

Latino Men Who Access HIV/AIDS Services in Ventura County

Report to HIV/AIDS Service Providers

by

Lyn Gesch, Ph.D., *Social Research Consultant*
Adina Nack, Ph.D., *California Lutheran University*

June 2007

TABLE OF CONTENTS

	<i>Page No.</i>
Acknowledgements	iii
Executive Summary	1
Study Authorization and Research Design	3
Methods	4
Who are the Men in this Study & What are their Sexual Identities?	6
Key Findings and Recommendations: How Latino Cultural Norms Inform Policy and Practice	9
Recommendation: Normalize HIV Testing	9
Recommendation: Expand and Improve Pre- and Post-Test HIV Counseling	10
Recommendation: Normalize Condom Use	12
Recommendation: Expand Programs on Prevention with Positives	15
Recommendation: Improve Services by Expanding Client’s Social Support System	16
Appendix A: Informed Consent Form (English Language)	21
Appendix B: In-depth Interview Guide (English Language)	22
Appendix C: Hand-out (Participant Demographics) from <i>HIV & Latinos: A Leadership Summit</i>	26

ACKNOWLEDGEMENTS

We would like to express our appreciation to all of those who helped with the different stages of this research project. Initially, Susan Attaway, Ventura County Public Health (VCPH) HIV/AIDS Education & Prevention Coordinator, played a key role in securing the funding and providing initial administrative support for this project, and to Doug Green, former VCPH Staff Services Coordinator, who assumed project administration. We appreciate Craig Webb, VCPH Education & Prevention Fiscal Agent, for his assistance on this project and his coordination of the CompassPoint Steering Committee. The CompassPoint Steering Committee provided key contributions throughout the research process: our thanks to Evelina Ochoa, Emperatriz Pinedo, Ruben Jimenez, Nicole Smith, David Valdez, and our wonderful facilitator Alfredo Vergara-Lobo. We also want to thank all of the service providers who participated in the focus group study that informed the design of the interview study. We especially appreciate the help of the following case managers in recruiting participants: Martin Perrier of Ventura County Rainbow Alliance, and Socorro Madrigal and Craig Webb of VCPH. In addition, we could not have conducted the interview study without the skills, compassion, and dedication of our two interviewers: Jessica Arciniega and Francisco Cacho. Our heartfelt thanks and admiration for the 28 men who courageously shared their stories with us. Finally, thanks to VCPH, the Ventura County AIDS Partnership, and of all the Summit Planning Committee members who created an amazing event at which we could share our findings with the members of Ventura County's Latino communities.

Adina Nack and Lyn Gesch
Co-Principal Investigators

Executive Summary

Background of Research Project

Latinos in Ventura County suffer from HIV disease at a disproportionate rate compared to that of the general population¹. Since 1995, Latinos have received a simultaneous diagnosis of HIV and AIDS 70.4% of the time compared to an average in Whites in Ventura County of 48.9%² – evidence that they are less likely to test early enough in the disease course to benefit from HIV treatment. This research project was commissioned to focus on Latino men and draw on the experiential knowledge of (1) professionals who work with this population, in order to assess what they see as major challenges in education, prevention, and service provision and (2) Latino men who are current clients of HIV/AIDS services in Ventura County, in order to understand how they experience the different stages of their illness. The overarching goal was to use these findings to inform how to do better outreach in Ventura County's Latino communities.

Key Finding

Latino men's subcultural norms and values must be analyzed contextually, according to sexual identity and sexual behaviors. Keys to improving HIV program design and implementation are the distinctive patterns which have emerged for those who self-identified as gay men and engaged in risky practices, those who have sex on the "down low," and those heterosexually-identified men whose early experiences of sex placed them at risk for HIV. To understand these three 'types' of Latino men, one must explore how they learned to "be a man," with specific attention to the construction of male sexuality norms and beliefs about HIV/AIDS. This study reveals how these constructions of meaning influence the men's sexual decisions, identities, and, ultimately, the ways in which they experience HIV/AIDS education and prevention.

Recommendations for HIV/AIDS Program Development and Implementation

Note: While *Ventura County Public Health*, *Planned Parenthood* and *Ventura County Rainbow Alliance* have prioritized education and prevention services for the Latino population, other health care providers have not necessarily prioritized HIV/AIDS education, testing, and healthcare services for Latinos living with HIV/AIDS. All of the following recommendations are predicated upon two overarching recommendation: (1) that there be more Latino (bilingual and bicultural) educators and service providers to better serve this growing segment of Ventura County's population, and (2) that there be a county-wide social marketing campaign to de-stigmatize HIV-positive status within Latino communities.

- 1. Normalize HIV testing.** Study participants suggested that men like them resist HIV testing because they fear knowing their HIV status and fear that having AIDS means certain death. They suggest that increasing the visibility of HIV-positive men in the community would help reduce the stigmas associated with HIV. Media campaigns are effective tools for introducing normative change at the community level. They can address fears of HIV and fears of using public services, and emphasize the services and support available for those who test positive.
- 2. Expand and improve pre- and post-test HIV counseling.** Latinos in this study were tested in a variety of public and private facilities, both in and out of Ventura County, and, unfortunately, their experiences of testing-related counseling vary as widely. Few recalled receiving any pre-test HIV counseling, and post-test HIV counseling was frequently limited or non-existent. Providing adequate, informed and compassionate pre- and post-test counseling should be standardized among all practitioners, and especially for those testers who are not HIV specialists.

¹ Incidence rate of AIDS over 7 years (2000-2006) in Ventura County Whites of 3.4/100,000 versus 6.0/100,000 in Latinos based on census data (p=.01).

² P=.01

3. **Normalize condom use.** Latino men commonly hold many negative beliefs about condom use. Study participants frequently explained their resistance to condom use by referring to how unprotected sex was the masculine ideal. For instance, beliefs about a “top” in anal sex being masculine and heterosexual (and, therefore, not gay) was connected to not needing to wear a condom. This relates to the perceptions of Latino men who had sex with men but believed HIV was a “gay disease,” i.e. not relevant to them. Individual counseling, sex education classes, and media campaigns linking condom use to Latino male gender norms and values of “being responsible” and “being a good provider” by staying healthy can begin to change attitudes toward using condoms.
4. **Expand “Prevention for Positives” programs.** Programs can be strengthened by drawing on traditional Latino norms and values about the male gender role to create messages to educate men about the relative safety of sexual practices and of their continued vulnerability to different strains of HIV, and discussions should focus on the ethics of disclosing one’s status in sexual encounters.
5. **Improve services by expanding client’s social support system.** Since a network of support is important to one’s mental and physical health, clients should be encouraged to re-evaluate their disclosure practices from time to time as they adjust to living with HIV, identifying their fears and assessing if they have changed over the months. In addition, county agencies should build on current services providing treatment and counseling which received the strongest support from clients.

Study Authorization and Research Design

In September of 2005 the State Office of AIDS authorized the Ventura County Department of Public Health the use of one-time augmentation funds to support locally-based research on the impact of HIV/AIDS in the Latino population who utilized Ventura County's HIV/AIDS services. The Ventura County Public Health Department subcontracted with CompassPoint Non-Profit Services to form the CompassPoint Steering Committee. The steering committee was charged with increasing our understanding of the local population in order to develop effective, targeted interventions.

The Public Health Department sought collaboration from within the local academic community: this resulted in a research plan for the HIV and Latinos project authored by co-Principal Investigators Adina Nack, Ph.D. (California Lutheran University) and Marilyn Gesch, Ph.D. (independent research consultant). This plan was approved by the California Lutheran University's IRB (9 December 2005) and by Ventura County's Medical Center IRB (13 January 2006). VCPH approved a scope of work that delineated a two-stage project involved, first, gathering data from HIV educators and case workers (a focus-group study, "Phase I") in order to inform "Phase II" of the study, an in-depth interview study of Latino men who were utilizing HIV/AIDS services in Ventura County. This study, along with Nicole Smith's 2005 Chart Analysis, laid the groundwork for what would ultimately become the first county-wide summit to focus on Latinos and HIV.

Why Conduct a Qualitative Study?

The research question should guide the selection of the research method. Quantitative survey studies make sense when the researchers believe that they know all of the questions that need to be asked and most (if not all) of the possible answers. The goal of such studies is usually hypothesis testing.

Public Health and the CompassPoint Steering Committee set the goal of better understanding the beliefs and experiences of Latino men in order to shed light on the obstacles to prevention, diagnosis and care of HIV infection and AIDS. We sought to learn from this sample of Latino male clients of HIV/AIDS services by asking them open-ended questions. In addition, due to the sensitivity of the research topic, we wanted to gather this data in a way that gave participants the greatest comfort and assured them of the confidentiality of their responses.

Our interviewers gathered a large quantity of rich, detailed data: ultimately we analyzed over 400 pages of transcribed interview data. While we do not seek to generalize the findings based on data collected from our sample of 28 men to all of the Latino men utilizing HIV/AIDS services in Ventura County, a demographic analysis of our sample revealed that these men reflect the range and proportion of traits that Nicole Smith identified in her 2005 chart-analysis study of all Latino men receiving HIV/AIDS services in Ventura County. (Please see Appendix D for the breakdown of their demographic traits.)

In our study, we aimed to increase the validity of the data by recruiting and training interviewers whose traits would increase the trust and rapport with each participant. Both interviewers were neutral parties (not employed by VCPH) who had no conflict of interest. We also allowed participants to choose the sex of their interviewer and the language in which their interview would be conducted. We designed a semi-structured interview schedule so that the interviewers and participants had more flexibility in exploring relevant tangents to our primary questions. Finally, the analytic process honored the participants' narratives, as we drew on their texts to develop coding categories as we looked for emerging patterns in how the 28 men's stories were similar and different.

Methods

Phase I: Focus Group Study of HIV Professionals to Inform Development of Phase II

On Wednesday, December 14, 2005, 8 of 17 invited HIV professionals attended a community-wide forum to discuss issues regarding HIV and Latinos. Participants represented Early Intervention programs at Public Health, education programs at Clinicas del Camino Real, and case management, education, and mental health programs at the Ventura County Rainbow Alliance/AIDS Project Ventura County. A full report on the contributions from that discussion is attached (see Appendix A).

Area professionals identified the cultural silence around sexuality and sexual practices as a distinct barrier to effectively serving Latino communities. Those Latinos with undocumented immigration status are particularly suspicious of contact with governmental institutions and are less likely to seek preventive medical treatment (e.g., HIV testing). Coupled with negative practitioner interactions, this can lead many to avoid testing, which leads to delayed diagnoses and a higher demand for critical health care services. Forum participants recommended that research take into account: (1) options for interviewee regarding the sex of the interviewer to accommodate preferences about with whom they could talk frankly about sex, (2) an assessment of family and community influences on beliefs, as well as messages received from social institutions including schools, churches and the media, and (3) an assessment of the range of interaction between client and specific components of the HIV health care system. It became clear that the service providers needed data that could facilitate a deeper understanding of behaviors and beliefs, and, for example, shed light on the differences between urban and rural county populations or why some Latino men continue to put themselves at risk, after receiving HIV education.

Input for the interview guide was subsequently solicited at three different points. First, both forum participants as well as others who had been invited but were unable to attend were invited to comment on a PowerPoint summary of the focus group. We received one response regarding perceptions of at-risk Latinos. Second, the same group of local professionals were asked to comment on the first draft of the interview guide. We received feedback from an observer at the forum. Finally, a third source of input came from interviewers Francisco Cacho and Jessica Arciniega who re-tested a revised guide. A final draft of the English-language guide was completed on January 31 and translated into Spanish by Ms. Arciniega for use with monolingual Spanish-speaking interviewees. (See Appendix B.)

Phase II: In-depth Interview Study of Latinos Receiving HIV/AIDS Healthcare in Ventura County

Recruitment of Participants

The participants in this phase were limited to HIV-positive Latinos who had made contact with the health care system regarding their HIV status, that is, eligible participants included those who have a diagnosis of HIV or AIDS and are participating in local health programs. A chart analysis research project conducted by Nicole Smith, MPH, in August and September 2005 provided data on 100 HIV-positive Latino clients in the county's Public Health HIV/AIDS programs. These individuals provided the most accessible population for our sample of 28 participants. Given the limitations of our sampling strategies, the findings are best suited for theory-building.

The research was designed to protect the privacy of clients during the recruitment process. To that end, we relied on case workers to make the initial contact with potential interviewees. Interested clients who agreed to have their contact information forwarded to the research team were contacted by one of the interviewers to schedule an appointment for the interview. Most interviews were conducted at the offices

of the Public Health Department or AIDS Project Ventura County, and when it was more convenient for the client, interviews the conference rooms at the Oxnard Public Library or the clients' homes were used.

We provided case workers at Public Health and APVC with a packet of information and forms to aid with participant recruitment and the submission of contact information to the research team. (See Appendix C.)

Sample Description

A total of 39 clients of Public Health and APVC programs were contacted about participation in the study. Of these, 28 scheduled and completed interviews. The resulting sample is closely representative of HIV-positive Latinos enrolled in Public Health programs. New cases of HIV in 2004 were primarily Hispanic males, aged 30-39, whose risk factor was men having sex with men.³ The average age of the 28 men in this pilot study was 38.6 with a range of 27-75 years. The median age group was 30-39, corresponding with county-wide statistics of HIV-positive Latino clients. The majority worked in service-industry occupations. (Please see Appendix D for a full statistical profile of the sample.)

Conducting Interviews

Of the 28 interviews, 17 (61%) requested that the interview be conducted in Spanish and half asked for a male interviewer (the rest either had no preference or asked that the interviewer be female). While interviewers conducted an equal numbers of total interviews each, there was a difference in the sample with sexual identity: the majority of the self-identified gay men preferred being interviewed by a woman; while the majority of the heterosexual and bisexual men preferred to be interviewed by a man.

³ Ventura County Public Health HIV/AIDS Surveillance Final Report, January 2004-December 2004. Prepared by Ventura County Public Health HIV/AIDS Center, Office of HIV/AIDS Surveillance. While the proportion

Sample Description: Who are the Men in this Study? What are their Sexual Identities?⁴

We found three kinds of sexual subcultures among the 28 men who participated in the in-depth interview study. Though we present these as “types” of men, keep in mind that these are terms for understanding different ways of looking at sexuality – how one identifies sexually as well as the kind of meaning one assigns to sexual practices. In this section we describe and summarize these types, and we will refer to them throughout the Recommendations section in regard to how programmatic changes can target specific cultural beliefs and norms.

1. Self-identifying Gay Men

- The first distinct characteristic of this sub-group is the gender role expectation of these men when they are in sexual encounters, particularly with Latino men who identify as straight.

Example:

The majority of the men, and especially Latino men, do not want anything with you, “only bend over and here I come.” They do not kiss you, they do not touch you, they do not caress you....This is not what I wanted because the only thing you feel is pain. I did not feel any type of pleasure... In my experience when I was younger, well, the men, they do not care...I was with many men who were married, men who had girlfriends or they said they “had privileges with a woman,” heterosexuals, men who work in the fields who maybe did it because there was not anything else. And when I was younger, I was very feminine and I [dressed like] a woman...the men, they did not care. (50-year-old Spanish-speaking, Mexican-born gay man)

- A second characteristic of this group of men is that they almost always felt a sense of isolation in both gay and Latino contexts. On the one hand, in gay subculture, the isolation is due to the way in which their ethnic identity is commodified as a valued characteristic among white gay men who stereotype Latinos as ‘hot lovers.’ In Latino communities, it is their sexual identity that creates barriers with others (silence about sexuality, fear of rejection, etc).

Example:

I have many clients who are [white] Americans. But, aye, they have a way of treating you so beautifully that it doesn't compare to the others. I want you to know that even the ugliest American treats you like a queen. (Do you have clients who are Latino men?) Yes, but they are very ugly, they treat you very bad. (How do they treat you?) It is like the Mexican who wants to treat his woman with the point of his boot.

- **Risk Factor:** Prescribed gender-based sexual role-playing, i.e., being the “feminine” partner in a sexual encounter with a straight man, can put a gay Latino in a less powerful role, more deferential to his partner’s preferences and not his own for practicing safer sex.
- **Note:** While there is a male-to-female transgender population among Ventura County’s Latinos, we were only able to interview one for this study, and would not want to present his case as representative of the larger population. However, this sub-population should be examined in future studies.

⁴ Also refer to Summit Hand-out in Appendices for general demographics on these participants.

2. Latino Bisexuals on the “Down low”

- The term ‘down low’ has been used to describe African-American men who are married or who have girlfriends but who also have sex with men.⁵ A significant portion of this sample fit the basic parameters of “living on the down low.” As such, their experience of sex in this context was qualitatively different from self-identifying gay Latinos. Latinos on the ‘down low’ did not identify as gay and did not consider the sexual behaviors they engage in with men as homosexual.

Example:

(I know that you cannot talk for your clients, but do you think that your clients consider themselves homosexuals?) *No. The truth is, I don’t understand because many times they are married and they have their wives and they are still with me... they do things with me, they touch me all over and I say,-- (So it is not only penetration?) No, it is very involved. So, I say, what do you call this, bisexual, homosexual? (37-year-old Spanish-speaking, Mexican-born gay man*

- An important characteristic of understanding sex on the “down low” is that it appears as a distinct subculture from American gay subculture.

Example:

I was in a committed relationship, but I used to go out on our relationship to meet other people, on the down low. (Did she allow you to be with men when you were together?) She didn’t know. It was just on the down low. I would say, “Oh my homeboy is here. He’s my best friend.” (But, I thought she knew you were gay?) Yes, but she didn’t think that I was pursuing men. [Because you were being with her as well?] Yes. (Note: This study participant is a 35-year-old English-speaking, U.S.-born man who self-identifies as bisexual and reported having ‘hooked up’ with a “supposedly straight” male partner for 15 years.)

Example:

(When asked, “Have you ever had sex with a man?”) *Yes. It brings me shame... (Do you prefer having sex with men, women or both?) With both men and women.... That was the first time that I had been with a man and I liked it, ...when they took me to jail, they did it to me against my will...I am married and at the same time I am like this or like that and I shouldn’t be doing this...(You had your wife and also a male partner?) Yes, but not daily. (47-year-old Spanish-speaking, Mexican-born bisexual man)*

- **Risk Factor:** Latino men who lead double-lives, with multiple partners outside of a committed relationship, are at risk for HIV because they do not perceive themselves to be vulnerable to it.

3. Heterosexual Men at Risk for HIV:

- The key characteristic of this group of men is their silence on issues of sexuality and sexual practices. As is typical with a socially dominant behavior (that is, behavior that is assumed to be known among all members of a society), these men were unable to talk specifically about what they did with sexual partners.
- Yet their early experiences of sex with women were often in contexts where protection from disease was not routinely considered. An obvious example is the number of men who talked about seeing prostitutes for their initiating sexual experience.

⁵ Sanders, Joshunda. 2005. “A Down Low Dirty Shame: The New Assault on Black Male Sexuality.” *Btich* 28 (Spring): 33-35.

Example:

...my dad used to take me to brothels...I was fourteen years old. It was my fault because I asked him to take me there. (Did he also go to those places?) No. The times that I went, he bought me the ticket and gave it to me. (So you have to buy a ticket to go in?) Yes. You give the ticket to the woman, she takes the ticket and then, "get naked and let's go."... (How old were you when you first had sex?) 15 years old. It was with a prostitute.... I felt the satisfaction that I was good because I had done it. But, I was lucky and very quickly it passed and right away I wanted to have sex again. (43-year-old Spanish-speaking bisexual who was born outside the U.S.)

Example:

My first sexual relation was with a prostitute and from that I got a disease...When I came here, I hung around friends that were older than me and they took me [to a prostitute]... I knew she was a prostitute, it kind of grossed me out because before me, others had been with her, [including] two people from my family. (41-year-old Spanish-speaking, Mexican-born bisexual man)

However, the practice of protection was not apparent in early casual experiences with women who were not sex-workers.

Example:

It was with one of my neighbors and she was a few years older than me and it was just one of those things. I guess this is what all the talk was all about and now I had experienced it and figured it was just going to become a natural part of my life after that. (39-year-old English-speaking, U.S.-born heterosexual man)

- **Risk Factor:** Cultural silences about sexuality and sexual practices put men at risk for HIV when safer-sex practices are not the normative behavior in traditional contexts of sexual maturation.

Key Findings and Recommendations for HIV/AIDS Educators and Service Providers

This study of Latino men utilizing HIV/AIDS services in Ventura County demonstrates the need to understand and apply the following arguments, made by Rafael Diaz in an online forum, for developing culturally-appropriate interventions. First, making a decision to be safer about sexual practices is not just a function of acquiring individual knowledge and skills but is complicated by contextual factors that produce what Diaz calls “difficult sexual situations...”⁶ Second, what he calls “resiliency factors” help mediate effects of negative social factors that increase one’s risk for HIV. These include being able to talk about what makes a sexual situation difficult and having a strong system of support (Diaz, 2006).

The findings from our study expand his arguments to include the following findings. First, how one manages a difficult sexual situation is shaped by one’s view of what it means to be a man in those situations. Second, community values and norms that may be viewed as barriers to sexual maturation and healthy sexual behaviors may also be appropriated and redefined to assist HIV/AIDS education and outreach efforts.

In this section we make recommendations for outreach, testing and services based on responses from 28 HIV-positive Latinos who shared their experiences in these areas, talked about the difficulty of sexual decision-making, and gave their views of what could be done differently for men in their situation.

I. Recommendation: Normalize HIV Testing.

Increasing HIV testing in the Latino communities is a challenge because it involves confronting highly stigmatized images of HIV, cultural silences around sexuality and sexual behaviors, and generally fatalistic views about illness. In addition, while many undocumented Latinos in Ventura County access public health services, many others who lack immigration documentation also lack access to preventive health care. In part of each in-depth interview, participants were asked to talk about their testing experiences. This data allows us to better understand the circumstances they encountered and the contexts in which they made HIV-related decisions.

A. Findings

The testing experiences of men in this study varied considerably by circumstances and the quality of pre- and post-test interactions with testing staff. There were a total of 30 testing experiences described to our interviewers.⁷ Of these, 19 were administered in the course of medical treatment. Sexual identity figures into understanding variations in these 19 cases: When medical practitioners suggested testing for HIV, the patient was likely to be heterosexual and not expecting a positive test result (7 of 9 cases). When patients initiated the request for an HIV test, they were likely to be homosexual and suspected they were HIV-positive because they had some awareness that past unprotected sex made them vulnerable to HIV (8 of 10 cases). Only two gay men in our sample overall did not expect to test positive and they were both tested in the mid-1980s when information was much less available.

In general, Latinos who were active in the gay community were aware of ways they could be vulnerable to HIV prior to testing. This is in no small part attributable to the education campaigns that many AIDS

⁶ In a paper on intimate partner violence, Feldman and Diaz (2006) define “difficult sexual situations” as those in which factors external to the individual challenge the individual’s ability to make rational choices about sexual practice.

⁷ Note: 30 does not represent the total number of tests taken by all of the men in this study, but 30 were discussed in enough detail to analyze.

service organizations and gay activist groups conducted in gay communities particularly in larger urban areas. Our participants mentioned seeing flyers in gay bars and other venues within the community. Secondly, because it was affecting the community, they were also talking about HIV in their groups of friends and learning about it that way and, as a result, HIV infections in gay communities started to decline in the late 1980s. These can be significant lessons for other communities to consider.

B. Implications for Policy and Practice

Media campaigns are the beginning of making normative changes in a community. When participants were asked “Should testing be more accessible?” they responded that having more testing sites is *not* the issue [17 of 28 cases]. Instead, they identified fear as the major problem with testing, specifically, one’s fear of knowing one’s HIV status and a fear that AIDS means certain death. What could make a difference? Participants in this study stated that increased visibility of HIV as a Latino issue is vital for social change to occur. What is needed, they say, is more community-based and school-based education in which, according to one participant, the “power of the Latino voice” can be heard in taking action. This calls for leaders in the community to step forward as advocates for change.

In addition, participants said that increased disclosure of HIV status among those who are positive would normalize HIV/AIDS in the community, and, if it’s more readily talked about, the idea of testing would be less stigmatized. By increasing knowledge about what it is like to live with HIV, one can begin to destabilize Latinos’ sense of invulnerability to HIV. Media campaigns must be developed to address fears and misconceptions about HIV to highlight the availability of treatment options and support services.

Example:

Now I know that [medicines] help me control the HIV....That [knowledge] would help people who do not want to get tested, so they won’t be afraid.... (A 27-year-old Mexican-born bisexual man)

II. Recommendation: Expand and Improve Pre- and Post-Test HIV Counseling.

A lack of pre-diagnostic knowledge leaves patients vulnerable to HIV infection, and a lack of post-diagnostic care leaves them vulnerable to emotional distress. Similar to hiring priorities of Ventura County Public Health Department, all public and private health care providers in the county need to assess their HIV testing and counseling programs to ensure that there are adequate numbers of Latino (bilingual and bicultural) health educators and/or HIV-testing counselors to provide these services as part of a healthcare team with physicians, nurses, and case managers.

A. Findings

Experiences of pre- and post-test counseling ranged from receiving the results over the telephone with no pre- or post-test counseling, to receiving results and assurances about treatments from the medical staff followed by same-day intake counseling at the public health department. Of 28 participants, 12 tested at public testing sites, 8 at private facilities, and 8 at facilities whose status could not be determined. Of the public sites, 9 were within the VCPH system where pre- and post-test counseling is mandatory procedure.

It is noteworthy that, among all participants’ stories, there were few consistencies in these experiences. Few could recall receiving any pre-test counseling (5 out of a total of 30 tests that were discussed). In fact, HIV awareness prior to testing was poor, particularly among heterosexual men, and the lack of pre-test counseling failed on two levels. First, it did not equip those getting tested with information on HIV

that would help them make choices about risky behaviors (in the event of a negative test). And, second, it did not prepare patients for the shock and inevitable depression following a positive result.

Example: Pre-test counseling can be very helpful, as exemplified by a participant who was tested at a university-based clinic:

The first time it was a guy and he told me that if I came out positive, they were going to be discrete, it was going to be by number and I could slowly tell my partner that I was positive. But it was negative and it was fine. It was social counseling in case I was positive, how to deal with the disease and how they were going to help me get through with it. (35-year-old English-speaking, U.S.-born bisexual man)

Only half of the participants used public health facilities or HIV-specific testing sites, leaving a significant portion of men who tested at sites that did not specialize in HIV. Many of those who went to general practitioners and clinics recounted negative experiences with post-test counseling, though most of these cases were immediately referred to HIV specialists or public health counselors. Doctors were described as “nervous,” “abrupt,” or “almost bothered or mad.” What was missing in these negative encounters was a sense of compassion, a sense of support, and a sense of a future.

Example: the absence of post-test counseling can devastate a patient.

I cried, cried, cried, and the doctor left the room. He did not tell me anything.” Another said that the doctor had “no bedside manner...making me feel like an outcast. (English-speaking, U.S.-born gay man)

Example: post-test counseling can be very helpful.

[The doctor said] “I can do the test again to be sure. There are organizations that can help you. There is counseling. There are doctors, medicine and nutritionists available to help you.” (28-year-old Spanish-speaking gay man born outside the U.S.)

B. Implications for Policy and Practice

It is imperative that comprehensive pre- and post-test counseling is provided to all who test at both public and private sites, including private physicians’ offices and private clinics that may not specialize in HIV. Medical practitioners who are not HIV specialists often test for HIV as part of their practice. These practitioners, in particular, need HIV/AIDS training in order to better prepare patients for the testing process. The practitioner’s level of comfort with HIV issues and his/her ability to dialog with the patient both before and after the test proved to be critical in shaping the testing experiences recounted by the study participants.

Specifically, those who deliver diagnoses must understand the sensitivity of disclosure and offer counseling to help the men decide who they can disclose to and how and when to do it. There are immediate fears of dying, of whether or not one has infected others, and of being “outed” and stigmatized for one’s sexual practices. While assurances of treatment options are important in providing a sense of action and moving forward, feelings relating to this “triple disclosure” issue are often what occupies the minds of those hearing for the first time that they are HIV-positive and possibly AIDS-diagnosed. Providers should be aware of this mix of feelings and that sexual “outing” includes not only gay men who may not have disclosed their sexual identity to friends and family, but also heterosexual men who are on the “down low” and trying to maintain a heterosexual identity in their community.

III. Recommendation: Normalize Condom Use.

The men in this study spoke both of the constraints and the values of learning how to be a man when growing up in their Latino communities. Because some of these ideas can run counter to conventional HIV prevention strategies, it may be easier to work first at normalizing condom use among Latinos rather than confronting beliefs about masculinity connected to having multiple sexual partners or the gender-role-playing with men as sexual partners. However, putting this into practice requires understanding the subtleties of how ideas of masculinity link to sexual practices.

A. Findings

The most frequently named source for learning about condoms and learning how to use condoms among men in this study was their public health case worker (post-diagnosis). The sources that were least cited were parents and school-based sex education courses. With this lack of formal knowledge, most men said that prior to their HIV infection, they associated condom use with pregnancy prevention, not disease prevention. And the consequences were, as one participant put it, "... that I never used a condom and no woman ever asked me to use one." That is, it is not normalized into sexual encounters.

Example:

[Being asked to wear a condom] would've made me a little uncomfortable, but back in those days, I mean, we never heard about HIV, so the most you were worried about was getting a girl pregnant, and back then the girls were always on the pill. (39-year-old Spanish-speaking, U.S.-born gay man)

Example: Another's comment suggests that "safe sex" can be judged by types of persons rather than encouraging safer sex practices regardless of the characteristics of the sexual partner.

What my parents taught us always was to be careful with who you were going to have sexual relations with. [37-year-old Spanish-speaking, Mexican-born bisexual man]

One common complaint about using condoms was that it diminished one's experience of sex. There were 7 mentions that either you "can't feel sex the same way," or that it "breaks the mood." One client (U.S.-born English-speaking gay man) admitted that he had a "mental issue" with condoms, that because he couldn't hold an erection, he didn't want to use them. He says he has less sex now and that he would use condoms if it was pleasurable for him, and if a partner wants to talk about it. He would see it as an opening to talk about "things that we can do differently instead of intercourse." This kind of honest assessment of one's views allows a window into the complexity of sexual feelings and practices, that despite what appears to be adequate training in his background (sex education in school, safer sex seminars in gay community), he was both knowledgeable about condoms but not able to resolve issues with use.

Another complaint is that it is either not masculine ("for wimps") or "it's only for the inexperienced." This coupling of ideas about masculinity with specific sexual practices forms the next theme in understanding condom use and HIV risk.

Participants said they learned that to be a man is to be responsible, to be a good provider for one's family, and, sexually, to have sex only with women. Men are expected to date women as young men and in many cases to initiate sexual experiences prior to marriage. Adulthood is characterized by becoming independent of one's parents, getting married, having children, and working to provide financially for the

family. Two participants also mentioned that being responsible means helping family members with their problems, so that there is a sense of mutual concern and loyalty when family members are in crisis. Regarding manhood and sexual maturing, the heterosexual men in this study provided an uncritical view of their sexual development (it just “happened”) and, consequently, a lowered sense of vulnerability to HIV because of the stigma that HIV is a “gay disease.”

Straight men did not question or elaborate on the experience of growing up into their sexuality. They followed expected paths to manhood by dating and having sex with women. However, when, as adults, some of these men had sex on the ‘down low’ or with feminine men, it did not change their self-identity as heterosexual. Being on the “down low” allows a heterosexual man to have sex with men and maintain his masculinity, but there are rules for maintaining masculinity in those sexual encounters. That is, “feminine” men take the passive, receiver role in anal sex, and “masculine” men take the active, inserter role. “Skills” such as communicating about safer sex threaten these rules and threaten their sense of masculinity.

Gay men in particular were also teased and scolded if they did not have masculine mannerisms as well.⁸ Acting feminine and having sex with men puts pressures on gay men for not fulfilling expectations to be masculine and increases their isolation within the family and the community. When the gay community is their primary source of support, it both increases their awareness and, at the same time, their vulnerability to HIV, even when they are knowledgeable about risk behaviors. First, several men in the study related that sexual negotiating is not a common practice in casual sexual encounters, and that talking about preferences and safe practices is done only with steady partners. They said that most communication in casual encounters is nonverbal and based on shared understandings of what can be done. In addition, those who have anonymous sex with straight males said they often deferred to their partner so that he would be most comfortable in continuing.

These two responses to learning manhood interconnect in a way that puts Latinos at risk for HIV. What men learn about being a man is problematic for men who have feminine behaviors and do not date women. By not demonstrating their manhood in expected behaviors, they defer to the only other role available, the feminine gender role. Translated to sexual practice, this deference becomes a passive (feminine) role in sexual encounters with men who do not feel vulnerable to HIV and do not use condoms. These are what Diaz calls “difficult sexual situations,” and they are key to understanding how men hook up with each other, the dynamic of interaction between them, and where normalization of condom use can be discussed as a prevention measure.⁹

B. Implications for Policy and Practice

There are two strategies that outreach workers can employ to increase normalization of condom use in light of these behavioral risks. First, re-contextualize and re-define the positive values of “being responsible” and “being a good provider.” That is, one’s financial obligations to one’s family extend to how one takes care of himself. Being a good provider is strengthened by taking care of one’s health. These kinds of messages are appropriate for adolescents and those young men who are still learning about manhood. Health classes for 6th to 12th graders can connect healthy behavioral choices with ideas of masculinity and provide a broader understanding of “responsibility.”

⁸ Examples of violations of masculine mannerisms include: having a small body, a high voice, crossing one’s legs when sitting. Participants who experienced this (13 of 14 gays in the study) said other children or even adults would call them “cascarita” or “mariconcito” or “viejita.”

⁹ It should also be noted that condom use can be complicated by other co-factors for HIV. Half of the participants in this study said they used drugs prior to their HIV diagnosis. While we did not specifically ask them to talk about drug use, eight, or over one-third, volunteered that they believed prior drug use was connected to taking behavioral risks that resulted in HIV infection.

While discussion of condom use is not often permitted in school contexts, it is imperative that sex education classes cover disease prevention in specific terms. Most of the men in this study did not learn how to use a condom until meeting with their case worker at Public Health or VCRA. Most of the rest learned from friends growing up. The meanings they attached to condoms also indicate that HIV prevention messages are not being adequately dealt with in school programs, when adolescents are learning about sex. Participants said they learned condoms were just for preventing pregnancy (5 mentions) and for disease prevention that did not necessarily include HIV (4 mentions), and that they diminished one's experience of sex (6 mentions).

Example: One participant explained his resistance to using condoms:

I had know about [condoms] when I was a child because of conversations I heard that it didn't feel the same doing it with a condom. That is why I never wanted to use one. (27-year-old Spanish-speaking, Mexican-born bisexual man)

Example: Another participant explained excuses he had heard from other men about not using condoms:

They'd say without a condom it feels warm when you are having sex. (43-year-old Spanish-speaking bisexual man born outside the U.S.)

Furthermore, when pregnancy prevention is the primary factor for using condoms, the assumption is either that the girl would take the responsibility and use the pill, or, in the case of MSM sex, it was not relevant. Add to that the desire not to inhibit the sexual experience, talking about condom use simply "breaks the mood." Again, it is vital that meanings connected to condom use extend to HIV prevention and be emphasized in school programs when adolescents are learning about sex.

For adult populations, the extension of ideas about manhood to condom use can be made in outreach efforts and media campaigns. In these media events, a new construction of manhood can show that a man who is responsible with his health is also being protective of his family. As one participant said, "...explain that if they have it [HIV] and they don't know it, they could transmit it to their family." [#22]

The second strategy can target normative change in specific types of sexual encounters. The participants in this study spoke of three avenues for seeking sex with men in the county.

1. First, obviously, is the interaction of self-identified gay men in venues within the local gay community and in gay venues in Los Angeles. These interactions are embedded in a subculture with behavioral norms that are sometimes opposed to safer sex practice, and it is important to understand which encounters are risky and how they are risky.
2. On a less visible level, however, men can seek out sex with men within a social-sexual network of heterosexuals in which those who do not identify as gay but seek out sex with men can do so in straight bars and adult video stores without tapping resources in the gay community (these are men on the "down low").
3. Third, links between the two sexual economies are made in other public sex venues such as public restrooms that are known as hook-up points. These encounters are usually anonymous and little if any verbal communication takes place.

The conventional prevention strategy is that sexual partners need to increase communication about safer sex and that sexual decision would then be rational behavioral choices. However, anonymous sex or other encounters that occur in public sex environments are governed by nonverbal interactions, and

participants are rarely considering sexual-health risks. (This applies to both homosexual encounters and heterosexual men on the down low.) Though these norms are difficult to change, the place to begin is by strengthening an available strategy and increasing possibilities for safer sex that don't require extensive interaction, that is, adding outreach workers, identifying and adding venues for targeted outreach, and increasing the availability of condoms in contexts where anonymous sex takes place – in *all* the places where it happens, and particularly because men on the down low would be the most difficult to reach. While Ventura County may appear to be a “sleepy” community, our study participants tell us otherwise, that much is taking place “under the radar,” and Ventura needs more than one street outreach worker to cover the territory.

IV. Recommendation: Expand Programs that focus on “Prevention with Positives”.

Preventing the spread of HIV continues to be a public health goal, even after an individual tests positive for the virus. It is key to understand the decision-making processes of Latinos living with HIV/AIDS so that we can ensure that medical, mental health, and social services both meet the needs of this population and also serve to promote the prevention of the spread of HIV.

A. Findings

Some gay men in this study, when talking about their current sexual practices, made statements such as, “I am a bottom, so it really doesn't make that much of a difference.” [English-speaking, U.S.-born gay man] He is suggesting that in that role he is not infecting another person, so condom use is not an issue.

Example: Another participant described restricting sexual activity to others who were also HIV-positive.

It's understood and it's talked about and it's okay with my partners. (To not use condoms?)...To not use condoms.... You don't have to worry about the coming out to them, the being as careful, the guilt of infecting somebody. (English-speaking U.S.-born gay man)

Though several gay men talked about condom use as a norm in gay culture (“commonplace,” and “the way to do things”), it was nevertheless, as these narratives demonstrate, not used all the time. However, this issue is not unique to gay men.

Example: A heterosexual man in the study did not use condoms with his wife or with men prior to diagnosis. Now he wants to protect his wife and others, but there's a concern with condoms breaking.

I think it feels like it is going to break and I am going to infect her. This just happened to us and we went to the clinic to talk to somebody and it has happened two times. They gave her pills to take in case and she had to take them for a month. (47-year-old Spanish-speaking, Mexican-born bisexual man)

B. Implications for Policy and Practice

As mentioned in the previous section, participants said condom use was something you talk about with a steady partner and not with casual dating. Are they using other safer sex techniques or is this, again, incompatible with the nonverbal communication of intimate encounters? Is talking about condom use just a thing for two committed partners to talk about? These are the kinds of issues that could be explored in counseling gay clients or in developing counseling practices. One participant [English-speaking, U.S.-born gay man] stated that he felt respected if a partner used condoms. This can be emphasized as a positive way to frame condom discussion between partners (rather than the more negative disease prevention meaning attached to condoms). Another said that he and his partner use condoms now when

they “finish,” so that they still have protection during penetration but incorporate sexual pleasure without condoms prior to that point.

In addition, “Prevention with Positives” programs need to be strengthened in three areas. First, they must specifically educate HIV-positive men who are “bottoms” on the possibility of re-infection with a different strain of HIV and of contracting other kinds of STDs. This applies here as well to those using sex only with HIV-positives as a safer sex strategy. Third, the ethics of disclosure should be addressed in terms of sexual encounters. Several men believed that it is up to their sexual partner to think about his health and take precautions, that is, ask about the client’s HIV status without him offering the information. This rationale presents a danger to the community as it doesn’t stop HIV from spreading.

V. Recommendation: Improve Services by Expanding Client’s Social Support System.

Diaz talks about the importance of “resiliency factors” in dealing with HIV. He defines these as a ‘connectedness to others’ that mediates the negative effects of social factors such as homophobia and racism on individual self-esteem. They are, in other words, a social support system.

We asked these participants to identify people and activities that are part of their social support networks – in both good times and bad. There are two significant findings. First, health care providers figure prominently in their circle of support. They are the number one source for health care decisions and they are often looked to as “family” for a general sense of well-being. Second, the stigmas associated with HIV are driving a significant minority of Latinos in the closet with their disease, thereby cutting them off from an important source of help. It is critical, then, to help identify the issues on a case-by-case basis that may be inhibiting expansion of a client’s support system.

A. Findings

We asked: “When you are depressed or lonely, where do you go or who do you talk to?” Nearly all participants reported having experienced depression at some point since their diagnoses. For some, the depression was debilitating; while others were able to anticipate and manage it via medication, contact with others, and other positive activities. Eight men mentioned seeking out others for companionship at these times. One man said he chose “friends & family that I am close with and know what I’m going through.” [English-speaking, U.S.-born gay man] While 20 men mentioned they preferred being alone, their responses ranged from taking a walk on the beach or painting or journaling, to closing oneself off in bedroom and crying.

Example: One participant spoke about the kind of depression that hits after receiving an AIDS diagnosis.

For three years I didn’t leave my house and I was in bed [with] depression for three years. I wasn’t dying, I couldn’t clean up. And for three years I was in a depression like that and I didn’t talk to people, I didn’t leave the house, the only person that I ever saw was my mom and my ex. I had no social contact. I was totally feeling bad. And that was the most depression I ever had. (42-year-old Spanish-speaking gay man born outside the U.S.)

For those who talked about depression as a daily management issue their remarks centered on the need for using distraction to get through a tough period. That is, the goal is to “not think about HIV” and the means to the end would include, for those who have developed specific coping practices, going out for a walk (alone or with a close family member or friend), journaling or writing down one’s thoughts, or seeking out the company of family and friends who understand what is happening. Several framed this as doing something affirming, either in the activity (walk on the beach or being in nature as affirming life) or

in the people they are with. For instance, for the alcoholic, going to an AA meeting and being around others who struggle with the temptation to drink is important support for countering depression.

Example: One participant spoke about the type of activities he engages in to decrease depression.

Being outdoors, once I get out in the sun and being in nature I realize I am still alive and this will pass, I have tomorrow...And, because I am spiritual, I dig from within.... Just a night of journaling and doing my art work, my creativity has pulled me out of everything. The more creative I am, the happier I am. I am blessed that I have a strong support system. I have people that I can go to and I have tools within myself that I can access, which is great. (43-year-old English-speaking, U.S.-born gay man)

Others succumb to closing themselves off from others, crying, or reverting to the familiarity of past risky behaviors such as drug use or prostitution.

Example: One man explained his depression.

Sometimes I sulk, sit at home and it's just me and my mom and dad live where I am now. Everyone else is gone. So sometimes I'll just go in my room, shut the door, put my headphones on with some music and sometimes I'll cry. But I know it's out there. (English-speaking, U.S.-born gay man)

There are two things to note from these themes. One is that one's choice of coping mechanisms is linked to the degree to which they have disclosed to others their HIV status. Since those who talked about being with others stress that they elect to be with those *who understand why they are sad*, it follows that the less disclosure, the fewer options one has for including contact with others in dealing with depression.

On the other hand, limiting disclosure protects the HIV-positive person from the harsh effects of stigma. This dilemma exemplifies the tension between seeking distraction and avoiding criticism and judgment. The following quote illustrates how one can still resolve this with positively adaptive strategies.

Example:

Perhaps because of the loneliness and because of a pressure that you have inside of you, like you can't tell other people that you have this disease because of the repudiation of the people. So I have always had to be alone here and deal with everything that I hold inside.... I go to the beach or I close myself inside my room and write and cry...because I feel it is a way to express what I feel, perhaps I do it or I think that my notebook is another person or is my friend that I am telling everything to or what I feel inside. I do it to let everything out because I feel a pressure and if you don't cry you can make yourself sick. (37-year-old Spanish-speaking, Mexican-born bisexual man)

Not only are fewer options left with limited disclosure, but they have their own weaknesses. One participant noted that medication is not a guarantee you will not experience depression. The answer seems to be to have a repertoire of responses – a variety of activities or a strong network of supportive friends or family – that one can turn to. What stands out in their responses is that loneliness is a particularly difficult aspect of living with HIV. Several participants expressed these feelings.

Examples:

I feel bad when I am alone and depressed. I don't do anything to feel better. I watch television. (27-year-old Spanish-speaking, Mexican-born bisexual man)

It's a very overwhelming feeling, I don't like it, but you just get through it. I don't know what to do about it. It overwhelms me. (42-year-old Spanish-speaking gay man born outside the U.S.)

There is not a remedy for that because I cry a lot, I cry a lot. And the dogs, the dogs or the cats, they are the ones who console me. I am changing and I am trying to find people. Yes, the animals can console you and they give you love, but no there is nothing like touching another human, another person. (50-year-old Spanish-speaking, Mexican-born gay man)

[I go] to my book and I draw. I'm an artist, I consider myself an artist. So I just draw, "disappear" for a while, [or I] take a walk, listen to music. As long as I know that I am not here, just over there for a while. You have to come back to reality, SNAP oh shit, I'm back. It was good to dream that you could have anything you want in life. Money, vacations, new cars, material shit that you need in life just to support [yourself], just to continue to go on. Nobody can take anything that goes in your mind so that's where I go. (37-year-old English-speaking heterosexual man born outside the U.S.)

Participants also emphasized the importance of being able to get one's mind focused away from HIV/AIDS.

Examples:

They [older sister and cousin] tell me to come to them and it just makes me feel better when I'm with them because not only knowing that they'll distract me, but I trust them. (English-speaking, U.S.-born gay man)

I have to entertain myself and if you're not entertaining me, then I'm entertaining you or I'm entertaining myself because if I don't do that, then I'll lose my mind. (43-year-old English-speaking, U.S.-born gay man)

When asked what they do to have a good time, on the whole, they were more likely to seek others out, underscoring the need to have people in the network who understand what it's like to live with HIV. Sixteen mentioned activities involving others (though not all mention seeking others out), and 12 mentioned solitary activity or no particular activity.

Another strong thread running through their responses is the contrast of "before" and "after" HIV. Post-HIV life is different, so they construct what it means to "have a good time" in a different way. Many framed their responses in terms of "what I did before" and "what I do now." For instance, "before HIV" behaviors would include going to bars and clubs, drinking and doing drugs. "After HIV" activities include visiting family, going to amusement parks or the beach, engaging in hobbies (dancing, running marathons, making model cars), and, going out to dinner and a movie with a friend or watching TV at home with a partner or friend. Many expressed the need for distraction, the need for a sense of control over one's time, and the need for affirmation from close intimates (or, in one case, the affirmation that prostitution provides).

Example: One participant mentioned how differently he viewed sex, before versus after HIV.

When I want to have a good time sexually, lately it has been non-existent except for maybe a bottle of lube and a rosy palm. It just depends, to me I get the same satisfaction from going and having a nice dinner out with a friend than having sex. I love sex don't get me wrong, it's not everything. I've learned that even though we have to have human contact, just being with a loving friend sometimes is enough. (43-year-old English-speaking, U.S.-born gay man)

In summary, the responses of Latinos in this study when talking about what helps them cope with HIV, the key idea is the need to disclose one's HIV status to enough understanding people in one's life so that they can be sources of emotional support at times of stress and even the good times. Emotional support from family, friends, and clinic/agency staff were the most frequently mentioned responses to the question, "What has helped you the most with this disease?" [16 mentions, or 43% of all responses, n=37] One participant who told his children said, "They have made me want to fight for my life" (45-year-old Spanish-speaking, U.S.-born heterosexual man). On the other hand, those who have disclosed the least are the most disadvantaged. For example, one participant who only disclosed to his wife [non-voluntary] said, "The truth, nothing. This is on my mind all the time and the truth is that this is finishing me" (35-year-old Spanish-speaking, Mexican-born heterosexual man).

What are the reasons why these Latinos chose to disclose or not to disclose to others? How can that help us learn how to develop ways to increase their sources of support? First, disclosing occurs over time and parallels an individual's process of reconstructing life with HIV. Initially, he doesn't want to spread information beyond an intimate circle until he is able to deal with the stigma and judgment of those who cannot be trusted to be nonjudgmental. Second, even when he has expanded the circle of those who know his status, he will still choose not to tell those who "don't need to know." These are primarily co-workers and employers, but also some extended family or family he is estranged from, as well as people who are only acquaintances and not close friends. There is a fear of rejection, certainly, but also of being treated differently or of being fired from his job.

In managing those cases where intimates need to be told something but the HIV-positive person wants to spare them the emotional pain of knowing he has HIV (in this study, this applied often to parents), there is the strategy of telling them about the symptomatic illness (cancer, pneumonia) but not of the HIV diagnosis. Along those lines, disclosing to parents is also complicated by dual disclosures of one's sexuality and one's HIV status. If one has already experienced personal rejection of one's sexuality, there is little motivation to disclose regarding health.

B. Implications for Policy and Practice

One way to increase these men's experiences of social support is to create strategies that tap into the already strong values of family loyalty and caring that exist in many Latino communities. Clients should be encouraged to re-evaluate their disclosure choices from time to time as they adjust to living with HIV.

Techniques for re-evaluation can include:

1. Reviewing one's support system both for who is in the circle and what kind of support they provide. What aspect of support seems to be missing? For instance, a client may have someone to go to for "good times" but no one he can count on when depression or loneliness hits. Are there ways to work on this one component of support?
2. Identifying current fears of disclosure and assessing if they have changed in the last months.
3. Determining if family or friends have changed as well and may be more open to accepting a family member or friend with HIV.
4. Determining how important it is to disclose at one's work site. Does not disclosing add to one's stress? If disclosing would be riskier than not disclosing, what are strategies for managing work contexts when not open about HIV? For men in this study the rationale that worked for them is the conviction that "it is none of their business."

Another strategy is to model a warm and supportive environment in the health provision contexts. Happily, many clients in this study spoke positively about their relationships with health care providers and case managers. This is an existing strength of Ventura County's current system and should be supported and enhanced. Qualities that clients named as supportive include both the positive interactions

in and the types of services received. The most effective programs named are the treatment protocols and related support programs (Medi-Cal, ADAP), individual and group counseling, and informational seminars and retreats.

One way in which these environments may be improved is assessing on a case by case basis whether an individual is comfortable talking to a man or a woman about his sexual practices and assigning case management or prevention counseling by gender of the health worker. Another way is assessing whether the case worker is providing the kind of culturally relevant knowledge that the client is seeking.

Conclusions: Recommendation for Future Research

Much of the research that is currently conducted on Latino populations in the U.S. focuses on urban locations, e.g., gay Latinos in San Francisco or diverse ethnic Latinos in New York City or Los Angeles. Urban environments usually provide larger sub-communities (of gay men, in general, or of gay men from specific ethnic backgrounds) that influence one's experience of HIV. Ventura County lacks a large, gay subculture.

This project adds to this knowledge with a first-hand look at a sample of Latino men living with HIV/AIDS in a small-town county where agriculture is a primary industry, though the majority of Latinos living with HIV/AIDS live in small cities and work in service industry jobs. While adjacent to Los Angeles County and relatively close to the Mexican border, Latino communities are small and anonymity is difficult for those who wish to pursue stigmatized same-sex sexual relationships and/or are living with a highly stigmatized disease.

Talking to this sample of men provides one piece of this puzzle. Through their narratives we heard of the women in their lives who are either infected with HIV or affected by HIV – the wives and girlfriends, as well as the young women with whom many of these men had early sexual experiences (both gay and straight men).

Future research can investigate (1) the similarities and differences between men and women in how they manage life with HIV, and, (2) the sexual attitudes and behaviors of HIV-negative partners of Latinos and Latinas.

APPENDIX A

A Pilot Study of HIV-Positive Latino Men in Ventura County *Informed Consent Form*¹⁰

You are invited to participate in a research study being conducted by Dr. Adina Nack, Ph.D. of California Lutheran University and Dr. Lyn Gesch, Ph.D., a social research consultant. We are working with local health care providers to find out how to better serve the community regarding HIV and AIDS issues. The results of our research will be provided to Ventura County's Public Health Department to help them better plan and provide health care services. If you would like more information, please contact Adina Nack at 805-493-3438 (English-speaking) or Jessica Arciniega at 805-486-9665 (Spanish-speaking).

We want to investigate how different groups of people experience living with HIV/AIDS. We would like to talk with people in our county about their sexual health experiences. This study will focus specifically on Latino men: your name was randomly selected from this group of people. We would like to find out what you have to say about being diagnosed with HIV or AIDS. We would also like to know about when you first learned about sex and health. We are also interested in your experiences with doctors and nurses. We would like to find out how you think having HIV or AIDS has affected your life today. We would like to know how easy or difficult it has been for you to find resources, health care services, and support for your sexual health concerns. Finally, we are interested in how you think your sexual health experiences may be different from other peoples' experiences because you are male, because you are Latino, because you speak Spanish, and because you live in Ventura County.

A professionally-trained interviewer would like to talk with you and either tape-record this conversation about your sexual health experiences. The interview should take approximately one hour, depending upon how much you would like to tell us. We may ask you to participate in another interview: this would be entirely voluntary on your part, and it would occur within approximately one year of the initial interview. The follow-up interview would address questions that we think of after listening to all of the initial interviews.

Every experience has the possibility for some benefits and some risks. The first benefit is that you will receive a \$30 gift certificate to a local retail store for being interviewed. Another benefit is that you may enjoy contributing to research that seeks to create more positive health care experiences for people in your community. You may enjoy helping health care providers better understand your life. We think there will be very little risk for individuals who choose to participate in this research.

We will protect your privacy. Your participation will be kept confidential: any written reports about this study will not use your real name. The audiotape of your interview and all other research materials will be kept in locked cabinets.

If you do not want to be interviewed, please tell your interviewer. It is your right to decide not to participate in this study at any time. For questions regarding your rights as a participant or any concerns about this study, please contact the principal investigator, Dr. Adina Nack, Department of Sociology #3800, California Lutheran University, 60 West Olsen Road, Thousand Oaks, CA 91360: 805-493-3438.

Please print and sign your name below if you understand the above information and want to participate.

Printed Name

Telephone Number

Signature

Date

¹⁰ A copy of the Spanish language consent form is on file with HIV Education & Prevention Programs, VCPH.

APPENDIX B

INTERVIEW GUIDE FOR HIV-POSITIVE CLIENTS¹¹ *Pilot Study of HIV-Positive Latino Men in Ventura County*

Thank you for meeting with me today. We'll be talking for about an hour and a half. I will be recording this conversation so that we can have your answers exactly as you have said it, so we can best understand your point of view. This tape will be kept completely confidential. That means that your name will not be put on the label, your name will not be connected to what you say, and only the researchers will have access to the tape and the transcript.

After we're finished with the interview, you will be given a \$30 gift certificate to Target as a thank-you for your participation today. To get us started, let's look at the Informed Consent Form for this research study. You may have already received a copy of this to look over. I have a copy here: can you please let me know if you have any questions about it and then date and sign it?

A. Let's begin by talking a little about your background. [5 minutes.]

1. How long have you lived in Ventura County?
 - a. [*If born here*]
 - i. Were you born here?
 - ii. What do you like about living here?
 - b. [*If moved here*]
 - i. Where were you born? Your parents were born there as well?
 - ii. How old were you when you came to the U.S.? How old are you now?
 - iii. Why did you move to Ventura?
 1. Do you work here? What do you do?
2. You had asked that this interview be conducted in [English/Spanish]. Is this your primary language? [What language do you speak most often?]
3. What is your relationship status right now?
 - *Probe*: married, single, divorced/separated, widowed, dating a woman, dating a man?
 - *Follow-up if married or dating*: has your spouse/partner ever tested for HIV? Do you know their status? What is it?

If you think back to your childhood...

B. [Sex:]

1. What did you learn from your parents about sex? How about your brothers and sisters? Friends? Teachers? your priest or minister?
 - i. Can you tell me more about this experience/conversation?
2. What, exactly, did you learn about what was right or wrong about sex?
 - a. What was right/good?
 - b. What was wrong/bad?
 - c. Thinking about women, what do you think were the sexual expectations for them? [For instance, are women expected to be faithful in a relationship? Should married women always say 'yes' to their husbands?]
 - d. Thinking about men, what were the sexual expectations for them? [Is cheating on a spouse or partner considered acceptable? Is it ok to use prostitutes? In what situations?]
3. How old were you when you first had sex?
 - a. How did you feel about that experience?

¹¹ A copy of the Spanish language interview guide is on file with HIV Education & Prevention Programs, VCPH.

- b. What did you learn about sex from that experience?
- c. How would you describe your sex life as a young, single man?

C. [Ideas about Masculinity:]

- 1. When you were growing up, what did you learn about the meaning of becoming a ‘man’?
 - a. What did you think you would have to do or be in order for others to view you as a ‘man’ instead of a boy?
- 2. How about now that you are an adult, what do you do that you know others regard as ‘manly’?
- 3. Did these expectations about being a man ever make you feel uncomfortable?

D. [Ideas about Marriage:]

- 1. What, exactly, did you learn about what was expected of you, in terms of marriage?
 - a. Who did you learn it from?
 - b. What did you learn about ‘good’ women versus ‘bad’ women?
- 2. How did you feel about these expectations for getting married?

E. [Marriage and other types of relationships:]

- 1. Have you ever been married?
 - a. *[If yes]*
 - i. How old were you when you got married?
 - ii. Are you currently married?
 - iii. Has your wife ever asked you to wear a condom?
 - 1. Would it make you uncomfortable if she did ask?
 - b. *[If no]*
 - i. Do you want to get married, or have you decided it’s not for you?
 - ii. Are you currently in a relationship with someone?
 - iii. Has your partner ever asked you to wear a condom?
 - 1. Would it make you uncomfortable if your partner did ask?
 - c. Have you ever had sex with a man?
 - i. Do you prefer having sex with men, or with both men and women, or just women?
 - ii. In terms of sexuality, how do you see yourself? [*Probe*: Straight, gay, bisexual]?
 - 1. *[If interviewee identifies as gay]* What is it like to be a Latino, gay man in Ventura County?
 - iii. Have you talked about safer sex practices with your male partners?
 - 1. How did it go?
 - iv. Are you usually the insertive or receptive partner?
 - 1. Is that what you prefer or is that what others tend to want?
 - 2. Can you describe how you usually talk to a first-time partner about positions?

Next I’d like to ask you about how and when you learned different things about HIV.

G. [STDs and HIV/AIDS:]

- 1. How did you first learn about sexually transmitted diseases? [book, doctor, family, friends, teacher]
- 2. How did you first learn about HIV/AIDS? [book, doctor, family, friends, teacher]
 - a. How old were you then?
 - b. During the time you’ve lived here in Ventura County, have you seen or heard advertisements about HIV/AIDS? [If yes, please tell me what you can remember about them]

H. [Condoms:]

1. How did you learn about condoms? [book, doctor, family, friends, teacher]
 - a. When you were a teenager, what did your friends think about condoms?
 - b. Did anyone teach you how to use a condom correctly? [who, when, where, reactions to this experience]
 - c. Have there been times you have had sex but have not used a condom?
 - i. What are some of the reasons why that happened?
 - d. How do you feel if a sexual partner asks you to wear a condom?
 - i. Did you feel differently before your diagnosis?

I. [HIV/AIDS Educational Outreach:]

1. Before you tested positive for HIV
 - a. had any health worker ever approached you about getting tested? [yes/no] What do you remember about this interaction?
 - b. had you seen any printed information
 - i. that talked about using condoms? [yes/no] Where?
 - ii. on how a person can get AIDS? [yes/no] Where?
 - iii. about getting tested for HIV? [yes/no] Where?
 - c. Did you feel that this information was important to you? [Why or why not?]
2. [If no to all of questions 1a-1d] On your own, did you ever try to find out more about AIDS? Why or why not?

J. Thinking about HIV testing...

1. How many times have you had a HIV test?
2. What were your primary thoughts and concerns before you decided to get tested?
 - a. What are some of the reasons why you didn't get tested? [*Prompt for explanation.*] What are some reasons why you did? [*Prompt for explanation.*]
3. When did you first get tested for HIV?
 - a. Where did you get this first test?
 - i. How did you find out where to get tested?
 - b. Did you tell anyone that you were going to get tested? [Who? Why?]
 - c. What do you remember about talking with the testing counselor before your test?
 - d. How did you feel while you were waiting for your test results?
 - i. Did you think that your result would come back positive? [Why or why not?]

K. Thinking about the time you tested positive,

1. What do you remember about the talk with the testing counselor during the appointment when you received your positive results? [What did s/he say? What did you say?]
 - a. How did you feel?
 - b. Did you ask any questions?
2. What were you most worried about when you left that office?
3. Thinking back about your past sexual experiences, how do you think that you became infected?
4. Did you tell anyone that you had tested positive? [Who? Why?]
 - a. Is there anyone among family, friends, co-workers, employers, etc. you have not yet told about your HIV status? Why not?

L. Thinking about this period of time since your diagnosis...

1. What do you think has helped you the most in dealing with this disease?
2. If you become depressed, where would you go or who would you seek out?
 - a. Why would you make this choice?
 - b. How about when you are lonely?

- c. Where do you go, or who do you turn to, when you need to make a health-related decision? (for example, deciding on HIV medications and treatment)
- 3. OK, how about, where do you go when you want to have a good time?
 - a. What do you like about that place?
 - b. Do you tend to go with someone, or meet friends there, or just see who you meet when you go?
 - c. [*If has had sex w/ man...*] Have you ever hooked up with another man there?
- 4. Now that you have been using services from Public Health or other agencies,
 - a. What have you found to be most helpful?
 - b. What do you think needs to be improved?
 - c. Do you know others who are hesitant to seek out Public Health services? Why do you think they are?
 - d. Would you and other people you know be more likely to use Public Health services if you could just drop instead of making an appointment?

M. Thinking about what you have learned from your experiences...

- 1. Do you think that some of your male, Latino friends are doing things that put them at risk for contracting HIV?
 - a. What, exactly, are they doing that you think puts them at risk?
 - b. What advice would you give to them? [*Use probes to encourage specifics: About sex? About condoms? About HIV/AIDS?*]
- 2. If testing were more accessible, do you think people would get tested? If accessibility isn't the problem, what do you think could motivate others to get tested?
- 3. Do you think subjects like HIV and AIDS should be dealt with on TV programs like the telenovellas? Or on Spanish-language radio programs? Do you think it would make your family or friends uncomfortable?

Thank you for participating in this study today. As I mentioned earlier, I have a \$30 gift certificate for you, as well as a copy of the Informed Consent Form with contact information included if any questions come to mind after you leave here today.

APPENDIX C

Data Summary Tables
Sample size = 28

I. Demographic Information

Age:	No. Cases
Under 30:	3
30-39:	12
40-49:	7
50 & over:	2
Not available:	3
Average:	38.6 yrs
Range:	27-75 yrs
Primary Language:	
Spanish:	17
English:	11
Place of birth:	
Mexico:	12
U.S.:	12
Other Latin Am. countries:	4
Years in U.S.:	
<u>Moved to U.S.:</u>	17 cases
Average years in U.S.:	14.6 yrs (n=15)
Range:	3-31 yrs
<u>Lifetime U.S. Resident</u>	11 cases
Employment:	
Yes:	15
No:	9
Unknown:	4
Sexual Orientation	
Homosexual:	14
Heterosexual:	6
Bisexual ¹² :	8

¹² Defined as men who have ever had sex with men and women. Three bisexuals self-identified as bisexual. The 5 who did not all mentioned sex with men in the past.

Marital Status History

Never been married:	17
Ever been married:	9

Current Relationship Status

<u>Living with partner:</u>	12
<i>Married</i>	5
<i>Unmarried</i>	7
<u>Single, may be dating:</u>	16

HIV Status of Primary Partner

<u>Female wife</u>	
Positive	1
Negative	4
<u>Male partner</u>	
Positive	1
Negative	2
Not tested	1
<u>Female partner (unmarried)</u>	
Positive	1
Negative	2

II. Sexual History

Age at First Sexual Experience:

Average age:	14.1 yrs
Range:	3-20 yrs
Under age 14:	12 cases

Type of First Experience:¹³

Nonconsensual: ¹⁴	6
Consensual:	25
<i>Non-penetrative:</i>	5
<i>Penetrative:</i>	20
<i>M-M:</i>	10
<i>M-F:</i>	10
Uncategorized:	3

¹³ 6 participants distinguished between early experiences of nonconsensual or nonpenetrative experiences (catalogued here) and their later first experience with consensual or penetrative sex, both documented in these counts.

¹⁴ Sexual abuse and/or while under age of consent

Sexual Behaviors

Heterosexual & Bisexual Men:

Pre-marital sexual experiences:

With women and men	2
With men	1
Only with women	6
No sex	1

Marital sexual experiences:

With wife only	2
Wife & boyfriend(s)	4
Wife & girlfriends	1
Unspecified	2

Gay-identified Men:

Sexual experiences:

With gay-identified men	11
W/ hetero-identified men	5
W/ women	3

III. HIV Testing

Testing Facility

Public	11
Private physician or clinic	8
Can't determine	9

Possible Mode of Transmission:

(number of mentions)

Unprotected sexual relations:	24
<i>Male to male:</i>	16
<i>Female to male:</i>	5
<i>Gender unknown:</i>	3

Contact with infected blood:	4
<i>Injection drug use:</i>	1
<i>Vitamin injection (Mexico):</i>	2
<i>Blood transfusion:</i>	1

Unspecified:	1
--------------	---

Duration of Illness:

Average age at diagnosis:	33.4 yrs
Average years living w/ HIV/AIDS:	7.4 yrs

IV. Use of Services (number of mentions)

Medical	11
Mental health	5
Financial support	14
Social support	2
Other	9

VII. Advice

Advice to Educators:

Is testing accessibility the issue?

Yes	9
No	17
Don't know	2

What would motivate more Latinos to get tested?

Increased visibility of HIV/AIDS information

More visible health campaigns 10

More disclosure/visibility of HIV-positive Latinos 3

Innovative programs/incentives 4

Improved sex ed classes 4

Destigmatization campaign specific to Latino community 5

Advice to Latinos

Use condoms	13
Look at reality of living with HIV	7
Delay sex with new partners	5
Get off drugs and alcohol	4
Learn safer sex practices	2
Don't use dirty needles	1