Introduction

Worldwide, women make up half of the 34 million people with HIV infection, and HIV is the leading cause of death among women of childbearing age. In the United States, one out of every five new HIV diagnoses is given to a woman. Even though women have been significantly affected by HIV for decades, the importance of the impact of HIV on women has often been overshadowed by the larger number of cases among men.

The good news is that over the last few years, the number of new HIV infections among women in the United States has declined by 21 percent. The bad news is that some populations of women, most notably Black women, continue to experience extremely high HIV rates. This issue of Perspectives will explore which groups of women are most affected by HIV, examine some of the factors that put women at risk for infection, and discuss ways of removing barriers women face when accessing HIV prevention, testing, treatment, and care.

Which Women Are Most Affected?

One in four of the people living with HIV in the United States is female. But some groups of women are far more likely to be living with or at risk for HIV infection than others.

Heterosexual Women. In the United States, 84 percent of HIV-positive women were infected through sex with men.

Black Women. Even though Black women only represent 13 percent of the U.S. female population, they made up 64 percent of all newly diagnosed American women in 2010. (See the figure “New HIV Infections Among Women & Girls and U.S. Female Population, by Race/Ethnicity, 2010.”) Black women in the United States have a rate of HIV infection that is 20 times that of White women, and HIV is the seventh leading cause of death for Black women ages 25 to 44.

Transgender Women. Although transgender women’s health has been inadequately studied, the research that exists shows an alarming community burden of HIV. A meta-analysis of research studies from 1980 to 2007 estimated that HIV prevalence was 27.3 percent for transgender women who did sex work, and 14.7 percent for those who did not do sex work. A respondent-driven San Francisco study of 314 transwomen published in 2013 found that 39.5 percent were HIV-positive. Being a woman of color, using injection drugs, and having less education were all associated with being HIV-positive in that study.

Young Adult Women. In 2010, the largest share of new infections in women were among women aged 25 to 34. Women of color, however, were more likely to be younger than White women.

Women Who Use Substances. Substance use remains strongly correlated with both HIV infection and sexual
behavior that can result in HIV infection. Sharing injection equipment accounts for HIV transmission to about 16 percent of women who become infected.

**What Factors Put Women at Risk?**

A variety of biological, socioeconomic, and interpersonal factors put women at risk for HIV. The female genital tract (in particular, the vagina and cervix) is more susceptible to infection than the male one (the urethra). This is because women’s mucosal membranes in the vagina and cervix are more likely to be exposed to HIV-infected seminal fluid than a man’s urethra is to be exposed to HIV-infected vaginal fluids or blood. In addition, immune responses and hormones women have that are designed to support a possible pregnancy may also allow HIV to take hold. Inflammation of the female genital tract is also linked to increased risk for HIV infection, and can be the result of infection (including sexually transmitted infections) or from tiny abrasions from sex, douching, or other causes. Since women are less likely than men to have symptoms in some cases, they are often not aware that they have a sexually transmitted infection (STI), and so they may not seek treatment, or be aware that they are at increased risk for HIV infection. Black women’s rates of STIs are significantly higher than those of White women’s, contributing to an increased risk for HIV.

Transgender people have rates of sexually transmitted diseases that are four times that of the general population in the United States. Of course, women have not only vaginal sex, but also anal sex. One national survey of more than 13,000 people published in 2011 found that 36 percent of U.S. women between the ages of 15 and 44 reported having had anal sex at some point in their lives. Yet anal sex is much less often mentioned as a source of infection for women than it is for men.

The risk of transmission for a woman who has unprotected anal sex once with an HIV-positive male partner is approximately 30 times greater than if she had vaginal sex with the same partner once. Yet condoms are often not used during heterosexual anal sex. A 2007 study of New Yorkers found that 5.6 percent of female respondents reported having anal sex in the past year. Only 23 percent of these women said that they “always used condoms” for anal sex, as compared with 61 percent of men who have sex with men who were surveyed. Women who used condoms for anal sex less often were also much less likely (35 percent) than women who reported condoms were used consistently (63 percent) to have had a recent HIV test.

Both unprotected receptive anal and vaginal sex with men are also important ways that many transgender women become HIV-positive. Whether or not a woman becomes infected with HIV is not only the result of her own behavior, but also that of her partners. Some women do not consider using condoms because they are unaware of their male partner’s risk factors for HIV (for example, that the male partner shares injection drug needles, or has unprotected anal sex with men).

Other women may not consider using condoms, or may not be able to negotiate sexual harm reduction because of societal messages about women and sex—for example, that women should not talk about (or have) sex, and that women should...
not assert themselves in romantic or sexual relationships. Since condom use requires participation by the male partner, gender-related power imbalances can result in lost risk-reduction opportunities. For a transgender woman, stigmatizing and discriminatory experiences can reduce self-esteem and damage her perception of her body’s beauty and value. This can make it harder for her to protect her health.\(^\text{14}\)

The overall prevalence of HIV in the sexual network a woman belongs to is also important. Black women, for example, do not have to engage in behavior that is riskier than that of White women to be at increased risk for HIV, since the prevalence of HIV is already so much higher in Black communities in the U.S. than in White communities, and since Black people often choose other Black people as sexual partners.\(^\text{6}\)

Societal factors such as poverty also play a crucial role in increasing women’s HIV risk. A 2010 national survey of urban, predominantly Black and Latino heterosexuals who were living in areas of high HIV prevalence found that people whose annual household income was less than $10,000 a year had an HIV prevalence rate (2.8 percent) that was more than twice as high as those whose household incomes were more than $20,000 per year (1.2 percent). Women are approximately 20 percent more likely to be living in poverty in the United States than men, and poverty rates in 2013 were highest among Black and Latina women, compared to women of other races and ethnicities.\(^\text{16}\)

Violence and abuse can directly or indirectly facilitate HIV infection. Sexual violence can result in damage to the genital tract that can increase susceptibility to infection.\(^\text{6}\) Women who are sexual abuse survivors are also more likely to have other risk factors for HIV, such as transactional sex for drugs, or having a partner who abuses her physically when he is asked to use a condom.\(^\text{6}\) Women who are living with HIV are much more likely than U.S. women in general to have experienced intimate partner violence: 55 percent versus 36 percent.\(^\text{17}\) And women who have experienced intimate partner violence are more likely to report unprotected sex, injection drug use, and alcohol abuse.\(^\text{16}\) Both violence and the fear of violence are disempowering. Women with a history of intimate partner violence are less likely to feel that they can prevent HIV infection and to keep health care appointments.\(^\text{16}\) And abuse often continues or intensifies after an HIV diagnosis. One in five HIV-positive women reported instances of physical harm since her diagnosis, and of these, half were thought to be related her positive status.\(^\text{16}\) Transgender women are especially affected by violence—a 2008 review found that an average of 58 percent of transgender women reported violence at home.\(^\text{15}\)

Improving Prevention, Testing, and Care for Women

Women at risk for and living with HIV need and deserve effective interventions at a variety of levels: societal, medical, institutional, and interpersonal. Among the strategies being proposed and pursued to address women’s HIV prevention and care needs are access to and awareness of testing, linkage to care, awareness of the role of violence in HIV risk, and development of prevention methods that women can control, including pre-exposure prophylaxis (PrEP).

Expanding Access to Testing.

Women are often caregivers for...
children, partners, and other family members, and frequently place the needs of others ahead of their own—including their need for health care. Often they do not have the time or resources to access multiple health services such as family planning, HIV testing, substance use counseling, and violence prevention services in separate settings. And many women of reproductive age utilize family planning clinics as their primary (60%) or sole (41%) source of health care. Yet in 2010, less than 1 million of the 5 million women who attended publicly funded family planning clinics received HIV testing services. Expanding testing in reproductive health settings would allow more women to access these services.

One area of great HIV-prevention success is the tremendous decrease in maternal-child HIV transmission, which used to be a significantly larger problem. Today, pregnant women are often routinely tested, and medication advances mean that proper treatment can reduce the risk of transmission from mother to child to less than 1 percent. Thus, since the mid-1990s, perinatally acquired infection of babies has dropped in the United States by more than 90 percent. The greatest success in identifying HIV infection lies with “opt-out” testing, in which pregnant women are informed that HIV testing will be included with a batch of other routine, pregnancy-related tests, unless they choose to opt out of the HIV test. Testing may be repeated during pregnancy, and rapid testing is also available at the time of delivery. When a pregnant woman’s HIV infection is detected, antiretroviral treatment is used to protect the mother’s health and to prevent transmission to her child.

Since 2006, the CDC has recommended routine testing in health care settings for all people, aged 13 to 64 years old. In 2013, the U.S. Preventive Services Task Force gave this strategy (but for people 15 to 65) a “Grade A” recommendation. The task force’s recommendations not only inform the policies of health care organizations and professional societies, they also determine which services insurers are required to offer under the Affordable Care Act. Greater access to routine testing means that more women (and their male partners) may become aware of their status and be able to receive treatment whether or not pregnancy is part of the picture.

Encouraging Testing and Awareness Through Media Campaigns. In 2012, the CDC launched a national campaign in 10 U.S. cities, called “Take Charge. Take the Test.” The campaign is designed to encourage young Black women between the ages of 18 and 34 to learn their HIV status. In 2013, the Kaiser Family Foundation and its partners introduced its new “Empowered” campaign as part of its “Greater Than AIDS” initiative. The campaign features musician Alicia Keys and HIV-positive women and uses graphics, video interviews, and social media to talk with women about HIV and how they can “change the course of the epidemic.”

Improving Linkage to and Maintenance in Care. Once a woman tests HIV-positive, it is crucial that she be linked to HIV care, and that linkage services include follow-up to ensure that the client actually connects to care. Further, linkage is effective only if care providers also strive to identify and overcome barriers to care, so that women are able to stay in care. In 2010, only approximately 53 percent of U.S. women with HIV were staying in care, and only 42 percent had achieved viral suppression. Significant barriers to care for women living with HIV include lack of transportation and childcare; lack of insurance; difficulty taking time off of work; being too sick; and the much more challenging conditions of poverty, depression, and substance use.

Referrals to case management services may help bridge the gap between diagnosis and care. Case managers can often assist clients in effectively responding to the
psychosocial challenges that prevent them from making and keeping appointments. Peer advocates—HIV-positive people who help newly diagnosed individuals navigate the health care system—may be a particularly important resource for women, since women have fewer HIV-positive role models and may feel that the HIV system of care simply isn’t set up for them. Research suggests the value of taking an “active” role in referring people to care, for example, by helping them make actual appointments, rather than the more passive option of giving them general referral information.  

Systematic provider follow-up after missed appointments is also crucial, both for identifying and overcoming barriers to care and in building the provider-client relationship to support the client’s health. And the more that services can be responsive to women’s needs (creating flexible appointment schedules, offering childcare, integration of case management, mental health, transgender women’s health services, and substance use services on-site), the more women may be able to transcend barriers to care.  

Since women of color, especially Black women, are disproportionately affected by HIV, it is critical that providers understand the impact of racism on the experiences of their clients, as well as the overarching impact of sexism on all women. Transgender women are also at heightened risk, and transphobia in health care settings, like racism and sexism, can deter the people most in need of services. In all of these contexts, general tools of cultural competence, complemented by specific culture-related knowledge and sensitivity, can create an environment of respectful communication. This environment can improve the likelihood that women will access and pursue HIV care and feel empowered to make decisions to support their own health.  

Acknowledging the Relationship Between Gender Violence and HIV.  
In September 2013, the White House released an Interagency Federal Working Group report titled “Addressing the Intersection of HIV/AIDS, Violence Against Women and Girls, and Gender-Related Health Disparities.” It calls for health care providers to use the provisions of the Affordable Care Act to expand counseling and testing; to increase screening for both HIV and IPV in health care settings, and to develop relationships with shelters and rape crisis centers. It also cites the need for more programs providing trauma-informed care for women living with HIV as a way to improve their health outcomes.  

Developing Woman-Controlled HIV Prevention Tools—Microbicides and PrEP. Many women face resistance, which may include threatened loss of financial support, and even sometimes escalating to violence, when they request that their partners use condoms. Although “female condoms,” which are inserted by the woman into her vagina or rectum, are highly effective, women have long clamored for more options, including those that would be less obvious, and might permit skin-to-skin contact. For many years, the hope was that effective vaginal and rectal microbicides would soon be developed to allow “woman-controlled” HIV prevention. Microbicides are chemical products that are applied to the vagina or rectum prior to sex in order to prevent HIV infection. Although numerous products have been studied over the past 20 years, no “magic bullet” microbicide has been developed. Trials for several different products that utilize antiretroviral medication in microbicide form are currently under way, including continued trials of tenofovir gel.  

Tenofovir has also recently garnered widespread attention for its part (together with emtricitabine) in a new prevention intervention—pre-exposure prophylaxis, or PrEP. PrEP
involves an HIV-negative person taking antiretroviral medication daily in order to prevent HIV infection. The iPrEx study, an international randomized controlled trial whose findings were announced in 2010, showed an HIV-prevention efficacy of 73 percent in subjects who took 90 percent or more of their daily doses, a risk reduction of 92 percent for those who had detectable levels of the drug in their blood. (Participants who adhered less well achieved far lower rates of protection.) Both the original iPrEx and the iPrEx OLE (open-label extension) studies recruited only MSM and transgender women participants, with no other women included as subjects.

The VOICE (Vaginal and Oral Interventions to Control the Epidemic) study examined the safety and efficacy of both microbicide gels and oral PrEP in 5,000 African women in five countries. While PrEP was found safe, the results of the study were disappointing and inconclusive—in part because so many women did not, in fact, take the drug. A Botswana study of more than 1,200 heterosexuals (46 percent of the subjects were women) found that PrEP was 62 percent effective in preventing infection. And a randomized trial of more than 4,700 heterosexual Kenyan couples found a 67 to 75 percent effectiveness. As in other studies, adherence was strongly related to effectiveness—participants with detectable levels of tenofovir in their blood had a higher rate of HIV-prevention effectiveness—82 percent.

In the United States, one nationally representative sample study published in 2013 found that 48 percent of early PrEP adopters have been women. Challenges to widespread uptake of PrEP among women include lack of awareness among both women and their medical providers of PrEP as an option; the perception that PrEP is only effective for men who have sex with men; concerns about how PrEP would be covered under insurance; and concerns about long-term medication effects. In May 2014, the Centers for Disease Control and Prevention (CDC) issued guidance recommending that HIV-negative heterosexual women (and men) who inject drugs, have HIV-positive partners, or who have unprotected sex with partners of unknown status who are at risk of infection should be considered as candidates for PrEP.

Conclusion

Women in the United States, particularly Black women and transgender women, continue to be at risk for and living with HIV. And not all women living with HIV are receiving the care that they need. Improved access to HIV testing, coupled with active linkage to care, and woman-friendly services can help women achieve and maintain their best health.
References


29. Marrazzo, J. and others. Pre-exposure prophylaxis for HIV in women: Daily oral tenofovir, oral tenofovir/emtricitabine, or vaginal tenofovir gel in the VOICE study (MTN 003). 20th Conference on Retroviruses and Opportunistic Infections. Atlanta, March 36, 2013; Abstract #26LB.


Test Yourself

Review Questions
1. In the United States, what proportion of new HIV diagnoses are among women? a) one-tenth; b) one-sixth; c) one-fifth; d) one third.

2. True or False: Since very few women have anal sex, unprotected anal intercourse is not an important potential source of HIV transmission for them.

3. Violence and abuse can directly and indirectly facilitate HIV infection. Which group of women does the article discuss as having been disproportionately affected by violence? a) young women; b) transgender women; c) poor women; d) lesbian women.

4. In the article, the importance of expanded HIV testing in reproductive health settings was discussed. Which of the following was not mentioned as a reason that this expansion is important? a) Very few women use family planning clinics, and having HIV testing available would attract more women to reproductive health services; b) Women do not have the time or resources to access multiple health services across separate settings; c) Women often put the needs of others before their own health care needs; d) None of the above.

5. What does it mean to make an “active” referral to care for a woman who has tested HIV-positive? a) The test counselor accompanies the client to the first appointment; b) The test counselor helps the client actually make an appointment, rather than just giving information; c) The test counselor role-plays with the client what the medical appointment might be like; d) All of the above.

6. Although Black women make up 13 percent of the female population in the U.S., they represent what proportion of women living with HIV? a) 28 percent; b) 44 percent; c) 64 percent; d) 89 percent.

7. Which of the following is a challenge to the widespread uptake of PrEP among women in the United States? a) Lack of awareness among women and their medical providers of PrEP as an option; b) The perception that PrEP is only effective for men who have sex with men; c) Concerns about insurance coverage for PrEP, and PrEP’s long-term medication effects; d) All of the above.

Discussion Questions
1. There are many significant barriers to care for women living with HIV. What resources in your community are available to assist women in overcoming these barriers?

2. Do you notice any differences in the barriers to HIV prevention that your female testing clients experience versus your male ones?

3. What does it mean to you to take an “active” role when referring HIV-positive women clients to care? What extra steps do you take to increase uptake of services and appointments?

Answers
1. c

2. False. Many women have anal sex, and unprotected anal sex is far more likely to transmit HIV than unprotected vaginal sex.

3. b, 4. a, 5. b, 6. c, 7. d