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Culture and Health Programme
AIDS Foundation of South Africa
237 Musgrave Road
Durban 4062
South Africa
Tel +27 (031) 277 2721
Fax +27 (031) 202 9522
Website: www.aids.org.za

Glossary of Terms

Adherence - means a person taking his or her medication correctly (time and dose) for as long as prescribed

ART – Anti retroviral treatment

ARV –Anti retroviral

Disclosure - Sharing information that was previously private knowledge, such as HIV status

Drug- Medicine.

Immune reconstitution syndrome – the effects of ART in lead to the immune system to recognising and unmasking hidden infections, t so that it he immune system will try to ride facts against those infections and that. The shock of this sudden strengthening of the immune system can lead to a person getting sick from a number of illnesses.

MDR – Multi drug resistance TB

OI's- Opportunistic infections.

Regimens – the A regimen is a combination of medicines and instructions for how to take the ARVs m, including dosage, schedule and length duration of treatments.

Resistance – the ability of certain micro-organisms to withstand drugs. If a patient has been on treatment for a long time or doesn't adhere to the medication, it can become less effective in fighting the virus they can develop resistance this is when medication stops working for them.

Side effects – are secondary or unwanted effects of drugs.

STIs – Sexually transmitted diseases

Symptoms - Changes in the body indicating that show a person has athe disease.

TB – Tuberculosis.

Triple therapy- treatment compromises of 3 tablets anti-retroviral drugs used at the same time.

Virology – The study of viruses.

Introduction

HIV/AIDS treatment literacy and behaviour change

How many of us know that exercise is important for health? Obvious, yes? How many of us get enough exercise? Not as many!

We all know that information does not translate automatically into knowledge and knowledge does not lead automatically to changes in attitude and behavior. The majority of people in South Africa have been exposed to information about how HIV is contracted, how it can be prevented and how it can be treated. Yet infection rates continue to rise, unplanned pregnancies continue and babies, children, mothers, fathers, brothers and sisters continue to die.

As we begin this course, it is estimated that 5.63 million adults and children are infected with HIV and AIDS. That is 17.8% of the adult population (aged 15-49). Of those people, just under 1.6 million need anti-retroviral (ARV) treatment but only 791,000 are currently on ARVs . This is partly because the government has not managed to make treatment accessible to everyone who needs it but also because many people still do not test or seek treatment when they become sick.

There are many reasons for this. Even though we are more than two decades into the epidemic, there is still much stigma attached to HIV/AIDS. Some of this is due to the fact that most HIV infection is sexually transmitted and there are taboos and denial around sexual behavior. Some stigma is due to the fact that for many years before treatment was available, diagnosis of HIV was seen as a 'death sentence'.

While it is important that everyone understands the ways in which HIV can be treated and patients can be managed and supported, that knowledge alone will not change the behaviours that spread the disease.

Therefore, as we look at all the different factors in keeping a person living with HIV/AIDS alive and healthy, we need to examine carefully how to share knowledge in a way that is meaningful, appropriate and useful to people in different cultural contexts. People have different belief systems, different cultural understandings of health, sickness and death, different lifestyles and different treatment and support needs.

This training guide, in focusing on treatment literacy and behaviour change, explores the following topics:

- Facilitation skills to reach the communities you work with
- Psychosocial support, including indigenous approaches
- Basic HIV science
- STIs and HIV
- Behaviour change
- Anti –retroviral treatment.
  HIV, Nutrition and traditional medicine

Overview

Purpose of the manual

This training manual is designed to equip facilitators and organizations with knowledge, skills and attitudes needed to address issues of HIV/AIDS status disclosure; stigma; adherence and support.

Who is the manual for?

The manual is primarily intended for trainers working in community-based projects who are interested in educating communities about the biology of the HI virus and AIDS, what this means and how it infects the body.

What does it cover?

This manual explores the basic biology of HIV/AIDS and related infections such as Sexually Transmitted Infections (STI's). The manual also looks at how this influences behavioural change as well as coping mechanisms to work against stigma and discrimination that an individual may experience. This training manual attempts to educate the participants and trainers about basic HIV/AIDS literacy and treatment such as Anti-Retroviral Treatment, legal issues and nutrition. It is a two-way process where both participants and facilitators share knowledge and learn together.

How to use the manual

The manual has been designed for a four-day training of trainers' workshop. Each day has practical activities to encourage participants to discuss and identify issues relating to their daily lives and local contexts. It can also be used as a source when using other training materials.
The manual modules use various training methods: formal classroom training, role plays, case studies, discussions and brainstorming.

Module 1: Re-cap on facilitation skills

By the end of this module the participants will be able to:

- Use the methods and tools of facilitation.
- Facilitate treatment literacy training in their communities.
- Plan and monitor their training workshops.

ELEMENTS OF FACILITATION

- As a facilitator you need to understand different elements of facilitation and integrate them.
- As a facilitator your whole self should always be present in the group and you need to be comfortable with your self.
- You need to able to notice what is happening in the group, this includes energy levels and the behaviour of individuals.
- As a facilitator you need to know when and how to intervene in a group situation, your decision to intervene is based on your interpretation of different things that you have noticed and the meaning that you have made out of your observation.

METHODS AND TOOLS FOR FACILITATION

Questions – questions are one of the main tools we have to work with in facilitation, and they are valuable because they get people to think

Individual reflection – This is often good to do before participants respond to a particular topic or issue. You can give them the opportunity to reflect on their experiences – and this is useful to gain material that you can all learn from that will allow each person to learn from the others.

Plenary – Occurs when all participants discuss an issue together in a big group.

Small groups – At certain points of the training is a good idea to divide people into smaller groups, which allows for greater participation as each person has a chance to say something on the same topic. May also encourage shy participants to speak up.

Case studies –These are usually real stories of how a particular problem was handled, participants engage with this story to draw insight for them selves and how they deal with the similar situation.

Role plays – The purpose of the role play is for participants to play out certain roles according to a scenario. While pretending to be someone else, they have to think about how that person would act and behave, thus forcing them to try and understand the motivations for such behaviour.

Brain storming –This is a quick way to get ideas from the group. There are no right or wrong answers.

Ice –breakers –These exercises help people to loosen up and relax, this can be done through games, singing and warm up exercises.

PLANNING, MONITORING AND EVALUATING A TRAINING WORKSHOP

1. Planning

In the case of the treatment literacy, the material and frame work have already been developed, you are free to add creative ways of presenting information to keep your participants alert and engaged in a process.

Don't forget to make plans for monitoring and evaluation of the workshop before it starts. If you forget to plan before the workshop, it will be hard to try and fit everything at the end of the workshop.

2. Target group and venue.

First decide on your audience, consider the unique things about this group, such as their gender, age and cultural background. The choice of venue can make a big impact on how comfortable people are.

Here are some questions you can work with when you begin to think about venue:

- Will it be easily accessible?
- What kind of a working space do we need?
- Will there be many things there to distract us?

3. Evaluation

The focus of this type of evaluation is on the participant's ability to demonstrate their understanding and awareness of the things presented in the workshop, It can be done when the workshop has finished. By hearing or reading their responses you will be able to tell if they learned what you set out to teach them.

Questions to ask:

- Have the participants learned the workshop content?
- Can they demonstrate that in some way?

Module 2: Psycho-social support

LEARNING OUTCOMES:

By the end of this module the participants will be able to:

Unpack the meaning of the word psychosocial

Understand the function of psycho social support

METHOD:

Participants brainstorm what they understand by psycho-social

In smaller groups they list the advantages and disadvantages of psychosocial support.

What does psycho-social mean?

- Psycho- to do with how people think and feel
- Social- to do with a patient's social environment – their home, community, job and entertainment.

What is psychosocial support?

- Psychosocial support is to assist the person living with HIV and AIDS to use healthy coping mechanisms, maximize positive aspects and enhance supportive relationships, needs and interventions should be taken simultaneously in context of family members, community and friends with whom the person is involved.
- What is the role of traditional healers in providing psycho-social support ?

Supporting HIV+ people

- HIV/AIDS affects people of all ages, stigma and moral judgments are often made on persons lifestyle, once it is revealed that he/she has HIV.
- People living with HIV/AIDS are often reluctant to seek help until very sick because of this, often the most meaningful form of support for a person living with HIV/AIDS is achieved by assisting their network, i.e. spouse/ partner, family , friends, community members.

EXERCISE:

In smaller groups participants must share advantages and disadvantages of psychosocial support in their communities and how this relates to ARV treatment and positive living.

Psychosocial assessment

What is psychosocial assessment?

It is to see what the persons life is like regarding the way he thinks,feel and lives .

- For us to be able to support our clients holistically we need to be able to understand their beliefs, social situations, disclosure issues, acceptance of their HIV status, their support system , nutritional and financial situations.

PSYCHOSOCIAL ASSESSMENT CHECKLIST

What kind of lifestyle does your client have?

What support systems does he/she have?

Has your client accepted his/her HIV status?

Has s/he disclosed to anyone?

Are there other sick people in the family?

Does he/she have alcohol or other drug issues?

Are there any opportunistic infections she/ he has experienced and how did s/he deal with those?

Does your client or anyone in the family have a regular income?

Module 3: HIV Basic Science

LEARNING OUTCOMES:

By the end of this module, the participants will be able to:

- Know how to use HIV knowledge to assist adherence.
- Explain what a CD4 count and viral load are.
- Understand the basics of the WHO staging system.

METHOD:

- Ask participants to draw a picture of what they think the HI virus looks like.
- Allow participants to share their own experiences on prevention methods.
- Divide participants into 4 groups where they discuss WHO HIV stages.
- Explain why people who have tested positive do viral load test and CD 4 count

What is HIV?

What is AIDS? Define the difference between HIV and AIDS.

THE IMMUNE SYSTEM

- The immune system of the body has several components which function together to protect the body from infections.
- Some of the cells that make up the immune system have specific receptors called CD4 receptors. HIV can infect cells that have this receptor.
- Once the cell has been infected by the HI virus it causes an auto immune response, where the immune system tries to contain the problem by destroying infected cells, over time the functioning of the entire of the immune system is highly impaired by the impact of the virus.

MODES OF HIV TRANSMISSION

HIV can be found in the blood, semen or vaginal fluids of the infected person

Sharing syringe needles for drugs

Contact with blood of someone who is infected

Vaginal or anal sex without a condom with someone who is infected

Mother- to- child transmission – during pregnancy, birth, or through breast feeding

Accidents or careless sterilisation in hospitals. For example, if a health care worker is pricked with a syringe needle (called a needle-stick injury) or cut with an unsterilised scalpel

RISK HIERARCHY OF HIV TRANSMISSION

The CD4 count test

- The CD4 count test is a measuring tool that is used to get an approximate measure of how damaged the immune system is.
- A sample of blood is taken and the number of CD4 cells in it is counted.
- A **normal** CD4 count ranges from 800 – 1200 cells/mm2
- Once the person is infected with HIV, the virus gradually infects and causes the destruction of more and more CD 4 cells, over time the CD4 count decreases.
- When the CD4 count drops the immune system weakens and the infected person become more vulnerable to infections.
- The presence of sexually transmitted diseases can increase the risk of infection.

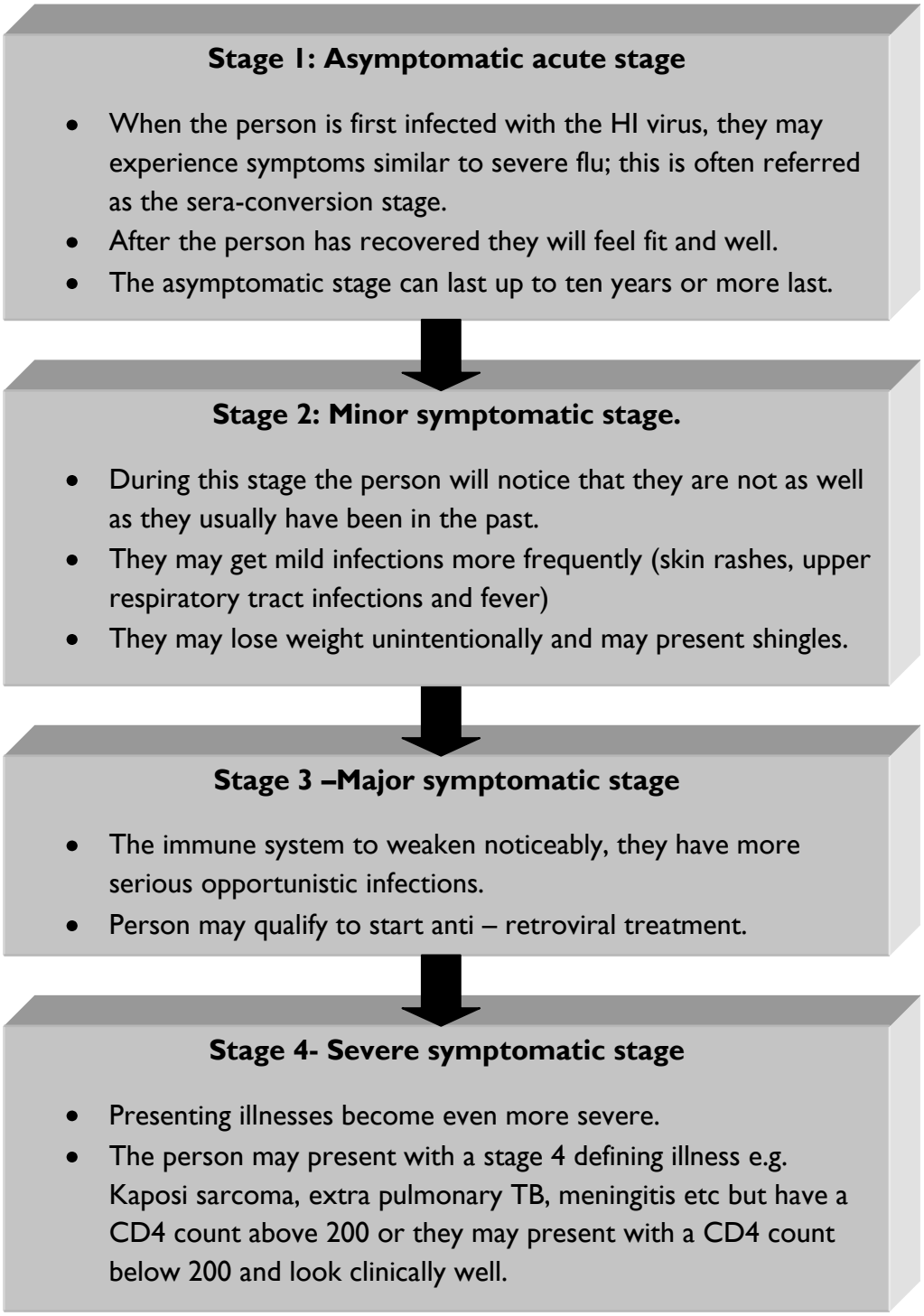
How does the CD4 count interact with the viral load?

The infected person's immune system and CD4 count are eroded over time until there are few remaining, there is therefore decreased resistance to infections, thus the viral load begins to increase again until death.

The viral load test

- This test is done to measure the concentration of the HI virus in the blood
- The virus replicates rapidly in the beginning stages of infection. When the person qualifies for anti-retroviral treatment this test is done frequently to measure the effectiveness of the treatment, including whether the client is adherent to ARV medication.

The four stages of HIV progression according to the World Health Organisation (WHO)



Module 4: The relationship between STIs and HIV

LEARNING OUTCOMES:

By the end of this module, the participants will have:

- Increased understanding of how STIs affect the human body.
- Discovered relationship between STIs and HIV.

METHOD:

- Ask participants if they understand the relationship between STIs and HIV.
- Brainstorm the common STIs, causes and what is commonly used to cure those STIs in their communities.
- Ask participants what can be used to prevent STIs, and different types of prevention methods

RELATIONSHIP BETWEEN HIV AND STIS

- STI's are caused by bacteria or viruses and are transmitted through sexual intercourse from one infected person to another, commonly by vaginal intercourse, but also by other types of sexual contact. STI's may also be transmitted from mother to child during childbirth.
- Some STIs such as Herpes and syphilis cause sores on genitals, when people have sores on their genitals it is even easier for them to get HIV. This is because the open sores allow the HIV virus to enter the blood directly. Therefore it is important that STIs are treated correctly and condoms are always used.
- These infections are transmitted through having unprotected sex, they are dangerous and can cause infertility, disability and death

What's the difference between Virus and Bacteria?

- Viruses must have a living host to multiply whereas bacteria can grow on non – living surfaces.
- Most bacteria's cause no harm to people
  The most important distinction between bacteria and viruses is that antibiotics drugs usually kill bacteria but are not that effective against Viruses

TABLE 1: Types of STIs and symptoms

Gonorrhea -This STI is caused by a bacteria.	• **Men** can have pus –like yellow discharge in the penis, stings when you pee, there may be blood in the urine, you might have swollen glands in your groin and the head of the penis may turn red. • In **Women,** there is usually not much showing up; redness around the cervix, discharge, pain in the pubic area, and frequent peeing. • If it occurs in the anus it may also be hard to pass stools, and if in the throat it may be hard to swallow.
Syphilis is caused by bacteria and can be passed from mother to child.	• A big, open sore forms. It is painless and forms exactly where you first had contact with bacteria. The sores last for a couple of weeks, but the disease continues to spread inside your body, In both in men & women it can be found on lips, tongue, anywhere inside the

	mouth, also on eyelids, face, chest , fingers and anus.
Cancroids is caused by the bacteria	• Painful sore, swollen glands near the affected area. You can get them in your mouth, throat, lips, tongue, anus, vagina and penis.
Venereal warts are caused by a virus called papilloma	• They have a cauliflower – like appearance, bumpy and fleshy, painless but can grow so big that they block the urethra, vagina, anus or throat. • The visible warts can be removed by freezing, laser surgery, painting them with a chemical that burns them off, or using a cream. There is also a vaccine that can protect people from HPV. Male circumcision can also help prevent HPV.
Herpes is caused by a virus called herpes simplex.	• The herpes virus is called cold sores when it is found on the mouth. There is a burning itching sensation with redness in the affected area, in a day a painful grape-like cluster of fluid – filled blisters appears. Within three weeks, these get healed up, leaving a red scar that goes away with time. In the vagina there may be some discharge.
Pubic lice - caused by a parasite called Phthirus	• They occur in pubic areas (around genitals) causing itching and redness.
Trichomona - a common STI caused by a tiny parasite that's spread by unprotected sex.	• Often men have no symptoms, but both men and women with trichomonas can have symptoms that are similar to Gonorrhoea and Chlamydia. Like bacterial infections, Trichomonas is treated • with antibiotics and it's important to take all your tablets to ensure that the infection is cleared. • Smelly, frothy discharge in vagina, itching, burning and redness.
Pelvic Inflammatory is a disease that is caused by two different bacteria	• It is found in women and can cause lower abdominal pain, abnormal vaginal discharge, fever, painful intercourse and irregular menstrual bleeding. It can effect the uterus, ovaries, fallopian tubes or other related structures. When it is caused by Gonorrhea and Chlamydia it may produce minor or no symptoms at all.

Module 5: Behaviour change

LEARNING OUTCOMES:

By the end of this module, the participants will be able to:

- Understand stages of behavior change.
- Explain the stages of behavior change.

METHOD:

- Divide participants into smaller groups in their groups they list specific problems of behavior in the communities present and must identify behaviors' that need to change and factors that influence certain behavior and steps to correct this behavior.
- The participants can also role play in their groups what behavior do they need to change , why it is important for them to change it could be losing weight , stop smoking etc
- Discuss barriers and facilitators of behavior change

COMPONENTS OF ATTITUDES - BEHAVIOUR LINK:

To understand the way people behave and the behaviour change cycle , we need to look at the link between attitudes , values, beliefs and behaviour.

- **Social identification and value relevance:** The more the attitude topic is important to defining who you are, or the more it reflects on your basic values the stronger its link to behaviour
- **Knowledge:** The more informed you are on the topic, the stronger your attitude typically predicts behaviour.
- **Self interest:** The more the topic affects you, the stronger the attitude behaviour link.

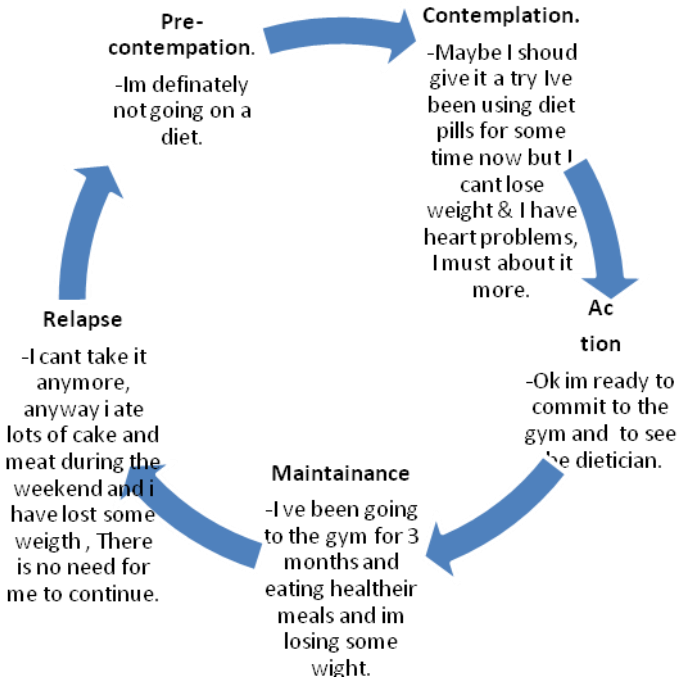
Behaviour change model.

- The behaviour change model is a process that people go through in all areas of life when they identify a need for change.
- It is difficult to change behaviour or habit, even if we know it is good for us, sometimes we change for a short while, but we slip back into old habits again.
- Some people change behaviour without much help, while others take a long time and need a lot of motivation before they change.
- People usually go through five phases when changing behaviour.

How does this model help us facilitate change in HIV –related behaviour?

- There are so many behaviours that are challenged when dealing with HIV.
- People must learn how to eat differently, how to use the condom, how to use medications every day, how to change certain behaviours.

Five behaviour change phases:
Example



EXERCISE: Comprehensive approach to Barriers and Facilitators of behavior change.

Participants discuss ways to minimize barriers and enhance facilitator behaviour in their communities by completing the table below. In the report-back the participants act out what they have learned in the form of role-plays and demonstrate the concepts of the theories in a practical manner.

Approach	***List barriers to behaviour change***	***List facilitators to behaviour change***
• *Workplace*		
• *Physical*		
• *Cultural*		
• *Social*		
• *Emotional*		
• *Intellectual*		
• *Financial*		
• *Sexual*		
• *Spiritual*		

TABLE 2: Phases of change and strategies to deal with issues at each stage

Stage	**What to do?**
Pre-contemplation	• Give good information about HIV, ARVs and benefits of being well. • Look at advantages and disadvantages of behaviour change.

Contemplation	• Discuss the client's barriers and facilitators re: adherence to ARVs and care. • Look at each area of wellness and see whether there are any major barriers or facilitators to ART.
Action	• Help the client make an action plan. • The plan should include ways to minimise barriers. • Ways to maximise facilitators • Break it into small achievable goals. • Write it down with time frames.
Maintenance	• Try to keep the barriers minimal and facilitators strong, each time you meet review barriers. • There maybe new barriers and there maybe new facilitators.
Relapse	• Create a trusting relationship with the client which will give the client the confidence to share with you if they stop the treatment. • Don't judge, check what happened, when, how often and what contributed.

EXERCISE:

Mr. Samuel has been drinking heavily since he lost his wife, when he started feeling sick he went to the clinic the counselor at the clinic advised him to stop drinking because his CD4 count is low and he needs to start ARVs. He said" I would like to stop drinking ,I've been trying to stop drinking for some time since my boss gave me a warning at work 2 months ago I'm scared I might also lose my job but all my friends drink and I miss my wife"

QUESTIONS: *Participants break into groups, discuss the following:*

- *What stage is Mr. Samuel in?*
- *What are the advantages and disadvantages of Mr. Samuel stopping his drinking and starting ART?*

Module 6: Anti-Retroviral Treatment:

LEARNING OUTCOMES:

By the end of this module the participants will be able to.

- Explain the terms used in anti-retroviral treatment.
- Explain how the drugs work to interfere with HIV life cycle.
- Name different anti-retroviral drugs and their side effects.

METHOD:

- Ask participants to differentiate between curable and manageable diseases
- Allow participants to discuss diseases that can be cured or managed traditional medicines.
- Encourage participants to share their stories on what they have heard or encountered when using ARVs and how they have dealt with side effects
- Divide participants into two groups of males and females and discuss PMTCT challenges focusing on male involvement in PMTCT, disclosure, stigma and cultural factors.

Goals of anti retroviral treatment:

Primary goal

- The primary goal of ART to decrease HIV related deaths , people who are infected should experience fewer HIV related illnesses and prevent new infections among children , adolescents and adults
- CD4 count should rise and remain above the baseline count and the viral load should be undetectable.

Secondary goal

- Reducing transmission in discordant couples (discordant couples means one partner is positive another negative)
- Reduce the risk of mother to child transmission

The basics of Anti –retroviral treatment.

- Anti-retroviral drugs work in the CD4 cell to prevent the HI virus from replicating.
- The drugs do not remove the virus from the body.
- They change the HIV from a terminal disease to manageable disease.
- ARVs reduce the ability of the HI virus to replicate; by so doing the immune system is able to increase its ability to fight opportunistic infections.

What is the correct way to take Anti-retroviral treatment?

Clients need to take:

- The correct dose.
- At the correct time for the rest of their lives.

For the drugs to be most effective in preventing replicating, the level of drugs in the blood have to be consistent, if this does not happen the HIV can begin replicating again.

When this happens it is called resistance, meaning the virus is now resistant to ARV treatment.

What is triple therapy?

- Standard antiretroviral therapy (ART) consists of the use of at least three antiretroviral (ARV) drugs to suppress HIV and stop the progression of HIV disease.
- The ARV drugs are of three different types and have their own specific purpose and act in a unique way within the CD4 cell to interfere with HIV replication.

Standardised National Eligibility Criteria for Starting ART Regimens for Adults and Adolescents:

Anyone with a CD4 count less than 200cells/mm3 irrespective of clinical stage

Those with a CD4 count less than 350cells/mm3 for:

- Patients with both TB and HIV
- Pregnant women

Anyone who has multi-drug resistant (MDR) or extremely drug resistant (XDR)TB irrespective of CD4 count

Anyone that is diagnosed as WHO Stage 4, irrespective of CD4 count

Require Fast-Track (i.e. ART initiation within 2 weeks of being diagnosed eligible for treatment)

- *Pregnant women eligible for lifelong ART*

OR

- *Patients with very low CD4 (less than100-200cells/mm3)*

OR

- *Stage 4, CD4 count not yet available*

OR

- *MDR/XDR-TB patients*

If the client is not yet eligible for ART but is diagnosed with HIV:

- *Transfer to a wellness programme for regular follow-up and clinical assessment/CD4 testing 6-monthly.*
- *Counseling on how to avoid HIV transmission to sexual partners and babies.*
- *Ongoing counseling is critical.*

ARV/ART TREATMENT REGIMENS

There are three regimens that are used in the Public sector in South Africa.

- Regimen 1a
- Regimen 1b
- Regimen 2

WHO TAKES REGIMEN 1A?

- Men: Both adult and adolescent.
- Women: Post –menopausal
- Women: Those who have had tubal–ligation or hysterectomy**. (Women who have potential of falling pregnant should not take this regimen because it contains drugs that may cause birth defects.)**
- All clients who are on T.B treatment. **(Regimen 1a has fewer side effects compared to 1b when combined with T.B treatment.)**

Who takes regimen 2?

- Clients suffering from severe side effects as a result of being either regimen 1a or 1b
- Clients who fail on regimen 1a or 1b.

Who takes regimen 1b?

- Women: Those who can still fall pregnant.
- Men and women: Those who cannot take regimen 1a because of night duty work or have serious clinical depression.

Early ARV Side-Effects

- Common symptoms include gastrointestinal and flu-like symptoms, headache, dizziness,
  Vivid dreams, rash, and hepatitis, tiredness, vomiting and abdominal pain.
- Immune reconstruction [reconstitution?] syndrome may occur.
- Remember that any drug can have side effects (e.g. Panado). Most side effects are mild and improve with good management over time.
- Some side effects develop after long-term use of ARVs.
- Side effects can be a barrier to adherence.
- Clients should continue taking their drugs when they experience mild side effects.
- Clients need to be referred to the nearest clinic or doctor for monitoring of side effects.
- Reassurance and encouragement as well as treatment are vital in aiding the client who is experiencing side effects.

When can a person change ART Regimens?

Substituting Drugs in First Line Regimen

- Symptoms of drug poisoning and of immune recovery are common immediately after initiation of
  ART, but usually resolve spontaneously.
- However, if severe substitution of an responsible drug may be all that needs to be done to solve drug poisoning.
- The responsible drug can be replaced with another drug from the same class that does not have the same adverse affect e.g. NVP for EFV.

Treatment Failure.

- In the guidelines, treatment switches are only where the number of viruses is not coming down despite the patient taking the medication properly. This is always due to not taking the medication regularly, often due to poor attention by the clinician to drug poisoning, or where social factors have not been addressed.

Rapid attention to drug poisoning or social factors, with better adherence, may allow re-suppression of the virus in many cases.

- Patients who fail clinically (new OIs while on treatment) or immunologically (CD4 count dropping)

Without virological failure a person is unlikely to benefit from treatment switches, and require clinical assessment and appropriate investigation.

- Adherence may be improved, but sufficient resistance has occurred for first line therapies to be ineffective. Patients who have experienced virological failure with good adherence may be changed to second line therapy.

EXERCISE:

Celiwe has come to see you as her ARV supporter during you conversation she mentions that she is worried because her sister is against her taking ARVs and she and her mother share a room with her as they are both not working her sister is the only one working ,She is also worried that her sister has also been coughing for the last two weeks.

Participants break into smaller groups and explore

–Social;

-Cultural;

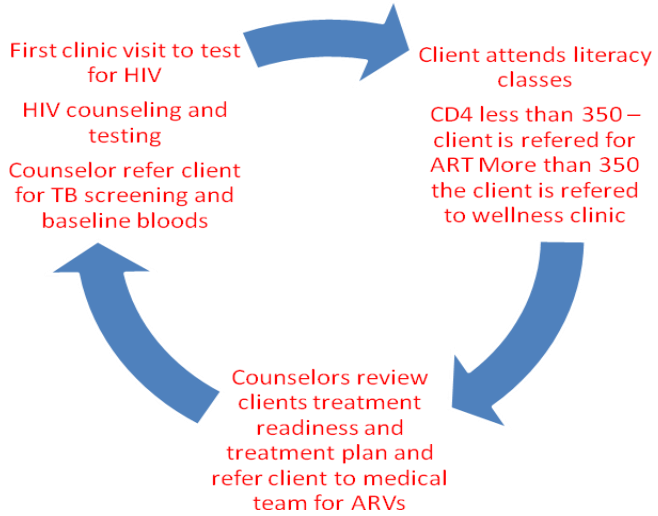
-Physical, and;

-Emotional Barriers to adherence

Management of Treatment Failure after Second Line Treatment

- Patients failing second line therapy have few treatment options. Failure is almost always due to poor adherence, and every effort should be made to address this.
- Alternative regimens may be available at selected referral sites, research groups, or through the private sector and this should be explored.

Patient pathway



MTCT Challenges

- An estimated 25% of pregnant women have never had an HIV test.
- Two thirds of women and girls have their first antenatal visit too late. They come to the clinic after 20 weeks although they should be taking ARVs by 14 weeks if they have tested HIV positive.
- There is a lack of collaboration between healthcare workers and social and educational services.
- Low male involvement in PMTCT limits women and children's access to PMTCT.
- Stigma and discrimination often stop women from testing and/or accessing PMTCT programmer.
- Mixed feeding, which increases the chance of infecting a baby remains high.
- There is a lack of post-natal care – this is one of the major obstacles to effective PMTCT.
- PMTCT programmes often fail to link mothers, babies and families to treatment care and support.
- Several thousand babies are not identified as HIV exposed and hence are not tested for HIV, nor are they placed on Cotrimoxazole, which prevents death from a severe form of pneumonia.

Standardised national eligibility criteria for starting ART regimens for infants and children

- Children 1 – 5 years with clinical stage 3 or 4 or CD4 ≤ 25 % or
  CD4 count < 750 cells/µl
- Children > 5 years to 15 years with clinical stage 3 or 4 or CD4 < 350 cells/µl
- Children less than 1 year of age
- Stage 4
- MDR or XDR-TB

Standardised national ART and ARV regimens for women who are HIV positive and pregnant and their infants.

- Eligible for ART (i.e. CD4 < 350 or clinical Stage 3 or 4) Start lifelong ART within 2 Weeks.
- Currently on ART they should continue with ART
- Not eligible for ART i.e. CD4 >350
  Start AZT from 14 weeks, NVP + AZT 3hrly during labour.
- Mother on lifelong ART NVP at birth and then daily for 6 weeks irrespective of infant feeding choice.
- If formula fed the baby can stop NVP at 6 weeks.
- Mother who did not get any ARV s Before or during delivery NVP should be started as soon as possible and daily for at least 6 weeks and be continued as long as any breastfeeding.
- Assessment for ART eligibility within 2 weeks after delivery is critical.

Disclosure to children

In most cultures sickness and death is not discussed with children the perceived benefit being to protect the child from emotional trauma.

The drawback is when death is not explained the child takes death as temporary and always expects the dead to come back, and when sickness is not explained they might feel responsible for the death and sickness of the parent.

Where it is explained the child understands sickness and is prepared for the loss, they understand the meaning, they know the person won't come back and are able to grieve death.

The drawback is the child might always associate sickness with death whenever someone is sick they think he/ she is going to die.

EXERCISE:

A young couple has been married for a year the wife is pregnant and has tested positive at the antenatal clinic. Her husband has gone for testing and he tested negative. The husband is furious and refuses to accept the child as his. They decide not to tell other family members they are staying with. When the child is born the mother in-law insist that the child be breast fed and drink some traditional medicine that will make the child strong.

In smaller groups brainstorm the main issues in this scenario, discuss what might cause the above issues, and how you could deal with them.

- *Stigma*
- *Denial*
- *Cultural /traditional believes*
- *Disclosure.*

Reasons for disclosing HIV status to children:

- Children can be actively involved in managing their health
- As the stage of children living with disease steadily increases it will result in a population of sexuality active young people with HIV infection , they need information to prevent themselves and partners from being infected
- Keeping the secret is a burden.
- Disclosure should always be in the interest of the child, this applies to the disclosure itself and the manner of disclosure.
- The child needs to prepare for sickness and painful procedures.
- Remember children know more than adults give them credit.
- When children are not told about the disease they often have much more anxiety and distress.
- Disclosure needs to take place before adolescent.

Guidelines for disclosure to children with HIV:

- Many parents are afraid of to disclose to their children, for this reason they need support, time and encouragement.
- Where possible enlist the help of the trained counselor.
- Assess the child's readiness.
- Plan in advance the time, place and people who will be present for the disclosure.
- Have a written plan of what should be disclosed to the child.

What is the right thing to say?

- Children need to know that they are loved and will be cared for.
- Find out how much the child knows about their illness and what he/she wants to know.

- They need to know that their illness or parents illness is not their fault or punishment for wrongdoing.
- Children need to learn basic HIV information.
- Consider the child's age when giving information.
- Be led by the child in terms of information he/she requires.
- Use appropriate language for the child's understanding and emotional readiness.
- Once the disclosure has happened monitor the child's behaviour, changes in the child's behaviour indicate that they need more support and intervention.
- Stories and book may assist.
- Despite the best planning, you cannot be certain how a child will respond.

Module 7: HIV and Nutrition and traditional medicines

HIV and NUTRITION

LEARNING OUTCOMES:

By the end of this module the participants will be able to:

- Understand the relationship between HIV/AIDS and Nutrition.
- Understand the importance of food security for households affected by HIV/AIDS.
- Understand the how to use herbs for nutritional value.

METHOD:

- Ask participants if the understand the relationship between nutrition and HIV.
- Discuss traditional herbs that are used before to cure or manage opportunistic infections and any harmful interactions they have experienced of traditional herbs and ARVs
- Divide participants into smaller groups where they draw plans of involving community members to improve food security.

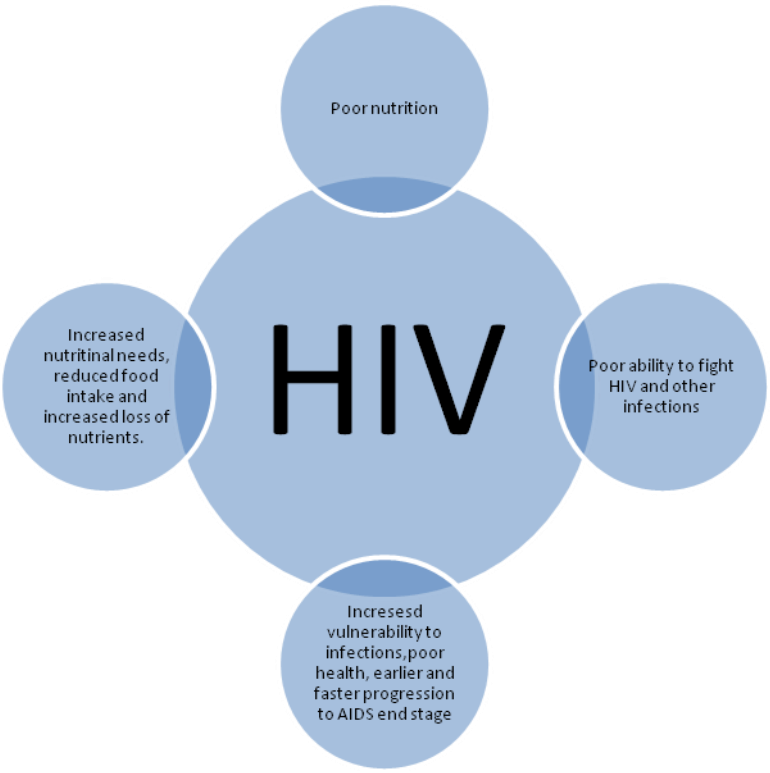
The relationship between HIV/AIDS and Nutrition.

- The virus itself has an effect on the nutrition of the person living with HIV/AIDS.
- The body reacts to the virus with an immune response that uses more energy and nutrients.
- When the immune system is weakened by HIV/AIDS, other infections start to occur and every new infection raises the need for nutrients and energy.
- Worry about the disease lead to high anxiety levels, which further weakens the immune system, certain nutrients are necessary to boost the immune system and the need for these is higher during the periods of stress.

HIV/AIDS lowers food intake.

- Infections and illness lead to poor appetite
- Mouth and throat infections cause difficulties with eating.
- Some medicines cause a poor sense of taste as a side effect.
- Both the expense of treatment and in ability to work affects income that leaves less money available for food.
- Isolation may result from social prejudice against people with HIV/AIDS, because food and eating is a social event, loneliness will affect the way the person eats.

The Cycle of HIV/AIDS and Nutrition:



Effective and inexpensive ways to deal with the cycle of infection and poor nutrition:

- Awareness of HIV status
- Good nutrition
- Good hygiene and food safely
- Learning to cope with problems of HIV/AIDS.
- Early detection and treatment of all infections.
- Increased food intake after illness
- Learning to cope with stress.
- Increased activity and exercise.
- Getting enough rest and sleep.

What is good nutrition for people with HIV/AIDS?

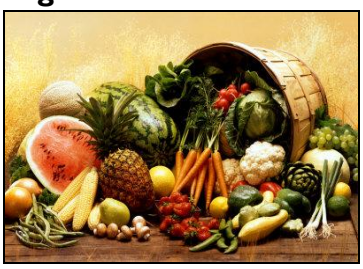
- Good nutrition means eating foods that supply the body with all the nutrients that are needed daily.
- Not only is enough energy needed mainly from starchy foods, fats and oils, but also proteins, vitamins, minerals and water.
- The right balance of these nutrients promotes health and well-being.
- They keep the weight stable, prevent loss of muscle and replace lost nutrients.
- They also help when recovering from infections and increase feeling of well being.

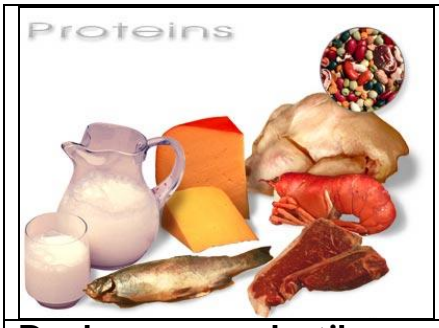
Food choices for people living with HIV/AIDS:

Eat a variety of foods.

- There is no single food is either good or bad. It is a combination of different foods eaten over a long time that leads to better health.
- Different types of food supply different combinations of the nutrients our bodies need.
- It is important that food choices are made from a wide selection of different foods.
- This way one is more likely to enjoy one's food that you need to include in your diet are discussed below.

TABLE 3: How to have a balanced diet

Make starchy foods the basis of each meal 	○ Starchy foods should make up the biggest part of the food intake. ○ These foods are cheaper and supply lots of energy. ○ They include: pap, bread, porridge, cereals, rice, potatoes, sweet potatoes, samp, mealies, and pasta.
Eat lots of fruits and vegetables 	○ Fruits and vegetables supply vitamins and other substances that keep the immune system strong. ○ These food are especially important for people living with HIV/AIDS to help fight against infections. ○ Include vegetables and fruits of a yellow, orange, red or dark green color. Examples include spinach, morogo, pumpkin leaves, green peppers, sweet potatoes ,pumpkin , carrots, yellow peaches, apricots ,paw -paws and mangoes. These contain vitamin A which helps with the lining of the gut and keep lungs healthy and so prevents germs from entering the body. ○ Citrus fruits like oranges, naartjies, grapefruit and lemons and guavas, mangoes, tomatoes and potatoes supply vitamin C which helps to fight infections.
Meat and dairy products	○ For people with HIV/AIDS it is important to maintain healthy and strong muscles. Foods from animal sources provide the body with proteins to build muscles and keep the immune system strong. All forms of meat and fish can be eaten daily, including organ meats (such as liver , kidney, heart and brains).

	○ Eggs milk, maas , yoghurt, buttermilk, milk powder, and cheese provide protein and calcium.
Dry beans, peas, lentils, peanuts or soya regularly. 	○ This group of foods from plant sources also supplies proteins and should be included in bigger amounts to help with weight gain. ○ These foods are also more economical protein source than foods from animals.
Include sugars, fats and oil  	○ Sugars, fats and oil are also part of a healthy balanced eating pattern. After periods of weight loss these foods should be included in bigger amounts to help with weight gain. ○ Add fats and oil to food to increase energy intake. ○ Please note that large amounts of fat at the later stage can cause diarrhoea.
Salt 	○ With diarrhoea and vomiting, salt is lost from the body. Some salt is necessary to replace such losses.
Drink lots of clean water.	○ Diarrhoea and vomiting both cause loss of water. Night sweats also causes large amounts of water to be lost. Losses have to be replaced by drinking enough fluids every day and more is needed if there is diarrhoea or vomiting. People with TB and HIV/AIDS can prevent

	dehydration by drinking water, cold drinks, fruit juice and other beverages (excluding alcohol).
Smoking 	○ Avoid smoking because it increases vitamin C requirements and is a known factor to chronic debilitating conditions such as certain cancers and heart diseases.
Exercise 	○ Moderate exercise is beneficial to the immune system, and can also improve mood and offer an important way of maintaining a healthy self-image. ○ Regular exercise may reduce the total body and trunk fat among HIV persons with body fat changes. ○ If taking ARVs, it is important to assess whether the changes in body shape are a side effect of the drugs. ○ Clients should be referred to medical personnel for advice.
Alcohol 	○ Drinking alcohol may affect the immune system and slow down recovery from infections. ○ Alcohol is processed by the liver and a healthy liver is essential for the body to process medicines effectively. ○ The increase in blood fat caused by some ARVs can be made worse by heavy drinking.
Nutritional supplements. 	○ In addition to healthy eating, nutritional supplements may be needed due to increased requirements. ○ Nutritional supplements are multivitamin/mineral tablet, capsule or syrup. ○ Remember nutritional supplements cannot make up for eating well.

Exercise:
Participants make a list of essential food items (i.e. not food groups but specifics such as maize meal, salt, oil, tomatoes) that a household usually purchases each month. Then they indicate next to each item whether they run out of it by selecting *'never', 'sometimes'* or *'often'*. In the instance of selecting 'often'; the participant is required to specify the amount of times the product runs out.

Food security for households affected by HIV/AIDS:

The food security of a household can be assessed by asking questions to understand the situation of PLWHA and their household members can be linked and referred to programmes for food aid or other community services.

Three components of food security:

Availability

- Is there enough food available in the home at the time of the visit?
- Is the household able to produce or purchase food to meet its needs?
- Does anyone in the household receive food donation?
- Is there a diversity of food in the household?
- Are there any other ways in which members of the household obtain food?

Accessibility

- Does every member of the household get enough food?
- Does every member of the household get a good variety of food?
- Are there members of the household who do not get adequate amounts of food?
- Is there anyone in the household who needs food to take their medication and does not get enough?
- If so, what are the reasons?

Utilisation

- Is the household adequately able to prepare process and store the food?

Using natural remedies

Traditional herbal therapy

- Most traditional herb therapies taken for HIV – related disease and symptoms have not been subjected to structured formal research.
- Therefore their effect on the course of the HIV-related diseases is unknown. Some PLWHA report short - term benefits of some of these herbs in relieving symptoms.

Some natural remedies may.

- Have food intake restrictions imposed.
- Have negative effects in the body.
- Interfere with the effectiveness of drugs one may be taking.

There is nothing wrong with using natural, complementary or alternative therapies if:

- They are used to supplement rather than replace standard therapy.
- They are not poisonous and do not overburden the system e.g. the liver or kidney.
- There are no interactions with other medications
- They have the potential to prevent, alleviate or cure symptoms e.g. (lower blood pressure, improve digestion and reduce severity of diarrhoea)

Exercise:
Participants are asked to group into smaller groups discuss traditional herbs that they may use to treat or manage opportunistic infections or other infections in relation to HIV/AIDS.

TABLE 4: Commonly used herbs, spices and medicinal plants

Name	Benefits	How to use
Aloe Vera	Relieves constipation, soothing and healing of wounds.	Boil and drink the concentrated water or apply fresh gel to wounds
Basil	Relieves nausea, assist in digestion and acts as an antiseptic for mouth sores.	Use for mouth sores: add two Tablespoons to a teacup of boiling water and rinse your throat and mouth.
Sutherlandia	For strengthening immunity and preventing diarrhoea.	Pour boiling water into half a teaspoon of powdered dry leaves in a cup, drink when cool.
Cayenne pepper	Stimulates appetite assist in digestion, assist in digestion.	Add a pinch to cooked or raw food , drinks or water.
African potato	Strengthen the immune system.	Add half a teaspoon in a half a cup of warm water not boiling

		not boiling.
Lemons and lemon juice	May act against herpes and shingles.	Drink the juice of one whole lemon in water every day.
Coriander	Controls bacteria and Fungi.	Add herbs to meals
Honey	For healing of wounds and as an antiseptic	Put little honey directly into the sore or wound.
Garlic	Helps soothe symptoms of thrush, mild diarrhoea and headaches. It is a natural antibiotic and anti-fungal.	Add to meals in small amounts
Tea made from lemon or guava meals	Used to treat sore throat and cough.	Add guava or lemon leaves to boiling water.
Ginger	Used for colds and sore throats.	Add to boiling water and drink when cool.

Module 7: Legal issues

LEARNING OUTCOMES:

By the end of this module the participants will be able to:

- Understand legal issues related to HIV testing in children
- Understand why people behave differently because of stigmatization.

METHOD:

- **Participants discuss how stigma is expressed in different communities and how they can eliminate stigma for HIV and ARV treatment.**

Legal issues

HIV testing for children

- HIV testing of any child may take place if it is in the best interest of the child and if a person is legally capable of providing informed consent provides such consent.
- The primary caregiver of the child should be able to consent for testing regardless of parental where about.

HIV testing without consent:

HIV testing without consent may happen if: - *a Health care worker may have contracted HIV due to contact in the medical procedure involving contact with any substance from the child's body that may transmit HIV.*

- *Any other person may have contracted HIV due to contact with any substance from child's body that may transmit HIV, provided it is authorized by the court.*

Who can give consent to take a HIV test

- *A child of 12 years of age or older can give consent on their own if they wish.*
- *The parent or care giver, if the child is under the age 12 years and is not of sufficient maturity to understand the benefits, risk and social implications.*
- *A designated child protection officer arranging the placement of child or the provincial head of social development ,the superintended or person in-charge of hospital and the children's court if the child is under the age 12 years and is not of sufficient maturity to understand the benefits, risk and social implications.*

PLEASE NOTE THAT

- The in-charge of the hospital can override the right of the parent or guardian if she refuses to give consent if the child has been abused because it delays comprehensive care of the child. When the child is orphaned the guardian or head of orphanage should give consent. It also important that children who orphans are tested as they might need MTCT.
- When there are HCT campaigns at school parents should give consent for those under 12 but it is also recommended that even those over 12 parents give consent as they will need support should they test positive and parents also will need support.

HIV testing for foster care or adoption purpose.

- If the HIV testing of a child is done for foster care or adoption purpose, the state must pay the cost of such tests where circumstances permit.

Confidentiality.

- Children above the age of 12 and who are legally able to provide informed consent to an HIV test are entitled to maintain the confidentiality of their HIV status. Consent to disclose the HIV status of such a child must be given by the child.
- In the case of children below the age of 12 and who cannot consent to HIV testing, consent to disclosure should be given by the parents or legal guardians.

STIGMA

What is stigma?

- Attaching a negative label to someone maybe based on partial truth or false information.
- Many things can be stigmatised:
- Poverty
- Divorce
- Illness
- Family troubles
- Look, dress and being different

Behaviours due to stigma

- Talk about people behind their backs
- Avoid someone who is stigmatised.

Laugh, tease or make fun of someone.

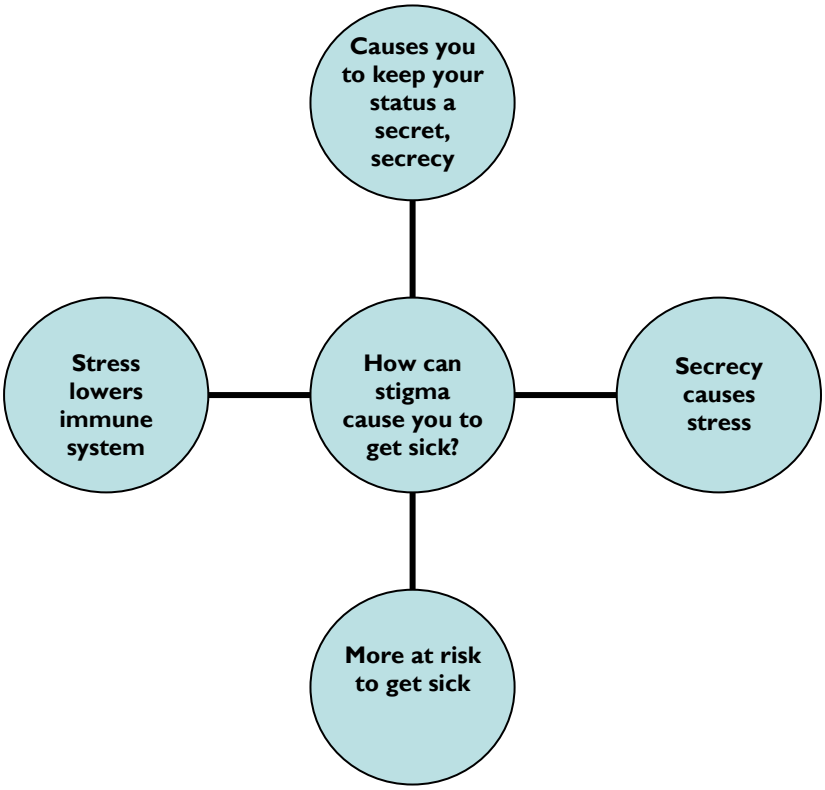
Why do people stigmatise others?

- Fear
- Insecurity
- Lack of knowledge
- Ignorance.

How do we join in stigmatising others?

- We can pretend it 'cannot happen to me'.
- Pretend we are better than they are
- Pretend we are not affected by HIV
- Hide our own HIV status from others

Persons who are victims of stigma may feel embarrassed, uncomfortable, hurt, ashamed, depressed, life not worth living and want to kill themselves.



Acknowledgements.

AFSA and Culture and health programme would like to acknowledge the following publications.

National department of health - Nutritional care for people living wth HIV and AIDS

- Clinical guidelines , Prevention of mother to child transmission, Management of HIV in children , Management of HIV and AIDS in adults and adolescents.

KZN department of Health –Adherence and treatment literacy training manual