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

Britt Rios-Ellis
California State University Long Beach

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

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 nu

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 inser

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 Trails 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.htmlAIDS%20Focus%20Slowly%20Turning%20Toward%20Women]. This resulted in the exclusion of women from scarce clinical trails 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

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]

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 sugg

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.

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, Jalísco 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

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

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.

References

[1] Vittinghoff, E., Douglas, J., Judson, F., et al. 1999. Per-contact Ri

[27] Kaiser Family Foundation. 2004. Kaiser Daily HIV/AIDS Report. HIV Prevalence among Mexican Migrant Workers Three Times as High as General U.S., Mexican Populations, Studies Show. November 2. Washington, DC
[28] NCLR. 2004. The Health of Latino Communities in the South: Challenges and Opportunities. Washington, DC.
[29] Rios-Ellis, B et al. 2002. The NCLR Latino Families HIV/AIDS Prevention Project. American Public Health Association Annual Meeting, San Francisco, CA, November.
[30] Rios-Ellis, B. 2004. Presentation made at the Latino Coalition Against AIDS Forum. Los Angeles, CA, October.
[31] Doty, MM and Ives, BL. 2002. Quality of Health Care for Hispanic Populations: Findings from the Commonwealth Fund 2001 Health Care Quality Survey, March.
[32] Rios-Ellis, B. 2004. Latinas and HIV. Presentation for the Latino Issues Forum, Orange County, CA, November.
[33] Rios-Ellis, B. 2003. Latinos and HIV Prevention. Keynote Address given for The Dallas HIV/SIDA Coalition Annual Meeting. December 1.
[34] Hirsch, J.S. 2003. A Courtship After Marriage: Sexuality and Love in Mexican Transnational Families. Los Angeles: University of California Press.