What’s a Girl to Do?

As new HIV infections among U.S. women keep rising, a new study probes America’s attitudes toward positive ladies. And the findings ain’t pretty.

May 1, 2008 By Regan Hofmann

In the United States, women now account for more than a third of new HIV infections and a quarter of new AIDS cases. The proportion of AIDS diagnoses among women has tripled since 1985. And recently released statistics from a Centers for Disease Control and Prevention (CDC) study indicate that one in four female Americans between the ages of 14 and 19 has at least one sexually transmitted disease (though, for some reason, HIV was not one of the diseases studied). Unless things change, it looks like the United States is headed in the direction of the developing world, where closer to 50 percent of all those living with HIV are women and where the odds for the ladies are getting worse all the time.

So why women and why now? Given the lag time between when women get infected and when they are diagnosed, and the secondary lag between those diagnoses and when that data are made public by the CDC and similar groups, it’s important to note that what seems like a recent spate of new infections among women likely represents infections that happened anywhere from three to 20-plus years ago. The truth is that women have always contracted HIV but that the numbers announced publicly have only recently gotten high enough to cause alarm.

Recognizing the fact that more women are living with HIV in the United States than ever before, the Foundation for AIDS Research (amfAR) hired the research firm Harris Interactive to chart the public’s opinions of HIV-positive women. The goal was to identify and eventually correct any misconceptions that could be leading to the swell of new infections among women and girls. Polling a wide cross section of more than 4,800 Americans, amfAR flushed out a truth that I, an HIV-positive woman, have long suspected: The stigma surrounding women and HIV is particularly severe.

The study confirmed my belief, for instance, that how a woman contracts the virus colors people’s perceptions of her. Nearly 60 percent of the respondents said they have a “very negative opinion” of a woman who contracted HIV through exchanging sex for drugs or money, 30 percent said they would look down on a positive woman who got the virus from “having multiple sexual partners,” 14 percent said they would scorn a woman who had sex without a condom, 12 percent were uncomfortable if a woman became positive as a result of not knowing the HIV status of her sexual partner. Even women who contract HIV via a rape or blood transfusion weren’t spared: About 5

percent of respondents said they would have a “very negative opinion” of them.

The idea that people who “do bad things” get HIV and that people who get HIV are bad sits at the core of our struggle to prevent a disease that is almost always preventable. Until we can convince people that the virus has no moral preference, some people will believe that their ideology, not actual sexual and other precautions, will protect them. True, certain acts are riskier than others, but a female prostitute who has unprotected sex with a client and a married woman who has unprotected sex with her husband after he cheats on her may experience the same risk. People’s opinions on the relative morality of those two circumstances may differ, but the virus is unaware of that distinction and will affect both people equally.

The Harris Interactive study does not attempt to conclude why women are prone to disproportionate levels of HIV infection. But in revealing Americans’ deep stigmatization of HIV-positive women, it suggests an endless cycle of cause and effect: The stigma stifles discussion of prevention and testing; the lack of awareness and testing increases infection; women who do test positive are made to think they are bad and should have known better, so they are driven underground, becoming invisible, further increasing stigma. And when HIV-positive women are afraid to come forward, suffering silently with their scarlet A, the public continues to think that women are not at risk, even as the numbers climb ever higher.

To truly understand the depth of people’s distaste for women with HIV, consider the study’s other findings. A mere 14 percent of people said women with HIV should have kids. Meanwhile, 59 percent said women with cancer should have kids, 47 percent said depressed women should bear children, 37 percent said women with multiple sclerosis should have kids, 20 percent said those with hepatitis C should conceive, 19 percent said women with Down syndrome should get pregnant and 17 percent said women with schizophrenia should have kids. If an HIV-positive woman decided to have a child, one third of Americans would not support her decision at all. I can only surmise that this speaks to the widespread ignorance of the fact that it is possible to prevent mother-to-child HIV transmission; that many HIV women will live long full lives and be able to care for their children; and that being pregnant has been proven to bolster the health of HIV-positive women.

Now that amfAR has identified how painfully our society can treat women living with HIV, perhaps our next step should be to focus on properly teaching girls and young women how to avoid HIV—and other STDs—and to work to diminish the devastating stigma that keeps women in hiding, thus perpetuating the myth that they are not increasingly affected by AIDS.

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