2- women + AIDS

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Battling **AIDS** in Africa by Empowering Women

BYLINE: By CLAUDIA DREIFUS

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BODY:

Lounging in a high-floor room at the St. Francis Hotel, drinking coffee served in perfect porcelain cups, Dr. Nancy Padian was far from the sad, overcrowded streets of Harare, Zimbabwe, but they and their beleaguered people remained on her mind.

Dr. Padian, 48, an epidemiologist who is director of research for the **AIDS** Research Institute of the University of California at San Francisco, is one the world's foremost experts on the heterosexual transmission of **AIDS.**

For the past seven years, she has commuted between San Francisco and Harare -- some 10,000 miles -- to help Zimbabwean health workers gain some measure of control over the **AIDS** epidemic tearing through their nation in southern Africa. Their chief weapon against H.I.V. has been the barrier method of contraception, using devices like condoms.

"There's this zeal to find this new magic bullet," Dr. Padian said. "But there are all these existing methods with great potential and they are right under our noses and that haven't really been looked at. I'm hoping that what we do in Harare will help the women there and, frankly, here too."

Q.: You've racked up thousands of frequent flier miles between San Francisco and Zimbabwe. What exactly do you do there?
A.: I run a series of studies as part of a joint project between the University of Zimbabwe and the University of California, San Francisco. We examine the effect of contraception in preventing H.I.V. in Zimbabwean women. In Africa, **AIDS** is mainly heterosexually transmitted. So what we are looking at in a country where 25 to 30 percent of the population is infected with H.I.V. is whether different forms of contraception might increase or decrease the acquisition of H.I.V.

We see a population of women who come to regular family planning clinics in Harare. About 30 to 40 percent are infected. The rate is much higher, of course, for women in the sex industry. In the one study, we try to help uninfected women to get their male partners to use condoms. We've been able to persuade people to use condoms far more than we originally thought we could. In fact, we've been able to get more than half the women in this category to do this.

For those women who aren't successful at that, we try to encourage them to use female methods of contraception: female condoms, spermicides, diaphragms. We are also looking at whether or not women who are using hormonal contraceptives are at increased or decreased risk of H.I.V. This study has just begun, so we don't have any answers yet.
Q.: The assumption has been that women in Africa and elsewhere cannot convince men to use condoms. What are you doing differently?
A.: Some women can't. But for others, it's a question of teaching them negotiating strategies. We do role-playing. We present the women with obstacles and have them work out ways to overcome them. We encourage them to think it's O.K. to talk about sexual activity with their partners, that these discussions are part of a healthy lifestyle.
Q.: What makes women in southern Africa so much more vulnerable to **AIDS** than American women?
A.: There is a higher prevalence of other sexually transmitted diseases there -- as well as a lack of male circumcision, which turns out to be a factor in the susceptibility of the man to **AIDS.** And you know, the rates of infection from parasites, poor nutrition, all contribute to the problem. In general, if a woman's immune system is compromised because of other infections and nutritional factors, that too increases susceptibility to H.I.V. once she's exposed.

There are some particular cultural factors, too. It is not uncommon also for African men to have multiple partners and still have their monogamous partner. The practice of "dry sex," which occurs in certain countries in southern Africa, almost certainly increases the susceptibility of women to H.I.V., if their partner is infected. Dry sex is when a woman uses a chemical or physical substance that she puts into herself to dry up the cervical and vaginal secretions in advance of having sex. Women sometimes engage in this practice because there's a belief that men prefer it.
Q.: The Colombian writer Silvana Paternostro claimed that the biggest **AIDS** risk factor for a woman in many Latin American countries was to be married. Is that true in southern Africa, too?
A.: I think that's true in Zimbabwe, where the infection rate is from 25 to 30 percent, and where the likelihood that a husband is infected is quite high. It's not a question of the woman having multiple partners. Unless they are sex workers, the women are generally monogamous.
Q.: To what extent do you think the power imbalance between African men and women contributes to the spread of **AIDS?**
A.: I think the gender imbalance is huge there and accounts for some of the transmission. One of the things I see as helping in preventing **AIDS,** are microloan programs for women's economic development. These are small loans to women to help them start businesses of their own. In order for women to really negotiate sexual activity, it's important for them to be economically empowered.
Q.: The president of South Africa, Thabo Mbeki, has issued some rather ambiguous statements on **AIDS.** He has raised doubts about whether H.I.V. causes **AIDS,** declared a need for an African solution to the epidemic and suggested that researchers should look at poverty as a root cause. Considering that the South African **AIDS** rate has increased 50 percent since his election, what do you believe he's thinking?
A.: I don't understand why he said it. I wondered whether he was confusing two issues. I completely agree that we need indigenous solutions to indigenous problems. You definitely can't export American models of behavior changes and expect to implement them in southern Africa. But to suggest that H.I.V. doesn't cause **AIDS** when all the evidence points to the contrary verges on being irresponsible. It delegitimizes prevention programs. Most prevention programs, after all, are geared at preventing someone from being exposed to H.I.V. And if H.I.V. is not the issue, then what are we doing?
Q.: Is President Robert Mugabe of Zimbabwe in similar denial?
A.: Denial may be too strong a word here. Mugabe has certainly not dealt strongly with the epidemic. He's not strongly supporting the national **AIDS** control program in promoting condoms. Whether that's denial or avoidance, it's a shame. Because your best chance of success is if you can engage the local leaders. If the government isn't behind it, it's much more difficult to have widespread effective programs throughout the

country.
Q.: How do you deal, emotionally, with the high death rate you are witnessing in Harare?
A.: I find it unbelievable, overwhelming. Among my colleagues at the university, someone I am working with is always off to a funeral. It's unbelievable. But I feel like I'm doing something. And that keeps me going. What makes me angry is when people say that it's all sealed and that it's too late and that you can't do anything more. Because I feel like even if I do a little bit, it will make a difference.
Q.: How did the epidemiology of H.I.V. in women become your specialty?
A.: I was in graduate school here at Berkeley in the early 1980's. I had originally wanted to be a psychologist, but fell in love with epidemiology because it seemed to be a good way to help a lot of people -- rather than one person at a time.

My graduate adviser, Warren Winkelstein, had a grant to look at the natural history of **AIDS.** H.I.V. hadn't been discovered as the cause yet. So at that point, no graduate student was interested in working on this. I got the job as his assistant because there were no other takers. He suggested that I look into the female partners of bisexual infected men in the group he was studying. That's when I started getting involved in the heterosexual transmission of **AIDS.**

Of course, what we found was, at that time, that male-to-female sexual transmission was a lot more frequent than female to male, that risk factors for transmission were primarily not using condoms, anal intercourse and S.T.D.'s in either partner.
Q.: You are about to go to India to start an **AIDS** study there. How bad is the problem on the subcontinent?

A.: The infection rate isn't that high, but the absolute numbers of people who are infected is huge. Huge! Given the numbers, one can only guess that the epidemic exists at an early stage. And, of course, all of the gender issues that we talked about in Zimbabwe are acute there as well. The women have little say. What I'm discovering as I travel the world, is that for women, power is an absolute dimension of physical health. The bottom line, universally is, If you cannot negotiate what you are doing with your body, you will not be able to lead a healthy and long life.

http://www.nytimes.com

GRAPHIC: Photo: Dr. Nancy Padian, an epidemiologist, has been evaluating contraceptives and helping health workers in Zimbabwe fight the **AIDS** epidemic. (Peter DaSilva for The New York Times)

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HIV/AIDS AND WOMEN

SITE MAP

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INTRODUCTION

Before you begin, take one moment to visualize a woman who has been affected by HIV/AIDS.

What type of woman do you see? It is absolutely imperative to realize that HIV/AIDS does not discriminate. It affects women of all ages, races, and types. No one can hide, and no one category of women is exempt. HIV/AIDS has affected mothers, daughters, sisters, friends, and partners.

Women infected with or at risk of contracting HIV are everywhere—in every region and country of the world. These women are rich and poor, young and old. They are our mothers, daughters, friends, partners, and sisters. The terrifying ripples created by this disease extend far beyond the lives of the women who have been infected. When women are hurt, so are their children, their families, and their communities.

There are nearly 14 million women worldwide already infected with HIV, the virus that causes AIDS. And the picture is still growing. Thousands of women are infected with HIV every day; some will be infected or will discover that they are infected as you read this. Women with HIV/AIDS face complex and multifaceted issues in their unique roles as caretakers and leaders that unite them. This brief outline is intended to provide a better understanding of why the devastating impact of HIV/AIDS on women is an issue for us all. Ideally, you will continue your investigation of HIV/AIDS and women by following the links provided and reading further from the resources cited.

Living and working together, WE CAN TRULY MAKE A DIFFERENCE. We can save lives. We can stop AIDS both here in the United States and internationally, and care for those already infected. We can affect massive change in the way we see and interact with each other.

AN OVERVIEW OF HIV/AIDS

There has been no worse plague in the modern era.

30.6 million people are living with HIV/AIDS worldwide, and hundreds of thousands have been taken too soon.

90% of individuals with HIV/AIDS live in developing countries.[1] 80% of the world's women with HIV live in Africa, and in a number of Sub-Saharan African countries upwards of 20% of pregnant women are infected.[2]

Individuals with access to the latest medication are living with HIV longer than ever before. But for those being left to die without treatment, and even for those with access to treatment, this pandemic rages on with no end in sight.

You should be alarmed.

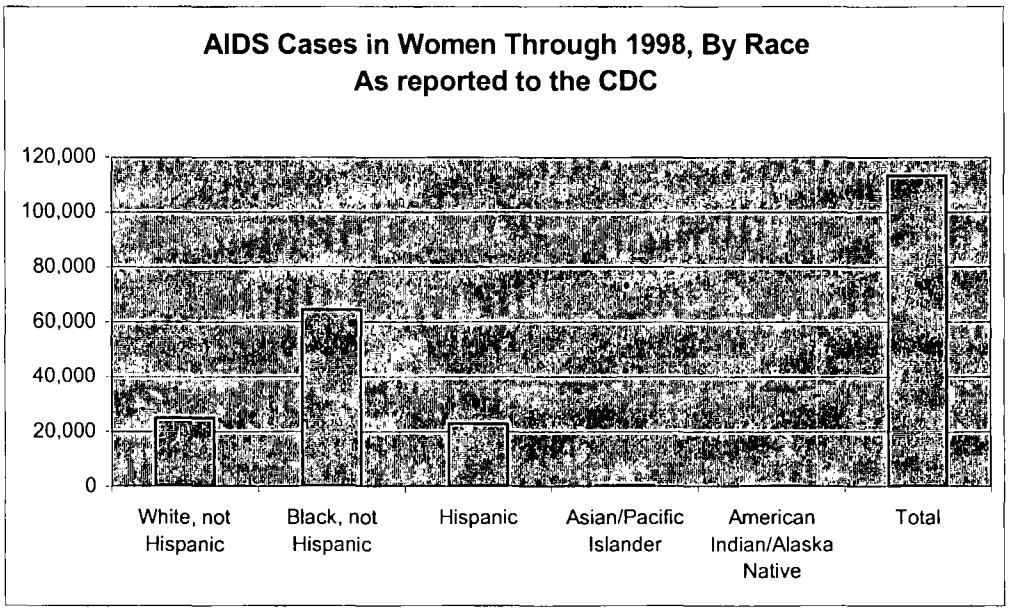
The Centers for Disease Control and Prevention (CDC) estimate that there are between 120,000 and 160,000 women living with HIV in the United States. However, these figures are low. The CDC is our best source of surveillance, but they only collect data from 33 states and territories. And there is no real way to gauge how many are dying without revealing what is killing them. More than half of the estimated 120,000 to 160,000 women living with HIV/AIDS are thought to be unaware of their own HIV-status or the status of their infected partner.[3]

Women who do not know their status are not getting the care they need and are spreading this pandemic (right along with infected men who do not know or do not inform their partners of their status). Many of these women will not be tested for HIV until they suffer from their first AIDS-related illness or until they are pregnant and seek prenatal care.[4]

Between 1994 and 1997, women accounted for 17% of AIDS diagnoses but 28% of HIV diagnoses, which means that the number of women with AIDS in the future will continue to grow. In the United States women are the fastest growing segment of the population at risk for HIV infection.[5]

In 1998 alone, there were 5,967 new HIV cases and 10,998 new AIDS cases reported for women in the United States. Although far from the 12,698 new HIV cases and 36,886 new AIDS cases for men, it is still a record high.[6]

In the United States, young women, low-income women, African-American women, and Latina women are particularly at risk for infection. While African-American women and Latina women comprise 25% of women in the United States, they make up 75% of all U.S. AIDS cases.



THE PUBLIC PERCEPTION OF HIV/AIDS

"For twenty years this nation has treated persons with AIDS as uniquely responsible for their own condition. Despite what we know about smoking and cancer, we have not done to smokers what we have done to persons with AIDS...

So deep has the stigma been, so controversial the epidemic, that more than a hundred thousand Americans had died of the disease before an American President dared to say the word "AIDS" in public."

Excerpt from "If Not Now..."
Address by Mary Fisher
Congressional AIDS Drug Assistance Forum
Washington D.C.
Thursday, April 17, 1997

There is little mystery left as to how HIV/AIDS is transmitted. We understand how this disease moves from one person to another. Women can contract HIV/AIDS through unprotected intercourse with an infected partner—heterosexual and same-sex intercourse, and oral sex, through injection drug use (sharing needles with an infected individual), and through mother to child transmission (through pregnancy, labor, and breast milk).

We know how to stop this disease but still the infection rate and death toll grow.

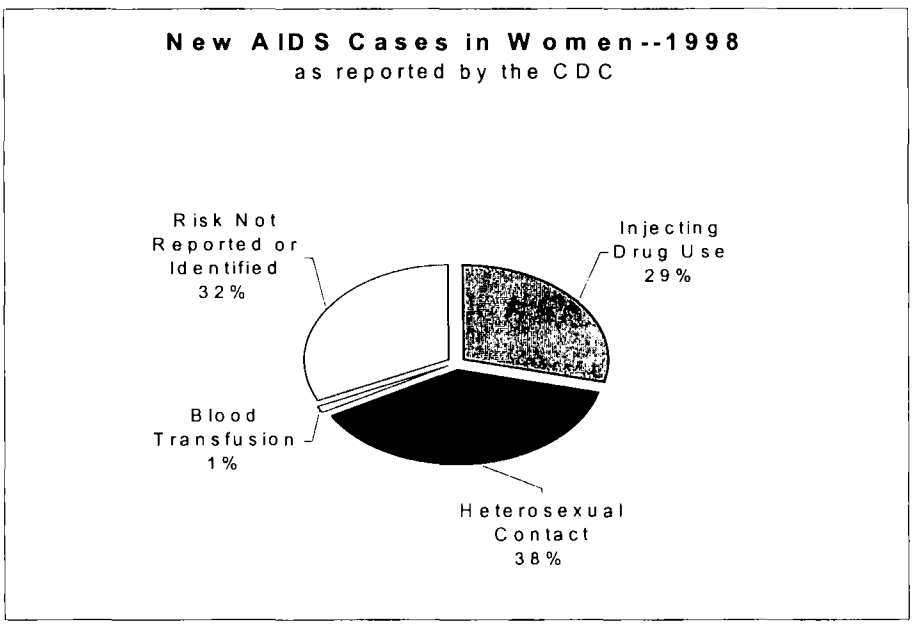
There is a stigma attached to HIV/AIDS. Individuals see themselves as immune to HIV/AIDS and so they do not get tested even though they may be engaging in high-risk behavior.

Individuals refusing to get tested, or ignoring their status, and continuing to practice high-risk behaviors then pass on the virus. It is a vicious cycle, and HIV/AIDS is growing exponentially before our eyes.

HOW HIV/AIDS IS TRANSMITTED

As stated before, women can contract *HIV/AIDS through unprotected intercourse with an infected partner—heterosexual and same-sex intercourse, and oral sex, through injection drug use* (sharing needles with an infected individual), *and through mother to child transmission* (through pregnancy, labor, and breast milk).

The percentage and number of women becoming infected through both heterosexual contact and injection drug use is increasing. Among adult and adolescent (over 13 years old) women in the United States reported with AIDS in 1998, 38% were infected through unprotected heterosexual contact with infected partners and 29% were infected through injection drug use. Cumulative totals of women infected with AIDS in the United States through 1998 show that 43% became infected through injection drug use and 38% through heterosexual contact.



But of course these statistics can only tell part of the story. Many women are unaware of their HIV/AIDS status and are therefore not reflected in these numbers.

Women are at a high risk of infection. HIV/AIDS is transmitted more often from a man to a woman than from a woman to a man. There are more men with AIDS than women, so women who have sex with men are thus more likely to have an infected partner. In addition, there is more exposed surface area in female genitalia than in male genitalia, leaving more room for transmission.[7] Also, individuals with sexually transmitted diseases (STDs) other than HIV are

more likely to become infected with HIV, as open sores and other symptoms of STDs facilitate transmission.

One of the most devastating aspects of this virus is that it can be passed from mother to child. Approximately 14,920 HIV infected infants were born in the United States from 1978 through 1993. The risk of transmission from an untreated infected mother to her unborn child is about 25%. However, the risk can be decreased to 8% if women take AZT during their pregnancy and labor and give their child AZT for the first 6 months after birth.

New research indicates that the risk may be reduced to 1-3% if a woman gives birth by Cesarean section, is treated with AZT, and does not breastfeed her newborn. In countries like those in Sub-Saharan Africa where 20% of all pregnant women are infected, there is not widespread access to the medications that can markedly decrease the risk of transmission. The same is true for women from low- and often even middle- income families in the United States. Remarkably few women have access to the medication that we know decreases the risk of mother to child transmission. In addition, women in many developing countries are faced with a lack of information about HIV transmission through breastfeeding. Because of such mixed messages regarding breast milk vs. formula effectiveness these women are often hesitant to stop breast-feeding even when equipped with knowledge of the risk involved.

The pandemic even strikes children not infected with HIV and AIDS. In the US alone there are approximately 30,000 children who have lost their parents to AIDS. By the year 2000, it is estimated that there will be 80,000 AIDS orphans in the US.[8] On an international level, there are more than 8 million children who have lost their mother to AIDS, with one third of all AIDS orphans worldwide are under the age of five.[9] There are expected to be 40 million children orphaned by AIDS by the year 2010, just 10 years from now.

There are myriad reasons why women are still becoming infected with HIV/AIDS in spite of the information out there. Women may not have access to the information. Women may ignore the information either because of an immortal-mentality or because they think it not applicable to them—that it is a gay man's disease. Women may be culturally or personally subordinate to their partners, and thus not able to negotiate safe sex.

PREVENTION

Preventing transmission of HIV does not end with using a condom or dental dam (a piece of latex used to prevent fluid transmission during oral sex). Barrier methods are not 100% effective and prevention efforts need to have a broader scope.

Factors critical to successful prevention include reaching young women with education, self-confidence, and a means of protecting themselves before they initiate sexual activity. Effective education strategies must address the fact that condom use should be a mutual decision. Also, women need access to protection they can control themselves. Because of cultural and personal power dynamics at work in a relationship, women are often at a disadvantage in negotiating

condom use. Developing female-controlled barrier methods such as microbicides, a bacteria and virus fighting topical agent, to prevent HIV transmission is an integral aspect of prevention. These need to be safe, affordable, and available on a confidential basis.

With the guidance of the President's Advisory Council on HIV/AIDS, the Clinton administration initiated a four-year, $100 million plan to develop such a product, for which research is still in progress.

Unimpeded access to health care, prevention and treatment of other STDs, and substance and drug abuse treatment are all components of a comprehensive, effective prevention plan.

Prevention efforts need to target young women of color in particular. African-American and Latina women are at a higher risk for infection and outreach efforts cannot be effective without taking their specific needs into account.

TREATMENT

"We do not blame you for our virus; we blame no one, even those who infected us. Millions of women with AIDS contracted the virus the way we'd hoped to conceive children, in loving relationships. But it's hard not to grow angry at the slow pace of research, especially for women. How is it possible this late in the epidemic to have so few women in trials that we don't yet know what works and what doesn't? How is it possible, so late, that we can not distinguish which symptoms are PMS and which are HIV-which belong to the virus, which to our hormones and which to your drugs?"

Excerpt from "Letter to a Young Physician"
Open Letter by Mary Fisher
Read at Wayne State University Medical School
Thursday, June 5, 1997

Treatment for women must be catered to women. It must account for their physical differences from men. Most AIDS treatment research has not taken into account the special needs of women. For instance, concern is often voiced that the medical community does not know whether specific anti-viral drugs work as well in women as in men. Overall, women have higher viral load counts when they begin treatment, and later are less likely to take a protease inhibitor, less likely to take an antiretroviral medication, less likely to be on a three-drug combination, and less likely to see a doctor regularly.

Supportive services for women with HIV are an integral component of a comprehensive and effective health care system. Women at the highest risk for HIV infection may face a multitude of other problems, including poverty, substance abuse, alcoholism, violence, unemployment, and unplanned pregnancies, and language barriers.[10] For many infected women, HIV/AIDS can not be their first priority; taking care of their very basic needs and their family's needs must take precedence. Women with children, for example, may neglect their own health care needs in order to support their children. Food & Friends is a Washington, D.C. based non-profit organization providing nutritious food to individuals living with AIDS that discovered just this.

They found that when they delivered food to women and not to their children, the children were the ones who were fed. In order for to get women the nutrition they need Food & Friends realized they needed to provide food not only for the women, but for the children and families of their clients.

HIV/AIDS is devastating enough alone, but when taken in combination with variables like hunger, homelessness, and domestic violence it is compounded immeasurably. Adequate childcare, transportation, and "one-stop shopping" service delivery models are essential to provide and maintain care for women.

WOMEN AND HIV/AIDS IN THE WORLD

Women with HIV/AIDS face a myriad of different challenges above and beyond their shared illness. While in this country, for example, some women may obtain state-of-the-art medications, a large percentage of infected women are unable to afford even the most basic care.

And their children will fair no better. By the year 2010, only 10 years from now, over **40 million** children will be orphaned by AIDS. In March of 1999, Sandra Thurman, director of the Office of National AIDS Policy, led a fact-finding mission to Uganda, Zambia, Zimbabwe, and South Africa to gauge the devastating effects of HIV/AIDS where children are hardest hit. In June,1999 she released recommendations to the President calling for increased support in that region [see Africa report].

In January of 2000 Sandra Thurman once again directed a trip, this time focusing on Uganda, Rawanda, Tanzania and Kenya. The purpose of this mission was to work with host countries and non-governmental organizations to develop implementation strategies for the newest LIFE initiative, which will provide an additional $100 million into the USG's global AIDS program. The funding will be used to provide basic health care and treatment, support for children orphaned by AIDS, and will work towards the development of an infrastructure so these goals can be realized.

Like nothing before, this terrible pandemic has shed light on issues of persistent gender, race, ethnic, sexual, and class inequity. In many ways, HIV/AIDS presents us the opportunity to learn to live together, to confront and overcome injustice.

WOMEN WHO KNOW SPEAK OUT

The following quotes are selected excerpts from a book titled, A Positive Life; Portraits of Women Living with HIV[11]. The book is excellent and presents a new angle on HIV/AIDS that is worth experiencing.

Lery Expinosa- 27, diagnosed HIV-positive in 1994, infected through sex

"Physically, I feel fine. Emotionally it's a burden that I have to carry every day. I got tested because I knew that I had been at risk. I just need to make sure that I was okay. I didn't really

think that I would actually test positive...Two weeks later they called from the doctor's office. I really didn't pay that much attention because I was sure that it was negative. When I realized it was the doctor that kept calling me, I went in right away (2)."

Lucy Rivera- 43, HIV-positive since 1985, infected through IV drugs

"When I go to the hospital and I see these people hooked up to all these tubes, I know I don't want to go through that kind of prolonged pain. I ask God, please let me go in my sleep. I'm really scared. I don't want to go through anymore pain. I don't want my family to have to suffer emotional pain.
I'm only 43. I'm not ready to die. I want to see sixty-at least sixty (9)."

Bunny-44, HIV-positive since December 18, 1990, infected through unprotected sex

"The hardest part was to tell my three children. I waited till after the holidays. I told Marquita, who is my oldest daughter. She cried and was very upset. Later that evening I told my other daughter. I wasn't able to tell my sun till three years later. He was the more emotional of my children...When I finally did tell him, he already knew something wasn't right. He was worried about who would take care of him if I died. I explained that his sisters would take care of him. They all thought I would be dead in a year (20)."

CONCLUSION

A chief impediment to ending HIV/AIDS is our continued societal "othering" of individuals unlike us. It is easy for some to ignore a disease they think will only affect *them, those other people*, whether *them* is the gay community or the people of Uganda. Through a look at the statistics from the CDC there is strong evidence to support the idea that all us will at some time be touched by this pandemic. Do your part and educate yourself about HIV/AIDS. Teach your friends. Make safe practices your only practices. Don't let this pandemic spread any further. Advocate on behalf of all of those individuals already infected with or affected by HIV/AIDS for better access to care, treatment, and research. Call and write your congressional representatives at the state and federal level (202-224-3121) and encourage them to increase funding for HIV/AIDS initiatives and service. Agencies like HUD (Housing and Urban Development, http://www.hud.gov/), HHS (Department of Health and Human Services, http://www.os.dhhs.gov/), and the CDC (Centers for Disease Control, http://www.cdc.gov) are working to lessen the devastation of HIV/AIDS. Contact them for more information, and discover your own role in this battle. Together we can truly make a difference.

Links

There is much work to be done on the issue of women and AIDS, and much good work that has been done, or is in process. Please take a look at some of these resources to further your understanding of the crisis.

Healthfinder

A service of the Department of Health and Human Services
http://www.healthfinder.gov/

The National Institutes of Health
http://www.nih.gov/

The National Library of Medicine
http://www.nlm.nih.gov/
http://www.hrsa.dhhs.gov/hab

Harvard AIDS Institute
In particular see the spring, 1999 issue of the Harvard AIDS Review, which focuses on Women and AIDS.
http://www.hsph.harvard.edu/Organizations/hai/home.html

Centers for Disease Control:
http://www.cdc.gov

HIV/AIDS Surveillance Reports:
http://www.cdc.gov/nchstp/hiv_aids/stats/hasrlink.htm

Joint United Nations Programme on HIV/AIDS (UNAIDS):
http://www.unaids.org

Sources

Gwinn M, Wortley P. Epidemiology of HIV Infection on Women and Newborns. *Clinical Obstetrics and Gynecology* 1996; 39, 2:292-304.

MMWR (*Morbidity and Mortality Weekly*)
Administration of Zidovudine During Late Pregnancy and Delivery to Prevent Perinatal HIV Transmission-Thailand, 1996-1998. March 6, 1998; 47, 8:151-153.

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[1] UNAIDS and WHO. *Report on the Global HIV/AIDS Epidemic.* December 1997.
[2] Harvard AIDS Institute. Harvard AIDS Review, Spring 1999. "Women and AIDS"
[3] HRSA Care*ACTION*, December 1998.
[4] HRSA Care*ACTION*, December 1998.
[5] CDC, January 1998
[6] CDC HIV/AIDS Surveillance Report, December 1998. Centers for Disease Control and Prevention. HIV/AIDS Surveillance Report, year-end edition 1998. Atlanta, Georgia: US Department of Health and Human Services, CDC, 1998. (Vol.10, no.2). The HIV/AIDS Surveillance Report can be accessed at http://www.cdc.gov/nchstp/hiv_aids/stats/hasrlink.htm.
[7] ibid.
[8] Elizabeth Glaser Pediatric AIDS Foundation, 1998. For more information on pediatric AIDS, contact the Pediatric AIDS Foundation at http://www.pedaids.org.

[9]UNAIDS Global HIV/ AIDS and STD Surveillance, 1998. For more information on the international AIDS epidemic, contact UNAIDS at www.unaids.org.

[10] Wortley, Fleming. AIDS in Women in the United States. *Journal of the American Medical Association* 1997; 278:911-916.

[11] A Positive Life;Portraits of Women Living with HIV. Huston, River. Running Press: Pennsylvania; 1997.

FORWARD

Joseph F O'Neill, MD, MPH

Dear Colleagues:

The Ryan White CARE Act program of the Health Resources and Services Administration is pleased to make this *Guide* available to clinicians caring for women living with HIV/AIDS. We believe it is the first comprehensive clinical manual on this topic, and the need for such a guide has never been greater. The World Health Organization estimates that the number of people living with HIV/AIDS is rapidly approaching 50 million, and that women constitute 45%–50% of the total. Already, in several regions of the world, more than half of the people living with HIV/AIDS are women. But these statistics tell only part of the story. In addition to facing unique clinical issues, women living with HIV/AIDS are often challenged by social isolation, poverty, discrimination, and lack of access to quality health care.

Please note that this *Guide* for the care of women has been written almost entirely by women. This is testimony to the enormous contribution that women have made in the battle against HIV/AIDS on every front and in every community across the globe. However, no medical guide can stand alone in assuring that women will receive the best treatment available. In addition to furthering our clinical knowledge, we must commit ourselves to addressing the myriad social and economic issues that hamper effective prevention and access to care for seropositive women.

Regard this preliminary edition as "our" *Guide*. It belongs to the global community of clinicians who struggle daily with HIV/AIDS, caring for people with competence, compassion and equality. Your comments, criticisms and suggestions are needed to shape this manual into a clinical tool that will be of maximum utility to all of us. Throughout the *Guide* you will find requests for your input. Please respond by post, fax, or e-mail. And, if you can, suggest partners who can help have this *Guide* translated into the many languages of "our" community.

We all owe a debt of gratitude to John G. Bartlett, M.D. His guide, *1999 Medical Management of HIV Infection* was the inspiration and template for this volume. He graciously allowed us to adapt many of the charts and algorithms for this book.

Finally, I want offer my personal thanks to the editor, Jean Anderson, M.D., for her tireless dedication and perseverance in creating this *Guide*. Her efforts have made a profound change possible. This *Guide*, I believe, will mark a turning point in significantly improving the care of women living with HIV/AIDS.

Cordially,

Joseph F. O'Neill, MD, MPH
Director, HIV/AIDS Bureau
Health Resources and Services Administration,
U.S. Department of Health and Human Services

Send Us Your Comments

E-mail: womencare@hrsa.gov

Fax to the attention of "Womencare": 301-443-0791 (USA)

Postal address: Womencare
Parklawn Building, Room 11A-33
5600 Fishers Lane
Rockville, Maryland 20857
USA

Note that this and subsequent editions of *A Guide to the Clinical Care of Women with HIV* will be available online.

Go to the HIV/AIDS Bureau Web site and click on the publication *Women's Guide*:
http://www.hrsa.gov/hab

Introd

Jean And

Despite the dramatic advances made in
HIV disease and the development of e
AIDS epidemic continues to grow. Anc
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poor, the disenfranchised, and the your
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The growing number of women livi
ture of the evolving epidemic. In additi
later and generally have poorer access t
have higher viral loads and lower CD4
also must contend with vulnerability rel
tic violence. Finally, women living with
meet the care needs of children and oth
are also HIV-positive.

For these, and other reasons, a manu
unique to women with HIV infection is
an attempt to fill this gap. Our target au
primary care to women. This *Guide* mig
seeking a more in-depth understanding
HIV/AIDS.

The book you have in your hands is
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n's Guide:

Introduction

Jean Anderson, MD

Despite the dramatic advances made in understanding the natural history of HIV disease and the development of effective antiretroviral therapies, the AIDS epidemic continues to grow. And that growth has displayed some disturbing trends. HIV/AIDS morbidity and mortality increasingly impact the poor, the disenfranchised, and the young. Women are traditionally over-represented in these groups.

The growing number of women living with HIV/AIDS is a dominant feature of the evolving epidemic. In addition, because they are often diagnosed later and generally have poorer access to care and medications, women tend to have higher viral loads and lower CD4 counts. Women living with HIV/AIDS also must contend with vulnerability related to reproductive issues and domestic violence. Finally, women living with HIV/AIDS are usually relied upon to meet the care needs of children and other family members, many of whom are also HIV-positive.

For these, and other reasons, a manual addressing the primary care needs unique to women with HIV infection is long overdue. This manual represents an attempt to fill this gap. Our target audiences are clinicians who provide primary care to women. This *Guide* might also be of interest to individuals seeking a more in-depth understanding of how to care for women with HIV/AIDS.

The book you have in your hands is a preliminary edition, a work in progress, and we welcome your comments and suggestions. Please send any feedback to the postal, fax, or e-mail addresses found throughout the book and on the inside covers. We are particularly eager for this *Guide* to be translated into other languages. Please let us know if you can help or suggest partners.

This preliminary edition is focused primarily on the problems facing HIV-infected women in the developed nations, primarily the U.S. Our goal is that in future editions of this *Guide* we can take a more global perspective and address the care of women with HIV/AIDS in both developed and developing nations.

I want to offer my personal thanks to Helen Schietinger and Magda Barini-García for their championing this *Guide* throughout its development, displaying enormous tact, tenacity, and attention to detail. Without them, this manual would never have been published.

Finally, we want to acknowledge the women with HIV/AIDS who have been the inspiration for this manual. Their strength is celebrated and their struggle is not forgotten. We offer this *Guide* as a tribute to them, and to the providers who have taken on this struggle and made it their own.

Jean Anderson, MD
Editor

I. Epidemiolog
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Ruth M. Greenblat

I. INTRODUCTION

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I. Epidemiology and Natural History of HIV Infection in Women

Ruth M. Greenblatt, MD and Nancy A. Hessol, MSPH

I. INTRODUCTION

The successful introduction and spread of the human immunodeficiency virus (HIV) into the global human population has occurred for many reasons. The discovery and wide spread use of penicillin and other antibiotics meant that there was treatment and cure for most sexually transmitted diseases. The existence of these new drugs changed how people perceived risks associated with sexual activity. Soldiers in World War II increasingly used prophylactics and the subsequent development of hormonal contraceptives hastened the pace of change in sexual practices, as prevention of pregnancy became a real possibility. Lifestyles also were changing: people were moving into regions that were previously uninhabited by man and long distance travel became easier and was much more common, allowing for more social migration and sexual mixing. Although the virus may have first been introduced to humans earlier in the 20th century (most likely contracted from infected animals), it was in the 1970's that wider dissemination occurred.

For industrialized countries, the first evidence of the AIDS epidemic was among groups of individuals who shared a common exposure risk. In the United States, sexually active homosexual men were among the first to present with manifestations of HIV disease, followed by recipients of blood or blood products, then injection drug users, and ultimately children of mothers at risk. Women have represented an increasing proportion of reported AIDS cases in the United States, accounting for 23% of adult cases from July 1998–June 1999. (CDC, 1999) Eighty percent of AIDS cases in women are in African Americans and Hispanics, as compared to 61% of cases in men.

In developing countries, the AIDS epidemic manifested itself quite differently, both because the signs and symptoms were harder to identify due to other competing causes of morbidity and mortality and because the epidemic did not seem to be limited to "high-risk" groups and, instead, was more generalized. Worldwide, women now represent 43% of all adults living with HIV and AIDS (Table 1-1, next page) and this proportion had been steadily increasing over time. (UNAIDS, 1998)

This chapter reviews the epidemiology of HIV/AIDS: beginning with how HIV is transmitted and the variables involved; the natural history of HIV infection in women, both without treatment and in the era of highly active

Table 1-1: Regional HIV/AIDS Statistics and Features, December 1998

Region	Epidemic Started	Number of Persons with HIV Infection	Number of Persons with New HIV Infection	Prevalence Among Adults	Percent of Infected Adults Who Are Women	Main Modes of Transmission for Adults
Sub-Saharan Africa	Late 1970s–early 1980s	22.5 million	4 million	8.0%	50%	Heterosexual contact
North Africa and Mid-East	Late 1980s	210,000	19,000	0.13%	20%	Injection drug use, heterosexual contact
South, South-East Asia	Late 1980s	6.7 million	1.2 million	0.69%	25%	Heterosexual contact
East Asia, Pacific	Late 1980s	560,000	200,000	0.068%	15%	Injection drug use, heterosexual contact, male/male sex
Latin America	Late 1970s–early 1980s	1.4 million	160,000	0.57%	20%	Male/male sex, injection drug use, heterosexual contact
Caribbean	Late 1970s–early 1980s	330,000	45,000	1.96%	35%	Heterosexual contact, male/male sex
Eastern Europe, Central Asia	Early 1990s	270,000	80,000	0.14%	20%	Injection drug use, male/male sex
Western Europe	Late 1970s–early 1980s	500,000	30,000	0.25%	20%	Male/male sex, injection drug use
North America	Late 1970s–early 1980s	890,000	44,000	0.56%	20%	Male/male sex, injection drug use, heterosexual contact
Australia, New Zealand	Late 1970s–early 1980s	12,000	600	0.1%	5%	Male/male sex, injection drug use
Total		**33.4 million**	**5.8 million**	**1.1%**	**43%**	

Source: Modified from UNAIDS, 1998.

antiretroviral therapy (HAART)
the HIV/AIDS epidemic.

II. HIV TRANSMISSION

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Rich, 1993; Sabatini, 1983)

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HIV/AIDS and Women

Introduction

Picture the women infected with or at risk of contracting HIV or AIDS.

Who do you see?

Women infected with or at risk of contracting HIV are everywhere—in every region and country of the world. These women are rich and poor, young and old. They are our mothers, daughters, friends, partners, and sisters.

There are nearly 14 million women worldwide already infected with HIV, the virus that causes AIDS. And the picture is still growing. Thousands of women are infected with HIV every day; some will be infected and discover they are infected even as you read this.

This pandemic reaches far beyond those infected. When women are hurt, so are their children, their families, and their communities. It is not just a horrifying emotional strain, but an economic strain as well. Life spans of workers and consumers are diminishing. Entire nations are being devastated by the pandemic—this disease of *all the people.*[1] We can not *afford* to let AIDS continue.

Women with HIV/AIDS face a myriad of different challenges above and beyond their shared illness. While in this country, for example, some women may obtain state-of-the-art medications, most infected women are unable to afford even the most basic care.

And their children will fair no better. By the year 2010, only 10 years from now, over **40 million** children will be orphaned by AIDS. This year Sandra Thurman, director of the Office of National AIDS Policy, led a fact-finding mission to Uganda, Zambia, Zimbabwe, and South Africa to gauge the devastating effects of HIV/AIDS where children are hardest hit. In June,1999 she released recommendations to the President calling for increased support in that region [see Africa report].

Like nothing before, this terrible pandemic has shed light on issues of persistent gender, race, ethnic, sexual, and class inequity. In many ways, HIV/AIDS presents us the opportunity to learn to live together, to confront and overcome injustice.

Living and working together, we can truly make a difference. We can save lives. We can stop AIDS both here in the United States and internationally, and care for those already infected. We can affect massive change in the way we see and interact with each other.

Many women who are at risk of infection (anyone engaging in sexual activities or sharing needles) do not even know they are at risk. They must be alerted. Those who are infected with or affected by HIV/AIDS must be given every opportunity to access the services they need.

This brief outline is intended to provide a better understanding of why the devastating impact of HIV/AIDS on women is an issue for us all. Ideally, you will continue your investigation of HIV/AIDS and women by following the links provided and reading further from the resources cited.

Overview

There has been no worse plague in the modern era.

30.6 million people are living with HIV/AIDS worldwide, and hundreds of thousands have been taken too soon.

90% of individuals with HIV/AIDS live in developing countries.[2] 80% of the world's women with HIV live in Africa, and in a number of Sub-Saharan African countries upwards of 20% of pregnant women are infected.[3]

Individuals with access to the latest medication are living with HIV longer than ever before. But for those being left to die without treatment, and even for those with access to treatment, this pandemic rages on with no end in sight.

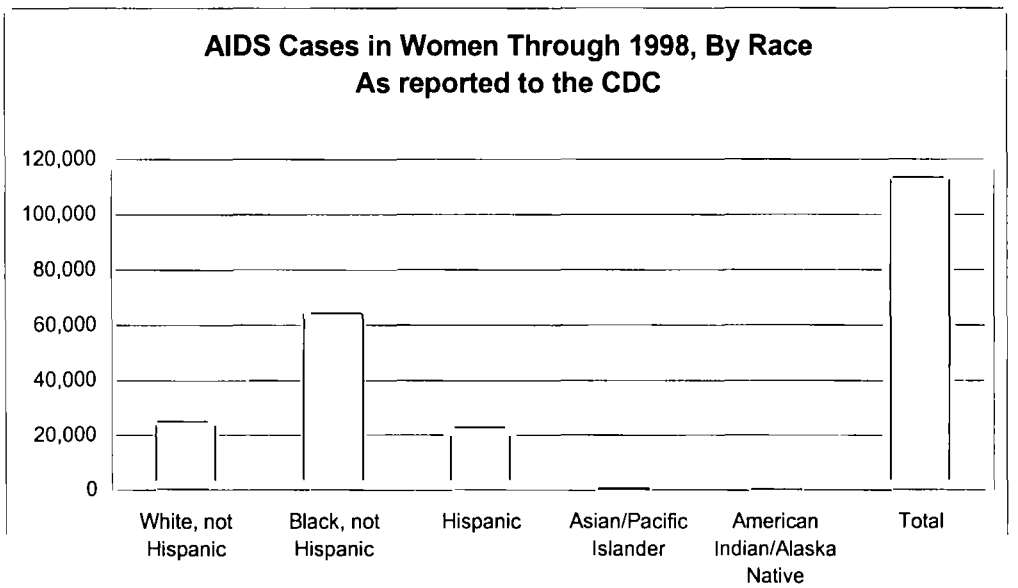
You should be alarmed.

The Centers for Disease Control and Prevention (CDC) estimate that there are between 120,000 and 160,000 women living with HIV in the United States. However, these figures are low. The CDC is our best source of surveillance, but they only collect data from 33 states and territories. And there is no real way to gauge how many are dying without revealing what is killing them. More than half of the estimated 120,000 to 160,000 women living with HIV/AIDS are thought to be unaware of their own HIV-status or the status of their infected partner.[4]

Women who do not know their status are not getting the care they need and are spreading this pandemic (right along with infected men who do not know or do not inform their partners of their status). Many of these women will not be tested for HIV until they suffer from their first AIDS-related illness or until they are pregnant and seek prenatal care.[5]

Between 1994 and 1997, women accounted for 17% of AIDS diagnoses but 28% of HIV diagnoses, which means that the number of women with AIDS in the future will continue to grow. In the United States women are the fastest growing segment of the population at risk for HIV infection.[6]

In 1998 alone, there were 5,967 new HIV cases and 10,998 new AIDS cases reported for women in the United States. Although far from the 12,698 new HIV cases and 36,886 new AIDS cases for men, it is still a record high.[7]



In the United States, young women, low-income women, African-American women, and Latina women are particularly at risk for infection. While African-American women and Latina women comprise 25% of women in the United States, they make up 75% of all U.S. AIDS cases.

There is little mystery left as to how HIV/AIDS is transmitted. We understand how this disease moves from one person to another. Women can contract HIV/AIDS through unprotected intercourse with an infected partner-- heterosexual and same-sex intercourse, and oral sex, through injection drug use (sharing needles with an infected individual), and through mother to child transmission (through pregnancy, labor, and breast milk).

But still the infection rate and death toll grow.

There is a stigma attached to HIV/AIDS. Individuals see themselves as immune to HIV/AIDS and so they do not get tested even though they may be engaging in high-risk behavior. Individuals refusing to get tested, or ignoring their status, and continuing to practice high-risk behaviors then pass on the virus. It is a vicious cycle, and HIV/AIDS is growing exponentially before our eyes.