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Geopolitical and Cultural Factors Affecting ARV Adherence on the US-Mexico Border

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Abstract

BACKGROUND—The data discussed represent the findings from a study by the NIH-funded Hispanic Health Disparities Research Center (UTEP), exploring the influence of institutional and psychosocial factors on adherence to antiretroviral medications (ARVs) by Mexican-origin persons living with AIDS on the US-Mexico Border.

METHODS—A qualitative approach was utilized consisting of clinic observations, baseline and follow-up interviews with patients (N=113), key informant interviews (N=9) and focus groups (5) with patients and health providers.

RESULTS—Findings include the social-normative, institutional and geo-political factors affecting treatment and service delivery as well as individual variation and culturally patterned behaviors.

DISCUSSION—ARV adherence and retention were found to depend on complex interactions and negotiation of co-occurring factors including the experience of medications and side-effects, patient/provider relationships, cultural norms and the changing dynamics of international borders. We note effects of drug-related violence which created border-crossing obstacles influencing mobility, access to services and adherence.

Keywords

ARV adherence; HIV/AIDS; Hispanic; US-Mexico border

INTRODUCTION

With the growth of populations tested and entering HIV care, the achievement of individual and public health benefits of HIV treatment requires increased efforts to enhance adherence and retention. This is a salient issue in addressing health disparities among US Latino populations, who have been disproportionately affected by the epidemic and who have poorer health outcomes than whites. Empirically-grounded knowledge of factors affecting adherence from patient and provider perspectives is especially urgent in resource-poor

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border areas where the threat of a drug-resistant epidemic has local, national, and international implications. This article draws from a qualitative study of a community-based HIV clinic on the US-Mexico border to address how the specificity of the border region, together with patient characteristics and clinic-level variables, affect ARV medication adherence and retention in care.

Background, Review of the Literature and Study Rationale

Latinos have been disproportionately represented in the HIV/AIDS epidemic, making up 20% of those living with HIV[1]. Health-related disparities have been identified for HIV+ Latinos: compared to HIV+ white populations, they have worse health outcomes, including higher death rates [2]. HIV+ Latinos are also more likely than white populations to face structural barriers to care, have stigma-related concerns and face barriers related to cultural norms regarding gender roles and health beliefs [3]. A recent study of race/ethnic disparities in life expectancy declines among HIV+ persons in the US found that years of life lost from late initiation and early discontinuation of therapy were greatest among Latinos [4].

There are few descriptive studies available on Hispanic communities and the factors affecting HIV/AIDS treatment and adherence [5-13]. Little research on Hispanics addresses health access, treatment follow-up and the management of chronic conditions in U.S.-Mexico border areas. As researchers increasingly document the diversity of population characteristics among US Latinos, regional specificity becomes an even more salient factor to consider. It is thus important to explore how cultural and geographic factors, and the conditions that shape mobility, influence care-seeking behavior as well as ARV adherence and retention.

Study Site: El Paso, Texas

El Paso, with a population of 800,000, is located on the U.S.-Mexico border directly across from Ciudad Juárez, Mexico. The majority of the population (80%) is Hispanic/Latino [14] and residents historically crossed the border into Mexico for health services because of lower costs and convenience as well as social ties, cultural familiarity, and perceived quality of care [15, 16].

In the year 2010, El Paso County ranked fifth in the state among the first 25 Texas counties with the highest number of cases of HIV infection, AIDS cases, and people living with HIV[17]. In 2010 there were 117 new reported cases of HIV infection, 47 cases of AIDS and 1,609 people living with HIV in El Paso. As of December 31, 2010, there were 2,482 cumulative HIV diagnoses in this county[17].

Under-utilization of health services on both sides of the US-Mexico Border is common [18]. Studies have been carried out which identify cross-border healthcare utilization in both directions for many reasons [19, 20], however the actual numbers of healthcare border crossers along the entire border region is not known. It is important to note that although health is a constitutional guarantee in Mexico (unlike in the United States), this right does not translate into equitable access to health care and resources for health-related quality of life [21, 22].

In the community-based clinic from which the study sample was recruited, approximately 90% of the patients accessed their medications at the clinic due to the patient population meeting income guidelines (e.g. 'indigent' level). Medications were also offered to patients via pharmaceutical patient assistance programs whenever available, as well as from a downtown El Paso pharmacy.

METHODS

Spanish-dominant male and female HIV/AIDS patients of Mexican origin were recruited from a community-based clinic serving this bi-national border population. Recruitment was carried out exclusively by clinic staff as per human subjects requirements. If patients decided to collaborate in the study, they were referred to the research coordinator to discuss more detail about the study and review the informed consent. Participants were given \$30.00 U.S. dollars for participating in the study.

Because it has been identified that adherence tends to decrease over time [23-25], the study was designed to document and explore reported changes in the experience of disease and medication adherence over an 18-month period of data collection. In addition, interviews and observation in the clinic were scheduled to reflect the seasonality of residence and behavioral modifications to capture the dynamic aspect of treatment and self-care, to document changes in relationships (e.g., provider-patient, partner, other support), the treatment environment, disease progression, side effects, medication changes and other key issues. The follow-up interview at 6 months was designed to document any changes in interactions with providers, perceived effects of medication side effects and behavior change over time.

Participation in the study was voluntary, and participants were informed that they could withdraw at any time. They were assured that neither their participation nor refusal would adversely impact their care in any way. All procedures to protect participant confidentiality were followed in obtaining informed consent, including HIPAA requirements in Texas. The study obtained Human Subjects approval, which was renewed annually for the length of the study by the university IRB.

In-depth, open-ended patient interviews involved the use of an interview guide rather than a questionnaire. Most interviews were carried out in Spanish by the PI, an experienced, bilingual medical anthropologist, and the Research Coordinator, a Mexican-origin, bilingual doctoral student. The PI trained and supervised the data collection and facilitated all focus groups.

A total of 113 patients were enrolled in the study; 61 participated in individual interviews and 52 in focus groups. Out of the 61 baseline participants, 53 returned for a 6-month follow-up interview. Five focus groups were conducted to address the issues of: cross-border healthcare users; women; treatment naïve men; treatment experienced men; and gay identified men. Nine key informant interviews were conducted with HIV service providers.

Theoretical Framework

Our ARV adherence study drew from two complementary models and adapted them to the issues of adoption and adherence to HIV medications: a dynamic model of culture, cultural diversity and cultural change[26], and diffusion of innovations theory (DOI) developed by Rogers[27] and expanded over decades by Rogers and others. These models provide the elements to explore health decision-making and behavior in context. These frameworks guide insights into how individual negotiations of medication regimens and side effects might have group resonance and thus inform new and effective institutional responses.

Analysis

The project used a mixed methods design, based on the construct of critical multiplism [28], which assumes that multiple ways of knowing require not only multiple methods but multiple triangulations, paradigms and perspectives. Data obtained in the form of audiotapes, interview instruments, observation notes, transcripts, clinical data, reports and

publications and content of media (notes or actual articles) were analyzed in Spanish using ATLAS.ti. The triangulation and integration of findings continued throughout the study. Findings identified and described modifications and changes in experiences over time and place (e.g., of disease, treatment and attributes of medications), using base-line and follow-up interviews. Interviews at two time periods assisted in exploring cultural, individual and contextual factors which appeared to affect adherence behavior. Comparisons were made by interview period, patient group and treatment characteristics.

Limitations

Because this was a qualitative study employing a convenience sample at one clinic site, the findings are neither representative of all Hispanic HIV+ patients in El Paso nor of this population on the US-Mexico Border. The two year funding period also confined the ability to observe changes in adherence behavior over time to an 18 month period.

RESULTS

Study Population

The majority of individual interview participants were men (75%). Most had been born in Mexico (59%). Documentation/legal status in the US was not asked, however providers at the clinic reported that the patient population included a range of documentation statuses and interviews revealed this range as well. (The clinic required only a local address for HIV care eligibility). The average age of the sample was 46 years, and the mean time in El Paso was 16 years; 59 percent of participants were born in Mexico and 39 percent in the U.S. Education ranged between elementary and high school, with the largest group of participants having completed between 7th and 12th grade (36%); a small proportion (16%) listed having some college education, and a smaller group completed a GED or technical education. More than half of all participants reported “single” as their partner status at the time of the interview (58%). The mean time since diagnosis was 9.7 years, and the mean time on ARVs was 8 years.

Healthcare Utilization

Most participants and key informants praised U.S. care and perceived a welcoming clinic environment and care which responded to their medical, psychosocial, and emotional needs. They noted staff professionalism and care, which included patient education on medications, side effects and coping with HIV/AIDS. Service challenges included: high staff turnover impacting patient's ability to develop relationships with staff; the limited number of physicians influencing wait times; and services targeting uninsured patients, which meant the insured experienced delays due to reviews of eligibility criteria needed. Patients saw services in El Paso as superior to those in Juarez. In fact, some patients reported staying in the area to continue receiving care in the US, even turning down employment in Mexico.

Reasons to Seek Care in the US vs. Mexico

Participants reported coming to the U.S. for better range of medications, more professional and respectful treatment, and a better life. As one focus group participant explained:

...it is embarrassing to say so, but in truth, the self respect they give you is very low (in Mexico). And apart from that, there are not sufficient medications (available there). If there are medicines, they are very expensive and apart from that, there is a certain discrimination....ignorance, in a sense.

All were in agreement that ARVs were acquired exclusively on the U.S. side of the border, as cost was higher and availability sporadic in Mexico. However, participants also discussed

purchasing other medications at lower cost in Mexico, such as those used for opportunistic infections and side effects of HIV medications.

Obstacles to Adherence

Many of the adherence challenges patients experienced appeared to be linked closely to the psychosocial dimensions of living with HIV. Some discussed delays in accessing care because of fears about initiating treatment and especially the *meaning* of treatment as acknowledgment of having HIV and thus having to confront their denial. Beginning medication for some meant the start of a life-long process of dependence and commitment, requiring the alteration of daily routines. Fears were also related to concerns about how medications might affect or alter their bodies and general health. Decisions treatment were also closely associated with disclosure issues, ranging from fear of being known to be HIV positive, to being perceived as gay or bisexual because of taking medications which might identify them as having “SIDA” (AIDS). Confidentiality was a salient concern for many. As one of the men explained ...” coming to a clinic like this one, you realize that no one will divulge (your status), here people have rights, in Juarez no, in Mexico no. Confidentiality does not exist...” Several participants also noted that lack of knowledge about the legal protections of clinic information might also affect retention and adherence.

Gender and Adherence

To the degree that the meanings of an HIV/AIDS diagnosis and ARV adherence were shaped by conceptualizations of how men and women behave *in general*, the responses of study participants suggested a strongly gendered dimension to the experience of treatment and its consequences. Perceptions of traditional gender roles and expectations in Hispanic culture also informed commentary on adherence. Interviews with patients and providers revealed their perception that the sexes deal differently with living with HIV and with treatment. They saw women as more adherent, especially because of their role as mothers and wives and the expectations attached to those roles. Others reported that women tended to be more responsible in disclosure because of concerns about infecting partners. Men were seen as more likely to be non-adherent because of use of drugs and alcohol, less likely to disclose to partners and less responsible in adhering to protocols. Participants discussed that for Mexican men, learning that wives/partners were HIV+ suggested they had “screwed around,” confounding the cultural norm of female “purity” and marital fidelity. *Machista* (male chauvinist) attitudes and behaviors were also discussed by both sexes.

Gendered ideologies were also present in discussions of coping. In individual interviews and focus groups, patients suggested that it was harder for men to live with HIV than for women. Both men and women believed that women could verbalize their feelings and express their emotions, negotiate and resolve problems among family members relating to their diagnosis, elicit support and adhere to treatment. Traditional norms regarding masculinity were seen as a challenge for men by isolating them from care, controlling the expression of emotions, and fostering denial of their condition. A number of participants reported that many Mexican men still believe that only “gays” get HIV, not only because AIDS is seen as a “gay disease,” but also because gay men's bodies were perceived to be “weaker” and more vulnerable to HIV. Heterosexual men were presumably “too tough.”

Because women tended to be socialized to take care of themselves and look “together” and healthy, some explained, they were likely to be more consistent than men in taking medications. The physical side effects of medications, however, were seen as potentially harder for women to manage because of this social emphasis on personal appearance. It was also pointed out that adherence may be harder for women because of the needs of child care

and domestic labor. At the same time, family responsibilities made women more proactive and consistent than men in taking their medications. As a participant explained,

I know that a lot of the women that are infected here in El Paso...have families and have kids, so they're more up to going and make each other take their medication and making sure they have the right medication. You know, because they want to be around for their family.

Border Crossing (Between Juárez and El Paso) and Violence as Barriers to Care

Women and men noted barriers to treatment due to drugs and violence in the region. An advantage of the follow-up interviews, in addition to documenting changing behaviors and perceived health, was to document changing social conditions. The increased security in the US/Mexico border, mainly in response to the violence in the area but also due to increased political mobilizations around immigration in the United States, had immediate implications for the lives of participants and had direct impact on care utilization in the U.S.

Participants noted drastic changes in the frequency with which they crossed the border to access services since their original baseline interviews. The decrease in border crossings was not only due to fear, but also the longer wait times, long lines at the bridge, and invasive searches. Clinic staff noted that violence “affected a lot of people...We've had several clients that have had their visas taken away, you know there goes their treatments...” Patients complained that crossing was difficult because, “...there are many soldiers and they check you all over and hold you up for two hours... you're not bringing anything, but nonetheless they hold you up.”

Many participants reported fearing that even though the clinic treats anyone regardless of their immigration status, the next time they came, border officials would be there waiting for them. They explained that they especially feared being deported because healthcare in Mexico was in no way comparable to that of the U.S. Others mentioned the problem of accessing medications consistently if they had to cross back and forth, with real possibilities that they would be unable to cross in time to make appointments and follow-up medication pickups. Even those who had documentation to cross the border reported concerns over back-ups because of border security.

Finally, participants reported not feeling safe anywhere in or near Juarez. The violence was seen to limit their mobility and cause stress. As a male participant stated, “You can get hit by a stray bullet at the gas station, at a café, at a restaurant, at the funeral home, at the hospital...”. The “stray bullet” comment illustrates the uncontrolled and anarchic nature of the violence these women and men had begun to experience in the period between the base line and follow up interviews.

CONCLUSIONS

Results of this study suggest that the utilization of HIV care and adherence to ARVs depend on how effectively individuals negotiate co-occurring factors at the individual, local, and international levels. This consideration is particularly important in border regions, where international immigration regulations and insecurity due to escalating violence combine with other individual and structural challenges to access and adherence. Well documented adherence-related factors such as gender norms, economic concerns, stigma and the meaning and management of side effects all reflect the influence of border culture and the geopolitical realities that affect all aspects of healthcare resources and access. Examples from this study illustrate the need to situate treatment and adherence within cultural, social, and political contexts that patients negotiate in order to succeed and survive.

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