Access to Care

among HIV+ Latino Immigrants

A special study of the
Comprehensive HIV Planning Committee
Houston Ryan White Planning Council

Approved
December 2006

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Introduction

In 2005, the Comprehensive HIV Planning Committee of the Houston Ryan White Planning Council commissioned three “special studies” focusing on populations of interest which were identified based on findings from the 2005 Needs Assessment and HIV/AIDS surveillance data. These populations were youth, MSM of color and Latino immigrants.

The purpose of this exploratory study was to better understand the factors that enhance or impede entry (and retention) into care for HIV+ Latino immigrants. The focus on entry to care was triggered by HRSA’s unmet need initiative, and the Houston Ryan White Planning Council’s efforts to bring HIV+ individuals into medical care. The findings in this study are based on the personal narratives of HIV+ Latino immigrants living in the Houston EMA. We chose to utilize one-on-one interviews in order to collect in-depth information not usually captured in quantitative surveys, and to give a direct voice to the experiences of HIV+ Latino immigrants.

Latinos in the Houston EMA & HSDA

An Eligible Metropolitan Area (EMA) is defined by the Health Resources Services Administration (HRSA) as an urban area hardest hit by the HIV/AIDS epidemic. These areas receive direct federal funds in the form of a Title I grant. The Houston EMA consists of six counties: Chambers, Fort Bend, Harris, Liberty, Montgomery and Waller. Health Service Delivery Areas (HSDAs) are areas that receive Title II grants. Title II funds are awarded directly to states from HRSA, and distributed by the states to HSDAs. The Houston HSDA encompasses a total of ten counties. These ten counties consist of the six EMA counties plus Austin, Colorado, Walker and Wharton counties.

Hispanics/Latinos make up 30% of the EMA population and 32% of the state population. Twenty percent of EMA and HSDA residents were born outside the U.S. This compares to 14% in the state of Texas. These foreign born residents most frequently come from North, Central and South America. Mexico is the most frequent place of foreign birth, accounting for about half of those born outside the U.S.

Approximately one-third of EMA and HSDA residents are "linguistically isolated," meaning they speak English less than "very well.” The predominant second language is Spanish.

HIV/AIDS among Latinos in the Houston EMA

During 2005, there were 7,406 living HIV cases (including 971 new HIV diagnoses) and 10,468 living AIDS cases (including 1,040 new AIDS diagnoses) in the six county Houston EMA. This included 214 new HIV diagnoses and 273 new AIDS diagnoses among Latinos.

In 2004*, a total of 407 Hispanics were newly diagnosed with HIV or AIDS in the Houston HSDA. This total included 337 (83%) new cases among Hispanic men and 70 (17%) new cases among Hispanic women. As with other populations, the 25 to 44 year age group is the largest (n=300; 74%), but infections among youth 13 to 24 years of age are increasing. Nearly 18% of Hispanics living with HIV are youth, while 6% of those living with AIDS are youth between 13 and 24 years of age.

Sexual activity, either men who have sex with men (MSM) or heterosexual, was the transmission mode for almost all Hispanics diagnosed with HIV and those living with HIV or AIDS. MSM represented a higher percentage of those diagnosed with HIV (58%) than those diagnosed with AIDS (41%). Forty-five percent of Hispanics living with HIV and 50% of those living with AIDS report MSM as their transmission mode. Heterosexual contact is the transmission mode for 23% of Hispanics living with HIV and 24% of those living with AIDS. Among diagnosed AIDS cases, intravenous drug use (IDU) was attributed to 3% of new HIV cases and 6% of new AIDS cases. MSM/IDU transmission was attributed to less than 1% of new HIV cases, and 3% of new AIDS cases. Mothers at risk constituted 1% of new HIV cases. No new AIDS cases among Latinas in 2004 were attributed to mothers at risk.

Harris County is home to 96% of Hispanics living with HIV or AIDS. In addition, Harris County had the highest proportion of new HIV infections and diagnosed AIDS cases among Hispanics during 2004. There was also a small portion of cases in Fort Bend County, Liberty County, Montgomery County, and Waller County.

2005 Needs Assessment

In the 2005 Needs Assessment, Latinos comprised 22% of the survey sample, and 27% of these people, or 41 respondents, were out-of-care. Out-of-care Latino consumer survey participants have the same gender and age profiles as those receiving HIV medical care. With 55% working either full or part time, out-of-care Latinos are employed to a greater extent than both in-care Latinos and other groups of out-of-care consumers. Despite working, 87% are uninsured.

Out-of-care Latinos were relatively newly diagnosed with HIV. Almost all were diagnosed after 1995, and 73% were diagnosed between 2000 and 2004. After diagnosis, 83% of the out-of-care never received HIV medical care, and 33% reported they were not referred for services. Few out-of-care Latinos were treated for co-morbid conditions in the last 12 months. Co-morbidities identified included current IV drug use (18%), current street drug use (30%) and homelessness (15%).

The most frequently identified reasons for Latino PLWHA being out-of-care included:

- ♦ I do not believe I need medical care currently because I am not sick (54%);
- ♦ I do not believe medical care would do me any good (29%);

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* 2005 HIV/AIDS demographic data on Latinos for the EMA/HSDA were not available at time of report.

- I was worried someone would force me to take medication (17%);
- I was actively using (street drugs or alcohol) (17%); and
- I was worried someone might find out about my HIV status if I went there (17%).

Barriers to care caused by consumers' housing situations were identified. When asked, "Thinking about your housing situation now, do any of the following stop you from taking care of your HIV?", nearly 70% of Latino respondents identified "I'm afraid of others knowing I am HIV positive."

Other barriers were identified with the question, "Do any of the following keep you from getting needed HIV medical care?", the most frequent responses included:

- I don't have a way to pay for it (42%);
- Fear of being deported (42%); and
- I can't get services because of immigrant/legal status (27%).

Out-of-care Latino's ten most frequently identified unfulfilled needs include:

Service Category	Proportion of Latino participants identifying service need as unfulfilled
Health Insurance	68%
Oral Health	61%
Primary Medical Care	54%
Utility Assistance	51%
Bus Pass	49%
Rental Assistance	48%
Vision Care	44%
Household Items	44%
Client Advocacy	44%
Food Bank	44%

Methodology

The findings of this study were based on 30 semi-structured one-on-one interviews with HIV+ Latino immigrants between the ages of 26 and 70. All participants received gift cards at the conclusion of each interview. All interviews were conducted in English by the Health Planner in the Ryan White Planning Council Office of Support, and interpreted by a Spanish-speaking consultant trained in medical translation and interpretation. Interviews were conducted at public clinics and community based organizations.

At the beginning of each interview, participants were informed that their participation was completely voluntary and that they could stop the interview at any time. A Research Assent form translated into Spanish, containing details of the study and assurances of confidentiality, was reviewed with each participant (see Appendix A).

Upon receiving the participant's assent, a brief one-page questionnaire was administered by both the Health Planner and interpreter (see Appendix B).

To further protect confidentiality, first and last names were not collected during the course of the study; participants signed only their initials on the Research Assent and gift card receipt forms. A unique identification number was assigned to each participant for purposes of data entry and analysis.

Interview items were based on findings from a literature search on access to care among HIV+ Latino immigrants. Interviews lasted between 30 to 100 minutes. Interview questions were posed to the participant in English, and participant responded in Spanish, with the interpreter translating between the two. All interviews were recorded using a digital voice recorder, transcribed into Microsoft Word and coded and analyzed using AnSWR, a qualitative analysis program developed by the CDC.

Participants

Thirty (N=30) HIV positive Latino immigrants participated in one-on-one semi structured interviews. Fifteen (50%) were male and 15 (50%) were female. None of the participants identified as transgendered. Ages ranged from 26 to 70 years, with an average age of 42 yrs (sd = 11.0). Seventy percent (70%) of participants identified as heterosexual (n=21; 70%), 7(23%) gay, and 2 (7%) bisexual.

The majority of participants were undocumented immigrants (identified as "Other" on the pre-interview survey). Four (13%) were permanent residents, three (10%) were citizens and one (3%) was a visa holder. One of the participants was in the process of applying for asylum due to her HIV status.

Most participants originally came from Mexico (n=19; 63%), followed by Honduras (n=6; 20%), and El Salvador (n=3; 10%). Two came from Columbia and Ecuador. The average length of residency in the US was 11 years, ranging from 3 months to 48 years. The majority of participants (n=19; 63%) had been in the US for less than 10 years, and 8 (27%) had been in the US for less than 5 years.

The following table shows additional demographic information for the 30 participants.

Participant Background Information (N=30)

Gender	Male = 15 (50%) Female = 15 (50%)
Age	Range = 26 – 70 Average = 42 yrs (sd*=11.0)

Immigration Status	Citizen = 3 (10%) Permanent Resident = 4 (13%) Visa = 1 (3%) Other = 22 (73%)
Country of Origin	Mexico = 19 (63%) Honduras = 6 (20%) El Salvador = 3 (10%) Columbia = 1 (3%) Ecuador = 1 (3%)
Years in US	10 years or less = 19 (63%) 5 years or less = 8 (27%) Range = 3 months – 48 years Average = 11 years (sd=10.1)
Sexual Orientation	Straight = 21 (70%) Gay = 7 (23%) Bisexual = 2 (7%)
Marital Status	Married = 11 (37%) Never Married = 11 (37%) Divorced/Separated = 6 (20%) Widowed = 2 (7%)
Job Status	Full time = 1 (3%) Part time = 6 (20%) Temp/Odd Jobs = 6 (20%) Do not work = 17 (57%)
Monthly Income	Range = $0 - $2000 Average = $693 (sd=514.0)
Live Alone?	Yes = 10 (33%) No = 20 (67%); Average = 2 other people
Have Children?	No = 9 (30%) Yes = 21 (70%); Average = 2 children
Length of Diagnosis	Within past 4 years = 16 (53%)
Frequency of Doctor Visits (for HIV)	Range = 2x per month – every 6 months Average = Every 3 months (sd=1.1)
Taking HIV Meds?	No = 3 (10%) Yes = 27 (90%)

Taking non-HIV Meds?	No = 13 (43%) Yes = 17 (57%)

* sd = standard deviation

Limitations

It is important to note that interviews were conducted with HIV+ Latino immigrants who were willing and available to talk about their experiences. Since study recruitment was conducted through service providers, all participants were receiving medical or supportive services at the time of the interview. Therefore, the findings may not fully reflect the experiences of out-of-care HIV+ Latino immigrants. These limitations may affect the generalizability of the findings.

In addition to participant names, the names of specific case managers, doctors and service providers have been removed.

Results

Reasons for immigrating

Financial opportunity was the most frequently reported reason for immigrating to the United States. Participants often stated they were seeking “a better life.”

> *“I came here to work. I have better opportunities here than in my home country.” Male participant*

> *“…I came to the US with my three sons so they could have a better life and education than I did.” Female participant*

Six participants reported immigrating to the US to receive health care or other services related to being HIV positive. Of these six participants, two had received HIV tests prior to leaving their countries of origin. The remaining four were tested in the US, but stated they were ill and strongly suspected they were already infected.

> *“I was diagnosed here in the US. The reason I came to the US was because my husband died of AIDS, so we knew the symptoms, and 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 to the US because they would not be able to send medications to my country.” Female participant*

> *“The only person I knew who was HIV positive was my husband, who told me 3 months before he died. He died very quick, and I knew I was going to die too, which is why I came to the US because I didn’t want to die alone.” Female participant*

Participants described the differences between HIV-related care in Houston versus HIV-related care in their countries of origin. Availability of resources, stigma, medications and HIV knowledge of physicians were key differences.

> *"The difference would be that people with HIV are discriminated. People are so afraid of transmission, and their education on HIV is very poor. Another big difference is that there are no big 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'." Female participant*

> *"After my husband died, everybody was talking about him and 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." Female participant*

HIV/AIDS Attitudes and Beliefs

Many participants reported that at the time of diagnosis, they believed that HIV was a "death sentence" with low chances of survival.

> *"The first time I went to [the public 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." Male participant*

> *"My thought of HIV was people with thin arms and big stomachs and marks all over their skin. That was my idea of HIV." Male participant*

> *"I went to support groups at [a Latino 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." Female participant*

> *"I thought I was going to die, and my son just cried and cried." Female participant*

A few participants reported that they were unaware of HIV, or that it could affect them.

> *"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." Male participant*

> *"I heard about AIDS, but I didn't think about Latinos with it. Because you only see African Americans and Anglos." Male participant*

Basic HIV education messages are important during primary prevention. Many participants discussed the lack of basic HIV education in Latino communities. In addition to primary prevention, HIV education for HIV+ Latinos is also important. For example, a participant did not believe that her breast milk could transmit the virus to her child.

> *"My child, I was worried because he would not digest regular milk well, it would make him sick. He did take breast milk, and people they said 'no, no' and [told me] to keep taking my medicine. But I prayed to God to make him better, and it did make him stronger. That's why my child is healthy – he took my breast milk. Otherwise, he would have been HIV positive. That is why I am sure that breast milk is not bad milk when one is HIV positive. The people that think that drinking breast milk is bad for the child are mistaken." Female participant*

HIV Testing Experiences

Most participants received their HIV diagnoses at public hospitals after seeking emergency care for severe symptoms, or at community clinics during prenatal care. Only three participants reported they initiated HIV tests as preventative measures. In most cases, post-test information was limited to a referral to the public clinic. A few participants reported that the Blue Book was a useful resource.

> *"They did not tell me much afterwards. Before I left, somebody gave me a piece of paper… they wrote the [name and address of the public clinic]." Female participant*

> *"…a young man came who spoke Spanish, and he was Hispanic and said he had HIV for 10 years. And I didn't believe him that he had HIV for 10 years, but he said he did and that gave me hope. The young man gave me a Blue Book and told me to use it for services." Female participant*

The majority of participants kept their HIV status a secret from friends and family. Less than five had disclosed their status to family members, and even fewer received positive support. Common reactions from friends and family members were denial, fear or rejection due to stigma and misunderstandings about transmission.

> *"My friend told me…he told me that I didn't have HIV, that it was a lie, and he didn't believe me so he didn't want to help me anymore… " Female participant*

> *"Until this day, I have no idea if my husband ever took an HIV test or if he is HIV positive because we separated that day in the hospital." Female participant*

> *"My brother, I used to take care of his children. But then he thought that I would infect his children. So he did not bring them to see me anymore." Female participant*

> *"…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. At the beginning, my sisters would be there and supportive of me. And when…all the doctors and nurses wore gloves and masks when they came into 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." Female participant*

> *"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 from a community organization] 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. [The Case Manager] offered to talk to them, but they just wanted to get as far away from me as possible." Female participant*

Entry into Care

The average amount of time between diagnosis and self-reported entry into care was 5 days, with total times ranging from 1 day to 7 years. Those who delayed entry into care for more than one month reported fear or denial, lack of information, work-related barriers or other circumstances.

Some participants reported fear or denial about confirming their status.

> *"My husband died in 1997 but I did not get tested until 2002 because I was fearful. When my husband died of AIDS, everybody was talking, and I was afraid of rejection. And it was also part of my ignorance. But I got so ill that in order to be there for my children, I needed to come to the US because I knew in the US I would receive better treatment. So I came to the US and within the week my sister took me to the HIV clinic." Female participant*

> *"My husband died 11 years ago. The reason I did not get treatment right away when I came to this country, was because I had forgotten that my husband died of AIDS. I told my son that his father had died of a heart condition." Female participant*

> *"Me personally, I would not have wanted to know I was HIV, but I only knew because I was so ill. Female participant*

After being diagnosed in the US, one participant did not seek services for 2 months because she feared rejection by service providers.

> *"I thought they would not treat me well, I thought they would reject me." Female participant*

In one case, a participant's doctor in Houston did not test for HIV despite her symptoms and risk history.

> *"I was having fever and tenderness around my liver and I started to get spots on my arms. I was also having headaches. I went to a doctor that was recommended by my family members. He looked at my rash and said it was herpes related. I told him I had been raped once. Then he took my blood and said I just had high cholesterol. A month later I got the symptoms again and I went to [a public hospital], and that's where I learned I had HIV." Female participant*

Another factor affecting entry into Houston's HIV care system was work-related barriers. Requesting time off from work for medical appointments was impossible for many participants. Many reported it as a reason for delayed 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 because I didn't have any opportunities, and I fell ill because of that. And she fired me because I got ill." Female participant*
>
> *"I went to a clinic and you have to wait for hours to see the doctor. But I would see the doctor standing around talking to people. And you have to understand, we have to take time off from work to go to the clinic, and to see the doctor standing around I did not like that. If I miss too much work then I will lose my job so I cannot spend all day at the clinic. And even though the clinic said they could mail the medication to me at my home, I still did not like that clinic so I did not go back." Female participant*

One participant reported falling in and out of care due to violence and abuse from her husband.

> *"The first 6 months I lived with my husband [after HIV diagnosis], I lived in total fear. My husband was accusing me of having an affair with [my Case Manager], he was accusing that the staff at [the Latino organization] were raping me. Also, he wouldn't touch me or let me cook. And one of my sisters in law told him that I was a prostitute in Honduras… one time, I got lost on the Metro going to [the public clinic] so when I finally got to the clinic I spent three hours with [my Case Manager] because I was crying the whole time. And when I got home, my husband was drinking and he accused me again of having an affair with [my Case Manager] and threatened to kill us both by setting the apartment on fire." Female participant*

Another participant reported that he did not enter Houston's HIV care system for two years because he was not informed of his status by the public hospital.

> *"In 2002, I found out I was already diagnosed in 2000, but I was never told about it. I went to [the public hospital] for a medical issue. I met the doctor, and the doctor opened my file and that's when I found out I had been diagnosed two years earlier. Many times prior to that day, I had been to [the public hospital] many times, but I was never informed that I was HIV positive. I feel that this was a very grave error because during those two years I could have been taking medications, because when I came to [a public clinic], my CD4 count was very low and I had an AIDS diagnosis." Male participant*

Barriers to Care

Overall, participants were satisfied with their HIV medical care and the range of HIV services available in the Houston area. However, when discussing barriers to current systems of care, participants most often identified language and immigration status as the two top barriers.

Language barriers were identified throughout the course of treatment, starting from diagnosis. When bilingual translators were not available or offered by providers, family members stepped in. This dynamic affected the participant's right to confidentiality, when providers disclosed their HIV status to family members without their consent.

> *"When they called with the results, they asked to speak to my husband because he spoke English better than me. And they told him that they would not be able to see me there any longer because I was a carrier of AIDS, and they referred me to [a public clinic]." Female participant*

> *"I arrived at the hospital…the doctor came and said I want to give you an HIV test because you show the symptoms. I signed the paper because I didn't think I had it, I wasn't expecting to have it. After that my husband's sister was there, and I was very ill. And my husband's sister asked the doctor what's wrong with her? Is she going to die? And the doctor said, she has a mortal disease. She has AIDS. I heard the results of my HIV in front of my sister in law. The results were given to my sister in law in English by a doctor who did not speak Spanish. She did not try to give me the results in my language, privately. As the first sister in law was hearing the results, another sister in law was coming into the room…and the first sister in law said, "she has AIDS!" Then the second sister ran out of the room to call my husband's family and told them." Female participant*

Several participants felt that they did not receive equal access to services because of their English abilities. They were frustrated by a system that they felt discriminated against non-English speakers.

> *"It is difficult to get services if you are Latino because, for example [a community organization] provides financial assistance, but they are only open for one hour a month, and only 20 people can get in. And if you don't speak English then it is*

> *difficult. That is why only the African Americans get services. It is hard for Latinos." Female participant*

> *"More interpreters need to be available. So that we can be treated equally. Without interpreters we have to wait longer." Female participant*

Participants also cited examples of how their language barriers prevented them from accessing services or information related to their medical care.

> *"I was never helped by anyone to help me understand the papers I was signing." Male participant*

> *"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." Female participant*

> *"When I was diagnosed, I didn't get much information from [the hospital] about HIV…I was in the hospital for three months and I did not get anyone who spoke Spanish to give me that information." Female participant*

Although translators are often available to address language barriers, participants were often unsatisfied with the quality and skills of available translators. One such issue was related to "spontaneous translation," where staff untrained in translation or not fluent in Spanish were pulled in at a moment's notice.

> *"Generally, when a doctor does not speak Spanish then they try to make sure an interpreter is available. However, in other departments that are smaller and faster and less important, then they won't have an interpreter, like signing papers for the lab. Then they will just bring a secretary or somebody to translate." Male participant*

> *"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. The majority of interpreters that I saw were administrative staff. In the ER department, the interpreters I received seemed like real interpreters but in the specialty departments they did not seem like real interpreters." Male participant*

Another issue was the proficiency of translators. Several participants described experiences with translators who did not speak Spanish fluently.

> *"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… you need really good speaking people there for Spanish.*

> *Also because it's for health, because if there is something really wrong with you, and you don't understand, then that is bad." Male participant*

> *"Sometimes they say, oh she speaks Spanish, but then when you try to speak Spanish then she doesn't even speak Spanish correctly. And you wonder why they told you she was bilingual but you cannot say anything." Male participant*

Immigration status was also a common barrier identified by participants. Fear of deportation was one main concern related to immigration.

> *"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 3pm and my average income for that work is 8 dollars a day… and so my great fear is that I get returned. And if I stay here, I can provide a better quality life for my children, because I want them to get the education that I didn't get. 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." Female participant*

> *"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." Female participant*

Participants also felt that the documentation required for services was difficult for many Latinos to produce.

> *"Many Latino immigrants do not have an ID or cannot get an ID, so the requirement of an ID can be a barrier for many folks." Female participant*

> *"The most difficult paperwork is proof of income. I was able to get a job at a car wash and so I could get the Gold Card for 3 more months. One time I got the Red Card, but with the Red Card you have to pay for services." Female participant*

> *"Sometimes they ask us to provide documentation of our employers, and not everyone 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." Male participant*

Other barriers to care identified by participants were cost of services and cultural attitudes.

> *"I think it's difficult for Latinos to access medical services in general, because services are very expensive." Female participant*

> *"I would say another barrier is Machismo. We see Latino gays going in to access services, not a problem, we see women, we see children accessing services. Not a problem. But when we hear a woman say I am infected because my husband infected me, and we say please tell your husband to come in, she says, oh I can't tell my husband because he will kill me. Or he will say that if I am infected, I infected him. And he will not accept it because it's only for gay people." Male participant*

> *"The Latino community in general has a difficult time accepting that Latino heterosexual men are also being infected. They are more accustomed to women now, but they are not questioning the population of straight men." Male participant*

> *"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 gays. 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, so I think it's important for the Mexican community to realize that we're in the US now. We need to look more through the lenses of what the US culture looks through, how the US culture looks at HIV." Male participant*

Reaching the Latino Community

When asked to recommend strategies for bringing HIV+ Latinos into care, participants said visibility and community education were the two most important approaches. Several participants who accessed services from Latino-specific organizations discussed the importance of receiving care in environments that were comfortable for them culturally and linguistically.

> *"When I was going to the other doctor, I would sit in the waiting room and I would see the other patients and they were white and spoke English. And I could not say hello or talk to them so I felt uncomfortable. They were Anglos, they were white people. And when I opened the door at [the Latino organization], I saw the population of people that were there. There were…mothers with children… young people and adults, and they were all Hispanics. So I immediately identified with them. It was not until then that I realized I was not the only Hispanic person with HIV." Female participant*

> *"[At the Latino organization] I was told for the first time that I did not have AIDS, I was told the difference between HIV and AIDS…that was important for me to hear because when I was first told that I had AIDS my whole world came down and I was so stressed out and so desperate and when I heard more specifically that I had the initial stages of HIV it gave me a lot of hope and it helped me change my attitude about my health." Female participant*

> *"While I was in the hospital…no one told me anything so I can't answer what medications I was on. I was not informed of any treatment they were giving me. It was not until I went to [the Latino organization] that I learned what a CD4 count or viral load was." Female participant*

All participants said that increased outreach, education and publicity were needed to help bring more HIV+ Latinos into medical care. Many also felt that in addition to basic HIV education, outreach messages should address fears of anti-immigrant sentiment. Also, publicity should inform community members that they can receive services regardless of immigration status.

> *"Now, there are already advertisements, but they do not mention that they will provide services regardless of your immigration status. But I think that's one way to promote services." Female participant*

> *"One time I heard on the radio a popular announcer talked about HIV and said it's not just gay people or white people, it's everyone who can get HIV. And then people started to call in and say my brother has HIV or my friend has HIV and that was good to hear it in Spanish on the radio because it was a popular radio show. But that was only one time and I don't hear that kind of thing on Spanish radio anymore." Male participant*

> *"I think in order to get undocumented to access services for medical the important thing is publicity. Because the publicity we're getting in our community is exactly the opposite of the kind of publicity that would help the undocumented access services. Because if you look at the TV…if you're undocumented we have a law going on that you'll be taken away and you have no rights. We've been seeing more publicity against undocumented persons, so that is giving the type of fear and effect that I don't have the right and they don't like me, so that makes it difficult for an undocumented immigrant to access medical services. And I think the popular Spanish news channels should say after news stories that you will not be deported if you access these services if you are undocumented. That does not take much time but it will be very important." Male participant*

Conclusion

Based on the narratives collected in this study, several themes have emerged related to access to care for HIV+ Latino immigrants. Barriers most often faced by the participants were related to language and immigration status. Participants felt that not only were more translators needed, but the quality of the translations could be improved. Several participants felt that they did not receive equal access to services because of their English abilities. Although translators are often available to address language barriers, participants were often unsatisfied with the quality and skills of available translators. One such issue was related to "spontaneous translation," where staff untrained in translation or not fluent in Spanish were pulled in at a moment's notice. Another issue was the proficiency of translators. Several participants described experiences with translators who did not speak Spanish fluently.

Documentation required for some services were reported as difficult to obtain for those who were not permanent residents or citizens. Still, participants overall felt satisfied with the services they were receiving.

Money was the most frequently reported reason for immigrating to the United States. Participants often stated they were seeking “a better life” and described the differences between HIV-related care in Houston versus HIV-related care in their countries of origin.

Most participants received their HIV diagnoses at public hospitals after seeking emergency care for severe symptoms, or at community clinics during prenatal care. The majority of participants kept their HIV status a secret from friends and family. Common reactions from friends and family members were denial, fear or rejection due to stigma and misunderstandings about transmission.

The average amount of time between diagnosis and self-reported entry into care was 5 days, with total times ranging from 1 day to 7 years. Those who delayed entry into care for more than one month reported fear or denial, lack of information, work-related barriers or other circumstances.

When asked to recommend strategies for bringing HIV+ Latinos into care, participants said visibility and community education were the two most important approaches. Several participants who accessed services from Latino-specific organizations discussed the importance of receiving care in environments that were comfortable for them culturally and linguistically.

> *“I used to yell at [my Case Manager], why me? I am a good person, I just came here for the American dream, and look at what happened to me. And he said, you are living the American dream, because you are given medication, you are given medical care, that is the American dream, because you are able to stay healthy so that you can keep on your goal which is to work and provide a better life for your children. That is the American dream.” Female – 10015*

APPENDIX A

RESEARCH CONSENT FORM

Barriers to Care Among HIV Positive Latino Immigrants in the Houston Area

A. PURPOSE AND BACKGROUND

The Houston Ryan White Planning Council is conducting a research study to help understand the experiences of HIV positive Latino immigrants when accessing medical care.

B. PROCEDURES

If you agree to be in the study, the following will happen:

1. You will be asked to complete a brief one-page questionnaire about your basic background and demographic information. It should take approximately ten minutes to complete the questionnaire.

2. You will be interviewed by Jen Haejin Kim, Health Planner for Ryan White Planning Council Office of Support. The interview will cover various topics related to your experiences as an HIV+ Latino immigrant. The interview will be recorded, and is expected to last about 60 to 90 minutes.

3. These research activities will be done at various agencies and/or other agreed upon locations, and will take a total time of about one and a half hours.

4. Data collected from the questionnaires will be entered into a database for summary purposes. No identifying information will be collected on the questionnaires or stored in any database. All participation is confidential. All interviews will be transcribed and stored as word processing files. No identifying information will be included in the transcripts.

5. At the completion of this study, you are welcome to request copies of the final report and any presentations.

6. If at any time during the questionnaire and/or interview you would like to stop participating, just let Jen Haejin Kim know.

C. RISKS/DISCOMFORTS

Some of interview questions or topics may make you uncomfortable or upset, but you are free to decline to answer any questions you do not wish to answer or to leave the interview at any time.

D. BENEFITS

There will be no direct, immediate benefit to you from participating in this study. However, the information that you provide may help planning bodies, service providers and health professionals better understand the experiences HIV+ Latinos face when accessing medical care.

E. COSTS

There will be no costs to you as a result of taking part in this study.

F. PAYMENT

You will receive $30 in Wal-Mart or Kroger gift cards for your participation in the study.

G. QUESTIONS

If you have any questions or concerns about participation in this study, feel free to contact:

Jen Haejin Kim
Health Planner
(713) 572-3729 – voice
(713) 841 – 0738 – pager
Jennifer_Kim@hctx.net

or

Tori Williams
Manager
(713) 572-3724 – voice
Victoria_Williams@hctx.net

H. CONSENT

PARTICIPATION IN RESEARCH IS ALWAYS VOLUNTARY. You are free to decline to be in this study or to withdraw from it at any point.

You may also withdraw your authorization (consent) for this study by contacting Jen Haejin Kim to inform her of your decision.

If you wish to participate in this study, you should sign below. You will be given a copy of this consent form to keep for your records.

__________ ____
Date Subject's Signature for Consent

__________ ____
Date Signature of Person Obtaining Consent

FORMULARIO DE CONSENTIMIENTO PARA EFECTUAR EL ESTUDIO

Barreras en recibir cuidado por los inmigrantes Latinos VIH positivo en el área de Houston

A. PROPÓSITO E HISTORIAL

El Concilio de Planificación Ryan White de Houston está actualmente conduciendo una investigación a efecto de un mejor entendimiento sobre las experiencias de los inmigrantes Latinos VIH positivos cuando acceden al cuidado médico.

B. PROCEDIMIENTOS

Si usted acepta participar en el estudio, los procedimientos serán los siguientes:

1. Le pedirán que complete un cuestionario breve de una página referente a su antecedente básico e información demográfica. Tomará aproximadamente 10 minutos para completar el cuestionario.
2. Será entrevistado/a por Jen Haejin Kim, Planeadora de la Salud de la Oficina de Apoyo del Concilio de Planificación Ryan White. La entrevista cubrirá varios temas relacionados a su experiencia como inmigrante Latino con el VIH. Dicha entrevista será grabada y podría durar de 60 a 90 minutos.
3. Las actividades de la investigación tomarán lugar en varias agencias y/o en otras ubicaciones confirmadas en concordancia y con anticipación. Tomará un total de aproximadamente una hora y media.
4. La información reunida de los cuestionarios será introducida en una base de datos con el propósito de hacer un resumen. No se reunirá o almacenará en dicha base de datos ninguna información que identifique a la persona entrevistada. Toda participación es confidencial. Todas las entrevistas serán transcritas y almacenadas en los archivos del procesador de textos. No se incluirá información identificable en la trascripción.
5. Al término del estudio, podrá solicitar copias del reporte final y de cualquier otra presentación.
6. Si en cualquier momento durante el cuestionario y/o entrevista desea dejar de participar, simplemente avise a Jen Haejin Kim.

C. RIESGOS/INCOMODIDADES

Algunas de las preguntas o temas de la entrevista podrían incomodarlo/a o preocuparlo/a. Usted puede libremente rehusar contestar cualquier pregunta que lo/a incomode. Inclusive, tiene el derecho de retirarse de la entrevista en cualquier momento que lo desee.

D. BENEFICIOS

Usted no tendrá ningún beneficio directo o inmediato por la participación en este estudio. Sin embargo, la información que usted provea ayudará a los grupos de planificación, a los proveedores de servicios y a los profesionales de la salud para alcanzar un mejor entendimiento sobre las experiencias de los Latinos con el VIH cuando acceden al cuidado médico.

E. PRECIOS

No tendrá gasto alguno de su parte por participar en este estudio.

F. PAGO

Recibirá una tarjeta con un valor de $30 de Walmart o Kroger por haber participado en el estudio.

G. PREGUNTAS

Si tiene preguntas o preocupaciones concernientes a su participación en este estudio, por favor contáctese con:

Jen Haejin Kim
Health Planner
(713) 572-3729 – voice
(713) 841 – 0738 – pager
Jennifer_Kim@hctx.net

o

Tori Williams
Manager
(713) 572-3724 – voice
Victoria_Williams@hctx.net

H. CONSENTIMIENTO

LA PARTICIPACIÓN EN LA INVESTIGACIÓN ES SIEMPRE VOLUNTARIA. Usted tiene la libertad de rehusar de la participación o el derecho de retirarse en cualquier momento.

También puede retirar su autorización (consentimiento) contactando a Jen Haejin Kim e informándole de su decisión.

Si desea participar en este estudio, debe firmar en la línea a continuación. Se le proporcionará una copia de este consentimiento para su archivo personal.

_______________ ____
Fecha Firma del Participante

_______________ ____
Fecha Firma de la Persona Obteniendo el Consentimiento

APPENDIX B

PRE-INTERVIEW QUESTIONNAIRE

Gender:	☐ Male ☐ Female ☐ Transgender
Age:	_______________
Year of arrival to the US:	_______________
Country of origin:	____
Immigration status:	☐ Citizen ☐ Permanent Resident ☐ Refugee ☐ Visa ☐ Other
Sexual Orientation:	☐ Straight ☐ Gay ☐ Bisexual ☐ Lesbian ☐ Prefer not to say
Job Status	☐ Work full-time ☐ Work part-time ☐ Temp work/Odd Jobs ☐ Do not work
Average monthly Income	_________________________
Marital Status	☐ Married ☐ Never married ☐ Divorced ☐ Widowed
Do you live alone?	☐ Yes ☐ No How many people do you live with? _______
Do you have any children?	☐ Yes How many?_____ Do they live with you? _____ ☐ No
Date of HIV diagnosis:	____________________
How often do you see a doctor for HIV?	___________________________
Are you currently taking any HIV medications?	☐ Yes ☐ No
Are you currently taking any non-HIV medications?	☐ Yes ☐ No

Acknowledgement of Receipt

I, ______________________, acknowledge that I received a $30 Walmart/Kroger Gift Card (_________________) in appreciation for participating in the Houston Ryan White Planning Council's Latino Study.

Initials of Participant: ____________________________ Date: __________________

Signature of Witness: _____________________________ Date: __________________

RWPC Copy

Acknowledgement of Receipt

I, ______________________, acknowledge that I received a $30 Walmart/Kroger Gift Card (_________________) in appreciation for participating in the Houston Ryan White Planning Council's Latino Study.

Initials of Participant: ____________________________ Date: __________________

Signature of Witness: _____________________________ Date: __________________

Participant Copy