The Uses of Self and Space: Health Providers' Approaches to Engaging Patients into the HIV Care Continuum

Natalie M. Leblanc, PhD, MPH, BSN, RN,¹ Laura Albuja, DNP, FNP-C,²
and Joseph DeSantis, PhD, ARNP, ACRN, FAAN³

Abstract

In the context of HIV prevention, the provider–patient relationship has been found to profoundly impact HIV screening, patient initiation into HIV care, and adherence to medication following an HIV diagnosis. Given the importance of the provider–patient relationship, insight into provider approaches to cultivate such relationships is essential. Such insight could highlight considerations for provider engagement with patients that can address the current challenges in HIV prevention and treatment. This qualitative descriptive study sought to describe current health providers' approaches to engage patients into the HIV care continuum (HCC). Findings from the content and thematic analysis indicated that health providers ($N=22$) used various approaches to engage patients/clients into HIV screening, and subsequent HIV care. Approaches were represented by an interpersonal process and a thematic analysis revealed the nuances in the approaches that manifested in the following themes: uses of self, normalizing disease, and engaging couples. This study demonstrated the importance for health providers to be aware of the specific context of patient's vulnerability to HIV infection and barriers to care. Self-awareness and the capability to self-reflect on one's personal practice also helped to ensure engagement of those vulnerable to infection or infected with HIV into the HCC.

Keywords: content and thematic analysis, HIV prevention, HIV provider practice, qualitative descriptive design

Introduction

THE PROVIDER–PATIENT RELATIONSHIP has long been established as one of the most influential components in the adoption of health promotion behavior.^{1–3} In the context of HIV prevention, the provider–patient relationship has been demonstrated to profoundly impact patients' engagement in every stage of the HIV care continuum (HCC): HIV screening, initiation into HIV care, and adherence to antiretroviral medication.^{3–7} The Treatment as Prevention paradigm has refocused HIV prevention to address engagement and retention of people living with HIV infection. However, challenges remain in ensuring that individuals who are HIV-infected are aware of infection status, engage in HIV care, and sustain antiretroviral treatment (ART) adherence.^{6–9} Given the importance of the provider–patient relationship in health attainment and HIV prevention and treatment, insight into provider approaches to cultivate such relationships is essential. Insight into these approaches could highlight considerations in provider engagement with patients that can address the current challenges in HIV prevention and treatment. Although war-

ranted, current perspectives are from patients' experience with providers and/or the healthcare system.^{10,11} The current literature does inform healthcare practice of what is important in the patient–provider interaction (e.g., communication), relationship (e.g., trust), and cultivation of patient autonomy,^{10–15} but there is a lack of provider perspective on exactly how the interaction unfolds and is cultivated. To address this gap in the literature, the aim of this article is to explore and describe current health providers' approaches to engage index patients and patients' partners in the HCC.

Method

Sample recruitment

Participants were recruited from four healthcare facilities in Miami-Dade County, Florida: two multi-service (i.e., primary care, mental health, drug treatment) community-based federally qualified health centers, and two hospital-based specialty clinics (HIV care and maternal HIV clinics). Health providers recruited from these facilities were required to have a minimum of 1 year of experience with HIV

¹School of Nursing, University of Rochester, Rochester, New York.

²Department of Pediatrics, School of Medicine, Pediatric Mobile Clinic, University of Miami, Miami, New York.

³School of Nursing and Health Sciences, University of Miami, Miami, New York.

screening and/or engaging people into the HCC. Contingent upon facility preferences, providers were recruited either directly via a recruitment email from the first author or an internal email blast from the agency's program department. After the first few interviews, snowball sampling commenced to recruit additional participants. Providers were offered a \$15 gift card for study participation. The [BLINDED] IRB approved the protocol for this study.

Participants

Health provider interviews were conducted in Miami-Dade County, Florida, from November 2015 to March 2016. The 22 health providers who participated in this study represented clinicians and other providers from several specialties (i.e., OB/GYN, family health, HIV care, and infectious disease) and disciplines (i.e., social work, psychology, nursing, and medicine). Clinical providers were mainly nurse practitioners ($n=8$) and nonclinical providers were program managers, HIV counselors, and licensed mental health providers. Ethnically, most providers ($n=14$) were of Latin American, Hispanic, and/or Caribbean descent, which is significant in the Miami-Dade County context, whereby 50% of the population are foreign-born and the majority of the population are from the Caribbean and Latin America.¹⁶ Providers collectively possessed 3–25 years of experience with most ($n=19$) reporting 5 years of experience or more in the given discipline. The different provider types in this study used both “patients” and “clients” as terms in discussing approaches to engage people into the HCC. For consistency and in alignment with the health provider narratives, the term “patient” will be used.

Data collection

A semi-structured interview guide (Table 1) informed by the literature on provider influence on HIV screening, couples testing for HIV infection, and engagement in the HCC

was developed to facilitate in-depth interviews. Discussions from peer debriefings¹⁷ with five health science researchers who collectively have expertise in HIV care, couples and family-based HIV prevention approaches, and qualitative research methodology helped to develop the resulting interview guide. The guide consisted of three domains: (a) provider perception of couples HIV testing and counseling; (b) provider approaches to engagement of clients into the HCC; and (c) provider perception of couples HIV testing and counseling in a clinical setting. The second domain is the focus of this article.

Interviews were conducted either by phone or in person by the first author. Interviews were completed in 30–90 min from November 2015 to March 2016 and audio recorded. Interviews were conducted until both an equitable number of clinically educated ($n=13$) and nonclinical ($n=9$) health provider participants were interviewed, and saturation was reached.

Data analysis

Qualitative descriptive design was the analytic approach used for this study.^{18,19} This approach allows for narratives not to be confined to a theoretical framework nor requires complex interpretations. Rather this approach fosters an analysis that maintains the participant's voice by remaining as close to the data while still demonstrating the nuances and providing details of the perspective that is the focus of the inquiry.^{18,19} Data analysis commenced with the transcription of the audio recordings via an online dictation software (Online Dictation, n.d.) program. The transcribed narratives were then uploaded and analyzed using the data analytic and management software program MAXqDA (Verbi GmbH, Berlin). Data analysis involved content analysis followed by a more thematic exploration of the narratives.

The content analysis phase involved developing manifest themes and further identifying patterns in the data. Certain elements of the narrative warranted greater exploration and resulted in a more latent thematic analytical approach.²⁰ The analytic approach included a three-step iterative process to code and ultimately identify thematic content: (a) the development of memos to record initial reactions and reflection on the narratives; (b) descriptive coding to label recurring elements and patterns within and across provider narratives, and development of a codebook; and (c) identification of the relationships among codes and development of latent themes. Following the first five interviews and ongoing during the data collection and analysis, peer debriefings²¹ among the authors and two of the five original health science researchers commenced to discuss initial findings, the applicability of the codebook, and establish consensus of emergent themes.

Results

Content analysis revealed that perceived provider responsibility and patient characteristics and vulnerabilities, informed health provider approaches to patient engagement (Fig. 1). Providers' approaches incorporated two separate but related processes to engage patients and partners and were categorized as (a) indirect and direct approaches to patients, and (b) passive and proactive approaches to partners. The nuances in the approaches that manifested in the following themes: uses of self, normalizing disease, and engaging couples.

TABLE 1. SAMPLE DOMAINS AND INTERVIEW PROMPTS

Domain	Sample interview prompts
<i>Sample domains and interview prompts</i>	
Professional history with HIV testing	Can you describe a time when you had to offer an HIV test to a patient (regardless of the outcome)? How did it make you feel? Describe how you felt about that encounter. What worked well and what would you have done differently?
History with engaging sex partners	Can you describe a time with a patient who tested seropositive where you may have thought about testing their partner(s)? What did you do to facilitate testing of the partner(s)? Was the partner ever tested? What are your thoughts on this? What worked well and what would you have done differently?

FIG. 1. Providers' approaches to engaging patients into the HIV care continuum.

Perceived provider responsibility to engage patients into the HCC

Providers' reported that HIV screening should be a part of patient wellness given the availability of the fourth generation HIV antigen testing and advancements in HIV treatment. Providers perceived that all attempts should be made to engage those diagnosed with HIV into care; and for some providers due to the interpersonal risk to HIV transmission, efforts should also be made to engage intimate partners.

Providers reported that being comfortable and confident in initiating conversations about one's sexual health is an important feature of engaging patients and partners. For these conversations to result in a positive health outcome (engagement in HIV screening, HIV care, and incorporation of the index patients' partner), providers spoke about the development of trust in cultivating the provider-patient relationship. Providers reported that this allowed for patients to reveal certain behaviors or other personal attributes that may impact engagement into the HCC. Providers perceived that this comfort allows for open communication between the provider and patient, and that it may take several encounters before a patient reveals a complete sexual history or come to terms with an HIV diagnosis.

"...I have an open relationship with the patient and that requires the development of trust and that can take some time for me to trust them and for them to trust me, to know who we are [in the relationship]...."

—Clinical provider, >20 years experience

Patient vulnerabilities and characteristics

A lack of formal education and English language proficiency was common among women, particularly immigrants who required providers to be cognizant of how providers engaged patients in health education and counseling. The lack of education and financial instability also made women vulnerable to HIV infection. If women were living with HIV infection, many providers reported women needing to avoid disclosure due to dependence on the male partner. Some health providers also noted that literacy limitations and the general lack of knowledge about HIV transmission and care

contributed to certain immigrant populations not seeking HIV screening or care.

"There are remarkable things between each population. I find that Hispanic populations from Central and South America have less knowledge... some of them still thinking like 1980's where you can die,... not many people have the education."

—Nonclinical provider, 16 years experience

Providers reported that poor mental health at times coupled with substance abuse encumbered the lives of some patients living with HIV infection or those vulnerable to HIV acquisition. These patient characteristics were occasional impediments to HIV screening, serostatus disclosure, engagement into HIV care, and adoption of HIV prevention strategies in general. Participants spoke to the uniqueness of these problems among varying populations in tandem with patient attributes. The saliency of depression among HIV-infected women was perceived to trigger the onset of post-traumatic stress disorder (PTSD) and/or more complicated mood disorders and can impact HIV care.

"Especially in women....some never get over the resentment or like a woman telling me that I got this from my husband and he is now dead from AIDS and he never told me...everybody to some degree or another has depression, sometimes psychosis...because it [being diagnosed] is a traumatic thing."

—Clinical provider, >20 years experience

Underlying depression among middle-age men who have sex with men (MSM) regardless of HIV serostatus was also a specific concern. Providers perceived men's feelings of isolation and loneliness cultivated a vulnerability for HIV transmission and nonengagement in HIV care. Provider concerns for younger MSM was due to the multiple concurrent sexual partners reported in tandem with inconsistent condom use and infrequent HIV screening observed with this population. Fueling these concerns were recurrent sexually transmitted infection (STI) acquisition coupled with concurrent drug use among young MSM.

Providers' efforts to help patients become informed of an HIV sero-status and to be emotionally and mentally sound to engage in the HCC involved building rapport and garnering trust from the patient. Providers relied on personal attributes and utilized intrinsic elements from experiences and practice to help cultivate specific approaches to engage patients.

Provider approaches

Indirect versus direct approaches to patient engagement. Provider approaches to engage patients in HIV screening and subsequent care can be represented across a spectrum from direct approaches to indirect approaches. An indirect approach entailed providers implementing routinized HIV screening. Either the facility instituted a system that every new patient is screened for HIV infection or HIV screening was one component of the annual health visit of existing and newly enrolled patients. Among HIV care specialists who provide health services to patients living with HIV infection, routine screenings for other sexually transmitted infections were included in regularly scheduled health/wellness visits. Direct approaches to HIV screening involved a patient health assessment that included provider-initiated sexual health discussion about the patients' vulnerability to HIV/STI risk or in response to a suspected infection whereby a determination was made that an HIV test was warranted.

"I make them feel comfortable. I ask them 'if there's anything you want to do or if you want me to test you more often, if there is any reason, just let me know and we will discuss it.' Or 'I noticed that you have had three episodes of gonorrhea this year, is there something you want to talk about?'"

—Clinical provider, 8 years experience

Passive versus proactive approaches to partner engagement. Approaches to engage couples or intimate partners of index patients can also be represented across a spectrum from passive to proactive approaches. Passive approaches involved working with an index patient in a single or in multiple encounter(s) to engage the partner to screen for HIV infection. This involved providers' efforts to facilitate patient disclosure and for the index patient to encourage partners to undergo HIV screening. Proactive approaches involved providers engaging directly with the partner. Providers who applied this approach reported having in-person or phone conversations with the index patient's partner to facilitate HIV/STI screening and/or engagement in HIV care.

"I am very assertive when it comes to STDs....if the guy [partner] is there I will focus my conversation on the guy and I will talk to him about STDs. I mean I will focus on the woman too, but if the partner is there [I will speak with him too]...."

—Clinical provider, >20 years experience

Uses of self

Providers' utilized personal attributes and/or elements of the surrounding environment to establish rapport with the patient and facilitate engagement in the HCC. The interaction of the health provider and patient was informed by providers' self-awareness and ability to self-reflect in the moment and within the work environment. Uses of self involved a few specific manifestations that included use of space/proxemics, use of the physical self, role adoption, and use of language. An embodiment of multiple uses of self and space is invoked by the following provider:

"Not only do I disclose it with them [that I am living with HIV]. I walk them to their first [HIV] appointments, they call me and text me even during the weekend and stuff like that."

—Nonclinical provider, 12 years experience

Use of space/proxemics. One element within the use of space involved provider awareness of the interpersonal space and an awareness of "the emotions and the energy" within a space that is manifested by the patient as a result of the provider-patient interaction. This interaction within the space, from the individual patient, and the provider-patient interaction, helps the provider ascertain the approach required to engage the patient.

"...I have to kind of respect their position because you get it is all about the emotions, the energy, those kind of things are important to people you serve because if people senses a certain vibe they don't want to continue [with the conversation]. So you [as a provider] have to have that same emotional intelligence. So you get the vibe and... have a different approach and when you do bring it up [HIV screening]...you may be able to get a better response."

—Clinical provider, 4 years experience

The use of space or proxemics was also invoked if the physical space was perceived not to be conducive to the patient's mood or needs, or perceived to stifle the development of the provider-patient relationship. This interaction then takes place external to the clinical space and can include a walk around the perimeter of the facility or simply stepping outside of the physical clinical space or health setting.

"...I take them outside because once you tell somebody a negative, like something negative, in my experience they start to hate this atmosphere. So I try to walk with them to breathe some air, to get out of that ugly set up where somebody told him bad news, then they start thinking differently."

—Nonclinical provider, 13 years experience

At times it is the patient's demand to avoid the physical environment that influences the provider to consider the place of interaction. For example, one provider met with a partner of an index patient in a nearby parking lot because the partner would not enter the health facility. This specific approach of using the external space was most common among male health providers who reported interactions with male patients who were newly diagnosed with HIV and challenged with engagement in HIV care or some other treatment (i.e., mental health service).

Use of the physical self. Some providers reported prolonged eye contact, positioning oneself closer to the patient, or inviting the patient to call anytime to establish a connection and establish sincerity in the provider-patient interaction. One provider recounted an interaction with a young newly diagnosis patient:

"...she knew I was out there in the community and she knew that's where I came from. So for whatever reason she looked in my eyes and I looked in her eyes and it is what it is and this is for real and she realized that, I guess in that moment, because it was just a quick moment, she believed in me for whatever reason I don't know, I can't really describe it."

—Nonclinical provider, 16 years experience

Use of the physical self also included more hands-on guidance and effort to facilitate engagement into the HCC. This involved constant follow-up via phone calls to the patient, physically picking a patient up at home for an initial HIV-related appointment, or making referral appointments on the patient's behalf. Some providers referred to this as

“hand-holding” due to the level of perceived oversight required to ensure the patient’s entry into care, and assistance navigating a complex system of care.

“...when I have a positive, I see their personalities and how to approach them. Some of them need to be babied and I baby them and they call me the father of the positives and I don’t care because some of them need to be babied.”

—Nonclinical provider, 12 years experience

Role adoption. Related to the use of the physical self, providers reflecting on patient interactions spoke of roles manifesting that facilitated HIV screening and subsequent engagement into HIV care. The following provider reports on adopting a role to facilitate an interaction with a newly diagnosed expectant patient who was resistant to HIV care and who insisted on breastfeeding

“...she [patient] said she will breastfeed no matter what and that is when I was really concerned... what I did to change her mind, I became her friend. After I become her friend I understand her more, she understands me more and then I can convince her. She become like [to] have a trust in me for the whole 7 months because she was already 3 months [pregnant] when we do the test.”

—Nonclinical provider, 15 years experience

Role adoption occurred in concert with helping patients to get to a certain level of understanding personal vulnerability to HIV infection, an HIV/STI diagnosis and to be ready to engage in the HCC. This was particularly the case when lack of education and/or English language proficiency were potential barriers to health education and engagement. One female provider reports how the adoption of a familial role allowed engagement with a newly diagnosed patient who required simplification of the language sometimes used in HIV prevention and treatment education.

“I wanted to talk to her in a way so that she can understand me because her educational level wasn’t up there. I usually bring myself down to their level and speak their language. I took it more personal because I felt like this could be my mother... so I was very sensitive towards her.”

—Nonclinical provider, 6 years experience

Use of language. Providers described how use of language would motivate some patients and allay fears or anxiety in others. Use of language also speaks to what is exactly said in the interaction to facilitate discussion regarding sexual behavior and sexual health.

“I usually approach the subject depending on the patient, I use appropriate words depending on the level of education. I don’t use the word gay or straight or hetero or homosexual. I try to, ‘do you date men, do you date women?’, that’s how I start, open the conversation and then I take it from there to see how comfortable they feel. This is something I may start and finish on the same visit or may last three visits until I get all the information or believe I got all the information.”

—Clinical provider, 8 years experience

Knowing what and how to communicate with the patient required a clear holistic perspective of the patient population and an understanding of community norms that supports communicating with cultural and personal saliency for the patient. One provider shared an experience with a married couple in which the male partner of a newly diag-

nosed pregnant patient initially refused HIV screening. The provider acknowledged that having a shared cultural background with the couple and a shared familial role as a parent guided the content of the provider’s communication with the male partner.

“I think it was the love for his kids and as a parent.... As a parent you never want to die and leave your kids behind because you believe that no one can do it like you. As soon as you mention you are doing it [engaging in HIV care] for your kids and your family, I think I touched a very sensitive place in that person’s heart and that is the reason I guess I convinced him to do it [HIV test].”

—Nonclinical provider, 15 years experience

Use of language also involved the broader ecological context where services are being conducted. Providers reported specifically discussing with those who were newly diagnosed the legal ramifications of nondisclosure and potential transmission to others within the state of Florida. This approach was used to ensure that the patient was aware of Florida’s HIV criminalization laws, but also spoke to the sensibilities of disclosure (reducing anxiety and garnering social support). None of the providers reported involving law enforcement or using the law to force patients to disclose, but mentioned this to patients as an act of due diligence as a health provider who conducts HIV screening in a state with HIV criminalization laws.

“We can’t force anything you know... when you are ready and if you want we have support services here to get people [to disclose] to the point where they are willing to and then of course we are obligated to inform them that exposing someone unknowingly to HIV in Florida is illegal.”

—Nonclinical provider, 12 years experience

Normalizing disease

Normalizing disease has dual manifestations. The first manifestation was in the semantics and the specific use of language demonstrated by both the patient and provider in conceptualization of HIV infection as a disease process. Some providers avoided the terms “disease” or “illness” in referring to HIV infection and opted to refer to HIV infection as a condition because of its chronicity and manageability.

“...I always try to introduce it [HIV infection] like that, a condition. It is not like you feel sickness or you sick because that is one of the biggest stigma most of the clients have... they are afraid, it’s scary, they don’t have any knowledge... about the difference between HIV or AIDS.”

—Nonclinical provider, 13 years experience

Normalizing HIV was used to help the newly diagnosed individuals cope. It entailed the provider’s assessment of the patient’s educational needs in the larger scheme of health-care or disease prevention. Providers attempted to demonstrate that HIV infection is akin to other diseases, by rationalizing that generally diseases may develop in the context of overindulgence in certain behaviors. The orientation provided was that illness can develop from overindulgence in either drug use, consumption of unhealthy foods, or engagement in unprotected sex with multiple partners and, therefore, in this context, HIV infection is just another disease.

"I try to get away from the HIV, I try to put it to something else that is similar. You can transmit as many diseases into your body through food, through anything that you do too much of or anything that you have too much pleasure from and it doesn't have to be sex."

—Nonclinical provider, 12 years experience

Some providers compared survivorship with HIV infection to other conditions. Providers informed patients that similar to other chronic conditions like diabetes, lifelong adherence to lifestyle changes and disease management can result in the absence of negative health-altering events, that is, amputations, loss of eye sight in the case of uncontrolled diabetes, and the progression to AIDS or death in the case of untreated HIV infection.

"You have to focus on what can you do to stay healthy and there is a lot of things nowadays and I had to put it to them in a way like, cancer is killing people more than HIV at this time."

—Nonclinical provider, 13 years experience

The second manifestation of normalizing disease was revealed in providers' reports of certain populations who remained engaged in high-risk behaviors even after discussions regarding sexual health promotion. Some providers believed that certain patient populations rationalize avoidance of HIV screening and sustained engagement in risk behaviors by normalizing HIV infection. These patients were perceived to have normalized HIV infection in such a way that one's mortality is inevitable and thus prevention of disease is not a priority.

"...I have some kids...they go to raves and they tell me 'I go and then I take ecstasy... I might as well have it [HIV] now so that way I don't have to worry about it and wait until it comes'...they feel like I am gay eventually I am going to get it."

—Nonclinical provider, 13 years experience

Engaging couples

Providers who engaged both the index patient and the intimate partner into the HCC and/or for STI treatment sought to ensure that partners' joint sexual health needs are met. Providers also sought to address recurrent STI infections particularly among those patients who were living with HIV infection. The presence of STI symptoms including HIV infection or a recurrent STI diagnosis at times warranted a proactive direct approach to encourage the index patient and partner to screen for HIV/STI.

"I mean there are plenty of wives who come in with chlamydia, I get on the phone because of their husbands...I get on the phone and tell him to just come in because he is just re-infecting his wife, because like I treated his wife for chlamydia [before] and he's just re-infecting her."

—Clinical provider, 8 years experience

Providers expressed comfort with engaging patients and partners jointly because some already engage couples in general health promotion. It was perceived to be easier to educate and orient partners together and speak to a joint HIV sero-status to ensure each person understood the implications of HIV sero-status in the context of the relationship. It was also seen as an opportunity to ensure that if warranted, both partners in a couple could be engaged in HIV care. Lastly, providers noted that with certain patient populations (i.e.,

HIV-infected pregnant women), it just made ethical sense and best practice to engage the male partner into HIV screening and subsequent care.

"...we offer assistance if they feel more comfortable bringing the partner, we bring the partner and we disclose in the room and we answer the questions to the partner. We spend a lot on the disclosure because our women are pregnant, and when the partner or when the father of the baby comes to the delivery there may be a chance he can know [the mother is infected] and also for the baby's follow up in pediatric clinic."

—Clinical provider, 16 years experience

Discussion

Few studies to date illuminate provider perspectives on the cultivation of the provider–patient relationship and facilitation of patient engagement in the HCC. Focus tends to be on patient satisfaction and from the patient perspective although warranted, narratives from providers are needed to capture the why, what, and how of evidence-based practice that is implemented in real world settings. Such description is also warranted to inform areas for intervention and to identify areas that can be enhanced in practice.

To address the gap in the literature, the aim of this study was to describe provider approaches to engage patients into the HCC. Although the findings from this study support previous understandings about patient–provider interactions in health promotion,^{22–25} contextualizing providers' experiences reveals the intricacies of specific approaches to address patient vulnerabilities. The provider narratives revealed that efforts and approaches aligned across disciplines indicating the influence of evidence-based practice in HIV prevention and treatment. This may also indicate intrinsic provider beliefs and practices shaped by the experiences of working with a population with unique vulnerabilities to HIV infection, with unique challenges to engagement in HIV care, but further complicated by a disease that remains highly stigmatized globally.

One of the most salient findings is the varied manifestations of the uses of self and space to engender trust, cultivate a relationship with patients, and facilitate patient entry into the HCC. Providers articulated a need to establish rapport to engage patients and collectively demonstrated the uses of self and space to normalize the disease, engage couples, and facilitate patient engagement. Through the uses of self, providers aimed to establish trust in the patient–provider relationship to help the patient achieve a level of health literacy and comfort to screen for HIV/STI and/or engage in HIV care or other STI treatment. Uses of self and space also involved transcending perceived structural/physical barriers of the health setting environment and/or the emotional/education barriers patients may possess that impedes engagement into the continuum. Narratives also revealed that the intrinsic uses of self require provider self-awareness and the capability to self-reflect on one's practice to ensure optimal engagement.

Findings highlight the importance of patient-centered care to incorporate and address the specific context of a patient's vulnerability to HIV infection and potential barriers to engagement in care. Salient to this is the undercurrent of mental health problems and substance use, which can hinder optimization of provider approaches to engage patients into the

care continuum. This finding aligns with other studies documenting the significance of substance use and mental health states in engagement in the HCC,^{22–24,26,27} and highlights the need for providers to be aware of the context of patients' lives and appreciate potential threats to overall patient well-being and engagement. Another threat to optimal well-being is the patient's health literacy. To meet health literacy needs providers mechanized the social process required for patients to be informed about the disease and to be motivated to engage in HIV/STI screening and care. The adoption of roles and the mindful use of language facilitated health communication and not only served to educate patients, but were also enacted to establish a connection and cultivate a relationship to move patients through the HCC. Findings from this study revealed the importance of the contextual influences on health including mental health, and health literacy among the patient population served, and implicated the unique needs for people living within the jurisdiction.

The implications of the dual manifestation (provider vs. patient) of disease normalization to conceptualize HIV infection, although on one hand helped to ease anxiety around a stigmatizing chronic illness, may also indicate a lack of patient confidence in HIV treatment or disbelief in one's self-efficacy to manage the disease. Although normalizing disease was a useful approach for providers in orienting those who were living with HIV infection, and served as motivation for some of these clients to engage in care; the conceptual orientation among some patients in normalizing disease actually demotivated some from HIV screening and subsequent engagement in risk reduction and/or HIV care. It may further indicate a patient's outlook on life and/or perception of health. Such an outlook can impede HIV screening and/or sustained engagement into care and thus warrants a provider assessment before efforts to engage patients in HIV screening and lifelong daily treatment. Certain populations may perceive engagement in health promotion behaviors like HIV screening and HIV care as less significant in the context of other perceived and actual threats.^{6,28} Therefore, it should not be assumed that certain populations are just fearful or in denial about personal risk or diagnosis, but perhaps HIV prevention and retention in care in the context of sexual health need to be perceived more holistically and part of one's overall wellness.^{29–31}

A broader perspective acknowledges the need to reconceptualize how institutions and individuals think about health promotion, wellness, and self-efficacy in achieving positive sexual health outcomes.^{25,30–32} The characteristics of health care settings that can impede or facilitate HIV prevention and care cannot be understated.^{25,33} Although attributes of the healthcare environment were not of focus in this article, providers did speak to hand-holding and “babying” the patient. This was not only due to the perceived need of the patient, but also due to the complexity of the healthcare environment for populations who may be unfamiliar with the healthcare environment. Some of these approaches and perspectives may be perceived as paternalistic that could raise questions about the nature of HIV care in the United States or reflects the perceived patient need and the provider's perceived responsibility to meet that need. Although not thoroughly explored in this particular article but related to patient navigation of the health system, the utilization of team-based and coordinated care approaches have been shown to opti-

mize engagement in HIV care by holistically addressing the contextual needs of vulnerable populations.^{6,7,25} Such approaches may need to be standard for HIV care and for complex conditions in general.

Another salient finding is that providers require comfort and confidence in speaking about sexual health with patients, to engender trust and allow the patient to share sensitive information in a trusting environment.^{4,34–37} Studies have shown that the quality of the interpersonal relationship between providers and patients, specifically communication, significantly predicts the likelihood of patients engaging in preventative healthcare.^{2,7,36–39} This reality underscores the importance of exploring and obtaining insight into the strategies used by health providers to engage patients and clients into care, a need this study aims to address.

Provider narratives have demonstrated a patient-centered approach to engage patients into the HCC. The approaches employed by providers in part were informed by the extant literature and training on contextualizing patients' vulnerability to HIV risk and nonengagement into the HCC. These approaches were also influenced by providers' ability to be self-aware and to self-reflect on their practice and the interaction desired to engender with patients. These approaches demonstrated empathy toward patients, which is in alignment with patient-centered care.¹ A lack of that insight can result in compromised care, engender provider bias and fuel stigma among the patient population, which are all provider-level factors that can impede engagement into the HCC and threaten positive outcomes for patients who are vulnerable to or living with HIV infection.^{34–39}

Limitations

This study has limitations that should be considered. A two-tier purposive sampling method was used for participant recruitment and aligned with the standards of sampling in qualitative research. However, the providers were self-selected indicating a potential sample bias. Most providers had over 5 years of experience in HIV testing and HIV care, and hence provided insight from utilizing approaches that take time to acquire and master. More novice providers may have had different insight. Experienced perspectives can better inform current practice and address challenges with engaging people into the HCC.

Another limitation is that this study was conducted in Miami, Florida, which has a very unique United States patient population, in that 50% of the population is foreign born,¹⁶ and this jurisdiction has one of the highest HIV rates in the United States.⁴⁰ This context may warrant certain efforts from providers to meet the needs of this unique population.

Acknowledgments

This article's development is supported by a postdoctoral fellowship to the first author from the University of Rochester, School of Nursing, and by the University of Rochester Center for AIDS Research (NIH P30AI078498). The authors would also like to acknowledge the insight of the University of Rochester School of Nursing Qualitative Health Research Group.

Author Disclosure Statement

No competing financial interests exist.

References

- Rathert C, Wyrwich MD, Boren SA. Patient-centered care and outcomes: A systematic review of the literature. *Med Care Res Rev* 2013;70:351–379.
- Underhill ML, Kiviniemi MT. The association of perceived provider–patient communication and relationship quality with colorectal cancer screening. *Health Educ Behav* 2012;39:555–563.
- Alli F, Maharaj P, Vawda MY. Interpersonal relations between health care workers and young clients: Barriers to accessing sexual and reproductive health care. *J Community Health* 2013;38:150–155.
- Flores D, Leblanc N, Barroso J. Enrolling and retaining human immunodeficiency virus (HIV) patients in their care: A metasynthesis of qualitative studies. *Int J Nurs Stud* 2016;62(Suppl C):126–136.
- Tomori C, Risher K, Limaye RJ, et al. A role for health communication in the continuum of HIV care, treatment, and prevention. *J Acquir Immune Defic Syndr* 2014;66:S306–S310.
- Barroso J, Leblanc NM, Flores D. It's not just the pills: A qualitative meta-synthesis of HIV antiretroviral adherence research. *J Assoc Nurses AIDS Care* 2017;28:462–478.
- Leblanc NM, Flores DD, Barroso J. Facilitators and barriers to HIV screening. *Qual Health Res* 2015;26:294–306.
- Gardner EM, McLees MP, Steiner JF, del Rio C, Burman WJ. The spectrum of engagement in HIV care and its relevance to test-and-treat strategies for prevention of HIV infection. *Clin Infect Dis* 2011;52:793.
- Skarbinski J, Rosenberg E, Paz-Bailey G, et al. Human immunodeficiency virus transmission at each step of the care continuum in the United States. *JAMA Intern Med* 2015;175:588–596.
- Broadus MR, Owczarzak J, Schumann C, Koester KA. Fostering a “Feeling of Worth” among vulnerable HIV populations: The role of linkage to care specialists. *AIDS Patient Care STDS* 2017;31:438–446.
- Van den Berg JJ, Neillands TB, Johnson MO, et al. Using path analysis to evaluate the healthcare empowerment model among persons living with HIV for antiretroviral therapy adherence. *AIDS Patient Care STDS* 2016;30:497–505.
- Dwamena F, Holmes-Rovner M, Gauden CM, et al. Interventions for providers to promote a patient-centered approach in clinical consultations. *Cochrane Database of Syst Rev* 2012;12:CD003267.
- Epstein RM, Fiscella K, Lesser CS, Stange KC. Why the nation needs a policy push on patient-centered health care. *Health Aff* 2010;29:1489–1495.
- Brennan N, Barnes R, Calnan M, et al. Trust in the health-care provider–patient relationship: A systematic mapping review of the evidence base. *Int J Qual Health Care* 2013;25:682–688.
- Diñç L, Gastmans C. Trust in nurse–patient relationships. *Nurs Ethics* 2013;20:501–516.
- United States Census Bureau. Quick Facts: Miami-Dade County. Available at: <https://census.gov/quickfacts/fact/table/miamidadecountyflorida/POP060210> (Last accessed November 1, 2017).
- Lincoln YS, Guba, EG. *Naturalistic Inquiry*. Newbury Park, CA: Sage Publications, 1985.
- Sandelowski M. What's in a name? Qualitative description revisited. *Res Nurs Health* 2010;33:77–84.
- Sandelowski M, Barroso J. Classifying the findings in qualitative studies. *Qual Health Res* 2003;13:905–923.
- Vaismoradi M, Turunen H, Bondas T. Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study. *Nurs Health Sci* 2013;15:398–405.
- Spall S. Peer debriefing in qualitative research: Emerging operational models. *Qual Inq* 1998;4:280–292.
- Gwadz M, de Guzman R, Freeman R, et al. Exploring how substance use impedes engagement along the HIV care continuum: A qualitative study. *Front Public Health* 2016;4:62.
- Kuchinad KE, Hutton HE, Monroe AK, et al. A qualitative study of barriers to and facilitators of optimal engagement in care among PLWH and substance use/misuse. *BMC Res Notes* 2016;9:229.
- Grau LE, Griffiths-Kundishora A, Heimer R, et al. Barriers and facilitators of the HIV care continuum in southern New England for people with drug or alcohol use and living with HIV/AIDS: Perspectives of HIV surveillance experts and service providers. *Addict Sci Clin Pract* 2017;12:24.
- Hawk M, Coulter RWS, Egan JE, et al. Exploring the healthcare environment and associations with clinical outcomes of people living with HIV/AIDS. *AIDS Patient Care STDS* 2017;31:495–503.
- Chen CM, Lee IC, Su YY, Mullan J. The longitudinal relationship between mental health disorders and chronic disease for older adults: A population-based study. *Int J Geriatr Psychiatry* 2017;32:1017–1026.
- López JD, Shacham E, Brown T. Suicidal ideation persists among individuals engaged in HIV care in the era of antiretroviral therapy. *AIDS Behav* 2017 [Epub ahead of print]; DOI: 10.1007/s10461-016-1666-5.
- Gurung RAR, Taylor SE, Kemeny M, Myers H. “HIV is not my biggest problem”: The impact of HIV and chronic burden on depression in women at risk for AIDS. *J Soc Clin Psychol* 2004;23:490–511.
- Douglas JM, Fenton, KA. Understanding sexual health and its role in more effective prevention programs. *Public Health Rep* 2013;128(Suppl 1):1–4.
- Satcher D, Hook EW, Coleman E. Sexual health in America: Improving patient care and public health. *JAMA* 2015;314:765–766.
- Jurgensen M, Sandoy I, Michelo C, Fylkesnes K. Effects of home-based voluntary counseling and testing on HIV-related stigma: Findings from a cluster-randomized trial in Zambia. *Soc Sci Med* 2013;81:18–25.
- Swartzendruber A, Zenilman JM. A national strategy to improve sexual health. *JAMA* 2010;304:1005–1006.
- Friedman EG, Crowley M, Howard KA, Pavel MP. Home improvement in HIV primary care: Investigating the patient-centered medical home model for people living with HIV/AIDS. *Popul Health Manag* 2015;18:323–329.
- Lettenmaier C, Kraft JM, Raisanen K, Serlemitsos E. HIV communication capacity strengthening: A critical review. *J Acquir Immune Defic Syndr* 2014;66:S300–S305.
- Murray B, McCrone S. An integrative review of promoting trust in the patient–primary care provider relationship. *J Adv Nurs* 2015;71:3–23.
- Dawson-Rose C, Cuca YP, Webel AR, et al. Building trust and relationships between patients and providers: An essential complement to health literacy in HIV care. *J Assoc Nurses AIDS Care* 2016;27:574–584.
- Haley B, Heo S, Wright P, et al. Relationships among active listening, self-awareness, empathy, and patient-centered care

- in associate and baccalaureate degree nursing students. *NursingPlus Open* 2017;3(Suppl C):11–16.
38. Wagner AC, Hart TA, McShane KE, et al. Health care provider attitudes and beliefs about people living with HIV: Initial validation of the health care provider HIV/AIDS stigma scale (HPASS). *AIDS Behav* 2014;18:2397–2408.
39. Stutterheim SE, Sicking L, Brands R, et al. Patient and provider perspectives on HIV and HIV-related stigma in Dutch health care settings. *AIDS Patient Care STDS* 2014; 28:652–665.
40. Centers for Disease Control and Prevention [CDC]. CDC Fact Sheet: Today's HIV/AIDS Epidemic. Available at:

<https://cdc.gov/nchhstp/newsroom/docs/factsheets/todaysepidemic-508.pdf> (Last accessed November 1, 2017).

Address correspondence to:
Natalie M. Leblanc, PhD, MPH, BSN, RN
School of Nursing
University of Rochester
601 Elmwood Avenue, Box SON
Rochester, NY 14642

E-mail: natalie_leblanc@urmc.rochester.edu