How to Better Serve Latinas who Access HIV/AIDS Services in Ventura County

Report to HIV/AIDS Service Providers & Educators

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Adina Nack and Lyn Gesch
Co-Principal Investigators

Executive Summary

Background of Research Project

This research project was commissioned to focus on Latinas who are either infected by or affected by HIV/AIDS. That is, we were interested in talking with women who, at the time of the study's inception, represented two sub-populations: (1) those who were current clients of HIV/AIDS services in Ventura County, in order to understand how they experience the different stages of their illness, and (2) those women who, as the intimate partners of HIV-positive clients, were experiencing HIV from the perspectives of partners and caregivers. The overarching goal was to use these findings to inform how to better serve the outreach, education, and treatment needs of Ventura County's Latinas.

Key Findings

Our findings regarding Latinas and their vulnerability to HIV are consistent with national data: e.g., most were exposed to HIV through unprotected sex with a man, and their risk was increased by lack of education about sex and disease prevention prior to engaging in high-risk behaviors, as well as the lack of discussions with their sexual partners about the use of condoms. As this report will explain, cultural conceptions of femininity and masculinity stigmatize condom use for women and promote an ideal of "good" girls/women/wives/mothers that assumes Latinas would have no need for knowledge about or use of condoms. This study's key findings include the following:

1. **Create empowering HIV prevention and education messages to address traditional cultural scripts for feminine sexuality**. Traditional sexual scripts create feminine roles, which scholars often refer to as *marianismo,* which do not allow women – "good girls" – to know about sexual matters prior to marriage and assume that they will defer to their husbands when it comes to matters of sex. These practices do not put Latinas in a position to protect their sexual health statuses and especially make immigrant, monolingual Spanish-speaking, and less assimilated Latinas more vulnerable to HIV infection. Handicapped by the lack of HIV/AIDS education in their countries of origin, these women pose specific challenges for our county's efforts to improve HIV prevention and increase HIV testing. However, there is a key 'window' of opportunity – that gap between their year of immigration and their year of diagnosis – to reach these women and make a difference.

2. **Create education models for negotiating condom use in power-differentiated relationships**. Traditional gender roles often impair these women's abilities to initiate strategies for protecting themselves in sexual encounters because there is an emphasis on self-sacrifice and submission. The infected and affected women in this study have employed a variety of responses to protect their sexual health statuses: either remaining single and celibate, or entering long-term relationships after HIV has entered their lives. Changing practices within the sexual encounter has to include skills-training for both men and women that addresses social norms structured by traditional gender roles.

3. **Address fatalistic ideologies when developing ways to help infected and affected Latinas cope with issues with HIV disclosure**. HIV-positive women who are in good health – and those women who are partners of healthy HIV-positive men – are able to enjoy social lives with family and friends without disclosing. However, their limited disclosure coupled with fatalistic views (common amongst Catholic immigrants from Central and South America) hinders their ability to access the kind of support they will likely need in the future. Considering their reticence, increased one-on-one counseling settings can encourage these women and provide skills-training for helping them expand their support system. Fatalistic scripts can also be addressed through increasing opportunities for rapid-testing in Latino communities. Rapid-testing can minimize the effect of fatalistic attitudes which have been shown to dissuade some Latinas from returning to a test site for their results.

4. **HIV/AIDS educators and service providers can proactively address traditional gender norms, lack of comfort and knowledge about condoms, and fatalism by examining the sexual self transformations described by women in this study and shaping education and prevention messages** that redefine healthy, female adulthood by focusing on how a "good" wife/mother takes care of her husband and children by taking care of her own health:

- moving women <u>from dependency to self-sufficiency</u> – teaching them the benefits of playing a more active role in sexual relationships and relying less on their partners for affirmation. This will give them the confidence to insist on condom usage with their partners because they will see protecting their health as the ultimate gift to their partners and children.

- moving women <u>from valuing naiveté in themselves to valuing their own sexual intelligence</u> – using existing 'safe spaces' (such as their children's schools) that tend to be viewed as women's domain for Latinas to learn about HIV and other sexual health issues, to practice the skills of educating their sexual partners about disease prevention, and to learn how to choose strategies that lower their risk of receiving or transmitting viral strains. Overall, a good wife/mother is an educated woman who has the knowledge that can help her keep herself and her family healthy.

- moving women <u>from being other-protective to being self-protective</u> – identifying women's protection of their own health as important to fulfilling the role of good mother and wife. In fact, a good wife/mother does not inflict suffering on her family by putting herself at risk for HIV/AIDS and all of the medical, emotional and social costs that come with it.

5. In addition to these recommendations focusing on women's skills and empowerment in regards to their sexual health, we also find that Latinas, both affected and infected, are highly supportive of HIV educators and case management providers in this community. In addition to needed emotional support, providers are primary sources of information for clients, and they work hard to obtain help with rent, food, and transportation, for these clients. However, these women struggle to negotiate the demands of their work and family lives with the needs of managing a chronic disease. When asked how services can be improved, they express both gratitude for what is offered and their ongoing concerns with housing, medical services (including dental and opthamological) and psychosocial support services. Given that all the women in this study have responsibility for child-rearing, we add to this a concern for allocating funds for childcare so that participation in health and education services among all women at risk for HIV can be enhanced.

6. **Finally, community leadership, such as that embodied by the county's Latino HIV Taskforce, should continue to be developed and work towards increasing the visibility of HIV prevention and education** measures in school programs on sexual health and in media campaigns to normalize condom use.

Study Authorization and Research Design

The Ventura County Public Health Department continued its support of locally-based research on the HIV experiences of Latinos in Ventura County with its funding of the current project. The HIV and Latinas project is a companion piece to the 2006 study on the Latino male population in Ventura County, focusing on women's experiences of being at risk for HIV and living with HIV, either infected with the virus, or as affected partners of an HIV-infected man.

The Public Health Department sought collaboration from within the local academic community, which resulted in a research plan 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 Ventura County’s Medical Center IRB (January 23, 2007) and by California Lutheran University’s IRB (February 2, 2007).

VCPH approved a scope of work in which both HIV-infected and HIV-affected women would be recruited to participate in a 90-minute, one-on-one, in-depth interview. The goals of the interview were to assess the sociocultural factors that affect women's risks for acquiring HIV and for managing life with HIV, including the challenges of appropriating safer sex practices, maintaining and negotiating relationships with partners and children, and establishing a social support system.

Throughout the process we consulted with community educators, advocates and service providers, seeking input from experienced professionals on cultural issues specific to recruiting and interviewing Latina clients.

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 set the goal of better understanding the beliefs and experiences of Latinas 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 Latina 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.

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. In keeping with research protocol on women subjects, we designed a same-sex interviewer-interviewee dyad and hired bicultural, bilingual, female interviewers. Their expertise in the community as sex educators was an asset for an interview designed to understand women’s sexual practices.

Participants could also choose the language in which their interview would be conducted and could request a specific interviewer. 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 stories were similar and different.

Methods and Sample Description

In-depth Interview Study of Latinas Receiving HIV/AIDS Healthcare in Ventura County

Recruitment of Participants

The research project 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. Craig Webb, from the Ventura County Public Health Department HIV/AIDS Programs, identified Public Health clients that fit the eligibility requirements for the study.[1] We then provided case workers at Public Health and AIDS Project Ventura County with packets of information and forms, including informed consent forms in both English and Spanish, to aid with participant recruitment and the submission of contact information to the research team.

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. Both the Public Health Department and AIDS Project Ventura County offered the use of their meetings rooms for conducting the interviews, but when it was more convenient for the client, the meeting rooms at the Oxnard Public Library or the clients' homes were used. At the beginning of each interview, the interviewer reviewed the informed consent form and collected a signed form from the participant. At the conclusion of the interview, each participant was compensated with a $30 gift certificate to Target stores. All interviews were audio-taped, and confidentiality was not only explained in writing, via the informed consent form, but also reiterated by the interviewer prior to the start of the audio-taping.[2]

Interview Instrument

Interview questions were constructed to elicit a better understanding of those factors that put Latinas at risk for HIV and those factors that shape how they manage living with HIV, either as infected or affected individuals. The interview questions are semi-structured, allowing the interviewer the possibility of conducting a follow-up interview. There are four distinct topic areas in the interview guide: women's sexual maturation experiences, their pre- and post-diagnosis sexual practices, their HIV testing experiences, and their post-diagnosis support systems. Women were also given the opportunity to offer advice to providers regarding the provision of testing and health care services, and to women like them regarding risks for HIV.

Sample Description

At the time of the study, VCPH had 35 Latinas living with HIV/AIDS and 41 married male clients who are HIV-infected (with some overlap between the two groups). We received 14 referrals from case workers and our interviewers successfully completed 11 interviews. Nine of these women were HIV-infected, though not all had AIDS diagnoses, and 2 of them were HIV-affected, or partners of someone who is HIV-infected, and who are themselves HIV-negative. (Only one of the HIV-positive women was involved in a *serodiscordant* relationship, her partner being HIV-negative.)

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[1] Women eligible to participate in this study had to be self-identifying Latinas who are either HIV-infected and clients of the Ventura County Public Health Department, or partners or spouses of HIV-positive male clients of VCPH.

[2] Audiotapes of the in-depth interviews were transcribed and translated by a bilingual transcriber. Audiotapes and transcribed manuscripts are the property and responsibility of Ventura County Public Health Department.

While we had a low response-rate, having interviewed 25% of the client population,[3] we are aware that significant socio-cultural barriers inhibit Latinas from engaging with HIV/AIDS research studies. First, disclosure of HIV status is highly stigmatizing in both Latino and white communities and few women have told anyone other than immediate family of their health condition (a key finding in this study). Talking with an interviewer and having that interview recorded – even though it would be protected and kept confidential – was too revealing for some women. One participant commented that she is uncomfortable when her doctor or other medical staff uses the language of HIV or AIDS in what is, for her, the public space of the clinic.

Second, denial regarding one's HIV status also operates to inhibit women from talking at length about HIV in their lives. One woman who initially was interested in interviewing but eventually declined, told the interviewer who contacted her that she feared that telling her story would force her to accept her disease.[4]

Though English- and Spanish-speaking women were targeted for the study, our resulting sample was entirely monolingual Spanish-speaking Latinas who were born outside of the United States. Because it has been reported in previous research that less acculturated Latinos are at more risk for HIV than those who are U.S.-born or who are bilingual, we collected data on the length of time they have been in the U.S., their work status, and their primary networks of family and friends. While there is no way to determine where they were living when they became infected, many interviews pointed to the likelihood these women were infected while living in their countries of origin.

In addition, women’s risk for HIV and STIs increases if their male partners are on the “down low,” being sexually active with men but not disclosing this behavior to their female partners (Harawa 2003).[5] We would expect that the women in this sample came from cultural and educational backgrounds in which HIV and other STDs were not discussed, particularly with women, and have had less exposure to HIV messages in various media.

The women in our sample ranged in age from 25 to 59 (median age group is 40-49), and those who are HIV-infected have been diagnosed on average 11.1 years. Ten of eleven women are mothers: the average number of children is 2.9 and their families range from young, preschool-aged children to adult-aged children. Twenty-two of 29 children were born in the U.S. All of the women came to the U.S. to seek a better life economically and, in two cases, to have access to better medical treatment.

Our study is limited by the low participation of HIV-negative, HIV-affected women, which will preclude a comparative analysis with HIV-positive women who are partnered. However, we are struck by the similarity of stories from women who are either infected or at risk of infection - the challenges of raising their children and making decisions regarding disclosure of HIV-infected family members, the decisions and struggles for maintaining or dissolving relationships with husbands or other sexual partners, and the struggles to manage the impact of HIV on their work lives and social lives. The narratives of HIV-negative women at risk for HIV add to these analyses as well as provide some insight into possible responses of women in their situations.

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[3] Nine (9) HIV-positive interviews out of a client pool of 35. This response rate is not unusual for qualitative studies that are exploratory in nature and consider participants as key informants in providing a rich description of their experiences with HIV.

[4] Source: Evelina Ochoa’s field notes on participant contact dated 11 June 2007.

[5] Harawa (2003), in a convenience sample of 1,353 men at 7 STI clinics, reported that foreign-born Latinos with STIs were more likely than U.S.-born Latinos to be married, to have had recent sex with both male and female partners, and most likely not to identify as homosexual.

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

This study of Latina women who are utilizing HIV/AIDS services in Ventura County demonstrates the need to more deeply understand the impact of culturally-specific gender norms and roles on women's risks for HIV and their ability to cope with HIV as a chronic disease. Women who are raised in traditional cultures learn the virtues of care-giving, virginity, and obedience to men,[6] which are found to delay a Latina's first sexual experience (Upchurch et al. 2001), and to shape women's fatalistic acceptance of suffering at the hands of men (Safa 1976; Ehlers 1991). We find that the results from our study support arguments regarding the negative effects of fatalism, as well as the potential for women's empowerment in that these concepts can be constructively applied to enhance the cultural relevance of HIV outreach and services.

In this section of our report we make recommendations for educational outreach, testing and service provision, drawing on the stories of HIV-infected and -affected Latinas in Ventura County who shared their experiences with HIV, talked about the difficulty of sexual decision-making, and gave their views of what could be done differently for women in their situation.

I. Recommendation: Create Empowering HIV Prevention and Education Messages to Address Culturally-specific Gender Roles and Norms

We preface this recommendation on the observation that traditional roles of submissiveness and obedience make women vulnerable to HIV and other sexually transmitted diseases due to their expected ignorance about sex and their passivity in sexual encounters. Because these social experiences leave women, raised in traditional cultures, vulnerable to sexually transmitted diseases, we frame the discussion of our findings regarding Latinas' knowledge of sex and sexual diseases in terms of the programmatic need to address traditional cultural scripts like *marianismo*.

A. Findings

All Latinas in our study were either uninformed or misinformed about sex when growing up. They attributed this to cultural norms ("In Mexico they don't talk about that" and "We didn't talk about that on the ranch") or family norms ("Parents didn't really communicate with their children" and "[Parents] probably didn't know how to explain it"). Some parents communicated messages to their daughters about waiting until marriage to have sex, or "having respect for your body by not having several partners," but one woman explained that her mother's attempt to "educate" her on sex only served to mislead her.

> My mom would tell me that only married people could have 'contact' with each other. Even after I was married, my mom would tell me that babies are born through your head. It wasn't until I had my children that I learned that it wasn't true. [*laughing*] My mom was really ignorant about sex and so was I. [43-year-old HIV-positive Latina][7]

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[6] Evelyn Stevens (1973) coined the term "marianismo" in relation to Latino *machismo*, and defines it as "the cult of female spiritual superiority which teaches that women are semi-divine, morally superior to and spiritually stronger than men" (1973:315). Stevens and others believe that *marianismo* can be an empowering as well as a restrictive phenomenon, that men's veneration of women can be used to women's advantage. Critics note, however, that this interpretation overlooks the very real difference in power between men and women, i.e., women's "power" in the home is nowhere near as liberating as men's financial independence of women. Instead, these critics suggest that the negative effects of *marianismo* can be effectively countered by increasing women's education levels and financial independence from men (Ehlers 1991).

[7] All original quotes are in Spanish but we are using only the English translations in order to preserve space and reduce distraction. Translations have been provided by a qualified bilingual transcriptionist/translator.

Only 2 of the women had some form of sex education in school. School instruction in these cases consisted only of learning what happens to the body in female menstruation and pregnancy. All of these women admitted that they learned about sex in their first sexual experience.

Excluding women from this knowledge during their formative years did not result in protection from disease but, in fact, put them at risk for it. While the average age at first sexual experience is older for these women than for the Latino men in our 2006 study (19 years vs. 14.1 years), supporting findings from previous research on Latinas with HIV (*see* Upchurch et al. 2001), nevertheless, they entered these experiences without knowledge of STIs or HIV. All participants reported they learned about HIV as well as protection methods from the doctor or nurse who informed them (or their partners) of their HIV diagnosis. Some said they had “heard things,” but they didn’t know how to protect themselves against the diseases.

> I remember hearing about it back in my country….I would hear about it but didn’t know what it was or how to prevent it. [43-year-old HIV-positive Latina] [And,] I would hear things, [but] only about venereal diseases. [59-year-old HIV-positive Latina]

One woman received counseling from her mother-in-law about the possibility of STIs due to her future husband’s sexual history.

> [She said] that I should be careful because my husband got around and there were diseases women could catch. That’s how I began to learn, through my mother-in-law, since she would explain to me what my mother never told me about venereal diseases, but never HIV. [59-year-old HIV-positive Latina]

It is important to note that sexual health researchers have found that women – of varied ethnic backgrounds – who received STI education prior to infection still felt ‘invincible,’ believing that only promiscuous women are at risk (e.g., Nack 2008).

Because their diagnoses were unanticipated, over half of the women said they were anxious to learn as much as they could when they or their partners became positive. Medical professionals, case workers, and community educators played a vital role in filling this gap in their knowledge. The women also sought out written material. One woman said she reads brochures at Planned Parenthood when she takes her daughter there. A few women are reluctant to learn more, however. One of the HIV-affected women said, “This is too painful for me….I haven’t talked to anyone about this.” [42-year-old HIV-affected Latina]

The expectation of men’s infidelity and women’s acceptance of this underscores the influence of culturally-specific gender roles in shaping sexual relations within marriage or long-term partnerships – situations which put these women at risk for HIV. Seven of the 9 women who were infected by sexual partners were living with these men at least one year.[8] We will explore this issue further in regard to women’s sexual practices, but at this point we want to emphasize that the traditions that do not allow a woman to know about sexual matters and to limit her sexual experience to one partner – her husband – do not protect women, and have not protected these women, from HIV.

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[8] The range of time spent in these relationships is 3 months to 16 years.

B. Implications for Policy and Practice

Because the Latinas in this study report that their service provider (doctor, nurse, case worker, community educator) was the first source of information on HIV and safer sex practices, it is important that funding sources fully support the range of outlets for comprehensive, culturally appropriate, and gender-specific HIV/AIDS education, prevention, and outreach programs. In addition to maintaining the education efforts currently in place, there is a strong need to target women who are new immigrants. Handicapped by the lack of effective disease prevention training in their countries of origin, these women would benefit from U.S. HIV prevention efforts that are culturally-appropriate for foreign-born, monolingual Latinas who have recently immigrated to the U.S. For this sample, 5 of 7 women who were infected through unprotected heterosexual sex with partners in the U.S. were diagnosed here.[9] Where can education/prevention efforts reach these women before they receive a diagnosis? Latina immigrants in our sample came to the U.S. primarily following family and seeking work, so immigrant work sites and neighborhoods should be key opportunities for targeted education/prevention messages.

As the women in this study were caught completely off guard by their diagnosis, the risk they faced – complicated by the effects of *marianismo* on their views of sex and male authority – should alert local agencies to target this population with innovative messages that acknowledge their naiveté and lack of concern with culturally appropriate language and novel venues. For example, identifying sexual diseases as a concern for all women would need to (1) use the appropriate language, e.g., women in this sample consistently used the now-outdated phrase, *enfermedades venerias*, instead of the Spanish-language equivalents of "STIs" or "sexually transmitted diseases," and, (2) be explicit about the sexual networks in which they are part and which put them at risk.

Would it help to hear directly from women who have been caught off guard by HIV? Yes, according to the women in this study. However, reticence in this group regarding sexual matters and HIV complicates development of effective responses. While these women observe risks among their co-workers and friends and think that Latinas would listen to stories like theirs, none would be comfortable filling that role, especially in a work setting. Some of the women talk to their co-workers about protecting themselves, but they speak about it without self-disclosure. Here is how one woman explains it:

> I don't think anyone who has AIDS or that is infected with HIV would say, "You know what? I am like this." It's hard. One of my friends or my boss – no, no, no. This is something horrible. I have never told anyone! Well, of course, I told my partner, because I don't want to hurt anyone….I don't think I'll ever do it, that I will ever [say], "You know what? I am [HIV-positive]." If I go to a conference or if the programs asks me to do it, like I am doing with you, I am talking with you, because, honestly, I don't think I will every see you again, but [*laughs*] if you were my friend or co-worker, I wouldn't do it. [27-year-old HIV-positive Latina]

To get the attention of women at risk, agencies should frame convincing arguments on the importance to these women of educating themselves on STIs, including getting tested and knowing one's HIV status. The challenge here is finding ways to counter arguments in which Latinas feel secure and unaffected by diseases that are transmitted sexually. But it is more than denial that is at work. If one accepts the premise of *marianismo*, that women as mothers hold an *honored* role in the household, then one can begin to understand that suffering in this role would be a virtue and what one expects from life – enduring a husband's infidelity or abuse is one's destiny, or fate. And it is these fatalistic scripts that make women's prescribed gender role expectations a major risk factor for Latinas. Reaching women in these situations

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[9] The average number of years between women's year of immigration and year of diagnosis is 6.2 years (range of 3 to 11 years).

requires connecting to them as mothers who need to protect their families – and themselves – by going against expectations and becoming educated about sex, sexuality, and sexual health. Currently, a well-used HIV campaign slogan quoted by one of the interviewees is "it's better to prevent than to regret." The task for educators is to not only make this relevant for all populations within Latina communities, but address the complexities of mixing messages of restrictive gender roles and fatalistic scripts.

II. Recommendation: Create Education Models for Negotiating Condom Use in Power-differentiated Relationships

If traditional women are excluded from knowledge of sex and disease prevention in their upbringing, it follows that they are also not taught to talk about sex with sexual partners. This means they are not asking them about their past sexual histories, sexual health, or using protection (Romero, Wyatt, and Chin, 1998). For many Latinas, including the women in our sample, this is anathema to a woman's role. In this section we will discuss how a woman's lack of power in her relations with men affects sexual encounters and how an HIV diagnosis has challenged and changed some of the women's responses, increasing their sense of control. The challenge for educators and case workers is encouraging these behaviors in HIV-negative women at risk.

A. Findings

All of the study participants related their observations from childhood that women and men have different responsibilities in life with little if any overlap: women must take care of the household and the children, and men must provide for them. Yet these spheres of responsibility were not equal. Our participants related that women were obligated to obey men[10] and that men controlled what women could do through controlling household finances.[11] In some societies, women were not expected to work outside the home but would often help their husbands in the fields.[12] In other areas, outside work was needed in order to supplement household income.[13] In neither case would a woman's household or child-rearing responsibilities be lessened.

Despite the rigid role expectations, half of the women in our sample were not unhappy in their relationships. For them, their first husband or long-term partner was their first sexual experience, and these women reported that, even though they were naïve, the experience was positive because they were in love.

> I was happy to be my husband's girlfriend. He was my only boyfriend. I felt good. I always wanted to get married and have children and raise them. I am happy about that. [43-year-old HIV-positive Latina]
>
> [Sex with husband] has always been positive. It was hard [at first] because you're not used to it, but little by little you begin to understand, to experiment. I figured it out by myself….I did it with love. I was conscious of what I was doing, although no one had talked to me about sex….Never [talked about condoms], because they taught me not to ask questions. If I thought about something, I kept it to myself….[Partner didn't use condoms] because for them [men] it's easier not to use one. Supposedly men feel more

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[10] "My uncles were drunks and it's about whatever your husband says. That's how it is over there." [01]

[11] "The husband would work and give his wife some money. My mom didn't know how to work [outside the home] because my dad wouldn't let her." [09]

[12] "I learned about being a housewife. To help my husband out in the fields. Women have much more responsibilities than men." [06]

[13] "[In Michoacan] all women work [and] children go to child care." [07]

> pleasure without one. It's more comfortable that way, I think. [33-year-old HIV-affected Latina]

For these women, the script of romantic love affirmed their status as "good girls" who were making the right choices and not in danger for disease.

Negative Sexual Experiences

For the other half of the sample, however, their naiveté did not serve them well and their sexual initiation was not a positive experience.

> I didn't learn anything. I think we were too young. You just go at it like animals, just to do it. You don't know what sensations to feel. I don't know how he felt, we never talked about that….I didn't like it the first time because it was painful. I didn't know it was like that. Later I found out why, because 3 layers [of tissue] are ripped and that is the pain you feel. What's more, I got a fever. It was not something pleasant. [34-year-old HIV-positive Latina]

Others commented about feeling confused or being scared about getting pregnant. Restricted to silence, their concerns went unaddressed and, as one woman put it, *tu solo vas aprendiendo*, or, "you learn as you go." [33-year-old HIV-affected Latina] The outcomes of these early liaisons for this subgroup include 4 pregnancies and 2 seroconversions.

For all these women, knowledge of disease prevention and condom use came long after they were sexually active: 10 of 11 women learned to use condoms and understand other aspects of safer sex practices after they or their partners were diagnosed with HIV. Two of them had heard of condoms before for preventing pregnancies, but only one woman in our sample had observed a male partner using them prior to an HIV diagnosis. Again, cultural norms operate to denote knowledge of or possession of condoms as a symbol of sexual promiscuity, and, thus, only the purview of street women. One woman who remembered that she and a friend would play with condoms "like they were balloons," said,

> It was ingrained in us that only street women used condoms. Respectable young ladies didn't need to use them because they stayed at home. [43-year-old HIV-positive Latina]

This carries over to the assumptions these women made in their long-term relationships that sex with spouses would be safe because they were entering a mutually monogamous partnership. The reality, of course, was that their partners had the potential for bringing disease into their relationship from past (or current) liaisons in which they had had unprotected sex. Traditional Latinas are often socialized not to make demands or talk about condoms, and male partners who embrace traditional gender roles usually view infidelity as the norm – not necessarily feeling compelled to disclose their extra-relational sex partners, leaving their female partners vulnerable to infection. The husband of one of our study participants didn't use condoms because, he told her later, "he wanted to have children." She found out she was infected with HIV after four children and after she had already become very sick. Her health has rebounded with medical treatments (and her children have tested HIV-negative), but her story illustrates the devastating consequences of sexual silences within long-term relationships.

The value of post-diagnosis education is evident in the ways in which women described their new-found knowledge. They not only learned about condoms but of a range of ways in which they can maintain sex lives and be safe.

> Teresa in the clinic gave me a lot of [information on] how to use a condom and that there are condoms for women. [27-year-old HIV-positive Latina]
>
> [Evelina (from Planned Parenthood)] talked to me about condoms and that there were other ways to have sex, make love. You don't always necessarily have to have penetration. [33-year-old HIV-affected Latina]

While this "tool kit" broadens their choices, the major obstacle remains of learning how to talk to partners about these possibilities. Women who enter long-term relationships established these parameters with their new partners. For the 6 women who were in a relationship at the time they or their partner tested positive for HIV, all said they started using a condom, in some cases relying on the authority of the medical professional's advice ("His doctor told him that he had to use a condom" [40-year-old HIV-positive Latina]). One woman who has remained in a sero-discordant relationship (she is HIV-negative) explained, "We need it now. I won't be with my partner without one….He has always agreed to use one." [33-year-old HIV-affected Latina]

Post-diagnostic Sexual Relationships

Those women who have entered new relationships since their diagnosis used disclosure of their HIV status as the argument to the new partner for making condom use "normal" in their relationship ("He knew that he always had to wear a condom" [27-year-old HIV-positive Latina]). Here is an example of one conversation in which the relationship progressed from dating to sharing a household, and from nondisclosure to disclosing her HIV status:

> Since he is not HIV positive – he is negative – I had to explain to him that I am HIV-positive and that to have sex we would need to use a condom. The first time we had sex, I didn't tell him I was HIV-positive, but I did tell him he had to use a condom….I spoke with a psychologist to find out if I needed to tell him that I was HIV-positive. The doctor said, "You will start to have feelings for him. He will start to have feelings for you and then later it will be harder. You will suffer more." So then he said, "You need to be honest with him. If he accepts it, ok. If he doesn't then it's still ok.'" [How did he react?] He couldn't believe it…..We always use a condom. [40-year-old HIV-positive Latina]

Once a partner agrees to this practice in principle, there is the continuing commitment to it that becomes part of one's life.

> We always think about our health. I tell him, "Look, let's use a condom because I don't want you to get infected or to have to go through what I am going through." I don't want to feel guilty. He says, "It's ok," that he doesn't really notice anymore. I ask, "What if the condom breaks?" He says he doesn't worry because I take my medications. We don't take it for granted, though, we always use a condom. No condom, no sex. He can go take a cold shower if necessary! [34-year-old HIV-positive Latina]

Both of these women have found a "voice" for talking about sex in their relationships – compelled by necessity, but also by a concern for protecting others, and informed by the efforts of local educators and providers.

Women who are single and decide to date face another set of challenges with initiating safer sex discussions each time it comes up (none said a date had ever initiated it with them) and with making the decision as to whether or not disclosure of their health status would be part of that conversation. Asked if she had talked to a health worker about protection methods, one woman said,

> Yes, with Carolina [Public Health case worker], about protection, [that] if I have a boyfriend, the importance of protecting myself. I don't have to tell him about the disease or anything, but protect myself either way. [39-year-old HIV-positive Latina]

Though only two women in this sample are currently dating, it is important to understand the difference between (1) their practice of nondisclosure in casual sexual relationships,(2) arguing for condom use as a "universal precautions" type of practice, and (3) disclosing only at the point when the relationship turns serious and they decide to live together. Looking at communication skills as a series of steps can allow women the time to consider options and develop confidence to talk about sex and HIV in the context of a maturing relationship.

For all the women who have dated since their diagnosis, practicing these negotiation skills with male partners forces them to confront a number of the cultural barriers to safe sex. In the following narrative, we see that this woman's male partner assumes that being asked to wear a condom implies he has had sex with "dirty" partners. He also assumes that he can identify "clean" and "dirty" from appearance (or, that viral infections should have physical manifestations). She challenges both ideas and her story provides an example of the kinds of arguments women can expect from the potential partner – as well as the likely outcome, i.e., no sex.

> There are men who won't [use condoms], who simply say, "No, I never use that. I have never used that. I don't have that many women and I haven't had that many women." Not too long ago, I went out with someone who didn't want to wear a condom…No matter how much I told him. I even told him, 'I have problems with my uterus.' I made stuff up…He said, "I haven't had that many partners and I'm not dirty. You don't trust me." He thought it was because of him…He thought it was because of him that I wanted him to wear a condom, right? I didn't tell him I'm sick. I couldn't. I couldn't because he…he got offen-… [He was offended?] Yes. They've been offended. Yes. And he said that the women he has been with have been few and that they have been, well, clean and pretty and very clean. Not everything that shines is gold!...Now matter how pretty you think they are, no matter how clean they look to you. I talked to him about AIDS because he is someone who is completely ignorant, who has never in his life heard of what has happened to me…[Okay, so then you talked about AIDS, but you didn't tell him…?] I didn't tell him I was sick. [And, did you have sex?] No, because he didn't want to [wear a condom]. And I told him, "No, then, no." He got kind of offended too. No, okay, perfect. [That's how you left it.] Ah-huh. [27-year-old HIV-positive Latina]

For some women this kind of scenario is too threatening or burdensome, and they have chosen another strategy, which is to be celibate: 2 of the 6 unmarried women and 2 of the 4 married women have chosen not to have sex. One of the unmarried women said her decision allowed her to avoid the difficulty of having to talk about protection with her dates:

> I am not an open person, so to prevent any embarrassment, I take care of myself, I take care of the other person, so then we just hold hands and kiss. [43-year-old HIV-positive Latina]

One of the married women who is in a serodiscordant relationship and who talked about refusing sex with her husband said that even though he has been diagnosed for 5 years and they are both now informed about safer sex methods, they are still too afraid to try.

In summary, one strategy for managing HIV disclosure and protection in sexual encounters is to use protection but limit disclosure of one's HIV status only to partners in a committed relationship. And, as noted earlier by a mental health provider here in the county, it is important to disclose early in that relationship in order not to contribute to any relationship problems. These are examples of women who have learned how to talk about sex and protection with partners and their successes underscore the important work of education and one-on-one counseling.

B. Implications for Policy and Practice

We have elaborated on these ideas about gender roles and how they operate in relationships that women establish – first as HIV-negative women who are unaware of their risks for HIV, then later as women who are positive, or who are married to HIV-positive men – in order to draw attention to the possibilities for change that are within the narratives themselves. The first conclusion we can draw is that women are socially at a disadvantage to engage with men regarding safer sex practices – "negotiating" is not part of their cultural repertoire as Latina women and the power deficit they incur inhibits a one-sided communication. Changing practices within the sexual encounter has to include skills-training for both men and women. With the reality that many men are bringing extensive sexual histories into their long-term relationships, particularly, where female partners are not assuming risks for sexually transmitted diseases, it is essential that social norm campaigns effectively convince Latino men to use condoms with any and all partners, whether they are casual sex encounters or marital commitments.

Second, we see that the possibilities for change that are evident in women's post-diagnosis narratives require support from medical authorities who are firm with patients about the need for instituting safer sex practices, as well as community educators, case workers, and mental health providers who use the one-on-one sessions with clients to role-play scenarios and help women acquire skills and confidence for handling these encounters. There is evidence here supporting education models that work with skills, such as step-wise learning, and gaining confidence within the context of relationships.

The challenge for AIDS prevention workers is to appropriate this knowledge for a population that is not yet aware of its vulnerability to HIV – the newly immigrant, monolingual Spanish Latinas. Coupled with the proposals under the first recommendation, the question would be, how can traditional ideas about gender – what we referred to previously as *marianismo* – be used to help women who have not yet adopted new ideas and behaviors in their new country? One suggestion is to build on the idea of women's marriage and family responsibilities by offering classes as part of their outreach programs (versus classes that may target clients only) that engage women in discussions about what it means to be in a relationship and what is involved with getting pregnant and having children. Both topics can support their circumstances while at the same time providing new information on subjects not broached in their socialization, i.e., information on STIs and how all women can be at risk for them. Providers can encourage newly pregnant women and those who aspire to become pregnant (newlyweds) that they should be HIV-tested for the health of their future babies. In doing so, they are appealing to a traditional norm to care for one's children.

A second suggestion from one of our participants is to create outreach activities at venues such as their children's schools where women are 'allowed' to be. Other possibilities for outreach interactions might be at children's doctor and dental appointments, ESL classes, and citizenship courses.

III. Recommendation: Address Fatalism in Developing Ways to Help Infected and Affected Women Cope with Issues with HIV Disclosure

Latinas are subject to a dangerous combination of effects from a traditional cultural socialization. They have had no instruction on sex or disease prevention, they are unable to talk openly about sex, even with husbands or long-term partners, and cultural scripts for men and women allow women the illusion of safety within long-term relationships. The consequences are evident in the circumstances of their testing experiences: all of the women in this sample were compelled by others' suggestions to test for HIV. Over half of them tested after their partners were diagnosed, 3 tested after seeking medical help, and 2 were tested in routine pregnancy exams.[14] This avenue into a life with HIV underscores the fatalistic view of one participant who said, "Life lives you, not the other way around." Women see bad luck befall them and feel powerless. In this recommendation we draw attention to the disempowering effects of fatalism on developing effective coping mechanisms and how they can be countered as Latinas reconstruct their lives around HIV. We will provide some examples of change from women in our sample and discuss ways in which elements of their experimentation can be useful in HIV education and services.

A. Findings

A diagnosis of HIV or AIDS is devastating and the women in this study like the men we studied last year are no less vulnerable to the depression and social isolation that accompanies the process of reconstructing one's life around a serious chronic disease. One of the first casualties of a diagnosis is often an intimate relationship. Eight of 11 women in our sample were in a relationship when they were diagnosed. Two of these women report their relationships were strengthened in the process of dealing with HIV.

> My husband, who has always supported me,…he never criticizes me for my past. We have changed our lives. He used to drink, but not anymore. He doesn't smoke or anything. Finding out I had HIV has helped us spiritually and it has helped us to mature. [34-year-old HIV-positive Latina]

In other cases, the relationship ended because of the death of the partner, or the relationships deteriorated because the HIV-positive partner was dealing with his own disease with anger and "behaving badly." While one woman has resigned herself to the abuse and stayed in the relationship, others have chosen to leave.

> He behaved badly with me despite the fact that I was sick. He had infected me…He didn't want to pay rent. He didn't want to help pay for food. I already had a son. He was bad with him too. He would scold him a lot. He would yell at him. When I had a child with him, we only lived together for a year and then we separated….He was bad to me….I felt hurt by him. More than anything he behaved badly with me, so that's why we separated. [27-year-old HIV-positive Latina]

Significance of Gender Roles

To understand the barriers to leaving, we return to their narratives on gender roles and note some of the points of resistance, or ways in which women may manage to increase their power despite the proscriptions of their roles. Here are some examples:

> My mom didn't know how to work because my dad wouldn't let her. She would prepare food and sneak it out to sell at the schools. I didn't understand. I think my dad would get jealous. He didn't want her to go out. [48-year-old HIV-positive Latina]

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[14] Six of 11 women tested when a partner became sick. Of these, 2 are still HIV-negative and test regularly. Of the 9 women in the sample who are positive, 8 said they contracted HIV from unprotected sex with a man.

> [My mom] would advise us: "Do this right [in reference to performing one's gender role appropriately], because when you get married, you'll take a frying pan to the head [if you don't]. Wash and iron the right way, cook well." [Interviewer: Who was going to hit you over the head with a frying pan?] Whoever I married! But, it's all backwards, because I would be the one that hit with the frying pan! [*Both laugh*.] [43-year-old HIV-positive Latina]

> I think [now] that we are both equal. I clean the house, you can clean it too, you have 2 hands. I work, you work too. [40-year-old HIV-positive Latina]

Women critique their roles from that standpoint – the "frying pan" story is such an example of turning the tables on power within the woman's sphere.

An HIV diagnosis also affects a woman's relationship with her children. Only three said they have told their children something about their health status. Determination to disclose to children is partially made on the basis of the children's ages. The mother of adult children was concerned initially that they would worry, but now they are a source of support for her.

> [Initially,] they were sad, because we never thought that would happen in the family, that their mother would have HIV. [But] not any more. We talk more. It's like they aren't scared anymore. They used to say, 'Mom is going to die.' Now they definitely motivate me more. They treat me normally. [59-year-old HIV-positive Latina]

With younger children the fear is that they will not be discrete and the information would find its way into the community at large, and the family would suffer the resulting negative effects of community stigma regarding HIV. Women assumed their children would "accidentally tell their friends who will then tell their parents. Our community rejects everything." [06] Some hope they can tell their children when they get older, saying that "when she can understand it better and she can keep it to herself, then I will talk with her. Not now." [34-year-old HIV-positive Latina]

Shame and embarrassment play a role in encouraging silence in those children who do know or who suspect something. One child knows his father is sick "but he hasn't asked why…He knows something is wrong [but] he knows what to do – stay quiet and not ask too many questions." [27-year-old HIV-positive Latina] In another case, a child knows he is HIV-positive, but "he never says anything. I don't understand why he has never asked me anything. He doesn't talk to anyone about the disease." [39-year-old HIV-positive Latina]

Impact on Reproductive Decisions

Reconstructing a life with HIV also involves making decisions about motherhood with future pregnancies. All of the women in our sample have children, and in all but one case, these children were either conceived or born prior to an HIV diagnosis. We asked for their thoughts on having more children and found that most of the women had considered this possibility early on and made decisions on sterility procedures (tubal ligation) or incorporating safer sex practices into their intimate relationships. Five women have chosen celibacy. Asked if they made this decision on their own, 3 women said, yes, and one added, "by myself, for myself.

> I didn't care what he said or didn't say. Nothing he said counted with me… because he infected me. [27-year-old HIV-positive Latina]

They have assumed a high risk of the baby being infected through the mother. However, one woman in the sample provides a different perspective and a different choice. Because she had not yet had children at the time she was diagnosed, with the help of her partner and her medical practitioner, she had 2 successful pregnancies, and neither her husband nor her children have seroconverted.

> I had 2 kids after knowing I was infected. I don't want more. It's a lot of responsibility. Because I didn't have kids before [infection], I really wanted a family. Luckily, they were born negative and I really took care of myself by taking my medications. I made that decision with my partner….We have always protected ourselves by using a condom. I got pregnant after we talked with our doctor and she said I could have a baby because the virus was undetectable. There wasn't much chance that he would get the virus…Thank God I had my husband's support and also I asked a lot of questions. My doctor said that if I continue with my treatments, there was a 5% chance my child would be born with it. That 5% tormented me. Both my kids were born negative and my husband is tested every 6 months and is negative as well…" [34-year-old HIV-positive Latina]

Not all women were comfortable with the risks involved, but this woman's story provides us with a picture of how women can make health decisions with the support and assistance from partners and doctors.

Limiting disclosure is a central strategy in these women's disease management. They are faced with changing communication practices in sexual encounters – or choosing celibacy. They are faced with the possibility of future pregnancies – or choosing sterility. And when encouraged to expand their support system as a positive coping mechanism, they choose social isolation. Is this secrecy serving them well? For women who may feel overwhelmed by the changes HIV brings into their lives, disclosing their status to others – even for those who have been diagnosed over 10 years – is threatening to their sense of normalcy and control over their environment. In all cases, only a few family members *at the most* know of their condition. In two cases, only one other person knows (partner or family member), and one woman who is newly diagnosed (one year) has not yet disclosed to anyone. They reason that by not disclosing they can avoid the possibility of rejection, or of their own sense of shame coming between them and others, and they don't have to worry their families. Many of them emphasized that with the medications they are healthy, and not disclosing allows them to interact with their families as they did before their diagnosis.

Family Support

It is not surprising then that half of these women found their children and their family to be the best help to them in coping with HIV.

> My children have motivated me to keep going. [43-year-old HIV-positive Latina]
>
> I think my partner has helped me a lot psychologically, with love, support. He lifts my spirits and tells me it's just like any other disease. [34-year-old HIV-positive Latina]
>
> You enjoy the time you have with your children, your mother. It makes you grow as a person. [27-year-old HIV-positive Latina]

However, case management and mental health services remain key sources of support for all of these women.[15] They are especially important since "no one on the outside knows." [59-year-old HIV-positive

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[15] See Appendix __ for a summary of their responses regarding use of county health services.

Latina] A case worker is not only important in connecting a client to services but is someone who can act as a confidant and friend.

> I can talk to her about my anxieties, depression, anything. [34-year-old HIV-positive Latina]
>
> [She] is always concerned about me. Sometimes she buys the children presents at Christmas time and when my son had an operation, she sent a card. She's a good person. [48-year-old HIV-positive Latina]
>
> [She] has a counselor there. [She] calls me every once in awhile to go talk to her. That helps. Sometimes I call her and she tells me to go over to talk. [48-year-old HIV-positive Latina]
>
> Those who take care of me, such as the social worker…I feel that they hear me out. They have the patience…to let me express whatever is going on at the moment, and what I feel, and they don't reveal what I share with them…. When I go to my appointments, they try to make me feel good. I've noticed that they try to motivate me – they ask how I'm doing and all that. To me, that counts, because it lifts my self esteem. [43-year-old HIV-positive Latina]

Mental Health Issues

Managing a chronic disease inevitably involves managing mental health, especially depression, so formal sources of support are critical for women who have chosen to limit their informal support system. Depression affects their relationships with partners and children. It often emerges from struggles with other aspects of their lives besides HIV, and it can sometimes spiral out of control. The complexity of causes and the diversity of patterns in how depression manifests itself make mental health services vitally important to these women's support systems.

> The psychologist was the one that helped me move forward. She knew how to explain HIV to me…. I can explain to the psychologist how I feel and she listens. My daughter listens, but it's not the same as when I open up my heart to someone who is able to help me. I don't want to…worry my daughter more." [59-year-old HIV-positive Latina]

B. Implications for Policy and Practice

The women in our sample are both constrained by and resisted fatalistic ideas. While HIV may be viewed as bad luck in their communities, we hear in these narratives how the women struggle to balance their needs with the consequences of disclosure. Because of their relative good health they can still enjoy a wide range of relationships with friends and family without disclosing their status. At the same time, the need for support from confidants is critical. It is imperative that mental health services and counseling opportunities be widely available in both public and private agencies in the county so that Latinas can get the support they need to manage living with this disease.

A broad range of client contact settings – mental health counseling, medical, case work, and education – can also assist women in preparing to disclose their HIV status to their children. As one mother, a 40-year-old HIV-positive Latina, described feeling frustrated when she disclosed to her children: "I didn't know how to explain it to them." After assessing their particular fears and concerns, service providers can practice role-playing by using sample scripts and wording that is appropriate for different ages of children. If the woman is herself fatalistic, they can work with her on how that sense of fatalism can be used in disclosing to children so that they feel less angry and more at peace with their mother's health status.

Most women we interviewed have been aware of education and prevention efforts since their diagnosis, i.e., materials and messages are being seen in the Latino communities in Ventura County. These media and education outlets should be tapped to encourage more rapid-testing in these communities because of the effect fatalistic attitudes can have in dissuading women from returning to the test site for their results. For one woman in this study, her family was too anxious to wait for the results and instead took her outside the U.S. for testing. She eventually moved back to the U.S. in order to have access to better medical care, but she did not return to the same county in which she originally tested. This kind of mobility disrupts women's disease management strategies and delays access to effective treatment. There is reason to believe that rapid, oral testing will improve the receipt of test results and increase the likelihood that those who test positive will receive HIV/AIDS services.

Conclusions: Recommendations for Future Research

Although this study is exploratory and included a small number of participants, the themes that emerged can be useful in developing further research, interventions, and prevention programs for Latinas. Overall, there needs to be culturally-sensitive efforts to redefine healthy, female adulthood in ways that emphasis how safer sex and HIV testing enhance a woman's ability to be a good wife and mother. In the words of one study participant, "[Women] need to love ourselves before our husbands and listen to our bodies." [33-year-old HIV-affected Latina]

Women in this study were naïve about HIV and sex prior to their sexual relationships and prior to their partners' diagnoses. Once that status was disclosed or their own seroconversion was identified, they actively sought out information and, in several cases, additional counseling for help on managing HIV. One challenge for educators may be to explore the possibility of translating these "post-diagnostic" traits into education and prevention messages for women who are "pre-diagnostic" and targets of their education programs. Specifically:

- Most HIV-positive women in this study moved <u>from dependency to self-sufficiency</u>, choosing to remain single and raise their children on their own.
- All of these women, either infected or affected, moved <u>from naiveté to sexual intelligence</u>, e.g., educating their sexual partners about disease prevention, and choosing strategies that lower their risk of receiving or transmitting viral strains.
- Women moved <u>from being other-protective to being self-protective</u>, in some cases preferring celibacy to the difficulties of negotiating condom usage within disempowering relationships.

For case workers and other counseling professions, a second significant finding highlights women's limited disclosure and the effect on their management of life with HIV. While increasing social support would benefit these women, how much can you move them to increase disclosure when it involves an 'outing' they are reluctant to make? When women state that even their clinic visits are too "public" for them, support in the form of rap groups may not be an effective solution. What is needed is the creation of a safe space, preferably one-on-one with a counselor, in which confidentiality can be assured, and in which trust and communication skills can be nurtured. From there women can gradually expand the circle of family and friends who can provide support.

Finally, Latinas' vulnerability to HIV infection and their social isolation in living with the disease underscores the need for developing leadership on HIV issues within Latino communities. Increased visibility of HIV prevention and education measures should be seen in school programs on sexual health and in media campaigns to normalize condom use and STI/HIV testing.

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APPENDIX A

Informed Consent Form
HIV-Positive Latinas

You are invited to participate in a research study being conducted by Dr. Adina Nack, Ph.D. of California Lutheran University and Dr. Marilyn Gesch, Ph.D., a sociologist and research consultant. We are working with local health care providers to find out how to better serve Latino communities 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 Anthony Flores at 650-9256 (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 Latinas, and your name was randomly selected from women who are clients of Ventura County Public Health Department. We would like to find out what you have to say about being diagnosed with HIV. We would also like to hear 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 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 female, because you are Latina, because you might speak Spanish, and because you live in Ventura County.

A professionally-trained interviewer would like to talk with you and tape-record your conversation with her about your sexual health experiences. The interview should take approximately one hour and 30 minutes, depending upon how much you would like to tell her. 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

Informed Consent Form
Latinas With HIV-Positive Partners

You are invited to participate in a research study being conducted by Dr. Adina Nack, Ph.D. of California Lutheran University and Dr. Marilyn Gesch, Ph.D., a sociologist and research consultant. We are working with local health care providers to find out how to better serve Latino communities 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 Anthony Flores at 650-9256 (Spanish-speaking).

We want to investigate how different people's lives are affected by having a loved one who is HIV-Positive. We would like to talk with people in our county about their sexual health experiences. This study will focus specifically on Latinas, and your name was randomly selected from women whose boyfriends or husbands are HIV-Positive clients of Ventura County Public Health Department. We would like to find out what you have to say about being in a relationship with a man who living with an HIV or AIDS diagnosis. We would also like to hear 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 a partner with 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 female, because you are Latina, because you might speak Spanish, and because you live in Ventura County.

A professionally-trained interviewer would like to talk with you and tape-record your conversation with her about your sexual health experiences. The interview should take approximately one hour and 30 minutes, depending upon how much you would like to tell her. 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.

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

____	_________________________
Printed Name	Telephone Number
____	_____________
Signature	Date

APPENDIX B

INTERVIEW GUIDE FOR HIV-POSITIVE CLIENTS
Pilot Study of HIV-Positive Latinas 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 any written materials from this project.

After we're finished with the interview, you will be given a $30 Target gift certificate as a thank-you for your participation today. To get us started, let's look at the Informed Consent Form for this research study. I'll read through it with you, and you can let me know if you have any questions about it. Then, I will ask you to sign and date it.

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

1. How long have you lived in Ventura County? [*answer: number of years in county, number of years in U.S.*]
    a. Where were you born? [*skip if life-long county resident*]
    b. Where were your parents born?
    c. [*If born elsewhere*] How old were you when you came to the U.S.? How old are you now?
    d. [*If born elsewhere*] Why did you move to Ventura County?
    e. 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?

[Social Support Questions – part 1]
B. I'm going to ask some questions now about your family. I won't be asking for names or information about family members that might reveal their identities.

1. Are you currently in a relationship? Are you currently married, single, divorced/separated, widowed, dating [*man, woman?*]
   [*Note: If respondent is single and not dating, skip question no. 2 about spouse/partner and move to question 3 regarding HIV status, omitting "or spouse/partner."*]
2. [*If living with spouse or sexual partner…*]
    a. How long have you been together?
    b. Where did you meet each other?
    c. Is your spouse/partner employed? What does s/he do?
3. Do you have children? [*If yes,*] How old are your children? [*If adult children,*] Do they live with you? *If not with you,* Are they living in the county?
4. Which of your other family members live here in Ventura County?
5. How often do you see or talk with your family members who are local? How about family members who don't live in Ventura County?

[Sex and sexuality questions]

C. In these next questions, we want to understand what you think about sex and what that has been like for you in the sexual relationships you have had. Since HIV can be sexually transmitted, we need to ask questions about sexual behaviors.

[Sex education]

1. First of all, what did you learn about sex when you were a child? *Prompts:* What sort of things do you remember people saying about sex when you were young? Who said them? Was it from your parents? Brothers or sisters? Teachers? Priests?
    a. Did your parents ever sit you down and talk about how babies are made? Why/why not?
    b. Where did you learn how condoms were to be used?
    c. Do you remember having sex education classes in school? What do you remember about those classes?
        i. Did they demonstrate to the class how to put on a condom?
        ii. Did you learn any other methods of birth control or disease prevention?

[Ideas about being a woman]

1. When you were a girl, what did you learn about what it meant to be a woman?
2. How about now that you are an adult, what do you think is expected of you as a woman? (*As a wife? As a girlfriend? As a mother?*)
    a. Was it expected that you would get married and have children?
    b. Was it expected that you would have to work outside the home?
    c. How did the women in your family and in your community manage their different roles of working, raising children and being a wife?

[Sexual relationships & safer sex practices]

1. Have you been married before or lived with a man prior to this relationship?
    a. How long did that relationship last?
    b. Have there been other sexual relationships in the past?
2. How old were you when you first became sexually active?
    a. How did you meet that first partner? How old was he (she)?
    b. Was that experience positive or negative for you? Why?
    c. Did you and this first sexual partner use a condom? Why/why not?
3. What did you or your friends think about condoms back then?
4. As an adult, have you talked about using condoms with sexual partners? Why/why not?
5. Do you talk about safer sex practices with your current partner(s)?
    a. What kind of protection do you use? [*How does respondent define "safer sex"?*]
    b. Can you give me an idea of what that conversation is like?
    c. Have there been times when you have not used a condom when having sex?
        i. What are some of the reasons why that has happened?
    d. Are there times when you wish you could talk about protection with your partner but you don't? What stops you?
        i. [*If fear of partner's reaction is involved*] Have you thought about how you would like to change that situation? What would you like your partner to do or say when you feel it is necessary to use protection? What would you like to do or say?
        ii. Has a sexual partner ever taken the initiative and used a condom before you have a chance to ask him?

   e. Have you ever talked to a health worker about safer sex practices since you tested positive for HIV? What did you talk about? Did you find it helpful to talk with someone other than a friend?

[HIV and other STDs]

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

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]

[HIV/AIDS Educational Outreach]

1. Have you ever had any health worker ask you about getting tested? [yes/no] What do you remember about this interaction?
   a. *If interviewee has children,* Do you remember if any health worker asked you about testing for HIV when you were pregnant with any of your children?
   b. Have you thought about having children since then? What decisions have you made about having (more) children? Did you make this decision with your partner?
2. Have you ever seen any printed information
   a. that talked abut using condoms? [yes/no] Where?
   b. on how a person can get AIDS? [yes/no] Where?
   c. about getting tested for HIV? [yes/no] Where?
3. Did you ever feel that this information was important to you? [Why or why not?]
4. [*If no to all of questions 1-4*] On your own, did you ever try to find out more about AIDS? Why or why not?

[HIV Testing Experiences]

E. In this next section we're going to talk about your experiences with HIV and AIDS.

1. Has your spouse/partner ever been tested for HIV? Do you know your spouse's/partner's status? What is it?
2. [*If she has a partner who tested for HIV*] Why did your partner get tested?
   a. Do you know when he was tested?
   b. Where did he go?
   c. Did you go with him?
   d. Were you there when he got his results?
   e. How did you feel when your partner told you the test results?
   f. Does he talk much about HIV? Why/why not? What does he say about it?
   g. How do you think that he became infected with HIV?
   h. Did your partner tell anyone that he had tested positive? [Who? Why?]
      i. Has he or you told your children? Why/why not? What sort of things have they said to you about their father having HIV?
      ii. If they haven't been told, do you think they should know? Does it bother you that they don't know? What would you do differently if they did?
   i. Is there anyone among family, friends, co-workers, employers, etc. he has not yet told about his HIV status? Why do you think he hasn't told them?

3. I'd like to ask some questions now about your testing experience.
   a. What prompted you to get tested?

    b. How many times have you had a HIV test?
    c. What were your primary thoughts and concerns before you decided to get tested?
    d. 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.]
4. What were the circumstances?
    a. How old were you when you first tested for HIV?
    b. Where did you get this first test?
    c. How did you find out where to get tested?
    d. Did you tell anyone that you were going to get tested? [Who? Why?]
    e. What do you remember about talking with the testing counselor before your test?
    f. How did you feel while you were waiting for your test results?
    g. Did you expect to test positive or negative? [Why or why not?]
    h. How do you think you became infected with HIV?
    i. Have you told anyone that you have tested positive? [Who? Why?]
        i. Have you told your spouse/partner? Why/why not? What was his (her) reaction?
        ii. Have you told your children? Why/why not? What sort of things have they said to you about your having HIV?
        iii. If they haven't been told, do you think they should know? Does it bother you that they don't know? What would you do differently if they did know?
    j. Is there anyone among family, friends, co-workers, employers, etc. you have not yet told about your HIV status? Why haven't you told them?

[Social Support Questions – part 2]

1. What do you think has helped you the most in dealing with your HIV status?
2. Where would you go or who would you seek out if at times you get depressed about it?
    a. Why would you make this choice?
    b. How about when you are lonely?
3. Where do you go or what do you do when you want to relax or have a good time?
    a. What do you like about that place/activity?
    b. Do you tend to go with someone, or meet friends there?
    c. Does your husband/partner come with you? When you go somewhere with him, is the choice of where to go his idea or your idea? Do you both have friends there, just his friends, or just your friends?
4. Who do you talk to when you need to make a health-related decision?

If applicable (i.e., if participant has a partner and if partner is HIV-positive):

- How about your husband/partner – does he talk to you or spend time with you when he's depressed about HIV? How does that make you feel?
- Does he come to you when he needs to make a health-related decision? (for example, deciding on HIV medications and treatment)

[Use of local health services]

1. Do you use any health services from Ventura County Public Health or other agencies?
    a. What have you found to be most helpful?
    b. What do you think needs to be improved?
2. Do you know others who are hesitant to seek out Public Health services? Why do you think they are?

[Advice to Latinas]

F. Finally, I'd like to ask you what advice you would give other Latinas about HIV.

1. Do you think that some of your women 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?

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 B

INTERVIEW GUIDE FOR HIV-AFFECTED CLIENTS[?]

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 any written materials from this project.

After we're finished with the interview, you will be given a $30 Target gift certificate as a thank-you for your participation today. To get us started, let's look at the Informed Consent Form for this research study. I'll read through it with you, and you can let me know if you have any questions about it. Then, I will ask you to sign and date it.

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

3. How long have you lived in Ventura County? [*answer: number of years in county, number of years in U.S.*]
    a. Where were you born? [*skip if life-long county resident*]
    b. Where were your parents born?
    c. [*If born elsewhere*] How old were you when you came to the U.S.? How old are you now?
    d. [*If born elsewhere*] Why did you move to Ventura County?
    e. Do you work here? What do you do?
4. You had asked that this interview be conducted in [English/Spanish]. Is this your primary language? What language do you speak most often?

[Social Support Questions – part 1]
B. I'm going to ask some questions now about your family. I won't be asking for names or information about family members that might disclose their identities.

6. Are you currently married, single, divorced/separated, widowed, dating [*man, woman?*] [*Note: If respondent is single and not dating, skip question no. 2 about spouse/partner and move to question 3 regarding HIV status, omitting "or spouse/partner."*]
7. [*If living with spouse or sexual partner…*]
    a. How long have you been together?
    b. Where did you meet each other? Where?
    c. Is your spouse/partner employed? What does s/he do?
8. Do you have children? Are they school-age or adults? *If adults*, Do they live with you? *If not with you, a*re they living in the county?
9. Which of your other family members live here in Ventura County? Do they work here? What do they do?
10. How often do you see or talk with your family members who are local? How about family members who don't live in Ventura County?

[Sex and sexuality questions]

C. In these next questions, we want to understand what you think about sex and what that has been like for you in the sexual relationships you have had. Since HIV can be sexually transmitted, we need to ask questions about sexual behaviors..

[Sex education]

2. First of all, what did you learn about sex when you were a child? *Prompts:* What sort of things do you remember people saying about sex when you were young? Who said them? Was it from your parents? Brothers or sisters? Teachers? Priests?
    a. Did your parents ever sit you down and talk about the "facts of life"? Why/why not?
    b. Where did you learn how condoms were to be used?
    c. Do you remember having sex education classes in school? What do you remember about those classes?
        i. Did they demonstrate to the class how to put on a condom?
        ii. Did you learn any other methods of birth control or disease prevention?

[Ideas about being a woman]

3. When you were growing up, what did you learn about being a woman?
4. How about now that you are an adult, what expectations do you feel you have as a woman (*wife, partner, mother, etc*.)?
    a. Was it expected that you would get married and have children?
    b. Was it expected that you would have to earn a living as well?
    c. What were you taught, or what did you see in the women in your family and in your community, about how to manage all these roles of working, raising children and being a wife?

[Sexual relationships & safer sex practices]

3. Have you been married before or lived with a man prior to this relationship?
    a. How long did that relationship last?
4. Have there been other sexual relationships in the past?
5. How old were you when you first became sexually active?
    a. How did you meet that first partner? How old was he (she)?
    b. Did you have sex with this partner more than once? About how often/over what period of time?
    c. Was that experience positive or negative for you? Why?
    d. Did you or your partner talk about using a condom? Why/why not?
    e. What did you or your friends think about condoms back then?
6. As an adult now, have you talked about using condoms with sexual partners? Why/why not?
7. Do you talk about safer sex practices with your current partner(s)?
    a. What kind of protection do you use? [*How does respondent define "safer sex"?*]
    b. Can you give me an idea of what that conversation is like?
    c. Have there been times when you have not used a condom when having sex?
        i. What are some of the reasons why that has happened?
    d. Are there times when you wish you could talk about protection with your partner but you don't? What stops you?
        i. [*If fear of partner's reaction is involved*] Have you thought about how you would like to change that situation? What would you like your partner to do or say when you feel it is necessary to use protection? What would you like to do or say?
        ii. Has a sexual partner ever taken the initiative and used a condom before you have a chance to ask him?

   e. Have you ever talked to a health worker about safer sex practices since your husband/partner tested positive for HIV? What did you talk about? Did you find it helpful to talk with someone other than a friend?

[HIV and other STDs]

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3. How did you first learn about sexually transmitted diseases? [*book, doctor, family, friends, teacher*]
4. 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]

[HIV/AIDS Educational Outreach]

5. Have you ever had any health worker ask you about getting tested? [yes/no] What do you remember about this interaction?
   a. *If interviewee has children,* Do you remember if any health worker asked you about testing for HIV when you were pregnant with any of your children?
   b. Have you thought about having children since then? What decisions have you made about having (more) children? Did you make this decision with your partner?
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7. Did you ever feel that this information was important to you? [Why or why not?]
8. [*If no to all of questions 1-4*] On your own, did you ever try to find out more about AIDS? Why or why not?

[HIV Testing Experiences]

E. In this next section we're going to talk about your experiences with HIV and AIDS.

1. Have you ever tested for HIV?
   a. What is your status?
   b. How often do you get tested?
   c. Does your spouse/partner accompany you?
5. Has your spouse/partner ever been tested for HIV? Do you know your spouse's/partner's status? What is it?
6. [*If she has a partner who tested for HIV*] Why did your partner get tested?
   a. Do you know when he was tested?
   b. Where did he go?
   c. Did you go with him?
   d. Were you there when he got his results?
   e. Did he tell you or did a doctor or health worker tell you? What did he say?
   f. Did any doctor or health worker talk to you afterward? What did they say?
   g. Did you or your partner ask the doctor any questions?
   h. How did you feel when your partner told you the test results?
   i. Did he want to talk about it then? Why/why not?
   j. Does he talk much about HIV? Why/why not? What does he say about it?
   k. How do you think that he became infected with HIV?
   l. Did your partner tell anyone that he had tested positive? [Who? Why?]

        i. Has he or you told your children? Why/why not? What sort of things have they said to you about their father having HIV?
        ii. If they haven't been told, do you think they should know? Does it bother you that they don't know? What would you do differently if they did?
    m. Is there anyone among family, friends, co-workers, employers, etc. he has not yet told about his HIV status? Why do you think he hasn't told them?

[Social Support Questions – part 2]

1. What do you think has helped you the most in dealing with your spouse's/partner's HIV status?
2. Where would you go or who would you seek out if at times you get depressed about it?
    a. Why would you make this choice?
    b. How about when you are lonely?
3. Where do you go or what do you do when you want to relax or have a good time?
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    c. Does your husband/partner come with you? When you go somewhere with him, is the choice of where to go his idea or your idea? Do you both have friends there, just his friends, or just your friends?
4. How about your husband/partner – does he talk to you or spend time with you when he's depressed about HIV? How does that make you feel?
5. Does he come to you when he needs to make a health-related decision? (for example, deciding on HIV medications and treatment)

[Use of local health services]

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[Advice to Latinas]

F. Finally, I'd like to ask you what advice you would give other Latinas about HIV.

3. Do you think that some of your women 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?]
4. 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?

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