The L+ Word

Lesbians living with HIV/AIDS may not register in the statistics, but they count as much as anyone else.

June 1, 2009 By Rachel Rabkin Pechman

Vanessa Campus has never had trouble discussing her sexuality. “I’ve been a tomboy since I was 11, and I grew into my sexuality at 16. I’m confident in being a lesbian,” says Campus, who is now 48 and was diagnosed with AIDS in 1996. She’s not afraid to talk with her doctor about being a lesbian either—but he doesn’t seem to share her comfort level. “He doesn’t talk about [my risk of] transmitting HIV to my partner,” Campus says. “It seems like it’s taboo for him to even bring it up.”

Campus’s experience seems all too common, and the quality of medical care for positive lesbians may suffer as a result. “People get jittery when you start talking about lesbians with HIV,” says Kimberleigh Smith, director of the Women’s Institute at Gay Men’s Health Crisis (GMHC) in New York City—where 14 percent of their female clients identify as lesbian or bisexual. “For many women, as soon as you tell your doctor you have sex with women, a certain line of questioning stops.” Many people—even within the health care and lesbian communities—still think that lesbians aren’t supposed to get HIV/AIDS and that woman-to-woman sex poses no HIV transmission risk. This hobbles HIV testing efforts among lesbians, who often conclude that they aren’t part of the at-risk population. It may also keep doctors from helping HIV-positive lesbians protect themselves from other sexually transmitted infections. “We need to stop equating [sexual] identity with risk,” says Smith.

“When a woman identifies as a lesbian, it doesn’t mean that she only has sex with women or doesn’t engage in other risky behaviors,” says Ana Oliveira, CEO of the New York Women’s Foundation and former director of GMHC. In fact, just the opposite is true, according to Amber Hollibaugh, chief officer of Elder and LBTI Women’s Services at Howard Brown Health Center in Chicago (and former director of the GMHC Lesbian AIDS Project/LAP). “Women who have sex with women fall into a multitude of categories where there is increased risk,” she says. They are often women of color. They may share needles. Or they may have sex with men in exchange for housing and food, to care for their children or to satisfy a drug addiction. “The reality of the epidemic is that people have complicated crossover degrees of risk,” Hollibaugh says, and this is especially true for lesbians. “Women who have sex with women are unseen—invisible!” Hollibaugh says. “As a result, it’s still considered appropriate to question whether lesbians can get HIV.”

A lack of realistic statistics also keeps positive lesbians below the radar. “The CDC does a very poor job of asking the questions that assess whether a women identifies as a lesbian,” says Alicia Heath-Toby, program coordinator of LAP at GMHC. “Once a woman says she’s had sex with a man, she’s put in the heterosexual category. Once she says she’s used IV drugs, she’s put in the IV drug user category. This means we’re missing a lot of the lesbian-identified women living with HIV.”

The errors continue in the privacy of the doctor’s office. “Both women and their doctors are unaware of the health risks of this population,” says Helena Kwakwa, MD, director of HIV clinical services at Philadelphia’s Health Department. “Because of that, you often have late [HIV] diagnosis and women who don’t alter their behavior before or after learning that they are positive.” Unlike Campus, many lesbians are afraid to talk openly with their doctors. “If you’re somewhere where it’s unsafe to talk about sexual partners, the last thing you’ll tell your doctor is that you’re sleeping with women,” Hollibaugh says. “Why tell? You know you’re going to be stigmatized.”

“HIV/AIDS is spread by ignorance, shame, invisibility and lack of resources,” Oliveira says, “so we need affirming messages about women who have sex with women.” Where can lesbians go to get these messages, be counted and get help? Campus advises following in her footsteps. “What helped the most was finding groups of women at GMHC—some lesbian, some bisexual—who were just like me,” she says. “I was able to talk about my struggles, my insecurities and my low self-esteem, and we empowered each other.” Campus was also given GMHC’s Pussy Pack, a safe-sex kit for women that includes dental dams, finger cots and female condoms. If there is no HIV/AIDS organization near you with a lesbian-focused division, visit gmhc.org or join the women’s forum at poz.com.

“The one thing I want to drive home is that wherever you are in your sexual expression is okay,” says Heath-Toby. “Know that you’re not alone.” Campus agrees. “I accepted my health status, got support and began to advocate for myself in every area of my life,” she says. “I learned that I do have a voice—and that my voice can be heard.”

SAFER SEX
Preventing woman-to-woman transmission of HIV

It is possible for HIV-positive women to pass the virus to female sexual partners, though the risk is low (and documented cases almost nonexistent). “Absence of proof isn’t proof of absence,” says Helena Kwakwa, MD, of the Philadelphia Health Department’s HIV clinical services. (Kwakwa reported one case of lesbian sexual transmission, which seemed to involve shared sex toys, in *Clinical Infectious Diseases* in 2003.) Fisting, rough sex or anything else that may cause torn membranes and bleeding might pose an HIV transmission risk.

- Rona M. Vail, MD, an HIV specialist at Callen-Lorde Community Health Center in New York City, helped *POZ* offer these safer-sex tips for lesbians:

- If you are positive, create an effective HIV treatment plan with your doctor. If your HIV/AIDS is well controlled, the risk of transmission decreases.
- Get tested and treated for other sexually transmitted infections (STIs). Unchecked genital herpes, gonorrhea and chlamydia not only create potentially serious problems for women, but also increase the risk of transmitting HIV.
- Don’t share sex toys, which can carry bodily fluids.
- Use protection (you might try finger cots) if you penetrate your partner when you have raggedy fingernails and recent cuts on your fingers. Sharp nails can tear vaginal membranes, and cuts can bleed during sex.
- Avoid oral sex during menstrual cycles or when a positive woman shows signs of irritation, sores, cuts or inflammation in either her mouth or vagina. Consider using barrier methods (such as dental dams) during oral sex.
- If you are a lesbian and you are HIV negative, get tested for the virus regularly, even if you only have sex with women.
