WORLD AIDS DAY2010

Briefing Paper

HIV and AIDS do not stigmatise - People do

> *Stigma and discrimination demean individuals affected by HIV and AIDS and make it more difficult to deal effectively with the disease. When those living with HIV or AIDS or their families are stigmatised, they are discredited, discounted, considered to have lesser worth in our eyes, and often also in their own, merely because they are HIV-infected and for no other reason.*
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> *Africa has so much AIDS because of its "terrain" of poverty and income inequalities; hunger; poor health; education and social welfare systems; unemployment; trade exploitation; global marginalisation (except when it is necessary to extract its natural resources); massive global patronising and stigmatising; in addition to the corruption, poor governance and conflicts that may owe as much to external as to domestic circumstances.*
>
> **Professor Michael Kelly SJ**

It is difficult to believe that up to 16% of the Zambian population is infected with the HIV virus. It has almost become normal. We want to forget about this disease. The government is also not eager to talk about the epidemic. This is what we often refer to as the *'normalisation'* of the epidemic.

This normalisation of the epidemic is largely made possible by the stigma that surrounds HIV and AIDS.

For example, as a result of stigma:

- Women are often unable to discuss the HIV virus with their husbands or partners and how to protect their family against infection with their husbands
- Couples living together may not share their HIV positive status with each other and/or the fact that they are on Anti-Retroviral Therapy (ART)
- People are afraid to disclose their HIV status to others and ONLY 16% of the Zambian population knows what their status is

HIV related stigma often prevents people from going for testing and counselling.

HIV related stigma is an immense problem that lies at the centre of the HIV and AIDS epidemic in Sub Saharan Africa. We believe that it is necessary to understand and analyse stigma and to decide on ways to effectively reduce the hold it has on our societies.

Understanding stigma and its results

The word ‘stigma’ comes from Latin and means to ‘mark’, ‘brand’, or ‘sign’.

AIDS-related stigma refers to the prejudice, the negative attitudes, the abuse and mistreatment directed at people living with HIV and AIDS.

The main reasons for stigma include incomplete knowledge, fear of death and disease, dominant sexual beliefs and values, ongoing myths and misunderstandings and a lack of effective recognition of stigma and its results.

Three types of stigma associated with HIV and AIDS:

- **Stigmatising yourself** — people often feel ashamed, often blame themselves and may even begin to hate themselves. They often feel they are being unfairly judged by others so they may isolate themselves. People Living with HIV and AIDs (PLHAs) often practice ‘self-stigma’, isolating themselves from their families and communities.
- **Others regularly stigmatise** — as a result of attitudes and beliefs in the community, people routinely stigmatise others living positively often with serious negative results
- **Practising discrimination based on stigma** — it is one thing to unfairly judge people but often others go further, taking unfair and discriminatory action against those living positively. This can have huge negative impact not just on those infected but also on their families etc.

Stigma is a process where:

- Differences among people are pointed out with disapproval, for example, *‘He is different from us — he coughs a lot’*
- Differences are blamed on negative behaviour, for example, *‘Her sickness is caused by her sinful and promiscuous behaviour’*
- People may be divided into two groups *‘us’* and *‘them’* and on this basis, people may be shunned, isolated and rejected
- As a result, those stigmatised experience a ‘loss of status and respect’, they may experience discrimination and may even have their rights abused or denied.

As a result of stigma, people feel rejected, condemned, useless; they may lose their job, their housing or their positions in the community; they may leave school or community organisations and in extreme circumstances, it can lead to depression, alcoholism and even suicide.

‘In 30 years, Africa may only have old people and children’

This is how one child described the future of Africa in 30 years if we do not stop this epidemic. At the moment, for every person put on ART, two more become infected. Soon it may be impossible to treat all those infected and people will die again in large numbers.

In this context, it is very important that we directly challenge the stigma that surrounds the virus and begin to effectively discuss ways to stop the spread of the disease. This is not easy because HIV is a sexually transmitted disease and sex is a difficult topic to discuss.

HIV – Human Immunodeficiency Virus

- Everyone has cells in their body that defend and fight off diseases – these are known as CD4 cells or are sometimes called *‘soldier cells’*
- HIV is a virus that attacks the soldier cells making it difficult for them to do their job of fighting off infections
- Once someone is infected with HIV, they become more vulnerable to other infections or diseases such as tuberculosis (TB), malaria, diarrhoea, etc.
- When a person is infected with HIV, they are said to be HIV positive. It is not possible to tell by looking at a person that they are HIV positive
- When a person is newly infected they may not feel any different and the virus cannot be detected by a standard HIV test until the virus has been in the body for around 3 months
- When a person is newly infected with HIV, they will have a lot of the virus in their bodies and if they have unprotected sex or engage in other risky practices, the other person is at an even greater risk of becoming infected
- To be HIV positive does not mean that the person has AIDS. Someone who is HIV positive can still live a healthy life for many years by living positively and taking care of their body.

AIDS – Acquired Immune Deficiency Syndrome

- HIV is the virus that causes AIDS. As the virus continues to attack and destroy the soldier cells the immune system becomes progressively weaker
- When the body is too weak to fight infection, the person may eventually develop AIDS
- There is currently no cure for HIV or AIDS. No one will develop AIDS unless they have been infected with HIV

How you can become infected with HIV and the risk factors involved:

- Sexual intercourse: anal, vaginal, or oral with an infected person
- Sharing drug needles/syringes/razor blades with an infected person
- Blood transfusions/blood products
- Transmission of mother to child during pregnancy, birth or breast feeding

High risk

- Unprotected anal or vaginal sex (without a condom)
- Oral sex: ejaculation into a partner's mouth
- Oral sex: during menstruation
- Oral sex contact with the anus
- Deep kissing

Low risk

- Using a condom without ejaculation during anal/vaginal sex
- Oral sex without ejaculation into the partner's mouth
- Oral sex before and after menstruation

No risk

- Insect bites
- Saliva /tears/sweat /urine
- Any casual contact including kissing/hugging
- Sharing food/drinks/utensils/clothes
- Coughing/sneezing

Risky behaviour that contributes to the spread of HIV

- Multiple sexual partners (concurrent sexual partnerships)
- Herbs and drugs that lead to dry sex
- Sharing sharp instruments such as razor blades, needles, horns, etc. for tattooing or traditional healing
- Spouse inheritance – sexual cleansing
- Having unprotected sex
- Young girls who have not yet fully developed physically having sex or being forced to have sex
- Lack of knowledge about how to use condoms

Have yourself tested
Protect yourself when you have sexual intercourse
Protect your loved one especially if you are already infected

REMEMBER 16% OF US ARE ALREADY INFECTED BUT WE ARE ALL AFFECTED

VCT – Voluntary Counselling and Testing

- **VCT is voluntary** - no one can force you to take a test
- **VCT includes counselling** - a trained individual will explain the procedure and ensure that you understand and are happy to be tested
- **VCT involves testing** – it involves the taking of a small blood sample from you which will then be tested to determine your status.

What VCT allows you to know: your status

What VCT allows you to do: to take charge of your life

Because HIV infection can affect anyone, your race, occupation, sex, sexuality, or age cannot prevent HIV infection

When you go for VCT you have the right to:

- Health
- Know your status
- Confidentiality - your results will not be shared unless you agree
- Refuse to take the test
- Be free from discrimination and degrading treatment
- Continue to work under fair and satisfactory conditions
- Receive equal pay for equal work
- Treatment (Anti - Retroviral Treatment or ART)

Some reasons you might go for VCT:

- You have had unprotected sex
- You have been sexually abused or assaulted
- Your partner is requesting you to go
- You have experienced a number of Sexually Transmitted Infections
- You have lost a partner to a HIV related illness
- You are considering starting a family
- You had a number of sexual partners whose status is unknown to you
- You are unsure if your partner is being faithful
- You want to plan for the future and live a healthy lifestyle

The three stages of VCT

1. **Pre-test Counselling**
2. **Testing**
3. **Post-test Counselling**

During pre-test counselling you will be asked:

- *Why you want to take the HIV test now?*
- *What you know about HIV and AIDS?*
- *If you know how HIV is transmitted and how it can be prevented*

Then…

- It will be explained to you what is involved in doing the HIV test
- You will be told how the test will be carried out and how long the test result takes
- The implications of a positive or negative result will also be discussed
- If you are happy to proceed at this stage, the test will be done. If not, then a follow-up meeting can be arranged. Testing can be done at your hospital, local clinic or VCT centre and your blood is drawn for analysis using either a needle or a finger prick.

It is important to note that if your results are negative, you need to return after 3 months for a re-test because there is a time gap between when a person becomes infected with HIV and when HIV antibodies can be detected. Nearly everyone who is infected with HIV (99%) will have antibodies detected (if present) after 3 months. This is known as the Window Period.

During post-test counselling:

- The result will be given to you by the counsellor and you will be given time to respond
- You can talk about the Window Period and the need to retest after 3 months
- You can discuss sexual behaviour change and about other issues
- You can arrange another visit if necessary
- You can discuss who you should/might share the results with
- You will have a chance to talk about how you feel – it is normal to feel shock, denial, anxiety, anger, depression, fear, etc. and talk about future plans
- You will learn about support groups etc.

If the HIV test is POSITIVE

- you should find out what your CD4 cells count
- your doctor will advise you whether or not you should start on ART
- once you are on ART, your life expectancy and chance of becoming sick are the same as someone who is not infected.

It is very important that you start with ART as soon as possible

You also need to think about:

- **Partner notification/disclosure** - it is important to let your partner/spouse know your status; sharing information with those whom you trust will help you cope better, should allow for greater personal and family care and allow you to plan together for the future
- **Healthy living and living positively** You must readjust your life and take responsibility to care for yourself, your partner and family
- **Avoiding further risky behaviour** - you should avoid behaviour that could lead to re-infection or worsening of your health status; you should avoid excessive drinking, smoking, multiple sex partners, unprotected sex and unplanned pregnancy. You will really only begin living positively if you accept your status, if you pay attention to your diet, if you exercise, if you ensure you live in a clean environment and if you seek early treatment
- **Re-infection** - if you have unprotected sex with another infected partner, you will contract the virus again and make it more difficult for your ARVs to work and limit your health status and life chances
- **Supportive Counselling** - you should access professional social and psychological counselling to help yourself through the most difficult days following diagnosis. It is important to not only focus on your physical health but also on your mental and psychological health in the medium to long term. Support groups in local communities can give advice and assistance and should also be able to talk about how they dealt with being diagnosed.

Anti-Retroviral Drugs (ARVs) and related issues

ARVs are drugs you take to keep yourself healthy and to live longer after a HIV positive test result. You begin to take them when your CD4 count is low and **You MUST take them every day, this is very important.** Your doctor will advise you when and how to take them.

How do ARVs work?

The HIV virus multiplies very rapidly, more than 1,000,000 times in 24 hours, so in order to stall or stop the HIV virus from getting worse, you may need to take at least three different types of ARVS. Most people in Zambia are on AZT, 3TC and NVP (mornings and evenings) or on FTC, TDF and EFV (a once daily regime). If your CD4 count is low, it also helps to take Septrim, a common antibiotic drug that helps protect the brain and helps prevent pneumonia. Septrim also makes your skin feel better and prevents diarrhoea.

The way ARVs work is best described by comparing the drug with a sleeping drug. If you take your ARVs, the HIV virus simply falls asleep. When it is sleeping, the virus cannot multiply and the number of virus particles in your blood stream will rapidly drop.

In order to keep the virus sleeping, you have to take your ARVS every day. If for example you take your ARV once per day (in the evening), and you forget to take the drugs one evening, around 4 am when you are still sleeping, your virus will wake up and will start multiplying again. This is a very dangerous situation. The newly formed viruses will have a look at the drug in your blood and will find out how the ARVs work. The ARVs will no longer be able to put the virus to sleep again. This is what we call resistance.

The virus multiplication is no longer stopped by the drugs. Your CD4 cells will go down again. You will develop diarrhoea, your skin becomes sick and you will start losing weight. Your doctor will conclude from this that your ARVS have stopped working. Your first line drugs have stopped working (resistance) and you will have to switch to another type of treatment (second line treatment).

Second Line Treatment - second line treatment always contains the ARV called Kaletra (LPV/r) in combination with two other drugs. Once you are on second line, you should be very careful not to miss taking your drugs. If your virus also finds out how your second line drugs work (resistance against second line), there are no more possibilities to treat you.

Third Line Treatment - there is a third line of treatment with drugs called Raltegravir and Maraviroc but these are extremely expensive. Maraviroc will cost US$300 per month and Raltegravir US$270 per month, so third line treatment will cost approximately 4 million kwacha per month – IT IS NOT FREE.

How long can you stay alive on ART?

The life expectancy of a person on ART is the same as a person who is not infected.

For how long are you to take the ART?

Once on ART, your CD4 cell count will start going up. Some people even reach a CD4 cell count of 1200 cells which is a normal non-infected CD4 cell count. These people should still continue to take their drugs every day. The virus is only sleeping and hiding in your brain and other places that are difficult to reach. The only time that someone who is infected with HIV is allowed to stop treatment is when we find a cure.

Prevention of Mother to Child Transmission (PMTCT)

The chance of infecting an unborn child if you are HIV infected is approximately 40%. This means that almost 1 out of 2 children born to mothers that are HIV infected (and are not on ARVs) will be born with the HIV infection. The virus is transmitted when the baby is in the womb of the mother and through breast milk. All pregnant mothers should be tested for HIV infection. If they are found to be infected, they are put on ARVs. This reduces the chance of infecting the unborn child significantly, even up to less than 1%. Where PMTCT is practiced, a child's chance of survival increases. The health of the mother and child also improves.

Should HIV positive women have children?

With ARVs (PMTCT), the chance of infecting your baby with HIV is very small. The pregnancy in itself is no longer dangerous when a woman is taking ARVs. With ARVS, women have the chance to help their children grow up to become healthy adults. It is therefore possible for HIV infected women to have children in a safe and responsible way. Please talk to your ART doctor about your wish to become pregnant. He or she can advise you on the best timing of your pregnancy.

HIV and children

Children do very well on ARVs. Today, we estimate that approximately 150,000 children in Zambia are living with the virus but only 10,000 are on ARVs. On ARVs children can develop, play, learn and grow up to be healthy adults. As babies have an immature (not fully developed) defence system the majority of the children that are infected with the virus around delivery and through breast milk die before they reach their second year in life.

It is therefore very important to prevent infection in children through PMTCT and test children as soon as possible after they are born (6 weeks after birth) and babies that are found to be HIV positive should be started on treatment immediately. **Early infant diagnosis saves lives!**

As with adults, children may have side effects from ARVs but your doctor will keep an eye on this and can change or switch any other drug whenever there is need to do so. It is very important that children are weighed during every visit and the drugs dosage needs to be adjusted to the changing weight. Children have much higher viral loads than adults, so it is vital that they take their drugs every day and never miss in order to prevent resistance.

Children should have one primary caretaker that is responsible for the child's ARVs. This caretaker is the one who accompanies the child to the ART clinic and gives the drugs every morning and evening.

Since the start of ART programme in Zambia in 2004, 300,000 Zambians have started taking ARVs. Zambia has approximately 12 million people and a HIV prevalence rate of 16%. This means that there are approximately 2 million inhabitants infected with the virus. The 300,000 people who are currently on ARVs are lucky that they have the possibility to access these life-saving drugs. In time all 2 million people that are HIV infected will need ARVs.

When to start taking ARVS?

In Zambia, guidelines say that everybody should start treatment at a CD4 cell count of 200 cells. Latest research data reveals that when started at a CD4 cell count of 350 cells, your life expectancy is best. The World Health Organisation therefore recommends ART should start at a CD4 cell count of 350 cells.

ARVs in Zambia

There are 20 different drugs from 3 drug types or groups available in Zambia and are most often administered in two drug combinations - first line and second line treatment. The choice of drugs to take can depend on a number of factors, including the availability and price of drugs, the number of pills, the side effects of the drugs etc.

It is very important for you to know the names of the ARVs you are taking.

ARVs side effects

All drugs have side effects. Most ARVs are very well tolerated and people have stayed on the drugs without any problems for up to 30 years. If you have side effects from one drug you can switch to another. This is why your doctor should check your HB, liver and kidney function tests at least once every year. **Try not to take medication on an empty stomach.**

HIV and AIDS: a cure?

ARVs are a treatment, not a cure. If you stop taking your ARVs, the virus will return. If you do not take your drugs every day, the ARVs will stop working (resistance).

Scientists all over the world are searching for a cure and we believe that cure will come. As Nelson Mandela has said *‘we will find a cure, it may take five or ten years, but we will find it. People that are HIV infected should be kept alive till the moment that the cure will be available’.*

The way to stay alive is by taking your ARVS and taking them every day. But, until we find that cure, everyone who is HIV infected will need to start on ARVs.

What about male circumcision?

Male circumcision is simple and common surgery that is done to remove part of the foreskin that covers the tip of the penis (male private part). Male circumcision reduces the risk of getting HIV by 60% but must be performed by trained health workers under safe and clean conditions. It also reduces the risk of getting other Sexually Transmitted Infections (STIs).

Male circumcision does not provide 100% protection; it only reduces the risk by half. It is therefore very important to protect yourself against infection with HIV through other methods (abstinence, being faithful to one sexual partner, and by condom use)

Basic hygiene principles to be applied in the home to protect everyone

Adapted from "HIV AIDS Care and Counselling", 2008, Alta van Dyke, Pearson Education South Africa: 360

- Wash your hands with soap and water before cooking, eating, feeding another person or giving medicine, after using a toilet or changing nappies, after changing soiled bed linen and clothing, and after having contact with body fluids.
- Use soap in a pumper dispenser rather than bar soap, if possible, because soap in a dispenser cannot be easily contaminated. If soap is not available, boil your own soap or use herbal or traditional alternatives.
- Keep wounds (small and large) covered with waterproof bandages or cloth. If these are not available, use a leaf or plastic wrap.
- Keep kitchen and bathroom surfaces clean at all times so as to prevent fungal and bacterial growth. Household bleach such as JIK is effective and cheap to use for cleaning.
- Keep bedding and clothing clean. This will help to keep sick people comfortable and prevent skin problems.
- Do not share personal items such as make up or anything that may pierce the skin, such as toothbrushes, razors, needles, or anything else that can cut or come into contact with blood. If any of these objects must be shared, boil it in water for at least 30 minutes before use.
- Use clean water whenever possible and boil drinking water, especially water that is going to be given to young children.
- Store food properly to prevent it from spoiling and causing infection
- When someone in the family is ill (with flu for example), wash drinking cups with water and soap before you share them.
- Cover your mouth and turn your head away when you sneeze or cough.
- Wash eating utensils, including items for babies, with soap and water.
- Wash all raw fruit and vegetables with clean water.
- Wash objects that a child or infant frequently puts in its mouth with soap and clean water.

Popular myths or untruths linked to HIV and AIDS

- Sexual intercourse with a virgin will cure AIDS **MYTH**
- Sexual intercourse with an animal will avoid or cure AIDS **MYTH**
- HIV antibody testing is not reliable **MYTH**
- AIDS can be spread through casual contact with an HIV infected individual including their sweat, tears, urine & Faeces **MYTH**
- HIV cannot be transmitted through oral sex **MYTH**
- HIV is transmitted by mosquitoes **MYTH**
- Condoms, foodstuff or drugs contain HIV **MYTH**
- Only sex workers/gay men can contract HIV **MYTH**
- Showering after intercourse will prevent AIDS **MYTH**
- HIV can infect only homosexual men, drug users and sex workers **MYTH**
- An HIV-infected woman cannot have children **MYTH**
- HIV cannot be the cause of AIDS because the body develops an antibody response to the virus **MYTH**
- Your blood will be used in rituals after testing **MYTH**
- Only a small number of CD4+ T cells are infected by HIV, not enough to damage the immune system **MYTH**

HIV and AIDS and Human Rights

HIV and AIDS are not just a health issue – they are a fundamental human rights issue.

Poverty in Zambia plays a major role in the spread of HIV as it denies people their basic rights – often forcing them to make negative life choices that can increase the risk of infection. When human rights are ignored or abused, an individual's or communities' vulnerability to HIV infection increases. Human rights can be denied through:

- **Education** - the lack of basic HIV and AIDS information and education with frequent misinformation leads to misunderstanding of the issues and contributes to the spread of HIV.
- **Health** - the cost and limited access to health services - including treatment for HIV and AIDS - the provision of condoms, access to PMTCT and treatment for STI's can lead to the premature loss of many lives, particularly in rural areas.
- **Shelter** - property grabbing which often takes place after the death of a spouse.
- **Water and sanitation** - without clean, safe and reliable drinking water and sanitation the body is at risk of a reduced immune system, which is essential in avoiding and fighting infection.
- **Lack of food nutrition** - poor diet dramatically limits the body's ability to fight infection and increases the chance of progression from HIV to AIDS.
- **Stigma and Discrimination** affects the struggle against HIV and AIDS as infected and/or affected individuals may be discouraged from disclosing their HIV status and as a consequence not accessing information and vital services.

> ***'Briefly, then, one can say that the more HIV and AIDS, the less justice—but the more justice, the less HIV and AIDS.'***
>
> **Michael J Kelly SJ 2006**

To put an end to stigma, we need to replace:

Fear with hope:
we must constantly affirm that there is life after HIV infection, there is life with AIDS

Ignorance with knowledge:
everybody needs to know that HIV is hard to transmit and cannot be caught by casual contact

Blame with respect:
there is a never-ending need to remind ourselves that every person has an inherent dignity and basic value that nothing can take away

Human concerns about promiscuity and lifestyles with broader understanding:
there is need to deepen the recognition that AIDS highlights many failures in the policies, functioning and structures of our society

Shame and denial with solidarity and openness:
it is necessary for every one of us to acknowledge that we are all in this together

YOU CAN MAKE A DIFFERENCE BY

LISTENING CARING EDUCATING
BEING SYMPATHETIC BEING NON-JUDGEMENTAL

**Published by 80:20 Educating and Acting for a Better World
and Art4Art, Lusaka in support of World AIDS Day 2010**