



## Are Lesbians at Risk for HIV Infection?

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The discussion of risk of human immunodeficiency virus (HIV) infection in lesbians is one that for the first decade of the HIV/AIDS epidemic focused narrowly on the biologic issue of female-to-female transmission. This special issue, on risk of HIV infection in lesbians, encourages the reader to view the question of whether lesbians are at risk for HIV infection within the paradigm of HIV risk being conferred on those segments of society who are most vulnerable to the forces of social inequality and social injustice. The invisibility of lesbians and other women who have sex with women (WSW) as at-risk populations is highlighted within the context of differences in methodological approaches found among the seven empirical studies in this special issue. A salient finding across several of these studies is the incompleteness of the use of only sexual behavior or sexual orientation in assessing risk of exposure to HIV infection. Studies found that self-identified lesbians may engage in sex with men, and similarly, self-identified heterosexuals may also have same-sex sexual partners. Recommendations for a newer paradigmatic approach to research, prevention, treatment, and public policy guidelines, whose goal is empowerment and community mobilization for lesbians and other WSW is discussed.

Key words: lesbians, sexual behavior, women who have sex with women, bisexuals, injection drug users, social vulnerability, ethnic minorities

The World Health Organization (WHO) has estimated that approximately 18.5 million adults and 1.5 million children globally are infected with the human immunodeficiency virus (HIV) and that almost 10,000 new infections occur every day (National Institutes of Health [NIH], 1996). Of these, it is estimated that more

than 40% of adult cases of HIV infection are in women (Shalala, 1996; Faden & Kass, 1996). The vast number of cases of AIDS and HIV infection in this country, as well as globally, can be accounted for as a result of two specific activities: unprotected sexual intercourse with an HIV-infected person or the use of drug injection equipment contaminated by the HIV virus (NIH, 1996). Often forgotten is that among these cases of women infected with HIV/AIDS are women who report prior sexual behavior with other women and, more specifically, women who self-identify as lesbians. Traditionally, one definition of being a lesbian is engaging in sex with women but not men; therefore, the presence of these women among HIV-infected cases has raised concerns about the neglect of considering risk from female-to-female sexual transmission and, more broadly, that their needs are being overlooked in AIDS prevention and treatment programs, which often assume that all women are heterosexual or that sexual orientation does not matter to a drug user in their treatment program.

Although we are 15 years into the U.S. HIV/AIDS epidemic and the general public has accepted that HIV/AIDS is a health concern for many women globally as well as in the United States, the Mays, Cochran, Pies, Chu, and Ehrhardt (1996) article in this special issue reminds us that, in 1996, basic questions regarding the risk of HIV infection in lesbians still remain unanswered. Is HIV/AIDS infection a warranted health concern for lesbians? Is there risk of transmission of HIV infection in the sexual activities between female partners? How prevalent in the lesbian community is drug use, including use and sharing of injection drugs as well as crack-smoking (that is associated with a host of risk behaviors for transmission of the virus)? What is the extent to which women who engage in sexual activities with other women have at-risk sexual histories from engaging in unprotected sexual behaviors with men? Is there something about the way in which HIV research is conducted that makes it unlikely that these questions will be answered in the near future? (see also Hollibaugh, 1993/1994).

Several of the articles in this special issue begin to provide clues to answer these questions as well as to raise others. Nevertheless, the goal of this special issue is not to answer the questions completely, but rather to begin to lay the groundwork in this direction. In this issue, through gathering empirically based studies that address themselves not to the biological issue of female-to-female transmission but instead to the behavioral and social context of HIV risk in lesbians and other women who have sex with women (WSW), we hope to provide some direction for future discussion. It is also the goal of this special issue to move the discussion of prevention of HIV transmission and infection in lesbians and other WSW from the now aging paradigm of the mid-1980s, in which individual behavior, education, and increasing one's sense of risk were core to infection control (Parker, 1996). We hope to broaden the perspective of risk to a reflection on how the social configuration of specific conditions of culture, economics, oppression, violence, social inequality, and social injustice contribute to conditions of risks that facilitate

transmission and exposure in some particularly vulnerable groups of women (Mann, 1993; Mays, 1992; Mays et al., 1996; Parker, 1996). In this second decade of HIV prevention, it is understood that the social nature of HIV requires that prevention move from models of behavior change whose focus is individualistic and information driven to multidimensional models whose goals include empowerment and community mobilization (Mann, 1993; Parker, 1996). For those who have worked for years in the battle against HIV/AIDS, these efforts have taught us that prevention must address issues of inequality and injustice, because it is these very social factors that create the conditions that foster the spread of HIV in socially disenfranchised populations (Mann, 1993; Mays, 1992; Mays et al., 1996; Parker, 1996). It is the fear, for example, of violence, reprisal, and homelessness that keeps some women from confronting a sexual partner about his or her HIV risk status. It is economics, in which women's labor market values and options are suppressed despite their primary responsibility for child care and head of household status, that contributes to the lure of informal economy labor market activities such as commercial sex work to provide family- and self-support. It is also the stigma of discrimination associated with being a lesbian in society that may encourage some women to engage in high-risk behaviors that result in exposure to HIV infection.

### IDENTITY OR BEHAVIOR?

In examining the issue of risk of HIV infection for lesbians, where one looks and how the population of "lesbians" is defined is critical in how the epidemic and population risk will appear. The lead article in this special issue, by Cochran, Bybee, Gage, and Mays (1996), combines three large self-administered surveys ( $N = 8,529$ ) in which participant-recruitment activities targeted the general lesbian population. Consequently, over 80% of the women in the studies self-identified as lesbians. In other words, these women were not selected based on risk but on community membership. Across the surveys, questions were asked assessing various self-reported prevalence of HIV infection, HIV-related sexual risk behaviors, experiences with sexually transmitted diseases, alcohol, and drug use. What we learn from this study is that, although few women who had been tested for HIV antibodies self-report being infected, some women, despite a lesbian identity, do report recent heterosexual sexual activity.

In contrast, there is the Deren, Goldstein, Williams, Stark, Estrada, Friedman, Young, Needle, Tortu, Saunders, Beardsley, Jose, and McCoy (1996) study, which recruited over 6,000 injection drug users and crack-smoking women from 21 sites throughout the United States. There is also the Moore, Warren, Zierler, Schuman, Solomon, Schoenbaum, and Kennedy (1996) study, which recruited approximately 870 HIV-infected women from four urban cities based on HIV-related risk histories. Both of these studies included a significant number of women who have had sex

with women and a lesser number of lesbians. The women in these studies were not specifically recruited because of their sexual orientation but rather on behaviors that would put them at risk for HIV infection or disease. However, when asked about their sexual orientation and same-sex partner activities, what emerged is that, within the segment of women at risk or HIV-infected, some are lesbians, bisexuals, and heterosexuals who engage in sexual activities with other women. Moore et al. found in their sample of HIV-infected women that women who had a history of sex with women as compared to women who have had sex with men only are more likely to report a history of injection drug use, trading sex for drugs or money, sex with a male injection drug user, multiple sex partners, and anal sex with a male partner. From this perspective, lesbians and other WSW appear to be particularly vulnerable to HIV infection because, in contrast to the heterosexual women studied, their behaviors seem more risky.

Thus, the answer to the question, "Are lesbians at risk for HIV?" depends in part on which view of the population is adopted. Both sampling strategies reveal that identity does not always perfectly correspond to behavior, a finding repeated in the Ziemba-Davis, Sanders, and Reinisch (1996); Gomez, Garcia, Kegebein, Shade, and Hernandez (1996); and Cochran and Mays (1996) articles. Also, Deren et al. (1996) and Moore et al. (1996) both underscore the importance of considering these distinctions in the behaviors of WSW. For example, in the Deren et al. study, when self-identified lesbians were separated into those who had sex with men in the last 30 days and those who did not, very different pictures of the risk for HIV infection emerged, even though both groups self-identified as lesbians. Deren et al., like Moore et al., make a strong case that sexual identity and sexual behavior are not synonymous and each should be studied independently in terms of their relationship to HIV-risk behaviors.

The issue of self-identified lesbians having sex with men is a finding that has long been known but which, for the most part, was ignored until lesbian sexuality became relevant relative to understanding the risk of HIV infection from sexual behaviors. Ziemba-Davis et al. provide us with a sense of the history of lesbians having sex with men. As part of the introduction to their study, which was conducted early in the HIV epidemic (1987-1988), they present us with a review of earlier studies that reveal that self-identified lesbians have perhaps always engaged to some extent in sexual activities with men. In one of their own previous studies (Reinisch, Sanders, & Ziemba-Davis, 1995), we learn that not only were self-identified lesbians engaging in sex with men but these men were likely to be gay or bisexual. Although the findings of this study were known to many, the early focus on biologic issues of female-to-female transmission muted the importance of these findings.

We know little of the motivation, necessity, or context of these sexual behaviors with men among women, many of whose primary sexual partner is another woman. Gomez et al. (1996) provide some clues from their sample of 481 women drawn from public venues in San Francisco of WSW and who have had sex with both

women and men in the previous 3 years. In this study, it was young lesbians who were more likely to engage in sex with men and to report a history of injection drug use when compared to the relatively older lesbians who had sex only with women. These findings are similar to those of Cochran and Mays (1996) who report on a study of young lesbians, aged 18 to 24 years, recruited at public gay and lesbian activities at two time periods, 1993 and 1995. They found that sex with men, particularly gay men, was more likely to occur among the younger women who did not yet consider themselves to be lesbians.

This finding of an imperfect match between identity and behavior is echoed across several of the articles, highlighting that these aspects of an individual are not synonymous, although they are not unrelated. A point to remember is that lesbians may have a multiplicity of identities including, for some, users of injection drugs or crack-smokers, commercial sex workers, and "all-girl queers" (Mays et al., 1996). The population is not homogenous, and several factors may contribute to different degrees of social vulnerabilities from differential gender and power relations.

Although it may be the case that lesbians are at risk for HIV infection, it is not true that this degree of risk is the same for all lesbians. In the mid- and late 1980s, HIV/AIDS was promoted as everyone's epidemic, as a democratic disease in which all were equally at risk for HIV infection. But this has proven to be no more than, perhaps, a necessary fiction needed to move those in this country beyond their complacency of belief that they were free of risk from this disease because they did not use injection-based drugs, engage in prostitution, or believed they had sex with high-risk partners (Richards, 1996). This perspective may also have contributed to a delay in focusing on how social, cultural, economic, political, gender, and sexual orientation factors contribute to some individuals being at more risk than others (Mays & Cochran, 1995). This heterogeneity of risk is as true for lesbians as it is for other groups in the United States, perhaps more so.

## SOCIALLY VULNERABLE POPULATIONS

What the Deren et al. (1996) and Moore et al. (1996) articles demonstrate is that, for some lesbians and other WSW, social vulnerabilities such as lacking economic resources, homelessness, instability of relationships, lack of employment, or histories of incarceration may contribute significantly to the conditions that confer risk for HIV. The ability to protect oneself from disease is often a function of resources, access to information, appropriate prevention services, and freedom from reprisal and violence (Krieger & Appleman, 1994; Krieger & Margo, 1990). Some lesbians and other WSW perceive prevention of HIV as beyond their reach because they are unable to access treatment services for their injection drug or crack use or because they find health care practitioners who dismiss their HIV risk because of their sexual

orientation. For others, the lack of information about the risk of HIV infection and its transmission during sexual activities with an HIV-infected woman cripples their ability to make sound and appropriate decisions in the midst of an information void.

This special issue, rather than answering the question of whether lesbians are at risk for HIV infection, tries to redirect and refocus the question regarding lesbians and the risk of HIV infection. It attempts, using the scarce research available, to educate the reader about the critical role that social, economic, political, and gender forces play in structuring the realities that face lesbians, particularly those socially vulnerable groups of lesbians or other WSW, who may be most likely to be among that group of at-risk women. Deren et al. (1996), Moore et al. (1996), and Mays et al. (1996) remind us that lesbians and other WSW will be found among injection drug users, sex workers, prisoners, the homeless, and within heterosexual relationships. Cochran and Mays counsel the reader not to view as frivolous the coming-out process of some young lesbians who also have heterosexual activities at times with their friends, who may also be young gay men experiencing the same societal pressures toward heterosexuality. It is, perhaps, in responding to these pressures, that young lesbians or other WSW at a vulnerable period, engage in risky heterosexual sexual activity.

### LESBIAN INVISIBILITY PERPETUATES SOCIAL VULNERABILITY

Finally, the invisibility of lesbians contributes to their social vulnerability. This invisibility occurs at many levels. Araba-Owoyele, Johnson, Mays, Truax, and Cochran (1996) warn us, the question of same-sex partners is not being ascertained equally for men and women in surveillance systems. A simple perspective on the lack of ascertainment could be the loss of infrastructure support as the number of cases grew, because the problem was greatest in the later years, 1990–1995. However, there may be other factors to consider. One wonders if, beyond the loss of infrastructure support that contributes to surveillance work, not asking the question of same-sex partners, particularly of Latino women, is a function of social discomfort that silences both those whose job it is to ask and those seeking services. Is it a tacit agreement that such behaviors do not exist or do not contribute to HIV risk? Is it a belief that the incidence of lesbianism or same-sex partners is so low that asking the question has little value? Or is it a fear that the asking will result in shame, embarrassment, anger, or discontinuation of the interview? Although unpublished reports from the Women Health Interview Survey and the Harvard Nurses Study tell us that women will answer questions addressed to them about same-sex sexual activities, it is not clear if this is true specifically for women of color living impoverished lifestyles who access public health services.

In other ways, the invisibility affects prevention activities and treatment options. Lesbians who are infected, such as the women in the Moore et al. (1996) studies and others, search desperately for support groups where they can discuss safer sex issues; the dynamics of serodiscordant same-sex relationships; the role of homophobia, powerlessness, and anger in their lives; and how to keep focused on living when almost every reflection in the treatment and prevention field tells them their experience is so rare that it does not merit attention (Mays et al., 1996). Lesbians and other WSW, their partners, and health care providers clamor for information other than that of whether HIV transmission is at all possible via sex between women. They want to know how risky is this behavior, how does one live with HIV? It is hoped that the articles in this special issue will push those who work with drug users, in prisons, and with women of any kind, to realize that among them are probably WSW and lesbians who may need HIV prevention and treatment services.

## CONCLUSION

In our early conceptualizations of the epidemic of AIDS, and later HIV infection, we were guided by the notion of risk groups. Although this approach is common in epidemiology, where identification of a population at risk for infection can help to focus infection control activities, it ran headlong into socially prejudiced views and misunderstandings, with calls to quarantine or tattoo members of high-risk groups. Early on, lesbians, as members of the homosexual community, were seen as equally vulnerable as gay men to HIV infection. Later, lesbians were viewed as somehow divinely spared from the epidemic.

But there are possibly more recent forms of this blame-the-victim approach to disease control that we must avoid, even as we focus in on those factors that put lesbians at higher risk for HIV infection. For example, to the extent that lesbians might be blamed if they engage in behaviors that put them at risk, or that their sexual behaviors with men are seen as unnecessary, or that if only they would stop having sex with gay or bisexual men or using drugs they would not be at risk for HIV infection. The burden of protecting the public health is to be entrusted with the responsibility that we must not fail our citizens, including those whose behavior sometimes puts them in harm's way. Effective HIV prevention and intervention for lesbians and other WSW implies understanding the realities of their lives within the context of the society in which they live and the interplay of these social factors on underlying motivations, necessities, and determinants of their behaviors.

The articles in this special issue were compiled in the hopes that, for those involved in prevention, they are moved into a paradigm of conceptualizing socially vulnerable groups and understanding the historical and structural forces that create the conditions for the spread of HIV/AIDS. The challenge with which many of the

authors have left the readers of this special issue is how to build an efficacious prevention agenda for those lesbians and other WSW who are most vulnerable to exposure to HIV infection by forging a bold new plan. This plan needs to be based on the necessary lessons of the first decade of HIV prevention, which tell us that all individuals can be biologically susceptible to HIV infection if exposed, and that it is individual acts of behavior that confer that risk. But this plan must also be grounded in the realities of what creates risk for the most vulnerable segments of the population of lesbians and other WSW. Prevention, research, treatment, and public policies, if they are to be efficacious, will need to understand the realities created by social inequality, injustice, prejudice, discrimination, violence, oppression, and exploitation in the lives of lesbians and their sexual partners, that places these women in vulnerable situations that increase their risk for HIV infection (Mann, 1993; Parker, 1996). Only prevention efforts that help lesbians and other WSW to empower themselves and mobilize as members of a community that can prevent their own risk of HIV infection will truly decrease the risk of HIV/AIDS for these women.

#### ACKNOWLEDGMENTS

This special issue, with its speedy completion, was produced only as a result of the hard work of many colleagues. Willing reviewers provided each author with thoughtful comments, suggested ways to sharpen the focus, and challenged us all to address the broad implications of our studies. Thanks also must go to the Editor, Tracey Revenson, Ph.D., for her nurturance of this special issue from the inception to the completion. She could always be counted on to provide astute guidance. And finally, a special thanks to Serena Chen, Editorial Assistant, who had the hardest job of all. But at every step of the way, she could be counted on to keep things from falling between the cracks. She was great at keeping authors, reviewers, myself, and the editorial staff at Lawrence Erlbaum Associates on task to produce this special issue.

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