 The Risk of HIV Infection for Lesbians
and Other Women Who Have Sex With
Women: Implications for HIV Research,
Prevention, Policy, and Services

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Research examining the risk of human immunodeficiency virus (HIV) infection in lesbians and other women who have sex with women (WSW) has long been dominated by discussion of whether or not female-to-female sexual transmission occurs and, if so, how frequently. In addition, HIV and AIDS surveillance data suggest that most HIV infections among lesbians result from behaviors associated with injection drug use (IDU) and sex with men, suggesting that whether or not a woman is lesbian or has sex with women is not relevant in HIV transmission. Increasingly, though, studies find that WSW recruited within high-risk cohorts, including ones comprised of women at risk from IDU or commercial sex work, may have a higher risk for HIV infection than their heterosexual counterparts. These findings underscore how little we know about the behavioral and social context that contributes to the risk of exposure to HIV for lesbians and WSW. This article reviews what is known in the research literature about HIV infections among lesbians and WSW and offers the reader a sense of the context for conceptualizing HIV prevention in this population. We highlight issues of treatment, prevention, and research directions in the hopes of focusing the HIV prevention agenda to develop efficacious methods that target lesbians and other WSW.

Key Words: HIV, female-to female transmission, lesbian, WSW, bisexual, policy, prevention, treatment, services, IDU, ethnic minorities.

In April 1995, at the invitation of the Centers for Disease Control and Prevention (CDC), a group comprised of women's health advocates, epidemiologists, consumers, behavioral scientists, and other experts in lesbian and women's health convened to examine the issue of the risk of human immunodeficiency virus (HIV) infection for lesbians. The CDC, the federal agency primarily responsible for the prevention of HIV infection and transmission in the United States, organized this meeting to facilitate a dialogue among lesbian activists, HIV researchers, and the CDC, itself. All attending shared a common concern about the growing rates of HIV infection in women, including lesbians. On the agenda were questions about the risk of HIV transmission among women who have sex with women (WSW), the factors and conditions that affect the HIV epidemic in lesbian populations, and whether or not there was a need for HIV prevention guidelines for WSW.

This was a historic meeting, representing an acknowledgment by the CDC, and by extension the U.S. government, that HIV infection is a concern for the lesbian community, despite lesbians commonly being labeled by public health officials as being at little or no risk for this disease. The meeting also raised a number of critical questions about our scientific understanding of the context and extent of lesbians' risk for HIV infection, as well as the status of research to shed light on the issue. As the various researchers and activists engaged in presentations concerning past and current research on the available, or in some cases unavailable, epidemiological

data, surveillance issues, problems of sexually transmitted diseases (STDs), drug use, and HIV risk in WSW, it became apparent that the prevention of HIV infection among lesbians may not be as simple as it seems. Some of the questions that framed the discussions follow:

1. Can the current CDC reporting guidelines documenting sexual transmission capture risk based on the behaviors that WSW engaged in with one another?
2. Do the current CDC guidelines provide adequate advice to lesbians and other WSW on the transmission and prevention of STDs and HIV?
3. Is there something in the way research is conducted that makes it unlikely that risk from female-to-female transmission will be determined except from anecdotal reports?
4. How should we be educating lesbians and other WSW regarding HIV transmission when the term *lesbian* is describing an identity, and some individuals with that identity may engage in behaviors that are known to involve higher HIV-related risk or some women may engage in sex with women but not self-identify as lesbian?
5. Why are lesbians with HIV invisible?
6. What do we know about HIV risk for WSW drug users compared to HIV risk for other women who use drugs?
7. Why has the research been so limited that these basic questions are still being asked in 1995?

As the discussions of these issues unfolded, it became increasingly clear to those present that little research exists to address these concerns and others, such as STDs in lesbians, that press for our attention. What is it about the issue of lesbians and HIV that makes it so difficult to amass a useful body of scientific and psychosocial information? Why is it that after more than 10 years of a pandemic that has left no one untouched by its reach, we are still unsure when faced with questions about WSW, lesbians, and HIV risk? And why is it we need to rely on facts distilled from scientific inquiry focused elsewhere to answer questions about lesbians risk for HIV infection?

Invisibility is not a new theme when it comes to lesbian life (Abbott & Love, 1972). But one consequence of it in the area of HIV is, perhaps, our uncertainty in answering the questions posed earlier. The invisibility of lesbians and other WSW in the surveillance data collected for the CDC (Araba-Owoyele, Johnson, Mays, Truax & Cochran, 1996), as well as the invisibility of these women in the prevention and service arenas, continues to frustrate those who work closely with these populations.

Both the historical invisibility of lesbians and the more recent emergence of gay liberation and women's rights over the last 25 years is reflected in the field of health-related research. In Figure 1, we present the results of a Medline (National

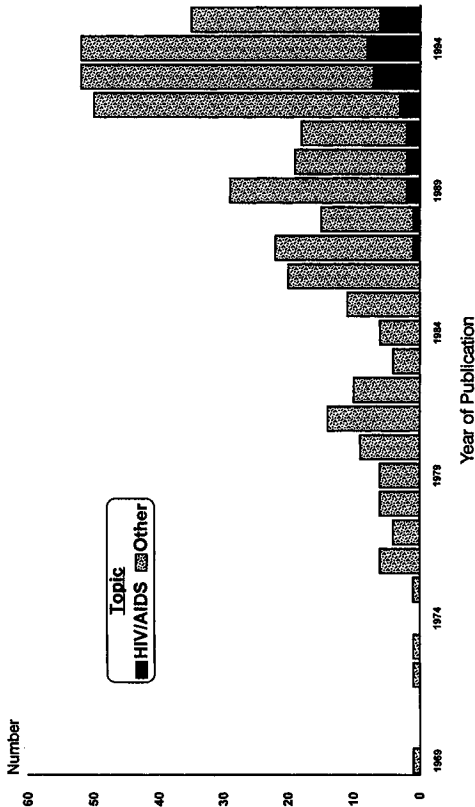


FIGURE 1 Number of publications accessed by the word *lesbian* from Medline (National Library of Medicine, 1996), as of June 1996.

Library of Medicine, 1996) search of the 27 years between 1969 and 1995 using only the word *lesbian* as a key word. The search, conducted in June 1996, revealed 371 articles and publications, more than half of which have been published since 1991. Only 32 of these articles are related directly to the topic of HIV or acquired immunodeficiency syndrome (AIDS). Although cataloging of 1995 articles is not yet complete, it will not substantially alter the observation that health concerns of lesbians, in general, and HIV-related issues, in particular, are not commonly addressed in the biomedical research literature.

It is not as if these issues do not exist. Several researchers have documented the fears of stigma and potential mistreatment experienced by lesbians in their pursuit of quality health care (Cochran & Mays, 1988; O'Hanlan, 1995; Smith, Johnson, & Guenther, 1985; Stevens, 1993; Warshafsky, 1992). Others have contributed significantly to our understanding of practitioners' views of lesbians and homosexual behavior, and the potential biases that arise in the delivery of health-related services (Eliason & Randall, 1991; Johnson, Guenther, Laube, & Keettel, 1981; Johnson & Palermo, 1984; Johnson, Smith, & Guenther, 1987; Matthews, Booth, Turner, & Kessler, 1986; Randall, 1989; Robertson & Schacter, 1981; Schatz & O'Hanlan, 1994; Stevens & Hall, 1990). And, women's health activists and researchers have written about the health concerns of lesbians, citing the complex social, political, economic, and cultural reasons that women who have identified themselves as lesbians have not always felt safe in publicly identifying themselves in these terms. (AMA, 1994; Dulaney & Kelly, 1982; Jay & Young, 1977; Steven, 1992; Tripett & Bain, 1993; Warren, 1993).

But generally when researchers, educators, and others talk and write about the subject of women and HIV, the women they are talking about are heterosexual women or, if not, women presumed to be heterosexual because they are at risk primarily through sexual contact with men. How a problem is defined determines to a large extent what is done about that problem (Mann, 1993), and if HIV infection in lesbians remains invisible little will be done to assess the magnitude, prevention, and treatment needs of HIV in this population. The result is that the behavioral choices that lesbians and other WSW can and will make in the face of the HIV epidemic will be shaped by a lack of knowledge of their true risks. As Mann eloquently reminded us: "People whom society discriminates against are less likely to receive information adapted to their needs, to have access to the range of critical health and social science, and to be able to organize as a community" (p. 1379).

Indeed, a recent book published on HIV, women, and childbearing (Faden & Kass, 1996) does not mention the topic of infected lesbians or other WSW. It is within this presumption of heterosexuality that lesbians and other WSW seek support groups, advice on possible transmission to their sexual partners, and health care practitioners who will be both sensitive to the inclusion of their partners and knowledgeable about gynecologic lesbian health issues.

The absence of a reasonable and more definitive body of research and public health guidelines specifically addressing behaviors and health conditions in lesbians and other WSW has long been noted for HIV, particularly by infected lesbians and their female sex partners (Chu et al., 1994; Cole & Cooper, 1990/1991; Deneberg, 1991; Gomez, 1995; Kennedy et al., 1995; Russell, 1993; Young, Weissman, & Cohen, 1992). At the heart of the debate over HIV risk for lesbian and bisexual women is a deep concern that risk from woman-to-woman sexual behavior is underestimated and that many of these women might be practicing high-risk behaviors, including injection drug use and unprotected sex with men, with little understanding of their true risk.

FEMALE-TO-FEMALE TRANSMISSION: THE NEED TO KNOW

The precise risk of HIV transmission through female-to-female sexual behavior is not known, although this uncertainty has been a topic of discussion among academics, researchers, epidemiologists, activists, and consumers. There has been little systematic research undertaken that would more precisely determine the magnitude of that risk. Lesbians and other WSW have a justifiable need to know whether or not sex between women represents a low or high risk for HIV infection. Behaviors that are not high risk, but that are prevalent, can constitute a public health concern (e.g., radon exposure) and the rationale for accurate information to allay concerns (e.g., risk of HIV transmission from household contact, dental visits). In this context, silence about HIV risks for the lesbian population is not reassuring. The behavior in question involves choices, and addressing women's concerns about risk associated with those behaviors is a responsibility shared by both public health practitioners and researchers.

The first question is, "What is the evidence for HIV infection risk arising from female-to-female sexual behavior?" Many factors influence likelihood of HIV transmission including infectivity, which varies by viral strain, route of transmission, host factors or resistance to infection, and prevalence of risk behaviors. The risk of transmission of HIV from female-to-female during sexual contact will be influenced by the frequency of exposures, the type of exposure (orovaginal, oroanal, vaginal-digital, during menses or not, or sharing vaginal secretions through the use of sex toys), the level of virus present, the presence of other STDs or conditions that compromise the integrity of mucosa or skin (such as ulcers), and the underlying prevalence of infected partners (Kennedy et al., 1995). In addition, not all persons who are exposed become infected. Although by far, the most infectious bodily secretions are blood and semen or seminal fluid, the virus is also isolated, but probably in lower concentrations in vaginal secretions, cerebrospinal fluid, and breast milk. For example, whereas semen can contain up to 3 million white cells

per milliliter with about 5% of the cells infected with the virus, vaginal secretions contain fewer cells (Johnson et al., 1989; Wofsy et al., 1986). Additionally, even using detection by highly sensitive techniques (e.g., polymerase chain reaction) among HIV infected women in Nairobi, Kenya who sought care at an STD clinic (Clemetson et al., 1993), the prevalence of HIV was low (33% of cervical swab specimens; 17% of vaginal swab specimens). Level of HIV in cervical and vaginal secretions may be affected by a number of factors, including menstruation, vaginal PH, genital tract inflammation related to STDs, or certain physical causes (e.g., spermicide use and stage of infection). (Highest levels of virus are detected during the acute and late stages of the disease; Mayer & Anderson, 1995). Though the level of HIV may be lower in vaginal secretions, much work remains in quantitating the level of HIV in cervical and vaginal secretions and what factors affect those levels.

Reflecting this, existing epidemiologic evidence strongly indicates that sexual behaviors presumably practiced between women are not as likely to transmit HIV infection as penile-anal or penile-vaginal intercourse (Chu, Buehler, Fleming, & Berkelman, 1990; McCombs, McCray, Wendell, Sweeney, & Onorato, 1992; Petersen, Doll, White, Chu, & the HIV Blood Donor Group, 1992). Still, recent studies of HIV prevalence of lesbian and bisexual women recruited within high-risk cohorts (Bevier et al., 1992; Friedman, Des Jarlais, Deren, Jose, & Neaigus, 1992), as well as increasing numbers of anecdotes of infected women from community activists (Mandasky, 1993), have raised concerns that HIV risks for lesbian and bisexual women have been poorly conceptualized. As has been cautioned, low risk does not mean no risk. Incidental cases of sexual transmission between women have been documented (Marmor et al., 1986; Monzon & Capellan, 1987; Perry, Jacobsberg, & Fogel, 1989; Rich, Buck, Tuomola, & Kazanjian, 1993), supporting the view that sex between women can constitute adequate contact between an infected and uninfected individual (Rothman, 1986).

The second question is, "How are we to make sense of what we know?" The relatively infrequent reported cases of HIV resulting from female-to-female sexual contact, the low prevalence of self-reported and occasionally objectively determined HIV infection across several studies of lesbians (Cochran & Mays, 1996; Cochran et al., 1996; Gomez et al. 1996) with the exception of the San Francisco study (Lemp et al., 1995), and also the infrequent case reports of HIV transmission via oral sex amongst heterosexuals (Perry et al., 1989) suggest that woman-to-woman sexually transmitted HIV will not emerge as an epidemic within the lesbian population (Jaquez, Koopman, Simon, & Longini, 1994). That is, given the relative inefficiency of HIV transmission associated with oral sex, either rates of partner change must be quite great or other sexual practices that are more efficient must be common among WSW for efficient HIV transmission to occur.

As to the former possibility, studies of lesbian sexual behavior patterns (Bell & Weinberg, 1978; Blumstein & Schwartz, 1983; Coleman, Hoon, & Hoon, 1983; Cotton, 1975; Gagnon & Simon, 1973; Loney, 1972; McCauley & Ehrhardt, 1980;

Peplau, Cochran, Rook, & Padesky, 1978), including some in this issue (Cochran & Mays, 1996; Cochran et al., 1996; Ziemba-Davis, Sanders, & Reinisch, 1996) find that lesbians' rate of partner change is much lower than that observed among gay men (Dean & Meyer, 1995), though perhaps greater than among heterosexual women (Tanfer, 1995). Other surveys of behavioral practices suggest that the sexual repertoire of most female-to-female sexual contacts includes oral sex, including during menses, manual stimulation, and, with a small, but significant percentage of contacts, other behaviors such as sharing of sex toys, some of which are used for vaginal or anal penetration.

Thus, from all we know, there is a small but as yet unquantified risk associated with common female-to-female sexual practices. Further research on the magnitude of the risk of HIV transmission during female sexual contact, and on contributing factors that affect that risk, is needed, however, to provide lesbians and other WSW with an accurate gauge of what can contribute to their risk for HIV infection. To date, information on HIV transmission among WSW has come indirectly, either from extrapolation of studies designed to address risk in men who have sex with women or men, or from analyses of data collected for other purposes, for example, natural history studies of HIV in women such as the HIV Epidemiologic Research Study or the national AIDS surveillance data. It has been thought by some that a prospective long-term follow-up study of discordant female couples would provide that needed information. However, this methodologic design has been used with mixed results to study heterosexual transmission, primarily because of the uncommon incidence of seroconversions among the discordant heterosexual couples (DeVincenzi, 1994; Downs & DeVincenzi, 1996; Padian, O'Brien, Chang, Glass, & Francis, 1993). An exception is the prospective longitudinal study on heterosexual transmission of HIV (DeVincenzi, 1994) that has provided us with an invaluable source of information on risk factors among serodiscordant couples. Because risk of female-to-female transmission is likely to be relatively low, the likelihood of useful information from a prospective study consequently is also low.

Although efforts should be increased to follow-up reports of possible transmissions among WSW whenever possible, and studies of selected, more common STDs among WSW should be conducted, a retrospective study design to determine the risk of HIV transmission also could be considered. One such design could be based on previous studies of the risk of HIV transmission among household contacts of patients with AIDS, a factor associated with very low risk (Friedland, Saltzman, Rogers, et al., 1986). Detailed interviews and tests for the HIV antibody were performed on all household contacts of AIDS patients for exposures and serostatus. Possible transmissions could then be investigated in detail and documented through DNA sequence analyses. A sufficient number of infected women with female partners is critical and because of this, considerable community involvement would be required for recruitment.

WHERE DOES PRIMARY HIV RISK LIE?

An exclusive focus of female-to-female sexual transmission of HIV to estimate the impact of HIV disease on the lesbian community will miss the nature of HIV infection patterns among lesbians. It will also hamper developing effective prevention programs and delivery of services to HIV infected women. To date, epidemiologic evidence suggests that from the beginning of the HIV epidemic in this country the primary route of HIV infections among lesbians has been through behavior associated with injection drug use, and to a lesser extent via sex with HIV-infected men (Chu et al., 1990; Chu, Hammett, & Buehler, 1992).

The IDU Connection

Little is known about either the prevalence of injection drug use among lesbian and bisexual women or whether or not lesbian and bisexual women who use injection drugs are more likely to have higher HIV risk profiles, for example through sharing of needles or engaging in high-risk heterosexual sexual behavior, than heterosexual women who also use injection drugs. Two of the articles in this issue provide some indications that drug injecting and crack-smoking lesbians and other WSW may be at higher risk of HIV infection than their comparable heterosexual counterparts (Deren et al., 1996; Moore et al., 1996). Deren et al., in their review of relevant literature of lesbian and other WSW drug using studies highlighted that in an Australian study of IDUs (Ross, Wodak, Gold, & Miller, 1992), lesbians were significantly more likely to be infected than either bisexuals or heterosexuals. In studies of IDUs in San Francisco and Los Angeles, the women who had sex with women (lesbians and bisexuals) were more likely to be HIV seropositive than non-WSWs, 11% versus 7% and 3.9% versus 1.6%, respectively. In the National AIDS Demonstration Research Project (NADR) studies, a multisite study of drug injection and crack users at risk of HIV infection, Deren et al. noted that Friedman et al. (1995) found that in the low seroprevalence cities, WSWs had a 5.42 increased risk rate of seroconversion. In studies conducted by Deren and her collaborators (Deren, Estrada, Stark, & Goldstein, in press), bisexual drug injectors and crack smokers were more likely, though not significantly so, to be HIV seropositive than lesbians or heterosexuals but were significantly more likely than lesbians and heterosexuals to have had greater numbers of sex partners within a 30-day period.

Deren et al. (1996) are not alone in finding that when the issue of same-sex behavior of women is examined within high-risk injection and drug using populations, relatively high proportions of those samples report engaging in same-sex behavior (Ehrhardt et al., 1995). Ehrhardt's study of drug using women found that over a quarter of her sample identified as lesbian or bisexual with almost half having

a history of same-gender sexual behavior at some point in their lives. Moore et al. (1996) found that those women who had a history of sex with women accounted for almost a fifth of their four-city sample. On further examination of their sample, when women who had a history of sex with only men were compared to women who had not, those women with a history or current same-gender sexual activity reported more HIV-related risk behaviors, consistent with the findings of Bevier, Chiasson, Heffernan, and Castro (1995) of women who had visited a New York city sexually transmitted disease clinic. Moore et al. also found that a disproportionate number of the bisexual women and lesbians in their study had traded sex for drugs or money when compared to heterosexuals.

Estimates of prevalent drug use from surveys of lesbian and bisexual women, sampled on the basis of sexual orientation, are few. In one recent study of 483 lesbian and bisexual women in San Francisco, only 2.3% of women reported injection drug use in the prior year (San Francisco Department of Public Health, 1993). Large surveys of lesbians and bisexual women suggest higher than expected lifetime prevalence of crack or cocaine use when compared to population estimates (Cochran et al., 1996). But definitive knowledge of whether or not lesbians and other WSW engage in greater rates of injection drug use is still lacking. If IDU prevalence is high, then lesbian and bisexual women may be at greater risk as a population, not through female-to-female sexual behavior, but through higher rates of injection drug use.

Even if use of injection drugs is equivalent or somewhat greater among lesbians and other WSW in comparison to heterosexual women, patterns of use and concomitant behaviors may differ in relevant ways. For example, as just reported in samples of female IDUs recruited for HIV studies, the prevalence of reporting sex with women may be greater (Bevier et al., 1995) than population estimates of similar behavior in population-based samples (Catania et al., 1992). Thus, recruited high HIV risk cohorts contain greater than expected numbers of women who are lesbian or report sex with women. Also as several of the previous studies have suggested, WSW who also use injection drugs may be characterized by higher risk HIV profiles than IDU women who only report sex with men. Thus, injection drug use among lesbians and bisexual women may be associated with greater HIV risk than it is for heterosexual women for reasons that are still unknown.

The Sex With HIV-Infected Men Connection

A second major route of HIV infection for lesbian and bisexual women is unprotected sexual intercourse with men (Chu et al., 1992). This finding has underscored the permeability of sexual orientation boundaries. Historically, research has repeatedly demonstrated that the majority of lesbian-identified women report past sexual intercourse with men (Bell & Weinberg, 1978; Cochran & Mays, 1996; Gomez et

al., 1996; Johnson, Guenther, Laube, & Keettel, 1981; Mays & Cochran, 1988; Peplau et al., 1978; Reinisch, Sanders, & Ziemba-Davis, 1990; Schwartz & Blumstein, 1983; Ziemba-Davis, Sanders & Reinisch, 1996), generally prior to or early on in their coming out process as a lesbian. Some lesbian-identified women also report current sexual behavior with men (Cochran et al., 1996; Deren et al., 1996; Moore et al., 1996; Reinisch, Sanders, & Ziemba-Davis, 1990; Ziemba-Davis et al., 1996) with studies reporting that for some women those male partners are gay or bisexual men (Gomez et al., 1996; Reinisch, Sanders, & Ziemba-Davis, 1990). And heterosexual behavior for women who generally have sex with other women may represent higher risk behavior. For example, lesbians may be more likely than heterosexual women to engage in anal intercourse with their male partners (Reinisch, Sanders, & Ziemba-Davis, 1990). Also, in a survey of HIV-infected women, those who reported having sex with men and women were more likely than women who did not have sex with women to also report high-risk heterosexual behavior including sex for money or drugs (Warren, Golden, & Miller, 1995). Finally, in a study of STD clinic attendees (Bevier et al., 1992), women who reported sex with women were more likely than women who reported sex with men only to engage in a wide variety of high-risk heterosexual behavior.

There are several issues to consider with regard to heterosexual activity among lesbians and other WSW, but two seem most critical and should not be lost in the simple observation that lesbians do at times have sex with men. First, although identity does not map isomorphically to behavior, that is the majority of lesbians do report a history of sex with men, among the population of WSW there are clear risk factors for such behavior including younger age, being single, not considering oneself lesbian, and engaging in commercial sex work. That is, the odds of having sex with men is not distributed homogeneously across the population of WSW. In contrast, the incidence of sexual activity with women among the population of WSW is by definition a common, widespread behavior, though younger, single women may still be more likely to have more contacts and with more partners.

Second, the risk accrued from sex with men varies tremendously with the nature of the population of male sex partners from which women select. Thus, women whose sex partners are HIV-infected gay men, who live in geographic areas such as San Francisco with high prevalence of HIV, or who engage in sex work with high numbers of male sex partners are at greater risk than others, particularly if behavioral practices (e.g., absence of condom use) lie in riskier domains (Gomez et al., 1996; Reinisch, Sanders, & Ziemba-Davis, 1990). Thus, although sex with men represents a risk factor for lesbians and other WSW, the extent of the risk is quite varied.

Although much of what we have just presented repeats the obvious, we wish to underscore the questions that remain. For most of these studies, there is a sense of putting to rest the question of female-to-female transmission by relying on studies of the biologic risk for HIV transmission. For most of these studies, transmission

risk appears to be a function of injection drug use or sex with high-risk men. Yet from the behavioral perspective, the question of what it is about the lives of WSW that leads us to consistently find them to have higher HIV seroprevalence, and at-risk drug and sex-related behaviors when compared to similar heterosexual women in studies where women are sampled via high-risk networks, is really the question that few if any of us have answered. Knowing just that this happens is only a beginning for those interested in the development of efficacious prevention efforts for lesbians and other WSW. In prevention, knowing that at-risk behaviors are occurring is an alert to action, knowing how to eliminate, change, or modify those behaviors, requires insight into why the behavior occurs and what supports or reinforces the behavior. It is knowing the social, interpersonal, and, particularly for women, economic reinforcing properties that those at-risk behaviors serve that is critical to successful attempts to modify or eliminate them. Deren et al. (1996) suggest moving beyond merely number counting and engaging in qualitative and ethnographic studies coupled with quantitative survey methods to better understand the social and contextual factors that contribute to the relatively high percentage of WSWs among drug-using women.

CONCEPTUALIZING THE HIV EPIDEMIC FROM A LESBIAN PERSPECTIVE

Over the years, HIV control in the United States has been approached from both the perspective of targeting high-risk groups, where behaviors that convey group membership, such as gay male sex, injection drug use, or commercial sex work, are directly or indirectly linked to risk of HIV transmission, or directing general prevention messages to the heterosexually active population. In an effort to effectively reach high-risk groups, both prevention messages and HIV support services are routinely tailored to their needs. Although lesbians and other WSW are among these populations, prevention messages directed at their concerns or support services for their needs are generally absent.

Prevention Needs of Lesbians and WSW

It is important to think clearly about the factors that contribute to the pattern of HIV infections that exists in the lesbian and other WSW population if effective prevention efforts are to be launched. Education and prevention of HIV infection in lesbians and other WSW, if they are to be effective must be appropriately tailored to the lives of these women in order to have the best prospect of effectiveness (Ehrhardt, 1994). Tailored messages for lesbians and other WSW must consider that lesbians are a diverse group who differ not just by race/ethnic group and

socioeconomic status, but by the extent to which they view themselves as members of the lesbian or bisexual community, by their membership in other communities such as that of injection drug use, or commercial sex workers. The invisibility of all but generally the privileged or out segments of the lesbian community has meant that as researchers, clinicians, and practitioners, little is known and appreciated of the influencing factors in the lives of these women. Yet if we are to tailor prevention messages that have a chance to work, it is important to understand how these factors influence help-seeking for health concerns as well as perceived credibility of health warnings.

The prevention efforts directed at lesbians cannot and should not be ones whose solutions lie solely in individual behavior change efforts (Mays, 1996; Mays & Cochran, 1995). Individually oriented behavior change principles ignore the influences of inequality experienced by many lesbians and some WSW on their lives and behavioral choices. Identifying the fundamental role that social and interpersonal factors play in disease and disease prevention is a start. For lesbians and some WSW, the differential status of such resources as money, power, social connectedness, prestige and knowledge are fundamentally linked to the ability to determine risk and avoid and minimize the consequences of HIV disease (Link & Phelan, 1996). For example, although many of the studies in this issue, as well as others, have identified that lesbian-identified women have sex with men, we are most likely to view this sex as volitional and based on desire rather than as utilitarian sex that is employed for the sake of earning money, in the interest of shelter or to avoid the stigma some experience in being a lesbian. We know this to be true from our studies of gay men's behaviors, yet biases about women's roles in society and ignorance about lesbian and bisexual sexuality, may blind us to developing insights that can be important to prevention efforts with lesbians and other WSW. This is why successful prevention efforts must involve lesbians and other WSW in their diversity, as participants who guide, organize, and take ownership of the efforts (Hunter & Alexander, *in press*).

As several of the articles have shown, lesbians and other WSW at risk for HIV infection will be found in the community of crack-smokers and injection drug users (Case, Downing, Fergusson, Lorvick, & Sanchez, 1988; Cochran et al., 1996; Cole & Cooper, 1990/1991; Deneberg, 1991; Deren et al., 1996; Moore et al., 1996), and they will be found among women in prison (Moore et al., 1996). At-risk lesbians and other WSW will also be found among the homeless (Cole & Cooper, 1990/1991; Moore et al., 1996). HIV counselors in New York estimate that approximately one-third of the women they see in the shelters are lesbians who have run away or been kicked out of their homes because of their sexual orientation (Cole & Cooper, 1990/1991; Hunter, Rosario, Rotheram-Borus, & Reid, 1993). It is during this period of homelessness when sex may be traded for drugs and money that some lesbians become HIV infected. We must also look among commercial sex workers (Case et al., 1988; Delacoste & Alexander, 1992) for at-risk lesbians.

We will also find lesbians and other WSW at risk for HIV infection among teenagers and young adults. For some, their friendship networks include young gay men, sometimes at higher HIV risk themselves, with whom they sometimes have sex for reasons not only of desire but also, perhaps, to test their sexual orientation (Hunter, Rosario, Rotheram-Borus, & Reid, 1993). In this age group, too, are young adults, age 18–23 years, who identify as “all-girl queers,” viewing AIDS as something spread by semen and drugs. They practice safer sex, not by using condoms, but by carefully picking sexual acts and partners that they believe will lower or eliminate the risk of HIV infection (Brownworth, 1992). For these young women and others like them who have sex with both women and gay or bisexual men, their views about what safer sex is for them and their partners has resulted in a creation of new rules.

Women of color may also need well-targeted prevention efforts. For some, the use of the word *lesbian* is viewed as a middle class creation of privilege that does not describe their world, particularly the view of lesbian separatism that says they should move away from gay men of color and institutions in their communities. We find segments of this community at risk as a function of their sexual behaviors with men, their drug use, tattooing behavior, or blood-letting gang activities. Yet we will not find them responsive to prevention efforts that do not incorporate the significance of culture, ethnicity, and racial group membership in its efforts (Flora, Schooler, Mays, & Cochran, 1996).

Treatment Needs of Lesbians and Other WSW

HIV services can only be effective in protecting and improving the health of lesbians and other WSW to the extent that women are aware of them, have access to them, and choose to use them. Just as the problems of HIV disease are caused by an interaction of biological, psychological, community, national, and global factors, so too must the solutions for these problems be based in a realistic understanding of the resources, the powerful forces of discrimination, cultural constraints, and realities of the priorities in the lives of these women (Leslie, 1992). Lesbians and other WSW need access to health care providers who have the knowledge and skill base to provide affordable, competent, compassionate, and nonjudgmental health care (Stevens, 1993). Women want practitioners who can provide balanced information on clinical trial participation, use and access to experimental drugs, knowledge about the effects of these drugs, and how they work when combined with alternative health practices.

For HIV-infected women concerned about their partners, they want to know more precisely risk associated with HIV infection. Just as gay male activists have long complained of the vagueness and uncertainty in the level of risk in oral sex, the same uncertainty exists for lesbians, other WSW, and their partners. Service

providers and infected women clamor for better guidance in issues of transmission and infectivity during cunnilingus, particularly if engaged in during menstruation.

Lesbians, particularly women who are HIV seropositive, want support groups that are sensitive, support groups that will address the issues of substance abuse, stigma, loss of control, powerlessness, anger, sex, and safer sex (Russell, 1993). But even when women seek support from within the lesbian community, it may not be safe:

I joined a support group for lesbians, and one day they started to talk about AIDS. None of these women were positive. They made comments like, "Could you imagine if you met a woman who was HIV-positive ... I couldn't ... I wouldn't touch her ..." They went on and on. I sat there alone and afraid. I couldn't say anything. (p. 4)

HIV-infected lesbians and other WSW want and expect greater guidance in starting new relationships; disclosing to their families, lovers, and children; and help in coping with their fears of losing HIV seronegative partners because of their own HIV seropositivity (Russell, 1993). Mental health providers, like others involved in HIV prevention, must broaden their agenda to include the service needs of lesbians and other WSW.

We need to know more about the desires of lesbians and other WSW in how they care for their health, their choice of type of providers, and their self or peer health needs. Providers must include lesbian and WSWs needs for alternative, self, and peer help activities.

MAKING THE DIFFERENCE

This special issue has provided some road maps for where to begin our prevention efforts. These efforts need to be directed towards those lesbians and other WSW who have been found to be most at risk. These lesbians and other WSW are injection drug and crack-users, they are those who share needles and injection drug works with other drug users and gay men, they are women who either by choice, need, or force have unprotected sex with higher risk men, whether that risk is accrued through sex between men, drug use, or residing in an AIDS epicenter. These women are also commercial sex industry workers and women who unknowingly have sex with a partner who is infected.

Bringing services and interventions to these women will not be an easy job if we engage in risk-group strategies of outreach, intervention, and prevention that use the lesbian community as the primary unit. Instead we need to work towards prevention through many routes. Each of the articles in this special issue has cautioned the reader against the acceptance of the assumptions embedded in the risk-group model in regards to the risk of HIV infection for lesbians and other

WSW. Risk group based prevention works best for those individuals for whom the risk group is: (a) a social grouping or social identity that they embrace, (b) viewed as a credible source, and (c) the primary shaper of cultural norms and standards. In contrast to efforts successful in the gay men's community, we often will not find these women in bars or through lesbian-identified social or political groups, thereby complicating who may be viewed as necessary sources of influence in their behavior change process. It is therefore important that the prevention agenda of many other groups, such as IDU or heterosexual women, also broaden their efforts to include lesbians and other WSW, for they will be found wherever women at risk for HIV transmission are found.

The articles in this special issue also provide some guidance in the challenge to reduce the risk of HIV infection in lesbians and other WSW. However, we must not take these articles as presenting a complete picture. What this special issue has failed to do well is to help the reader to grasp the consequences of racial/ethnic group membership and socioeconomic status. The life experiences of lesbians and other WSW of color must have a strong role in the design of prevention efforts. Indications from some of the studies in this special issue are that this task will not be easy, but that we must rise to the challenge.

Addressing the issue of the risk of HIV infection among lesbians and other WSW, in terms of prevention and treatment for those affected, will only be achieved through changing our priorities, radically transforming the direction of women's prevention efforts, and including lesbians and other WSW as the architects of these efforts. In doing so, we must be willing to create new methods and approaches, drawing from what is already known in the HIV arena, but also discarding and transforming that which does not meet the needs of lesbians and other WSW.

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