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The Politics of Statistics

Jennifer Burroughs

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officials in order to provide referrals and create resources for recently released prisoners, and again, I have been ignored.

The situation for HIV-positive women in prison is really dismal, and it will remain dismal as long as we allow the secrecy and fear of dealing with HIV and AIDS in prison to prevail. But there are things we can do about it. We can write to the California Department of Corrections in Sacramento, and we can write to our legislators, and tell them that we know about this situation and we would like them to do something about it. We can talk to each other and talk to our friends about what we learned here and what we hope to learn in the future. And we can demonstrate at the prisons for improved education, support, and medical care. The prisons’ number one weapon is secrecy, so as long as we allow AIDS in prison to remain a secret, these women are going to die. HIV-positive women are being denied basic human rights that we all deserve, and I think that these women deserve those rights as well.

Comments by Jennifer Burroughs:†

The Politics of Statistics

I will start by talking a little bit about my own experience. I have been a nurse practitioner for seven years. I started out working with homeless people in Boston and New York, and that is where I first saw HIV-infected men and women. Then I took a job in an AIDS clinic. When I first started working there in 1989, about one in ten of our new patients was female. When I left in 1991, one in three of our new patients was female. I suggested to the male doctors that we should pay more attention to women’s health needs such as gynecological care, but there was no response and I found myself very frustrated. I was happy to move out here to the Bay Area because of the attention and resources given to HIV and AIDS issues, though we could always use more attention.

The statistics from the Centers for Disease Control (CDC) reflect the themes of this symposium. Back in 1986, about two percent of the people diagnosed with AIDS in the United States were women. By 1992, it was between twelve and thirteen percent.1 AIDS as a cause of death among women aged twenty-five to forty-four is on the rise. It is the forth leading cause of death among all women,2 and is the leading cause of death among

† Jennifer Burroughs is a nurse practitioner at the University of California at San Francisco's Women and HIV Clinic.


black women in the New York City metropolitan area. The ratio is clearly changing and will continue to change. These numbers reflect two things. First, more and more women are getting infected. Second, more women are being tested, which is a major advance. We cannot identify and treat cases if we do not know people are infected.

In January of 1993, the Centers for Disease Control expanded the definition of AIDS, which will change the statistics drastically. The CDC definition now includes recurrent bacterial pneumonia, pulmonary tuberculosis, and invasive cervical cancer. However, in my own experience, both here and in New York, I have not seen a case of cervical cancer in a woman with HIV infection. I think, certainly, that there are women in the Bay Area who died of cervical cancer who did not know they were HIV infected, but the incidence of cervical cancer and HIV has been documented at higher rates on the East Coast. Although the CDC only included one gender-specific disorder, I think the other changes are going to be more helpful to women than the inclusion of cervical cancer. My sense, given the new definition, is that we will see a larger percentage of women being diagnosed with AIDS, and a large increase in the number of cases for all people across the nation.

Nationally, AIDS is a very racist epidemic. African Americans are quite unfairly affected. A recently published study looked at anonymous serologies done in 1989 and compared rural results with urban results. In the South and the Northeast, rural areas have been heavily affected. The tests were done in hospitals on maternal blood taken from the umbilical cord at birth to check for genetic abnormalities. Thirty-five states agreed to test anonymously for HIV infection to get a sense of what the epidemic was like in their states. This study found a seroprevalence rate that ranged from three to thirty-five times higher for African American women than for white women in rural areas. In Texas it was three times higher, and in South Carolina it was thirty-three times higher. This study identifies where education efforts and services need to be directed.

Another important issue concerning HIV infection in this country is injection drug use. It continues to be the main route of documented transmission. The CDC reports that in 1992, drug injection accounted for forty-five percent of reported cases of AIDS in women, sex with an injection drug user accounted for twenty-one percent, and heterosexual transmission

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3 Richard M. Selik et al., HIV Infection as Leading Cause of Death Among Young Adults in US Cities and States, 269 JAMA 2991, 2993 (1993).
6 Id.
7 Id. at 1041.
with a partner of unknown risk accounted for eighteen percent. Diseases such as pulmonary tuberculosis and bacterial pneumonia are very common in both men and women who have used intravenous drugs, so I think the inclusion of these illnesses in the expanded CDC definition is very important. But the way that the route of transmission is determined for the purposes of statistics is misleading. Anyone who has ever used a needle once is identified as an injection drug user. It makes some sense epidemiologically and medically, because injection drug use is a more efficient method of transmission than sexual contact, but many women who were counted as injection drug users may have actually contracted the virus through sex and not through intravenous drug use. This also has important implications for medical care providers. Once someone is labeled as a substance abuser, no one wants to care for them. There is a sort of prurient, voyeuristic aspect to the virus, where people always want to know the route of transmission. Who cares? They have the virus! Medically, we need to take care of them. If a patient is not actively using drugs right now, then it should not affect our care of her. I see this as an issue in the epidemic constantly, particularly for women.

Although intravenous drug use is the most efficient route of transmission, an ongoing study on heterosexual transmission has produced some interesting results. This California partner study has been going on for eight or nine years, and the most recent published data found that male-to-female transmission was eighteen times more efficient than female-to-male transmission. This study also found that the presence of other sexually transmitted diseases seems to cause the transmission of HIV to occur more frequently. With this kind of efficiency, we are going to see the ratio of male to female cases change, with the rate of infection in women increasing.

I also want to speak a little about the San Francisco/Berkeley women's surveys that were done on women who self-identify as lesbian or bisexual. There were two surveys; one on HIV seroprevalence and risk behaviors, and another on health behaviors. The women included in these surveys were randomly sampled at twenty-five public locations such as women's bars and clubs, and gay events such as street fairs. I want to point out that the women included in this study are women who go to these events and who are willing to self-identify as women who have sex with women. They are a very specific community of lesbians and bisexuals, and

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8 Clark R. Hankins et al., supra note 1 at 122.
10 Id. at 1666.
11 Surveillance Branch, S. F. Dep't of Public Health, HIV Seroprevalence and Risk Behaviors Among Lesbians and Bisexual Women: Results from a Community-Based Survey (1993).
should be treated as such. The most important message for me in the health behavior study is that only four percent of the 483 women interviewed consider lesbians to be at risk for HIV infection.\(^{12}\) We all need to be careful about what we think our clients know about HIV infection. They may be unaware of their risks, or they may be in denial.

In the seroprevalence study, 498 women were surveyed; sixty-eight percent self-identified as lesbians, and about twenty-two percent identified as bisexual.\(^{13}\) Of the women surveyed, 1.2% were HIV-infected, which is about three times higher than in the general population of women in San Francisco County.\(^{14}\) The seroprevalence study did not document any evidence of woman-to-woman transmission. However, the study did show that the rate of high risk behavior involving drug use was fairly high. Of the women surveyed, 10.4% had used injection drugs since 1978, 3.8% had used injection drugs in the past three years, 7.4% had shared needles since 1978, and 3.2% had shared needles with gay or bisexual men.\(^{15}\) There was also evidence of high risk sexual behavior: 56.3% reported unprotected oral sex with men, 39% reported unprotected vaginal sex with men, and 10.9% reported unprotected anal sex with men.\(^{16}\) Many people assume that because a woman is gay, she is low risk for HIV, but we need to ask questions about that person's behavior to identify other risk factors involved. This study highlights the need for increased education. The Surveillance and Prevention Branches of the Department of Public Health conducted these studies because they recognized that lesbian and bisexual women are at risk, and the surveys proved this to be true. As service providers, we need to be aware of these issues. Effective education and treatment are dependent on awareness and recognition. As I said before, we cannot help women with HIV if we do not know they are infected.

**Comments by Marina T. Sarmiento:**

*The Legal Needs of Women with HIV*

### I. Introduction

I am the Outreach Director at the AIDS Legal Referral Panel. We provide legal counseling to clients throughout the Bay Area. Since I took

\(^{12}\) *Prevention Services Branch, S. F. Dep't of Public Health, supra* note 11, at 19.

\(^{13}\) *Id.* at 1, 9.

\(^{14}\) *Surveillance Branch, S. F. Dep't of Public Health, supra* note 11, at 4.

\(^{15}\) *Id.* at 20.

\(^{16}\) *Id.* at 22.

† Marina T. Sarmiento, Esq. is the Outreach Director for the AIDS Legal Referral Panel of the San Francisco Bay Area. Founded in 1983, the AIDS Legal Referral Panel (ALRP) is an independent non-profit agency sponsored by Bay Area Lawyers for Individual Freedom (BALIF) and the Volunteer Legal Services Program/Bar Association of San Francisco (VLSP/BASF). ALRP