

# Training For Community Mobilisation

For Antiretroviral Therapy  
In Resource Limited Settings

By the Pan African Christian AIDS Network (PACANet)

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## OBJECTIVE OF THE COURSE

To prepare and equip the participants for total community mobilisation in view of the ultimate purpose of engaging and/or soliciting community support in the fight against HIV/AIDS.

### *Specific objectives*

By the end of this training, participants will be expected to:

1. To demonstrate understanding of the basic facts about HIV/AIDS.
2. To analyse the problem of HIV/AIDS in the area.
3. To have their knowledge of HIV/AIDS reviewed and updated.
4. To improve upon or develop the attitudes necessary for leading, motivating and mobilising for community action.
5. To acquire skills necessary for effectively mobilising different levels of the community.
6. To develop a joint as well as an individual plan for mobilising the community within one's catchment area.

# Chapter One

## Community Mobilisation

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### **Training Aim**

To enable the participants to understand and put into perspective the need and justification for mobilising communities for partnership in the fight against HIV/AIDS; a partnership which is aimed at harnessing input from all the stakeholders.

### **Training objectives**

By the end of the training, the participants will be expected to:

- define and explain “community”
- understand why we should involve communities
- understand the process of community mobilisation
- identify the challenges and causes of failure in community mobilisation

### **Course content outline**

- Definition and characteristics of the community
  - Composition of a community
  - Engaging and involving communities
  - Who to consult and involve
  - The process of community mobilisation
  - How to harmonise disparities among stakeholders
  - What kills community mobilisation programmes?
  - Challenges in community mobilisation
  - What it will take to mobilise communities
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# COMMUNITY

## *Working Definition*

A community is defined as a group of people living together in the same geographical area and share the same customs, practices and beliefs.

## *Characteristics of a Community*

1. *Leadership*: Every community has a form of leadership - be it elected, hereditary or appointed. This leadership is respected by the people in the community. Therefore, in order to influence the community, one needs to recognise and involve the leadership. Forms of Leadership are also present in the various institutions found in the community e.g, school governing boards, clinic committees, church elders etc.
2. *Community structures and institutions*: In a given community, there are structures and institutions. These structures and institutions depend on the level of leadership found in the community, the level of awareness in the community and the resources available in the community. Examples of structures and institutions found in the community include schools, clinics, churches, community halls, tribal courts, community projects etc.
3. *Rules and regulations/ code of conduct*: Every community has rules and regulations which govern the way people live and behave towards each other. These rules and regulations are often unwritten but known by everyone.
4. *Presence of social deviants*: In every community, there are people who do not follow the norms or expectations of the community but choose to do things contrary to what everyone else is doing. These people are referred to as social deviants.
5. *Shared geographical location*: People in one community live within the same geographical location/ area.
6. *Young and old people, males and females* are found in every community.
7. *Communities highlight wrongs more than rights*: It is human nature to remember the wrong things done more than they remember the good things. It is therefore important to be a role model as a community mobiliser because all the good you have done can be undone by one wrong thing.
8. *Medium of communication*: In every community, there are ways of communicating that are peculiar to the community and are understood by the people hearing the message. For example, the beating of the drums in a certain rhythm sends across a message that the community can understand.
9. *Culture, customs and beliefs*: Every community has its culture, customs and beliefs which are shared by everyone. This is expressed through language, dress, relating with elders, food, initiation into adulthood etc.
10. *Survival instinct*: Every community protects itself against extinction. Some of the ways in which this is done include securing food, security and health.
11. In every community, there is *an observed need for entertainment, socialisation and recreation*.

### GROUP WORK

1. Define a community
2. What are the characteristics of a community?
3. What are the components of a community?

12. *There is individual and communal responsibility in every community.* This means that there is respect for individual and community rights and responsibilities, and that both the community and the individual know them and carry them out.
13. *Shared language and dialect:* Every community has a common language and dialect with which they communicate with each other.
14. *Diversity:* Not everyone in the community has the same opinions about everything, yet the members of the community are able to live together in harmony. Therefore, there is unity in diversity.
15. *Shared experiences:* In every community, the members have undergone some similar experiences which bond them together and with which they identify. Examples of shared experiences include droughts, famines etc.

### ***Composition of a Community***

Communities are comprised of different categories and classifications of people. However, the proportions of each may differ from one community to another. These are:

- Leaders
- Male and female
- Different generations
- Clans
- Structures - schools, places of worship, hospitals etc.
- Assorted groups such as organised clubs, women groups, youth groups, societies etc.

## **WHAT IS COMMUNITY MOBILISATION?**

Community mobilisation in HIV/AIDS refers to the deliberate soliciting of community support, involvement and action in the fight against AIDS. It is based on the belief that communities have in them untapped or under-tapped abilities (Social capital) which could enhance or accelerate the interventions in prevention, care and support.

### ***Why Involve Communities?***

We need to involve communities in HIV/AIDS interventions as allies. This is because:

1. When communities are involved in matters affecting them, they feel honoured and respected
2. The communities can only know about HIV/AIDS and what to do about it if they are engaged and helped to think about what is happening to them.
3. The people living with AIDS are within the communities and are a part of the communities. One therefore needs to involve the community to accept and support them.
4. Communities have attitudes, behaviours and practices which may hinder efforts towards prevention, care and support of the infected and the affected.
5. The best psycho-social and spiritual support can be solicited from within the community where the People Living With AIDS (PLWA) live.
6. The community knows its affairs best therefore, in order for any intervention in the community to succeed, it needs the input of the community.

7. There are resources already existing in the community which can only be tapped and utilised to serve the people with the involvement of the communities themselves.
8. It is possible to trace clients through confidential contact tracing systems within the community for encouragement and non-intimidating support.
9. When the community buys into what the community mobiliser is advancing, it helps to influence rather than fight unacceptable attitudes and practices within the community.
10. For the sustainability of the interventions beyond the initial funding, both in vision and resource mobilisation.
11. To enable the community to effectively play its part in caring for the infected and affected e.g. caring for the orphans, burying the dead, and other practical contributions.

### ***Whom to Consult and Involve in Community Mobilisation***

Each community has opinion leaders; the people who make things happen in the community by virtual of their roles or positions. These should not be bypassed if community mobilisation is to be effective. They should instead be respectfully seen and engaged as agents of change. These opinion leaders are:

- Kings
- Chiefs
- Traditional healers
- Religious leaders
- Political leaders
- Women leaders
- Village celebrities (these could even be deviants who command a following)
- Village elders
- Youth leaders
- Professionals

### ***Harmonising Disparities among Stakeholders***

In any collaborative partnership or project, some disparities between stakeholders are expected to occur. It is imperative that strategies to contain and harmonise these disparities are built into the project so as to protect the project from any negative impact. Some recommendations in the process of harmonising include:

1. An initial consulting process at the individual level - on a one to one basis.
2. Holding a joint event that brings all the stakeholders together.
3. Recognise and acknowledge the contributions of the humble and lowly people in the project.
4. The better informed and well-placed should be willing to understand, accommodate and be patient with the others without compromising standards.
5. Build a spirit of team work.
6. Avoid patronising language and use acceptable terms which aim at building and encouraging each other.
7. Compare notes on each other's expectations and reconcile and harmonise them with the actual project expectations

8. Invest resources in informal partnership building events or activities. It pays off in the long-run.

### ***What Kills Community Mobilisation Programmes***

Well intentioned and properly planned interventions do not necessarily succeed. Intentions to galvanise community resources and input die off due to the negative attitudes of the planners or the failure of the planning and implementation processes.

Some of the errors include:

- When we place the value of money above that of people.
- When we give all powers relating to the project to professionals.
- When we identify the project with individuals such that if they are not there, the project does not continue.
- By not involving ordinary people in service delivery.
- By not putting some accountability structures in the community.
- When we forget that projects in the community take time to take root.
- By addressing and rebuking mistakes in public.

### ***Major Challenges in Community Mobilisation***

When we embark on a community mobilisation process, it is important to acknowledge and anticipate some challenges and find ways of dealing with them or coping with them so as to accelerate progress. Some of the likely challenges one is likely to encounter are:

1. Traditional mind-sets and attitudes which may be difficult to change.
2. Because there are many people involved in the project, the progress may be slower than anticipated.
3. Absence of skills to manage different levels of professionals and non-professionals involved in the programme.
4. The balancing of community standards with internationally acceptable standards and yet achieve desired results.
5. Reluctance by qualified professionals to take up community programmes because they do not find them attractive.
6. When there are hidden selfish motives (individual, political etc.) in being involved in the project.

## Chapter Two

# Basic Facts about HIV/AIDS

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### Aim

To review the scientific HIV/AIDS facts and discuss how they apply to the community.

### Training objectives

By the end of the training, the participants will be expected to:

- identify myths and misconceptions about HIV/AIDS prevailing in the community and discuss ways of dispelling them
- review and acquire up to date accurate information/knowledge on HIV/AIDS
- identify modes of HIV/AIDS transmission and how to prevent infection

### Course content outline

- Prevailing community myths and misconception about HIV/AIDS
- Definitions and meanings
- The relationship between HIV and AIDS
- The progression of HIV/AIDS in the human body
- Modes of HIV transmission and their prevention
- Ways HIV cannot be transmitted

## PREVAILING COMMUNITY MYTHS ABOUT HIV/AIDS

There have been a number of attempts in communities to explain the AIDS pandemic. The explanations reflect misconceptions and myths surrounding HIV/AIDS. It is important to identify and where possible, demystify HIV/AIDS with factual information about the virus and the pandemic.

### *Myths and Misconceptions*

The following are some of the myths and misconceptions prevailing in the community regarding the origins, transmission and prevention of HIV/AIDS.

*Myth 1:* AIDS is a result of aborting and it affects the woman and the man who sleeps with her.

*Myth 2:* HIV came from baboons. A human being had sex with a baboon and later spread the virus to other human beings.

*Myth 3:* AIDS is not real. What we see are the effects of eating processed and/or genetically modified foods.

*Myth 4:* AIDS is a punishment from God.

*Myth 5:* AIDS is a result of poverty.

*Myth 6:* AIDS is caused by witchcraft and black magic.

*Myth 7:* HIV came from America.

*Myth 8:* It is America's way of discouraging sex

*Myth 9:* It originated from homosexuals and they are they ones who are spreading it.

*Myth 10:* AIDS attacks only the poor

*Myth 11:* AIDS can be healed through spiritual healing powers - through cleansing practices.

*Myth 12:* AIDS is transmitted by immunisation vaccines

*Myth 13:* AIDS is a result of family planning programmes; the provision of contraceptives

*Myth 14:* Condoms have worms and women who use them develop vaginal worms

#### GROUP WORK

1. Identify and discuss the myths and misconceptions about HIV/AIDS prevailing in the community
2. Define and show the difference between HIV and AIDS
3. What are the implications of the difference?
4. Outline and discuss the various modes of HIV transmission from one person to another
5. How can HIV transmission be prevented in each of the modes you have mentioned above?

*Myth 15:* AIDS is anthrax and it is acquired from infected animals

*Myth 16:* Insects, for example mosquitoes, transmit HIV.

Myths are based more on attitudes than facts. The only way to counter these attitudes is to provide factual information. This information should be simple enough to understand yet factual enough to dispel the prevailing attitudes and misconceptions.

## **HIV/ AIDS: Basic Facts**

### *Definitions and Meanings*

HIV is an abbreviation for Human immunodeficiency virus.

**H= human**

*Meaning:* The virus lives only in human beings.

**I= Immunodeficiency**

*Meaning:* The virus attacks and progressively destroys the body's defence system.

**V= Virus**

*Meaning:* A very small germ.

AIDS is an abbreviation for Acquired Immune Deficiency Syndrome

**A = Acquired**

*Meaning:* This means that the person did not genetically inherit the virus, but that the person got it as a result of exposure to the virus in the course of his/her life.

**I = Immune**

*Meaning:* This refers to resistance against infections.

**D = Deficiency**

*Meaning:* This refers to when a person lacks natural protection as a result of the virus that causes AIDS.

**S = Syndrome**

*Meaning:* This is a term used to refer to a group of symptoms.

A virus by the name of HIV causes AIDS. HIV stands for Human Immunodeficiency Virus. This is a virus that attacks and progressively destroys the immune system of the body. The purpose of the immune system is to naturally defend the body and permit the body to resist and overcome all kinds of infection.

A virus is a very small germ. It cannot be treated with the aim of destroying it. The virus must run its course in the body. The body either overcomes (gets better) or fails to resist

(chronic illness or death) the virus. With HIV, the normal course of the virus is chronic illness and ultimately, death.

HIV is a human virus. Although it may have similarities to viruses found in animals, it is specific to human beings. This is one of the reasons why a vaccine is difficult to develop. At present, there is neither a vaccine nor a remedy for HIV.

### ***The Relationship between HIV and AIDS***

To help us to establish the relationship between HIV and AIDS, it is helpful to use the analogy of the hippopotamus. When in the water, the greater part of their mass is submerged and only the top, which is a small part, is seen. The larger part of the hippo, which is unseen, is the most dangerous. It is only when the hippo emerges from the water that its enormity is appreciated. It is the same with HIV and AIDS. Someone with HIV, whose symptoms are not visible, is a greater threat to the community than a person with AIDS whose illness is visible. This is because other people in the community are able to see the symptoms of AIDS and protect themselves.

It is not possible to identify HIV infected persons by just looking at them. People who carry HIV in their bodies can look perfectly healthy for many years and continue to live healthy and active lives without showing signs of the disease to the casual observer.

It is only when the virus advances within the body that people begin to show certain signs of infection and serious illnesses that indicate a broken down immune system. At this point, these people are referred to as Persons Living With AIDS (PLWA).

Once HIV does enough damage in a person's body, the body can no longer resist infection. The person frequently becomes ill. This stage is what we call AIDS. HIV cannot be seen with the naked eye whereas AIDS can be diagnosed. Diseases such as cancers, tuberculosis and skin problems develop at this stage. These diseases overtake the body which cannot defend itself. At this point, the person is usually close to death.

### ***The Progression of HIV in the Adult Human Body***

There are six stages of HIV progression in the human body that have been identified. They are:

1. The point of infection
2. The window period
3. Sero conversion point
4. Asymptomatic period
5. Symptomatic phase I
6. Symptomatic phase II

#### **1. The Point of Infection**

This is when the virus enters the human body. The person being infected is usually unaware that s/he has become infected. The person may either feel sickly and/or experience an unexplainable discomfort. This may last from a few days to a week. After this, the person continues feeling healthy. During this period, the person can infect

another with the virus. However, when the person is tested for HIV, the results are negative.

## **2. The Window Period**

During this period, the person is well and healthy though highly infectious. The person still tests negative for HIV. This period lasts from three to twelve weeks for an average person. For others, it could take longer.

## **3. Sero Conversion Point**

The person is healthy yet highly infectious. S/he starts to test positive for HIV.

## **4. Asymptomatic Period**

The person shows no symptoms of AIDS and continues to be healthy. S/he tests positive for HIV and may be less infectious.

## **5. Symptomatic Phase I**

The person begins to get bouts of sickness. However, AIDS can still not be diagnosed. S/he tests positive for HIV and is highly infectious. It is at this period that the person can revert back to the asymptomatic period depending on a number of factors such as prompt medication, appropriate treatment and good nutrition.

## **6. Symptomatic Phase II**

This is the last phase. During this period, a combination of diseases are manifesting in the person. The doctor can clinically diagnose a person as having AIDS. Many persons, especially the terminally ill, test either positive or negative at this point. A person in this phase is highly infectious especially if there is contact with his or her body fluids. This period could end in death.

### ***Modes of HIV Transmission and Their Prevention***

HIV presence can be detected in almost all human body fluids. However, it is found in different degrees of concentration. Fluids with a high concentration of HIV are infectious when they get into contact with the human body through body openings. Fluids which are highly infectious include the semen, breast milk, vaginal fluids and blood. Body fluids with low concentration of HIV to be insufficient for infection by themselves include urine, saliva, sweat, tears etc.

#### **A. Blood Related Transmissions**

This happens when there has been blood contact with a HIV infected person. This happens through:

1. Receiving infected blood through blood transfusion.
2. Sharing of sharp body piercing instruments e.g. syringes, needles, razor blades etc.
3. Having blood contact during accidents (road or clinical) especially when one has open wounds.
4. Receiving organ transplants from HIV infected donors.

#### ***Prevention of Blood Related Transmissions.***

- ◆ Avoid avoidable accidents.
- ◆ Ensure that body cuts are covered by bandage or plaster.
- ◆ In case of accidents, adhere to first aid rules and guidelines.
- ◆ Avoid sharing body piercing equipment.
- ◆ Use properly sterilised equipment.
- ◆ Avoid the need for blood transfusion by seeking prompt medication in case of sickness and disease and by ensuring proper nutrition.
- ◆ In case of sickness, go to proper and qualified medical personnel.
- ◆ Counsel potential blood donors about HIV.
- ◆ Offer preventive counselling

## **B. Vertical Transmissions**

This refers to the transmission of HIV from the mother to the child. This can happen in three ways - during pregnancy, at the time of delivery and after birth {*please refer to the section on Prevention of Mother to Child Transmission (PMTCT)*}.

### ***Prevention of Mother to Child Transmission.***

- ◆ Counselling men, women and couples whenever possible, on the consequences of pregnancy where there is HIV infection.
- ◆ Seeking proper education and provision of family planning services.
- ◆ Prompt treatment of sexually transmitted infections.
- ◆ Attending early and regular ante-natal clinics.
- ◆ Attending post-natal clinics.
- ◆ Educating birth attendants about HIV/AIDS, especially on how to prevent its transmission.
- ◆ Ensuring the proper preparation and use of equipment needed to facilitate labour and the delivery of the baby.

## **C. Sexual Transmission of HIV.**

Sexual transmission of HIV accounts for the majority of infections. Infection occurs when an infected person engages in unprotected sexual intercourse with an uninfected person. Sexual transmission occurs through most, if not all, of the various forms of sexual intercourse or sexual contact practised in our communities. These include:

- a) Penile/ vaginal penetrative sex - this refers to sexual intercourse between a man and a woman which involves the penis penetrating the vagina.
- b) Penile/ Anal sex - this refers to sex between a man and a man or a man and a woman where the penis penetrates the anus.
- c) Oral sex - sex where the mouth comes into contact with the genitals (either the sucking of the vagina or the penis).

NB: Whereas under normal circumstances kissing should not pose a risk, there are situations where it can be risky. This could happen when there are sores in the mouth.

### ***Prevention of Sexual Transmission of HIV***

- ◆ Abstinence - this can either be in the form of total celibacy where a person decides to live without sex or it refer to situations where one refrains from sex until the right time and the right partner come along for a steady permanent relationship.
- ◆ Faithfulness to one equally faithful sexual partner.

- ◆ Zero grazing - In cases where one is involved with many sexual partners, for example in polygamous relationships, it is advisable that the partners involved remain faithful and limited to sexual relations with those within the circle.
- ◆ Reduction of the number of sexual partners.
- ◆ Exploring and engaging in non-penetrative forms of as will be deemed convenient and acceptable to the individuals.
- ◆ Avoiding circumstances that can tempt you to have unplanned sex.
- ◆ Proper and consistent use of condoms.

### *Ways HIV Cannot Be Transmitted*

If there is no exchange of bodily fluids through sexual contact, if there is no exposure to blood, HIV will not be transmitted in activities of daily living. Therefore;

- AIDS is not transmitted through ordinary social contact, daily family activities, through the workplace ...
- HIV is not transmitted by toilets, or by public transport.
- AIDS is not transmitted through sharing food, towels or paper.
- AIDS is not airborne (cannot be transmitted by coughing or sneezing)
- AIDS cannot be caught by shaking hands.
- AIDS is not caught by living in the same home as a sero-positive person, nor by touching that person, nor by eating with that person.
- An HIV+ child can go to school without presenting a risk of infecting classmates.
- An HIV+ adult can continue working without presenting a risk to colleagues through simple or ordinary contact.

#### **CONDOMS**

A condom provides a physical barrier between the penis and the vagina (or other body openings) and limits the exchange of body fluids. A condom is only effective if used 100% correctly, for 100% of partners, and for 100% of sexual intercourse. The condom must be used before its expiry date, not be exposed to body or environmental heat during storage (not carried in a pocket, not left in a sunny place or locked inside a vehicle for prolonged periods). Due to all these factors, especially human error, use of condoms ought to be considered "safer sex" rather than "safe sex".

#### **Correct use**

The condom must be applied to an erect penis. It is held in place at the base of the penis at the time of withdrawal. It must then be removed and tied (and/or wrapped in toilet tissue) and be discarded in the rubbish bin. Do NOT throw it into the toilet, or on the ground where a curious child may play with it.

#### *Advantages of condom use:*

- It is in cheap supply
- It is readily available
- It helps to prevent pregnancy and sexually transmitted infections.
- It allows for no exchange of sexual fluids.

#### *Limitations of condom use:*

- Existing community perceptions.
- May increase involvement in sexual activity as a result of a sense of security.
- It has an expiry date.
- It requires proper disposal.

## Chapter Three

# Factors Fuelling the Spread of HIV/AIDS

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### Aim

To facilitate the participants to identify and discuss the factors that fuel the spread of HIV/AIDS in their communities. Also, to help participants to understand how HIV/AIDS has affected the community and the wider society.

### Training objectives

By the end of the training, the participants will be expected to:

- identify the factors that cause the spread of HIV/AIDS in the community
- discuss the link between HIV/AIDS and some social behaviour practices in the community
- explain the effects of the HIV/AIDS pandemic

### Course content outline

- Social/ cultural factors
  - Economic factors
  - Physical and biological factors
  - The impact of HIV/AIDS on the individual, the family, the community and the nation
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## Factors Fuelling the Spread of HIV/AIDS

Transmission of HIV/AIDS is enhanced and facilitated by various factors. Some factors may be specific to a given area whereas others may be general. Below are some of the factors identified for most regions.

### A. *Social/Cultural factors*

1. Having multiple partners
2. Widow inheritance
3. Traditional healing practices e.g. body cuts, tattooing
4. Alcohol and drug abuse
5. Religious teachings, practices and beliefs
6. Social pressures e.g need to prove fertility
7. Ignorance or lack of education
8. Peer pressure
9. Gender inequalities
10. Stigma and denial
11. Cross-border migration/mobility
12. Misconceptions and myths about HIV/AIDS
13. Media influence
14. Casual attitude towards sex
15. Break down of family structures

### B. *Economic factors*

1. Unemployment
2. Cross-border trade
3. Commercial sex work
4. Poverty
5. Economic inequalities - big differences between the rich and the poor.

### C. *Physical and Biological Factors*

1. Geographical location of the region or nation
2. Aggressive and brutal sex e.g. rape
3. Untreated sexually transmitted infections
4. Female biological make-up e.g. wearing-off of the vaginal lining during menstruation and the fact that women have a wider surface area of the mucus membrane in the vagina when compared to that of the penis.

#### GROUP WORK

1. Identify and discuss the factors fuelling the spread of HIV/AIDS in your community:
  - a) Social/cultural factors
  - b) Economic factors
  - c) Physical and biological factors
2. What is the impact of HIV/AIDS?:
  - a) On the individual
  - b) On the family
  - c) On the community
  - d) On the nation

## IMPACT OF HIV/AIDS

The HIV/AIDS pandemic has touched every aspect of the society. Its impact has been felt in all aspects of the society. Outlined below is the impact AIDS has had on the individual, the family, the community and the nation of Namibia.

### A. On the Individual

- May cause stigma and discrimination
- One becomes open and vulnerable to diseases.
- One's life may be shortened.
- It may increase stress.
- It may cause depression and its consequences such as suicide.
- It may lead to early retirement/ loss of job resulting in loss of income.
- Finances are stretched because of increase medical expenses.

### B. On the Family

- Loss of income which might lead to poverty.
- An increase in health needs.
- Family may feel disgraced.
- Increases orphans and vulnerable children.
- Increases single parent households.
- Increases spending on funerals.
- Stigma and discrimination.
- Children are forced to take up some parental roles e.g income generation.
- Children's education may be interrupted.

### C. On the Community

- Creates child-headed households.
- Leads to an increase in poverty.
- Minimises community activities because more attention is directed towards HIV/AIDS related activities e.g burials, orphan care
- Leads to an increase in orphans in the community
- May lead to conflicts especially when AIDS is linked to witchcraft.
- May lead to an increase in crime rates mainly due to loss of income.

### D. On the Nation

- Increase in government spending on health.
- Loss of skilled and qualified personnel and expertise.
- Slow population growth.
- Reduction of life expectancy.
- May lead to increase in crime due to poverty.
- May lead to importation of manpower.
- Decrease in productivity which slows down the growth of the economy.
- Increase in the dependency ratio.
- Sensitivity and loss of national pride

- Sensitisation towards behaviour change
- Emphasis on networking and collaboration (e.g. among different faiths, NGOs, corporations etc)

## Chapter Four

# Living Positively with HIV/AIDS

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### **Aim**

To help participants to understand and explore the various possible ways of living positively with HIV/AIDS in the community

### **Training objectives**

By the end of the training, the participants will be expected to:

- explain the concept of positive living
- identify the different aspects of positive living
- understand what is meant by proper feeding for infected persons
- explain the roles of various actors in positive living for a person living with HIV/AIDS

### **Course content outline**

- Responsibilities of the infected person
  - Proper feeding and nutrition
  - Energy giving foods in the community
  - Body-building foods in the community
  - Disease fighting foods in the community
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## LIVING POSITIVELY

### *Community, Family and Individual involvement*

The concept of living positively with HIV/AIDS was developed in the late 1980s. The concept is built on the understanding that an HIV infected person can still live a healthy, fulfilled and productive life. To effect positive living, one needs to acknowledge the fact that HIV/AIDS is a reality and that the infected and affected have to live with it.

In order to live a positive life while one is infected with HIV, there is need for the individual, the family and the community to take responsibility. The primary facilitation for positive living with HIV/AIDS belongs to all the stakeholders; the nation, the community and the family. This is done by setting a conducive and enabling environment and requires having positive attitudes towards the entire HIV/AIDS struggle, people living with AIDS and their families. The community has to create an environment which enhances responsibility towards the infected and the affected.

The family should be supportive of and be involved in the life of the infected person. The family should demonstrate positive and accepting attitudes and offer both moral and practical support.

Positive living is the primary responsibility of the infected person. The individual can seek the support of the family and the community. It is important for the individual to keep in mind that the kind of support he or she will receive will depend on the attitudes the family and the community have towards HIV/AIDS.

### **For the individual, taking responsibility includes:**

1. Accepting your HIV positive status
2. Keeping a positive attitude towards life.
3. Seeking on-going supportive counselling.
4. Maintaining a healthy life by avoiding life endangering habits like smoking, drinking alcohol and taking drugs.
5. Exercising the body
6. Avoiding re-infection with the virus
7. Avoiding avoidable sicknesses by protecting yourself.
8. Registering for HAART
9. Ensuring proper and nutritious feeding

### *Proper or Good Feeding and Nutrition*

To ensure good feeding, it is important to have a feeding plan. Good feeding is not necessarily expensive. A good feeding plan is influenced by what the virus is doing in the body. The virus basically does three things to the body:

- a. The virus is breaking down the body, so rebuild the body.
- b. The virus is taking your energy, so restore the energy.
- c. The virus is weakening your ability to fight disease, so build the ability of your body to fight diseases.

## Energy Giving Foods in the Community

Sorghum  
Millet  
Sweet potatoes  
Maize  
Rice  
Banana  
Potatoes  
Cassava Flour

## Body Building Foods in the Community

Meat  
Fish  
Eggs  
Fresh Milk  
Beans  
Groundnuts  
Chicken  
Peas

## Disease Fighting Foods in the Community

Green vegetables  
Carrots  
Mango  
Pineapple  
Cabbage  
Pawpaw  
Guava  
Watermelon

### GROUP WORK

Identify different foods which are readily found in the community and categorise them into different groups. Arrange the same foods into a daily and weekly feeding plan.

## Chapter Five

# The Concept of Helping

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### Aim

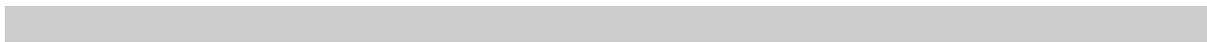
To equip the participants with the skills and attitudes which will enable them to effectively offer help to the community in a mutually respectable manner.

### Training objectives

By the end of the training, the participants will be expected to:

- understand the principles which guide offering and receiving help
- identify the qualities of a helper
- explain the process of offering help
- demonstrate necessary attitudes and communication skills required of a helper

### Course content outline

- Principles of helping
  - Qualities of a helper
  - The process of helping
  - Positive attitudes
  - Good communication skills
- 

## THE CONCEPT OF HELPING

### *Introduction*

All human beings at one time or another require help. Helping is often taken for granted and is seen as an obvious thing to do. On the contrary, helping should never be taken for granted. Since it is a concept which forms an integral part of community life, it should be approached with sensitivity, respect and dignity. The following story sheds some light on this:

A Dutch missionary, by the name of John, was invited by a friend to Botswana to serve as a missionary. When he arrived in Botswana, he heard of the village of Raykops. He visited the village and decided to work there. At the time, the community had a hospital and two schools but no running water supply. John observed this and decided to do something about it. He contacted his country, asked money to dig a borehole for the community, got the money and contracted engineers from Francistown (the nearest city) to do the work. When the borehole was completed and operational, he invited the people to use the borehole. After some time, out of curiosity, some of the people in the community wanted to find out how the machine operated and in the process broke down the machine. John had to get the same engineers from Francistown to repair the borehole. When it was ready, he invited the community to make use of it. This time, the community did not openly use the borehole. They would wait to hurriedly use it when he was away because they were afraid of him and his borehole. In no time, it broke down again.

Did John help the people of Raykops? No, because he did not consult the people before digging the borehole. People should have identified their problem and found a way, together, to solve it. Perhaps, the community did not need a borehole since they had survived all along without one. He took a decision on his own and executed it and expected the community to appreciate the results. The borehole was not a felt need of the people but an observed need of the helper.

There are some fundamental principles or understandings that need to be considered before help is offered.

### *Principles of Helping*

1. Help should be offered with the aim of benefiting the people;
2. Help must meet the felt needs of the community and not the observed needs of the helper;
3. Help should be offered on mutually agreed terms between the helper and the community;
4. Help should never dehumanize the one to whom it is being offered;
5. The helper needs to seek the consent of the one to be helped before offering help;
6. There should be mutual respect between the helper and the one being helped;
7. The helper does not take over but he or she should seek to empower, support and supplement the efforts of the people so as to enable them to help themselves;
8. The helper should bear in mind that every community has untapped abilities/potential. Therefore, one should aim at awakening the latent potential in the community so that the people can take responsibility for themselves.

## Qualities of a Helper

- Trustworthy
- Understanding
- Ability to listen
- Generous heart
- One who is a role model
- Friendly
- Patient
- Approachable
- Demonstrates love
- Empathetic
- Knowledgeable and skilled
- Discreet
- Confidential
- Sincere
- Supportive and understanding
- Respectful
- Self-motivated
- Positive attitude
- Good communication skills
- Socially acceptable
- Sensitive
- Availability
- Diplomatic

### Role Play

1. A community mobiliser visits a family in the community. At least three generations are represented in the family; a man, his wife, his mother and children.

2. A community mobiliser visits the village chief. What should be the approach?

3. Communication skills  
Practice listening skills. Show how to and how not to listen

## *The Process of Helping*

<b>Stage 1</b> Help the person tell the story	<b>Stage 2</b> Explore options	<b>Stage 3</b> Make a plan
Positive attitudes		Good communication skills

Helping is not a one off exercise. It is rather an ongoing relationship between the helper and the one who is being helped. The process of helping, especially in HIV/AIDS work, is built on two pillars. These pillars are:

1. Positive attitudes
2. Good communication skills

## Positive Attitudes

A community mobiliser needs to have the necessary positive attitudes if he or she is going to succeed in helping the community. These attitudes include:

- To accept the community as it is;
- To have a non-judgemental attitude towards the community;
- To be willing to learn from the community;
- To maintain confidentiality when people in the community talk to you about their personal lives;
- Be knowledgeable about what you are talking to the community about;
- Be patient;
- Be caring;
- Be able to identify with the needs of the community and help (empathy).

## Communication Skills

In order to communicate effectively with the people in the community, it is important to know and understand them. This will enable you not to use words, gestures or postures that are unacceptable in the community. Some of the things to keep in mind while communicating are:

- Take the socially acceptable posture while talking to the leaders, the women and the men;
- Listen attentively - this is expressed through appearing relaxed, being open, leaning forward and establishing eye contact.
- Asking questions - questions that require a yes or no answer should be avoided. Ask questions that will provide the information you need. Do not ask questions in an interrogatory manner;
- Answering questions- if you do not have the answer to a question, it is okay to admit it. It is good to exercise caution when answering sensitive questions. It is sometimes advisable to refer back the question to the audience so you can get their opinions and suggestions;
- Checking understanding -This is done so that you can check if you have been understood by the people and whether you have understood what the people are saying to you. This can be done by repeating back to someone what he or she has said by summarising the topic of discussion or paraphrasing what is being said;
- Facilitation skills - This enables you to involve everyone in the group and to draw attention away from yourself.

## Stages of the helping process

The helping process progresses through three stages:

### Stage one

This is the initial stage. It is at this stage that rapport between the helper and the person being helped is established. The person is helped to tell his/her story with the aim of soliciting information with as much ease as possible. This stage entails establishing a relationship by utilising positive attitudes and good communication skills. One should start with greetings and introductions. After this, one should find out what the person(s)

already know. As the discussion continues, one should utilise the opportunity to deliver factual and correct information and correct any misinformation the person(s) may have.

### **Stage two**

At the stage, the person(s) should be helped to explore the options available. Find out what can be done from the person(s). Outline the options mentioned and discuss the implications and practicality of each option. Thereafter facilitate the person(s) to decide to take on one or two most practical and manageable options.

### **Stage three**

By now a realistic work plan for action should be made. This will involve reviewing the preferred options; discussing and setting in place the implementation modalities or action points; identifying resources that will be required; and reminding the person(s) of the implications of their choice.

# Chapter Six

## Conducting Group Sessions

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### **Aim**

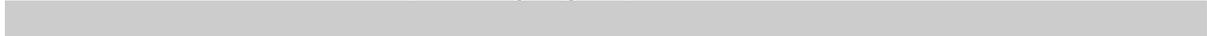
To discuss group dynamics and equip participants with basic group facilitation skills.

### **Training objectives**

By the end of the training, the participants will be expected to:

- understand the importance of conducting group sessions
- identify situations where group sessions are possible to conduct
- identify ways of selecting a group
- identify things to consider when planning group sessions

### **Course content outline**

- Importance of group sessions
  - Situations where group sessions are possible
  - Guidelines for selecting a group
  - Points to consider when planning a group session
- 

## CONDUCTING GROUP SESSIONS

### *Working Definition of a Group Session*

People who have met together in one place for a specific purpose and in most cases have a facilitator.

### *Importance of Group Sessions*

1. Group sessions enable the people present to share different experiences and opinions;
2. They enable the participants to identify and share with others facing similar problems;
3. They encourage people to share their problems by assuring them that they are not alone;
4. They hasten the process of HIV/AIDS information dissemination at the community level thereby saving time;
5. They provide an opportunity for individuals to discuss and learn facts about HIV infection and transmission and how to address the problem in the community;
6. They provide an opportunity for those in the group to harmonise their ideas;
7. They enable individuals to discuss issues that can promote their health status;
8. They provide people with an opportunity to learn about HIV/AIDS together, which can enhance the process of behaviour change in a given society;
9. It helps to save time as it helps to disseminate AIDS education further in a given single setting.

### *Situations Where Group Sessions Are Possible*

1. Individuals living in social groups e.g. youth football clubs, women groups, church youth groups etc;
2. High risk exposure groups - commercial sex workers, truck drivers, traditional doctors community care-givers etc;
3. Individuals in institutions - prison inmates, students, church members, soldiers, health workers etc

### *Guidelines for Selecting a Group*

There are a number of criteria one can use to select a group. These are:

#### **A. Gender**

Gender refers to both the male and the female sexes. Gender composition can influence the development of a group session. There are two forms of gender groups:

- a. **Single sex groups:** This refers to groups where all group members are of the same sex- female groups and male groups. Single sex groups have strong gender-based practices which are quickly established in a group and tend to be consensual. The gender practices tend to be accepted as roles within the group. These groups have a tendency of overlooking the perspectives of the other gender. Single sex groups have an atmosphere that encourages free expression of views. Members easily identify with each other.

- b. Mixed sex groups: this is where group members consist of both males and females. These groups enable both sexes to understand and appreciate each other's feelings, attitudes and challenges.

The use of either single sex or mixed sex groups will depend on the task and purpose of the group.

## **B Age group of the group members**

When one is selecting a group based on age, there are two categories to consider:

- a. Narrow age range; these groups cover a narrow age limit. Adolescent groups belong to this category. Narrow age groups are usually uniform in regard to age and character. Members easily identify with each other and they are free to express their views without fear of intimidation or feelings of incompetence.
- b. Wide age range; these groups have big variations in that they tend to have broad life experiences. Adult groups belong to this category. Members tend to identify with their own peers and this leads to the formation of sub-groups. When this happens, there is likelihood for one age bracket to dominate and suppress the views of other members.

## **C. Language:**

Language can also be used to determine the composition of a group. It is important to ensure that all group members are fluent in a common language.

### ***Size of the group***

The size of the group should be determined based on;

- a. Having a face to face relationship as this creates closeness and confidence among the group members.
- b. Achievement of constructive criticism - the size of the group should enable the group members to have time to offer criticism in a constructive manner as this helps the members to learn from each other.
- c. Sharing of experiences - the number of group members should be large enough to enable sharing of sufficient experiences and knowledge.
- d. Absence of cliques - the size of the group selected should not encourage the formation of sub-groups based on personal agenda, but rather the whole group should develop a strong sense of group identity.

#### **Role Play**

A community mobiliser visits an antenatal clinic. The sitting arrangement is haphazard. The patients are a mixture of noisy couples, quiet people, crying babies and others. How should the community mobiliser handle the group and manage to accomplish his/her objective for the visit?

### ***Points to Consider When Planning a Group Session***

It is important to take into consideration the following factors when preparing to conduct a group session. These are:

- A Nature of the people - their education level, gender, occupation, marital status etc. This determines how you will approach the group, the language you will use and the depth of the content;
- B Topics for discussion - the specific topics of discussion during the group meeting;
- C. Venue - where you intend to hold the group meeting;
- D. The time of the meeting.

***Always Remember:***

- To give information of referral centres or places where individuals can go for more information, counselling, HIV testing or medication;
- Ask each group member if they have any questions;
- Listen to each member of the group attentively;
- Check that each member of the group has understood what was being discussed;
- Ask group members questions with the aim of drawing out what they already know;
- Try to find out if anyone in the group can answer the questions being asked before you respond to them.
- Ensure that the sitting arrangement encourages maximum participation.

## Chapter Seven

# Going Public with HIV Status

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### Aim

To help the participants to identify and discuss the implications of going public with one's HIV status in a given community and the kind of support that is likely to be required by the individual.

### Training objectives

By the end of the training, the participants will be expected to:

- understand the benefits of going public with one's HIV status in the community
- understand the limitations of going public with one's HIV status in the community
- understand the kind of support an individual who has gone public with his/her HIV status needs

### Course content outline

- The benefits of going public with one's HIV status
  - Disadvantages of going public with one's HIV status
  - The process of going public
  - The responsibilities of the individual and the community when he or she goes public with the HIV status
- 

## GOING PUBLIC WITH HIV STATUS IN THE COMMUNITY

Going public with one's HIV status should not be approached lightly. When an individual decides to declare his/her HIV status to the public, there are advantages to be gained both by the individual and the community. In the same way, there are some disadvantages for both the individual and the family that should be borne in mind. The two are outlined below.

### *Advantages of going public with one's HIV/AIDS status*

When a HIV positive person makes their status known publicly, there are some advantages to it. Some of those advantages include:

- The society can learn by example because there is an experience to relate to;
- One can easily get support from the people since they will be knowing what kind of support one may need;
- It helps to reduce transmission of HIV because it creates awareness;
- It may minimise stigma and gossip since one's status is now known publicly;
- It may enhance the coping mechanism of the infected person when the attention of the community has been acquired;
- It reinforces the need for behaviour change in the community so as to avoid more infections;
- It reinforces positive living for the infected person;
- It may transform people living with AIDS into agents of change;
- It can encourage some people to go for testing.

#### **Group Work**

1. Discuss the advantages of going public with one's HIV status
2. Discuss the disadvantages of going public with one's HIV status
3. What should communities do for people living with HIV/AIDS

### *Disadvantages of going public with one's HIV/AIDS status*

It is important to know that there are some disadvantages of going public with one's HIV/AIDS status. This prepares one for the different reactions one is likely to get from the society in general. Some of these disadvantages include:

- It may lead to stigma (rejection) by the society;
- It may stigmatise the partner of the infected person;
- It may lead to rejection by one's family members and friends;
- It may lead to a loss of integrity in the community;
- It may lead to discrimination at the workplace;
- It may lead to the loss of one's role and position in the society;
- It may lead to a loss of income.

## *The process of going public*

*Bearing the above advantages and disadvantages in mind, the question should not be whether one should go public or not, instead, the important thing to do is to help the person to understand what to expect if he or she goes public. It should be the individuals' initiative. The individual should be offered on the spot initial counselling. He or she should be referred to a qualified counsellor for holistic counselling.*

## Chapter Eight

# The Continuum of Care

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### Aim

To categorise the various possible actors in the continuum of care and identify the various roles each of them can play if mobilised.

### Training objectives

By the end of the training, the participants will be expected to:

- understand and identify the roles of the individual and the family in caring for the infected person
- identify the roles of institutions in caring for the infected person
- identify and discuss what the community can do for the infected person

### Course content outline

- Role of the individual
- Role of the family
- Institutional care
- Community care

## THE CONTINUUM OF CARE

A person with HIV/AIDS needs to be offered a comprehensive sequence of services. There is no single individual or institution that can adequately and comprehensively do this. However, if various service providers join hands in a coordinated and networked manner, the infected person can receive all the care and support he or she needs.

The various actors in the continuum of care have varied roles to play as shown below:

### ***A. Role of the Individual***

In caring for him or herself, the individual's responsibility is:

- Caring for his or her hygiene and health
- Seeking social support
- Acquiring financial support for his or her needs
- Seeking spiritual care and support

### ***B. Role of the Family***

The family complements the efforts of the individual. The family needs to be empowered so as to play its role. In caring for an HIV positive individual, the family of the infected person has the responsibility of:

- Spending time with the infected person
- Washing and cleaning the patient
- Providing spiritual support by praying together
- Helping and supporting the patient to eat in case he or needs help.
- Sharing the patient's responsibilities e.g. paying school fees for the children.

### ***C. Institutional care***

This includes hospitals, clinics, non-governmental organisations and other institutions that provide care for the HIV infected. Some of the services provided by institutions include:

- Providing clinical care
- Offering professional counselling
- Providing physiotherapy
- Offering HIV testing and viral load count
- Offering aromatherapy
- Offering any other specialised or technical services

### ***D. Community care***

The following are services the community can provide for an HIV infected person:

- Visiting the family and the patient in particular.
- Caring for orphans
- Contributing material assistance to a general pool e.g clothing, food
- Forming support groups in times of trouble
- Involving people living with AIDS in community events
- Visiting the family to offer social and emotional support

- Promoting behaviour that stops the spread of HIV
- Accepting and acknowledging that AIDS is a problem in the community and seeking positive action from the people

## Chapter Nine

# Networking and Collaboration

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### **Aim**

To discuss the need for networking and collaborating when working towards a common goal and to identify the principles on which good networking practice is founded.

### **Training objectives**

By the end of the training, the participants will be expected to:

- explain the benefits and challenges of networking and collaborating
- discuss the principles of networking
- identify and discuss types of networking and possible networking partners

### **Course content outline**

- Benefits of networking
- Challenges of networking
- Principles of networking
- Types of networking
- Possible networking partners

## NETWORKING AND COLLABORATION

The concept of networking and collaboration is a crucial aspect in tapping all the potential to fight HIV/AIDS within a given community. Networking refers to working independently as organisations in consultation with others in the same field of work. The greatest beneficiary of networking is the community because it receives a complete package of services. Community Based Organisations (CBOs) and Non-governmental Organisations (NGOs) complement each other.

### *Benefits of Networking*

The following are some benefits of networking and collaborating with other organisations or stakeholders in the community with the aim of offering the best services to the community:

1. Lessons, ideas and experiences can be shared with other organisations;
2. Organisations and individuals can learn from one another;
3. Networking ensures that efforts are not being duplicated;
4. As a result of input from other people, there is added value and quality to our programmes;
5. As a result of interaction one gets to know what is going on in the community;
6. It promotes unity of purpose and provides a model to be followed by others who are being mobilised for action;
7. It avoids contradiction of messages relayed to the community;
8. It makes it easier to have concerted efforts towards different situations in the community;
9. It provides an opportunity for joint advocacy effort on issues affecting the community.

### *Challenges of Networking*

The following are some challenges organisations are likely to encounter as a result of networking and collaboration:

1. Underlying motives may be different and clashes may occur;
2. Organisations may be at different levels of experience, involvement etc and therefore have different perspectives and outlook of the problem;
3. Networking partners might have feelings of inferiority and superiority;
4. There may be inequitable distribution of resources;
5. The human factor - the more the people, the higher the chances of conflict are.

### *Principles of Networking*

For networking and collaboration to bear the desired results, the following principles should guide the relationship:

1. There should be a purpose for networking
2. There should be mutual respect between networking partners.
3. Define and agree on terms of the relationship.
4. Maintain regular interaction for purposes of information sharing and support.
5. All the networking parties should share the benefits of their efforts and not just one party.

### *Types of Networking*

1. Informal partnerships
2. Parallel programmes or activities - each organisation works in a given programme or area and another organisations works in a different area or field.
3. Joint activities or events - e.g declaring a week of networking which will culminate in a joint gathering, or have a joint march for an event.
4. Formal partnerships
5. Networking based on geographical coverage

### *Possible networking partners*

- Families
- Business community
- Faith Based Organisations
- Government institutions
- Non-governmental organisations
- Community based organisations
- Traditional healers.

## Chapter Ten

# Voluntary Counselling and Testing

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### **Aim**

To equip the participants with sufficient knowledge and offer justification for Voluntary Counselling and Testing (VCT) to enable them to effectively mobilise the community

### **Training objectives**

By the end of the training, the participants will be expected to:

- Explain the importance of testing for HIV/AIDS
- Understand the nature of testing
- Identify challenges and barriers of VCT
- Understand the role of VCT in the provision of ART

### **Course content outline**

- Benefits of VCT
  - Types of tests
  - Possible barriers to testing for HIV
- 

## VOLUNTARY COUSSELLING AND TESTING

Voluntary Counselling and Testing (VCT) starts with a decision, made without coercion, to undergo counselling which in turn empowers one to make an informed choice as to whether or not to take an HIV test. It is an intervention in HIV/AIDS prevention and care.

This process helps the willing client to take responsibility for his or her life and actions as far as HIV/AIDS is concerned. The process also helps the client to receive the necessary information which enables him or her to make an informed decision as to whether or not to test for HIV.

The irony of VCT lies at the beginning of the process- how do the people go for the service voluntarily if they are unaware of it? This therefore places community education and mobilisation at the very start of the intervention. The people in the community need to be informed not only of AIDS, but they also need to be mobilised to voluntarily go out and seek counselling and testing services.

### *Benefits of VCT*

HIV testing should ideally be recommended to everyone, especially to those who are sexually active. There are enormous benefits of knowing one's HIV status. VCT aims at communicating these benefits without failing to state the possible negative consequences of testing.

### **Benefits for HIV Positive Persons**

1. HIV positive persons get to know their status, the implications of their positive status and the choice they have of doing a number of things that will enable them to live a normal and fulfilled life in spite of the infection.
2. HIV positive persons can seek and receive social support from those who are already providing this support to People Living With AIDS (PLWA).
3. HIV positive persons can join peer support groups.
4. Couples, women and partners who know their status have a choice to make informed decisions about future pregnancies and fertility.
5. A person who knows his/her HIV positive status can help prevent the transmission of the virus to a HIV negative or untested partner.
6. HIV positive persons can be assessed for enrolment for antiretroviral therapy (ART).
7. Newly identified infected persons can be helped to understand and cope with the diagnosis and as a result adopt a lifestyle that will help them live longer.
8. Mothers identified as being HIV positive can take antiretroviral drugs and change infant feeding practices aimed at preventing mother to child transmission. This can result in an upto 50% reduction of HIV infection of their infants.
9. HIV positive persons can receive prompt medication for other infections they might have.

### **Benefits for HIV Negative Persons**

Whatever the prevalence or situation of HIV, there are still more HIV negative people than are HIV positive people. Even for those who are HIV negative, there are great benefits for seeking voluntary counselling and testing. These include:

1. Knowledge of one's HIV negative status can reinforce positive behaviour to ensure the negative status is maintained.
2. For mothers, a negative HIV status should allow for more appropriate counselling about infant feeding practices.
3. Knowledge of one's negative status will enable a person to make informed choices about future plans, for example as regards pregnancy.

There are benefits of testing that are specific to expecting mothers, husbands, infants, families and the community. For these, one should refer to community based counsellors where they exist, or community health workers and/or institutional based counsellors and social workers.

### *Types of Tests*

1. ELISA - Enzyme Linked Immunoabsorbent ASPA.
2. Rapid Tests
3. Western Blot

### *Possible Barriers to testing for HIV*

1. Fear of knowing one's status.
2. Perceived lack of benefits to the individual.
3. Perceived lack of resources for the HIV positive individuals.
4. Emotional stress.
5. Fear that HIV testing may create disharmony in the family.
6. Fear of an increase in violence and abandonment of people who test HIV positive.
7. Fear that the counsellor or the health worker or the service provider will tell the community.
8. Fear of blame and stigmatization of people living with AIDS in the community by leaders such as religious leaders, health workers etc.
9. Non involvement of male counterparts.
10. Fear of having an HIV positive test result.

### *Conclusion*

It is important to note that the testing of an individual should be done with the consent of the individual, whether it is the Opt-in or the Opt-out approach to testing. However, counselling can be made compulsory to all people, especially to those considered to be highly at risk or already suspected to be infected on clinical grounds.

Voluntary testing should be encouraged and provided with appropriate counselling services. Note that counselling should be done by a trained counsellor, who is either based in the community or at an institution such as a VCT centre, a hospital or clinic or an AIDS service organization. Community mobilisers should have knowledge of VCT, but they should refer the clients to trained counsellors or health personnel.

Information about the HIV status of individuals should be treated with confidentiality. It should not be disclosed without the consent of the individual. We should apply the principle of shared confidentiality for those who need to know for the purpose of providing appropriate health and social welfare care. The infected person has a moral obligation and responsibility to protect others from infection, and he or she should be made fully aware of this responsibility.

## Chapter Eleven

### Prevention of Mother to Child Transmission

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#### **Aim**

To enable participants to discuss and explore possible ways of involving communities in programs aimed at the prevention of mother to child transmission of HIV

#### **Training objectives**

By the end of the training, the participants will be expected to:

- explain how mother to child transmission takes place
- explain how mother to child transmission can be minimised
- explain the role of the community in supporting programmes for PMTCT
- Understand factors which affect and accelerate mother to child transmission

#### **Course content outline**

- HIV and pregnancy
- Mother to child transmission
- Mobilising the community for PMTCT

## PREVENTION OF MOTHER TO CHILD TRANSMISSION

### *HIV and Pregnancy*

#### **Fertilisation**

Fertilisation is the uniting of the sperm cell from a male, with an egg cell from a female to form a cell that will develop into a new individual.

#### **HIV Infection**

Sperm cells are contained in a man's semen. Both semen and sperm cells enter the woman during sexual intercourse. HIV infects cells contained in the semen but it does not infect the sperm itself. Therefore, HIV is not passed on to the foetus by the man's sperm or the woman's egg. This means that a child conceived by an HIV infected man or an HIV infected woman is not infected at conception.

#### **Pregnancy or Conception**

After fertilisation, the new cell is implanted inside the uterus (womb). The new cell gets its nutrients from the lining of the uterus and is not part of the woman's body. It gets food from the mother but is not part of the mother.

The foetus (baby) is attached to the mother's uterus by the *placenta* which is a temporary organ designed for this purpose. The placenta does not come into contact with the mother's blood at all.

Note that HIV is not passed on from the mother to the baby by the regular mixing of the blood of the mother with that of the baby because blood from the two does not mix. Were it possible for the blood from the two to mix, all babies born to HIV infected women would be born HIV positive, but this is not the case.

HIV infection that takes place during pregnancy (in the uterus) appears to be due to a disruption of the placenta.

#### **The Placenta**

The Placenta has four functions:

1. **Respiration:** The baby does not breathe in the uterus. The exchange of air (oxygen and carbon dioxide) for the baby occurs in the placenta.
2. **Nutrition:** Food for the baby comes from the mother's diet. By the time it reaches the placenta, it has already been broken down into simpler forms. The placenta sorts and selects what is required by the body.
3. **Storage:** Because the foetus' (baby's) features are not fully formed, the placenta stores food nutrients (sugar and vitamins) so that they are readily available when the baby needs them.
4. **Protection:** the placenta allows good things to cross to the foetus (baby) e.g. nutrients, antibodies, oxygen. It prevents most, though not all of the harmful

things from crossing - things like disease causing germs and harmful drugs. But there are some germs that can cross the placenta and cause illness to the baby. These include bacteria that cause such diseases as syphilis and tuberculosis, and viruses including HIV.

HIV can cross the placenta to the baby and cause infection. The chance of this happening will depend on the level of infection with its corresponding viral load and how healthy the placenta is.

*More in-depth facts about HIV infection, pregnancy, counselling, nutrition and the impact of pregnancy on the immune system can be got from further training, for example, Counsellor training.*

## ***Mother to Child Transmission (PMTCT)***

### **Rates and Timing**

Transmission of HIV from mother to child can occur in three ways: during pregnancy, during labour and delivery and after birth (during breastfeeding). It is estimated that 40% of babies born to HIV positive mothers will be HIV positive.

The highest risk of infecting the baby is thought to be during labour as 50% of all infections happen at this time. The rest of the infections are as follows; 30% through breastfeeding and 20% during pregnancy.

We therefore can conclude that of all the babies born to HIV positive mothers, the greater number will not be infected with the virus.

### **Factors Affecting PMTCT**

There are factors that make it more likely that a mother will pass on the virus to her baby. These factors are as follows:

1. The chance of transmission of HIV to the baby is increased if the mother is in the advanced stages of HIV infection or if the mother has AIDS.
2. Women who have recently been infected tend to have higher levels of HIV in their blood and breast milk hence making it more likely for them to pass the virus on to their children.
3. Deficiency in nutrition in HIV infected pregnant women has also been associated with an increase in mother to child transmission.
4. Some behaviours and habits are also associated with an increase in the risk of infection. These habits include smoking cigarettes, use of hard drugs and having unprotected sexual intercourse during pregnancy.
5. Labour and delivery factors. As already observed, much of the HIV transmission takes place around the time of labour and delivery. This is due to exposure of the infant to the mother's HIV infected blood. The labour and delivery factors include; premature delivery, severe bleeding, prolonged rupture of membranes, use of equipment and cutting of the birth canal.
6. Infant factors which include premature infants, infants with low birth weights, birth of twins and babies born with oral thrush.
7. Feeding practices or factors. Transmission through breast feeding is more likely to occur if the mother is malnourished and/or has clinical signs of AIDS. It could also

happen as a result of poor breast feeding techniques resulting in breast engorgement. Cracked nipples also facilitate transmission. Babies with oral thrush are likely to be infected through breast feeding.

## **Prevention of Mother to Child Transmission**

The purpose of the PMTCT programme is “prevention of HIV transmission from a mother to the child.” This can be done from a three dimensioned intervention strategy:

- A. Primary prevention of HIV infection in the mother by:
  - ◆ promoting change of behaviour and
  - ◆ prevention and treatment of sexually transmitted infections.
- B. Prevention of unwanted pregnancies in HIV-infected women by:
  - ◆ counselling and voluntary testing and
  - ◆ providing family planning services.
- C. Reduction of the risk of HIV infection to the baby in HIV infected pregnant women by:
  - ◆ offering counselling and voluntary HIV testing;
  - ◆ giving antiretroviral drugs to the mother and the infant;
  - ◆ modifying midwifery and obstetric practices;
  - ◆ providing formula for infant feeding instead of breast feeding.

## **Comprehensive PMTCT Interventions Include:**

- ◆ Information and education for women, partners, families and communities.
- ◆ Counselling for all pregnant women, partners and families.
- ◆ HIV testing for women and their partners.
- ◆ Antiretroviral therapy and on going counselling for HIV positive women.
- ◆ Obstetric interventions during labour and delivery.
- ◆ Infant feeding counselling for all women and infant formula offered to HIV positive women.
- ◆ Monitoring and evaluation.

## ***Mobilising the Community for PMTCT***

Whereas PMTCT services may be available to both women and their partners, they may only be accessed when people know the service is available, and more importantly, when they feel that there are benefits for using these services. Hence, there is need to mobilise for information delivery and education about the programme.

## **In Mobilising, We Should Aim To:**

- Increase/ create community awareness of PMTCT.
- Promote support for women enrolling in the PMTCT programme.
- Promote male involvement in PMTCT programmes.
- Reduce stigma of HIV in the communities.
- Promote advocacy for the support of the PMTCT programme through allocation of adequate resources.

## **The key aspects of mobilisation programmes could include:**

- Programme awareness through printed materials -posters, leaflets, pamphlets, newsletters.

- Use of the mass media - radio, TV, newspapers.
- Education using videos - documentaries and dramas on PMTCT.
- Drama performances and concerts.
- Mobilising community support for women enrolling for PMTCT through workshops or meetings or outreaches in the village.
- Advocating for the PMTCT programme through sensitisation of political and community leaders, policy makers and health managers.

# Chapter Twelve

## Antiretroviral Therapy

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### **Aim**

To help participants to understand and explain Antiretroviral Therapy (ART) in simple understandable terms to the community.

### **Training objectives**

By the end of the training, the participants will be expected to:

- define and explain ART and how it works
- explain the implications of ART
- explain the relationship between ART and prevention

### **Course content outline**

- The work of ART
- Is ARV therapy a cure for AIDS
- Adherence to ART
- Who gets ART?
- ART and other medicines
- Side effects of ART
- ARV therapy and prevention of re-infection
- Mobilising the community for ART

## ANTIRETROVIRAL THERAPY

### *Antiretroviral Therapy*

Antiretroviral therapy (ART) refers to a combination of medicines that are taken by an HIV positive person so as to reduce the amount of HIV in the body. These medicines should only be given by a special health care team which may include doctors, counsellors, social workers and other health care workers.

### *The Work of ART*

Antiretroviral therapy slows down the development of HIV in the body. This in turn allows one to live a healthier and more productive life. If taken according to the doctor's instructions, the medicines help the body to become stronger. The person will then suffer from fewer diseases and will have a better chance of staying alive longer.

### *Is ART A Cure For AIDS?*

ART medicines reduce the amount of the virus in the body and make a person feel better once the person has started taking them but they do not cure AIDS. HIV still remains in the blood. Even though a person may feel better, he or she ought to continue living responsibly by observing positive sexual behaviour.

### *ARV Therapy is For Life*

Once a person begins ART, the person needs to continue with it for the rest of his or her life. If one stops taking the medicines even for a little while, the medicines may no longer work and this will reactivate HIV to become stronger.

Once on ART, these medicines become a very important part of one's life. A person ought to commit to the therapy and in return, he or she will be able to live a healthier and often normal life.

### *Adherence to ART*

Adherence to ART refers to always trying to take the right medicine, in the right way, everyday, at prescribed times. This is always prescribed by the health care team. Therefore listening to the advice of the team will ensure that the therapy works best.

ART cannot be shared with anyone. Each person who needs ART will be given his or her own right medicines which will be effective for him or her. This must be personally assessed too.

Each time a person forgets to take his or her medicines, he or she helps the HIV to become stronger. Therefore, taking these medicines in the right way is very important if ARV therapy is to work well for the person.

## ***Who Gets ARV Therapy?***

The people that are to be provided with ART are:

- a. People with AIDS
- b. People who have HIV but have not yet developed AIDS.

Not everyone who is HIV positive needs ART. It is only for those people whose immune system has been seriously weakened by HIV. An HIV positive person should go to the hospital for assessment where she/he will be advised whether she/he needs ARV therapy. But the decision on whether or not to commit to the lifelong ARV therapy is for the individual to make.

## ***ARV Therapy and Other Medicines***

A person should always tell the health care team about any other medicines or herbs he or she may be using. Once a person starts on ARV therapy, the person should talk to the health care team before using any other medicines. One should also tell his or her traditional healer that he or she is on ART.

## ***Side Effects of ART***

Side effects refer to the unwanted reactions that a person's body may have towards the medicines one is taking. Almost all medicines used to fight diseases can cause side effects in some people. These side effects usually go after a little while, but some may remain for a longer period of time.

With ART, side effects can also occur. Some of the side effects of ART are:

- Painful stomach
- Nausea and vomiting
- Diarrhoea
- Skin rash
- Excessive tiredness
- Headaches
- Sleep disturbances - vivid dreams
- Tingly feeling in the fingers and in the toes.

If a person experiences side effects, he or she should contact the doctor immediately but should not stop taking the medicines. Most of the times, the side effects are mild which allows one to continue with the therapy.

## ***ART and Prevention of Re-infection***

Anyone on ART is still HIV positive. This means that one must continue to live a positive lifestyle so as to help the ART to fight the HIV in the body for a healthier and stronger life.

A person on ART should continue to observe positive sexual practices and behaviour such as abstinence, condom use at all times and faithfulness to only one partner. If the person does not do the above, he will still infect others who may be uninfected or he may re-infect himself or herself.

## *Mobilising the Community for ART*

This can be done by:

- Creating awareness about ART in the community and its availability at the hospital;
- Showing the community the need to test for HIV and how to manage the effects of the results, which might include enrolling for ART;
- Mobilising the community to support people with HIV/AIDS to register for ART and to work with them on their treatment (this especially applies to families of the infected persons);
- Engaging the community to be involved in HIV/AIDS campaigns with a view to reducing stigma which is a great barrier to both ART and PMTCT.