



Welcome to South Africa

A Word from WISE

Flying early morning into Durban, South Africa, one can peer out of the airplane window and see a rose colored landscape meet the deep blue of the Indian Ocean. The two colors do not blend, but touch. White, cresting waves brush and collide onto shore, forging a middle ground between land and sea. It is a beautiful sight, reminiscent of a sunny, southern Californian beach. From above, one feels as though they are going on holiday. There are no signs of catastrophe from the airplane window. But, on land, the AIDS epidemic in South Africa is clearly catastrophic.

Statistics Do Not Bleed

With about 20% of the population living with HIV, South Africa is among the countries with the largest number of HIV-positive people in the world. In some areas of the country, one in three women are positive. It is estimated that in just five years, one in two teenagers under the age of fifteen will be living with HIV.

But statistics do not bleed. It's easy for numbers to lose their meaning. Yet, once you leave the air and touch land in South Africa, you begin to understand the meaning of numbers. You learn about the lives these numbers try to (but can never) represent.

The numbers are families—not just one son, daughter or parent, but entire families, many spanning two and three generations. As one woman plainly remarked, “I am a woman and a mother living with HIV. I am also an orphan, as my own children will be. What will happen to the children of women in Africa when we die? Who will care for who them? Who will care for us, for we are also children?”

Women in the Epidemic

In South Africa, as in many places around the world, women are particularly affected by HIV. Low social status, poverty, violence, silence and women's very own bodies make them vulnerable. Indeed, many argue that HIV/AIDS has highlighted gender inequality more profoundly than any other issue or disease in human history.

For most positive women in South Africa, there is little to no hope for treatment. Money and politics are among the deciding factors—and most South African women simply lack financial and political power. Of course, many South African men lack such power too. But for families with limited access to medications who are faced with the decision of who to treat or who to save, the answer is usually the father, the husband or the son.

Similarly, in poor settings where access to treatment is scarce, advances in preventing mother-to-child transmission benefit the child, not the woman caring for the child. And so the catastrophic cycle continues—until we all decide to break it together.

**“I am a woman
and a mother
living with HIV.
I am also an
(AIDS) orphan,
as my own
children will be.”**

continued, page 2

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what's inside

Welcome to South Africa	1
Power and Prevention	2-3
Snapshots at Durban	4
Pregnancy	5
Women and Disease Progression	6-7
Structured Treatment Interruptions: In Brief	8

Breaking the Silence

The International AIDS Conference lasted six days. Its theme was appropriately called *Breaking the Silence*. In each conference session, no matter what its

focus, attendees broke the silence about issues of access—who gets treatment for HIV, who does not and why.

The most profound assessment of this dilemma was made by HIV-positive, South African Judge Edwin Cameron who declared, “Amidst the poverty of Africa, I stand before you because I am able to purchase health and vigor. I am here because I can pay for life itself.”

♦ ♦ ♦

Only five blocks away, in a dark room in a Durban theatre, local HIV-positive women who could not afford to attend the conference gathered each day at a satellite meeting

called Ununbano LoMama (Women Working Together). Against the threat of violence and abandonment, they also broke the silence that had enfolded their lives.

♦ ♦ ♦

They told stories about burying countless children and never understanding why. They expressed rage at their male partners and the political system, especially during apartheid, for years of abuse and neglect. And they described the fear they felt about their own impending deaths.

Slowly, the women broke down the myths that lead to their own rejection from hospitals, clinics and homes. They asked hard questions about HIV—what is it, how to stop it and why it kills. But the hardest question they asked that still resonates in the minds of all who attended those long and difficult sessions was: will the government, media, activists and scientists who gathered in Durban from around the world continue to listen and support the African woman who bravely broke the silence?

Will we?

Angela Garcia

Angela Garcia

Project WISE/Women’s Treatment Information and Advocacy

Power and Prevention

For poor countries unable to afford anti-HIV treatment, prevention remains the foremost tool against HIV. Still, many barriers exist for people—especially women—trying to prevent HIV and other sexually transmitted diseases (STDs).

Not only are women biologically more susceptible to contracting HIV, but they also face social barriers that prevent their access and use of available prevention methods. The recognition of gender-related constraints for HIV prevention has led to the demand for female-controlled and initiated methods of protection. Below is an update of two advances in this field.

The Female Condom: Reality or Farce?

In recent years, a great deal of attention has been paid to the female condom. The theory is that the condom provides women with more control in protecting themselves and/or their partners from HIV and STD infection (as opposed to the male condom). The question is whether the female condom really works as intended. Apparently, the answer depends on who you ask.

Reports from Brazil, Thailand, South Africa and Zimbabwe show a general acceptability among women (including positive women) of female condoms. They suggest that, when combined with education about using it correctly, there is a strong likelihood of the female condom being included in a woman’s sexual activity, providing a woman-initiated method for preventing pregnancy and the transmission of STDs and HIV.

The cost of the female condom prohibits many women around the world from using them (they cost ten times as much as male condoms). This leads many to question whether poor women will be able to access them.

continued, page 3

“The challenge is to move from rhetoric to action, and action at an unprecedented intensity and scale.”

*Nelson Mandela
Durban 2000*

Treatment Action Campaign (TAC) march on HIV treatment access, July 2000.

Durban, South Africa



Power and Prevention, *continued*

“ We need to be able to protect ourselves and our families. We need to be able to do this and not put ourselves in danger. ”

Eka, South Africa



The safety and effectiveness of re-using the condom is also being examined. Because the female condom is made of polyurethane and is quite strong, some researchers believe that re-use may be possible. The main issue is figuring out a safe method for cleaning and storing it after each use.

It's recommended to use a new condom each time, while many educators agree any use is better than none.

Not everyone is sold on the female condom. Aside from its expense, its critics say that its visibility and noisiness requires the buy-in of male partners. Unfortunately in the sessions, little attention was devoted to the role of men in the use of female condoms.

Previous observations in the US and Canada suggest that heterosexual couples who can negotiate safer sex often prefer the male condom. Because the female condom is so “obvious,” it's unlikely that women who cannot negotiate safer sex in their relationships will have any greater success with the female condom.

Some women report ongoing problems with cervical pain related to consistently using the female condom. Proponents and educators agree that, over time and with good education, women get better at inserting the condom correctly and complaints of discomfort or pain decrease significantly.

Making Microbicides Happen

A potentially more realistic method of female-controlled and initiated prevention may be microbicides. These sub-

stances (gel, cream, sponge, vaginal ring or vaginal wipe that kill pathogens) are being studied to see if they can reduce transmission of sexually transmitted diseases when applied to the vagina or rectum. Microbicides might be able to prevent STDs, including HIV, but allow for pregnancy.

The effect of microbicides works for both partners, so that STD infection is prevented as with barrier methods (like condoms). Microbicides are generally inexpensive and can be used with far less of the partner's cooperation. There is even the possibility of using a microbicide mouthwash for oral sex. Sounds great, right?

The problem is that development of microbicides has been slow, partly because public interest in them is low. So, while many products are currently under research, only three are in late-stages of development.

One substance that held much promise (nonoxynol-9) has just been determined to *increase* likelihood of STD infection. Microbicide researchers and advocates agree this news is a setback, but they're encouraged by promising research of other approaches. These include specific anti-HIV therapies that have a basis for inhibiting HIV entry when used on the skin.

The Bottom Line on *Power and Prevention*

Not only are female-controlled STD and HIV prevention devices (including those that allow for pregnancy) long overdue, they are absolutely necessary to save the lives of women around the world. Although there's enormous interest in the female condom, it's unclear how to turn this interest into protected sex.

Microbicides may be a better alternative, but for now that's a theory, not a fact. More money and research are needed. Many researchers believe that—with sufficient investment (including from pharmaceutical companies) and political involvement—a microbicide could be developed within five years. To make this happen, advocacy for a real commitment to invest in microbicide research must occur on a global level.

Still, we need to be realistic. Five- and ten-year time frames have been promised repeatedly by vaccine researchers over last 20 years with no real success yet. And microbicide research faces some of the same problems that hold up vaccine researchers.

We must remain focused on the underlying goal: to find a way to achieve female-controlled prevention—to-day—by whatever means necessary.

Snapshots from Durban

Many of the scientific and treatment issues covered at Durban, and in the following pages, are presently clinically irrelevant to most HIV-positive women worldwide. Heightened levels of women's advocacy and research have begun to close this gap. But, a great deal of work still needs to be done to make research more meaningful to *all women*. This requires economic and social change, as well as a real commitment by researchers, politicians, industry, advocates and people living with HIV alike.

Human Papilloma Virus (HPV)

Human papilloma virus (HPV), the sexually transmitted virus that causes genital warts, is linked to developing cervical and anal pre-cancerous conditions (called *dysplasia*) and cancer. Studies show

that compared to HIV-negative women, women with HIV—particularly those with low CD4+ cell counts—have a higher rate and severity of HPV-related cervical dysplasia. Several studies presented at Durban confirmed these findings, underscoring the need for regular GYN exams to screen for HPV-related dysplasia in order to detect and treat early signs of cervical cancer.

Like cervical HPV, anal HPV and dysplasia is common in HIV-positive women. In fact, in one recent study, anal HPV proved to be more common than cervical HPV in HIV-positive women and their negative counterparts. Among HIV-positive women, other risk factors for anal HPV included lower CD4+ cell count, presence of cervical HPV, younger age and Caucasian/white race.

Because anal HPV is linked to increased risk of anal dysplasia—a precursor to anal cancer—these results may indicate an increased risk of develop-

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ing anal cancer. Moreover, they suggest the importance of regular anal exams to detect anal dysplasia. This procedure is not currently or routinely performed in women or men. Like cervical Pap smears, some researchers and health advocates argue that including

anal Pap smears in routine healthcare visits could catch dysplasia early and prevent progression to cancer.

Lipodystrophy

There were numerous presentations on lipodystrophy (the general term describing fat redistribution and lab value changes, like cholesterol). The overall picture of what lipodystrophy is, what it's caused by and how and if it can be treated remains unclear. What is clear is that lipodystrophy is a real concern for many people living with HIV. One study found that it's an increasingly common reason why some people decide to stop, delay or switch therapy.

Several studies tried to determine risk factors for lipodystrophy. Some found a connection between d4T (stavudine, Zerit) use and fat loss, and between protease inhibitor use—especially ritonavir (Norvir) and indinavir (Crixivan)—and fat gain. Older age and sex may be important factors, too. Several studies showed that women may experience more fat gain, and men more fat loss. Other factors include advanced HIV disease, duration of disease and duration of earlier anti-HIV therapy. Unfortunately, many of these studies continue to use different definitions and ways to measure it, making it difficult to compare one to another and draw conclusions. The field remains full of contradictions and unexplained phenomena.

A vital reminder from the TAC march



HIV and HCV Co-infection and Pregnancy

Many women living with HIV also live with hepatitis C virus (HCV). The effect of living with both viruses (called *co-infection*) on pregnancy and mother-to-child transmission is a new area of research. Some studies suggest that co-infection is connected to increased risk of HCV transmission. However, more research is needed to determine if this really is the case.

A study of 509 co-infected women conducted in Europe looked at the effects of mode of delivery and infant feeding on risk of HCV transmission. Women who delivered by C-section were much less likely to transmit HCV than women who delivered vaginally. While only 13 women breast-fed, breast-feeding was significantly associated with HCV transmission compared to other forms of feeding (35% vs. 13%). Similarly, children who were HIV-positive were also more likely to be HCV-positive than children who were not infected with HIV.

These findings suggest a possible interaction between HIV and HCV that may affect the risk of mother-to-child transmission. More research to determine the nature of this interaction and possible risks of co-infection on disease progression in both mother and child is needed.

Mother-to-Child Transmission

Preventing mother-to-child HIV transmission was one of the major themes of the conference. Results from several studies suggest that very short courses of therapy with either nevirapine (Viramune), or AZT (Retrovir, zidovudine), or AZT and 3TC (Eпивir, lamivudine, the combination of AZT+3TC is Combivir), are able to lower transmission rates by about 50%. With better access to therapy, it's possible to significantly reduce vertical transmission rates in resource poor countries.

The Achilles heel of preventing mother-to-child HIV transmission remains breast-feeding—a necessity for many women around the world. Two major studies report a decrease in the protective effect of short-course anti-HIV therapy to reduce transmission as a result of breast-feeding.

By 12 to 18 months after birth, transmission rates rose to 24% and then 30%, respectively, as babies became infected through breast-feeding. Thus, strategies to reduce mother-to-child HIV transmission must address related social and economic issues, such as child feeding.

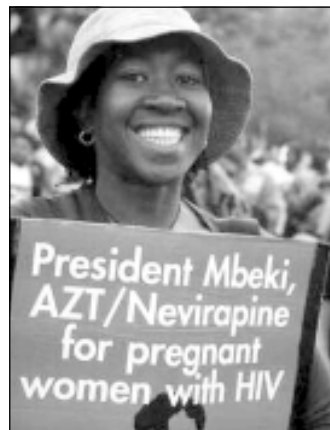
There are several studies now looking at different kinds of strategies for safer breast-feeding. Early results from one such study suggest that *mixed* breast-feeding—where breast milk is supplemented with cereal, juice, water and so forth—has a higher risk of transmission than *exclusive* breast-feeding. Interestingly, there was no difference between the rates of transmission among women who exclusively breast-fed or exclusively formula-fed their children. More study is needed to determine the reason for these surprising results.

Stopping or Switching Treatment

There's a growing trend of people stopping or switching their anti-HIV regimens. Reasons for stopping or downshifting (changing from a HAART to a non-HAART regimen) are often related to side effects, treatment fatigue, stage of HIV disease or lifestyle issues.

One large study of over 1,000 women reported that, after three years on HAART, 20% of them switched to less intensive regimens. Another 17% stopped therapy altogether. Women with low viral load and high CD4+ cell counts were just as likely to stop or downshift therapy as women with high viral load and low CD4+ cell counts. This suggests that the response to treatment is not necessarily the reason people decide to stop or switch therapies. More research is needed to understand the effects of reducing or stopping therapy in this group of women.

Whatever the reasons you may have for switching or stopping therapy, it is always good to talk them over with a doctor before actually switching or stopping the drug(s).



Activists making their demands known at theTAC march

Women and Disease Progression

Though earlier studies of HIV disease focused mostly on men, ongoing research points to differences between men and women, like those in drug levels (metabolism) and side effects. Some studies report that women have lower viral levels than men. In addition to gender differences, there are potential differences in disease progression seen among women. These may be influenced by issues like age, race and access to treatment. Below are highlights of some presentations that focused on gender issues in HIV disease progression and unique treatment issues for women.

Women and Viral Load: What is It? What Does it Mean?

In March 1999, *WISE Words* reported on gender differences in viral load seen among participants in the ALIVE study

(*AIDS Linked to the IntraVenous drug Experience*). The study found that women had HIV levels about 50% lower than men with similar CD4+ cell counts. It suggested that women with half the viral load of men had the same risk of progression to AIDS.

These findings raised questions as to whether guidelines for starting treatment should be different for women. However, the study did not include information on initial viral levels, an important indicator of disease progression. Experts agree, at the current time, that no changes should be made in the guidelines for using anti-HIV therapy based on gender.

An updated analysis of the ALIVE study examining HIV progression in women was presented at Durban. This time, study volunteers were included only if a blood sample was available

within twelve months of testing positive (seroconversion) and at least three subsequent samples were available.

The study enrolled 202 volunteers (46 women and 156 men). Time between seroconversion and first viral load was similar in both men and women (4.3 months and 4.1 months) and fewer than 5% of volunteers received highly active antiretroviral therapy (HAART).

As in the 1998 analysis of this study, viral load differences were seen again, with women having lower viral levels than men. The study also compared the volunteers' initial viral load with their progression to AIDS. It found that the predictability of initial viral load was unclear in women if below 20,000 copies, but was more predictive if at higher ranges.

No gender differences in initial CD4+ cell count were noted among volunteers who progressed to AIDS and those who did not. There was also no overall difference in time to AIDS based on gender.

The 2000 ALIVE study suggests that viral load appears to be lower in women than in men early after HIV infection. Also, the same viral load after seroconversion does not carry the same risk of progression to AIDS.

Study researchers recommend rethinking the treatment guidelines for starting anti-HIV therapy for women. They conclude that it may be appropriate to begin therapy at lower viral loads in women. However, if differences in viral load for men and women are short-term (more prominent only within the first few years after initial HIV infection), it is unclear if starting therapy is necessary. Until the meaning of these viral load differences are fully understood, it may be wise to more closely monitor CD4+ cell counts in women early in disease.

Clearly, starting anti-HIV therapy needs to take into account more than viral load measurements. How you feel about starting therapy, understanding its risks and benefits, considering your CD4+ cell counts and the rate of CD4+ cell decline, and whether you're ready for the sometimes rigorous demands of adherence—among other factors—need to be considered when making your decision.



For more information, read *Anti-HIV Therapy Strategies*, available through Project Inform's Hotline. For a discussion of gender and viral load, request *WISE Words* #3.

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ALIVE 2000:
Baseline Viral Load and Progression to AIDS

TABLE 1	Gender	Baseline VL (copies/mL)		
		Overall Average	Progressor to AIDS	Nonprogressor to AIDS
	Women	15,103	17,149 (n=15)	12,043 (n=31)
	Men	50,766	77,822 (n=29)	40,634 (n=127)

The Age Effect

More women over the age of 50 are living with HIV than ever before. Because older age is associated with a decline in the body's ability to fight off infection and disease, it's not surprising that unique concerns and questions exist for older women, not the least of which is how HIV affects menopause.

Another concern is whether older women have a higher risk of disease progression and death than younger women. Earlier studies in men suggested that, at least without treatment, older age affected the rate of disease progression. A study by the WIHS evaluated whether aging affects HIV disease progression. The results were somewhat surprising.

The WIHS study grouped 2,065 women by their age: under 30, 30-39, 40-49, and over 50. Excluding women with AIDS at study entry, researchers analyzed the effect of age on progression to AIDS and death. Other factors like initial CD4+ cell count and use of HAART were also considered.

While in general, older women over the age of 50 tended to be at increased risk of disease progression, using anti-HIV therapy appeared to greatly lessen this risk. In fact, older women who used HAART were among the least likely to

progress to AIDS. For unexplained reasons, older women seemed to benefit even more than younger women from using therapy. Also, surprisingly, older women with CD4+ cell counts below 300 tended to fair much better than younger women below 300.

This may be good news for women over 50 but is puzzling for younger women. Researchers did note that a number of non-HIV-related factors, including violence and substance abuse, may contribute to the poorer outcomes of younger women in this study. Factors such as adherence and commitment to using therapy may also play a role. Although these data certainly are encouraging for women over 50, more research is needed to further explain the impact of age on HIV disease progression.

Anemia, HAART and Survival

Anemia is defined as low red blood cell counts (red blood cells carry oxygen throughout the body). People who experience anemia often complain of fatigue as an early symptom.

Anemia is common in people living with HIV; and it is especially common among people in later stages of illness and with lower CD4+ cell counts, Afri-

can-American race and using certain anti-HIV therapies, like AZT (zidovudine, Retrovir). *WISE Words* has repeatedly encouraged women to check for anemia as it may be especially common among women and its effects include increased risk for disease progression—as confirmed by a recent study by the WIHS.

The good news is that the same study shows that using HAART for at least 18 months is significantly linked to a resolution of anemia

in women. The protective effect of HAART is likely due to the improvement it confers on the immune system, as noted by increases in CD4+ cell counts.

While there are other ways to manage anemia, anemic women considering anti-HIV treatment may be encouraged by these results. Caution in determining the right therapy is needed because certain drugs that are a common part of a HAART regimen, like ritonavir (Norvir), are known to increase the risk of anemia in women.

Older women seemed to benefit even more than younger women from using therapy.

The Bottom Line on Women and Disease Progression

The decision of when to start therapy is based on many factors. With the increasing number of women in studies, we're beginning to learn more about gender differences in these factors as well as how gender and age affect disease progression and treatment. However, current results are inconclusive. More studies focused on these issues in women are needed and should be a key target for women's AIDS activism.

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Structured Treatment Interruptions: In Brief

Recently there has been a great deal of interest in Structured Treatment Interruptions (STIs) among researchers and people living with HIV.

One potential goal of STI is to improve a person's immune response against HIV so it can help control viral replication with less aggressive treatment or no treatment at all. Another potential goal of STI is to replace drug-resistant virus with non-resistant (wild-type) virus, thus restoring a person's sensitivity to drugs that had previously become ineffective due to resistance. Also, STIs might give people who are experiencing treatment fatigue or severe side effects a break from therapy long enough to allow some degree of healing, both physically and psychologically.

A slight variation on STI, called Structured Intermittent Therapy (SIT), is also being researched. SIT seeks to determine if it's possible to control HIV by using anti-HIV drugs at regular in-

tervals rather than every day, while still maintaining control of viral load. If this could be done without harm, it could greatly lower the cost of treatment and perhaps reduce the risk of some side effects.

Early results have recently been reported from a few small SIT studies and a couple of larger STI studies. These results have been quite mixed although some are encouraging. Early results from one study suggests that the majority of people in a cycle of seven days on anti-HIV therapy and seven days off were able to keep their HIV levels under the limit of detection with currently available viral load tests. Several other studies are ongoing to determine how STIs and SITs could fit into a long-term treatment strategy.

Project Inform will co-sponsor a second STI workshop in October 2000 to identify potential gaps in the research and to brainstorm on how the studies may be enhanced. The Forum for Collaborative HIV Research (FCHR), the Foundation for AIDS and Immune Research (FAIR) and the Treatment Action Group (TAG) will also co-sponsor this event. So stay tuned!



For more information on STIs and SITs, call Project Inform's National HIV/AIDS Treatment Hotline and ask for the publications, *PI Perspective #31* or *Structured Treatment Interruptions*.

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