

CHAPTER ELEVEN

Gender, prevention, treatment and care

By Belinda Beresford

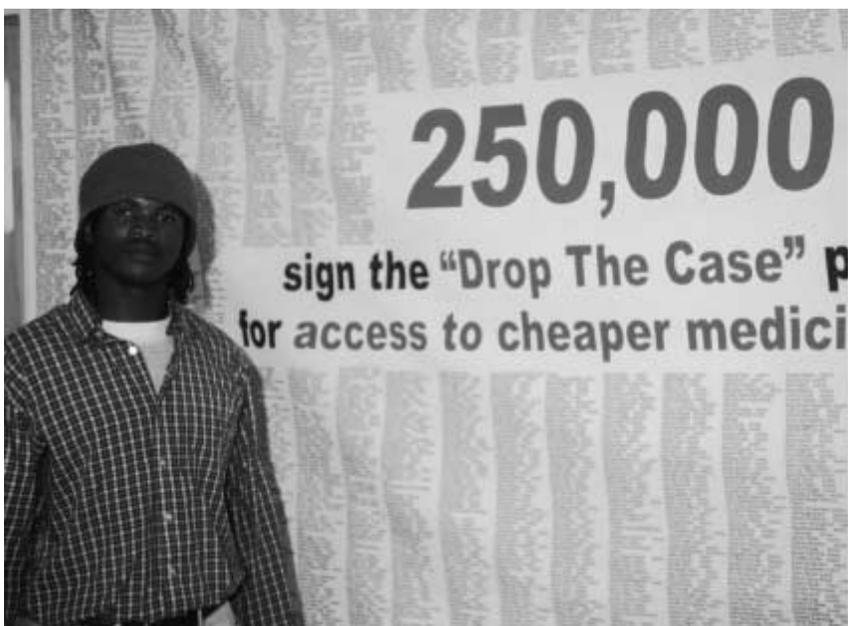
“ Amidst the poverty of Africa, I stand before you because I am able to purchase health and vigour. I am here because I can afford to pay for life itself... Given the epidemic’s two most signal changes, in demographics and in medical science, it must surely be that the most urgent challenge it offers us is to find constructive ways of bringing these life-saving drugs to the millions of people whose lives and well-being can be secured by them. Instead of continuing to accept what has become a palpable untruth (that AIDS is of necessity a disease of debility and death), our overriding and immediate commitment should be to find ways to make accessible for the poor what is within reach of the affluent. ”

(Women’s Net, Women and Human Rights Reference Group, 12 August 1999.)



Objectives

- To provide an in-depth understanding of HIV/AIDS and treatment options currently available to people with HIV/AIDS.
- To examine the gender dimensions of HIV/AIDS prevention, treatment and care.
- To illustrate how treatment and care programmes often put the burden of guilt and greater responsibility on women.



Introduction

Treatment and care have become highly controversial issues. While anti-retroviral drugs are now available to help prolong the life of those with HIV/AIDS, their accessibility and affordability still put them well out of the reach of poor women and men.

The gender dimension of the global AIDS pandemic has become more prominent, especially when the features of the pandemic in highly affected areas are considered. Alongside the gender dimension of the pandemic has emerged a gender dimension to treatment and care.

Women, in particular, have few options open to them when it comes to their own treatment and care once they are infected with HIV/AIDS. They are often the caregivers and have little time or resources to seek treatment and care for themselves.

In her book, "AIDS Africa", Helen Jackson uses World Bank data to estimate that for every 1,000 cases of unprotected sex with a man with HIV/AIDS, one or two women will be infected with the virus. Women are more likely to get infected from a man than vice versa, because the infected seminal fluid stays inside the woman's body. This increases the chances that the virus will make its way past the body's defence systems. In contrast, infected vaginal fluid mainly stays outside the man's body, unless he has an open sore or injury.

Treatment for HIV/AIDS is often taken automatically to mean antiretroviral therapy (ART) using antiretroviral drugs, often abbreviated to ARVs. These usually work by preventing HIV from reproducing. This reduces the strain on the immune system, which is better able to mop up virus in the body. ARVs cannot cure HIV/AIDS, but they can buy time. How much time, is variable – it can range from a few months to many years.

These drugs, unless heavily subsidised or provided for free through the public health system, are not accessible to a large majority of women – especially to the swelling population of poor women, who are among those with the highest rate of HIV infection.

The assumption that the poor will not be able to take their anti-retrovirals – if made easily available to them – is not borne out by many researches and pilot studies. A hospital in Cape Town has reported that its indigent patients – black and from some of the worst townships in South Africa – have compliance rates on a par with patients in the United States.

Women in the United States and Western Europe have tended to be less compliant in taking their medicines than men. The same is not true in South Africa, where women appear to be at least as good as men at sticking to the treatment regime. Doctors suggest that this is because in Western Europe for example, high levels of women with HIV/AIDS are also intravenous drug users – not a group that is likely to be good at taking medicine. In South Africa with its heterosexually transmitted epidemic, women with HIV/AIDS are much more representative of women as a whole.

handout thirty-eight

A profile of HIV/AIDS

Researchers discovered what is now called HIV-1 in 1984, three years after it became clear that a previously unknown disease was loose in the world. A French team of scientists first identified HIV, but international politics led to an American team being given joint recognition for the discovery of the virus.

Viruses related to HIV appear to have been living in relatives of humans such as monkeys and apes for a long time. No-one knows when the virus later identified as HIV first colonised human beings, but we do suspect that it has happened more than once. There are at least two different kinds of HIV, labelled HIV-1 and HIV-2. HIV-2 was isolated from patients in West Africa in 1986. This strain is less virulent, it kills more slowly and appears to be less infectious than HIV-1. At one time scientists hoped that having HIV-2 would “vaccinate” people against the more dangerous HIV-1, but this does not appear to be true. People have been identified carrying both HIV-1 and HIV-2 simultaneously.

HIV has many related viruses, which infect other animals such as SIV (simian immunodeficiency virus in monkeys) and FIV (feline immunodeficiency virus in cats). Some of these related viruses do not appear to harm or kill their hosts – this is a sign that the virus and the host have lived together for a long time, and have fought each other to a form of truce. The fact that monkeys live with their form of SIV, which is very similar to HIV, without getting sick, suggests that the human virus developed from the simian one, rather than the other way around.

It is possible that HIV has made the transition to humans from monkeys many times, but that the infected person or people died without transmitting the virus on in large enough numbers to create an epidemic. HIV is a sensitive virus. It dies rapidly outside the body and it is very vulnerable to disinfectants.

HIV itself does not kill

It is not the virus itself that kills people; rather the virus destroys the human immune system, opening the door for lots of other infections, which are the ones that eventually kill.

Human beings are under constant attack by different bacteria, fungi, moulds and viruses, most of which the immune system fights off before we get sick. But when the immune system is trying to combat a growing number of HIV particles, and is itself being destroyed by HIV, it starts to fail against other disease-causing agents. This is when a person starts to move from being infected with HIV, to living with AIDS.

Weakened by the loss of some of its defence mechanisms and trying to control this flood of virus, the body ceases to be able to defend itself effectively against day-to-day infections. This results in the person being affected by opportunistic infections, which may either be common illnesses which can normally be fought off, like thrush, or rare diseases like Kaposi Sarcoma.

An epidemic is not just the result of an infection agent, it is also the social and cultural setting in which the disease is spreading. What makes HIV so effective is that it has a long incubation period, which gives plenty of opportunity for infected but healthy people to unwittingly pass the virus on. It is also transmitted through some of the most basic human activities, sex and breastfeeding. Gender inequalities, poverty and ignorance – which are all linked – help create an environment where HIV can spread successfully.

How long can you live with HIV?

It is hard to know how long people live with HIV before becoming AIDS sick, because it is so difficult to know when a person actually became infected. There are no obvious and immediate signs of having HIV – either at the point of infection or for years afterwards, this is why HIV is sometimes referred to as a silent epidemic.

In developed countries such as the US and the UK, it is estimated that on average eight years elapse between initial infection, and the person becoming AIDS sick. Without treatment, particularly anti-retroviral treatment, the average person lives with AIDS for an average of three before dying.

However, it is uncertain whether people living in less affluent or developed areas such as Sub Saharan Africa would live on average for the same amount of time with the virus. It was thought that people in less developed countries would be likely to sicken and die faster, because their immune systems would be under greater assault as a result of unclean water, lack of sanitation, and the prevalence of microbes such as malaria.

Whether this is true or not is still unclear. Several studies have suggested that people in developing countries live for the same amount of time on average with HIV/AIDS as those in developed countries. But doctors working on the ground are wary of these findings. One research team for example, points out that South Africans infected with HIV/AIDS tend to die quickly because of tuberculosis. There is still a lot that is unknown about HIV.

Preventing sexual transmission

In sub-Saharan Africa, the main form of transmission is through sexual intercourse. Any sexual activity that brings the bodily fluids of one person into contact with those of another can also spread HIV/AIDS. Oral sex, anal sex and vaginal sex are all potential ways of transmission. Conversely, anything that prevents fluid-to-fluid contact will reduce, or remove, the chances of HIV infection. At the moment this primarily means condoms, whether male or female. If a man or woman is giving oral sex to a woman, they can use a dental dam – piece of latex – to prevent contact with her vaginal fluids.

It is the male condom, which is regarded as the basic way to curb the spread of HIV/AIDS. However, while the male condom has the advantage of being cheap, use of it is totally controlled by the man. A woman can almost certainly never force a man to unknowingly use a male condom.

The female condom gives more control to the woman, and there have been reports of women using them without their sexual partners being so aware of it. Female condoms however are slightly harder to use, and are much more expensive than male condoms.

Exercise one

Ask participants to conduct *vox pop* interviews with members of the public about the female condom. It might be advisable for female participants interview women interviewees, and for men to interview fellow men. First off, each interviewee could be asked if they have heard of the female condom. Those who have then could be asked whether or not they and their partners have ever tried using one during sex. Those who have could be asked what they think of the female condom. Those who have not used one could be asked if they would consider doing so. If possible, the journalists could have a female condom with them to show the interviewees. The findings of the interviews could then be presented to the group.



Tips for trainers: Campaigns promoting the use of female condoms in Southern Africa are few and far between, so it is likely

that awareness of the female condom may be low among interviewees and journalists alike. Problems raised by the interviewees should be noted down for future reference. For example, perhaps the majority of the interviewees had not heard of, or had not tried using the female condom. Or perhaps those who had used one did not like it because it was too noisy. Participants could then discuss how media might be used to address the problems highlighted by the interviewees.



Preventing parent to child transmission

Another way HIV is transmitted is through mother to child transmission, now known as parent to child transmission.

For every 1,000 pregnant women with HIV/AIDS, between 130-480 are likely to pass the virus on to their child, although this can be reduced dramatically by using preventative drug treatment. As a rule of thumb, it is usually said that up to a third of newborns will contract HIV/AIDS from their mother in one or another way. Conservative estimates are that up to half of these new infections could be prevented with the use of antiretroviral drugs like AZT or nevirapine.

HIV infection of newborn infants has been cut to less than one percent in some developed countries, thanks to the use of anti-retroviral drugs, caesarean deliveries and artificial feeding of the infant. In many less affluent countries, women cannot get access to any of these facilities, let alone the full armoury.

Babies become infected in the womb before labour, during labour and after birth, through breastfeeding. The chances of infection are reduced if the amount of virus the child is exposed to is reduced, for example if the mother is taking on-going anti-retroviral therapy. But this is not a possibility for most women in developing countries, which is why scientists have come up with two shorter, and cheaper alternatives. Just giving one pill of the anti-retroviral drug, nevirapine, to a pregnant woman in labour, and then another dose to the child after birth, will cut by about 50 percent its chances of contracting HIV/AIDS. Giving AZT over a period of weeks before and after birth achieves similar results.

Caesarean births reduce the risk of infections because the child is not forced through the birth canal, risking breaks in its skin and close exposure to infected maternal blood. But even if a caesarean birth is not possible, other measures eg. not breaking the waters until as late as possible, can also protect the child.

Discussions about programmes to prevent transmission of HIV from pregnant women to their babies often focus on the infant. This is compounded by use of words like 'innocent' to describe the baby, which in turn implies that the mother may be 'guilty' or at least 'not innocent', and therefore less deserving of care and attention.

The crucial point about PTCT programmes is that they focus on preventing the child from being infected with HIV/AIDS. They are not holistic treatment programmes and do not provide treatment for the mother. There sometimes seems to be an implicit assumption that by providing MTCT the women are also being helped. They are, but in a very limited way. Giving a woman advice, counselling, and a few pills to help save her baby during labour, will not necessarily help her physically several weeks down the line. Nor will such an intervention help a baby with HIV/AIDS, or children with a sick or dead mother.

Underlying debates and media coverage about vertical transmission of HIV from parent to child is based on the assumption that all the mother cares about is saving her unborn child from the virus. What is often forgotten is that the odds are that a pregnant woman with HIV/AIDS may already have children to whom she may have a greater emotional attachment than to the unborn child. That alters the real choices that women face, and the decisions they make.

Consider a woman advised to bottle feed her newborn to prevent it becoming infected with HIV/AIDS during breastfeeding. She may understand the need to bottle feed, but choose not to if doing so diverts scarce resources from her older children.

To be really effective, PTCT programmes should aim to help the mother as well as the child. Giving vitamins, ongoing support and advice, artificial baby food, food supplements for the rest of the family, are all issues that can help the mother longer term. So too can taking proper care of her physical state – ensuring that she has recovered from any trauma during childbirth, checking that she is being treated for opportunistic infections, giving her counselling and emotional support.

In the longer term neither the short courses of AZT, nor nevirapine will protect the child from catching HIV/AIDS through its mother's breast milk.

Exercise two

Hand out the article, "The Need for Nevirapine" in **Handout thirty-nine** to participants and ask them to read it and identify the gender issues raised by the article.



Tips for trainers: Use the article to examine the media's coverage of the options available to a pregnant woman with HIV/AIDS. Participants should think about how the article portrays women, as mothers and as individuals, and what options are available to them in both capacities.

Breastfeeding

Breastfeeding is best for children, but it also risks giving them HIV/AIDS. Bottle feeding reduces the chances of HIV transmission, but drastically increases their chances of dying from intestinal infections or malnutrition. Artificial feeding is costly, both financially and in terms of time. It requires the artificial food, clean water, facilities to sterilise the bottles and keep them sterile and time to do the cleaning, sterilising, mixing and feeding.

One World Health Organisation doctor recounted his unease at having to recommend that women bottlefeed their babies. He had spent a large part of his professional life promoting the concept that "breast is best" to save infants from illness and death due to intestinal infections and malnutrition, and now had to accept that in ideal circumstances breast may not be best.

Whether to recommend breastfeeding or bottlefeeding depends on the mother's circumstances. A woman with access to all the necessary resources would probably be encouraged to bottlefeed. A woman with none of the resources needed may have no choice but to breastfeed.

Preliminary research has indicated that exclusive breastfeeding – which means nothing else is given to the child, not even water – can be as safe as being bottlefed for the child. The problem is exclusive breastfeeding means that the mother must be able to feed the child continually day and night – difficult if she is working and cannot take the baby with her. Exclusive breastfeeding also puts a strain on the mother's body, and some researchers say is likely to accelerate the death of malnourished women.

Many media reports on breastfeeding are either explicitly or implicitly critical of women. They ignore the fact that women as the traditional nurturers of the family are often faced with the most heartrending decisions. And then there is the issue of the formula food itself. Too expensive for many women, even giving it out for free doesn't always help. There are reports of families using formula food intended for a newborn to feed older children, and even adults. This is sometimes represented as foolish or selfish of the woman and her family, when really their actions need to be put in context.

Exercise three

Break participants into groups and ask the groups to discuss the following questions for a report back.

- What is the message being given to women, and to men about feeding babies?
- Should this differ now, in the age of HIV/AIDS, compared to two decades ago when the campaign first really got underway?
- What is the real impact of the campaign on women and their choices, particularly in the light of the HIV/AIDS epidemic?
- Does the campaign provide enough information? If not, what more information should be given and how?
- Should the "breast is best" slogan still be used?



Tips for trainers: The exercise aims to discuss the "Breast is best" campaign, which has formed an integral part of the messaging sent to pregnant women over the last three decades. The gender dimensions of the campaign should be discussed – women are made solely responsible for feeding babies; if they cannot breastfeed, they are assumed not to care about their children.

handout thirty-nine

The need for nevirapine

By Lynne Gidish

HIV positive pregnant women don't have to pass the virus on to their babies. Early testing, bottle-feeding and a single dose of Nevirapine means new-borns have a nearly 90 percent chance of starting their lives HIV-free. **Lynne Gidish** investigates.

Today is a great day for Sarah*, 26, and her 16-month old boy, Siphon*. She's beaming from ear to ear because she's just been informed that Siphon has tested HIV negative. Everything she's been through – all the hardships she's endured – have finally paid off.

Sarah only discovered she was HIV positive when she fell pregnant with her son. She admits she's been lucky. "I was given Nevirapine," she says, "and now that my child is negative, I no longer have to feel guilty. I'm positive, it's only my problem to deal with. What would I do if Siphon had been positive too?"

Realising in retrospect that she'd been infected by her previous boyfriend, who has since died, Sarah never disclosed her status to Siphon's father. "I was too scared to tell him when we were together," she says. "And now that we've broken up because of his womanising, we have no contact whatsoever. He hurt me so much in the past that I really don't care whether he has the virus or not, and if he's infected and is passing it on to his other women, it's of no concern to me."

Explains Manko Ngakane, a counsellor who runs the follow-up clinic of the Perinatal HIV Research Unit (PHRU) at the Chris Hani-Baragwanath Hospital in Soweto: "Sarah's attitude is very common among our women and it's mainly because they're angry. At the clinic, we try, firstly, to help them through their anger about men and, secondly, to explain that they have a responsibility to reveal their status. But it takes time."

Sarah is still in the first stages of anger and has only revealed the fact that she's HIV positive – and took Nevirapine – to her mother. The stigma and pressure attached to her status are far too high for her to risk telling anyone else. But so is the stigma of not breast-feeding her child (HIV can be transmitted through breast milk).

"The trouble is the community," Sarah says. "What woman doesn't breast-feed her child? I felt really guilty that I couldn't. Everyone kept asking me why I was giving Siphon a bottle. I had to lie and say my milk was no good. Then there was the worry of finding money to pay for formula. My mother works so she was able to help, but it hasn't been easy."

Having spent so much time living in secrecy, clouded by anxiety and guilt, Sarah admits the results of Siphon's HIV test are "the best news ever".

"Everything's been worth it. We've both been blessed. Siphon has been given a clean bill of health – and a future."

It's stories like Siphon's that warm Manko's heart and reinforce her belief that every pregnant mother who is HIV positive should be given Nevirapine. "It's hard to describe the looks on the faces of mothers who are told their babies are negative," she says. "They have a long wait; the babies can only be tested one year after birth. But thanks to the drug, there are fewer and fewer of them who do test positive."

Without anti-retroviral drugs and with prolonged breast-feeding, 42 out of every 100 babies born to HIV positive mothers contract the virus. Research has shown that when Nevirapine is administered and the babies aren't breast-fed, this figure drops to 13 out of 100 babies.

One child who hasn't been as lucky as Siphon is four-year-old Mbali*, whose mother Nonhlanhla* discovered she was HIV positive two years ago. "I thought I'd been infected by the man I was involved with at the time," Nonhlanhla explains. "It was only later, when I heard Mbali's father had died of AIDS, that I had her tested and discovered she was positive too. When I heard my results, I was angry. When I received hers, I felt it was the end of the world."

Nonhlanhla only now realises the importance of knowing your HIV status during pregnancy. "You always think: "It can never happen to me," but it can – and it does," she says. "I really feel bad that because of my ignorance, I wasn't given a chance to take Nevirapine to prevent Mbali becoming infected too."

Manko believes the importance of anti-retroviral drug awareness campaigns can't be over-emphasised. She'd like to see more of them in churches, community centres and other public places. "It all starts with being tested – regardless of whether you're pregnant or not," she explains. "The problem is our men. They just don't care."

Says Nonhlanhla: "Our men refuse to wear condoms so even if I try to be responsible, it doesn't work. When I meet a man and tell him I'm HIV positive, he looks at me and laughs. He says I'm too fat and healthy-looking to have the virus, and thinks I'm lying – so we have unprotected sex."



Dr Glenda Gray, the recipient (together with Professor James McIntyre) of the 2002 Nelson Mandela Health and Human Rights Award, and who heads up the PHRU comments: “Generally, people in South Africa don’t talk about sex, so trying to talk about sex and HIV and death all at once is almost too much to handle. Furthermore, black South African women usually have a subordinate status in relationships and their men neither believe them nor take them seriously. Mbali’s situation highlights the very definite need for something to be done to empower women with the skills to communicate effectively with their partners, as well as change men’s attitudes about listening to them. It also highlights the importance for all pregnant women to be offered HIV testing during pregnancy, especially given the high rates of HIV in South Africa, where more than one in four pregnant women are HIV infected.

“Knowing your HIV status empowers you. It can help you access treatment if you’re infected, and you can get treatment to help prevent your baby getting HIV from you.

“Yet, despite pregnant women wanting the best for their babies, there’s still a stigma attached to being HIV-positive in the community,” Glenda continues. “As a result, women struggle to disclose their status because of the fear of rejection and shame about being infected. This is complicated by the fact that they’re also often ostracised because they’re not breast-feeding their babies.”

Adds Manko: “Not being able to breast-feed their babies is a huge issue for many women. Besides being scared of abandonment and of physical abuse should their partners ever discover their HIV status – and this fear is far worse if the woman is unemployed – many infected women have to deal with both their maternal instinct and the cultural pressure to breast-feed their babies.

“When women are given Nevirapine, we stress the importance of feeding their children formula. And because they’re terrified to reveal their status, like Sarah, they often resort to lies. They tell family and friends they have breast cancer, that their doctors have told them they have no milk – anything, in fact, to give their babies a chance.”

There’s been huge controversy recently surrounding the use of Nevirapine in South Africa. According to Glenda, the government has a pilot programme using the drug to prevent mother-to-child transmission. “This is thanks to the Treatment Action Campaign winning a court case in the Constitutional Court against the government,” she says.

“It forces the government to roll out this programme so that all HIV infected pregnant women can get access to Nevirapine, the drug that the World Health Organisation, UNAIDS and UNICEF organisations have all endorsed for the prevention of mother-to-child transmission of HIV. Nevirapine is widely used in the world in mother-to-child transmission programmes.

“Yet despite the fact that we need to eradicate paediatric HIV in this country, we’re stymied by the unavailability of the drug in the public sector and the slowness of the government in implementing its programme nationally,” Glenda continues.

“To date the introduction of free healthcare and good immunisation programmes have done a lot to control infant mortality in South Africa, but HIV is now threatening these programmes.”

Zackie Achmat, chairperson of the Treatment Action Campaign (TAC) agrees: “HIV is a threat to South Africa’s development,” he says. “However, we can overcome this threat by ensuring that mother-to-child transmission prevention is implemented in clinics throughout the country and by introducing anti-retroviral treatment programmes in the public sector for people with HIV who have developed AIDS.

“The situation in Gauteng, Western Cape and KwaZulu-Natal is improving with a steady roll-out of mother-to-child transmission prevention. We believe the North-West Province is also making an effort. However, the TAC is unhappy with the roll-out in a number of other provinces, particularly Mpumalanga, where nothing seems to have been done.

“On the positive side,” Zackie adds, “the national director-general of health has assured us that efforts are being made to implement the judgement of the Constitutional Court. This is the first step in the government’s moral obligation to develop and implement a comprehensive treatment plan that will save hundreds of thousands – even millions – of lives.”

Adds Glenda: “More than half the children admitted to the Chris Hani-Baragwanath Hospital are HIV infected, and two-thirds of all deaths among children in our hospital are HIV-related. This occurs because mothers didn’t receive any interventions during pregnancy, which I find totally unacceptable.

“HIV infection in children is preventable by using simple interventions during pregnancy and labour, and I believe we all have a moral and ethical obligation to make sure the children in our country are born uninfected. These are our future leaders and without programmes like this – without the free availability of Nevirapine to every pregnant infected mother – we face their decimation.”

*(*Not their real names.)*

(Source: True Love, November 2002.)

Blood transfusion

Blood transfusions, occupational injuries and needle stick injuries, when a healthcare worker is pricked by needle previously used on a patient with HIV/AIDS, are the other main ways of getting HIV/AIDS. Untreated HIV infected blood will almost certainly result in the recipient becoming infected with the virus, as will organ transplants. Occupational injuries, including needle stick injuries, carry varying amounts of risk. The chances of being infected can be lowered if the person potentially exposed to the virus is given anti-retroviral therapy.

Testing for HIV

Most tests do not actually measure the presence of HIV in bodily fluids; rather they look for the antibodies – the signals that the immune system is fighting HIV. Some tests do look for the virus itself, but they tend to be expensive and not as widely used. The usual anti-body tests are regarded as extremely accurate.

Usually it is the blood of a person, which is tested for HIV, but there are also tests for saliva and urine. Saliva and urine tests are regarded as slightly less accurate and so should not be used for diagnosing HIV infection without a confirmation from a different kind of test.

Rather saliva and urine tests are widely used for anonymous surveys to find out the level of HIV infection in a particular group. They are particularly used by employers to get some idea of what proportion of the workforce may be HIV positive.

There is a window period when someone is newly infected with HIV, and their body will not yet have manufactured the antibodies to the virus. This period, prior to seroconversion (from a negative test response to a positive one) is also a time when the person is highly infectious.

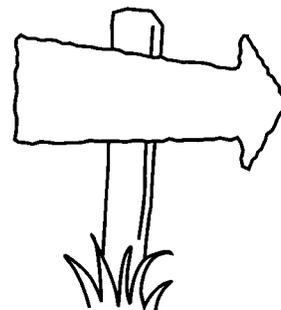
Like all other medical tests, HIV tests are not infallible, but they are highly unlikely to give the wrong result. HIV tests have to be accurate and sensitive. Accurate means they identify which samples are infected with HIV. Sensitive means they identify which samples are not infected. So an accurate and sensitive test will reduce the chances of getting the wrong result.

But, people do get misdiagnosed. This can be because of shoddy work in the laboratory; it can be because they have not yet seroconverted; or it could be because some other infection is confusing the test. This is why ideally people are not diagnosed as being HIV positive on just one test result.

In practice in poorer countries, doctors often make a clinical diagnosis of HIV/AIDS. They look at the physical state of the patient, consider the illnesses he or she has and decide whether they have HIV/AIDS. The odds are that a very thin and wasted woman with Kaposi's sarcoma, oral and vaginal thrush, and constant diarrhoea has HIV/AIDS.

Unless having a definite diagnosis will change the treatment or prognosis for the patient, doctors sometimes do not do the blood test. Without access to anti-retroviral treatment, and with the stigma surrounding HIV/AIDS in many communities, an individual may be better off just being treated for their symptoms. Especially if doing an HIV test is going to use scarce resources of either the patient or the medical facility.

See also exercise five, Chapter three (Communicating HIV/AIDS) on sending reporters out to get tested during training; as well as the article in **Handout eleven** – “Time for A New Start”



Drug Treatment for HIV/AIDS

The first ARV identified and used was AZT. It was used as mono-therapy – i.e. only AZT was given to patients. Although it had a miraculous effect initially, the impact of the drug rapidly wore off as it took just one mutation of the virus to make it immune to AZT.

Box ten: What are anti-retroviral drugs

Anti-retroviral drugs are chemical compounds that either kill retroviruses, or prevent them from replicating so that when the existing virus particles die, they are not replaced. Sometimes anti-retrovirals are known by the more general name of antivirals – drugs that work against viruses – and are often referred to as AIDS drugs.

Reverse transcriptase inhibitors interfere with reverse transcriptase, the enzyme used by HIV to hijack the DNA of human cells and make them produce more HIV.

Protease inhibitors work by interfering with the creation of the protein coat around HIV, again preventing the creation and release from human cells of fully functional virus.

For further information on antiretroviral therapy, drugs, and different forms of therapy, a good starting point on the Internet is the HIV InSite website. www.hivinsite.com or alternatively www.thebody.com

The next step in anti-retroviral therapy was duo-therapy, when two drugs were given together. This means that if the virus is immune to one drug, it should still be vulnerable to the other. Some drug combinations also reinforce the effectiveness of each other – AZT/3TC for example.

The discovery of protease inhibitors, which really came onto the market in the West in 1996, heralded Highly Active Antiretroviral Therapy or HAART.

This is the so-called “gold standard” of antiretroviral therapy today. Usually three different drugs are given, each killing or preventing reproduction of HIV in a different way. Even if a person has a virus population, which is immune to one kind of drug, it will succumb to one or both of the others.

Effective though triple therapy is, it is not infallible. Some people cannot handle the side effects of three highly toxic and powerful drugs at once. Sometimes the drugs damage the patient so much that he or she has to stop taking them. Doctors in the US report more patients dying as a side effect of the drugs, than as a result of HIV/AIDS. But, they balance this against the fact that the patients would probably have died years earlier if they had not taken the ARVS.

The trend seems to be that the longer you take drugs the less effective they get, because HIV eventually mutates to such an extent, that it can cope with all three drugs. This drug resistance is probably the biggest problem in treating HIV, if you exclude access to resources.

Box eleven: Drug resistance

There will be many differences between virus particles in any given person. These differences may be slight, the result of different mutations as virus particles replicate. Among those mutations will be some that confer immunity to one or another anti-retroviral drug.

As a person takes the drug, the virus particles, which are immune to it, manage to duplicate while the particles, which are not immune, do not replicate as successfully, if at all. The result is that after a while the drug resistant form of the virus will become most common. When this occurs the side effects and health risks of taking that drug outweigh any potential benefits, and the patient must stop taking it.

Multi-drug treatment, using two or more drugs together, attempts to get around this problem. A virus population that is resistant to one drug should not also be resistant to another, and so the second compound will kill it

But for this to work the patient must be taking the treatment properly – and that means taking their medicines exactly as prescribed. If this adherence to treatment falls below about 95 percent, then the patient will almost certainly become resistant to the drug. Unfortunately, this also tends to mean that it is resistant, to varying degrees, to all other drugs in the same class. And since there are only four classes of drugs, someone who doesn't take their treatment properly will fairly quickly become at least partially resistant to all the available anti-retrovirals. This is one reason why some people are taking four or even five drugs together as they try to exploit any vulnerability on behalf of the virus.

Drug resistance does occur even when patients fully comply with their treatment regimes. The ideal is for patients to stay on one particular drug combination for as long as possible before having to move onto the next. Hopefully this way new drugs will be discovered before the patient becomes resistant to all the existing ones.

Who gets treated?

For most low and middle-income countries, anti-retroviral treatment is available to those who can afford it. This may mean travelling to another country with doctors who are experts in treating the disease – South African doctors say they have many patients who fly down from other African countries for anti-retroviral therapy.

The most obvious problem in getting anti-retroviral therapy is the cost of the medicines. Pressure by local and international activists has seen a dramatic fall in the price of anti-retroviral drugs from thousands of dollars to hundreds in some cases. And the prices in South Africa at least look set to fall further under ongoing legal pressure from the Treatment Action Campaign and others. For more information on this complicated and long running debate start with the websites of the Treatment Action Campaign, www.tac.org.za and the Consumer Project on Technology www.cptech.org.

The publicity about the treatment means that more people are aware of, and want access to anti-retrovirals. But, lowering drug prices is having some unexpected hazards. In particular people are being treated by doctors who do not understand the complexities of anti-retrovirals and may inadvertently kill or fail to help their patients. Alternatively, they may only be able to afford one or two anti-retrovirals with consequent risks of drug resistance, or perhaps be unable to afford proper monitoring tests.

There are also growing anecdotal reports of people buying anti-retrovirals on the black or grey market and not knowing whether they are indeed getting the proper drug, or a fake. Blood tests should pick up if someone is not being given the proper drugs – but they have to be able to afford the tests.

Probably the most common way of accessing such treatment is through employers or private medical schemes.

Employment-related treatment

Increasingly, employers are recognising the benefits of giving proper care, including anti-retroviral therapy to employees. Largely this is due to self-interest, in a continent that suffers a shortage of skilled labour, it can be cheaper and easier to keep the workers you have alive, rather than let them die and have to search for new employees.

Box twelve: Case study of Debswana

The Debswana diamond company is half owned by De Beers and the Botswana government. It is estimated that one in three adult Batswana is infected with HIV/AIDS. Debswana has announced that it will give anti-retroviral drugs to all employees who needed it, and one dependent. In South Africa, a growing number of employees have had access to anti-retroviral therapy through their private or employer medical schemes. However these individuals tend to be of higher socio-economic status, and have lower prevalence rates. To some extent therefore, Debswana's move is regarded as a test of just how well mass anti-retroviral therapy can be given.

Media reports on employee access to antiretroviral drugs rarely look at the gender implications surrounding the issue. If men are more likely to be formally employed than women, and especially if they tend to be in higher level jobs, then they are more likely to get access to anti-retroviral treatment.

Similarly, the kind of employment matters since companies may be willing to give antiretroviral therapy to permanent employees, but not to contract workers. This has resulted in a spate of outstanding of perceived high-risk job categories as companies try to limit the effects of HIV/AIDS they face.

The issue of giving antiretroviral therapy to a dependent or dependents is a minefield, particularly in environments of migrant labour.

Exercise three

Break participants into groups and ask each group to answer the following questions and to give feedback on their discussion in plenary.

- What are the practical and emotional difficulties when a family faces limited access to anti-retroviral drugs?
- How easy would you find it to take a life saving drug, while watching your children and/or spouse die of the same disease?
- Would you want to/try to share the drugs? If so, what would be the likely result?
- Some companies put a financial limit on the amount of medical care a family can receive in one year. Do you think women would be expected to put the health of their husband above their own?
- Is a woman who is able to get anti-retroviral drugs likely to face more pressure to not take or share her drugs with her husband than if the situation was reversed?



Tips for trainers: This exercise attempts to unpack the gender dimensions of treatment and the particularly difficult choices that poor women may face in accessing life-saving drugs.

Human guinea pigs

Clinical trials are, often quite rightly, controversial. They are often regarded as the poor becoming human guinea pigs and testing drugs they are unlikely to be able to afford. So the poor put their health at risk for the benefit of the rich.

In Africa this view has the added weight of race – poor black people in Africa are testing drugs for rich white Europeans. This viewpoint has been exacerbated by the undoubted abuses that have occurred during clinical trials, which after all represent a lot of money to the drug company and usually to the

people running the trial. Ethics have a tendency to get slightly obscured where money is involved, which is why there is a need for international clinical trial guidelines.

But, clinical trials often represent the only chance that people have of getting proper medical care. This is particularly true in the case of anti-retroviral therapy, where the drugs are very expensive and need trained doctors to dispense and monitor. Incorrect use of anti-retroviral drugs can kill a person faster than the virus alone will do.

Exercise four

Devise practical exercises for participants to find out what trials are going on, and for what companies, using what products. Some important questions include:

- Why are these medicines being tested in your country rather than in the country that the sponsoring company comes from?
- Obey the fundamental rule of journalism – follow the money. How much money do clinical trials bring both your country, the organisation running the trial and the doctors and nurses involved?
- Focus on one or two trials and look at the terms and conditions facing people taking part in them. What protections are there? What happens for example, if someone on a trial for anti-retrovirals gets a different illness, say a sexually transmitted infection, would the doctors running the trial treat them, and if so who pays? Are there any national guidelines on clinical trials? And if not, why not?
- Who is running the trial? Is it a private for profit company, a not for profit company, a research unit, or part of the public health sector?
- Who bears the real cost of the trial, the drug company or the public health sector? Consider – if someone on the trial gets sick as a result of the drugs is he or she treated in a state hospital or private one?
- In particular what happens when the trial ends? Do people who have been taking part continue to get the drugs? What are the short and long term implications for the health of the people concerned?
- How do the terms and conditions surrounding a clinical trial in your country differ from those that would surround a similar trial in the drug company's home country?



Tips for trainers: Almost certainly, the sponsored drug company is going to be from Europe or America. In addition, almost as certainly, a lot more trials will be underway than you expect. Try and assess if there are gender dimensions to these trials.

Other forms of treatment

One of the key factors to living successfully with HIV/AIDS is to reduce stress on the immune system. If the body has to use resources to fight many other infections, it will have less resilience at holding back a chronic HIV infection.

Helping the immune system can be done in a number of ways, from alleged immune system boosters, to improved nutrition. Similarly, treating or preventing opportunistic infections removes an added burden from a person's body. In some cases people are given a broad spectrum and cheap antibiotic, Bactrim, to take to prevent bacterial infections developing.

Public health measures such as improving access to sanitation and potable water also reduce the chances of other diseases that will strain the immune system. Relieving psychological stress is also important, which is where counselling and support groups can play an important role.

Monitoring and testing

The two main HIV/AIDS related tests are for viral load and CD4 count.

The viral load is the number of copies of HIV in a cubic millimetre of blood. The higher the viral load, the sicker the person is likely to be, and the more infectious they are. A person who is on successful anti-retroviral therapy, or whose immune system is still holding its own against HIV, will have an undetectable

viral load. This means that there are less than 50 copies of the virus in each ml³ of blood; it does not mean that they are no longer carrying the virus.

CD4 cells are part of the human immune system. HIV destroys them, and so the number of CD4 cells is used as an indicator of how strong a person's immune system is. One of the definitions of AIDS is if a person's CD4 count drops below 200/mm³. Internationally it is now recommended that people start anti-retroviral therapy when their CD4 drops under 350. At a certain level, the CD4 count becomes less meaningful. Whether a person has a CD4 count of 12 or 32, is somewhat irrelevant. Without anti-retroviral treatment, and possibly even with it, they are dying.

Anti-retrovirals are very powerful drugs and work by affecting the basic biochemistry of HIV. But, that means they can also affect the biochemistry of the person on the therapy, resulting in a number of potentially fatal side effects such as kidney failure. To prevent this, patients must have liver function tests and blood tests at regular intervals.

Unfortunately, these also tend to be a significant expense because while the cost of drugs may be coming down, the price of tests is not dropping as quickly. Increasingly activists are turning their attention away from pushing companies on the prices of anti-retroviral drugs, to demanding cheaper monitoring tests.

At the moment treatment protocols – the standard way of giving the treatment – is based on giving treatment in the US or Europe. Such protocols may not be the best for developing or middle-income countries. For example, the litigation conscious doctors in the US may be over-monitoring their patients in an attempt to prevent being sued by unhappy clients.

In Africa the main problem of treatment is scarcity of resources – doctors may rather choose to increase the intervals between monitoring because their patients or the state medical services cannot pay for more.

Gender, prevention, treatment and care

Exercise five

Divide the group into buzz groups to discuss whether there are gender dimensions to this holistic approach to treatment.



Tips to trainers: Women tend to be less likely to help themselves in these basic ways. The female role as nurturer can mean the woman of the household eats last, or least, if there is a shortage of food. Women are also more likely to be faced with caring for people who are sick, and their bodies are subjected to great strain by pregnancy.

handout forty

Gender, prevention, treatment and care

- Women are more likely than men to become infected with HIV through heterosexual transmission, yet women have few options open to them when it comes to treatment and care.
- Drug therapy is often out of reach for the large majority of poor women who comprise the highest numbers of those infected with HIV.
- The female condom, the only preventative method which gives women more control is slightly harder to use and is more expensive than male condoms.
- HIV-infected women often report discriminatory treatment during maternal and antenatal care.
- Preventative drug treatment, when available can cut parent to child transmission dramatically. But, PTCT programmes are not holistic and do not provide treatment for the mother.
- Men make up the ranks of those in formal employment, and are therefore more likely to gain access to antiretroviral treatment through employment-related treatment programmes. Dependents are often not included in such schemes.
- The HIV/AIDS pandemic has led to an increase in female-headed households.
- These households are poor and where care is required, it is provided by the women whose own care, if they have HIV/AIDS, is neglected.
- Families quickly fall into destitution when the male dies and his income, often the only one, is lost. Family resources often go towards the care of men, and when they die, the women left behind have little independent access to resources.
- In rural areas, where women are responsible for subsistence farming, their care burden reduces productive time in the fields, threatening the family's food security. Children are withdrawn from school to provide extra labour.
- Payment for drugs, in these situations, cannot be considered. The most pressing needs become food and money.
- When faced with little resources, the choice of who will be provided with treatment and care in an HIV-infected household, often favours men.
- Women are less likely to benefit from the effects of holistic treatment due to the burden of care they carry which puts stress on their immune system. The female role as nurturer can also mean that women eat last, or least, if there is a shortage of food, which means women are more likely to be malnourished than men.
- The HIV/AIDS pandemic has made apparent how false the savings are when the state cuts back on public expenditures for welfare and health care. These costs do not disappear; they fall to women.

("Turning the Tide, CEDAW and the Gender Dimensions of the HIV/AIDS Pandemic".)



Story ideas from this chapter

- Re-examining campaigns like “Breast is best” in light of the HIV/AIDS epidemic – an investigative piece on counselling and options provided to mothers in your country;
- Hard Choices – are women with HIV/AIDS the last to be treated? A story that explored this issue in the context of poor communities and community-based care.
- An investigative story on clinical trials of new HIV/AIDS drugs in your country.
- An investigative piece on the black market for anti-retrovirals.



Key learning points

- Women are more vulnerable to HIV infection during heterosexual transmission than men and have increasingly become the human face of HIV/AIDS, yet they have less access to treatment and care.
- The female condom is the only form of preventive method available to women, which gives them a measure of control for safer sex, but it is more expensive and less available than the male condom.
- Parent to child transmission puts more emphasis on the child over the mother. PTCT programmes are not holistic and do not provide treatment for the mothers.
- Employee access to anti-retroviral drugs is more likely to benefit men, since more men are formally employed than women.
- Campaigns such as the “Breast is Best” highlight many of the conflicting issues of treatment and care that have arisen for women and children in light of the HIV/AIDS pandemic.



HIV/AIDS Awareness Day at the Polytechnic of Namibia.