TIKAMBE
DISCUSSION GUIDE

Let's Talk About It:
HIV-related Stigma and Discrimination
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Tikambe (Let’s Talk About It), explores how HIV/AIDS-related stigma and discrimination is affecting ordinary Zambians’ lives. The video provides a personal and compelling portrait of people who are both ordinary and extraordinary. They are average families just like yours, but they are extraordinary in their candidness, strength and courage in sharing their personal experiences. These are the stories of real people, not actors. This documentary video profiles the actual experiences of two Zambian families told from the heart.

*Tikambe* helps us reflect and personalize the problem of HIV/AIDS, while also encouraging open communication between men, women and families. It forces us to face the reality of HIV/AIDS in our own lives; whether we are infected or affected. Who then is the person with HIV? She is my sister, my brother, my wife, my child…myself.
Using the *Tikambe* Video to Stimulate Discussion

The video consists of two separate stories, each 20 minutes in length. The first one highlights the story of Alice & Paul Yengwe (Banja la Yengwe). The second one, “Harriet” follows, with Harriet Mulenga’s story. If you have time to show both videos, start with Alice & Paul’s which is found first on the tape. At this point you may stop the video and have a discussion about their story before moving on to Harriet’s story. If your time is limited, it is recommended that you only show Harriet’s story and hold a discussion after its completion. *Tikambe* was not meant to be shown without a discussion so please be sure to allow enough time for viewers to talk through the many issues which these stories raise.

This discussion guide is divided into two parts. The first section focuses on questions and discussion points pertaining to Alice & Paul’s story and the second section refers to Harriet’s. You can refer to either section as you see fit and may want to bring up issues in both stories.

**Role of the Facilitator**

The *Tikambe* video provides an opportunity for discussion around many issues relating to HIV/AIDS. Some of the issues which may be raised are quite sensitive which makes it all the more important for the facilitator to create an environment which is respectful of everyone’s opinions and comments. Viewers should be made to feel comfortable and confident enough to speak freely and gain extra information and answers to their questions. Consequently, the facilitator must guide discussion without dominating it.

Each person viewing *Tikambe* will bring their own personal experiences to the discussion. Each viewer must feel valued and their comments appreciated to fully engage the group and create a lively discussion. The facilitator will likely need to actively encourage participation in interpreting and discussing the film. Some viewers will differ in opinion as existing beliefs are challenged. Open discussion and respect for everyone’s ideas is essential in stimulating critical thinking and opening up to share personal experiences.

Where possible, involving people living with HIV as facilitators or co-facilitators is always recommended.

While many viewers will want to discuss their feelings about the video, many will also request more information. It is the hope that those questions can be answered using this guide wherever possible.
Technical Notes for Showing the Video

Preview the video before the event. Prepare yourself as the facilitator.

To show Tikambe, you will need a television and VHS video player and a video cable that connects the two. If there is no electricity where you are showing the video, be sure to take along a generator. Before the audience arrives, make sure that all of the equipment works.

Place the television where there is no direct sunlight on it to make sure there is no glare. Ensure that everyone can see the screen from where they are seated. You may have to move the television higher up if people in the back cannot see the screen. Also make sure that everyone can hear the sound on the television so that nothing is missed during the screening.

Audience

Tikambe can be used with a wide variety of audiences. There are elements of the video that will appeal to all, young and old.

Here are some ideas for use:

- Community-Based Organisations/ NGOs/NHCs
- Family members/parents
- People Living with HIV/AIDS (PLHA)
- Peer educators
- Schools, colleges, universities and anti-AIDS clubs
- Home Based Care groups & caregivers
- Provincial and District AIDS Task Forces
- Policy makers
- Communities using Mobile Video Units (MVUs)
- Counsellor trainings
- Waiting rooms at VCT centres and health clinics
- Workplaces
- Churches and other places of worship
- On long distance buses

Introducing the Video

Give a brief introduction to Tikambe, but it is important not to give too much information, as this will prejudice the viewer’s ideas. Make it very brief so that the viewers only know the overview of the stories. (See following pages for the description).
In addition, a short discussion before *Tikambe* is shown allows the facilitator to raise key issues which the stories address, particularly around stigma and discrimination. By setting points for discussion before viewing the film, the facilitator provides a natural link to the larger discussion which will take place after watching the video.

**Discussion after the Video**

Once the video is over, viewers should be given the opportunity to ask their own questions for discussion and make comments first. From there, the facilitator may want to then refer to the discussion questions under each of the two stories to further stimulate the conversation. (See below.)

It is also important to be mindful of the size of the group. The facilitator will treat a small group differently from a large one. In the case of a large group, it may also be useful to divide the group into smaller sub-groups to discuss their feelings about stigma. With a smaller group, the facilitator should also try to encourage shy people to speak and get involved in the discussion.
Alice & Paul

Alice & Paul Yengwe are a happily married couple. Paul is a police officer whilst Alice is a housewife. They have been married for 18 years and have 4 children. This film will show how the Yengwe’s married life went as they come to terms with their HIV positive status.

Show Alice and Paul’s story at this stage

After this show, ask participants to work in pairs to discuss what they have seen.

Possible Questions for Plenary Discussion

1. What do people say about people who are HIV positive in your community? (List their responses on a flip chart and go through the list with the group. Ask if what is said is always true).
2. What do you think was going on in Alice’s mind when returning home after learning her status?
3. Think of one time when you felt alone, how did it feel?
4. What would you do if you were Alice or Paul?
5. What do you think about Alice’s decision to tell Paul about her HIV status after she went for a test?
6. Why do you think people decide to have children even after they know that they are HIV positive? How do you feel about this?
7. How does your community support people living with HIV? If they don’t, why is this so?
8. What were the challenges that Alice & Paul faced in disclosing their status?
9. Alice & Paul are living positively. How can people with HIV live healthy lives?
10. What makes it difficult to tell people your HIV status if you are HIV positive?
11. How will you be supportive of PLHA in your community?
Facilitator summarises the key issues

- Stigma & Discrimination
- Mother to Child Transmission of HIV
- Positive Living
- Voluntary Counselling & Testing
- Disclosure - to tell and who to tell.

HIV can feel very humiliating but teamwork is very important such as the way Alice and Paul supported each other. They did not point fingers at each other but accepted that they could not change their HIV positive status and tried to live a positive life thereafter. The communication between them and support of one another has made a big difference when dealing with the attitudes of others. They have dealt with the stigma and discrimination of their family members and neighbours but are still strong and supportive of each other every day in their positive living. All of us can do it. Going for VCT is the first step to learn about one's status.
The second film on the video shows Harriet Mulenga, a widow, who is HIV positive. The stigma and discrimination she felt from within her own family and community almost killed her. Harriet rebounded due to starting a course of ARVs.

Before Showing the Video:

Divide the group in small groups of maybe four. Let the groups discuss what happens when a family learns that one of their family members is HIV positive.

- What are the IMMEDIATE reactions?
- What are the LONG TERM effects?
- What are the effects on the person living with HIV?

Some Reactions the Group Might Identify:

Shock; disappointment; worry; grief; sorrow; fear of caring for PLHA (why?); burden; fear of infection; wish to put person in an isolated bedroom; fear of neighbours finding out and being stigmatized; family denial or refusal to accept results; not knowing what to do; hatred within the family; blaming and shaming.

Show Harriet’s Story at this Stage

Possible Questions for Discussion after the show to help the group understand how Harriet and her family managed to cope with the situation:

1. What did you feel after watching this story?
2. Does this happen in your own community or family?
3. How does that make you feel?
4. How does stigma affect the person living with HIV?
5. Why did Harriet’s family behave the way they behaved? Is this common where we live?
6. Is it important for family and communities to support people living with HIV and AIDS?
7. What stops families from helping their relatives who are HIV positive?
8. What practical things can you do to fight stigma in your family and community?
9. How does this film challenge your ideas about people living with HIV?
10. The film shows a number of misconceptions about HIV/AIDS. What are they and why do you think people have them?
11. What do you know about treatment for HIV/AIDS?
12. Do you think it helps to disclose your status if you are HIV positive?
13. Are antiretroviral drugs available at your clinic/hospital?
14. Is HIV a death sentence?
15. Do you think the church has a responsibility to talk about HIV?
16. How does your religious community deal with the HIV crisis?

Summarise with Key Issues:

- Stigma & Discrimination
- Voluntary Counselling & Testing
- Positive Living
- Antiretroviral Drugs (ARVs)
- Care and Support

Other Presentation Ideas

This film can even come after a short sketch about HIV in the family which would end where the family knows that one member is HIV positive.
What is Mother To Child Transmission (MTCT) of HIV?

Mother to Child Transmission (MTCT) of HIV is when the virus passes from an HIV positive mother to her baby during pregnancy, child birth or breast feeding.

HIV is the virus that causes AIDS. HIV is present in the body fluids of an infected person. The virus can pass from an infected person through sexual intercourse without a condom and using sharp instruments or needles previously used by an HIV positive person without proper cleaning.

Approximately 4 out of every 10 HIV positive mothers will pass the virus on to their baby during pregnancy, breast feeding or delivery if no preventive steps are taken.

How is HIV Transmitted from the Mother to her Child?

1. During pregnancy: There is a chance of the virus passing from the mother to the child in the womb.
2. During delivery: HIV may be passed to the baby through direct contact between the mother’s blood or vaginal fluids and the baby’s blood.
3. During breast feeding: HIV is present in breast milk and may be transmitted from the mother to the baby. This risk may be increased by improper feeding techniques or by an infection on the mother’s nipple.

How to prevent Mother To Child Transmission of HIV

Get Tested! To keep the baby safe from HIV, the mother must first know her own HIV status. This is the first and most important step.
If she tests negative?

The best way for the baby not to get HIV is for the mother to be HIV negative. Once the mother knows she is negative she should:

- Get tested and treated for Sexually Transmitted Infections (STIs) that may increase her risk of getting HIV
- Make sure her partner is also tested for STIs and HIV. If he tests positive then use of a condom during sex is encouraged, to protect the mother and the child from STIs and HIV infection
- Use condoms correctly and consistently during pregnancy if she is unsure of her partner’s HIV status
- Stay faithful to her one uninfected partner to avoid risk of STIs and HIV infection.
- Mothers who get infected during pregnancy are more likely to pass HIV on to their baby.

If she tests positive?

Knowing her positive status means the mother can take some steps to reduce the chances of the virus passing from her to her baby. Some of the things that she can do are:

1. **During Pregnancy:**
   - Prevent malaria by sleeping under an insecticide treated bed net and take the malaria prevention medicine given by the health worker
   - Some mothers may qualify for ARV drugs during pregnancy
   - Delivering at a health centre with a trained health care provider is very important for all mothers but particularly for HIV positive mothers. Have a detailed plan of how, when, and with whom you will get to the health centre as well as what you need to carry with you (especially money for transport and things for the baby)
   - Join a mothers’ support group if one is available, to get help and advice

2. **During Child Birth:**
   - Always deliver with a skilled birth attendant
• Have a family member or friend for support during labour and delivery
• Avoid early pushing and breaking of water if possible
• As soon as labour pains start, take the anti-retroviral drugs (like Nevirapine or AZT) the health care provider has given her
• If she vomits the medicine within 30 minutes of taking it, she has to take it again
• If she has lost her medicine, or forgets to take it, she must notify the health care provider immediately for a replacement dose

3. Feeding the baby
• Get advice on feeding options ahead of time from her health care provider. See the positive and negative of breast feeding and formula feeding below.
• Decide whether she wants to only breast feed or only give the baby other food that the health care provider recommends.

4. In general
• Eat normal meals and get enough rest so she can be strong to look after her baby
• Use a condom every time she has sex to avoid reinfection
• Seek immediate treatment for any other illnesses or infections so that she can stay strong
• Talk to the health care provider about getting Anti-Retroviral drugs that can make her healthier by reducing the HIV in her blood
• Learn about the different feeding options

Exclusive Breast Feeding (If this is the chosen option, breast feeding must be completely stopped at 6 months and other foods must be given.)

<table>
<thead>
<tr>
<th>Good</th>
<th>Bad</th>
</tr>
</thead>
<tbody>
<tr>
<td>Has all the nutrition a baby needs</td>
<td>Can contain the HIV virus if mother is positive</td>
</tr>
<tr>
<td>Cheap, easy and available anywhere</td>
<td>Breast engorgement, cracked nipples, breast infection can increase the risk of HIV virus going to the baby</td>
</tr>
</tbody>
</table>
Exclusive Replacement Feeding (Talk to your health care provider about what you can give your newborn baby instead of breast milk.)

<table>
<thead>
<tr>
<th>Good</th>
<th>Bad</th>
</tr>
</thead>
<tbody>
<tr>
<td>Removes the risk of HIV virus transmission</td>
<td>Can be expensive, especially the baby formulas, and may not be easily available in all parts of the country</td>
</tr>
<tr>
<td>Less stress on the mother if she is not healthy, has poor nutrition or is weak</td>
<td>Depending on what the replacement food is, it may not give the baby as much nutrition as breast milk</td>
</tr>
</tbody>
</table>

Looking at the good and bad, the mother and her family have to make a choice. The important thing is **NOT TO** mix breast feeding and giving other foods to the baby at the same time.

Take the baby for regular well-baby check ups to see how he/she is growing. At 18 months the baby can be tested for HIV. Babies born to HIV positive mothers (whether they are HIV positive themselves or not) will be given a mild antibiotic called “Septrin” to guard against pneumonia and other infections.
Positive Living with HIV if You Test Positive

Positive living with HIV is a lifestyle in which someone who has the HIV virus aims at delaying the onset of AIDS. It is about not infecting others as well as not re-infecting yourself. It is also about having a positive attitude and a healthy lifestyle.

You have tested positive for HIV

Talk to your counsellor. The counselor will listen to your fears and anxieties and will give you support and information on how to care for yourself. You can come back to talk to a counselor any time you feel like talking to someone.

Accepting your HIV positive status

Before learning to accept your status you may go through some or all of the following stages when you first hear the results of your HIV test:

Denial: It’s common to deny your status the first time you hear about your results. Speak to your counselor on coping with that.

Anger: You may become angry and hate yourself and others around you. You may become angry at the person who infected you, with yourself or even the person giving you your result. Feelings of guilt are also common. Do not rush into decisions which may endanger you further, like wanting to avenge yourself by having unprotected sex and infecting others.

Depression/Withdrawal: Sometimes you may go into withdrawal and not want to talk to anyone. Take time to pray and try to be in the company of friends and relatives who can love and support you.

Acceptance: This is the stage when you start confiding in some friends and relatives. Think about how to plan for your future. You are now looking for sympathy and support. Once you open up you will slowly get the support you need.
With whom can I share?

Think of the friends and family in your life and start by talking to the person or people who you think you can trust. Talking to someone you trust will help you cope with stress and help you ease your tension or lighten your load. It is important to be with and mix with people.

Some steps to help you live positively

Today, being HIV positive does not have to be the end of the road. There are many things you can do to reduce your worries, improve your health and live your life more fully. Positive decisions can help you and your family:

**ARVs:** Antiretroviral drugs or ARVs, for short, are medicines that can bring a person with AIDS back to good health and keep an HIV positive person healthy. When you take these drugs, you are said to be on Anti-Retroviral Therapy (ART).

In Zambia today, some infected people are living healthier and prolonged lives because they are taking ARVs. Go to your nearest health centre to learn more about these drugs.

**Dealing with depression:** Being in the company of people, laughing and talking more about your feelings can help counter depression. When you feel depressed, you should avoid being alone. If you need more help you should see a counsellor.

**Work, if possible:** Work will keep you busy and your mind occupied. If you are well enough to be at work, you should be. You will be able to provide for yourself and your family and that will leave you feeling good about yourself.

**Diet:** Food is an important part of staying strong. Food does not have to be expensive to be nutritious. Fruits and green leafy vegetables are good for your body. Eating normally is the most important thing.

**Treating sickness quickly:** When you have HIV, your body can get sick easily. It is important to try and avoid getting sick, especially with malaria, STIs or chest infections like TB. If you do get sick, go immediately to your nearest health centre for treatment.
**Exercise:** Regular exercise like walking, deep breathing, gardening and even housework can keep you feeling well. However try not to get too tired. Rest is also equally important.

**Practicing safer sex:** An HIV positive person can pass on the virus to a partner through unprotected sex. Using a condom also protects you from getting other infections. It is therefore very important that you abstain from sex or continue to practice safer sex by using a condom correctly every time.

**Get involved:** Some of the best advocates of HIV prevention are People Living with HIV and AIDS (PLHA). Talking about being HIV positive and how people can prevent the infection or live positively can be very effective in reaching others and feeling good about yourself. Schools, workplaces, churches and your community are some places where you can talk openly and help others avoid infection, think about getting tested, and living positively. Join support groups for positive people if you have access to one. If one does not exist near you, maybe you can form one.

**Positive Prevention**

Finding out you are HIV positive, does not mean you can’t have sex. What it does mean, though, is that you have to practice safe sex which means using a condom every time.

Condoms protect your partner from HIV if they are negative and protects both of you from getting re-infected (getting more of the virus). Your immune system might be attacked faster and you could become sick sooner. By avoiding re-infection, you and your partner can stay healthier for a longer time.

Either male or female condoms can be worn. Condoms used correctly stop HIV from passing from one person to another when having sex.
A person carrying the HIV virus is more likely to become sick because of the weakened defence system in the body until eventually they are no longer able to fight infections. This stage is called AIDS. However, there are some drugs which reduce the level of HIV in the body thereby slowing down the progression towards AIDS. **You must know you have HIV before taking ARVs by going for voluntary counselling and testing.**

**These drugs are not a cure for HIV but can help you to stay well and extend your life.**

When to take the treatment: ARVs are not suitable for every HIV positive person. Treatment is usually recommended when the body becomes vulnerable to repeated infections. Your health care provider will examine you by checking for any illnesses or infections and recommend when to start treatment. It is dangerous to take ARVs without your health care provider’s approval. Special blood tests are done before you begin taking the medicine to determine how much HIV is in your body.

**Once you start taking ARV drugs, you must continue the treatment at the specified times for the rest of your life.**

- ARV drugs should never be shared. When they are prescribed for you, they are for you alone.
- Do not buy drugs from a pharmacy without a prescription.
- You should be supervised by a health care provider when you are taking these drugs and they should be taken at the same time every day.
Stigma & Discrimination of People Living with HIV/AIDS

What is Stigma? If you are HIV positive you may find that some people treat you differently because of your HIV status. Stigma refers to negative thoughts others have about a person because of their real or suspected HIV status.

HIV/AIDS Stigma: Silence, exclusion and isolation that limit the ability to provide the care and services needed by PLHA or those perceived to have the disease.

PLHA are Stigmatized Because:

- HIV/AIDS is life threatening and people are scared of contracting it.
- HIV is sometimes associated with behaviors that are considered shameful and are therefore wrongly condemned.

Self-stigmatization: Shame felt by an individual after internalizing the negative responses and reactions of others.

Signs of Self Stigma: Withdrawal, feeling of worthlessness, blaming oneself; this can lead to suicidal thoughts.

Recognizing Stigma: Stigma is harmful, since it can lead to feelings of shame, guilt and isolation of PLHA. Negative thoughts often lead individuals to have negative behaviors that are harmful to others or deny them the services they need and deserve.

Stigma Includes:

- Denying friends/visitors for a person thought to be HIV+ by pretending that they are sleeping or busy because they are ashamed of their illness
- Isolating them from the rest of the family members
- Ridicule and gossiping
Effects of HIV/AIDS Stigma:

- Violence against PLHA and those perceived to be positive
- Loss of employment
- Rejection
- Depression
- Saps the community and/or individuals of the strength to fight the scourge
- Loss of self-esteem and feeling of worthlessness
- May lead to suicide, or thoughts of wanting to avenge or kill oneself
- Gives birth to discrimination and negative behaviors

What is Discrimination? A distinction made against a person that results in their being treated unfairly on the basis of their perceived HIV positive status. It includes:

- Giving them separate cups, spoons and plates
- Refusing PLHA employment or training because of their status
- Segregating them in schools
- Denying them the right to marry
- Subjecting them to verbal and physical violence
- Rejection by communities

Overcoming Stigma:
Accept reality that this disease affects each one of us in one way or the other. If you are not infected, you are affected.

People living with HIV/AIDS need everyone’s support as they have human rights like anyone else.

You can:

- Avoid blaming yourself or blaming others
- Look for solutions to make the lives of the affected and infected easier
• Give PLHA full support and care
• Involve PLHA in all community programs and allow them to speak about themselves and their status if they so wish
• PLHA should be given an opportunity to work for as long as they are able to
• Strengthen individual and family counseling
Evaluation & Feedback Form

After showing *Tikambe*, please fill in this form to provide us with feedback.

Name of Facilitator: ________________________
Location: ________________________
Type of Audience: ________________________
Number in Audience: _____

How did the audience respond to the video?
________________________________________________________________________
________________________________________________________________________
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________________________________________________________________________

Did you watch both stories? Yes ☐ No ☐

What was the most compelling question raised during the discussion?
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What did you find to be the most difficult question raised during the discussion?
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Discussion Guide

Evaluation & Feedback Form

On the scale of 1 to 10 how do you rate this video overall? ____/10

Why did you give the score you did?

Will you use this video again? Yes  No

If yes how many times do you think you will use it?

If No - Why not?

Mail this form to:

Health Communication Partnership Zambia
Plot 3020 Mosi-O-Tunya Road, Woodlands House, Woodlands
P.O. Box 37230
Lusaka,
Zambia
or Fax: +260-1-266022

Zambia Centre for Communication Programs (ZCCP)
Plot 9684 Central Street, Chudleigh,
P.O. Box 31469
Lusaka,
Zambia
or Fax: +260-1-295402
Ikambe (Let’s Talk About It), explores how HIV/AIDS-related stigma and discrimination is affecting ordinary Zambians’ lives. This video provides a personal and compelling portrait of people who are ordinary candid, strong and brave in sharing their personal experiences. These are the stories of real people, not actors. This discussion guide will help to raise the key issues that the film addresses. In this way the group’s as well as personal opinions and views can be discussed to create an even greater understanding from the group dynamics.

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