider also emphasized the importance of listening to patients as a way to encourage ongoing engagement in care.

Valuing a patient as a human being, as an equal, or even as family, was another way that PLWH said HCP showed their respect: "The doctors that gain my confidence are the ones that treat me like I'm a person." Another PLWH described this as, "When they're talking to you like you're somebody, like you are important, you mean something to somebody in the world." HCP also echoed this sentiment:

[P]art of that trust is making people feel important and valued. I think that that goes a long way with the engagement piece, you know, because a lot of individuals who live with this virus have very few people in their lives that make them feel consistently important and valued, and even though as providers we're busy, and we have a lot of competing priorities, if you can just lock in with that person at that moment and really engage, and believe in them, and make them feel valued, I think that really helps with trust and following through on plans.

As this provider explained, valuing patients facilitates the response to HIV. A patient who trusts her/his provider may be more likely to follow recommended therapies. This may be particularly important for patients with lower levels of health literacy, who may not be able to understand specific details about, for example, how medications work, but who need to be on medications. If trust and respect exist, the patient may follow treatment regimens more effectively.

Similarly, respect for patient experiences can be important. Many patients feel that HCP cannot truly understand HIV because they are not living with the disease themselves.

That's what I tell my doctor all the time. I said, "I wish you just would take my meds for 1 week, 'cause you don't know what you go through when you got to take that mess." She might be smart on a lot of stuff, but ...

And an HCP said,

Maybe they tell you, "For you it's easy because you don't have this, its me." And you have to understand that it is valid for them to tell you ... So I have to understand and respect and validate all of their anger. There's some that come fighting from the moment they have an appointment and walk through the door. And that is something that you have to go little by little.

Respect also included acknowledging and validating the patient's knowledge and expertise regarding their own bodies and illnesses.

A lot of times you know I'm just as knowledgeable as my doctor is and we're able to have a rational discussion about what's going on. The doctors that scare me are the ones that come in there and think that I don't know anything and that I'm gon' believe whatever line of crap they gon' give me.

PLWH participants discussed feeling disrespected by HCP who did not acknowledge that their lived experiences of HIV were important to how they experienced and participated in their care. From the patient perspective, PLWH should generally be seen as experts about their own experiences of the disease. In addition, many patients had high levels of health literacy, and were active in learning about the disease, by asking providers or others living with the disease, or through online research, for example. From both the PLWH and HCP perspectives, providers who respect patient experiences and knowledge may be better able to build trusting relationships with their patients.

Partnership

Another important aspect of building trust over time was the concept of partnership between patients and providers. The providers who were most respected by patients, and who PLWH participants returned to over time, were those who were open, discussed options with patients as equals, educated patients as necessary, and allowed patients to direct their own care if that was what they wanted.

I think of myself as a race car driver, and my medical team is my pit crew. And I'm in charge ... I'm the one who has to take the meds, I'm the one who has to take the tests, give the blood, so I mean, they respect me a lot where I go, and ... I feel that my doctors are really concerned about me.

Another participant added, "I've always said that the relationship between doctors and patients, and persons living with HIV, is a relationship between two specialists. [Providers] study everything about the process of HIV and [patients are] the specialists on what happens."

A number of patients expressed the idea that they were in charge of their own care, with the active support of their providers, who gave them information, helped them understand and evaluate options, and gave them advice. Providers echoed the idea of working together with

patients: “[I]t’s a lot of getting information about the disease, their prognosis, and how we’re going to deal with this together.”

I think a standard part of my clinic visit is to always ask, “Is there anything going on that we need to talk about? [Are] there any questions that you have that we can discuss?” ... We look up things together [in the electronic medical record], and I always end the visit with asking, “Is there anything else that you need? Is there anything else that we need to discuss?”

When HCP respected patients’ knowledge and experiences, and saw patients as equals, a more effective and trusting therapeutic partnership could be developed over time. The two parties shared information—what the science recommended, what the effect was on the patient’s experience—and worked through issues in partnership. This may be particularly true for a chronic illness such as HIV, which requires long-term attention and care, and the science of which continues to develop at a rapid pace. Patients and providers both felt that this partnership was important to developing trusting relationships and to improving care.

Iterative Process - It Takes Time

Developing trusting relationships—through respect and partnership—was something that both patients and providers saw as occurring over time. Time was important for two reasons. First, when patients were newly diagnosed, or still early in treatment, they might not have been fully ready to accept a diagnosis of HIV or engage with HIV treatment or providers:

[T]he “leave and come back later” is important because sometimes people aren’t ready. And we will see, it will take 10 admissions before they are ready to talk to us about anything ... You just have to go on their time and not rush things.

Again, HCP needed to respect the full patient experience, and the process through which individual patients became engaged in care.

Time was also important because it allowed patients and providers to assess and accommodate each other’s styles and learn to engage and trust each other. It also allowed the opportunity to give and take between the patient and provider. As one patient said,

I have that connection with [my providers], because I was diagnosed in 2002, so I had that bond with them. So they know when I’m in a funk or when something is wrong with me. They know because they know me like that. It didn’t just happen overnight; it took a minute, but you know, I talk to them. If something’s going wrong, I share with them.

And an HCP stated,

I think everything that we do with clients has to be tailored based on that individual relationship that you develop with that person. Also, you don’t figure it out the first time, either. I think a lot of what we’ve said about the repetition, also the trust level that you’re able to build. Because they may not be comfortable telling you the first time, “I don’t know what you’re talking about.” But as that relationship builds, you’re able to get to it more and more.

As this patient and provider explained, developing a deep trusting relationship takes time. And while some patients may inherently trust providers to a certain degree, as described previously, the trust that this patient and provider described was deeper. It is not just trust that the provider wanted to help and was knowledgeable, but rather a sense that the provider understood the patient beyond his/her HIV illness, understood the patient's level of health literacy, understood how the patient wanted to be treated, and understood that the provider wanted to work with and for the patient.

Discussion

Our study provided evidence that, from the perspectives of PLWH, HCP, and PCTM, HIV health literacy and how it is defined is dynamic and multidimensional, and is influenced by the relationship between PLWH and their providers. It encompasses more than reading and understanding medication names and schedules, and may be related to some of the disparities we see in health outcomes.

Provider perspectives on how people understand information has focused on ensuring that patients receive disease and treatment information at the correct reading level and in the correct language (Shiffman, Gerlach, Sembower, & Rohay, 2011); on the importance of taking HIV medication (Millard, Elliott, & Girdler, 2013); and on how to address symptoms and manage side effects (Okonsky et al., 2014). It does not always, however, prioritize building and maintaining long-term relationships between patients and providers, as our data suggest is so important. While provider knowledge and skills are important to health outcomes in HIV (Kitahata et al., 2003), both PLWH and HCP participants from our study voiced other issues that were critical for patient care and for their interest in and ability to absorb information about their disease; these include trust, respect, and partnership.

While some PLWH intrinsically trust HCP, many do not, and there is much historical context for such feelings (Heller, 2015). Many PLWH are also socially marginalized for issues related to race, poverty, and gender (Lanier & DeMarco, 2015). HCP may also stigmatize patients involved in substance use (Westergaard, Ambrose, Mehta, & Kirk, 2012) and other "unhealthy" behaviors, which may make PLWH hesitant to reveal important information about themselves and their health conditions. The additional stigma of low literacy/numeracy (Parikh, Parker, Nurss, Baker, & Williams, 1996) may make it difficult for patients to reveal their lack of understanding about medications or even the terminology that is used. These issues form the social context within which many patient-provider interactions occur, helping us to understand why patients may not initially trust providers. Our data support this notion, but also suggest that trust can, in fact, be established between patients and their providers. In many cases, building trust occurs over time and over multiple clinical visits. Most of the HCP in our study understood the mistrust that PLWH might feel and were willing to put in the effort necessary to build trust over time. In addition, many PLWH mentioned long-term relationships with providers that they had come to trust over the years.

We found that respect and partnership were two important parts of developing a trusting relationship. For PLWH, respect means that providers listen to them, treat them as individuals and not just as patients, and value their knowledge of their own bodies and

illness experiences. More than one study participant mentioned that HCP could not fully understand the experience of HIV or of taking medications, as they did not live with the disease themselves (as far as the PLWH knew). Because of this, it was particularly important to PLWH that providers listened to them and validated their lived experiences of HIV and their knowledge of the disease and of their own bodies. The relationship between patient and provider must be a partnership, in which both sides share their knowledge and understanding of HIV. Our study data highlighted the need for HIV providers to validate the patient experiences, knowledge, and expertise that come from living with HIV.

The results of our study support prior work in the area of HIV health literacy and patient-provider relationships. Extensive research has shown the importance of trust between patients and their providers for better health outcomes, both for PLWH and for individuals with other health conditions. Cunningham, Sohler, Korin, Gao, and Anastos (2007) identified two levels of trust as it related to HIV: the interpersonal relationships that patients had with their primary care providers and trust in the larger system of health care and the government. Whetten and colleagues (2006) found that, for PLWH, having trust in one's primary care providers was associated with better mental and physical health as well as with more appropriate use of health care services, including attending clinic visits, adhering to medications, and having fewer visits to the emergency room. And, while our participants had high levels of trust in their HCP, there was a much lower overall level of trust in the health care system, particularly for minority participants. Carr (2001) reported more specifically on interpersonal relationships between PLWH and their primary care providers. As he explained, building trust was a negotiated process that occurred over time. Trust was fluid and changed over the course of a patient-provider relationship. In addition, patients actively sought out providers they trusted.

Limitations and Strengths

Expanding our view of what health literacy means to patients and how it is understood and assessed by providers needs further study. While we addressed a more nuanced understanding of health literacy, there were several limitations. First, because our questions focused on the sources from which PLWH get information about their disease, our results may have been biased toward the process of information gathering, rather than on the more relational aspects of health literacy. However, the fact that so many participants from all groups discussed the issue of trust indicated its importance within the context of health literacy. Secondly, we recruited participants from clinics and community-based HIV service organizations, which could have biased our findings toward individuals/patients who had a good understanding of HIV treatment or providers who were more focused on relationship building than on patient education per se.

One of the strengths of our study was that we drew participants from multiple U.S. locations, including Puerto Rico, and one international setting, Botswana. Our analysis drew from the major themes found in these data but our sampling method did not strive for saturation, which is a method that is often used to ensure credibility in qualitative data. In addition, our eligibility criteria for PLWH participants included an MMSE score that indicated no cognitive deficits. It is possible that PLWH who were not eligible to participate in the study

because of low levels of cognition may have had a different way of expressing their understanding of HIV information that did not focus on relationships with their HCP. For primary care providers and other health care staff, we did not collect data on their training or direct experience with health education but asked specifically about teaching or communicating HIV-related health information. Professionals who are experts in patient and health education may use a method of assessing health literacy that includes relationships and trust, as we have found in our data.

In spite of limitations, our study included a focused, intensive training by one investigator on using the interview guide, and a shared multi-site protocol for data collection, which increased rigor for the study. In addition, we used data collected through multiple perspectives, not just from the recipient or consumer of information, but also from those who were working to address literacy with their patients.

Conclusions

The data from our study about health literacy in HIV care tell a larger story about what is important for individual understanding of HIV and what it means to PLWH from the perspectives of PLWH, HCP, and PCTM. Participants said that having an ongoing and trusting patient-provider relationship was one of the overarching contributors to health literacy and ultimately to the health of PLWH. These data demonstrate that both participants and their HCP felt that a long-term relationship was an essential part of HIV treatment over the course of having HIV, starting with initial diagnosis, to entering treatment for HIV, to learning about HIV, to adhering to medication regimens, and to staying connected to care. PLWH, HCP, and PCTM all emphasized that this relationship was critical to the well-being of PLWH. Further, the process of building trust was described as an iterative, dynamic, and mutual process, one that involved providers and the patients they cared for, and that occurred over time. Not only do patients need to trust providers, but providers also need to trust patients.

Health literacy is an important area of study as global efforts strive to provide the best HIV care, to support adherence to treatment for the long term, and to increase the quality and equity of HIV care. Current literature on HIV health literacy and health literacy in general has focused on measurement and getting the message across and not on concepts such as trust, relationship, and the iterative process of building a relationship as important pieces of the definition and meaning of health literacy. Our research has demonstrated the need to include these concepts in future studies about health literacy.

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Key Considerations

- Health literacy, which is linked to HIV treatment outcomes, may be related to the disparities seen in HIV outcomes.
- A patient's trust in a provider is an important component of long-term engagement in HIV care.
- From the perspectives of people living with HIV and their providers, the meaning of health literacy is multidimensional and dynamic.
- Building a trusting relationship between patients and providers is critical for managing HIV disease throughout the care spectrum.

Table 1

Participant Demographics

Demographic Characteristics	PLWH (<i>n</i> = 135)	HCP (<i>n</i> = 32)	PCTM (<i>n</i> = 39)
Age, years (mean)	48.00 ± 9.18 (range 21–68)	45.41 ± 10.16 (range 28–63)	42.72 ± 11.14 (range 25–72)
Gender ^a			
Male	65 (48.15%)	6 (35.29%)	6 (27.27%)
Female	68 (50.37%)	11 (64.71%)	16 (72.73%)
Other	2 (1.48%)	0 (0.00%)	0 (0.00%)
Race/ethnicity			
African American/Black	60 (45.11%)	3 (9.38%)	6 (15.38%)
Hispanic/Latino	30 (25.56%)	8 (25.00%)	3 (7.69%)
Non-Hispanic White	23 (17.29%)	11 (34.38%)	20 (51.28%)
Asian/Pacific Islander	0 (0.00%)	2 (6.25%)	4 (10.26%)
Native American/Indian	0 (0.00%)	1 (3.13%)	0 (0.00%)
Other	20 (15.04%)	7 (21.88%)	6 (15.38%)
Education level			
11 th grade or less	35 (26.52%)		
High school or GED	49 (37.12%)		
Associate degree/2 years college	28 (21.21%)		
College (BA or BS)	12 (9.09%)		
Master's degree	2 (1.52%)		
Doctoral degree	1 (0.76%)		
Other	5 (3.79%)		
Work for pay (<i>yes</i>)	47 (35.07%)		
Adequacy of income			
Totally inadequate	15 (13.64%)		
Barely adequate	66 (60.00%)		
Enough	29 (26.36%)		
Have health insurance (<i>yes</i>)	104 (77.61%)		
Year diagnosed with HIV (mean)	1998.91 ± 8.37 (range 1974–2012)		
Ever had an AIDS diagnosis (<i>yes</i>)	54 (40.30)		
Taking HIV meds	124		
Health care providers (prescribers)			
Nurse practitioner/APN		14 (45.16)	0 (0.00%)
Physician		11 (35.48%)	0 (0.00%)
Professional care team members (nonprescribers)			
Licensed Clinical Social Worker		0 (0.00%)	3 (7.89%)
Registered Nurse		3 (9.68%)	15 (39.47%)
Case Manager		0 (0.00%)	4 (10.53%)
Other (e.g., medical assistant, licensed vocational nurse, pharmacy technician)		3 (9.68%)	16 (42.11%)

Note. PLWH = people living with HIV infection; HCP = health care provider; PCTM = professional care team members; GED = graduate equivalency degree; BA = bachelor of arts; BS = bachelor of science; APN = advance practice nurse.

^a. At most sites, gender was self-reported current gender; in Cleveland, it was sex at birth.

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