



Lesbians and the Risk of HIV Infection: Does Surveillance Underestimate HIV Risk?

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State-run surveillance programs for reported acquired immunodeficiency syndrome (AIDS) cases and results from public human immunodeficiency virus (HIV) testing sites provide important information for gauging the risk of female-to-female sexual transmission. However, these data can vary in completeness and thus may underassess the risk faced by women who have sex with women. We examined the extent to which

complete sex behavior histories are asked of adult women, including questions regarding sex with men and sex with women, as indicated by care providers and surveillance personnel on the HIV/AIDS reporting system form that is sent to the California Department of Health Services AIDS registry. Among the 29% of AIDS cases with incomplete sexual behavior reporting in adult women, approximately 22% did not have sexual behavior histories indicated and 65% were missing information on possible sexual histories with women. Although complete data are obtained in over 90% of adult women tested at publicly funded sites, a quarter of women who test HIV positive have incompletely ascertained sexual behavior histories. Nearly all incomplete reports of sexual behavior histories from public HIV testing sites lacked information on whether or not women had sex with other women. The incompleteness of these data hampers efforts to accurately gauge the risk of female-to-female sexual transmission.

Key words: HIV, AIDS, women, lesbian, risk behavior, surveillance, California, transmission.

The two earliest reports of possible female-to-female sexual transmission of human immunodeficiency virus (HIV) infection (Marmor et al., 1986; Monzon & Capellan, 1987;) generated significant interest in the risk of HIV transmission among women who have sex with women (WSW). Since then, a number of studies have concluded that the occurrence of HIV transmission among (WSW) is rare (Kennedy, Scarlett, Duerr, & Chu, 1995; Marmor et al., 1986; Monzon & Capellan, 1987; Rich, Buck, Tuomala, & Kazanjian, 1993; Sabatini, Patel, Hirschman, 1984). Studies assessing risk of HIV infection in WSW find that these women are more likely than heterosexual women to report injection drug use, needle sharing, or unprotected anal sex with men as well (Bevier, Chiasson, Hefferman, & Castro, 1995; Cohen et al., 1993; Chu, Buehler, Fleming, & Berkelman, 1990; McCombs, McCray, Wendell, Sweeney, & Onorato, 1992; Raiteri et al., 1994).

A few of these reports based their conclusions primarily on retrospective studies of national surveillance databases of HIV testing and reported cases of the acquired immune deficiency syndrome (AIDS) among women in the United States (Chu et al., 1990; McCombs et al., 1992; Peterson, Doll, White, Chu, & the HIV Blood Donor Group, 1992). These data were collected as part of cooperative agreements between states and the federal Centers for Disease Control and Prevention (CDC). Although AIDS surveillance data are reasonably complete and accurate (Buehler, Berkelman, Stehr-Green, 1992; Rosenblum, Buehler, & Morgan, 1992), to the best of our knowledge no study has examined completeness of reporting of the sexual risk behavior variables used in these retrospective analyses. Because these variables are used in the hierarchical assignment of the probable mode of HIV exposure, such information is a valuable quality measure of these widely used databases.

California is one of the earliest AIDS epicenters in the United States. The state has the second largest cumulative number of AIDS cases, next to New York State, and the largest publicly financed HIV testing program in the world. Although HIV disease has disproportionately affected gay men in California, recently more women are being diagnosed with the disease (Araba-Owoyele, Singleton, & Kuan, 1993). Appropriate HIV prevention strategies must be evidence-based and targeted (Mays, Cochran, Pies, Chu, & Ehrhardt, 1996).

We examined the completeness of reporting sex risk behavior history on the HIV/AIDS reporting system (HARS) form sent to the California Department of Health Services, AIDS registry from local health departments and care providers in the state as part of an ongoing quality control exercise. The California Department of Health Service, Office of AIDS routinely examines AIDS registry data for completeness, accuracy, and timeliness. This article addresses one of the recent efforts to assess whether or not sexual risk behavior history of persons with AIDS and those who are tested for HIV-1 infection in publicly funded test facilities are completely ascertained by their care provider and surveillance personnel before being entered on the HARS by local health jurisdictions.

METHODS

To assess the completeness and consistency of AIDS surveillance data in ascertaining risk behavior history of women, we conducted extensive reviews of AIDS cases reported through January 1, 1996, in adult women. The HARS confidential case report form contains questions on sexual risk behavior of the patient (see Appendix). The three options to each of the questions on the patient's history are yes, no, or unknown. If none of these options are selected on the form, then the response is treated as missing. When entered into the HARS software, this information is partly used to assign the likely mode of HIV exposure of the patient.

In our analysis, a report of the sexual risk behavior is defined as fully ascertained when (a) only one of the three options to each sexual risk behavior question is checked on the case form, and (b) the response is consistent with former or later responses on the form. When a response is deemed incomplete, we prepared a computer program to determine if the incompleteness is due to partial or inconsistent response(s) to the sexual behavior history questions. We then enumerated the incomplete responses to know exactly what was inconsistent about them.

We analyzed completeness in AIDS cases among adult women by region and demographic variables and determined relative differences in completeness between these variables. Because the HIV antibody testing program collects similar data on sexual risk behaviors, we examined 80,064 publicly financed HIV test data collected in the first 10 months of 1995 to assess their differences and similarities with the AIDS case data. We defined WSW in two ways: (a) specifically, to include

women who have had sexual contact with only women since 1978, and (b) broadly, to represent women who reported sexual contact with a woman within the same time period.

RESULTS

Of 5,248 AIDS cases in adult women reported in California, slightly over 70% ($n = 3,735$) had their sexual contact history fully ascertained (see Table 1). The majority of these women ($n = 3,486$) reported sexual contact with only men since 1978. WSW accounted for 2.1% of adult women with AIDS and 3% (112/3735) of women with complete sexual contact history. By comparison, the completeness of sexual risk behavior history on the reporting form is much higher (92.4%) in HIV testing, no matter what the result, than in AIDS data. However, among women who received an HIV+ test result, about one in every four had an incomplete sexual risk behavior history taken.

Of the AIDS cases with unascertained sexual risk behavior history ($n = 1,549$), slightly over one-fifth resulted either from missing data ($n = 48$), or sexual risk behavior unknown to the care provider or the AIDS surveillance personnel ($n = 289$). The remaining cases ($n = 1,211$) were a result of partial reporting of sexual

TABLE 1
Ascertainment Status of Sexual Risk Behavior History of Adult AIDS Cases (1978-1995) and HIV Antibody Testing (January-October 1995) Among Women in California

Ascertainment of Sexual Contact	AIDS Data ^a		HIV Antibody Test Data ^b			
	No. of AIDS Cases	% of AIDS Cases	No. of Tested	% Tested	No. of HIV Positive	% of HIV Positive
Ascertained sexual risk behavior history	3,735	70.6	74,012	92.4	277	74.3
Sex with women only	32	0.6	1,745	2.2	29	7.8
Sex with men and women	80	1.5	6,469	8.1	8	2.1
Sex with men only	3,486	65.9	64,874	81.0	236	63.3
No sexual contact	137	2.6	924	1.1	4	1.1
Unascertained sexual risk behavior history	1,549	29.3	6,065	7.6	96	25.7
Incomplete						
Partial	1,068	20.2	4,169	5.2	19	5.1
Inconsistent	143	2.7	0	0	0	0
Missing	48	0.9	1,896	2.4	77	20.6
Unknown	289	5.5	0	0	0	0

^a $N = 5,284$. ^b $N = 80,077$.

TABLE 2
 Incomplete Cases of Sexual Risk Behavior History in Adult Women
 With AIDS and Women Tested at Publicly Funded HIV Antibody Test
 Site in California

<i>Cases of Incomplete Sexual Risk Behavior History</i>	<i>AIDS Cases^a</i>		<i>HIV Testing^b</i>	
	<i>No. of Cases</i>	<i>% of Incomplete</i>	<i>No. of HIV Test</i>	<i>% of Incomplete</i>
Incomplete report				
Had sex with a male, but sex with a female is "unknown"	943	77.9	0	0.0
Had sex with a male, but sex with a female is "missing"	54	4.5	3,986	95.6
Had sex with a female, but sex with a male is "unknown"	6	0.5	0	0.0
No sex with a male, but sex with a female is "unknown"	5	0.4	11	0.3
No sex with a female, but sex with a male is "unknown"	57	4.7	129	3.1
No sex with a female, but sex with a male is "missing"	3	0.2	43	1.0
Inconsistent report				
Had sex, but gender of sexual contact is "unknown" for both sexes	67	5.5	0	0.0
Had sex, but gender of sexual contact marked "no" for both sexes	65	5.4	0	0.0
Had sex, but gender of sexual contact is "missing" for both sexes	10	0.8	0	0.0
Had sex, but gender of sexual contact is "unknown" for male and "missing" for female	1	0.1	0	0.0

^a*N* = 1,211. ^b*N* = 4,169.

contact history (*n* = 1,068), or the reporting of inconsistent information about the patient's sexual risk behavior (*n* = 143).

As shown in Table 2, among female case reports with partial reporting of risk behavior history, a disproportionate number had sex with men indicated, but a history of sexual contact with women was marked by the care provider or the AIDS surveillance personnel as unknown or missing. Nearly all cases of reported inconsistent sexual risk behavior data were seen in women with AIDS who in spite of reporting heterosexual sex with an injection drug user, bisexual male, or a person with HIV/AIDS, still had the sexual contact history with a male or female marked as no, unknown, or missing. By contrast, although HIV testing data also had some partial reporting of risk behaviors, there was no reporting of inconsistent sexual behavior information.

Completeness of reporting sexual risk behavior information among adult women with AIDS varied significantly by region of residence in California, and race/ethnicity. Los Angeles County has the highest proportion of AIDS cases in adult women (32%), and the second highest proportion of WSW cases (21%), next to San Francisco County (25%). However, almost 60% of the cases with unascertained sexual risk behavior history are from Los Angeles County, a proportion four times higher than the rest of the state. Ascertainment of sexual risk behavior history was about 40% less complete among Latinas throughout the state than for all other racial/ethnic groups combined.

Incomplete ascertainment of sexual risk behavior history varied by year of AIDS diagnosis. Adult women who were diagnosed with AIDS between 1990 and 1995 were more likely to have incomplete sexual risk behavior history ascertainment (23%) than those diagnosed in 1980 through 1989 (20%; $p = 0.06$).

DISCUSSION

In this study we were able to ascertain that the thoroughness of determining the sexual risk behavior histories of women in AIDS surveillance data, and to a lesser extent the HIV test data from publicly funded sites for the State of California, may vary by geographic regions, period of data collection, and ethnic group. Our study reveals that approximately one-third of the AIDS cases in women and one in every four women who received an HIV+ test had an incomplete sexual risk behavior taken. In the case of the AIDS surveillance data, that information was most likely to be partial reporting in which history of sexual contact with men was completed, but whether or not these women had sexual contact with a woman was marked as unknown or missing. Among women with positive HIV tests, those with incomplete reporting were most likely to be missing information on histories of sex with women.

Unfortunately what this study does not tell us is what factors contribute to the incomplete reporting of women's sexual risk behavior, particularly their possible sexual contacts with other women. The authors can only speculate on the role that language, assumptions of heterosexuality, beliefs about lesbian sexuality and risk of HIV infection, and embarrassment or reluctance in asking about same-sex risk behaviors play as contributing factors to this incomplete reporting problem. Further, challenges in county surveillance infrastructures where there are increasing caseloads but fewer resources may result in less than full reporting. The greatest percentage of cases of AIDS in women is in Los Angeles County, which also has the second highest percentage of cases of AIDS in women who have sex with women. In recent years, Los Angeles County, in particular, has suffered from widespread cutbacks in county health resources.

Nevertheless, given the extensive use of surveillance data in many of our HIV planning and prevention efforts and decision-making for targeted prevention activities, efforts to facilitate ascertainment of complete sexual behavior histories by HIV test counselors and surveillance staff will substantially contribute to understanding the extent of exposure and risk of transmission of HIV infection in women engaged in sexual activities with other women.

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APPENDIX

Patient Sexual Behavior History Questions on the Adult HIV/AIDS Confidential Case Report Form

AFTER 1977 AND PRECEDING THE FIRST POSITIVE HIV ANTIBODY TEST OR AIDS DIAGNOSIS, THIS PATIENT HAD

(Respond to ALL Categories):

	Yes	No	Unknown
• Sex with male	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Sex with female	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
HETEROSEXUAL relations with any of the following:			
• Intravenous injection drug user	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Bisexual male	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Persons with hemophilia/coagulation disorder	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Transfusion recipient with documented HIV infection	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Transplant recipient with documented HIV infection	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Persons with AIDS or HIV infection, risk not specified	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Data from the Adult HIV/AIDS Reporting System form provided by the Centers for Disease Control and Prevention (1993).