

Latinas and Deadly Sex: The Politics of HIV/AIDS Reporting

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Abstract

HIV and AIDS cases in the United States are affecting lower income persons and minority females and adolescents largely when compared with other groups. Individuals infected with HIV often survive for lengthy periods without knowledge of their own infection prior to developing AIDS. Since the beginning of the U.S. epidemic in 1981 an estimated 1.5 million persons have been infected and over 500,000 have died from AIDS. Although new HIV infections appear to have slowed, data from several states with at-risk populations are still not included in the national surveillance reports. These states, which include Alaska, California, Connecticut, Delaware, the District of Columbia, Illinois, Kentucky, Maine, Maryland, Massachusetts, Montana, New Hampshire, New York, Oregon, Pennsylvania, Rhode Island, Vermont and Washington are excluded based on the objection to the name based HIV reporting criteria required by the Centers for Disease Control and Prevention (CDC). HIV/AIDS cases in the US are growing at a phenomenal rate for certain groups while other groups seem to have stabilized. This paper examines the reporting system for new HIV infections in the U.S. Analyses of the reporting system indicates that certain groups known to be at disproportionate risk are underreported, while others are reported more specifically and consistently from the local to the national level. The obvious question arising from this inconsistent reporting system is the accuracy and utility of semi-accurate and incomplete HIV national and state data. Moreover, why are these data inaccurate and incomplete given the devastating effects of the infection? This paper will utilize data on the Latino community to focus on the problem of the national underreporting of HIV infection.

Keywords: HIV, AIDS, Latinas, Latinos, HIV testing, heterosexual, HIV transmission

HIV and AIDS

The general public first acknowledgement of AIDS in the United States occurred in the early 1980s when Rock Hudson became infected and subsequently died. In the 1990s, largely due to categorization of the virus as Gay Related Immune Deficiency (GRID), and subsequent neglect by the nation's political system, the virus quickly spread to previously uninfected populations (Shilts, 1986). Human Immunodeficiency Virus (HIV) is caused by exposure to infected blood, semen, vaginal fluids, and breast milk. When an individual's CD-4 or T cell

count falls below 200 and/or the individual begins to experience serious complications, the Acquired Immune Deficiency Syndrome (AIDS) is diagnosed as a disease. [<http://hopkins-aids.edu/publications/pocketguide/pocketgd0105.pdf>]. As the science of treatment improved and public health surveillance and treatment systems were established, HIV infected individuals with knowledge of the risks of infection and access to health care progressed much more slowly to AIDS. New AIDS cases experienced a dramatically curbed escalation in 1996 with the introduction of Highly Active Antiretroviral Therapy (HAART).

[<http://www.cdc.gov/hiv/stats/2003SurveillanceReport.pdf>]. Although cases of AIDS decreased markedly due to improvements in treatment, overall HIV infections did not.

Although modes of infection have been clear for some time, reporting mechanisms within the country have been obscured by many issues including the requirement of the Centers for Disease Control and Prevention (CDC) to report all HIV infections using a confidential, albeit not anonymous, system of name-based reporting, to which some states, like California, have objected. Due to the extensive window period that can average 10 to 15 years wherein HIV infected individuals experience no symptoms, comprehensive data collection and reporting on HIV infection becomes imperative if the US is to accurately target HIV prevention and management efforts, particularly among underserved populations.

The Reporting System: HIV versus AIDS

Public health in the US begins at the local level and involves both private and public health providers. Early work with other sexually transmitted diseases such as Gonorrhea and Syphilis at the local level initiated and improved the reporting process from the local level to the state. [<http://www.cdc.gov/std/Syphilis2003/SyphSurvSupp2003.pdf>]. Nationally, the Atlanta-based CDC initiated the collection of AIDS case data from the states.

As an understanding of HIV's progression to AIDS matured, terms such as ARC, (AIDS Related Complex), were eliminated and the staging became reduced to HIV and AIDS as measured by T cell or CD-4 cell counts and more recently viral load. [<http://hopkins-aids.edu/publications/pocketguide/pocketgd0105.pdf>]. Although AIDS cases are reported by each state to the CDC, many states have been slower in their progression to HIV reporting. A major issue among and between the states and the CDC arose as to the classification system to be used for reporting of HIV and AIDS cases, one that has still not been fully resolved for 19 states and the District of Columbia. Exposure categories for adults are further broken down into the two categories of HIV and AIDS. This paper analyzes the categories of exposure for adults, with emphasis placed on the emergence of HIV and AIDS in the Latino population, particularly among women.

Due to HIV underreporting or reporting practices that do not meet the CDC requirements of name-based case identification, the most recent edition of the CDC's HIV/AIDS Surveillance Report includes HIV data from only 31 states. [<http://www.cdc.gov/hiv/stats/2004SurveillanceReport.pdf>]. The underreporting of HIV to the CDC is problematic for a number of reasons, as it fails to provide the nation with the information needed for an effective HIV/AIDS prevention and management strategy. This is particularly true among underserved populations such as Latinos, who are often

uninsured or underinsured and may lack access to culturally and linguistically appropriate health care and HIV prevention information. In addition, the lack of complete and/or timely data that reveal projected changes in new infections among at-risk populations will not be available for several years, thus obfuscating the information needed by public health officials to successfully target prevention and management activities. In addition, the issues related to heterosexual categorization complicate the accuracy of reported data and gravely undermine the actual risk for heterosexual African American and Latina women.

The US Virgin Islands and 29 states have reported HIV infection data for the five-year period before 2004 (1998 through 2003). [<http://www.cdc.gov/hiv/stats/2003SurveillanceReport.pdf>]. These 29 states are Alabama, Arizona, Arkansas, Colorado, Florida, Idaho, Indiana, Iowa, Louisiana, Michigan, Minnesota, Mississippi, Missouri, Nebraska, Nevada, New Jersey, New Mexico, North Carolina, North Dakota, Ohio, Oklahoma, South Carolina, South Dakota, Tennessee, Utah, Virginia, West Virginia, Wisconsin, and Wyoming. In addition, Kansas and Texas began reporting HIV in July and January of 1999, respectively. It should be noted that New York, California, and Illinois for example, states with significant Latino populations, were not included in the comprehensive national HIV data. Although the CDC issues guidelines to states in 1998 stating that states hesitant to shift to a name-based reporting system could submit data via a comparable method of choice, the CDC is still currently awaiting the inclusion of data from name-to-code and code-based surveillance pending evaluations demonstrating “acceptable performance under CDC guidelines and the development of methods to report such data to CDC.” Some states, such as Maryland, have been successfully submitting data to the CDC by a code-based system since 1993. Although the CDC has had over a decade to evaluate the tenacity of the data being submitted by the State of Maryland, these data are still not included in the national HIV data. [www.statehealthfacts.kff.org/cgi-bin/healthfacts.cgi?action=compare&category=HIV%2FAIDS&subcategory=HIV+Testing&topic=Name%2FCode-Based+Reporting; www.sfaf.org/policy/names_reporting_facts.html]. The insistence on name-based reporting is an appreciable issue for many states, such as Massachusetts and others, wherein submission of the patient’s name would be inconsistent with state law ensuring patient’s rights (MGL Chapter 111 Section 70F). [www.mass.gov/dph/cdc/aids/hivque.htm] Name-based reporting is also problematic for many high risk populations such as homosexuals and IDUs who may fear reprisal from the government were names to be submitted due to the legacy of discrimination exemplified by homophobia and our lack of understanding regarding issues related to chemical use and dependency. In 1997 one study of gay males seeking anonymous HIV, testing in California found that 68% of them would not be screened if they knew that their names were going to be reported to the government [www.sfaf.org/aboutsfaf/newsroom/dcd_guidelines.html]. Latinos, African Americans, and other populations of color who have experienced a legacy of discriminatory practices in the U.S. may also fear reprisal and avoid testing if knowledgeable of the name-based reporting requirement.

In 2001, California instituted a non-name based HIV reporting process that includes a non-name code which consists of the patient’s Soundex (a four digit alphanumeric code obtained from the patient’s last name, date of birth, gender and last four digits of the social security

number. The laboratory is responsible for submitting the partial non-name code to the health care provider, who when receiving this information completes the code by adding the last four digits of the social security number, which is then reported to the California Department of Health and Human Services. The California DHHS then turns it over to the HIV/AIDS Surveillance program. [www.dhs.ca.gov/AIDS/]

Although the strides taken to report HIV infection without compromising confidentiality are admirable, that it took one of the states most affected by the virus almost two decades to work out the process by which reporting could occur is not: the fact that the virus itself may be mutating faster than the dispersal of information needed to better target prevention efforts does not say much for the willingness to acknowledge the spread of the virus to emerging populations. In addition, the inclusion of the social security number in the code building process seems to indicate that the state is not aware of the high-risk profile of its undocumented residents. It is also problematic due to the validity of the social security number as these numbers are often borrowed or purchased at well-known sites. As we well know, documented status has nothing to do with HIV infection, and the shortsightedness of having to include this number, as opposed to another randomly generated number based on other data, such as birthplace, seems sophomoric at best. Massachusetts code-based system is described as using the first two letters of the first name, number of letters in the last name, gender, date of birth, last four digits of the Social Security Number (a random, non-identifying string). [www.mass.gov.dph/cdc/aids/hivque.htm] This code does comply with the state confidentiality law, while not requiring the social security number of the patient. Whether or not these codes are later deemed acceptable by the CDC remains to be seen, and in the interim the cases will not be counted.

As more Latinos become privy to the exclusion of HIV-infection specific data at the national level, and its subsequent effects on the Latino population, political inroads are being made to rectify these issues. California State Senator Nell Soto recently introduced SB945 in an effort to assure that HIV data from California be submitted in a manner that satisfies the requirements of the CDC to ensure maximum accuracy of the data. The legislation reads: Section 1: The Legislature intends to enact legislation in subsequent amendments to require the State Department of Health Services to collect HIV test results, for epidemiological purposes only, in a manner that satisfies the federal Centers for Disease Control and Prevention's need to ensure maximum accuracy of the data. (Soto, California Senate Bill SB945, 2005). Whether or not the states themselves or the CDC is to blame, HIV will continue to emerge within at-risk populations such as Latinos, and their cases will be left uncounted and/or unreported.

Reporting Categories: What Exactly is Measured?

The HIV data from these states and the US Virgin Islands are collected and classified into five risk exposure categories: 1.) Male-to-male sexual contact (MSM); 2.) Injection Drug Use (IDU); 3.) Male-to-male sexual contact and Injection Drug Use (MSM + IDU); 4.) Heterosexual contact; and 5.) Other. Due to the fact that these data presume that a given population engages in predetermined sexual activities is an inference problematic in itself, particularly as HIV/AIDS becomes better known as a problem of a given risk group as opposed to a problem associated

with a risk behavior. For example, although anal sex is an increasing practice among heterosexuals and some MSMs regularly report exclusive oral sex practices, reporting mechanisms assume that all MSMs do engage in anal sex and that heterosexuals do not.

Although unprotected oral sex does pose a definite risk for HIV infection, it is much less than that experienced by one engaging in unprotected anal sex.¹ In addition, there is still no dual category for heterosexuals and IDU, although the combined category was initiated for MSMs and IDUs in 1992. The risk group categories, although somewhat useful for targeting prevention, have resulted in the common perception, particularly among populations that are linguistically isolated, that HIV and AIDS should not be of concern to those who are not homosexuals, IDUs, sex workers, or any resulting combination.

As alluded to earlier in this manuscript, AIDS data collected by the CDC come from all 50 states and US territories. However, AIDS represents the end stage of a very long infection that is often eluded for lengthy and inconclusive amounts of time do to HAART, and failure to obtain data from all 50 states and US territories for HIV results in inaccurate and incomplete aggregate data and poor epidemiological information from which to effectively target interventions. Moreover, some states, such as Texas, have particularly exclusive criteria for the Heterosexual category. Although the first three risk categories previously listed are descriptive of the populations exposed, the heterosexual category is particularly deceptive. Heterosexual contact is defined as sexual exposure with a **known HIV/AIDS partner**.²

[www.tdh.state.tx.us/hivstd/legislature/default.htm] This classification omits all cases where the exposed person does not know the status of the sexual partner but reports the only risk as heterosexual exposure. Therefore, if an HIV case is to be reported as heterosexual it must have resulted from sexual contact with a “known” infected sexual partner for inclusion in the state data. This blurs the accuracy of the heterosexual category to a far greater extent, resulting in inaccurate and incomplete state and national data because women who report contact with a male will not have their status categorized as heterosexual unless it is known that their partners are HIV infected. It is interesting to examine Texas data following the implementation of the aforementioned criteria. From 2002 to 2003, the heterosexual risk category among women who tested positive for HIV fell from 51% to 39%, whereas the Unknown category for HIV positive women rose from 30% in 2002 to 49% in 2003.

[www.tdh.state.tx.w/hivstd/stats/pdf/qtr20034.pdf]

The CDC categorization criteria are as follows, “Persons whose transmission category is classified as heterosexual contact are persons who report specific heterosexual contact with a person with, or at increased risk for, HIV infection (e.g., an injection drug user).”

[<http://www.cdc.gov/hiv/stats/2003SurveillanceReport.pdf>]. This practice not only results in the underestimation of the potential of heterosexual contact, but also silences the risk associated with the sexual experiences of women, mainly Latinas and African Americans, who represent 83% of women with new AIDS cases in 2003. [<http://www.kff.org/hiv/aids/6007-02.cfm>]. This reporting structure assumes that women are knowledgeable at best, and accomplices at worst, in the often-surreptitious sexual and chemical use patterns of their male partners. In addition, it fails to acknowledge the ways in which the socioeconomic status of women contributes to their HIV risk.

Unfortunately, the majority of poor women, both Latinas and African Americans, are not often privy to the private lives of their partners. The only timeframe in which women are automatically offered an HIV test is during pregnancy. Due to measures taken with treatment during pregnancy, perinatal infections have drastically decreased. Although the incorporation of testing during pregnancy is admirable, many Latinas perceive the HIV test as inclusive in other prenatal screening, and decline the HIV test erroneously. In addition, linguistic and literature level barriers may inhibit pregnant women from understanding the information being provided to them. By silencing the risk of heterosexual transmission, particularly among women of color who have demonstrated higher rates of infection, and not publicly stressing the need for HIV screening, many more women of color will face an increased risk of infection due to a general lack of awareness.

The Reporting System: Other Category

The Other category is the catchall home for all cases involving hemophilia, blood transfusion, perinatal transmission, risk not reported, and risk not identified [<http://www.cdc.gov/hiv/stats/2003SurveillanceReport.pdf>]. There are epidemiological and legal reasons provided for this reporting methodology, but these do not appear valid in the midst of the rapidly growing heterosexual epidemic. From 1985 to 2003, newly diagnosed AIDS cases resulting from heterosexual transmission have risen from 3% to 31%. Congruently, newly diagnosed AIDS cases among men who had sex with men fell from 65% to 42%. [<http://www.cdc.gov/hiv/stats/2003SurveillanceReport.pdf>].

Furthermore, the strategy of excluding those who report heterosexual transmission without definitive knowledge of their partner's HIV status eerily resembles issues regarding the exclusion of women experienced earlier in the epidemic. Heterosexual transmission through vaginal sex was often publicly denied, and HIV positive women who reported risk through vaginal sex were questioned with regard to the veracity of their statements.³ Women were scrutinized about the exclusivity of their heterosexual relationships and their honesty regarding history of anal sex and injection drug use. In addition, women early in the epidemic were referred to as vessels of infection and "reservoirs of transmission" and were given value in the public health discourse merely with regard to their potential for infecting their infants and male partners. Within Latino cultural norms women are still of late dichotomized into "good" and "bad" girls based on their sexual practices, and HIV is most commonly associated among women engaged in sex work and/or IDU.⁴ However among Latinas, particularly immigrants, heterosexual HIV infection, just as it first appeared in Mexico and many other Latin American countries, is becoming very predominant among married women and those with long-term male sexual partners. Their situations resemble the first female AIDS case in Mexico. Diagnosed at age 52, the only risk taken by this Mexican housewife was having had unprotected sex with her husband.^{5 6} The risk of heterosexual contact with a primary partner is not recognized as a high-risk behavior within the CDC, although the synergy of culturally bound expectations of fidelity and sexual mores and the socioeconomic situations faced by many Latinos clearly indicate that expectations and behaviors are dynamic and dependent on many environmental factors.

Although alteration of the formerly stated “homosexual” category to MSM was a positive stride in alleviating stigma, Latino males do not necessarily consider either category as an appropriate definition of themselves. It has long been known that Latino males (particularly Mexicans) who have sex with men do not often classify themselves as homosexual if they are the active or inserting partner.⁷ In anal or oral sex, the inserting partner is able to retain his masculinity, is referred to as a *mayate*, whereas the receptive partner is the *joto* or *maricon*, and is thus effeminate. Few males want to admit to a sexual preference for other males, particularly to their wives, lovers, children, co-workers, and family. Consequently, homosexual males or those with a preference for sex with other males, attempt to live a heterosexual lifestyle for as long as they can to avoid the social stigma of being gay in a homophobic environment and culture. The stigma potential does not prevent males from having sex with other males, including those infected. However, the combination of stigma and machismo, coupled with the CDC’s categorization methods does not build an impetus for HIV education and awareness among Latino males. The false security of machismo, in an oppressive environment does not result in the vulnerability needed to admit risk for HIV. In the words of one *mayate*, “We don’t put words on everything like you all do. We do not have all the labels that they have in America to describe ourselves...Everyone knows me [in Mexico]. Some people have diseases and some people don’t.” [www.dallasobserver.com/issues/2005-01-13/news/feature.html]

Not all males are placed at risk for HIV because of MSM practices. Males living away from their families often reside in crowded conditions with several men sharing a crowded apartment. Sex workers often frequent these dwellings and charge males, particularly in groups, a deeply discounted fee for sex. In the words of one male participant in a national assessment of Latinos and HIV conducted by the National Council of La Raza, “The economy has affected me...Now instead of buying the women who charge \$20 I buy those that only charge \$5 to \$10.”⁸ This results in a type of sex production line, wherein exposure can be exacerbated if the sex worker or any of the males are infected.

In the U.S. today, Latina and African American women are gravely neglected by current prevention strategies that target gay men of color and focus only on women who are pregnant, and have a history of sex work, IDU or a combination of the two aforementioned factors. Although women have perhaps the most influential role in educating their respective families and communities, little is being done to target Latinas and build well-integrated and collaborative projects that aid in preventing HIV infection. Furthermore, not only are their sexual experiences silenced within their environments, but when attempting to access the health and human sector for testing or prevention activities, they find little support and voice among those whose role it is to advocate for the underserved.

Epidemiological practices in many states such as Texas and California border of late border on such travesties. In Texas if a heterosexual woman with AIDS cannot confirm the HIV seropositive status of her male partner, her case is then classified as “other.” Thus, the heterosexual risk is denied and ignored. According to one HIV caseworker in Los Angeles County, when having to enter data for a new HIV infection if specified as heterosexual, an “ARE YOU SURE?” prompt is shown on the computer screen before allowing confirmation of the

entry.⁹ One may preclude that the aforementioned prompt is revealed to assure the accuracy of reporting. However, if this were an accurate interpretation of the data entry process, the prompt would appear equally regardless of risk category, and it does not. The authentication is needed only if verifying a heterosexual transmission. Although it is important to attempt to understand the full nature of the HIV positive woman's risk and to determine the underlying risk behavior of her sexual partner(s) what is of critical importance is that she herself was infected via heterosexual sex. The failure to categorize her infection as heterosexual risk demonstrates the unwillingness of those in positions of power to acknowledge and address changes in the epidemic that gravely threaten women, in particular Latinas and African Americans, who are currently bearing the burden of the overwhelming majority of HIV/AIDS cases. This threat is definitively more exacerbated among Latina women, many of whom are linguistically isolated, of low socioeconomic status, and dependent on their male partners for economic survival.

Although women are increasingly included in research and receiving HAART treatment strategies, in 2000 they comprised just 17% of the total participants in Adult AIDS Clinical Trials Group trials enrolling women.¹⁰ It is important to acknowledge the historical neglect relating to the acceptance of women's potential for HIV infection. Not until 1992, over 10 years into the epidemic, were female-specific medical HIV/AIDS related issues, such as cervical cancer, added to the official lists of related symptoms for medical classification. This did not occur until after heterosexual transmission surpassed IDU as the primary mode of transmission. [<http://vhaaids.info.cio.med.va.gov/aidsctr/newsletters/women/women1.html>AIDS%20Focus%20Slowly%20Turning%20Toward%20Women]. This resulted in the exclusion of women from scarce clinical trials and medical treatments. The masking of the risks of heterosexual infection, particularly to underserved women of color, as "risk/unknown" or "other" will only serve to exacerbate the misinformation, denial, and destruction of families that has already become a common experience among these populations.

Epidemiological shifts in HIV/AIDS worldwide mirror those, which are taking place among Latinas in the US. Whereas the infection among women was thought to affect mainly sex workers and IDUs, housewives and women with long-term partners were thought to be relatively safe; this is no longer the case. In Latin America 60 to 70% of women were HIV were both faithful and monogamous and lived and had not engaged in sexual intercourse with men other than their primary partners. [<http://www.whrnet.org/docs/issue-AIDS.html>]. In Africa, women now represent 12.2 million of the of the 22.2 million infected adults and over 3 million children under the age of 15 with HIV/AIDS the majority of whom were infected through perinatal transmission.¹¹ Denial of the potential of heterosexual infection will only bring us closer to catapulting our underserved minority women into a similar state.

In a 14-site national needs assessment conducted by the National Council of La Raza involving 321 HIV positive at at-risk Latinos, women repeatedly contributed their HIV risk to their long term male partners' infidelity, unwillingness to use condoms, and the lack of power they experienced to change their risk profiles. Focus groups and interviews with male participants confirmed the issues of infidelity as well as the resistance of males to use condoms.¹²

The National Spread of HIV/AIDS among Latinos

Latino immigration to the US is the driving force behind population growth. Latinos today arrive into the US from all of the countries to the south beginning with Mexico and the Caribbean. Once in the US, the CDC has examined the AIDS cases diagnosed among Latinos and found that behavioral risk factors vary among the various nationalities. For example, the CDC reports that Latinos of Central American (52%), Mexican (57%) and Cuban (50%) ancestries, particularly so if they are from the lower socioeconomic classes, contract HIV from sex with other males more so than Puerto Ricans. In the case of Puerto Ricans, 45% of HIV infection is due to IDU. IDU and alcohol consumption often lead to unprotected sex, thus exacerbating risk through a depleted immune system accompanied by exposure to the virus.¹³ Furthermore, the lack of subpopulation data regarding new HIV infections further thwarts the effectiveness of efforts targeting particular Latino subpopulations, as we are not able to discern the changing context of risk within the lives of newly infected Latinos.

According to the CDC's 2004 Surveillance Report, African Americans currently experience the highest AIDS case rate in the US of 75.2 cases per 100,000 people. Latinos have the second highest rate of 26.8 per 100,000.¹⁴ Latinos account for 18.6% of the cumulative 929,985 cases diagnosed since the beginning of the epidemic and 20% of all people in the United States living with AIDS." Although the picture of AIDS cases is relatively clear, the lack of HIV reporting, particularly given the effectiveness of HAART, greatly obscures our ability to accurately assess the impact of HIV infection rates among Latinos.¹⁵ While it is obvious that African Americans are the minority that is most affected by AIDS, the 26.2% in new HIV cases among HIV reporting states demonstrated among Latinos indicates that the epidemic may be shifting and that the Latino population is at an increasing risk for HIV infection. Although African Americans share many commonalities with Latinos, such as greater poverty rates and lack of education, it is important to distinguish between these minority groups and identify how HIV risk and access to testing and care differ among them. African Americans are U.S. citizens and not denied medical or social services, as are undocumented persons or resident aliens. Although still faced with lack of insurance and underinsurance, African Americans are largely free to seek diagnosis and treatment for illness of any sort and may obtain health care without the ever-present threat of deportation.

Latinos, on the other hand, are often faced with institutional, political and cultural barriers to health care. Issues related to sexuality are predominantly seen within the Latino community as taboo and the stigma associated with a sexually transmitted infection, although present in every racial/ethnic group, are exacerbated even further in the Latino population due to a synergistic combination of factors. These include institutional, cultural, homophobia socioeconomic and political factors such as gender roles and expectations, religion, low socioeconomic status, lack of transportation and/or child care, and lack of knowledge and poor access to health and human services. According to the CDC, the majority of Latino males are exposed to HIV via MSM behavior, followed by IDU and heterosexual contact while most Hispanic women are exposed to HIV through heterosexual contact, followed by injection drug use. [<http://www.cdc.gov/hiv/stats/2004SurveillanceReport.pdf>]. Clearly, Hispanic women

unknowingly are contracting HIV from infected male partners that had unprotected sex with other males and females, usually without a condom. Due to a lack of HIV related knowledge, a general lack of health care, denial, machismo, and myriad of other factors, Latino males are often unaware of their HIV status or withhold their status from their female partners. In addition, many Latino males are highly resistant to condom use. A national study commissioned by the National Council of La Raza found that Hispanic males more often than not engage in unprotected sex without the use of condoms and that the suggestion of condoms into the relationship can be perceived as a lack of "*confianza*" or trust and indicate either the male's or female's infidelity. Moreover, Hispanic women were found to perceive themselves as relatively powerless to negotiate condom use with their male partners. Many Latinas who had suggested condom use had been accused by being promiscuous and/or infected with HIV from the prospective male partner.¹⁶ Moreover, Latinas are often at risk for violence and sexual abuse from their primary male partners, which may be exacerbated by the suggestion of condom use.¹⁷

For immigrant Latinos these barriers are exacerbated and include ineligibility for health programs, fear of deportation or inability to achieve US residency and citizenship. Even when documented, Latinos are the least likely to have health insurance and often cannot afford the time missed from work to attempt to access care. Moreover, in the case of Latinos without US citizenship, their identification as an HIV positive case could adversely impact their immigration status. The number of persons with an immigration status of undocumented or resident alien who have not sought diagnosis or testing is unknown. If an undocumented person or resident alien is HIV positive but undiagnosed and untested due to immigration status consequences, hence unreported, their sexual partners once infected, diagnosed, and tested may also not be included in the heterosexual category for CDC reporting purposes.¹⁸ Once HIV/AIDS is diagnosed, immigrants can no longer receive full legal permanent residency and therefore do not qualify for Medicaid benefits.¹⁹ In addition, undocumented Latinos may experience additional barriers to HIV testing due to the recent increase in deportation raids by the INS, which have resulted in substantial decreases in clinic and hospital visits and appointments, many for preventive care such as prenatal visits.²⁰

Furthermore, finding appropriate HIV prevention and AIDS management information in Spanish or their respective indigenous language is extremely difficult, as there are few culturally and linguistically relevant medical professionals. Moreover, although free or low cost HIV testing options are available in many urban centers, Latinos remain unaware of their testing options and often assume that their routine medical examinations, if they do have an exam, have included an HIV test. In addition, many of the free to low cost clinics nationwide are not found in highly Latino populated areas, thus limiting the community's access to both testing and HIV prevention education.

As previously stated, data on new HIV infections have been slow to emerge, particularly among underserved populations of color. As states continue to battle the requirement for name-based HIV reporting, people of color continue to be infected and AIDS related mortality continues to climb. Latinos and African Americans are more likely than any other group to reside in states for which data on HIV infection are not included in the national surveillance report. For

example, in the most recent HIV/AIDS Surveillance Report detailing cases of HIV/AIDS from 2000 through 2003, over 50% of the Latino population and 40% of the African American population are excluded from these data, as they do not reside within the reporting areas.

**Table 1:
Top states and Puerto Rico with Latino AIDS Cases & HIV Reporting Status***

State	Number of Latinos 2003	Percent Latinos in Area 2003	Percent of US Latino Population 2003	Time Initiated HIV Reporting	New Latino HIV Cases in CDC Surv. Rep.	Latino AIDS Cases 2003	Type of Reporting
NY	3,132,186	16.32%	7.85%	December 2000	No	20,419	Name-based
CA	12,176,08	34.31%	30.52%	July 2002	No	15,387	Code-based
PR	3,894,855	100%	**	January 2003	No	1,458	Name-based
FL	3,160,287	18.56%	7.92%	July 1997	1,230 (2002)	7,472	Name-based
TX	7,556,869	34.16%	18.89%	January 1999	1,021 (2003)	7,153	Name-based
NJ	1,254,466	14.52%	3.14%	January 1992	521 (7/03-6/04)	3,521	Name-based
PA	423,499	3.42%	1.061%	January 2002	No	2,125	Name-based
IL	1,726,822	13.65%	4.33%	July 1999	No	2,119	Code-based
CT	351,881	10.1%	0.882%	January 2002	No	2,080	Code-based
MA	478,350	7.4%	1.199%	January 1999	No	2,073	Code-based

Sources : <http://www.factfinder.census.gov>, www.cdc.gov/hiv.stats/2003SurveillanceReport.pdf, www.doh.state.fl.us/Disease-ctrl/aids/trends/msr/msr.html, www.state.nj.us/health/aids/qtr0406.pdf, www.tdh.state.tx.w/hivstd/stats/pdf/qr20034.pdf, www.statehealthfacts.kff.org/cgi-bin/healthfacts.cgi?action=compare&category=HIV%2FAIDS&subcategory=HIV+Testing&topic=Name%2FCode-Based+Reporting

*The Commonwealth of Puerto Rico's population is not included in the US Census.

**N/I signify that the data are not included in the US population statistics.

The majority of Latinos in the US live in states with an inadequate history of reporting HIV. Latinos in these states are the most likely to be affected through a lack of general information and no targeted prevention or treatment programs. This is compounded by the fact that those who are most disproportionately affected by HIV/AIDS, African Americans and Latinos, are also those who tend to be poorer, less educated, underinsured or with no health insurance, and are less likely to see a physician for regular preventive examinations.²¹

Changing Demographics = Changing Pandemic

As the HIV/AIDS epidemic has grown so has the U.S. Latino population. Since 1980, the U.S. Latino population has grown from 14.6 million to over 39 million in 2003, having surpassed African Americans a decade earlier than predicted to become the largest U.S. minority population in 2000. Unfortunately, AIDS cases within the Latino population have also grown

in addition, although Latinos represent 13% of the U.S. population, they now comprise over 20% of the nation's AIDS cases.²² While African Americans continue to comprise the greatest share of AIDS cases among minority groups, AIDS diagnoses among Latinos increased by 8% between 1999 and 2003, more than any other racial/ethnic group. Additionally during this timeframe, Latinos were the only racial/ethnic group to demonstrate an increase in deaths among persons with AIDS, underscoring their lack of access to early HIV testing, related services, and HAART.²³

Upon further analyses of the HIV infection data reported by the CDC in 2004, of the 10 areas with the highest proportion of the nation's Latino population including Puerto Rico, only 4 states reported HIV infection data, representing only 29.95% of the Latino population. Therefore, over 70% of the Latino population was not represented in the HIV statistics. Between 1999 and 2002 over 70% of the Latino population lived in states wherein HIV was not reported in a name-based fashion to the CDC for the comparative time period necessary, and was therefore not included in national surveillance data. In 2004, with the inclusion of Kansas and Texas, this number fell to 51%.

Since 1993, estimated AIDS prevalence among Latinos rose by 130%, compared to a 68% increase among non-Hispanic whites.

[www.nastad.org/DOCUMENTS/PUBLIC/HIVPREVENTIONPROGRAMS/2003723ADDRESSINGAIDS...LATINOPERSPECTIVESANDPOLICYRECOMME.PDF]. Although the introduction of HAART has curbed AIDS cases among all populations, Latinos continue to experience a decline in AIDS cases that is significantly less than that of non-Hispanic whites (56% vs. 73%) indicating less access to HIV related care and treatment. According to the National Alliance of State and Territorial AIDS Directors (NASTAD), resource allocation for HIV/AIDS has been markedly less in states with the largest growth in Latinos, receiving less funding per AIDS case for both prevention and care than the national average.

[www.nastad.org/DOCUMENTS/PUBLIC/HIVPREVENTIONPROGRAMS/2003723ADDRESSINGAIDS...LATINOPERSPECTIVESANDPOLICYRECOMME.PDF]. The lack of resources allocated for prevention among Latinos contributes to a disproportionate risk for HIV/AIDS that is further compounded by a lack of culturally and linguistically appropriate health education and care. From 1999 to 2002 new HIV infections among Latinos increased by 26.2%, the largest increase in any population.²⁴ With the addition of Texas and Kansas' specific HIV data from 2000 to 2003 HIV the estimated number of persons living with HIV/AIDS increased by 35.34% among Latinos, in comparison with 11.85% among whites and 12.39% among African Americans. [<http://www.cdc.gov/hiv/stats/2004SurveillanceReport.pdf>]. In terms of the top five highly populated Latino states, Florida and Texas are the only states with five-year histories of HIV reporting. Although data comparisons are slowly becoming available, we are left with little constructive information with which to justify and build an HIV prevention policy argument for Latinos.

Furthermore, subpopulation consideration is warranted as Latinos represent diverse groups of persons with distinct origins and the spread of the epidemic varies across Latino

subgroups. Specific socioeconomic groups of Latinos in given regions are experiencing increases in HIV infection. For example, HIV prevalence among Mexican migrant workers has been found to be three times as high as the general population with as many as 1% testing positive for the virus. Latinos identifying as Mexican/Mexican American/Chicano represent 2/3 of the Latino population. Although this category includes those of Mexican origin who were born in the U.S., it is important to note that there were only two Latino subpopulations to experience increases in AIDS cases by place of birth from 1992 to 2001, were Latinos born in the US (from 32% to 43%), and Mexicans (7% to 14%), respectively. If the US is to curb the spread of HIV among its fastest growing population, careful observation of the changing patterns of new infection warrant an increased understanding that is comprehensive in scope.

Globalization leads to an HIV pandemic: *Sin Fronteras*

Transmigration of Latinos to and from the US has been shown to increase HIV infection among women and families in their countries of origin, particularly in rural Mexico, wherein 25% of AIDS cases were among men who had traveled to the US, compared to only 6% among Mexican urban AIDS cases.²⁵ HIV prevention education and treatment is scarce if nonexistent. For example, among persons with AIDS in two rural areas of Mexico, over 50% of those in Degollado, Jalisco and 39% of those in El Fuerte, Michoacán, had been to the US.²⁶ The poignancy of the widely used phrase “HIV/AIDS knows no borders” is increasingly felt among communities with very few resources with which to battle infection. It is essential that we learn from the early mistakes in the epidemic made in Puerto Rico. There the virus was allowed to escalate considerably prior to the government’s allocation of prevention and management resources. It is critical that these lessons be applied to Mexico before the epidemic is allowed to devastate an already underserved nation. According to recent research projects currently being conducted along the border and among migrant workers in the US, HIV infection is on the verge of a rapid escalation in this population and the prevalence observed in Mexican migrant workers may eventually be mirrored by the US Latino population overall.²⁷

As the Latino population continues to diversify throughout the United States, Latinos with AIDS are now found throughout the country, with rapid increases taking place in the Southeastern US and other regions. Upon examination of the growth and distribution of AIDS cases among Latinos in the US, geographic shifts can be clearly observed. From 1998 to 2000, while AIDS case rates continue to remain highest in the Northeastern US, they are beginning to shift to the South along the Southeastern migrant corridor with increases in AIDS cases among Latinos observed in Virginia, North Carolina, South Carolina, and Mississippi. Although AIDS case rates should be interpreted with caution due to the fact that they may be more indicative of a small Latino population, considerable strategic changes are necessary for effective health services and prevention efforts given the definitive growth of the Latino population in the Southeastern US.²⁸ The necessity of more complete HIV infection data from every state cannot be overstated. Without a clearer picture regarding how HIV is affecting Latinos, whether MSM, IDU or heterosexual, the population will continue to be underserved and under targeted in prevention education and HIV related services.

La Muerte: Latinos, Particularly Latinas, are Often the Last to Know

Latinos, particularly women, are often the last to learn of their HIV infection. Research demonstrates that Latinos are more likely than all other racial/ethnic groups to have an AIDS diagnosis within 12 months of testing positive for HIV.

[www.nastad.org/DOCUMENTS/PUBLIC/HIVPREVENTIONPROGRAMS/2003723ADDRESSINGAIDS...LATINOPERSPECTIVESANDPOLICYRECOMME.PDF]. A study conducted of clinics in East Los Angeles found a statistically significant decrease in CD-4 or T cells upon first HIV diagnosis when compared to Anglos and African Americans.²⁹ Persons involved in sexual relationships with infected but undiagnosed persons do not learn of their exposure until late in the process of the disease. This is particularly true among Latinas who may, for reasons ranging from cultural mores and economic dependence to domestic violence, not question their partner's sexual behaviors. In the words of one participant of the NCLR Latinas and HIV Needs Assessment, "This is his fault. I never thought this would happen to me because I never left the house. 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."³⁰

Latinos are also less likely than all other racial/ethnic groups to have access to the health care system. According to the Commonwealth Fund's 2001 Health Care Quality Survey, 46% of Latinos under the age of 65 reported having gone without health insurance some period of time in the year previous to the survey.³¹ Due to the fact that the majority living in the US receives most health related information in the medical setting, the poor access of Latinos to health coverage and subsequent services indicates a large gap in public health knowledge.

The lack of funding being afforded HIV prevention alone indicates the dearth of vision from a preventive stance. Within the specific \$27.75 million allocated for prevention, CDC initiatives are currently focusing on the identification of HIV positive gay males of color and vaccine preparedness. Although these are worthy efforts, women are again being denied their full significance and heterosexual women and men, who are being exposed to the virus as such, are not being targeted to the extent needed.

Additionally, identified HIV and AIDS populations will continue to receive the meager budget allocations presently affording preference to those infected and being tracked who are mainly men who have sex with men and IDUs. An estimated 79% of all diagnosed HIV cases in 2003 for women in the US were reported as coming from heterosexual contact, the fastest growing category of infection. This figure is greater than the sum of all other categories of transmission yet excludes those cases of women who cannot or do not identify their sexual partner as an infected person. [www.cdc.gov/hiv/pubs/facts/women/htm]. The exclusivity of the heterosexual category unfairly targets unsuspecting women and places them at greater risk of infection from undiagnosed or untested males. Latinos are made invisible once again because the larger numbers of HIV cases in the Latino community are emerging from heterosexual sex between unsuspecting females and infected but not diagnosed or tested males. Although HAART has been very successful in treating and slowing disease progression, the US public has, to a certain extent, become placated by mass media reporting on the HIV/AIDS epidemic as being managed and treated given the low numbers of AIDS cases reported from the states. The

historical neglect of highly populated Latino states and Latino populations in such states as New York and California has resulted in an inaccurate perception of risk within the general Latino population. These factors, combined with little to no access to the health care system, a grave lack of culturally and linguistically relevant prevention education and HIV related testing and care, lead to high rates of infection among Latinos.

Historically, approaches to prevent HIV infection among women have included reduction of multiple sex partners, promotion of monogamous relationships, abstinence or safer sex practices (i.e., condom use), and screening and treating sexually transmitted diseases (STIs). [www.undp.org/hiv/publications/ issues/english/issue10e.htm] Unfortunately, just as in underserved countries, these strategies have little relevance on Latina communities at greatest risk for HIV infection in the US today. Many Latinas with HIV/AIDS have had sex with only their husbands or long term sexual partners, and changes in their individual behavior, with the exception of leaving their families and remaining abstinent for life, would therefore not be applicable or appropriate. It is essential to acknowledge that many Latinas are dependent on their male partners for economic sustenance and may not have alternatives for family survival. Many Latinas also depend on men for social access and privilege within society and a break up of the relationship may be seen as her failure regardless of the precedent behavior of her male partner. Moreover, Latinas often have little control over their husband's extra-relationship activities and are powerless to enforce fidelity. In the words of one NCLR Latina focus group participant, "If you want to prevent HIV, talk to our husbands."³² In addition, to admit the infidelity of one's male partner is perceived as having personally failed in providing him satisfaction within the relationship. Given the many barriers Latinas experience in acknowledging and confronting the potential infidelity of their male counterparts, the popularity of the common saying "*Ojos que no ven, corazón que no siente*" (Eyes that don't see, heart that doesn't feel), should not be surprising.

Assuming the aforementioned barriers to HIV prevention among Latinas, the strategy of condom use becomes a definite alternative however, there are substantial problems with this assertion. Men use condoms, and with the exception of the female condom, which is not commonly used and is quite costly, women can only ask that they be used. Within Latino culture, as in many others, condom use acknowledges a lack of *confianza* (trust) that can lead to perceptions of infidelity by both males and females. The common saying in Spanish "*No es igual comerse la paleta con la envoltura*" (eating the popsicle with the wrapper on just isn't the same), was found to be commonly stated in the NCLR HIV/AIDS Needs Assessment.³³ Many Latinas live within relationships wherein domestic violence is an imminent threat and condom negotiation or confrontation regarding suspected infidelity could incite abuse of both women and their children. Just as Latinas are often not aware of their HIV risk, the potential for HIV infection is also unknown. In addition, sexually transmitted infections (STIs) such as gonorrhea or syphilis often remain asymptomatic in women for long periods of time. Prior to diagnosis STIs, deplete regional immunity thus placing the woman at increased risk of HIV infection if exposed. STI services, if available and accessible, are often not provided in a culturally and linguistically appropriate manner, thus leading to poor follow up and long term prevention.

Until public health professionals are willing to combine efforts to move beyond the alteration of individual behavior within a culturally competent framework through the creation of long-term socioeconomic and political opportunities for Latinas, we will continue to fail in our HIV prevention efforts. In the words of Jennifer Hirsch,

Culture, and its programmatic corollary cultural appropriateness, has been embraced because they are an easy pill to swallow in public health. They suggest that if we capture just the right culturally appropriate perspective, if we could just tell people how to be healthy in the right words, they would listen and all would be well. A social perspective on sexuality, in contrast, might force us more in the direction of political economy.³⁴

It is essential that the heterosexual risks experienced by all women, particularly Latinas, are given voice by both the state departments of health and the CDC. By deflating the relevance of heterosexual risk behavior as a growing trend of the HIV pandemic, we commit a grave failure to recognize HIV risk context as similar for underserved women in the US when compared to Africa or Latin America. We also inflate our denial of class as an issue that affects the health status of women. As we work toward a more comprehensive agenda that relates directly to the contexts within which Latinas are infected with HIV, a focus on individual behavior change fails to acknowledge the many constraints that inhibit safer sex behaviors. Creative HIV education and prevention strategies, such as peer education (*promotores*) programs that provide Latinas, particularly immigrants, with segue into the formal US health workforce, are both effective in outreach and training potential. These approaches, if compensated, also create mechanisms of resistance and empowerment wherein Latinas can begin to see their worth as women, and not merely the sexual and maternal gratification they provide for their husbands and children.

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