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ORIGINAL PAPER

Addressing the Need for Access to Culturally and Linguistically Appropriate HIV/AIDS Prevention for Latinos

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Abstract This article reports a comprehensive national needs assessment of Latinos' access to HIV/AIDS prevention and education services in 14 cities throughout the United States and Puerto Rico. Interviews and focus groups were conducted with Latinos who were HIV-positive and at risk for HIV infection. The study explored risk behaviors, access to health care services, and exposure to HIV prevention messages. Differences in predictors of risk behaviors were noted by sex. For women, increased age, being married, foreign-born, and a U.S. resident, and having tested for HIV previously, were associated with reduced HIV/AIDS risk. Thematic analysis of qualitative findings revealed limited awareness of risk factors, and a need for culturally and linguistically appropriate, family-centered HIV/AIDS education incorporating Latino values. Findings were incorporated into culturally relevant brochures featuring vignettes and quotes. Brochures were distributed and evaluated by 71 community-based organizations (CBOs) in the U.S. and Latin America. Evaluators responded positively to the brochures, and Latino-serving organizations in 48 states now use them for HIV/AIDS prevention outreach and education.

Keywords HIV/AIDS · Latino/Hispanic · Prevention · Culture, Language

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Introduction

Increasingly, HIV/AIDS has disproportionately affected the Latino population in the United States [1]. As of 2005, Latinos had the second highest annual AIDS case rate among all ethnic minorities (24.7 per 100,000) following African Americans (71.3 per 100,000), and greatly surpassing Whites (7.3 per 100,000) [2]. When HIV diagnoses are factored in, the HIV/AIDS case rate for Latinos retains second ranking among other racial/ethnic groups, but increases to 39.4 per 100,000. While Latinos comprise 14% of the U.S. population, they accounted for 19% of the

cumulative 956,019 AIDS cases reported to the CDC through 2005 [3, 4]. As Latino mega-states such as Texas have joined states reporting HIV using name-based criteria as specified by the Centers for Disease Control and Prevention (CDC), the number of reported HIV cases has risen by 35% among Latinos [5].

There are approximately 42 million Latinos living in the United States [6], including persons of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin, regardless of race. Since 1999, Latinos living with AIDS have resided in all 50 states, the District of Columbia, Puerto Rico and the U.S. Virgin Islands, with 91% of these concentrated in ten states and 60% in 10 metropolitan areas [7]. The impact of AIDS among Latinos has varied by country of birth, with the majority of cases concentrated among those born in the continental U.S. (32%), Puerto Rico (18%), and Mexico (18%), followed by Central and South America (10%) and Cuba (2%), with 20% among persons of unknown birth place [8].

It is difficult to measure prevalence among this vulnerable population, due to discrepancies in federal and state reporting requirements. For example, newly diagnosed HIV infections are not published in the CDC Surveillance Report from four of the top ten states within which 37% of the nation's Latinos reside, and which have the largest number of Latino AIDS cases: California, Illinois, Connecticut and Massachusetts [9]. It is also likely that many HIV cases are undiagnosed among Latinos living in the southwestern border states, as current immigration policy excludes persons known to be HIV positive from obtaining legal residency in the United States [10, 11]. Therefore, a large number of Latinos may be unwilling to test for HIV for fear of jeopardizing their future residency status.

Through 2004, HIV/AIDS transmission patterns among Latino men were similar to other racial/ethnic groups, with the majority of infections attributed to male-to-male sexual contact. However, injection drug use (IDU) and heterosexual contact accounted for a greater share of overall Latino infections when compared to white men. Latinas, similar to white women, were more likely to be infected through high risk heterosexual sex, but Latinas were at slightly reduced risk for infection through injection drug use [12, 13]. Additionally, there are significant differences in the modes of transmission dependent upon birth country. Male-to-male sexual contact was the most common transmission category for Latinos born in the United States, Central/South America, Mexico, and Cuba, followed by high-risk heterosexual contact. Those born in Puerto Rico, however, were more likely to have been infected through IDU [14].

The increasing rate of heterosexual transmission among Latinos reflects women's greater biological vulnerability for HIV infection and suggests a growing threat to Latinas' health and concern for Latino families. Many Latino men who have sex with both men and women are married or involved in heterosexual relationships in which sex with other men is not acknowledged or disclosed. Latinas in long-term relationships often identify themselves as being invulnerable to HIV infection because they perceive HIV as a disease that only affects homosexuals, sex workers and IDUs [15, 16]. Latina women are thus often completely unaware of their risk for HIV until their husbands or partners become ill, they are tested during pregnancy, or they become symptomatic [17].

Finally, the advances in HIV/AIDS treatment that have led to declines in new diagnoses and deaths among whites and other minorities have not benefited Latinos. While both African Americans and whites experienced slight decreases in the number of deaths from AIDS between 2001 and 2005, for Latinos the number of deaths remained stable [18]. In 2003, the HIV/AIDS death rate was 2.7 times higher for Latino males (9.2 per 100,000) than for non-Latino white males, and 4.5 times higher for Latina females (2.7 per 100,000) than for non-Latina white females [19].

Latinos face many barriers to medical care as a result of higher than average rates of uninsurance, language and literacy barriers, and prevailing treatment modalities that run counter to their cultural practices, beliefs and behaviors [20, 21]. They are also less likely to use preventive health services than other population groups [22]. Specific barriers to HIV testing include, for Latino males, perceptions of not being at risk and not thinking about being tested [23]. Barriers for Latina females include lack of cultural support, knowledge or skills needed to effectively communicate with their partners about sexual topics, and lack of awareness of their male partners' high risk behaviors increasing their vulnerability to HIV [24–26].

Still, there are few culturally and linguistically appropriate HIV/AIDS prevention, screening, or disease management programs for medically underserved Latinos living in the U.S. A recent meta-analysis of interventions for people living with HIV (PLWH) demonstrated the efficacy of interventions that were well grounded theoretically, delivered in appropriate settings by respected providers or counselors, and provided behavioral skills training [27]. While there have been few studies on HIV interventions in the Latino community that would meet the rigorous criteria of this meta-analysis, some examples appear consonant with its findings and also illustrate the importance of employing culturally appropriate methods and media such as story-based *fotonovelas* and *radionovelas*. Use of these media to disseminate HIV/AIDS information to Latino migrant farm workers resulted in improved knowledge, attitudes, and use of condoms among prostitutes [28–32] and in a national campaign to promote family acceptance of members with AIDS [33].

Consonant with the federal effort to reduce health disparities for racial and ethnic minority populations, and in response to the paucity of research related to HIV risk among Latino migrants [34], the National Council of La Raza (NCLR) initiated the NCLR Latino Families HIV/AIDS Prevention Project in 2000 with a needs assessment to determine Latinos' HIV infection risk, barriers to prevention, exposure to media messages and HIV prevention education among Latinos, and the medical and social support needs of HIV-positive Latinos. This article reports findings from the needs assessment and describes the subsequent development of culturally and linguistically relevant written health education materials. The manuscript also discusses community reactions to the health education materials, and presents preliminary evaluation findings from staff and clients of the community-based organizations currently using project materials.

Methods

Study Objectives

The Latino Families HIV Needs Assessment Project began in 2000. Researchers conducted focus groups with Latino men and women at risk for and living with HIV infection, and individual interviews with Latinos who were HIV positive. The first 2 years involved women only and the third year involved both men and women in an effort to corroborate female reports of potential male risk behaviors from the first 2 years. These methodologies were designed to be complementary. The interview format can yield rich information related to the contexts of risk from an individual perspective and often allows for more in-depth exploration of personal issues. The focus group is particularly useful for studying dominant cultural values and for gathering information that results from the group process itself [35].

Project activities took place over a 3-year period in 14 cities throughout the United States and Puerto Rico. (See Table 1 for project sites.) The objectives of the needs assessment were to: (1) describe the risks associated with HIV infection among Latino project participants; (2) identify barriers to Latinos' use of preventive HIV/STI health practices; (3) assess Latinos' exposure to HIV prevention education and media messages; and (4) document the needs of HIV positive Latinos. Each project participant engaged in only one activity. Data were collected, transported and analyzed by experienced project staff to protect the confidentiality and anonymity of research participants.

Data Collection

Sample Selection and Recruitment

Using NCLR's existing network of hundreds of Latino community-based organizations (CBOs), 14 cities across the U.S., District of Columbia and Puerto Rico were selected for this project using the following criteria: AIDS case rates of over 25 per 100,000 Latinos; areas with high incidence of substance use among Latinos; states with the

Table 1 Latino families HIV/Latino needs assessment study design

	Year 1	Year 2	Year 3
Site selection criteria	High Latino AIDS case rates	High Latino AIDS case rates	High Latino AIDS case rates
	High case rates of women with AIDS	High case rates of women with AIDS (Latinas if possible)	High population growth in new Latino immigrants 1990–2000
	High incidence of substance use and dependency among Latinos	High incidence of substance abuse and dependency	Large Latino state population
		Large Latino population and diverse Latino groups	Proximity to Mexican border
Sites selected	Miami, FL	Harlingen, TX	San Ysidro, CA
	San Juan, P	San Antonio, TX	El Paso, TX
	Paterson, NJ	Los Angeles, CA	Durham, NC
	Hartford, CT,	Boston, MA	Hattiesburg, MI
	New York, NY	Washington, DC	
Methods	Focus groups with high risk and HIV + Latinas	Focus groups with high risk and HIV + Latinas	Focus groups with at risk Latinos and Latinas
	Interviews with HIV + Latinas	Interviews with HIV + Latinas	Interviews with HIV + Latinos and Latinas
Participants	$N = 47$ focus group	$N = 70$ focus group	$N = 84$ focus group
	$N = 43$ interview	$N = 43$ interview	$N = 35$ interview

largest Latino populations and proximity to the U.S./Mexican border; and significant growth and diversity in Latino immigrant populations over the past 10 years. (A list of sites and selection criteria are detailed in Table 1).

The Latino Families HIV/AIDS Prevention Project team identified community based organizations (CBOs) in each of the 14 cities to assist in conducting the needs assessment. Organizational selection criteria included: (1) provision of HIV services to women in particular; (2) a successful history of conducting HIV prevention programs with Latinos; and (3) trained staff with experience in working with HIV-infected Latinos. The NCLR Project Coordinator designated and trained the Community Coordinators and key members of the CBO staff to screen, recruit and consent project participants through the provision of recruitment and interview manuals, telephone conferences, and on-site trainings. The Project Coordinator arrived on-site 1–2 days prior to the first round of interviews and focus groups to assist with recruitment, scheduling, data collection and interview/focus group administration.

Flyers were posted within participating CBOs to recruit both focus group and interview participants. When sufficient numbers of participants were not available from within their organizations' client base, Community Coordinators recruited within correctional facilities, chemical dependency treatment programs, churches and religious institutions, and surrounding neighborhoods using study fliers and posters asking interested Latinos who were HIV-infected or who suspected they may be at risk for HIV infection to contact the CBO anonymously.

Individuals interested in the study were asked to complete a P*articipant Information Form*, which included his or her name, project alias, and the time, location, and process for contacting the participant about the study. Eligibility screening took place in person or by telephone. Potential participants were required to be "at risk" for HIV infection as defined by having one of the following eligibility criteria: (1) unprotected sex with at least one partner in the past year; (2) sex with an intravenous drug user (ever); (3) sex with a man who had sex with a man (ever); (4) recent incarceration (within the last 5 years); (5) intravenous drug use (ever); and (6) any self-reported "at-risk" behavior. Those agreeing to participate were informed of the study's purpose and procedures, and their confidentiality rights prior to providing informed written consent to participate and to allow release of personal information pertinent to the study from the CBO, such as HIV status (self-reported by participants to the CBO). In some cases, the recruitment process required multiple attempts to contact prospective participants, and several calls or meetings to obtain consent. Partner CBOs received a stipend for their assistance in recruiting community members, and participants received grocery store certificates as compensation for their time.

Using an iterative approach, initial results were used to modify methods used in subsequent years. For example, early in the project it was evident that the focus group format was ideal for those who were "at risk" for HIV, but who were still uninfected, whereas the personal interview format was more conducive to discussing confidential and difficult issues regarding personal risk and the context of daily living with HIV. During the first 2 years, project participants were HIV-positive and "at risk" Latinas. Data collected early in the project highlighted the need to include diverse rural and urban Latina subpopulations, especially women from the border regions. Further, the study population was broadened to encompass heterosexual women involved in long-term relationships who did not engage in "high-risk" behaviors as traditionally categorized by the CDC. Based on findings from the first two years, Latino men were included in the project as significant participants in Latinas' HIV-related risk or preventative efforts.

Key-informant Interviews and Focus Groups

Focus group and interview guides were developed with input from CBO staff and the content of the questions was the same in both settings. All instruments were prepared first in Spanish and then translated to English. The English version was then back-translated to Spanish by a native speaker of a different country of origin to assure the accuracy and universality of Spanish across all Latino subpopulations. Finally, an expert in working with low-literacy level Spanish-speaking populations assessed the instruments for reading levels to assure that the reading level was appropriate for the population.

Individual key-informant interviews and focus groups were held in non-threatening settings within participating CBOs that were convenient for participants and allowed for the protection of privacy. Participants received food and drinks during the data collection processes. The in-depth, semi-structured interviews were 1–2 h in duration and were conducted by trained bilingual/bicultural interviewers skilled in HIV/AIDS ethnographic data collection methodology. The focus groups were 2 h in duration and conducted by a doctoral level, bilingual/bicultural facilitator with considerable experience in HIV/AIDS ethnographic research. She was assisted by a master's level coordinator. All staff involved in the research process were trained in interviewing and focus group facilitation skills and data collection techniques to obtain personal information in a non-threatening, culturally appropriate manner.

Demographic, Acculturative, and Risk Behavior Measures

An in-depth questionnaire was administered to all participants prior to the focus group or interview, which included demographic, acculturative, health status and risk behavior measures. For purposes of this paper, the sexual risk behavior outcomes of interest included: (1) whether or not the participant was sexually active in the past 2 years (yes/no); (2) whether he/she had more than one partner (yes/no); and (3) whether or not the participant had sex in the past two years without using a condom (yes/no).

Additionally, select demographic and behavioral factors were analyzed including: sex; age; country of origin (US, Mexico, or other Latin country); country of residence (US vs. Mexico/Puerto Rico); employment status (working vs. not working at time of the interview); participant's weekly income (intervals of $100); marital status (married or living with a partner vs. single, divorced, separated); parity (children vs. no children); and education (high school graduate vs. high school not completed); previous HIV testing behavior; and HIV status (self-reported).

The impacts of language acculturation and time in the U.S. were also examined for non-U.S.-born participants. Native language retention is an important indicator of level of acculturation [36, 37]. Therefore, acculturation was measured by English language use and preference in various social contexts based on a four-item scale validated with Latino populations and demonstrated to be ideal for administering in community research settings. Using a scale from 1 to 5, which measured the percent of Spanish or English language spoken, participants were asked: what language he/she speaks; what language is spoken with friends; what language is spoken at home; and in what language he/she thinks. A mean score of 2.99 or below indicated low acculturation [38].

Data Analysis

Demographic and risk behavior-related data were entered into a data base and analyzed using the Statistical Package for Social Sciences (SPSS) software (11.4 version). Descriptive statistical analyses were performed, and Pearson Chi-square and Logistic Regression analyses were used to evaluate bivariate and multivariate relationships.

An extensive literature review yielded general cultural, contextual and behavioral themes related to HIV risk and Latinos. These general themes were agreed upon by the research team and used to construct the questions proposed during the interviews and focus groups. Qualitative data were transcribed by a national bilingual court reporting service and project staff. All transcriptions were verified for accuracy by a bilingual team of researchers. For analyses purposes, "a priori" contextual coding was conducted on interview and focus group transcripts, and a thematic matrix based was developed. In keeping with an emic approach, additional thematic categories emerging during the focus groups and interviews were deliberated and added to the Matrix; an approach frequently used in qualitative research [39]. Three individuals, including the first author, completed the first contextual coding independently. NCLR project staff then recoded each transcript, using a color coding system to represent the various themes and prepared written summaries for each focus group and interview site. The first author and graduate assistant coders then reviewed the original matrices and summaries and coded responses that they agreed to include in the site-specific analyses. Discrepancies in coding were flagged and deliberated until the coders reached agreement. When consensus was not reached the selected text was discarded from the final analyses. The "consensus based dispute resolution" approach [40] resulted in an inter-rater reliability of 100%. These activities produced site-specific thematic analyses for each project site that were combined into a comprehensive thematic matrix used for cross-site analysis.

Results

Participant Demographics

At the end of the 3-year project, a total of 322 participants were enrolled in the study, the majority of whom (80%) were women. The study sites were fairly evenly represented with 5–8% of participants from each site (Table 2), with the exceptions of Durham (9.6%), El Paso (10.2%) and San Ysidro (11.5%). Focus group participants comprised a little over 62% of the sample, and focus group and interview participants were mutually exclusive.

Immigrants from Mexico were the largest group of participants (32%) followed by individuals born in the United States (30%), Puerto Rico (19%), and other Latin countries (19%). (The authors chose to keep the U.S. born participants in this sample as a large number of participants traveled across the border frequently, and the border communities were reportedly cohesive indicating a shared culture irrespective of birth country.) The vast majority of participants resided in the United States at the time of the study (90%). The remaining 10% of the sample was comprised of Puerto Ricans residing in San Juan and Mexicans residing in Matamoros and Tijuana, who traveled to Harlingen, Texas and San Ysidro, California. In all, non-U.S. born participants originated from15 distinct Caribbean and Latin American countries and the mean number of years lived in the U.S. among this group was 13.5 years. The language acculturation level among this sample of

Latino U.S. residents was low (mean score of 2.36), and varied considerably depending on whether one was born in the U.S. (3.52), or born outside of the U.S. (1.78). Acculturation scores ranged from a low of 1.38 in Washington, DC to a high of 3.60 in Paterson, New Jersey.

Just fewer than half of the participants (47%) were married or living with their partners. Less than half (39%) reported they were working at the time of interview, however, 55% of the sample reported a median weekly income of $101–200. The mean number of individuals living in each household was 3.66, with a range from 1 to 25. Of the 262 participants who reported having children, 70% had 1–4 children, while the remaining 12% had 5–12 children. The mean number of children was 2.36, ranging from 1.52 in Durham to 3.17 in Washington D.C. The majority of participants (58%) had not completed high school; 23% had never attended high school and 10% had not completed primary school. Of the 38% who had completed high school, only 6.5% graduated from college. The mean sample age was 35.86, and ranged from 15 to 72 years.

HIV Status and Risk Behaviors

Almost half of the participants (45%) had been diagnosed with HIV/AIDS, and 81% reported they had tested for HIV prior to study involvement. Eighty-five percent of participants reported they were sexually active in the past 2 years, 64% reported they had sex in the past 2 years without using a condom, and almost 30% reported they had more than one sexual partner in the past 2 years. Although the sample sizes are very small, for purposes of comparison, condom use was least prevalent in Durham, North Carolina, where slightly over 90% of participants reported having had unprotected sex in the previous 2 years, followed by Miami, Washington, DC, and San Antonio where 83–76% of participants had experienced unprotected sex within the past 2 years. New York had the lowest rate of unprotected sex at 33.3%. In summary, the lack of condom use within this sample even for participants who reported only one sexual partner represents a significant risk factor considering that 80% of the respondents were women whose primary risk is unprotected sex with their main partner.

Quantitative Findings

Bivariate analyses of key variables revealed differences by sex in the relationships between HIV/AIDS diagnosis and length of stay in the U.S., and the study outcomes of interest. For example, for females, those who had HIV were significantly less likely to have had sex in the past 2 years without a condom compared to women who were HIV-negative ($\chi^2 = 13.893$; $P < 0.001$). Furthermore, again for women only, there was a statistically significant

Table 2 Distribution of study variables[a]

Study variables	Women		Men		Full sample	
	$n = 259$		$n = 63$		$n = 322$	
	%	Mean	%	Mean	%	Mean
Dependent variables						
Sexually active past 2 years						
Yes	86.1		82.5		85.4	
No	13.5		17.5		14.3	
Sex past 2 years no condom						
Yes	63.7		65.1		64.0	
No	26.6		27.0		26.7	
More than 1 sexual partner past 2 years						
Yes	26.6		41.3		29.5	
No	63.7		58.7		62.7	
Independent/Intervening variables						
Study site						
Boston	6.9		0		6.5	
DC	9.7		0		7.8	
Durham	5.8		25.4		9.6	
El Paso	6.2		27.0		10.2	
Harlingen	9.3		0		7.5	

Table 2 continued

Study variables	Women		Men		Full sample	
	$n = 259$		$n = 63$		$n = 322$	
	%	Mean	%	Mean	%	Mean
Hartford	5.0		0		4.0	
Hattiesburg	3.5		14.3		5.6	
Los Angeles	8.1		0		6.5	
Miami	6.9		0		5.6	
New York	9.3		0		7.5	
Paterson	7.3		0		5.9	
San Antonio	8.5		0		6.8	
San Juan	6.2		0		5.0	
San Ysidro	6.2		33.3		11.5	
Gender						
Female					80.4	
Male					19.6	
Age		36.53		33.21		35.86
Birth country						
Mexico	27.0		52.4		32.0	
United States	29.0		34.9		30.1	
Other Latin	44.0		12.7		37.9	
Country of residence						
United States	90.0		92.1		90.4	
Puerto Rico/Mexico	10.0		7.9		9.6	
Years in the U.S.-non US born only	($n = 166$) 14.51		($n = 41$) 11.02		($n = 207$) 13.50	
Language acculturation						
Total U.S. residents	($n = 228$) 2.38		($n = 56$) 2.28		($n = 284$) 2.36	
U.S. born residents	($n = 74$) 3.61		($n = 20$) 3.18		($n = 94$) 3.52	
Non-U.S. born residents	($n = 154$) 1.79		($n = 36$) 1.77		($n = 190$) 1.78	
Marital status						
Married or living w/partner	48.6		38.1		46.6	
Single or separated/divorced	51.4		61.9		53.4	
Employed at interview						
Yes	34.4		57.1		38.8	
No	65.6		42.9		61.2	
Median weekly income		$100–200		$1–100		$100–200
Education level						
HS not attended or completed	63.3		52.4		61.2	
HS diploma	36.3		47.6		38.5	
Individuals per household		3.50		4.10		3.66
Had children						
Yes	90.0	2.63	50.8	1.27	82.3	2.36
No	10.0		49.2		17.7	
Had HIV/AIDS Yes	48.6		28.6		44.7	
No	47.5		54.0		48.8	
Had tested for HIV						
Yes	84.2		68.3		81.1	
No	15.8		31.6		18.9	

[a] Missing data are present where categories do not total 100%

Table 3 Characteristics independently associated with sexual activity without a condom during the preceding 2 years among Latina women ($n = 206$)

Characteristics	Women	
	OR	CI
Age	0.96*	0.92, 0.99
Married or living as married[a]	0.88	0.44, 1.73
Birth country[b]		
Mexico	1.34	0.53, 3.39
Other latin country	1.66	0.75, 3.69
Resides in the U.S.	0.67	0.19, 2.32
High school graduate	1.24	0.62, 2.49
Employed	1.02	0.49, 2.14
Has children	1.32	0.44, 4.04
Had HIV test	0.11*	0.01, 0.906
More than one sexual partner	1.64	0.717, 3.72
Diagnosed with HIV/AIDS	0.56	0.28, 1.10

Note: OR = odds ratio; CI = confidence interval

[a] Referent group = single, separated, divorced, widowed

[b] Referent group = U.S. born

* Significant at the $P = < 0.05$ level

Table 4 Characteristics independently associated with having more than one sexual partner during the preceding 2 years among Latina women ($n = 215$)

Characteristics	Women	
	OR	CI
Age	0.96*	0.92, 0.99
Married or living as married[a]	0.39**	0.19, 0.80
Birth country[b]		
Mexico	0.14***	0.05, 0.38
Other Latin Country	0.21***	0.09, 0.46
Resides in the U.S.	0.17**	0.06, 0.50
High school graduate	0.59	0.28, 1.22
Employed	0.48	0.21, 1.05
Has children	0.53	0.16, 1.69
Had HIV test	0.37	0.13, 1.04
Diagnosed with HIV/AIDS	0.59	0.28, 1.24

Note: OR = odds ratio; CI = confidence interval

[a] Referent group = single, separated, divorced, widowed

[b] Referent group = U.S. born

*** Significant at the $P < 0.001$ level; ** Significant at the $P < 0.01$ level; * Significant at the $P < 0.05$ level

negative relationship between HIV/AIDS diagnosis and having more than one sexual partner in the past two years ($\chi^2 = 7.205$; $P < 0.01$). Finally, length of stay in the U.S. was associated with reduced likelihood of having unprotected sex in the past 2 years for women ($\chi^2 = 9.29$; $P < 0.01$).

Additional analyses were conducted to enhance understanding of HIV/AIDS risk factors among women in this study. Multivariate analysis indicated that when controlling for a number of predictors (Tables 3, and 4), the relationships between HIV diagnosis and length of stay in the U.S. with reduced risk behavior did not hold. However, women of increased age and those who had tested for HIV in the past were less likely to have had sex without a condom in the preceding 2 years (OR = 0.956 and 0.112, respectively, $P < 0.05$). Further, increased age (OR = 0.955, $P < 0.05$) and living in a marital or marital-like status (OR = 0.389, $P < 0.01$) were associated with a reduced likelihood of having more than one sexual partner in the past 2 years. Likewise, women who were born in Mexico (OR = 0.136, $P < 0.001$) or other Latin American and Caribbean countries (OR = 0.207, $P < 0.001$) were less likely to have had more than one partner when compared to women born in the U.S. Finally, women residing in the U.S. were also at reduced risk for having more than one partner (OR = 0.168, $P < 0.01$). When stratifying by residency status and birth country, no significant relationships were found between language acculturation status or time in the U.S. and the risk behaviors of interest in this study.

Qualitative Findings: Key Themes

A total of 23 principal themes were identified from the interviews and focus groups using content analysis. Machismo, condom use and negotiation, stigma/perceived vulnerability, infidelity, disclosure, economic issues, needs of the HIV infected, exposure to media messages, and recommendations were the themes mentioned that most often defined the context of HIV risk within Latinos' lives. (See Table 5 for a complete list of themes.) These themes are complex and illustrate the complicated context of HIV risk and how it is reflected in risk behavior and decision-making. The themes became the primary guiding factors in the development of the educational materials and are illustrated below with quotes (in Italic text) from participants.

Machismo

The Latino cultural expectation of male dominance and protection strongly influenced many aspects of family and sexual relationships. Latina participants reported fears of angering their partners and making them suspicious, as well as disillusionment about their partners' protective roles.

> No matter how much they say they love you, and you're the woman of their life, and you are the

Table 5 Themes list

Theme	Definition
Machismo	Male dominance, protection, jealousy
Marianismo	Female submission, dependence, limited choices
Condom use and negotiation	Male resistance, female fear of asking partner to use
Stigma/perceived invulnerability	Females oblivious to risk, teenagers and males perceptions of invulnerability
Disclosure	Males seldom told female partners
Abuse	How does abuse affect risk for HIV infection?
Chemical use and dependency	Hard to find culturally and linguistically relevant treatment for women and families
Religion	Source of comfort and guidance; source of expectations regarding women's behavior that maintain women at high risk; source of contraceptive and condom use restrictions that result in high risk context
Cultural expectations and norms	Women: Marry and raise children. Men: Provide for and protect women, children
Racism and discrimination	Does being Latino increase risk for HIV due to discrimination? If so, how? Does being HIV positive increase discrimination? If so, how?
Risk among lesbians	To what extent are women who have sex with women at risk for HIV infection?
Risk among homosexuals	To what extent are men who have sex with men at risk for HIV infection?
Medical risk	To what extent do participants believe they are at risk for HIV when visiting a doctor, a dentist, or other healthcare setting?
Economic issues	Single mothers as daytime sex workers in border areas; females dependent on males to provide for the family; females subjugated to meet male sexual expectations as a result of the nexus of their relationship status and their economic dependence
Exposure to HIV prevention	Empowerment prerequisite
Prevention program needs	What prevention program needs can participants identify?
Media message exposure and recommendations	Recall of messages in targeting Latinos in general, Latinas, and other groups
Placement/location of HIV prevention messages	Where do participants believe would be the most effective locations/settings to place HIV prevention messages targeting Latinos?
U.S. Country of origin differences	How is risk different in the U.S. when compared to HIV risk experienced in their home countries?
Male/female sexual scripts	What are the sexual expectations for males and females and how do they differ?
Needs of HIV+ Latino Families	What special needs do HIV+ families experience?
Target audience	What target audiences do participants believe to be the most important when creating HIV/AIDS prevention programs?
Gangs and street violence	How do gangs and street violence impact HIV risk?

> mother of their children…they will not really take care of you.

> We're at risk because they're 'machos.' They like to control us. They make the decisions and it's all about them.

Male participants confirmed problems associated with machismo, but also referred to machismo as a potentially positive set of attributes. They characterized a macho male in the truest sense as someone who protects his family and demonstrates honor in his relationships. Differing perceptions of machismo were widely discussed by participants.

> I think that the word macho has become distorted through the years...A macho was considered a man who was the head of the family. He protected his family, was faithful...it has been twisted into 'he beats her up, he does this, he does that.'

Condom Use and Negotiation

Both male and female participants noted resistance to condom use. Women did not expect men to use condoms, and were afraid to ask them to do so. Participants of both sexes confirmed that condom use implied infidelity on the part of either partner. The vast majority of female participants stated that their suggestion of condom use could result in risking their relationships or their physical well being. Some women felt that suggesting condom use to their male partners would be tantamount to condoning their infidelity. In addition, women stated that condoms were used by "prostitutes."

> I'm too scared to ask him to use condoms. He might think I'm unfaithful...and I'm scared of what he might do to me.

> I don't know how to ask him to use condoms. We never talk about those things.

Third year male participants confirmed their resistance to condom use, stating that condoms often resulted in the diminishing of their erections and thus threatened their manhood. Condom use was discussed as a demonstration of diminished trust or *confianza* in the relationship, thus jeopardizing the existence or perception of "true love." Many HIV positive couples reported not using condoms because they were both infected, they believed condom use would not make a difference in their health status, and were uninformed about the risks of HIV superinfection.

Stigma/Perceived Invulnerability

Many women stated that it never occurred to them that they could be at risk for HIV in that they perceived HIV risk as invariably associated with homosexuals, sex workers and injection drug users; populations with which they did not identify.

> Latinas don't know how to prevent HIV because they think that this disease is only for homosexuals, so the average housewife doesn't think of protecting herself because she doesn't belong to this risk group.

> I thought that people like me couldn't catch AIDS.

Latino participants demonstrated a great deal of concern for youth, and fear of teenagers considering themselves to be invulnerable to HIV. HIV positive participants reflected on their attitudes during their youth and mentioned the sense of imperviousness that places youth at high risk.

> Teenagers, they don't understand, they think, 'It won't happen to me,' because that's how I used to be.

Infidelity

HIV positive Latinas who had been infected by their primary partners reported difficulty conceiving of the ways in which risk may come from outside of their homes. Even when the women suspected infidelity, they considered it unlikely if their partner complied with the traditional expectations of a male partner.

> He always slept in our bed and he always spent Sundays with the kids....I really never thought he would be unfaithful. He was a provider, a good father and a good husband.

> I never knew about it until my husband became ill and died. I never went out looking for this. He brought the disease home to me.

Disclosure

Few Latino men disclosed their HIV positive status. Instead, many women who were infected by their husbands or long-term partners discovered their infection by routine prenatal screening or after they began experiencing symptoms of illness.

> He never told me. He knew he was infected and he knowingly infected me and got me pregnant. Thank God our child is HIV free.

Economic Issues

One important finding was the number of daytime female sex workers who traveled across the border to participate in the study. Unlike the sex workers encountered in the U.S., these women were not chemically dependent or users of illicit drugs. They were single mothers or women abandoned by their husbands or partners who worked in the United States as day sex workers out of economic necessity. The *maquiladoras* (plants for assembling goods to be shipped to the United States) were known for hiring only very young women without children, which presented severe job limitations for women with children.

> I'm so ashamed but I have no other choice. There are no jobs. I have to do this to feed my children. I cross the bridge to work in the U.S. while they're in school.

Experiences of HIV Positive Latinos

Participants' experience of being HIV positive differed throughout the sites, with the majority reporting a decreased sense of social support, especially from family members upon learning of their HIV infection.

> Since my family found out I have HIV they hardly speak to me. They're afraid I will infect them. When they invited me for Christmas dinner, they served my food on paper plates with plastic utensils. I felt terrible.

The need for education among HIV-affected families was great. This was true not only to inform family members of the lack of risk due to casual contact, but also to increase a sense of duty regarding the providence of love and care to an HIV-infected family member, just as they would if s/he were suffering from another type of illness, such as cancer.

Media Message Exposure

Perhaps the most relevant finding in the study was the lack of exposure of participants to culturally-based HIV prevention and education information. Not one participant could recall a message in the U.S. targeting Latinos or Latinas. The only message participants remembered was a commercial broadcast in Mexico creating an analogy between an electrical system blowout and HIV infection.

> There aren't any commercials directed at Latinos. We don't have the information we need.

Participant Recommendations—La Voz de la Comunidad

Participants reported a need for culturally relevant Spanish language messages, the involvement of HIV positive Latinos and Latino celebrities, positive messaging, and involvement of men and families in prevention. They suggested that print advertisements be positioned at laundromats, bus stops, schools, taverns, markets, and dance halls, and that prevention messages be placed on television, radio, and as public service announcements preceding pornographic films. Another innovative recommendation was the creation of *telenovelas*, or Spainsh language soap opera style television broadcasts, which would deal with HIV in a culturally and linguistically relevant context.

The need for HIV prevention information that educates and empowers Latinos within the context of HIV risk as experienced in their daily lives became apparent during the data collection processes. Although the *novela* approach would dramatize this context to a certain extent, the popularity of *novelas* has helped make Spanish language television the fastest growing television market and the most watched local networks in many urban centers. Furthermore, Latinos tend to watch more television than the general market and prefer Spanish language programming [41, B. VanOss Marin Personal Communication].

Intervention Description—Educational Brochures and *Novelitas*

To respond to participants' expressed need for culturally and linguistically relevant HIV prevention educational materials to support Latino-serving CBOs in their efforts and follow participant recommendations, the project team of researchers, students, CBO staff, and Latino behavioral psychologists developed eight educational brochures in Spanish and English. These brochures used vignettes (*novelitas*) to address the multifaceted contexts of HIV risk Latinos may experience in their daily lives.

To assure that Pan-Latino Spanish was used, a team of immigrants from seven different Spanish-speaking countries worked with key researchers to prepare all written materials. All materials were first developed in Spanish and then translated into English and back-translated into Spanish. A graphic artist from Mexico with expertise in developing culturally appropriate health publications created the design and art work for the brochures, using a common format, layout and style to create a "family" of communication pieces.

The brochures featured an upbeat, positive, *simpatico* approach. The focus on family enabled project staff to emphasize the positive aspects of Latino culture, including the potentially protective aspects of machismo. There were four separate brochures targeted to: Latino parents, women, men having sex with men and women (MSMW), and youth. The brochure content was placed on story boards and focus group-tested with groups of outreach staff and their clients in NCLR affiliate CBOs to assure they resonated with mainstream Latinos who may not identify themselves as at-risk for HIV. Additionally, six distinct focus groups were held comprised of 8–12 individuals each representing HIV/AIDS service staff, Latina women, self-identified heterosexual Latino males, Latino families, and Latino youth of both sexes to further test the appropriateness, acceptability and responses to the intervention materials. The brochures targeting MSMW were focus group-tested separately for appropriateness with a group of openly gay Latinos. Suggestions and ideas garnered from

Table 6 Brochure evaluation by community based organizations[a]

Measure	Number	Mean/%	Score Min/Max	S.D.
Appropriateness of language level[b]	75	70%	3.00	n/a
Relevance of statistics	74	4.35	2.00–5.00	0.766
Effectiveness of the novelitas	76	4.50	2.00–5.00	0.621
Utility of HIV/AIDS education	73	4.36	2.00–5.00	0.754

[a] A total of 71 distinct CBOs submitted 76 evaluation surveys

[b] The scale for this measure assessed language appropriateness on a continuum from (1) "too simplistic" to (5) "too advanced." The majority of respondents (70%) selected a score of "3" or "completely appropriate." All other scales noted are likert scales with (after recoding) (1) indicating the lowest possible score while (5) is the highest

these focus groups were incorporated into the final versions of the intervention materials.

Brochure Content

The brochure for parents emphasized family communication about sex as a means to protect the family unit from this health risk; *novelitas* covered teen sexuality and parenting, infidelity and disclosure, and family support of HIV positive members. The brochure targeting Latina women offered practical advice on sexual communication and information on Latinas' HIV risk factors; *novelitas* covered domestic violence, alcoholism, empowerment, single parenting, treatment of the HIV infected couple, and perceived invulnerability and immigration. The brochure for men having sex with women and men (MSWM) discussed responsible sex and machismo, fidelity and respect for women, effective sexual communication and HIV prevention. *Novelitas* addressed homophobia and HIV disclosure, immigration and male sexuality, drugs and needle sharing, condom use among discordant couples, male perceived HIV invulnerability, and HIV testing. The brochure targeting teens and young adults discussed sexual readiness, HIV/AIDS and Latino youth, HIV prevention and safer sex tips. *Novelita* topics included teen pregnancy, parental responsibility, perceived invulnerability and high risk behavior, pornography, male fantasy, abstinence, self worth and sexual communication. The message was not abstinence only, but rather provided youth with the information and role model scenarios needed to improve communication with adult family members and potential sex partners. Furthermore, it presented the reader with criteria to measure the health of a relationship and the knowledge needed to make responsible sexual decisions.

Intervention Evaluation

A brief questionnaire was included with each bulk mailing of educational brochures, and follow-up calls were made to the recipient CBOs to encourage completion and submittal of the questionnaire. As of May 2007, a total of 76 evaluation surveys were completed by 71 distinct CBOs. The following satisfaction measures were assessed on a likert scale of 1–5 with 1 as the highest ranking: (1) relevance of statistics; (2) effectiveness of the novelitas in capturing the experiences of the Latino community; and (3) usefulness of brochure in meeting the HIV education and prevention needs of your Latino clientele. Additionally, the appropriateness of language level for the target population was assessed. Scores were reversed for analysis purposes, and results of these evaluations are summarized below in Table 6. Results indicate that the brochures were highly rated on each measure.

Dissemination of the Intervention

Since April 2003, over 420,000 brochures have been distributed throughout 48 states, four Spanish speaking countries, over 300 community based organizations, and to dozens of individuals and organizations at health conferences and events. Organizations report utilizing the *novelita* portion of the brochures to initiate community-based *charlas* (chats) to introduce basic HIV prevention education. Publication of the *novelitas* in Texas Spanish language newspapers resulted in a dramatic increase in the calls received by the project's 1–800 telephone line. Organizations using the brochures range from the largest Hispanic HIV service providers in their respective regions to smaller CBOs and health and human service professionals that are just beginning to recognize the HIV-related needs of their client populations.

Discussion

Developing and delivering culturally and linguistically appropriate HIV/AIDS prevention services to Latinos requires an understanding of many different perceptions, attitudes and behaviors that are deeply influenced by Latino culture and values. The research team sought to use positive aspects of Latino cultural context to develop messages that would resonate with underserved Latinos at risk for HIV or living with HIV, and their families.

The results of bivariate analyses suggested that for women at least, there was an association between HIV/AIDS diagnosis and a reduction in risk behaviors, in that the vast majority (80%) had been diagnosed with HIV longer than the 2-year measurement time frame. However, this relationship was not detected for men, which may be a function of small sample size ($n = 18$ men with HIV). This finding should be explored further as it may have important implications for future prevention efforts among similar populations in that it suggests that the HIV positive men in this sample did not curtail risk behavior following an HIV/AIDS diagnosis.

Multivariate analyses revealed differences in HIV risk by sex. For women, increased age, being married, foreign-born, and a U.S. resident, and having tested for HIV previously, were associated with a reduction in the HIV/AIDS risk behaviors of interest. However, these findings do not account for their partners' risk behaviors, which, for many Latinas, may constitute a significant HIV risk. Additionally, the acculturative measure was limited to language use

and it is possible that more in-depth acculturative measures would yield varied findings. Therefore, stratified analyses with larger samples should be repeated to verify these regression results.

One possible explanation that income level was not associated with risk behavior may be the inherent barriers to collecting household income data illuminated in this study including: (1) concerns about immigrant status; (2) fear of losing public benefits; (3) other household members were contributing income of unknown amounts; and in many cases (4) the amount varied considerably by week/month and was difficult for participants to quantify. For example, participants who reported no weekly income were likely benefiting from other household income contributors and therefore, may not have been among the lowest relative household income bracket. This suggests that careful attention should be given to constructing income-related measures that make sense for this population.

The content analysis findings identified many different barriers for Latino men and women to learn about HIV/AIDS risk factors and how to prevent infection, resulting from a host of inter-related cultural beliefs and patterns of behavior. For the four principal target subgroups—families, women, men and youth—the project team developed a set of communication pieces with both a common appearance and a common overarching theme—family protection—that illustrated the key themes from the needs assessment with vivid anecdotes and quotes for the *novelitas*. The theme of protection was a positive approach to dealing with the risk of HIV/AIDS, acknowledging and valuing the positive sacrifices many Latinos make for their families.

One clear finding was that men and families must be involved in HIV prevention efforts. Incorporating HIV education into programs that encompass family protection issues removes the stigma of HIV as a gay disease and invites participation based on responsible parenting and/or self care. The *novelitas* revisiting machismo show how machismo can be positively framed given the context of changing male expectations [42]. They also incorporate the recognition that machismo is the result of many influences, including the social, cultural, economic and contextual factors, combined with discrimination and hardship often faced in the U.S. upon immigration [43], and not merely a set of cultural attributes.

The initiation of sexual and reproductive communication within the family setting is difficult, and not only for Latino families. However, because sex education is not a fundamental part of school curricula and low-income parents are less likely than their middle class counterparts to discuss sex with their children, families must be targeted [44]. Given the linguistic isolation many Latino parents experience as their children acculturate [45], this task becomes even more difficult. However, the changing context of risk experienced by Latino immigrant families may also give rise to opportunity, as parents can be encouraged to become involved to protect their children from harm in a new environment.

The potential to incorporate *novelitas* in HIV/AIDS education and outreach is promising. The *novelitas* could easily be adapted as mini-*telenovelas*, which would utilize the overwhelming popularity of this form of media to further educate Spanish-speaking Latinos. We envision their use by schools, libraries, health centers, community-based organizations, and Spanish language networks to incorporate the cultural, socioeconomic and environmental factors that influence risk factors for HIV within Latino families.

Limitations

One limitation of this study was the small sample size of interview participants in some sites; Hartford, the District of Columbia, Durham and Hattiesburg-Jackson had five or fewer interview participants. A second limitation was the imperfect measure of acculturation. However, given the focus of the study, the short acculturation scale provided information about participants' language preferences in an efficient and minimally intrusive manner. The small number of male participants is third caveat to this study. Since males were not incorporated into the needs assessment until the third year of the data collection phase, we were unable to conduct meaningful comparisons in our stratified analyses. That said, the inclusion of males was designed to confirm the responses of their female participants and this was accomplished. Fourth, the present study participants do not constitute a representative sample of Latinos at risk for or living with HIV and as such, these findings are not generalizable. Additionally, the self-reported data used in this study may be subject to participant recall bias.

The use of print media is only one component of any effective health education intervention, particularly in that people with very low literacy skills cannot access the information provided in the materials. However, the methodology used in their development, and the contextual framing of risk within the Latino community, provide the reader with steps that can be used to develop effective HIV prevention print material. In addition, the Pan-Latino approach used with a relatively low-cost intervention provides one HIV education component for organizations with little or no resources to conduct HIV prevention targeting Latinos. Furthermore, while CBOs rated the brochures favorably, the degree to which the materials are effective in reducing HIV risk is not known.

Implications for Practice and Research

The needs assessment findings and intervention described in this article are but one small part of a major and ongoing public health education effort designed to inform Latinos about HIV/AIDS risk and to encourage preventive behaviors. Its principal elements are a family-based approach that builds on the positive aspects of family strength, while utilizing both machismo and Latina empowerment to strive for more open communication with children and other family members about sex. The educational materials link HIV/AIDS with other issues that impact the socio-environmental context of HIV risk and risk behavior (economic dependence on male partners, multiple partners, intravenous drug use/sharing needles, unprotected sex, traditional sex roles, family expectations, and poverty) in the Latino community. The materials, developed for and by Latinos, also use culturally and contextually appropriate messages to encourage readers to protect themselves and their families by communicating and seeking HIV education, testing and services.

The next stage of the prevention project, begun in fall 2005, involved developing a CBO media kit for family-oriented Latino HIV/AIDS prevention to be distributed to over 500 organizations, complemented by Spanish language Public Service Announcements (PSAs) for radio and television, outreach cards and the brochures. In 3 of the 14 sites where the needs assessment was conducted, the curriculum is being used to recruit and train community lay health workers (*promotores*), some of whom are HIV positive (peer advocates) to implement a peer education and outreach program for HIV/AIDS awareness and prevention. Utilizing indigenous peer educators further solidifies the knowledge base of HIV/AIDS within the community, and adds to its intangible asset and advocacy base [46]. The overall project approach is based on the Community-Based Outreach Model, developed by the University of North Texas, School of Public Health in collaboration with the National Heart, Lung, and Blood Institute (NHLBI) and the National Council of La Raza (NCLR). This model emphasizes behavior change and communication about health conditions that disproportionately affect Latinos and the use of cadres of peer health educators and culturally and linguistically appropriate communication strategies and health education materials [47].

Future research and evaluation efforts must necessarily focus on outcomes, to assess the effectiveness of interventions such as the print *novelitas* on reducing the incidence of HIV and AIDS in Latino communities throughout the nation. Furthermore, the scarcity of research on Latino family sexuality must be challenged with new theoretical frameworks that explain the contextual factors affecting health-related behaviors without vilifying culture and stereotyping behavioral manifestations, such as machismo, as definitive cultural attributes [48]. To effectively battle HIV and the many other issues affecting sexual and reproductive health among the fastest growing segment of the U.S. population, intervention strategies must avoid the cultural menu approach and be willing to explore the context of HIV risk as it occurs among all Latino groups. Culturally familiar approaches such as *telenovelas* should also be tested. Since Latino families tend to watch television together, *telenovelas* with HIV/AIDS storylines would provide a stimulus for a family discussion of this topic. Above all, inclusion and involvement of Latino-serving community-based organizations and community members throughout all phases of community focused efforts are keys to reducing rates of HIV infection and AIDS among Latinos.

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