“Where It Falls Apart”: Barriers to Retention in HIV Care in Latino Immigrants and Migrants

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Abstract

Latino immigrants in the United States are disproportionately affected by HIV. Barriers to consistent attendance (retention) in HIV primary care constrain opportunities for HIV treatment success, but have not been specifically assessed in this population. We conducted semistructured interviews with 37 HIV-infected Latinos (aged ≥ 18 years and born in Puerto Rico or a Latin American Spanish-speaking country) and 14 HIV providers in metropolitan Boston (total $n = 51$). The Andersen Model of Healthcare Utilization informed a semistructured interview guide, which bilingual research staff used to explore barriers to HIV care. We used thematic analysis to explore the processes of retention in care. Six ubiquitous themes were perceived to influence HIV clinic attendance: (1) stigma as a barrier to HIV serostatus disclosure; (2) social support as a safety net during negative life circumstances; (3) unaddressed trauma and substance use leading to interruption in care; (4) a trusting relationship between patient and provider motivating HIV clinic attendance; (5) basic unmet needs competing with the perceived value of HIV care; and (6) religion providing a source of hope and optimism. Cultural subthemes were the centrality of family (*familismo*), masculinity (*machismo*), and trusting relationships (*confianza*). The timing of barriers was acute (e.g., eviction) and chronic (e.g., family conflict). These co-occurring and dynamic constellation of factors affected HIV primary care attendance over time. HIV-infected Latino immigrants and migrants experienced significant challenges that led to interruptions in HIV care. Anticipatory guidance to prepare for these setbacks may improve retention in HIV care in this population.

Keywords: foreign-born/immigrant, HIV/AIDS, retention in care, qualitative research, Latino/Hispanic

Introduction

THE UNITED NATIONS “90–90–90” target to identify, treat, and achieve viral suppression in 90% of HIV-infected persons requires engagement in all steps of the HIV care continuum.¹ In the United States, approximately one-half of HIV-infected individuals are not retained in HIV care, which can lead to compromised virologic control and reduced survival.^{2–5} Of the 70% of individuals without virologic suppression in the United States, 66% were not engaged in HIV care.⁴ In addition to gaps in care attendance, missed HIV primary care visits are associated with a greater likeli-

hood of virologic failure, AIDS-related clinical events, and death.^{6–8} Irregular attendance in HIV primary care represents a particularly severe yet unaddressed problem for Latinos, threatening the promise of these individual- and population-level goals for an AIDS-free generation.^{9,10}

Immigrants and migrants across racial and ethnic groups bear a disproportionate HIV burden.^{11–13} In US-based Latinos, immigrants comprise 42% of HIV incidence.¹³ Latino immigrants in the United States have particularly low rates of HIV testing predisposing them to delayed HIV diagnosis.¹² Geographic variation in healthcare access and quality, inadequate health insurance due to residency status, and HIV

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criminalization laws threaten health outcomes in HIV-infected Latinos.¹⁴ On an individual-level, limited English language proficiency, cultural values that limit active questioning of authority figures such as physicians, strict gender roles, and lack of familiarity with the complexities of the US medical system compromise active health-seeking behaviors for Latino immigrants and impinge on effective utilization of HIV prevention and healthcare services.^{15–21}

Much of what is known on HIV service utilization in Latino immigrants and migrants has focused on HIV prevention, testing, and adherence to antiretroviral therapy (ART), as well as psychosocial consequences of HIV/AIDS.^{22–26} Recent qualitative research on barriers to retention in HIV primary care has included racially and ethnically diverse samples, including Latinos, but has not specifically focused on Latino immigrants.^{27,28} A large survey-based sample of young HIV-infected men who have sex with men (MSM) found that young Latino MSM were at high risk for poor retention in HIV care, particularly those who reported a poor rapport with their HIV provider.⁹

In the present study, we collected qualitative data from HIV-infected Latino immigrants/migrants and HIV providers to understand psychosocial, cultural, and logistical processes involved in sustained attendance in HIV primary care in these populations. We framed our interviews around the Andersen Model of Health Services Use, a widely used theoretical model that accounts for determinants of healthcare utilization and has been applied in HIV health services research.^{29,30} The model is composed of domains of predisposing, enabling, and need characteristics that influence health behavior

and use of health services. Gelberg et al. adapted the original behavioral model of healthcare utilization specifying domains relevant for vulnerable populations, with specific attention to individuals who are homeless.³¹

Based on published literature on healthcare utilization in Latino immigrants, we adapted the Andersen model (Fig. 1) to inform the domains of the semistructured interview probes: environment (e.g., clinic, healthcare system, and provider), predisposing and enabling characteristics (e.g., stigma, gender, social support, insurance, health beliefs, culture), and health behaviors (e.g., personal health choices, use of health services, use of ART and other medications). We took an ethnographic approach to solicit cultural themes through which patients and providers could respond to open-ended questions regarding retention in care and address potential competing unaddressed areas of concern.

Methods

Study design and overview

We collected qualitative data using semi-structured interviews from HIV-infected Latino immigrants and migrants and HIV providers in metropolitan Boston, MA. Our objective was to obtain qualitative data on barriers to and facilitators of consistent attendance in HIV primary care for Latino immigrants/migrants to develop tailored interventions. A qualitative approach is ideal for uncovering socio-cultural influences, attitudes, and psychological processes that may influence decision-making in HIV-infected Latino

FIG. 1. An adaption of the Gelberg–Andersen model of healthcare utilization to describe barriers and facilitators to retention in HIV care for HIV-infected Latino immigrants and migrants.

immigrants/migrants around retention in longitudinal primary HIV care.³²

Study setting and population

HIV-infected Latino immigrants/migrants as well as HIV providers in the Greater Boston area were interviewed between December 2013 and April 2015. Criteria for enrollment in the client sample were (1) HIV-infected status; (2) age ≥ 18 years; and (3) self-identified Latino. Eligible individuals needed to be born in Puerto Rico (US migrant) or other Latin American Spanish-speaking countries (US immigrant). Participants did not have to be literate but had to be able to speak English or Spanish and provide verbal consent. For the provider sample, eligible individuals were age ≥ 18 years and served as an HIV provider in the greater Boston area.

Recruitment

Individuals were recruited through local HIV and primary care outpatient clinics and community organizations. To establish trust with participants, potential interview participants were told about the study by a key informant (e.g., staff member of the clinic or local service organization, or interview participant who agreed to conduct recruitment after participation).³³ Passive recruitment occurred through clinic and community-based flyers placed in homeless shelters, substance abuse programs, sporting venues, community organizations, and AIDS service organizations in areas of high Latino density.

We used purposeful sampling to maximize a broad representation of the target population, targeting recruitment by age (18–25 and ≥ 26 years), gender (male and female), and HIV clinic attendance (inconsistent and consistent clinic attendance).³⁴ Definitions of clinic attendance were informed by national HIV consensus guidelines and validated in multiple settings.^{7,35,36} Inconsistent clinic attendance was defined as not retained in care (at least one 6-month interval without a primary care HIV visit in the 12 months before the interview) or missing appointments (at least one missed HIV appointment in the 12-month period).³⁷

A bilingual research coordinator trained in human subjects' research performed a telephone screen for eligibility of individuals who were referred to the study and gave permission to be called or called themselves. We enrolled participants until the data reached saturation and no new information or themes were elicited.³⁸ We aimed to enroll at least five individuals in each subgroup (age, gender, and clinic attendance) to maximize detailed comparisons.^{39,40} We confirmed demographic details and clinic attendance by electronic medical record or provider report.

Provider participants were recruited into the study by direct outreach to HIV clinics and AIDS service organizations. We targeted provider recruitment to obtain a diverse representation of HIV service providers (i.e., physicians, nurses, community health workers, social workers, and case managers). Clients and providers received a \$40 gift card for completing the interview and clients received \$5 for transit.

Informed consent

Since potential client participants may have been concerned about documenting their name on paper due to either

HIV or immigration status or both, verbal rather than written consent was obtained. This study was approved by Partners Healthcare Institutional Review Board (Boston, MA).

Data collection and preparation

The interview protocol was framed around the adapted conceptual model (Fig. 1). We used a semi-structured protocol to facilitate 90-min discussions with clients. The interview began with a short quantitative in-person questionnaire covering demographics, clinical history, mode of HIV transmission, and HIV medical status. The questionnaire was followed by a semi-structured interview with key themes addressing (1) barriers to retention in medical and HIV care; (2) psychosocial challenges to retention; (3) linguistic and cultural factors; (4) structural and environmental challenges; (5) HIV stigma and disclosure of HIV status; (6) health beliefs; and (7) feedback on community HIV programming (Table 1).

We began with ("grand tour") questions such as: "Tell me about when you were first diagnosed with HIV?" We followed with structured probes (e.g., age, gender roles, fatalism, acculturation, stigma, and social support) to elucidate cultural beliefs and values.⁴¹ We addressed patient-provider and patient-health system factors through probes on perceptions of HIV care and ART. We also addressed the process of emigration or migration to understand socioeconomic and cultural changes, as well as perceptions of barriers and facilitators to HIV care as an immigrant. The provider interview protocol was briefer than the client-based protocol, but with a similar structure.

We pilot tested the interview protocol and procedure with three individuals who were similar to our client study population to assess cultural and linguistic acceptability of the interview guide. During the pilot test, we assessed participants' comprehension of the study questions and solicited their feedback. Since no changes were required to the interview protocol, these data were retained for analysis. Sessions were digitally recorded with participant permission, transcribed, and translated to English. All Spanish language interviews were professionally transcribed and translated. All transcripts were reviewed for quality and edited as appropriate to maintain accuracy with the audio recordings.

Data elements

We extracted all attended and missed HIV primary care appointments from the medical record. A primary care HIV appointment was defined as a medical visit with an HIV provider, physician, or nurse practitioner.⁴² Missed visits were defined as an unattended scheduled appointment without prior cancellation. Inconsistent appointment attendance was defined as at least one 6-month interval without a primary care HIV or at least 1 missed HIV appointment encounter in the 12 months before the interview.^{35,37} We used the most recent CD4 count and HIV RNA obtained before the interview.

Analytic approach

We first applied an inductive analytic approach to the data to develop observations on determinants of retention in care for each participant as well as to develop an explanatory model of the barriers to retention in medical and HIV care.

TABLE 1. QUALITATIVE PROTOCOL FOR SEMISTRUCTURED INTERVIEWS WITH HIV-INFECTED LATINO IMMIGRANTS AND MIGRANTS

<i>Question topic</i>	<i>Question example</i>
Overview	<ul style="list-style-type: none"> Some people have problems coming to medical appointments in general. Do you or do you not have difficulty attending medical appointments in general and why?
Sociodemographic barriers	<ul style="list-style-type: none"> How do you think your ability to speak English influences the kind of HIV care you receive, in either a good way or not a good way? How does your ability to speak English affect or not affect your ability to keep your HIV appointments? How do you think that your status as an immigrant is a barrier or not a barrier to coming to your HIV appointments? How do you think family responsibilities make it difficult or not difficult to come to your HIV appointments?
Psychosocial and cultural barriers	<ul style="list-style-type: none"> Do you feel that you have support from friends and family? If you feel you do not have enough support does this make it difficult or not to get HIV care, and if so, how? What do you think about letting others, like friends and family, know about your HIV status? If you keep your HIV status private, does this make it more difficult or not make it more difficult to get HIV care for yourself and if so, how? To what extent do you believe that if a person gets HIV/AIDS it was meant to happen and there was nothing you could do to change it? Why or why not? How does visiting the HIV doctor or taking HIV medications say something about your intimate or personal life? Your strength as a man? Or your ability to project your family or keep them healthy? Why or why not?
Structural/ environmental barriers	<ul style="list-style-type: none"> What about not being able to get to your HIV appointments, due to clinic's location? How do you think location is a challenge or not a challenge to getting care? What about the cost of HIV medical care, such as services, medicines, and tests? How do you think the cost of HIV medical care is a challenge or not a challenge to receiving care?

This approach is relevant to observing relationships and processes within the data without imposing prior assumptions.³⁴ Two study staff reviewed all transcripts and systematically extracted information relevant to HIV care retention. Using thematic analysis, we identified themes (e.g., family values, gender roles, social support, and unmet needs) that were common to participants with attention to psychosocial processes and cultural assumptions.^{43–46} We used NVivo qualitative software to retrieve instances of each theme. We developed a codebook that listed each theme.⁴⁷

To assure reliability, two study staff tested a random sample of 20% of transcripts, coding independently and comparing results until both coders identified and marked each theme when it appeared in the transcript. Computed Kappa statistics $\kappa \geq 0.70$ indicated sufficient inter-rater reliability.^{44,46,48} We grouped similar coding categories together to calculate kappa statistics and report them here (Table 1). Once we achieved reliability, we continued to code the remaining transcripts independently and resolved inconsistencies with a third study staff member.

To determine differences in barriers and facilitators, we compared responses by inconsistent and consistent attendance, gender (female vs. male), place of birth (Puerto Rico compared with other foreign-born country), and age (18–25 and ≥ 26 years). To maximize validity of the data interpretation, we reviewed findings with an HIV-focused community advisory board as well as Latino-focused HIV patient support groups.⁴⁹

Results

Participant characteristics

Fifty-one individuals were eligible and enrolled in the study; 37 were client participants and 14 were HIV service providers (Table 2).

Clients. Eighty-five individuals underwent telephone screening for eligibility. Five were ineligible because they were born on the US mainland. Of the 80 eligible individuals, 37 were enrolled and 43 were not enrolled. No one declined to participate. Those who were not enrolled ($n=43$) were due to reaching

TABLE 2. INTER-RATER RELIABILITY FOR EACH CODED DOMAIN FOR INTERVIEWS WITH HIV-INFECTED LATINO IMMIGRANTS/MIGRANTS AND HIV PROVIDERS

<i>Code</i>	<i>Patient interviews Kappa value</i>	<i>Provider interviews Kappa value</i>
Stigma	0.72	1.00
HIV serostatus disclosure	0.72	1.00
Social support	0.88	0.80
Mental health and substance use	0.88	1.00
Immigrant status and low English language proficiency	0.93	0.90
Culture (family orientation, gender roles, religion)	0.91	0.95
Financial insecurity	1.00	1.00
Patient-provider relationship	0.79	0.88

thematic saturation to balance the perspectives across categories of HIV clinic attendance, age, and gender. Therefore, 93% ($n=40$) of those who were not enrolled were consistent attendees of HIV primary care. For those with available data on age ($n=42$), 100% were ≥ 26 years. Males comprised 63% ($n=27$).

Of the enrolled client cohort, 86% ($n=32$) were age ≥ 26 years, 14% ($n=5$) were young adults age 18–25 years, 68% ($n=25$) were male, 43% were born in Puerto Rico, and 16% in the Dominican Republic (Table 3). Spanish was the primary language for 86% ($n=32$). Median years living in the US mainland were 12.5 years [Interquartile range (IQR) 4.1–30.3 years]. The group was overall impoverished with 70% ($n=26$) reporting an annual income $< \$10,000$ and 73% ($n=27$) unemployed.

At study enrollment, median CD4 count was 428 cells/ μ L (IQR 309–555 cells/ μ L) and 84% ($n=31$) had virologic suppression. Sixteen individuals ($n=43$) inconsistently attended HIV primary care appointments in the past 12 months. HIV risk factors differed by gender. In males, 36% ($n=9$) reported MSM sex as the single HIV risk factor, 36% ($n=9$) reported heterosexual contact, of whom five out of the nine reported heterosexual sex and Injection Drug Use (IDU), and 28% ($n=7$) reported other risk factors or refused to answer. In females, 75% ($n=10$) reported heterosexual transmission, of whom 1 out of the 10 was combined heterosexual contact and IDU.

Providers. Fifty percent ($n=7$) of providers identified as social workers or medical case managers, 22% ($n=3$) were physicians, 14% ($n=2$) were community health workers, and 14% ($n=2$) were nurses (Table 3).

Qualitative results

We uncovered six key structural and psychosocial themes that influenced retention in HIV care in this sample of HIV-infected Latino immigrants and migrants: (1) stigma as a barrier to HIV serostatus disclosure; (2) social support as a safety net during negative life circumstances; (3) unaddressed trauma and substance use leading to interruption in care; (4) a trusting relationship between patient and provider motivating HIV clinic attendance; (5) basic unmet needs competing with the perceived value of HIV care; and (6) religion providing a source of hope and optimism. Cultural subthemes were the centrality of family (*familismo*), cultural conceptions of masculinity (*machismo*), and the importance of trusting relationships (*confianza*).

Stigma as a barrier to HIV serostatus disclosure. HIV-related stigma was frequently reported as the most influential barrier to consistent HIV clinical attendance. Participants described discrimination, threats, physical abuse, and unfair treatment by family, friends, and community members due to HIV. This treatment was rooted in widely held beliefs of HIV as a fatal illness associated with social transgression due to sexual impropriety or drug use. Conversations about HIV were taboo and therefore silenced:

I don't know about other cultures but in our culture, people don't want to talk about it. They dismiss it. [Patient, Male, Age 43, Foreign-born, Heterosexual]

...I mean, they're dying from afar. I imagine that they're dying on the inside when they treat you that way in your home, or with the people, and let's not start on if the people ... knew because people don't know. [Provider, Female, Case manager]

TABLE 3. CHARACTERISTICS OF PARTICIPANTS IN THE QUALITATIVE STUDY ON BARRIERS TO RETENTION IN HIV CARE IN LATINO IMMIGRANTS AND MIGRANTS

Characteristics	Cohort $n=51$ (%)
Client characteristics	$n=37$ (%)
Sociodemographic characteristics	
Age	
18–25 years	5 (14)
≥ 26 years	32 (86)
Sex	
Female	12 (32)
Male	25 (68)
Place of birth	
Puerto Rico	16 (43)
Dominican Republic	6 (16)
Honduras	6 (16)
Guatemala	3 (8)
Mexico	3 (8)
Columbia	2 (6)
El Salvador	1 (3)
Arrival in the United States, median years [IQR]	12.5 [4.1–30.3]
Primary language	
Spanish	32 (86)
English or bilingual	5 (14)
Annual income	
$< \$10,000$	26 (70)
$\geq \$10,000$	11 (30)
Clinical and attendance characteristics	
HIV RNA < 200 copies/mL	31 (84)
CD4 count cells/ μ L (median), [IQR]	428 [309–555]
Inconsistent HIV primary care attendance	16 (43)
HIV risk factors	
Male	25
Male-to-male sexual contact	9 (36)
Injection drug use	0 (0)
Male-to-male sexual contact and injection drug use	0 (0)
Heterosexual contact	4 (16)
Heterosexual contact and injection drug use	5 (20)
Other ^a	7 (28)
Female	12
Injection drug use	0 (0)
Heterosexual contact	9 (75)
Heterosexual contact and injection drug use	1 (8)
Other ^a	2 (17)
Provider characteristics	$n=14$ (%)
Social worker/medical case manager	7 (50)
Community health worker	2 (14)
Nurse	2 (14)
Physician	3 (22)

^aIncludes hemophilia, blood transfusion, perinatal exposure, and risk factor not reported or not identified.
IQR, interquartile range.

Unjust treatment due to HIV status resulted in intense feelings of shame and self-loathing:

But within friends and the Hispanic community, they discriminate against you when they find out that you have a disease or something...One time, I was so affected that

I locked myself in and would not eat. [Female, Age 58, Foreign-born]

the social isolation when it comes to being fearful, or of 'oh can you see it in me? Is it tagged in me?'... And it's something that we've worked for so long since I started working with her... [Provider, Female, Community Health Worker]

Patients were concerned that they were “tagged” by HIV, and this led to strong feelings of social exclusion.

A common coping mechanism to HIV-related stigma was social withdrawal, avoiding situations, including attendance at HIV service facilities, which could lead to disclosure of HIV serostatus. These reactions were common at HIV diagnosis but more typically sustained in those who inconsistently attended HIV appointments. The following two quotes reflect commonly reported concerns about meeting people in the clinic:

Look, when I went to start my treatment, the person that they assigned as my case manager, her son played ball with my son, and her husband knows me... I don't want them [case manager and her family] to talk about me in front of them [patient's children] because I haven't talked to my children about this yet. [Patient, Male, Age 30, Puerto Rican-born, Heterosexual]

Because I know that they're going to ask me, 'What are you doing here, and for what reason are you here in the area for that disease?'...by sitting down, I know that I'm going to see the HIV doctor, but for a friend to come and see me sitting there, I'd be a dead man, totally. [Patient, Male, Age 40, Puerto Rican-born, Sexuality “not sure or in transition”]

While patients with inconsistent clinic attendance relayed greater exposure to or anticipation of stigmatizing events, all patients described the challenges of balancing their privacy with attending HIV care for fear of social rejection:

I don't tell them [family] I'm going to my HIV appointment. Again, I keep things under wraps as tight as I could. Not to say I'm scared, but again, I don't know what to expect. [Patient, Male, Age 43, Foreign-born, Heterosexual]

One of the things that culturally is very strong in Latinos is privacy and this issue about confidentiality. So most of my Latino patients have a very hard time A) accepting the disease, and B) disclosing or coming out with it. So think if there were any particular barriers, it is long term engagement. [Provider, Female, Physician]

Within those who inconsistently attended HIV appointments, avoidance of HIV-related care as a response to HIV-related stigma was more common in young adults, MSM, and foreign-born Latinos (compared with Puerto Rican-born), particularly recent arrivals to the United States. The reasons for this behavior differed by these subpopulations. In younger clients, the fear of social approval was salient. Avoiding social disapproval and family conflict through events associated with potential of HIV disclosure seemed to outweigh, for some, the potential benefits of attending HIV care:

One of the difficulties you might face is when you live with another person who doesn't know about your condition.... So, for me that has been a problem, because I have to lie about why I am coming here. [Patient, Male, Age 20, Foreign-born, MSM]

Why am I hiding it? Well, because—well, in my country there is a lot of discrimination, you know? So, when someone is this way, with this condition, they prefer to keep it separate. [Patient, Male, Age 21, Foreign-born, Heterosexual]

Cultural conceptions of masculinity, *machismo*, and social taboos against homosexuality often led MSM to avoid disclosure of HIV status for fear of the association of HIV with homosexuality, potential family conflict, and physical and emotional threats or harm:

...muy machista. Like they don't believe in homosexual...like, it's a sin. And HIV is a pest that god sent to kill homosexuals. That's the mentality my community have about people with HIV. [Patient, Male, Age 53, Puerto Rican-born, MSM]

... there is a lot of stigma in a lot of Latino communities around GLBT stuff...because a lot of times folks have been shunned from their families, or they've come from other countries where they have been discriminated or had violence against them for those reasons. [Provider, Female, Social worker]

Clients born outside the United States experienced strong deterrents to HIV care from stigma due to HIV-related misconceptions and health beliefs. This group reported commonly held beliefs in their countries of origin that AIDS inevitably led to death or that medication use was reserved only for severe illness. These conceptions challenged their comfort in attending HIV appointments. This group feared legal consequences, including deportation, from disclosure of their HIV status or seeking HIV services:

So, people think it's possible that they could be deported. They prefer to hide their health situations and not go to the doctor. There is a lot of fear. Many complications. [Patient, Male, Age 33, Puerto Rican-born, MSM]

And she told me that 'if I receive services they're going to take my residency away, so I have to be very careful because I don't want to go to jail. And I don't want my daughter to go to jail.'...So there's a stigma around that. [Provider, Female, Case Manager]

Particularly in recent arrivals to the United States, these beliefs and fears resulted in delay of HIV care until expression of symptomatic disease and/or utilization of emergency rooms for triage.

Social support as a safety net during negative life circumstances. Emotional support buoyed periods of low motivation, and instrumental support came from financial assistance or appointment or medication reminders. The following quotes reflect common responses when participants were asked about the influence of close family members, *familismo*, on patients' ability to attend HIV appointments:

She [daughter] calls me every day. She knows how I am, and if I need anything...And sometimes she sends me money. [Patient, Female, Age 48, Puerto Rican-born]

I always try to be—to remember everything, but they [partner and sister] are also very mindful in telling me, 'remember that your appointment is next week.' And sometimes I'll say, 'I know, I haven't forgotten,' but—but they are also aware of my appointments.' [Patient, Male, Age 45, Foreign-born, MSM]

While social support was critical to sustaining long-term HIV care, the experience of migration separated Latino immigrants and migrants, in both Puerto Rican and other foreign-born Latinos, from their family and friends leaving them vulnerable to social isolation once in the US mainland:

I don't have friends, and family—my whole family is in Puerto Rico. The only family I have is my children. [Patient, Male, Age 30, Puerto Rican-born, Heterosexual]

Nobody is there to check if they are taking their medication, if they are getting up, if they are doing well... And depression—whatever mental issues they have can lead to depression. So, many fall into drugs.... [Provider, Male, Case manager]

The aforementioned quotes describe this social isolation, which, in part, was contributed by geographic separation from family and friends but also exacerbated by an interest to avoid negative social criticism or negative social support. In those who inconsistently attended appointments, a common theme was a preference to maintain no or few social contacts rather than risk negative influence or rejection by others. Familism, or a strong family orientation, was widely upheld as a critical factor that could both facilitate and hinder HIV care attendance. A strong family connection countered the negative effects of HIV-related stigma because the preservation of family ties outweighed the risk of HIV disclosure. Both men and women described parenting responsibilities and avoidance of becoming a burden on family as motivations for staying healthy:

So to me there's no cure for HIV...I want to do the best I can for as long as I can. I have two grandchildren, too. They are part of a motivation on a daily basis. [Patient, Male, Age 50, Puerto Rican-born, Heterosexual]

I am a mother of three, on my own...When I get sick, I can pick myself up. When I would [drug use] relapse before, I couldn't get better. It was too difficult, because I didn't have enough experience. But now I've relapsed so many times that I know how to push through it, most of all because of my kids. It's easier. [Patient, Female, Age 23, Puerto Rican-born]

Not only did family responsibilities motivate self-care but the importance of close family relationships gave a reason to be healthy as well, such as seeing children or grandchildren grow up. Patients described taking care to protect family from contracting HIV, even if they knew HIV could not be spread by casual contact. They noted distancing themselves from relatives (particularly children) and cleaning kitchenware for fear that these beliefs were a concern of others. Family relationships could often be conflicted when relatives were the source of discriminatory behavior as well as the only source of support (e.g., money, transportation, treatment reminders) as reflected in the following two quotes:

So, sometimes my daughter can't bring me...and that causes me problems from time to time because I don't have money for transportation...Sometimes I have to be asking for favors. My niece also can't, and the whole world has their commitments. And sometimes I miss my appointments... [Patient, Female, Age 58, Foreign-born]

He [patient's father] told me because he didn't want sick people in the house in Miami... So, I—I mean, he excluded me. He still excludes me. He still doesn't accept me now... My challenge is my father who defied me. He has a lot—plenty of money in Miami, and he doesn't want to help me. [Patient, Male, Age 49, Foreign-born, Heterosexual]

Patients were vulnerable to missing appointments during periods of family conflict or lack of family availability to provide support that was instrumental to attending HIV appointments.

Unaddressed trauma and substance use leading to interruption in care. Mental health conditions, such as depression, anxiety, post-traumatic stress, and substance use, were com-

mon factors that interrupted engagement in HIV care for Latino immigrants and migrants. Individuals described significant traumatic events in addition to the diagnosis of HIV. Male and female patients frequently reported exposure to traumatic events, including the circumstances of the HIV diagnosis, intimate partner violence, sexual violence during migration, and physical and verbal assaults. Trauma manifested in anxiety, depression, and hypervigilance. The following quotes from patients illustrate how unaddressed trauma and substance abuse interfere with consistent HIV primary care attendance. The first patient describes feelings of fear and panic provoked by attending HIV appointments because they remind him of the events of the initial HIV diagnosis. The second patient experienced multiple prior physical traumas and describes how disruptive these experiences are emotionally and physically on her ability to attend her HIV appointments:

What fear does is that sometimes, when I'm the happiest ever, I stop laughing, I get serious, and everything is fear...I panic, yes, but, like, I stop completely, I think a lot of things, but I do get fearful when I go out to the street more. [Patient, Male, Age 40, Puerto Rican-born, Sexuality "not sure or in transition"]

...because it already happened once; and now, again. This is unbelievable. So, now I cry a lot, I'm not sleeping, and I'm always home. And when I go out, I'm very fearful, and I have to look everywhere. [Patient, Female, Age 57, Foreign-born]

Substance use also inhibited consistent HIV care attendance because the demands of substance use on physical, emotional, and financial resources outweighed the relative importance of care attendance. The following quotes reflect the challenges of consistent HIV care attendance in the setting of substance use disorders. In the first quote, a patient with injection drug use history, recently entered recovery and describes how drug use funnels all personal resources away from attending HIV appointments. The second quote, from a physician provider, reiterates the challenge of untreated substance use disorders on HIV care attendance:

I wouldn't go to my appointments: I wouldn't eat; I wouldn't do anything, as I only had time for drugs. [Patient, Male, Age 50, Puerto Rican-born, Heterosexual]

Some of our clients are substance abuse users. Like once you are a user, you're always a user, even if you stop. So a lot of them relapse. A lot of them go missing for a while. So imagine if drug is most important. What about your healthcare? Least. [Provider, Female, Case manager]

Patients described relying on family and their HIV provider for assistance with managing relationships with active drug users, but still feeling isolated from a substance-free social network. Providers, though, describe the challenge in connecting patients to substance use services because of the lack of availability of culturally and linguistically tailored treatment programs:

I live isolated...I had a friend...and what she'd take me was drugs, and I use to do cocaine. And I distanced myself from her because I knew that sooner or later, that was going to cause me more problems. I talked to my doctor about it here, and gave in again when she'd give me a drink. [Patient, Female, Age 58, Foreign-born]

So I've had patients that speak zero English...where they're sitting in groups [reference to substance use recovery programs]

where everything is being spoken in English and they're just kinda sitting there. [Provider, Female, Physician]

Lack of recovery support due to insufficient social support and culturally and linguistically appropriate mental health and substance use services impinged on the ability of individuals to effectively engage in mental health and substance use services.

A trusting relationship between patient and provider motivating HIV clinic attendance. Patients and providers described the importance of a trusting relationship with an HIV provider in supporting consistent attendance in HIV care. In addition, both patients and providers described the value of different team members. For example, psychosocial concerns, such as family conflict, concerns around substance use relapse, were more easily confided in near peers, such as community health workers or case managers. Patients underscored the authoritative role of physicians who served as the primary source for health information and motivated patient behavior:

Because they would tell me the doctors 'come to the appointment because it's for your own good'...And that's why I was trying—even if I got there a bit late, I would get to my appointments. [Patient, Male, Age 42, Foreign-born, MSM]

So much of this is just about relationships, right? If a patient feels really connected to their provider, and feels like it is beneficial and that it's adding to, rather than subtracting from...it's seldom that adherence is an issue. [Provider, Female, Physician]

Personal aspects to the relationship with all HIV providers, such as telephone calls and home and inpatient visits by providers, both physician and nonphysician, were aspects of patient engagement that strengthened patient trust, *confianza*, in their providers and their commitment to HIV care.

Language and cultural discordance between patient, provider, and healthcare system diminished trust in the patient-provider relationship and made the HIV clinic an unwelcoming environment for patients. Access to Spanish-speaking professional interpreters was critical to adequate communication with non-Spanish speaking providers, although participants often questioned the fidelity of the interpreter's information, feared lack of discretion with personal information, and disliked any barrier of direct communication with their physician. The following quotes describe the barriers to communication when patients could not communicate in their primary language:

Sometimes, I don't share—like, I have to look for anyone here or there to be an interpreter. And in the end, I wouldn't know what to think of that person, whether he or she is discreet and can keep my secret from the world. [Patient, Male, Age 44, Foreign-born, Heterosexual]

Here a provider describes the challenge in patients utilizing referrals when the treatment plan was not communicated in Spanish in an adequate format:

I always get the feeling from them [patients] that they didn't connect with any of these places [referrals for services]. And partly it's because maybe they didn't understand what the benefit was of this, or to a certain extent that was sending them somewhere, and they really want to be here. So sometimes I think that things get lost in translation. [Provider, Female, Physician]

Basic unmet needs competing with the perceived value of HIV care. HIV-infected Latino immigrants and migrants often faced competing interests between HIV care attendance and basic unmet needs such as food, clothing, housing, employment, and transportation. Foreign-born, compared with Puerto Rican-born individuals, experienced greater challenges in accessing services and described the hardship due to limited employment opportunities if they lacked legal residency documentation.

Young clients were often breadwinners for their relatives, having to earn for financial dependents, including parents in the US mainland and in their place of origin. Unlike older clients who were uniformly unemployed or on disability, younger clients often held multiple jobs and described this employment-related stress as well as having little flexibility in their schedules. Periods of financial difficulties and instability and unexpected demands at work for patients conflicted with attending medical appointments:

And now, since my parents have both died, we are passing through difficult times. Three sisters have problems with cancer, too. And it's a big problem in our country. There is little income, little money for healthcare. Everything is very difficult... [Patient, Male, Age 38, Foreign-born, MSM]

I help my mother, and I help my brothers. And I'm still paying back the loan my friend gave me to come here. So, that sets me behind in some things...I still don't have funds or resources saved...So that's why right now I still can't be missing work for a month or a few months. So, for now I have to keep working. [Patient, Male, Age 21, Foreign-born, Heterosexual]

Religion providing a source of hope and optimism. For many participants, religion provided a source of hope and optimism through faith in a higher power. Across age demographics, faith in a God was described as a source of comfort, healing, and recovery. Finding or deepening faith helped many individuals gain resiliency in the devastation of the HIV diagnosis and committing to HIV care.

There were complex relationships between faith and self-determination. While many clients identified a central role of religious faith and trusted God as an omnipotent healer, they still highlighted their behavior, including taking ART and attending appointments, as valuable in keeping them healthy. The following quotes reflected commonly reported perceptions of faith and the role of faith in patient engagement in HIV care; in the first quote a patient reports the central role of God but also the deification of the physician who is influential over the patient's behavior, making reference to coming to appointments and taking ART:

What's going to help me is believing and having my faith in Him. Again, she's [the physician] in a sense like the God. I'm not going to pray to her, but she has control over what I do. [Patient, Male, Age 33, Puerto Rican-born, MSM]

The one that cause diseases is down there, which is the devil, but you can say that it's destiny...preventing would be taking your medications and using protection when you have intercourse. [So, you think that by visiting your doctor or taking the HIV medications you can improve?] Oh, yes, a lot...because if you don't take medication, any other disease can affect you too. [Patient, Female, Age 30, Foreign-born]

For each individual patient, the ability to attend appointments varied over time and depended on the balance of barriers and facilitators at any given point in time, including

mental and physical status, social support, economic status, motivation, and underlying problem-solving or coping skills. Not only was the type of barrier to HIV care attendance important but also the quantity and variability of these factors over time. For example, multiple co-occurring barriers caused patients to actively or passively weigh the benefit of attending an HIV appointment against a singular overwhelming or multiple competing interests:

Sometimes I can't get there due to lack of money, lack of time, and sometimes I can't find anyone to take me. Do you understand? ...well, if it was easier for me, I'd go—I wouldn't miss them. [Patient, Female, Age 58, Foreign-born]

I was running around here and there, looking for things, finding food, you know? I didn't have a job. And that's why because there was so much going on that sometimes I would forget about my appointments. [Patient, Male, Age 42, Foreign-born, MSM]

Some barriers were chronic, punctuated by periods of intensity, such as financial insecurity with periods of greater financial demand (e.g., unemployment or eviction), substance use with periods of relapse to drug use among those with addiction disorders, exacerbation of familial conflict, or acute flare of chronic physical or emotional symptoms. There was also the acute emergence of new barriers to attendance such as sudden illness, grief associated with familial loss, or change in eligibility for services. The following quotes illustrate examples of the shifting balance of priorities that could interfere with HIV care attendance:

...after six months [from HIV diagnosis]...my suicidal desires went away...like I was being reborn, with an ability to manage the virus in my body. Well, later, after two years, I got very depressed again, and I began to drink a lot of alcohol and to use...And afterward, again, I got better, and I began to recover. [Patient, Male, Age 38, Foreign-born, Heterosexual and MSM]

I think where it falls apart is where there are life priorities that get in the way so that either logistically they can't, or there's a lot of embarrassment or fear about interaction with the system, or they've just completely lost interest in themselves as a body that needs to be cared for. [Provider, Female, Physician]

Discussion

Six major factors emerged as most influential on HIV primary care attendance in HIV-infected Latino immigrants and migrants. Participants uniformly experienced discrimination, most often from other Latino community members and family. Coping mechanisms in those who inconsistently attended appointments relied on social withdrawal to avoid the risk of HIV disclosure. While responsibilities to family were a central concern, those who inconsistently attended appointments had little to no functional social safety network during acute life stressors. Mental health consequences were salient and manifested around stress with dealing with the HIV diagnosis, consequences of social isolation, financial insecurity (e.g., homelessness, food insecurity, and unemployment), and limited access to substance abuse support. Personal assets (e.g., family pride and obligation to be well for others, spiritual faith, and respect in and sense of obligation to HIV provider) facilitated appointment attendance.

All individuals reported episodic periods of engagement and disengagement depending on their proximity to HIV

diagnosis, their development of coping strategies, and the numerous barriers and facilitators they balanced at any point in time. While multiple co-occurring barriers to healthcare have been reported in general and in HIV outcomes in Latinos,^{15,50–52} we found a unique application of these findings in the process of retention in HIV care in Latino immigrants and migrants. Administrative definitions of retention in care provide a glance of HIV appointment attendance, usually over a 12–24-month period.^{2,7,37} These definitions characterize individuals as “retained” or “not retained.” Further qualitative research in Philadelphia showed that HIV-infected individuals not retained in care reported more barriers, particularly logistical and structural, than those retained.²⁷

In our study, the majority of participants articulated that attending HIV care was important to them (e.g., knowing their disease trajectory and cultivating a trusted relationship with their physician). However, acknowledging the importance of HIV care and feeling motivated to attend was insufficient to assuring HIV care attendance. Therefore, the ability to attend an HIV primary care appointment depended on the balance of these factors from moment to moment.

Cultural factors were salient to consistent appointment attendance such as strong attachment to family (*familismo*),⁵³ strict identification of masculinity with power and aggression (*machismo*),⁵⁴ the respect held for the authority figure in physicians (*respeto*),⁵⁵ and satisfaction with the clinical encounter when met with courtesy and closeness (*cortesía and confianza*).¹⁸ Fatalistic beliefs have been associated with religiosity in Latinos and refusal of HIV prevention behaviors.^{56,57} While participants reported optimism from their faith and a belief in a divine supremacy, most individuals reported that their fate depended on their actions. This finding may relate to the higher degree of acculturation of the sample who largely were not recent arrivals to the US mainland.⁵⁸ Further, while these cultural themes are common in Latino populations, they may also be relevant to other immigrant populations that share similar cultural values as well as experience social inequality and discrimination from HIV.^{28,59,60}

Within our sample, we identified subgroups who expressed greater challenges with consistent HIV primary care. MSM discussed the challenge of confronting strict cultural norms on gender identity and sexuality. These men faced the challenge of disclosing two stigmatizing identities, being gay and having HIV, in the publically visible behavior of attending HIV care. This is consistent with HIV prevention and adherence research in Latino men where internalized beliefs of *machismo* and where homosexuality is a sign of weakness and an embarrassment to family and community reduce likelihood of HIV self-care.^{24,61,62}

Young adults, while representing a small segment of our sample, uniformly had multiple competing challenges to HIV care attendance, including employment and responsibilities to family such as child care and financial support of dependent relatives. For young adults, HIV care was often less relevant to the many high-priority areas demanding their attention. Attending an HIV appointment risked disclosure of HIV serostatus if the patient were seen by someone known to him or her from the community. This inadvertent disclosure could lead to social disapproval and shaming by family and friends, a finding consistent with other studies.⁹

Foreign-born Latinos, compared with Puerto Rican-born, described a heightened fear of attending HIV care. Concerns of deportation were a barrier to HIV care attendance even though the United States travel ban on HIV-infected visitors was lifted in 2009.⁶³ The internalization of HIV-related misconceptions from the country of origin such as the association of HIV and medication consumption with serious illness and death, and lack of familiarity with English language and institutions, challenged the ability to form strong trusting ties with HIV providers. Puerto Rican-born participants strongly identified as “not immigrant” although as migrants to the United States they described social and financial commitments that straddled the US mainland and the country of origin, causing individuals to migrate back and forth as well as send remittances. The effect of migration and transnational social networks on retention in HIV care has been understudied and could provide insight into how to engage these patients in sustained HIV primary care.^{64,65}

The study also has several limitations. Although the cohort demographics were similar to the demographics of Latinos in the Greater Boston area, this may limit generalizability to other geographic regions where the distribution of Latino subpopulations differs. Young adult Latinos are a sizeable portion of new HIV infections in Latinos, yet comprised a small proportion of the client participants. While study staff made great efforts to solicit rapport with participants, sexual and substance use risk behaviors may have been underreported. Finally, as with any qualitative study, the data are limited by the sample size and the lack of ability to make statistical inferences about the population.

Adherence to ART has become simpler, with more forgiving regimens in the past 10 years. Accordingly, for those who are not on ART or have difficulty with adherence to ART, strategies to maximize retention in care will remain essential for achieving virologic suppression. Further, HIV primary care serves as a gateway for key non-HIV-related services (e.g., mental health and substance use referrals, dental care, transportation, housing, food supplementation). Research on interventions that can address the social determinants of HIV outcomes, such as those identified in this article, may further elucidate how to maximize these outcomes in vulnerable populations such as Latino immigrants and migrants.

We found that HIV-infected Latino immigrants and migrants experience significant often co-occurring barriers to retention in care linked to HIV-related stigma, cultural norms, trauma, addiction, and logistical constraints in accessing care that change over time. Anticipatory guidance and contingency planning during linkage to care may be critical to avoid interruptions in HIV care and promote re-engagement after setbacks. Tailored solutions to assist clients through these barriers require an assessment and understanding of the culturally related challenges for each patient.

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