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ORIGINAL PAPER

Sociocultural and Structural Barriers to Care Among Undocumented Latino Immigrants with HIV Infection

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Abstract Timely entry into HIV care is critical for early initiation of therapy, immunologic recovery and improved survival. However, undocumented Latinos are more likely to enter HIV care late in the disease course and with concurrent AIDS. We conducted a qualitative study to examine the circumstantial, situational and social factors that uniquely affect entry and retention in care for this population. Between June and August 2006, we conducted semi-structured, in-depth, individual interviews with 22 undocumented Latino immigrants living with HIV infection. The interviews were audiotaped, transcribed and reviewed for accuracy. Data was analyzed using a grounded theory approach. Word content was coded and sorted by themes using AnSWR software. Emergent themes related to health care barriers include (1) the challenges of dealing with HIV stigma and rejection from family and community; and (2) the experienced and perceived structural barriers of accessing care as an undocumented individual. Societal intolerance of HIV and stigma-related experiences result in feelings of secrecy and shame. In addition, the undocumented state complicates the situation even further. These unique barriers include fear of deportation, work restrictions, inadequate translation services and difficulties meeting paperwork requirements. This study offers insight into the unique sociocultural and structural barriers faced by undocumented Latinos with HIV infection. Understanding and addressing these barriers will prove vital in the development and implementation of strategies to promote early entry into HIV care.

Keywords HIV · AIDS · Illegal immigrant · Undocumented · Latino · Hispanic · Qualitative research

Background

Timely care is critical for achieving long-term survival with HIV infection. Delayed entry into HIV care means delayed initiation of antiretroviral therapy, lower CD4 cell counts at baseline, and lower survival rates [1]. Delayed diagnosis and treatment also carry significant public health ramifications. Patients with untreated HIV infection have higher levels of circulating virus and are more likely to transmit the virus [2].

Latinos in the United States (US) have been significantly impacted by HIV. They comprise 16% of the US population, but 18% of the HIV infected population [3]. HIV-infected Latinos who are undocumented are more likely to enter HIV care with advanced AIDS than Latinos who are documented, whites and blacks [4]. Foreign-born HIV patients from Latin America are also significantly more likely to reactivate latent tuberculosis [5]. In addition, those who fear immigration authorities are significantly more likely to delay seeking care despite having symptoms (OR 3.89, CI 1.34–11.36) and expose an average of 10 close contacts [6]. Like tuberculosis, delayed entry into HIV care

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may increase opportunities for spread of disease. The success of HIV and tuberculosis prevention and treatment programs is contingent on screening and treating vulnerable populations early and understanding why certain populations, including undocumented Latino immigrants, present late to HIV care.

The concept of undocumentedness carries unfavorable sociopolitical connotations such as “illegal, illegitimate, immoral, uncounted, undercounted, unaccounted for, invisible, blamed, vulnerable, exploited, marginalized, or uninsured” [7]. Few studies have examined the familial and societal stresses faced by undocumented Latinos or the fears and challenges associated with being undocumented and seeking health care in the US. The available studies on undocumented Latino immigrants suggest lower education, income, health literacy, insurance coverage and ambulatory health care use than their US-native counterparts [8–10]. In addition, undocumented Latino immigrants are less likely to have a usual source of care than their documented counterparts [9, 11]. Individuals with limited knowledge of HIV are less likely to seek HIV testing, and individuals who do not have a usual source of health care have less opportunities for physicians to offer HIV screening [12]. Fears of deportation may exacerbate these gaps in education, income and access to health care. Undocumented Latino immigrants who express fear of deportation are significantly less likely to seek medical attention and are more likely to experience extrafamilial stress and report worse health status [13, 14]. Limited studies on Latino immigrants who are documented and living with HIV infection highlight lack of HIV/AIDS knowledge, HIV/AIDS stigma, language barriers and confidentiality concerns as possible barriers to timely HIV care [15, 16]. To our knowledge though, no published studies have qualitatively assessed the circumstantial, situational and social factors that affect Latino immigrants who are undocumented and living with HIV infection. Understanding the role of undocumentedness on HIV disease trajectory and the distinct health care barriers imposed by the undocumented state is vital to optimizing HIV care. This article focuses on the personal narratives of 22 undocumented Latino immigrants living with HIV infection in Houston, Texas.

Methods

Participants

The study population was based on a nonrandomized convenience sample of undocumented Latino immigrants with HIV infection living in the Houston Eligible Metropolitan Area (EMA). Eligibility criteria included age 18 years or older, Hispanic/Latino ethnicity as determined by country of origin, entry into the US after 1994, HIV infection, undocumented status, and residence in one of the 6 Houston EMA counties. Participants who lacked US citizen, permanent resident, refugee or visa status, and marked “other” under immigration status, were classified as undocumented. We recruited participants with fliers distributed to HIV case managers and health and social service agencies that target Latinos. Service providers also assisted in identifying eligible individuals. Individuals interested in participating in the study contacted a health planner from the Houston Ryan White Planning Council to schedule an interview.

Data Collection

Between June and August 2006, a health planner from the Houston Ryan White Planning Council conducted in-depth, face-to-face, semi-structured interviews with undocumented Latino immigrants living with HIV infection. We obtained written informed consent prior to interviews. A brief questionnaire collected demographic and HIV history. We did not collect personal identifying information. Audiotaped interviews took place at service locations in conjunction with existing appointments, and lasted 60–100 min. An interpreter with training in medical interpretation and a background in HIV service provision provided simultaneous translation during the interviews. Participants received a $30 grocery voucher and refreshments.

Measures

A single investigator (JHK) conducted the interviews using an interviewer guide that was developed using input from various stakeholders. The interviews consisted of open-ended questions related to reasons for immigration, attitudes about HIV transmission, risk behaviors and treatment, HIV/AIDS knowledge and beliefs before and after diagnosis, HIV testing experience, entry into HIV care, clinic care and service utilization. The open-ended interview format served to capture cultural and contextual nuances about HIV health care experiences. Major topics and key questions are outlined in Table 1.

Data Handling and Analysis

A professional transcriptionist transcribed the interpreter’s English translation. Transcripts were reviewed against the audiotapes for accuracy then imported into AnSWR, a word-based data analysis program developed by the Centers for Disease Control and Prevention (CDC). A single investigator (JHK) coded the data using a coding scheme

Table 1 Major topics and key interview questions

Personal history
When did you come to the US? Why did you decide to immigrate here? Did you come alone?
When was the first time you ever heard about HIV? What did you hear?
Where did you get tested? How did you hear about this place? What were the reasons you received an HIV test?
Support networks/community attitudes
Where do you live? How long have you lived there? Is that your permanent place of residence? Who do you live with? Do they know you are positive?
Who are the important people in your life? Who do you count on for support? Do these people know that you are positive?
Are you out about your HIV status? Do you feel comfortable talking with other people about being HIV positive?
Doctors and service providers
Do you have a regular doctor? How do you get to doctor appointments?
When was the last time you saw a doctor? What was the reason you had the appointment? How often do you go?
Do you like your doctor? Why or why not?
Do you have a Case Manager? How often do you see your Case Manager?
What kind of things makes someone a good doctor? Do you think it's difficult to find someone like that in Houston?
What kind of things makes someplace a good clinic? Do you think it's difficult to find a clinic like that in Houston?
Needs and barriers
Is it difficult to get the services that you need? Why?
Do you ever feel afraid that you cannot receive medical care because of your immigration status? Social services?
What are your biggest needs or concerns right now? (does not have to be HIV related)
Many Latino immigrants in Houston are not able to receive medical care. Do you think this is true? What do you think are some of the reasons?

developed prior to analysis and supplemented by additional codes that emerged during analysis. Conventional content analysis was used to identify emergent themes reflecting barriers experienced by participants in accessing HIV-related care [17].

The study was originally commissioned as a quality improvement project to assess the unmet needs of Latino immigrants living with HIV infection. The Comprehensive HIV Planning Committee of the Houston Ryan White Planning Council approved the study protocol and instruments, including the consent forms. At the time of reanalysis for dissemination and publication, only de-identified data was available and the Baylor College of Medicine Institutional Review Board determined the study did not meet criteria for human subjects research.

Results

Participant Characteristics

We interviewed 22 undocumented Latino immigrants living with HIV infection. Baseline characteristics are shown in Table 2. Nine participants were male and 13 were female. All 13 women identified as heterosexual, and 5 of 9 men identified as homosexual. Their mean age was 39 years and they had lived in the US a mean of 8 years. The majority originated from Mexico (14 of 22). Half of the participants worked. The average time from HIV diagnosis was 6 years. All but 2 participants reported taking HIV medications at the time of interview.

Reasons for Immigrating

Participants most frequently cited work as the reason for immigrating to the US. They reported seeking better lives for themselves and their families, and felt the US offered more work opportunities than in their countries of origin. Many participants sent portions of their earnings to support relatives back home.

Six of 22 participants reported HIV care as a reason for coming to the US. They described the US as offering greater availability of medications, quality of health care and acceptance of persons living with HIV infection. Two of these six participants tested positive prior to immigrating. The other four, all women, received their HIV diagnoses after immigrating to the US. All suspected they were HIV infected following the illness or death of their husbands. A 36 year-old woman from Honduras described coming to the US after her husband's death:

> I was diagnosed here in the US. My husband died of AIDS [in Honduras] so I knew the symptoms. Then I started to have the symptoms and I was becoming ill. So my mother contacted my sister who was here in the US, and it was recommended that I come because

Table 2 Demographic characteristics of participants (N = 22)

Characteristic	N	%
Gender		
Male	9	41
Female	13	59
Age (years)		
Mean (standard deviation)	39 (8.9)	–
Minimum, maximum	26, 67	–
Sexual orientation		
Heterosexual	17	77
Homosexual	5	23
Length of residency in the US (years)		
Mean (standard deviation)	8 (4.2)	–
Minimum, maximum	2, 19	–
Country of origin		
El Salvador	2	9
Honduras	6	27
Mexico	14	64
Job status		
Full time	1	5
Part time	6	27
Temp work/odd jobs	4	18
None	11	50
Monthly income ($)		
Mean (standard deviation)	$537 (427.2)	–
Minimum, maximum	$0, $1,200	–
Live alone		
Yes	8	36
No	14	64
Household size (persons)		
Mean (standard deviation)	3 (2.2)	–
Minimum, maximum	1, 8	–
Length of HIV diagnosis (years)		
Mean (standard deviation)	6 (5.2)	–
Minimum, maximum	0, 19	–
Taking HIV medications at time of interview		
Yes	20	91
No	2	9

> they would not be able to send medications to my country.

A 28 year-old homosexual man from Mexico described the lack of HIV resources and expertise in his country:

> There are no big HIV clinics like there are here. If you have AIDS or HIV, you go to the general hospital or see general practitioners who don't know much about HIV. And you are given the message 'don't come back.'

Several participants felt the US offered greater acceptance and support for people living with HIV. They discussed the negative attitudes held by community members and providers towards people with HIV, and how those attitudes affected them. A 33 year-old woman from Honduras described how the community's reactions after her husband's death affected her:

> After my husband died, everybody was talking about him. My dentist told me not to come to her. She said 'I cannot help you anymore.' I was so shocked. I was too scared to see a doctor so I didn't get any medicine and I got very sick.

A 41 year-old woman from Mexico had not told anyone of her HIV status, and felt she would be outcast if others knew:

> The only person I knew who was HIV positive was my husband, who told me three months before he died. He died very quickly and I knew I was going to die too, which is why I came to the US. I didn't want to die alone.

Beliefs and Attitudes About HIV/AIDS

Many participants discussed how personal and community beliefs and attitudes about HIV/AIDS affected their experiences at time of HIV diagnosis. A few participants reported that prior to diagnosis, they were not aware of how HIV/AIDS affected Latino communities. A 35 year-old heterosexual man from Mexico said he did not believe HIV to be real.

> I was surprised when the doctor suggested the HIV test, because I did not believe HIV was a real disease. Many people in my family said it did not exist. Yes, I did see promotions on TV, but I thought they were just promotions to help doctors become rich.

Participants also said they did not believe Latinos as susceptible to HIV. Some attributed these perceptions to media messages, as described by a 49 year-old heterosexual man from Mexico.

> I heard about AIDS, but I didn't think about Latinos with it because you only see African Americans and Anglos.

A 31 year-old homosexual man from Mexico felt that compared to the US, the Latino community still viewed HIV as a homosexual disease.

> I think that the US culture is different than the Mexican or Latino culture in that in the US culture, I see a lot more acceptance of HIV. Everyone can have

> HIV now – women, men, children, everyone. Not just homosexuals. All people can have it, and all people are accepted. But in the Latino culture or Mexican community that's not quite the case yet.

Many participants reported that at the time of diagnosis, they believed HIV signified a "death sentence." A 34 year-old heterosexual man from Honduras and a 32 year-old heterosexual woman from Mexico described feeling resigned to imminent death.

> The first time I went to [the HIV clinic], I thought I was going to die in two weeks. I thought I was going there to die and I would never come out.

> I went to support groups at [a Latino HIV organization], and people there told me they had HIV for 25 years, and I told them they were lying to me to make me feel better.

Secrecy and Shame

The majority of participants kept their HIV status a secret from friends and family. Five of 22 disclosed their status to family members, and only two received positive support. Common reactions from friends and family included denial, fear or rejection due to stigma and misinformation about transmission.

A 40 year-old woman from Mexico described being rejected by her entire family after being diagnosed with HIV infection.

> All my sisters and brothers had a family meeting and decided that I had to be removed from the family circle. This was during the 9 days I was in the hospital. And when all the doctors and nurses wore gloves and masks when they came in to see me, that made my family believe even more that HIV was a contagious disease, even though the doctors told them that it was to protect me and not because other people were in danger.

A 34 year-old woman from Mexico described a similar experience of rejection from her family.

> After I left the hospital, I went home to my family's house. And they were OK with it at first. But then [a Case Manager] came to visit me at the house. After he left there was some anxiety again about my HIV and they didn't like that I was sharing the bathroom with our grandmother who had diabetes. And all the grandchildren were not allowed to come to the house while I was there. So eventually I was told to leave the house so I moved out and went to an apartment, and that was very difficult for me. It was like hell.

Our data suggests that only a select minority of undocumented immigrants suspected or knew of HIV infection prior to migration, and the overwhelming majority of participants came to the US for better jobs and greater life opportunities. In actuality, those infected with HIV find themselves caught in the middle. On the one side, the morbidity and stigma associated with disease hinders their ability to access those opportunities and contribute to the workforce. On the other side, their undocumented and immigrant state complicates the situation even further, in the form of experienced and perceived barriers to accessing health care.

Language Barriers

Participants experienced language barriers that made navigating through the health care system difficult. A 43 year-old homosexual man from Mexico described feeling lost and not understanding his paperwork or medication regimen.

> I was never helped by anyone to help me understand the papers I was signing. I felt lost because I did not have someone to give me information in Spanish. I felt like when I was diagnosed I had no guidance as to other services, and I did not get a clear understanding of what medications to take and what the side effects were.

Many local service agencies and clinics employ interpreters and/or bilingual staff to address language barriers. However, participants often described situations where they were provided an interpreter but the interpreter was not fluent in Spanish. A 43 year-old homosexual man from Mexico described his experience with under-qualified interpreters.

> Sometimes I would get a translator that was not so good, they spoke what we'd call Spanglish, which is not really Spanish but a mixture of English and Spanish. Or you go into hospitals, and they say a bilingual person is here but the only Spanish thing about them is their last name because their Spanish is really, really bad. Or they speak 25% Spanish and 75% English. So you don't understand what they are saying.

Barriers Due to Undocumented Status

In addition to language, all participants discussed barriers related to undocumented status. Common themes included work restrictions, fear of deportation and difficulties meeting paperwork requirements.

Participants who worked often did not receive employee benefits such as paid leave, and those who no longer worked due to illness did not collect unemployment or disability benefits. They tended to work in low wage, physically demanding and poorly regulated jobs. Many feared that requesting time off from work for medical appointments meant risking losing their job. For participants supporting families abroad, maintaining an income was the priority. A 42-year-old woman from Mexico reported work as her reason for delaying entry into care.

> I was working for a woman from Chile, and she had two children and she was very strict and did not allow me to take any medical appointments. So without work I cannot make money. I have to work and make money so I can send it to my family, so my family can eat. I didn't follow up on medical [care] because I didn't have any opportunities, and I fell ill because of that. And she fired me because I got ill.

Fear of deportation as a result of utilizing services represents a stark reality for undocumented immigrants and a recognized barrier to general health care. Participants explained that returning to their countries of origin meant losing access to HIV treatments and the ability to support their families. A 45 year-old woman who supported her mother and children in Mexico explained her fear of deportation.

> I have definitely feared asking for services due to my immigration status. I don't want to be caught, and I don't want to be returned to Mexico because in Mexico I would only… my only option is to work in the fields, and I've done that, I've worked in the fields from 7am till 3 pm and my average income for that work is 8 dollars a day… and so my great fear is that I get returned…. And so sometimes I think when I try to access, I get scared that they might send me back and that would mean I would be without income and also medicine for my HIV.

This fear did not appear to dissipate over time. Even participants who had accessed services for several years continued to fear deportation. A 52 year-old homosexual man from El Salvador described this persistent fear.

> Now as far as the fear of people…there is the fear that they will be sent back. That is the fear. Now I have never heard of a situation that someone tried to get a service and then was sent back, but that does not mean the fear is not there.

Certain participants reported difficulties providing documents required for entry into health care. Several noted, "Many Latino immigrants do not have an ID or cannot get an ID." Proof of income or employment was also difficult to obtain. The overwhelming majority of working age undocumented adults work [8]. However, those who are paid with cash or do not work due to illness may have difficulty meeting proof of household income requirements. Furthermore, unemployed HIV-infected individuals may feel reluctant to solicit a statement of financial support from friends and family due to privacy concerns regarding their illness. A 38 year-old heterosexual man from Mexico talked about difficulties providing such documents.

> Sometimes they ask us to provide documentation from our employers, but not everybody works. Or they ask for a statement from someone supporting us, but not everyone wants to tell their family members they have HIV. So it is difficult for many people.

Discussion

This study provides insight into the sociocultural and structural barriers to optimal HIV care experienced by Latino immigrants who are undocumented. The major challenges include (1) dealing with HIV stigma and rejection from family and community; and (2) the experienced and perceived structural barriers in accessing health care due to lack of legal documentation.

Societal intolerance of HIV and stigma-related experiences result in feelings of secrecy and shame. These have negative effects on HIV prevention and management. If patients are afraid to talk about HIV due to overwhelming stigma, then they are more likely to delay testing and seeking care. In a study of 828 gay and bisexual men who did not know their HIV status, two-thirds cited stigma as a reason for not getting HIV testing [18]. In another survey of 221 HIV-positive men and women, stigma-related experiences were significantly associated with depressive symptoms, poor medication adherence and poor clinic attendance [19]. Holzemer's conceptual model of HIV/AIDS stigma recognizes the impact of power differentials in the propagation of stigma, both experienced and internalized [20]. However, little is known about the broader notions of power within the economic, political and legal context as it relates to HIV/AIDS stigma in the undocumented population. Undocumented individuals stand at the bottom of societal hierarchy, and this power differential may augment the propagation and perception of HIV/AIDS stigma. Not only do they have to deal with stigma as an HIV-infected individual, they have to deal with it in the context of being undocumented with HIV. Given the HIV/AIDS stigma and socioeconomic disparities experienced by undocumented Latino immigrants before and after migration, this area of study merits further exploration to better understand its relation to HIV prevention and treatment.

Most HIV-infected undocumented Latino immigrants receive their diagnosis at public hospitals after seeking emergency care for severe symptoms. Undocumented individuals are guaranteed emergency care under the 1986 Emergency Medicaid Treatment and Active Labor Act (EMTALA). However, they may face certain hurdles in linking to chronic HIV care after hospital discharge. Undocumented individuals with low literacy and linguistics barriers may have difficulty filling out forms required for access and feel overwhelmed navigating health care systems [10]. Additionally, perceived barriers such as misconceptions about deportation risks and lack of awareness about available HIV services contribute to delayed HIV diagnosis and linkage to HIV primary care.

To put our findings in context, Texas provides relatively comprehensive HIV care and no major policy barriers to care based on immigration status exists. Although public insurance programs like Medicaid and Medicare prove difficult to access, other public programs fill the gaps in HIV care. In Texas, the AIDS Drug Assistance Program (ADAP) provides funding for HIV medications regardless of immigration status, and there is no waiting list for receipt of HIV medications. Additionally, access to Ryan White funded clinics, Federally Qualified Health Centers, and traditional safety-net local providers are typically available regardless of immigration status. While comprehensive HIV care is available, persistent patterns in delayed entry into care among undocumented Latino immigrants support the development of education and advocacy programs to increase HIV awareness and ensure that individuals receive the health benefits which they are entitled to by law, regardless of immigration status.

The findings in our study should be interpreted with the following limitations in mind. Our participants reside in the greater Houston area and the findings may not be generalizable to HIV-positive undocumented Latinos across the US. Participants volunteered to share personal experiences, and differences may exist between those who did and did not volunteer to participate. Service providers played an active role in recruitment and all participants received medical or social services at the time of interviews; therefore, these findings may not be generalized to out-of-care undocumented Latino immigrants living with HIV.

This study identifies unique barriers to HIV care involving undocumented Latino immigrants, which include fear of deportation, work restrictions and difficulties meeting paperwork requirements. Our findings suggest that the added element of undocumentedness may exacerbate sociocultural and structural barriers already faced by Latino immigrants with HIV infection. Intervention strategies to promote early entry into HIV care need to reflect the reality of the undocumented state, and take into account the time and economic pressures experienced by undocumented workers when making clinic visits. Specific interventions need to take place at the time of diagnosis to increase linkage to HIV care, for example basic education on the types of HIV care available (i.e., HIV diagnosis is not a death sentence), and education to overcome assumptions about structural barriers to HIV care based solely on the undocumented state.

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