National Women's Health Report
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Women & HIV

After 11 years in an abusive marriage to an alcoholic, Diane Schuster,* a 44-year-old mother of two from Norwich, NY, did something she would come to regret for the rest of her life. She had an affair with a man from work. Within a few months, Ms. Schuster became ill with flu-like symptoms. After searching on the Internet, she realized her symptoms resembled those of acute retroviral syndrome—an early sign of HIV infection. Sure enough, testing showed she was HIV positive.

Within days, Ms. Schuster's world flipped upside down. Priorities went from figuring out what's for dinner, checking her daughters' homework and rebuilding her relationship with her husband to worrying about viral loads, CD4 counts and T cells.

She's learned a lot about her disease since her diagnosis on March 14, 2006, but the biggest lesson she learned has nothing to do with the immune system: "I learned that HIV is *not* a disease of homosexual men and IV drug users," she says.

Indeed. Today, the face of the HIV/AIDS epidemic is increasingly feminine. Worldwide, nearly half of all AIDS cases occur in women,[1] while in the United States, 27 percent of those with AIDS today are women, compared to just seven percent in 1985.[2] Additionally, the annual number of estimated AIDS cases increased 15 percent among women but just one percent among men between 1999 and 2003.[3]

Most infected women are young and black: AIDS is the leading cause of death for African-American women ages 25 to 34 in the U.S. Overall, African Americans make up nearly 60 percent of all AIDS cases in women in the U.S. with a diagnosis rate 25 times that of white women and about four times that of Hispanic women.[22] Hispanic women come next, making up about 20 percent of women with AIDS, while white women account for 16.8 percent.[2]

And, as many people are aware, the epidemic is much worse in other countries. In sub-Saharan Africa, for instance, women now outnumber men as victims of the epidemic, making up almost 60 percent of adults living with HIV and 75 percent of those between the ages of 15 and 24.[1]

The reason? "It goes back to literally centuries of unequal treatment of women," says Karina Danvers, director of the Connecticut AIDS Education and Training Center at the Yale School of Nursing in New Haven, who is HIV positive herself.

"I think HIV/AIDS is one of the many symptoms that come from inequality and society's concept of where women belong." That's one reason she sees for the higher rates of the disease in African-American and Hispanic women in this country: "They've been taught to be even more submissive."

"Submissive" means that many women feel powerless to insist that men use condoms during intercourse; that they can be sexually abused and raped; that they may turn to

*Not her real name.

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drugs or prostitution to cope with sexual abuse, poverty and hopelessness.[4] In fact, the majority of infections in women in the U.S. are due to heterosexual transmission (80 percent) or injecting drug use (19 percent).[2]

The Virus in Women

Although AIDS began as a gay men's disease, the virus seems to infect women more easily. In fact, studies find that the virus is two to four times more transmissible to women than to men.[4]

Other gender-related findings on the disease:

- Having another sexually transmitted infection (STI), such as genital herpes, increases the risk of HIV infection up to tenfold, and women are more likely to have an STI than men.[4]
- Using hormonal contraceptives such as injectable progesterone or birth control pills may increase a woman's susceptibility to infection.[5] However, most of the studies of hormonal contraceptives and HIV have been conducted among women at high risk of HIV infection, including sex workers in Africa. It remains unclear whether hormonal contraception increases the risk of acquiring HIV in other populations. Condoms are the only method proved to prevent HIV transmission.
- Adolescent girls are particularly vulnerable to HIV infection. Among the possible reasons: sexual intercourse often results in tiny tears in the genital tract, allowing the virus to enter;[4] their immature genital tracts provide more exposure for the virus; and they're more likely to engage in high-risk activities such as having unprotected sex and multiple sexual partners. They are also less likely to negotiate condom use.[22]
- The risk of HIV infection doubles during and immediately after pregnancy. This may be due to high levels of progesterone, which has been shown to increase susceptibility to infection in primates.[6]
- Women tend to be poorer than men, and HIV infection is linked to poverty. One reason: Women of higher economic status know more about HIV prevention than poorer women. In fact, women without a high school education are 50 percent more likely to be infected with HIV than women who graduated high school, says Ms. Danvers.

Once infected with the virus, women are affected differently than men. For instance, women appear to have lower levels of the virus present in the first several years of infection.[7] No one knows why this is, says Stephen J. Gange, PhD, associate professor in the department of epidemiology at Johns Hopkins Bloomberg School of Public Health. But researchers are actively searching for answers. Women also have more difficulties accessing care, usually because of economic issues. Plus, they often don't have the time or make the effort to take care of themselves before taking care of others.[4]

"The social and medical aspects of HIV are tied together," says Ms. Danvers. "If you have to take care of the children, the household and everything else, you're going to put yourself last on the list. If you do that, you're not going to do as well."

That could be one reason studies show that just one in four women eligible for the antiretroviral therapy known as HAART—highly active antiretroviral therapy—are on the regimen.[8]

"If their kids have HIV, women will make sure their kids take their medicines, but not themselves," says Ms. Danvers. One woman she knows sent her kids to summer camp instead of using the money to buy a refrigerator

for her medications. "She felt her kids' needs came first."

Other issues that may predict why women don't take HAART include a history of sexual abuse, illegal drug use and race, with white women being twice as likely to be on HAART as African-American or Hispanic women. One reason may be that women who have been sexually abused find it difficult to have trusting relationships with their health care professionals, preventing them from sharing personal information. Additionally, a damaged self-image can lead women to ignore their own care.[8]

When researchers in the Women's Interagency HIV Study (WIHS) asked eligible women why they weren't taking HAART, 15 percent said their health care professionals hadn't prescribed it. The rest said they felt "too healthy, wanted to wait, were afraid of side effects or had difficulty taking the medicine."[8]

Breakthrough Medical Therapies: Women's Mixed Blessing

The introduction of the anti-retroviral drugs in the mid 1990s changed the outcome of AIDS like nothing else. "We have witnessed one of the most remarkable reversals of fortune in any disease in the history of medicine," noted an editorial in one medical journal in 2004. In 1984, the median survival for someone just diagnosed with AIDS was six months. Today, it is at least 10 years.

"We no longer talk about the pure natural history of HIV/AIDS," says Dr. Gange. "We talk about the treated history of HIV infection."

The therapies have been a mixed blessing for women, however. While they work just as well in women as in men, they seem to cause more frequent and more severe side effects than in men, including diarrhea, nausea, nerve damage, kidney stones and pancreatitis.

Ms. Danvers, who was infected by her ex-husband in 1984 and diagnosed five years later, can definitely relate. "I have diarrhea six times a day, I'm constantly nauseous, and a terrible headache has become part of the background every day. It's not life-threatening, but it's life-affecting."

Stigma Remains

Even though the AIDS pandemic is more than 20 years old, the stigma attached to the infection remains, particularly for women, says Gina Wingood, ScD, MPH, associate professor of behavioral science and health education at Emory University in Atlanta.

"The stigma that is directed toward women with HIV is different and more damaging than the stigma for men," she says. "When you talk about women living with HIV, you're raising issues of her having had sex with a drug user, being unfaithful to a partner…. We don't have these social gender-stigmatizing issues toward men, even heterosexuals." This, in turn, affects women's self-esteem and makes them less likely to seek HIV testing because of their fears of stigma.

"A lot of people are ignorant about AIDS," says 45-year-old Sharon,* who has been HIV positive since 1994 when she was infected while she worked in a health care facility. "They don't understand it, and they still don't know that this is not a disease where if you hug someone you're going to get infected."

The stigma can be especially strong in certain cultures, like the Hispanic culture. That's one reason for a grassroots social marketing effort called "HIV Stops with Me" (www.HIVstopswithme.org). It aims to reduce the stigma associated with HIV and acknowledge the powerful role HIV-positive people have in ending the epidemic.

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Women make up 27 percent of those living with AIDS in the U.S. today, compared to about seven percent in 1985.

Resources

AIDS Vaccine Clearinghouse
www.aidsvaccineclearinghouse.org
Launched by the AIDS Vaccine Advocacy Coalition (AVAC), a nonprofit community and consumer-based organization, the clearinghouse is a comprehensive and interactive source of AIDS vaccine advocacy information.

The Body.com
www.thebody.com
Offers bulletin boards, breaking news, research information and other content on HIV and AIDS. Its mission is to demystify HIV/AIDS and its treatment, improve patients' quality of life and foster community through human connection.

U.S. Centers for Disease Control
1-800-232-4636
www.cdc.gov/hiv
The CDC provides information about the prevalence of HIV and AIDS as well as consumer information on the disease and treatment.

National Association on HIV Over Fifty
617-262-5657
www.hivoverfifty.org
Provides educational, prevention, service and health care programs.

National Institute of Allergies and Infectious Diseases
301-496-5717
www.niaid.nih.gov
Part of the government-funded National Institutes of Health. Provides consumer information on the virus, treatment, research and clinical trials.

**Not her real name.*

The majority of infections in women in the U.S. are due to heterosexual transmission (80 percent) or injecting drug use (19 percent).

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One of those people is Maricela Berumen, a 29-year-old Hispanic woman who posted her story on the campaign's Oregon Web site. "At first I kept my HIV status a secret," she wrote. "I didn't want anyone to find out, not even my family. I was afraid of their reaction, afraid of being rejected and feared the indignation if people found out I was infected with the virus (HIV)." She eventually went public, she wrote, because "HIV/AIDS is real and affects all races, ages and genders."

Another major issue for HIV-infected women is whether to tell their children. Sharon still hasn't told her 21- and 17-year-olds. "I'm not sick as long as I keep taking my meds," she says. "I just don't feel my children need to know."

Meanwhile, Karen,* 43, has told three of her five children, ages 29 to 16. "They didn't understand at first," she says, but some family and individual counseling helped. "Now they understand, and they know that I'm not going to die."

She gave birth to two of her children after her diagnosis in 1983, but thanks to the drugs she took during pregnancy and labor (see HIV & Pregnancy on page 6), neither has the virus.

Ask these women what message they'd like to pass on to other women with the virus, and they don't hesitate: "Don't put yourself down. Learn and understand about the disease, find a support group and know that you're not alone."

**Not her real name.*

The Women's Interagency HIV Study

At the start of the AIDS epidemic in 1983, the National Institutes of Health began a large, multicenter study designed to collect information on the disease, its treatment and its victims—in men. It would be another 10 years, however, before it funded a similar study for women—the Women's Interagency HIV Study (WIHS).

But the researchers in the WIHS have more than made up for lost time. Since it began, it has enrolled more than 2,800 HIV-infected and 950 HIV-uninfected women in six sites around the country, making it the largest study in the United States to focus on HIV infection in women.

One critical finding: The virus has no sex bias. Overall, says Stephen J. Gange, PhD, associate professor in the department of epidemiology at Johns Hopkins Bloomberg School of Public Health and principal investigator of the study, "the general pattern that predicts the occurrence of opportunistic infections and death is pretty similar in men and women." In other words, women get sick and die at the same rate and in the same timeframe as men.

Over the years, the study has shaped the way HIV/AIDS is treated in women. It identified the best time to begin HAART in women, evaluated women's satisfaction with their medical care and discovered that HIV-infected women have increased rates of infection with HPV, the virus that causes cervical cancer. Researchers also learned that hormonal contraceptives have no impact on the effectiveness of HAART, a study responding to concerns raised by a participant of the study's community advisory board.

Ongoing studies are examining the impact of menopause on retroviral therapy and HIV-infected women; the long-term effect of retroviral therapy as women live longer with the disease; changes in blood fats and glucose levels from HIV therapies; and how the virus and treatment impacts women's cardiovascular health.

One of the most impressive aspects of the study, says Dr. Gange, is the long-term commitment of its participants, most of whom are inner-city, low-income, minority women. More than 80 percent have participated more than five years.

One reason for their commitment, he says, is the respect and caring shown by the study's health care professionals. "They've formed a strong link," he notes. "We're saying that we don't view you as research subjects; you are participants in a study, and hopefully we'll be able to show that this research is relevant to your own lives."

To learn more about the WIHS, go to https://www.statepiaps.jhsph.edu/wihs/.

Of Microbicides & Vaccines

The more you read about women and HIV, the more depressing it can get. But there is hope on the horizon—closer than you might expect. While HIV vaccines have garnered most of the attention and funding, a more realistic preventive approach for women is microbicides, "chemical condoms" that sabotage the virus.

Since the beginning of the epidemic in the U.S., 176,190 women and female adolescents have been diagnosed with AIDS.

"While condoms are excellent (at preventing the virus from infecting another person), it's often difficult for women to negotiate the use of condoms," says Betsy C. Herold, MD, professor of pediatrics and microbiology at Mount Sinai School of Medicine in New York and a leading researcher on the use of microbicides to prevent HIV. "It's imperative that there be alternative strategies available to women for their own health."

Enter microbicides. The microbicide is a substance that will either kill or reduce the infectivity of the virus. Microbicides could be infused into sponges, formed into time-release suppositories or developed as intravaginal rings that work for weeks or months.

Microbicides come with an added bonus: Many are also effective against other sexually transmitted infections, including herpes, chlamydia and gonorrhea.[11]

Today, five microbicides are being tested in six late-stage clinical trials involving tens of thousands of women in the United States and developing countries. Some work by disrupting the viral envelope, blocking the virus's entry into cells or making the vagina itself hostile to the virus, while others disrupt the virus's life cycle.

The trials are expected to wrap up in 2007 at the earliest, says Dr. Herold, at which time the U.S. Food and Drug Administration will consider their approval.

While microbicides show great promise, safety is a major concern. Studies found that one microbicide thought to protect against HIV—nonoxynol-9—actually increased the risk of transmission, because it irritated the lining of the vagina.

Once one or more microbicides are approved, Dr. Herold predicts that future research will focus on developing combination microbicides, "so we can hit the virus at several different steps." This would also help prevent the virus from becoming drug resistant.

"The concept of vaccines is very exciting, and they are our greatest hope for HIV prevention in the long term, but they have a long way to go in their development," Dr. Herold says. One challenge is that the virus attacks the immune response, yet vaccines rely on a strong immune response to prevent infection—a kind of medical catch-22. Another challenge is that the virus is constantly changing. Developing a vaccine that will work long term is like trying to hit a moving target.

Nonetheless, the National Institutes of Health has initiated or conducted more than 75 clinical trials of more than 35 vaccines. Ten new vaccines entered clinical trials in the past two years and six to eight are expected to begin testing within the next 18 months.[12]

However, despite almost twenty years of research and more than $500 million spent in recent years on vaccine research (compared to about $52 million a year for microbicidal research),[13] a safe and effective vaccine is not likely to be available for at least another five to 10 years, she predicts.

HIV/AIDS Glossary

- **Antiretroviral:** A drug that suppresses the activity or replication of retroviruses such as HIV by interfering with various stages of the viral life cycle.
- **Acquired Immunodeficiency Syndrome (AIDS):** A disease of the body's immune system caused by the human immunodeficiency virus (HIV). AIDS is characterized by the death of CD4 cells (an important part of the body's immune system), which leaves the body vulnerable to life-threatening conditions such as infections and cancers.
- **AZT (zidovudine):** Sold under the brand name Retrovir, a drug approved for use as part of combination antiretroviral therapy to treat HIV disease.
- **HAART:** Highly active antiretroviral therapy. Combinations of drugs people with HIV take to control the virus.
- **Human Immunodeficiency Virus (HIV):** The virus that causes Acquired Immunodeficiency Syndrome (AIDS).
- **Microbicide:** An agent that inactivates, kills or destroys microbes like viruses.
- **T cell:** A disease-fighting white blood cell, including CD4 and CD8 cells. HIV infects and kills CD4 cells, weakening the immune system. The number of CD4 cells in a blood sample indicates the health of the immune system.
- **Viral load:** The amount of viral genetic material in the blood or other tissues, often expressed as number of copies per milliliter (mL).

HIV & Pregnancy

When the AIDS epidemic began, its most innocent victims were the babies. Infected in utero or via breastfeeding, most died before they were old enough for kindergarten.

Today that's all changed. Given the appropriate treatment, the transmission rate from mother to infant is as low as two percent, with some studies showing a zero transmission rate, says Susan R. Barringer, RN, MPH, a consultant for the Connecticut AIDS Education and Training Center at the Yale School of Nursing in New Haven. Without treatment, however, women have a one in four chance of passing the virus on to their babies.

Those figures are important, since between 6,000 and 7,000 HIV-infected women give birth every year in the U.S.[14] It's a figure likely to increase as the virus becomes more prevalent in women and as more HIV-positive women, optimistic about their future because of the newer therapies, choose to have babies.

As one HIV-infected woman wrote on an Internet bulletin board for women with the disease: "Having a child is, in my book, the one thing I don't think I could live without … I think it is time for (HIV) positive women to recognize the possibilities for them of childbirth."

Still, about 90 percent of pregnancies in HIV-infected women are unplanned.[15]

The good news is that infected women who become pregnant do not have higher rates of miscarriage, ectopic pregnancy and stillbirth than women not infected with the virus, indicating that HIV-positive status does not necessarily affect the pregnancy itself.[15]

The first step to preventing transmission between mother and baby is identifying HIV-positive pregnant women. Yet in 2000, 29 percent of HIV-infected infants (between 80 and 110) were born to mothers who either didn't know or didn't tell anyone they had HIV infection prior to the birth.[16]

One reason pregnant women don't get tested is because their health care provider doesn't recommend it or doesn't send the message that it's important. If they do, Ms. Barringer says, "women are very, very open to testing," particularly if they trust their provider and the issue is framed as a way of maintaining good health for mom and baby.

To that end, Ms. Barringer has a message for women's health care professionals who don't recommend screening: "Make no assumptions about your patients' risk or apparent lack of risk."

As soon as an HIV-positive woman finds herself pregnant, or a pregnant woman tests HIV-positive, she should discuss treatment during pregnancy with her health care professional. If she has a low viral load and a high CD4 count, and she hasn't started retroviral therapy yet, she may only need to take AZT (zidovudine), the first drug ever approved for the treatment of AIDS, during pregnancy. Most women, however, will likely need a combination of drugs.

Another way to reduce the risk of transmission to the baby, says Ms. Barringer, is to have an elective caesarian. This avoids the trauma of a vaginal birth, during which tiny tears and scrapes in the baby's skin could provide access to the virus.

After birth, babies born to HIV-infected women test positive for the virus, because they have their mother's antibodies (HIV tests measure antibodies to the virus). The infants' true status, however, won't be known for another three to six months. Nonetheless, all of the babies receive treatment just in case, until their HIV status is verified.

After the birth, HIV-infected women should not breastfeed, said Ms. Barringer, because breastfeeding increases the risk of transmission by 15 percent. The only exception is if women live in areas with unsafe water, are unable to provide formula for their babies or face stigma associated with not breastfeeding that could threaten their safety.

In the end, she says, the message she'd like to get to pregnant women or women planning a pregnancy is that testing for HIV not only benefits their own health, but their babies', too. "I think that's a really important message for women to share with others they know." ✘

Commonly Asked Questions about HIV/AIDS

Q Can I get HIV through oral sex?

A Yes, you can. While the likelihood of the virus's transmission isn't as high during oral sex as during vaginal or anal sex, there are cases in which the virus has been transmitted this way. For instance, you may have sores or cuts in your mouth through which the virus could enter. And, of course, semen and vaginal fluid may contain the virus, which could enter your body through cells lining your mouth.

If you choose to perform oral sex, make sure your male partner uses a condom. Female partners should use a dental dam or a cut-open condom in their mouth to create a barrier. You can even use plastic food wrap as a barrier during oral sex with a woman or as an added protection during oral sex with a man.

—Beryl A. Koblin, PhD
Head, Laboratory of Infectious Disease Prevention
Member, Lindsley F. Kimball Research Institute
The New York Blood Center
New York, NY

Q I've just been diagnosed with HIV. I'm so confused and upset I don't know what do. Where do I start?

A The first step, if you haven't already, is to find a physician who specializes in HIV/AIDS. This disease and its treatment are so complicated that a general practitioner will not be able to take care of you as well.

Ask what your viral load is (how much virus is in your system) and get your T-cell count, which tells you how well your immune system is doing. These numbers provide a picture of your medical status.

Then identify a support system. Your support system doesn't have to be large; just one or two people you trust and feel comfortable with. In fact, it's a good idea to let them know you're going to be tested and have one of them with you when you get the results.

If you need to start on antiretrovirals, decide if you want to go through your insurance company—which alerts them to your HIV status—or pay for it yourself to protect your privacy. I also recommend you have a support system in place when you start taking the drugs and take some time off from work, because the initial side effects can be harsh.

You also need to learn to incorporate the virus into your life, particularly your sex life. That means practicing safe sex. If you don't know how to use condoms, or how to negotiate their use with your partner, talk to a social worker or counselor who specializes in HIV/AIDS.

Then there's the issue of when to disclose your status. When to tell can be very tricky. Some people might treat you well, but others may start seeing you as a dying person. Ditch the latter—you don't need that type of person around.

—Karina Danvers
Director of the Connecticut AIDS Education and Training Center
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Living with HIV: How to Make it Easier

HIV: yet another health issue we now know has unique effects on women. But thanks to intense research over the last 10 years, our understanding of this dreadful disease has grown significantly. However, if you're living with HIV, you may feel there's so much more you need to learn.

By Pamela Peeke, MD, MPH
NWHRC Medical Advisor

Dr. Peeke is a Pew Foundation Scholar in Nutrition and Metabolism, and Assistant Clinical Professor of Medicine at the University of Maryland in Baltimore. She writes about health and lifestyle issues important to all women.

For example, you need to know how to manage your disease beyond medication. As with any chronic health condition, lifestyle choices can make a huge difference in your health. They can work with medication to strengthen your immune system and reduce side effects.

Specifically:

1. **Quit smoking.** Maybe you think that since you're sick anyway, it doesn't matter if you smoke. Well, it does. A study on men (there's one on the way about women) found that HIV-positive people who smoked were more likely to develop respiratory symptoms, chronic obstructive pulmonary disease and bacterial pneumonia than HIV-positive men who didn't.[17] Doesn't your body have enough to deal with without adding tobacco to the mix?

2. **Talk to someone.** There's a misconception out there that just because we now have fairly effective therapies for HIV/AIDS, those living with the disease have an easier time of it emotionally. One of the few studies to look at the psychological state of HIV-infected women taking retroviral therapies, however, found most were still very distressed and having significant difficulties adjusting. I urge you to find a therapist, support group, a friend, a spiritual leader—anyone—who will listen to your concerns with empathy. Many clinics offer such counseling for HIV-infected people on a sliding-scale or free basis.[18]

3. **Seek help for depression.** In a woman with HIV, one study suggests that the worse the depression, the higher the amount of virus in your blood and the less likely you are to take your medications.[19] If you're feeling depressed, talk to your health care professional. A combination of counseling and/or antidepressant medications may help.

4. **Try to see an HIV or infectious disease specialist.** Studies show that women are more likely to receive recommended antiretroviral therapy from these specialists than from other doctors.[20]

5. **Get regular Pap tests.** If you have HIV, you're more likely to develop cervical lesions that could lead to cervical cancer. In fact, the development of cervical cancer is now considered a sign of AIDS for women with HIV. The U.S. Centers for Disease Control recommends a Pap smear upon diagnosis and six months later. If neither show any problems, you should have one every year thereafter if you don't have symptoms, every six months if you have HIV symptoms, prior abnormal Pap smears or signs of HIV infection.

6. **Follow a low-fat, high-fiber diet.** You have a higher risk of developing high cholesterol, most likely because of the antiretroviral therapy. Saturated fat —found in whole-fat dairy and other animal products—is one of the major culprits when it comes to high cholesterol levels.

Meanwhile, fiber is important, because people taking certain antiretroviral medications tend to develop lipodystrophy, a condition in which fat accumulates in the back of the neck and around the abdomen. These medications may also increase your risk of diabetes. There's some evidence, however, that a high-fiber diet can reduce some of this fat accumulation and the risk of diabetes. Try a Mediterranean diet, which includes lots of whole grains, vegetables, fruits and healthy oils, like olive and fish oil, and small amounts of animal protein.[21]

7. **Hit the weight room a couple of times a week.** Building muscle is important in this disease, in which "muscle wasting" may occur. It can also help prevent insulin resistance, reduce triglycerides and shrink abdominal fat if you have lipodystrophy. And don't forget regular aerobic exercise, like walking, running on a treadmill, riding a bike or swimming. Talk to your health care professional before beginning any exercise program.✘