

# HIV & AIDS: a WOMAN'S STORY

by **KAREN PLATER**

MARIA SILO HAS AN ENGAGING SMILE. Her easy demeanor belies the challenges she has faced as a woman living with HIV in southern Africa.

Maria was diagnosed with HIV in 1998 at Ekwendeni Hospital, a mission hospital of the Church of Central Africa Presbyterian in Malawi. The hospital had encouraged her to be tested after she and her youngest son Edward struggled with recurrent illnesses. It was a difficult time. Her husband died in 1996 in a car accident when she was pregnant with Edward. She had just lost her mother to cancer and her elder sister and brother had also died. Her house had collapsed in a rainstorm and she was struggling to provide for her four children and nieces and nephews with food, clothing and an education.

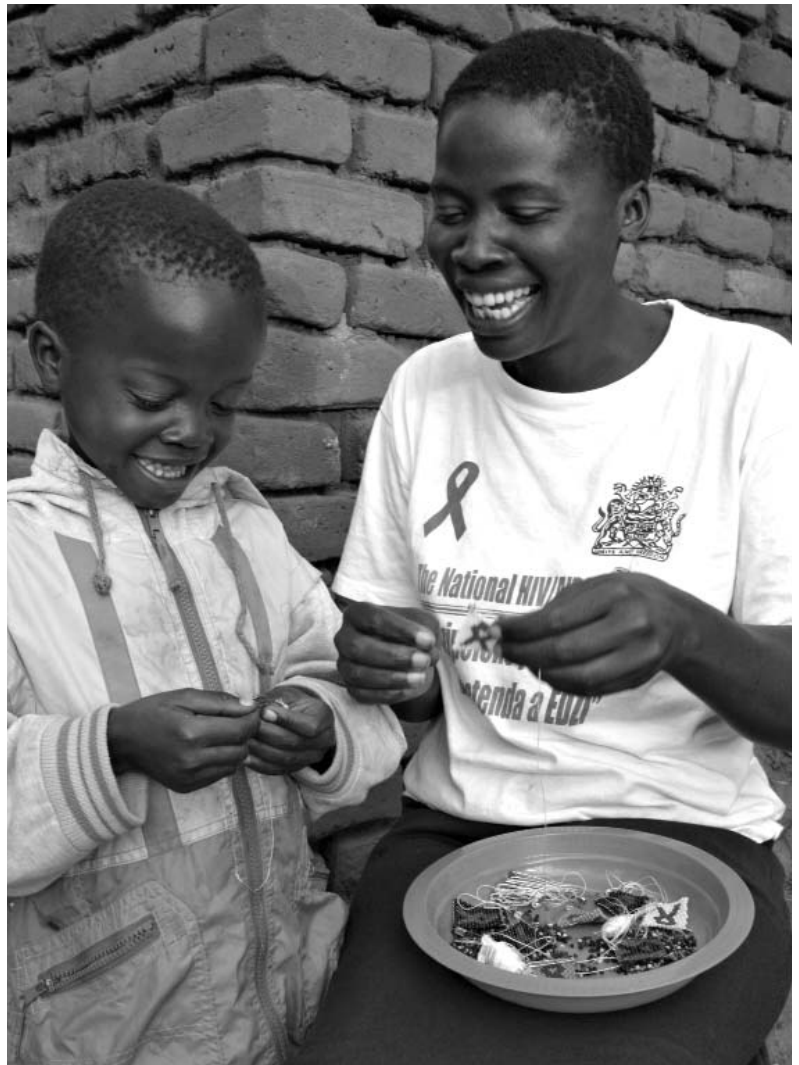
At the time of her diagnosis, there wasn't much hope for a woman in her situation. While successes with triple combination anti-retroviral therapy were being seen elsewhere, they weren't available in Malawi. Like many in her country, she also struggled with seasonal malnutrition – a factor that can lead to a faster progression to AIDS. She faced incredible stigma and discrimination from people in her community, both as a woman and a person living with HIV. People did not want to talk about HIV or AIDS. They did not want to admit it existed. She saw how many, after a positive diagnosis, gave up and waited to die.

Maria was lucky. She had friends and family who cared for her and supported her when she shared her news. She had a church community that embraced her when many were turning their backs. She decided she wasn't going to give up and die. She wanted to fight it. She wanted to share her story.

So Maria began to talk about HIV: what it was, how it could be prevented, that people infected and affected by the disease needed love and support. She encouraged people to go for testing and counseling. She formed a support group for people living with HIV.

Ekwendeni Hospital's AIDS program helped her with housing and basic supplies – food, soap, clothing, bedding and school fees for the children. When they began an ARV program she convinced the hospital she should be on it. When funds became available they brought her on staff.

Today Maria is the home-based care coordinator encouraging testing and counseling and building support groups throughout the region. Maria continues to struggle – to provide for her family and herself – to stay healthy and positive – but she is not giving up. She shares



Maria and her youngest son Edward are making AIDS pins as an extra source of income to support her family.

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### Women and HIV in 2006

- ◆ There are at least 17 million women who are living with HIV comprising about 50% of infections worldwide. In sub-Saharan Africa, women and girls make up 60% of people living with HIV.
- ◆ Over the past two years, the number of women and girls infected with HIV has increased in every region of the world, with rates rising particularly rapidly in Eastern Europe, Asia, and Latin America. In some places, girls are the fastest growing group of people newly infected and may outnumber their male counterparts 2 to 1.

(UNAIDS/WHO AIDS Epidemic Update: December 2006  
available at [www.unaids.org](http://www.unaids.org))

not only her smile with others, but also her spirit of hope and determination.

#### Women Face HIV and AIDS

MARIA IS ONLY ONE OF MANY WOMEN who have been infected or affected by HIV. Hers is a unique story of hope, tenacity and perseverance. As you listen to stories of women throughout the world, you cannot help but see that this disease is affecting them on all levels. They are caregivers: for people who are sick, for orphans. They are volunteering at community-based orphan care centers. Grandmothers, mothers, aunts, sisters, wives, daughters – whether infected or affected – have been devastated by the disease.

There is still much work to do, particularly in areas that affect women. Understanding these issues is essential for developing programs that will really be effective in halting the spread of HIV.

#### Women and Prevention

WOMEN ARE PARTICULARLY VULNERABLE to HIV. In addition to being biologically more susceptible to heterosexual transmission of HIV, economic, social and cultural barriers can make women more vulnerable to infection.

Women are often financially dependent on their husbands or partners and families. Girls are more often withdrawn from school to look after sick parents or younger siblings – or never get the chance to go to school in the first place. They are more susceptible to poverty which increases their vulnerability to HIV. Chronic malnutrition makes individuals more vulnerable to infection when coming into contact with the HIV virus. Sex may be exchanged for money or favours like food or books for school. Poverty frequently means women don't have access to health services where they can learn about HIV and access care and support to maintain their health.

Women often have less control over when, where, and how sexual relations take place. They may not be able to determine when they have sex with their husband

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Women often know less than men about how HIV/AIDS is transmitted and how to prevent infection, and what they do know is too often rendered useless by a lack of choice, discrimination or violence. But promising developments have been seen in recent years in the fight against AIDS. High profile figures like Stephen Lewis, Bill and Melinda Gates, Bill Clinton and Oprah Winfrey have raised the profile of AIDS and led the way for increased private and public funding for HIV work, and increased access to treatment and prevention programs.

Yet the sad reality is much more work is still needed. The statistics show that the number of people living with HIV continues to grow along with the number of people who have died of AIDS-related complications. The crisis continues to reverse development gains and exacerbate existing emergencies. The increase in infection rates in young women and girls are alarming. Complex social, cultural and economic issues need to be addressed to ensure the effectiveness of prevention and care programs.

or if he uses a condom. (Many HIV-positive women in Sub-Saharan Africa and Asia have only ever had sex with their husband.) Child marriage often makes it nearly impossible for a young wife to negotiate the terms of these relationships. Violence and abuse are used against women to force them to submit to their partners' wishes. Rape is too often used as a weapon in conflict or war situations, spreading HIV rapidly among men, women and children. In areas where intravenous drug use is driving the pandemic, women are often doubly susceptible to the disease through either intravenous drug use or as sexual partners of drug users.

Many women hold out hope for the development of microbicides which they could apply before sex to protect them from HIV and other sexually transmitted infections. While some have reached the testing stage, so far none have proven viable and some actually appeared to increase transmission of HIV. The female condom is more difficult to use and is often not readily available nor



**MOTHERS AT A SUPPORT GROUP MEETING IN EKWENDENI, MALAWI:** Ekwendeni Hospital uses Neviraprine to reduce transmission of HIV from mothers to their children. Mothers who are HIV-positive join support groups that help them monitor their health and learn how to use the resources they have to stay healthy. The hospital's new CD4 count machine is helping monitor the health of their immune system and show when they need to be put on antiretroviral therapy which is becoming more available with funds from the Global Fund against HIV, malaria and tuberculosis.

## Prevention of mother-to-child transmission of HIV

WITHOUT ANY PREVENTATIVE MEASURES, approximately one in three babies born to mothers with HIV will contract the virus. Of these babies, about 15-20% acquire the virus in pregnancy, 50% in labour and delivery, and another 33% through prolonged breastfeeding. The risk of transmission can be reduced to below 2% by interventions that include: antiretroviral (ARV) drugs given to women during pregnancy and labour and to the infant in the first weeks of life; obstetrical interventions including elective caesarean delivery (prior to the onset of labour and membrane rupture); and completely avoiding breastfeeding.

In many resource-poor settings, elective caesarean delivery is seldom available and/or safe, and refraining from breastfeeding is often not acceptable, feasible or safe. To date, efforts to prevent transmission from mother-to-child in resource-constrained settings have mostly focused on reducing transmission around the time of labour and delivery using ARVs, particularly a single dose of Neviraprine. They have also encouraged exclusive breastfeeding – no other food or water – for the first six months and then stopping breastfeeding as soon as other food or

drink is introduced. Early studies have shown this can reduce transmission of HIV from mother to child.

The use of single-dose Neviraprine has been controversial. It only needs to be administered once to the mother and child, making it easier to use and less expensive than other antiretroviral drugs used to prevent mother-to-child transmission of HIV. However, studies have found that single dose Neviraprine can build up resistance in the mother and child, compromising the future use of antiretroviral therapy with Neviraprine or Efavirenz (a related drug). This could have serious consequences for future antiretroviral treatment of mothers and infants.

Other short-course treatments require women to take antiretroviral therapy during and after pregnancy as well as during labour and delivery, making them much more expensive in resource-poor settings. Single-dose Neviraprine is still often used in regions where medical resources are limited. Work needs to be done to ensure care for mothers extends beyond pregnancy and allows them to survive to care for their children.

~ Karen Plater

### HIV in the World in 2006

- ◆ 39.5 million people were living with HIV, 2.6 million more than in 2004
- ◆ 4.3 million people were newly infected with HIV, 400,000 more than in 2004
- ◆ Young people accounted for 40% of new HIV infections
- ◆ 95% of people living with HIV are from the developing world; two-thirds of people with HIV live in sub-Saharan Africa and almost three-quarters of deaths due to AIDS occurred in sub-Saharan Africa.
- ◆ In the past two years, the number of people living with HIV increased in every region in the world. The largest increases occurred in East Asia, Eastern Europe and Central Asia, where the number of people living with HIV in 2006 was over one-fifth higher than 2004.

(UNAIDS/WHO AIDS Epidemic Update: December 2006 available at [www.unaids.org](http://www.unaids.org))



seen as socially acceptable.

Gender roles constructed for men and boys also need to be addressed. Men may feel pressured to gain sexual experience or to have more than one sex partner. They may be encouraged to seek women for sex at a young age and encounter fewer restrictions on their sexuality. In some countries, many boys have their first sexual experience with a commercial sex worker and visits to brothels are a socially acceptable

are the last to receive healthcare and food resources, so many suffer from AIDS-related symptoms sooner than do men. In addition, in many countries women have no land rights, increasing the likelihood that they will not have a way to generate an income should their husband die. Frequently, women with HIV infection carry a heavy burden of caring for children and other family members who may also be HIV-infected. They often lack social support and face other challenges that may interfere with their ability to obtain or adhere to treatment.

### HIV, Women and the Church

IN RECENT YEARS, CHURCHES have begun to wake up to the role they can play in confronting AIDS. Frontline workers and ecclesiastical leaders are beginning to see that churches need to stand with communities to confront this epidemic. From leading effective prevention programs to working against poverty, stigma and human rights violations that accompany AIDS and contribute to the spread of HIV, churches can help in the fight against AIDS. Christ provided the example of reaching out to the most vulnerable and marginalized so that all people can live life to the fullest, with hope for today and tomorrow.

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activity for men. Men are often encouraged to initiate and control sexual interactions and decision-making. At the same time they are generally not the targets of reproductive health information and this makes for a dangerous combination.

### Women Living with HIV

WOMEN WHOSE HIV INFECTIONS are detected early and receive appropriate treatment survive as long as HIV-infected men. However, coupled with their greater vulnerability to becoming infected, women are less likely than men to be diagnosed early, have less support and are significantly more likely than men to experience AIDS-related discrimination after infection. While women suffer many of the same AIDS-related symptoms as men they may also suffer gender-specific symptoms which have not been as quickly identified.

Already discriminated against for being female, women living with HIV are often stigmatized and blamed for bringing HIV into the family. They may not seek care for fear that their children will be taken away from them. Their lower status within families means they

The church must recognize the unique vulnerabilities and challenges that women face in this pandemic. And then churches need to respond by listening to and incorporating the experiences and enthusiasm of women living with HIV into their programs. Many, like Maria Silo, have the ideas and ability to lead the response to the pandemic, but they need support to do so.

When the church rises to the challenge of the AIDS pandemic, the results can reveal the work of God. Gracia Violeta Ross Quiroga, a dynamic Bolivian woman providing leadership in the International Community of Women, living with HIV and daughter of a Baptist minister, was afraid to tell her family and her church. "What will they say if I tell them?" She was surprised by their reaction "because when I finally told them, they accepted me, acting with love and mercy as Christ taught. They were real Christians". 

### For reference and further reading:

Canadian HIV/AIDS Legal Network: [www.aidslaw.ca](http://www.aidslaw.ca)  
Interagency Coalition on AIDS and Development: [www.icad-cisd.com](http://www.icad-cisd.com)  
International Community of Women living with HIV/AIDS: [www.icw.org](http://www.icw.org)  
UNAIDS: [www.unaids.com](http://www.unaids.com)