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Healthcare provider perspectives on barriers to HIV-care access and utilisation among Latinos living with HIV in the US-Mexico border

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Abstract

Latinos living with HIV residing in the US-Mexico border region frequently seek care on both sides of the border. Given this fact, a border health perspective to understanding barriers to care is imperative to improve patient health outcomes. This qualitative study describes and compares experiences and perceptions of Mexican and US HIV care providers regarding barriers to HIV care access for Latino patients living in the US-Mexico border region. In 2010, we conducted in-depth qualitative interviews with HIV care providers in Tijuana ($n = 10$) and San Diego ($n = 9$). We identified important similarities and differences between Mexican and US healthcare provider perspectives on HIV care access and barriers to service utilisation. Similarities included the fact that HIV-positive Latino patients struggle with access to ART medication, mental health illness, substance abuse and HIV-related stigma. Differences included Mexican provider perceptions of medication shortages and US providers feeling that insurance gaps influenced medication access. Differences and similarities have important implications for cross-border efforts to coordinate health services for patients who seek care in both countries.

Keywords

HIV; Latinos; ART; barriers to care; US-Mexico border

Introduction

Individuals living in the US-Mexico border region, including HIV-positive patients, frequently utilize health services on both sides of the border (Landeck and Garza 2003; Servin et al. 2012; Su et al. 2011; Zúñiga 2012). The US-Mexico border region is approximately 1969 miles long and is one of the fastest growing regions in the USA. It is, however, also one of the most medically disadvantaged regions in the USA, with persistent

high rates of uninsured and medically underserved citizens and with a high burden of diseases such as obesity, diabetes and HIV (Ramos et al. 2009; United States-Mexico Border Health Commission 2010). This border region is home to the sister cities of San Diego (California, USA) and Tijuana (Baja California, Mexico), one of the largest conurbations in the world and home to the busiest international land-border crossing (Bureau of Transportation Statistics 2012; California Border Alliance Group 2009; Instituto Nacional de Estadística y Geografía 2010a; US Census Bureau 2010). San Diego also has a larger proportion (43%) of Latino HIV cases when compared to the rest of the USA (San Diego County Health and Human Services Agency 2010). The state of Baja California has the third highest cumulative HIV/AIDS incidence among Mexico's 32 states, with 202.8 cases per 100,000 (Centro Nacional para la Prevención y Control de VIH/SIDA 2013); this incidence is driven largely by the State's most populous city, Tijuana (Instituto Nacional de Estadística y Geografía 2010b).

In this border region, healthcare utilisation practices are important to consider among Latino populations given their current and growing demographic density in the southwestern USA (Ennis, Rios-Vargas, and Albert 2011) and frequent border crossing behaviour, including Latinos living with HIV. Latinos in the US border region have been significantly impacted by the HIV epidemic and face substantial health inequities when compared to non-Latino Whites. They comprise approximately 16% of the total US population yet account for 20% of new HIV infections (Centers for Disease Control and Prevention 2013). Furthermore, timely engagement into HIV health care is critical given its correlation with desirable health outcomes (Mayer and Krakower 2012; Yao et al. 2013) – it is well established that delayed entry into HIV care often results in late initiation of antiretroviral therapy (ART), higher viral load levels and lower CD4 cell count, leading to an increased risk of HIV transmission, rapid disease progression and death (Catz et al. 2000; Paterson et al. 2000).

Previous studies have documented that cross-border healthcare utilisation is common among individuals living in this border region. Many US residents face numerous barriers to healthcare in the USA, and many Latinos and other populations who are able to cross the border to Mexico do so in search of healthcare services, in order to take advantage of relatively lower costs, to seek out Spanish-speaking care providers, or for other reasons (Byrd and Law 2009; Escobedo and Cardenas 2006; Macias and Morales 2001; Seid et al. 2003). For individuals with poorly managed or undiagnosed HIV, cross-border care-seeking behavior may contribute to disease transmission and/or fragmented care (PAHO 2007). Migration policy in the USA, including recent large-scale deportation of persons (including those who are HIV-positive) of Mexican origin to Tijuana and other Mexican border cities, contributes to healthcare fragmentation (Deiss et al. 2009; Muñoz et al. 2013a). Our earlier work indicates that HIV-positive deportees may face additional burdens on care continuity and access to treatment once deported to Mexico, including adaptation to a different system of clinical care (Muñoz et al. 2013a). Undocumented persons of Mexican origin comprise approximately half the total Mexican immigrants living in the USA (Capps et al. 2013). Severe restrictions imposed on immigrants' eligibility for Medicaid-funded services followed the passage in 1996 of the federal Personal Responsibility and Work Opportunity Reform Act and the Illegal Immigration Reform and Immigrant Responsibility Act (Nandi et al. 2008). Undocumented immigrants represent a vulnerable population at higher risk for

disease and injury than either documented immigrants or native-born US citizens (Kullgren 2003; Marshall et al. 2005).

Because HIV clinical care providers in the border region are in a position to observe, at first hand, structural barriers and patient behavior issues that may undermine patient health, research efforts must include perspectives of clinical care providers from both sides of the border. Prior research analysing barriers to HIV care access and utilisation among Latinos has focused primarily on patients' experiences and perceptions (Cavaleri et al. 2010; Keese, Natale, and Curiel 2012; Zúñiga et al. 2012). Research with HIV care providers has focused more commonly on HIV testing, new clinical care guidelines, HIV-related stigma and best clinical care practices (Beach et al. 2010; Bogart et al. 2008; Georgeu et al. 2012). Since HIV service providers play a key role in helping patients engage and remain in care, research with them about barriers to care faced by their patients' remains an important yet unfilled research gap, especially in a border context where Latino patients are known to access HIV care in both countries. To address this knowledge gap, we undertook the present qualitative study to explore and understand Mexican and US service providers' perceptions on barriers to HIV care access and service utilisation among Latinos living with HIV in the US-Mexico border region.

Materials and methods

Recruitment, interview procedures and guide

The current study was conducted as part of a community-based participatory research study designed to identify barriers to care among HIV-positive Latinos in the San Diego-Tijuana border region (Zúñiga et al. 2011). The outreach team, in coordination with a Binational-Community Advisory Board, provided a list of HIV care providers, who were invited to participate in the present study. Potential participants were drawn from the four major Mexican public health institutions and social service agencies in Tijuana and from three HIV clinical and social service agencies in San Diego. A total of 20 HIV care providers were invited to participate, of whom all agreed except one (in San Diego) due to limited time. In-depth qualitative interviews were conducted with 19 HIV health care providers in Tijuana ($n = 10$) and San Diego ($n = 9$) between July and December 2010. These HIV health care providers were >18 years of age, had provided HIV care for at least 10 HIV-positive Latino patients in the last 6 months and provided voluntary and informed consent. Interviews (ranging from 45 to 60 minutes in length) were conducted by trained, bilingual members of the study team in Spanish ($n = 11$) and English ($n = 8$) depending on the participant's preference. This study was reviewed and approved by the Institutional Review Board at the University of California, San Diego and the Bioethics Committee of the Tijuana General Hospital. Study methodological details have been published elsewhere (Muñoz et al. 2013b). Members of our research team developed the interview guide based on quantitative and qualitative findings (i.e., cross-sectional survey and focus groups conducted in both regions) from our prior border research (Zúñiga et al. 2007; Zúñiga et al. 2008). Interview questions were designed solely for the purpose of this study. The 16-question guide included key issues pertaining to HIV healthcare, ART adherence, use of complementary and alternative medicine and barriers to healthcare services. Examples of interview questions included: 'In

your experience, what are your patients' reasons for not attending their medical appointments?' and 'In your experience, what have been the most frequent factors in influencing your patients with high antiretroviral adherence rates?' Interviews were digitally recorded and audio files were identified using only a study-unique ID number.

Data analysis

Since all analysis team members were bilingual (Spanish/English), transcriptions were not translated and were read and coded in the language in which the interview was conducted. We analysed the interview transcripts based on principles of grounded theory and the constant comparison method (Corbin and Strauss 2008) to identify themes related to provider experiences and perceptions about factors that interfere with HIV healthcare among their HIV-positive Latino patients. Team members initially read three complete interview transcripts to identify initial coding themes. They then met to discuss themes and develop an initial coding scheme of key themes. A final coding scheme was created based on coder consensus. Using the final coding scheme, we assessed inter-coder reliability and achieved greater than 80% consistency between the coders (Miles and Huberman 1994). The principal investigator and the research team coded interviews independently with coding revisions agreed upon by research team members.

Findings

Of the 19 participants, 7 were female and 12 were male. Of these, 13 self-reported their ethnicity as Latino, 3 as non-Latino White, 2 as Asian and 1 as Greek. The mean age was 45 years (range 27–59). Participants reported an average of 10 years of providing clinical care to HIV-positive Latinos. Participant occupations included a wide range of healthcare professions (i.e., general practitioners, nurses, HIV specialists, psychologists etc.). Participant characteristics are shown in Table 1. Emerging themes related to barriers to HIV care access and health services utilisation identified were: (1) compromised access to ART medication, (2) mental illness and substance abuse and (3) HIV-related stigma. Each of these themes is described below.

Compromised access to ART medication

Patient access and adherence to ART are essential to prevent viral failure and disease progression and, overall, is the base of successful outcomes for HIV-positive patients. Providers from the US side focused more on the lack of access to ART due to health insurance lapses, expiration of coverage and unaffordable co-payments. These different structural issues on both sides of the border compromised access to HIV medications, care and treatment of their Latino patients:

One barrier to treatment is for example the patients that have Medi-Cal, they run out of coverage and they don't have a way of obtaining it ... they charge them a co-payment that's too expensive ... (San Diego provider)

Service providers from San Diego also mentioned that the lack of insurance coverage for other HIV-related and non-related health services (e.g., internal medicine, preventive

medicine and nutritionists) and co-morbidities (e.g., mental health) is also a factor that may interfere with patient treatment and adherence that needs to be properly addressed.

Most providers from the Mexican side of the border expressed concern about lack of access to ART due to medication shortages, they mentioned that this is an issue that must be addressed by government authorities since it is one of the main barriers in the continuity of HIV treatment observed among their patients.

Providers from Tijuana mentioned that, in Mexico, health insurance is not necessarily the problem since access to HIV care and to ART among Mexican HIV-positive patients is free. However, in some health institutions there are insufficient ART medications available for the patient to obtain their prescription or, in some cases, health institutions may not have the appropriate administration dose available:

The institution contributes to the lack of adherence because sometimes ... the amount of medication available is not what it is supposed to be ... and the availability is compromised. (Tijuana provider)

... Some of the factors that interfere with adherence are the availability of ART, having the adequate prescription available. For example, for pediatric patients they require liquid [medicines] ... not having the correct medication affects adherence. (Tijuana provider)

Both San Diego and Tijuana providers mentioned that patients may seek alternatives when they face these structural barriers, including changing the ART regimen and or type of medication. Although, other alternatives may provide HIV treatment to patients, these changes in ART can interrupt adherence and affect the treatment success. All participants emphasised that HIV care service utilisation on both sides of the border is very common among Latino patients and they considered that this situation poses a serious problem to the continuity of HIV treatment. Providers also stressed the complexity of providing healthcare for individuals who access care in both countries. They indicated that coordinated monthly meetings with counterparts on the other side of the border or sharing patient information are critical to avoid ART resistance and failure in HIV treatment.

Mental illness and substance abuse

Half of the providers mentioned that depression, schizophrenia and bipolar disorder are health conditions that may interfere with HIV care, and that underdiagnosed and/or undertreated mental illness is common. They also mentioned that some patients have mental health disorders as a consequence of their substance abuse. Participants from both sides of the border explained that in some cases patients who have been recently diagnosed with HIV or those who have not learned to cope with the disease tend to be more depressed, while among other patients delirium, personality disorders or chronic mental illness are common and often not diagnosed or not adequately treated:

The patient falls into depression ... this makes the patient non-adherent to treatment. Depression makes the patient stop taking their medication and has severe setbacks. We had three severe cases of depression where there have been setbacks,

hospitalizations and one case where the patient died because he abandoned [HIV] treatment. (Tijuana provider)

We are not sensitive to underlying psychiatric illness ... I think ... and if someone has schizophrenia, if someone has depression and they are not adherent ... we just blame it as opposed to trying to understand it a little bit more and trying to treat it. (San Diego provider)

About 30% of service providers from both cities acknowledged substance use as a factor interfering with HIV care. however, this was noted more often from health care providers in San Diego. Some mentioned that between 25 and 50% of their patients have substance abuse problems, with the most common substance reported being alcohol. Providers also noted that substance abuse may affect directly or indirectly adherence to HIV treatment. Sometimes patients under the influence of substances may forget to take their medication or, if they are in prison due to substance abuse, they may not be able to obtain the HIV care that they need:

Substance abuse, alcohol or other types of substance ... some patients are using crystal meth ... it's making them fail in their treatment because sometimes they don't even know if they took it [ART] or not. (San Diego provider)

Substance abuse including alcohol is the most common reason why people just disappear from the clinic ... sometimes some of my patients disappear because they are incarcerated. (San Diego provider)

Two providers from San Diego mentioned that is important to identify the type of substance use problems that patients face. In their experience, patients with alcohol dependence more often forget to take their HIV medications than patients who are using illegal drugs.

HIV-related stigma

Providers from both Tijuana and San Diego recognised the impact that HIV-related stigma had on their patients. Almost all mentioned that HIV-related stigma could be the result of lack of knowledge about HIV in the patient's workplace, among family and even among health providers. HIV-related stigma also impacts on how patients feel when they present for care at the clinic:

So many are ashamed, the first time they come they say 'Oh no! It's horrible to come here' and [the patients] sit in the back, put their cap or sunglasses on, [patient] and don't like to be seen. They say: 'If I come here [HIV clinic] I will be identified'. (Tijuana provider)

Service providers also mentioned that it is common for patients to not disclose their seropositive status due to fear of being labeled or discriminated against because of their HIV status. Patients may opt to not take their medications in front of family or friends and sometimes they may miss their dosages because they do not wish to be questioned about the medications:

A stigmatizing environment at home or with friends: I have patients that are not able to take their medications at home because their family doesn't know, so they have to hide them. ... That for me as a provider is a barrier.(San Diego provider)

... there's always the patient who's afraid to share their diagnosis. Often times their own family becomes a concern to them, they hide their medicines, they hide the way they dose, the adherence and things like that. (Tijuana provider)

San Diego providers were more likely to observe internalised forms of stigma, or stigma related to how the person feels about themselves, among their patients. Tijuana providers, on the other hand, identified actualised stigma (e.g., discriminatory acts from others) from employers and non HIV-clinics that negatively influence HIV-care seeking behavior and affect the patient's willingness to take ART. Providers mentioned that the burden of HIV-related stigma can be greater than mental illness or other physical health conditions:

A patient, at his work they found out that he is HIV [positive] and he lost his job, had no money and it was an impediment to continue his treatment. (Tijuana provider)

... Here [at the HIV clinic], we have patients who are not treated at any other hospital because the doctors or dentist refuse to see anyone who is HIV-positive. (Tijuana provider)

Discussion

The results of this study indicate that HIV clinical providers on both sides of the US-Mexico border identify a range of individual patient circumstances (substance abuse and mental illness) and structural issues (availability of and access to ART) that undermine the health of border-dwelling Latino patients. Findings may inform development of future educational interventions to improve service provider knowledge of the needs of HIV-positive patients living in this border region.

We observed differences in provider perspectives on barriers to HIV care access in the healthcare system on each side of the border. That providers from San Diego more frequently mentioned health insurance barriers among their patients, and Mexican providers emphasised shortages of ART, speaks to differences between these two health systems: the USA with a largely decentralised system of care and Mexico with a largely centralised system, including the centralised distribution of medication. Health insurance-mediated barriers to ART medication and care mentioned by US providers are not surprising given the high level of un-insurance, under-insurance and inability to pay for out-of-pocket medical expenses among Latinos in US-Mexico border communities (Fisher-Hoch et al. 2010; United States-Mexico Border Health Commission 2010). Although not explicitly mentioned by US providers, disparities in access to health insurance among undocumented US Latinos are prominent and may further undermine access to care for an already vulnerable group with limited access to government-sponsored insurance. In this context, it remains unclear how the new US Patient Protection and Affordable Care Act healthcare coverage law will impact access to care among undocumented persons. However, it is widely anticipated that access will worsen (Jerome-D'Emilia and Suplee 2012; Zimmerman 2011).

In contrast to perceived insurance-mediated barriers to ART medication in the USA, our study findings reveal that clinicians perceived ART medication shortages as a barrier to ART in Mexico. Interestingly, however, this perception does not reflect official reporting of Mexico's ability to supply adequate levels of ART, where a 0% gap in ART medication supply was reported in 2010 (PAHO 2012). The discrepancy between Mexican clinician perception of gaps in medication supply and official reports is an important issue that could benefit from rigorous research that includes physicians, patients and pharmacies.

Care continuity in a cross-border context emerged as an important and complex issue, which clinician's feel undermines patient care continuity. Patients may be accessing care on both sides of the border for a variety of reasons (e.g., absence of insurance on one side of the border, deportation, relocation etc.), and studies are needed to document the actual interruptions in care, duplication of services or apparent losses to follow up, to which our study and earlier studies have eluded. Clinicians' desire to improve care coordination is a laudable goal that should be informed by good scientific evidence. However, there is some reason for optimism given the increased availability of telemedicine and cell phone technology allowing clinicians to communicate with one another (Garfein et al. 2012).

Providers from both Tijuana and San Diego agreed that substance use was one of the main barriers that interfered with HIV care. Previous studies have documented that substance use may be prevalent among people living with HIV (Polk et al. 2013) and offers a barrier to engagement in HIV care (Conover et al. 2009; Knowlton et al. 2001). Healthcare utilisation is lower among substance-using populations, their health declines more rapidly, and they have increased morbidity and mortality compared to their non-substance-using counterparts (Cunningham et al. 2006; Kapadia et al. 2005; Merlin et al. 2012). Our findings suggest that substance use contributes to treatment disruption in multiple ways: through incarceration or re-incarceration for probation violations or offences, by affecting HIV care and when under the influence and by interfering with ART adherence. Substance use is also linked to psychiatric comorbidity and has been implicated in HIV disease progression (Jia, Mehlum, and Qin 2012; Pompili et al. 2013; Zimpel and Fleck 2014).

In this study, approximately half of the providers mentioned that mental health problems interfered with HIV care utilisation. Those with serious alcohol dependency were more likely to forget to take their ART medication than individuals using other substances. Our findings, underscore the importance of successfully identifying substance use among patients living with HIV and engaging them with treatment and harm reduction. Previous strategies that have shown promise for HIV-infected substance users include integrated treatment models, directly observed therapy and incentive-based interventions (Krüsi et al. 2009; Lambers et al. 2011; Spector and Pinto 2011). Improving communication between the and justice systems as part of standard care may also potentially benefit patient care continuity in both countries.

Lastly, HIV-related stigma and discrimination present formidable and complex barriers to ART adherence. Our study revealed, however, that circumstances surrounding HIV-related stigma as an access-to-care barrier may differ between patients in San Diego and those in Tijuana. Stigma and discrimination take on different forms and are manifested at different

levels, e.g. – for example societal, community and individual – and in different contexts (Parker and Aggleton 2003). Stigma has long been associated with HIV and AIDS. Previous studies have shown how internalised stigma, which stems from fear of stigmatisation (Earnshaw et al. 2013; Jacobi et al. 2013) can lead to unfavourable outcomes for people living with HIV and trigger low adherence to ART, increased high-risk behaviours decreased help-seeking behaviours, and poor quality of life (Bogart et al. 2013; Brener et al. 2013; Wilson et al. 2011). Although providers from both Tijuana and San Diego clinics recognised and described instances of patient experience with HIV stigmatising attitudes, San Diego providers mentioned experiences related to felt stigma and Tijuana providers mentioned that their patients suffer from more overt stigmatising and discriminatory attitudes (e.g., among family members or employers) that appear to affect patient care utilisation. These observations suggest that research is needed to develop culturally appropriate interventions to address HIV-related stigma at different levels, especially to assist patients in their ability to improve ART adherence (Bos, Schaalma, and Pryor 2008). The constant bi-directional, cross-border migration and mobility that characterises this border region calls for local as well as bilateral intervention development. For example, interventions geared towards patients living in Mexico may need to address strategies for managing disclosure to family and work-related discrimination.

Although our findings provide insights into similarities and differences in provider-perspectives surrounding Latino patient barriers to HIV care, this qualitative study has inherent limitations. As a small qualitative study, findings cannot be generalised to other providers or regions. However, study participants from Tijuana represented almost all of the institutions providing services for HIV-positive individuals (four government health clinics and one non-government institution), which allows for understanding cross-institution perspectives. Subsequent border studies should include a larger, representative sample of providers from other US-Mexico border contexts.

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Table 1

Characteristics of Mexican and US HIV healthcare provider.

Characteristics of participants	N	%
Age		
Mean (SD)	45 (5)	
Range	25–59	
Gender		
Male	12	63
Female	7	37
Ethnicity		
Mexican/Hispanic/Latino	13	69
Non-Latino White	3	15
Korean/Japanese	2	11
Greek	1	5
Site		
Clinics from Tijuana	10	53
Clinics from San Diego	9	47
Years of work experience with HIV-positive patients		
<1 year	2	11
1–10 years	7	37
11–20 years	8	41
>20 years	2	11