Women and AIDS

Issues

Women and AIDS

Women living with HIV/AIDS often place the needs of their families ahead of their own, including health care. Ryan White outreach and primary care programs empower these women to live longer, healthier lives and HRSA works to better educate providers to address the unique needs of this population.

Women and the Ryan White HIV/AIDS Program

Of the approximately 1.1 million people living with HIV/AIDS in the United States today, more than 280,000 are women. Although men who have sex with men represent the largest number of people living with HIV/AIDS, rates of HIV infection among women, particularly racial and ethnic minority women, continue to climb.

Health disparities among racial and ethnic minorities are a major issue in the fight against HIV/AIDS. Women accounted for 26 percent of estimated AIDS cases in 2008,* of which 84 percent were among women of color. Even with the availability of life-saving antiretroviral drugs, AIDS is still the fourth leading cause of death for Black women ages 25 to 54. This is, in part, due to late diagnosis; in 2010 an estimated 30 percent of women in States with HIV name reporting developed AIDS within a year of their diagnosis. Women of color living in urban areas such as Atlanta, Chicago, Los Angeles, Miami, New York, Philadelphia, San Francisco, and Washington, DC, have historically been hit especially hard by the epidemic. Today, AIDS among women of color is on the rise in the South.

In the Beginning

In the earliest days of the AIDS epidemic, scientists and researchers focused their energies on understanding this disease that was mysteriously killing gay men. Soon, however, it became apparent that the new condition (called “the gay cancer” and “gay-related immune deficiency” [GRID]) was about much more than men who have sex with men.

In the July 9, 1982, edition of Morbidity and Mortality Weekly Report, the U.S. Centers for Disease Control and Prevention (CDC) reported on 34 cases of Kaposi’s sarcoma and opportunistic infections in Haitians, 4 of whom were women. These cases had the hallmarks of the immunodeficiency disorder previously diagnosed only in gay men. The report led to a dramatic advancement in understanding of the new disease, its associated risk factors, and potential modes for transmission. It also foreshadowed a torrent of infections among women—especially minority women—over the coming decades.

*The most recent year for which data are available.
Living With a Scarlet Letter

Shortly after HIV cases were found among Haitians, the first case related to a blood transfusion was documented. The CDC quickly began to construct a profile of people at risk, which included the following groups:

- gay and bisexual men
- sex workers
- intravenous drug users
- Haitians
- female sexual partners of men who have AIDS, and
- people who had received a transfusion of infected blood.

It had become clear that the new killer was not isolated to the gay community. By the end of July 1982, the CDC changed the name GRID to acquired immune deficiency syndrome (AIDS).

While the medical research community was slowly getting a better handle on what behaviors made women vulnerable to HIV/AIDS, the CDC’s definitions and risk categories made it easy for mainstream America to remain in denial. It was somebody else’s problem. Women all over the country breathed a collective sigh of relief when media spread the word that the only way they could get this disease was through prostitution, sex with a gay man who had AIDS, injection drug use, or transfusion with tainted blood products. The definitions were so narrow that most women never saw themselves at risk—nor did their health care providers.

As the epidemic evolved, a lack of accurate information about what behaviors put women of all ages at risk coincided with growing HIV incidence among this population. By 1986, women represented 7 percent of all documented AIDS cases in the United States. While an article in the January 1988 issue of Cosmopolitan, a publication that many young women looked to for information on sex and relationships, declared that a woman could indeed safely have unprotected intercourse, even if her partner was HIV positive.

HIV/AIDS-infected women not only bore the effects of the disease itself but also lived with stigma. They were deemed socially unacceptable, and like their gay male counterparts, they were told that they brought the disease upon themselves. They were often ostracized by family, friends, and their communities. “It was like living with a scarlet letter on your chest,” said a woman who did not fit any of the risk profiles when she was diagnosed. “I didn’t try to get any treatment after I found out, because I didn’t want to deal with all that goes with it.”

This patient was referring in part to the question that many women living with HIV/AIDS dread and fear: “How did this happen to you?” It is a question that kept—and continues to keep—women from telling even their closest friends and family that they have HIV/AIDS. Women who were diagnosed in the 1980s talk about feeling isolated and being the only woman in a sea of gay men at clinics trying to get care. “There is so much that goes into anybody

Who’s at Risk: Public Perception and HIV

Mary Fisher, a White woman from a wealthy Detroit family, did a lot to change the face of the disease for mainstream America when she spoke in 1992 at the National Republican Convention about living with AIDS. Her impassioned speech helped to slowly move the public’s perception of the epidemic as affecting only gay men or injection drug users to something that could happen to anyone, including a married mother from one of the wealthiest suburbs in the Nation. And Elizabeth Glaser, a woman who was infected with AIDS through a tainted blood transfusion, helped the world to understand mother-to-child transmission of the virus. She lost 2 of her 3 children to AIDS before losing the battle herself.

Ryan White HIV/AIDS Program providers often assist patients in required paperwork to ensure receipt of- and coverage for- services. This assists in breaking down barriers that may keep many women accessing care.
admitting that they have HIV/AIDS,” says one woman who was diagnosed in 1988, “but in being a woman, there is so much judgment of you and who you are.” She says that the way people have treated her, even in health care settings, kept her out of care for the first 10 years. “Things have gotten better, at least with the doctors and clinics, but I am still very careful who I tell in my personal life.”

Need for Federal Intervention
After the emergence of AIDS, time soon showed that all women may be at risk and that HIV disease strikes throughout society. Like diseases from malaria to diabetes, however, HIV/AIDS affects women living in poverty, especially minority women, at highly disproportionate rates. Most women living with HIV/AIDS, past and present, were living in poverty at the time of their infection or were forced into poverty because they lost their jobs or were too sick to work.

Compounding the challenges facing women in the early days of HIV was the fact that the first AIDS service organizations and community-based organizations addressing HIV/AIDS were born in large part from the gay rights movement. They knew little of the needs of women and lacked the skills and resources with which to serve them. In addition, because the manifestations of HIV disease are different in women and men, the experience that clinicians were gaining among men was not always applicable to their female patients.

“We seldom saw the Kaposi’s sarcoma that we saw in gay men who came in. Instead, we were seeing cervical cancers and other things that showed us that the progression was different in women,” says Diana Travieso-Palow, formerly with the Department of Obstetrics and Gynecology at the University of Miami School of Medicine, and currently with the Health Resources and Services Administration (HRSA), HIV/AIDS Bureau. “Even with zidovudine [AZT],” Travieso-Palow adds, “most of the early studies had been done on gay men, and there was not a lot that clinicians knew about the effectiveness and long term impact of the drug on women.”

Women who came into physicians’ offices and clinics were at risk for being misdiagnosed. Throughout the epidemic, a misunderstanding of the risks for and manifestations of HIV/AIDS in women has contributed to late diagnosis of the disease. Many HIV-infected women have discovered their status only after having sought prenatal care.

First Federal AIDS Program
As more women were infected and sought out care, it became clear that there were not enough community-level resources available to help address their special needs. A Federal-level intervention was needed. In 1986, HRSA launched the AIDS Service Demonstration grants, the first Federal AIDS care program and one of the first national AIDS-specific programs in the country of any kind. At $15.3 million, the program offered much-needed support to cities hit hardest by the AIDS epidemic. These early grants later became the foundation of Part A funding in the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act.

Although the proportion of infections among women was much lower than it is today, women were nevertheless eligible to be served through the AIDS Service Demonstration grants. Many of the cities receiving the first grants, however, were overwhelmed by the needs of gay men, and that population was the primary focus. Moreover, the size of the grant for each city was small, and few programs had yet been conceived to deal with the needs of women of childbearing age—let alone their HIV-infected children.
Though the first reported cases of possible HIV transmission from mother-to-child was in December 1982, women of childbearing age continued to face significant stigma as the numbers of infected children slowly rose during those early years.\textsuperscript{12}

HIV-positive children were most often born to severely overburdened families. Some infants were abandoned in hospitals, and few foster care arrangements were available for babies who were being orphaned by the epidemic.

Thus, the Pediatric AIDS Service Demonstration grants, first awarded in 1988, represented a giant leap forward in the care of women and their families. These grants responded to many harsh realities.

Approximately $4.8 million was appropriated during the first year of the program where 13 grantees were awarded funding and rose to $20.9 million in FY 1993 with 25 grantees. The Pediatric AIDS Service Demonstration grants made a whole new level of care available to families—especially to children. They successfully addressed the unique needs of women and children and gave the Nation a model for developing programs in new locations. Ultimately, these grants became the framework for Title IV (now Part D) program for women, children, infants, and youth.

The programs receiving funds approached women with a degree of cultural competency that had not been previously seen. They reflected that women experience gender roles and sex and sexuality differently from men. The programs also took into account that women’s level of education, fear of physical abuse and, more generally, gender inequality in relationships are all factors in seeking and staying in care.\textsuperscript{13,14} (See the HRSA CAREAction newsletter on this topic.)

These new programs also reflected that many HIV-positive women are mothers struggling to take care of themselves and their children. For them, having HIV/AIDS is just one more overwhelming problem to deal with, behind providing food and a place to live for their children; keeping the lights on; and, often, other medical issues, such as diabetes, mental health issues, substance abuse, and even managing the health needs of a child who was born with HIV.

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### HIV-Positive Women and the Ryan White HIV/AIDS Program: Milestones in Care

In August 1990, the Ryan White CARE Act, today known as the Ryan White HIV/AIDS Program, was signed into law. Passage of the CARE Act represented a breakthrough in access to services for women living with HIV/AIDS—indeed, for all people living with HIV disease. By providing funding for services through a variety of grant programs, the new legislation became a lifeline to necessary medical and social support services. The CARE Act offered comprehensive care to people who would not otherwise be able to afford it.

In some cases, the new program supported a continuation and expansion of services that had been funded through HRSA's pre-CARE Act programs. In others, it brought Federal funding for serving people with HIV/AIDS into communities for the first time.
The CARE Act reached HIV-positive women through all of its grant programs. In addition, the new legislation reflected that women, children, youth, and families had unique needs that warranted special focus. That focus had been embodied in the Pediatric AIDS Demonstration grants which continued after the CARE Act’s passage and were eventually folded into the CARE Act in 1993 under Title IV (Part D).

**Part D: Targeted Response to Women, Children, Youth, and Families**

Most HIV-positive women (76 percent) are caring for children under age 18 in their homes. This fact alone highlights the special care needs of women and their children and may complicate women’s ability to manage their own illness. The responsibilities inherent in women’s central role in the family can affect their ability to make decisions about their own health and medical care, because they often prioritize the needs of others before their own, thereby causing a delay in—or complete avoidance of—treatment.

The Part D program grantees provide an array of services reflecting their clients’ unique clinical, psychosocial, and support services needs. In the Part D Program, funds are

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**In the mid-1980s, Pediatric AIDS Service Demonstration Grants provided children living with and affected by HIV/AIDS essential medical and support services.**

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According to a Kaiser Family Foundation report, women are responsible for 90 percent of the health care management for their children, including selecting their doctor, taking them to appointments, and choosing their health plans.---

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### RYAN WHITE HIV/AIDS PROGRAM PART D

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used not only by the grantee but through a number of providers that constitute a cohesive network focusing on the same client base. Together, these providers

- coordinate care for women and for other family members;
- facilitate access to clinical care;
- enlist women in programs such as WIC (Women, Infants, and Children), which offers nutritional services to pregnant women, new mothers, and young children; and
- create co-located medical services for the entire family in some cases.

Support and care through the Ryan White HIV/AIDS Program was and is still considered funding of last resort for the most vulnerable women and children, who often have fallen through the cracks of other public safety nets. Without the Ryan White HIV/AIDS Program, many of these medically underserved women and children would not receive care and services.

In FY 2010, approximately $77.8 million in grants was awarded to 2,157 Part D providers across the country to offer family-centered outpatient or ambulatory care (directly or through contracts) for women, infants, children, and youth with HIV/AIDS. Grantees provide primary medical and specialty care, treatment, and support services to improve access to health care. The funding also helps grantee sites educate women about the benefits of enrolling and participating in research.

Part D services include treatment of HIV-positive pregnant women and women of childbearing age. Services offered through Part D are having a significant impact on the health outcomes of children born to HIV-infected mothers. Studies show that these children are most often born HIV free if their mother is in a Part D treatment program.

For example, the Detroit Medical Center's Perinatal Infectious Disease clinic in Michigan, provides prenatal and postpartum care to HIV-infected women. As a result of the clinic's comprehensive work through Part D, no cases of perinatal infection have occurred among clinic patients in more than a decade. In Atlanta, Georgia, programs such as the Grady Family Clinic and SisterLove are a part of the Atlanta Family Circle Network, a group of Part D-funded providers. They work together to provide primary and specialized care, substance abuse treatment and support, oral health care, mental health, and social services. Many children who were born infected with HIV have grown up in Part D programs and have benefited from intensive case management throughout their lives.

Prevention of Perinatal Transmission

In March 1987, the U.S. Food and Drug Administration (FDA) approved the first anti-retroviral drug to be used in the treatment of AIDS: AZT. Seven years later, in 1994, findings from the National Institutes of Health AIDS Clinical Trial Group (ACTG–076) demonstrated that with a particular regimen of AZT, the chance of perinatal HIV transmission plummeted. Preliminary findings showed that AZT was responsible for a 67.5 percent reduction in the transmission of the virus from mother to child. “Even though it was a clinical trial, the benefits were so significant that the study was halted in order to enable provision of AZT to more women in care,” Travieso-Palow says.

Jean Anderson, director of the John Hopkins HIV Women’s Health Program, remembers the impact of the ACTG–076 trial. “Before this intervention . . . between 25 and 45 percent of babies born to infected mothers would be born with HIV,” Anderson says. “We found that by using AZT as early as 14 weeks of pregnancy, we could cut transmissions by two-thirds and offer real hope to pregnant women with HIV.”

HRSA worked with partners throughout the Public Health Service to create guidelines for administering the AZT regimen for all Ryan White HIV/AIDS Program grantees as well as for providers in the many other HRSA programs. When the guidelines were issued, Philip R. Lee, assistant secretary for health and director of the Public Health Service, said, “In response to these important findings about the use of AZT in the

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**Darlene is healthy and able to play with her great-granddaughter thanks to the treatment and services she receives at the Madison Clinic at Seattle’s Harborview Medical Center, a Washington State-funded satellite clinic that receives Part A and C grantee funding.**

**HRSA in the News**

In 1995, HRSA awarded $23.3 million in grants to improve access to HIV comprehensive care and clinical research trials for children, youth, and women.

In 2000, the FDA implemented the Clinical Hold Rule as new drugs were being rushed to clinical trials. The new ruling allowed the FDA to suspend any clinical trial that excluded women because of their reproductive potential.
perinatal setting, these programs will also emphasize prevention and early intervention for women and their children, and the integration of HIV prevention and treatment into broader systems of primary care.20

The National HIV Pediatric Resource Center, a project of the University of Medicine and Dentistry of New Jersey that is supported through a HAB cooperative agreement, used the AZT study findings to provide technical assistance to clinics across the country.

HRSA added new standards of care for HIV-positive pregnant women to its expectations for grantees. In addition, training, technical assistance, and onsite support were made available to all organizations funded through the Federal Community and Migrant Health Centers Program.

HAB Produces a Guide to the Clinical Care of Women With HIV/AIDS

More than 20 years of the epidemic has shown conclusively that the clinical care needs of women differ, sometimes radically, from those of men:

- Women are more biologically susceptible to HIV infection (e.g., male-to-female transmission is 2 to 4 times more efficient than female-to-male transmission).21,22
- Women with HIV/AIDS may have more difficulty than men accessing treatment and health care.23
- Women are often diagnosed later in their disease than men. Even when they know their status, approximately 1 in 4 women postpone medical care as a result of barriers ranging from unstable home life, intimate partner violence, caregiving responsibilities, and depression, among others.24
- In order to reduce mother-to-child transmission, women in pregnancy need access to and monitoring of antiretroviral medications.
- HIV-positive women are at higher risk for abnormal pap smears, human papillomavirus (HPV)—an STD that causes cervical cancer—and reproductive tract problems.25,26

In 2001, HRSA’s HIV/AIDS Bureau released A Guide to the Clinical Care of Women With HIV/AIDS, a manual to help the medical community understand the health issues that women who were infected with HIV/AIDS faced and how to best care for them. Anderson, the guide’s editor, says, “Even if doctors saw a large number of AIDS patients, it didn’t mean that they understood the unique health issues of an HIV-infected woman.” Anderson adds that even providers who worked with women were often at a loss for how to treat this population. She says that over time they learned that women with HIV experience more gynecological issues than otherwise healthy women.

A Guide to the Clinical Care of Women With HIV/AIDS is being updated for re-release in late 2011. It is the first publication to offer clinicians specific guidelines for treating women with HIV/AIDS and remains the preeminent textbook on the topic the world over.

SPNS Women’s Initiative

To address the treatment, engagement, and retention needs of HIV-infected minority women, the Part F Special Projects of National Significance (SPNS) Program has funded the Enhancing Access to and Retention in Quality Care for Women of Color Initiative. Launched in 2010, this project funds 11 sites (five urban and six rural) to develop improved outreach and intervention strategies to better care for HIV-positive women of color.

Women of color account for one-third of the female population but approximately 84 percent of the estimated number of women living with AIDS.27 Many of the factors that render women of color especially vulnerable to HIV infection, such as higher rates of poverty and lack of health insurance, also serve as barriers to effective linkage to and retention in care. Moreover, lower retention and adherence rates for women of color translate to lower rates of response to treatment and survival.28

HIV/AIDS and Women: A Global Perspective

UNAIDS estimates that of the approximately 33.4 million people living with HIV/AIDS worldwide, one-half (16.7 million) are women.

In creating the first Guide to the Clinical Care of Women With HIV/AIDS, input was sought from the global community at the International AIDS Conference prior to its publication.

Though women of color represent only one-third of the female population, they account for 84 percent of the estimated AIDS cases among women in the U.S.37
Reflecting HRSA’s commitment to involving people living with HIV disease in program planning, many of the Quality Care for Women of Color Initiative sites are developing innovative community-based strategies, including training peers to serve as positive role models and encourage women to improve medication adherence and medical follow-up. Other interventions include community-based outreach, patient education, intensive case management, and patient navigation strategies to improve health outcomes.

The initiative will last 5 years, so grantees are still in the early stages of implementation. Outcomes will be published in 2014. Preliminary efforts have given grantees valuable insight into the unique barriers facing women of color in various communities as well as a greater understanding of potential strategies for overcoming these obstacles.

Albert Einstein College of Medicine in Bronx, New York, the evaluation and support center for this initiative, will provide technical assistance to the demonstration sites and assess the effectiveness of the selected models.

SPNS initiatives focus on high-needs populations and emerging trends to explore innovative and replicable models of care. While this is the first SPNS project to focus entirely on women, many HIV-positive women have benefited from SPNS services. One such example was under the Targeted HIV Outreach and Intervention Model Development and Evaluation for Underserved HIV-Positive Populations Not in Care initiative where the University of Miami School of Medicine targeted minority seropositive women and children.

AIDS, Women, and the Ryan White HIV/AIDS Program Today

Approximately 33 percent of Ryan White HIV/AIDS Program clients are women, most of whom are women of color. The Program has so much more to offer women today than it did when it was first enacted into law some 20 years ago. We have moved from a time in the epidemic when treatments were limited and short lasting to one in which treatments offer women the potential for long-term health and a productive life.

The main thrust of today’s Ryan White HIV/AIDS Program is clinical care, primarily to ensure that women reap the benefits of combination antiretroviral therapy. Today, this is the standard for all HIV patients including pregnant women who were previously on a regimen of AZT alone. Antiretroviral therapy use has reduced perinatal transmissions to as low as 1 to 2 percent or less. These medications have also significantly reduced mortality rates. Because of the Ryan White HIV/AIDS Program, these so-called miracle drugs are accessible to women who have neither private health insurance nor the financial resources to pay for the medications on their own.

From the beginning, Ryan White HIV/AIDS Program grantees have reached out to women who know their status but are not receiving care. They work with key entry points, such as testing facilities, hospitals, family planning clinics, community health centers, and providers of social services. These investments are paying off: More HIV-positive women are entering and staying in care and fewer children are born with HIV/AIDS.
In fact, in many Ryan White-funded clinics perinatal transmission rates are now zero. In instances of infection, most occur among HIV-positive women unaware of their status thus Ryan White providers continue to work with community partners to encourage testing and enrollment in necessary health services.

Of course women are being served in a challenging environment for both them and their service providers. We live in a time of few new financial resources for grantees and a time of economic hardship for many women most at risk for HIV/AIDS. Comorbidities such as mental illness and addiction continue to threaten the health and quality of life for HIV-positive women.

Ryan White–funded clinics across program Parts are continuing to offer “one-stop shopping” where possible to fully address these patient medical, psychosocial, and support services needs. They are also building ever-stronger relationships with organizations that meet the needs of HIV-positive women. A number of Ryan White-funded clinics are securing other funding sources to increase research on prevention methods pertinent to women as well.

**Aging: The New Face of HIV?**

Although the CDC says that young women ages 15 to 39 are the largest age demographic of women living with HIV/AIDS in this country, a trend of women being diagnosed in their 40s and 50s is emerging. The CDC also estimates that 11 percent of people living with HIV/AIDS are age 50 or older, and the new cases among people in that category are growing twice as fast as the new diagnoses in the 13 to 49 age group.30

Women over age 50 continue to be misdiagnosed or never diagnosed at all. Statistics are showing that many midlife women are being diagnosed later and are often coming into medical care with AIDS.31,32

New infections among this population are driven in part by social and biological factors. For example:

- Older women are less likely to have accurate information on HIV transmission, less likely to see themselves as at risk, and less likely to undergo HIV testing than younger women.30,34,35
- Many people age 50 or older are newly single, are widowed, or have grown children, leaving more time for sexual activity.
- New treatments for erectile dysfunction facilitate sex.
- Older people may be unfamiliar with condom use or reluctant to use them because there is no need for birth control after menopause and condoms can make it difficult to maintain an erection.
- Vaginal dryness is common among menopausal women, making tiny cuts and tears during sex more likely.

When older people do not have accurate information about HIV transmission, the risks associated with those factors are intensified. To shine attention on this increasing trend, HRSA published an issue of HRSA CAREAction titled “The Graying of HIV.”

**Looking Forward**

A diagnosis of HIV/AIDS was almost always a death sentence in the early years but support systems and access to care are helping newly diagnosed women reframe their lives. “Health, Hardship and Renewal: A Research Study of the Economic Strategies of Women Living With HIV/AIDS,” a recent study of low-income women who are living with HIV/AIDS in Chicago, shows that as physically devastating as an HIV/AIDS diagnosis may be, many women have gone on to improve the quality of their lives. The researchers say that the diagnosis often makes women take
stock of their lives and becomes a turning point that gets women into medical care. The Ryan White HIV/AIDS Program can help link women to services and support systems so that they can create a positive new chapter for them and their families.

Today with access to antiretroviral therapies there have been significant reductions in morbidity and mortality enabling women to live more productive lives and have a potentially normal life span. One woman who has been a long-time client of the Ryan White HIV/AIDS Program has been able to stabilize her health enough to get a college degree and a good job with health insurance to support herself and her children. She says, “Once I figured that this disease wasn’t going to kill me, I decided that it wasn’t going to define me either. Thanks to the help I have gotten since my diagnosis, I am writing my own life script. HIV isn’t writing it for me.”

Credits and Sources

Sources


Online Resources

- HRSA Maternal and Child Health Bureau
- AIDS Education and Training Centers National Resource Center
- Ryan White HIV/AIDS Program Part D
- HRSA CARE Action Newsletters
- A Guide to the Clinical Care of Women
- SPNS Women of Color Initiative
- Connecting to Care: Addressing Unmet Need in HIV
- Medical Care of HIV-Infected Substance-Using Women
- Medical Care for Menopausal and Older Women with HIV Infection
- Recommendations for Use of Antiretroviral Drugs in Pregnant HIV-1 Infected Women for Maternal Health and Interventions to Reduce Perinatal HIV Transmission in the United States
- How to Get Involved in HIV Research
- CDC’s HIV/AIDS Among Women Fact Sheet
- Women and HIV Resource Center
- The Feminization of an Epidemic
- Young Women of Color Initiative
- Timeline of Women and HIV


Photography
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