



Tsha Tsha DVD DISCUSSION GUIDE

This training guide and accompanying DVD form part of a strategy to broaden the reach of the television drama series, *Tsha Tsha*, to non-broadcast environments.

A selection of key themes from series four are presented that highlight strategies towards the effective management of HIV/AIDS.

The key themes are:

- ❖ HIV risk and having many sexual partners
- ❖ Orphans and vulnerable children
- ❖ Prevention of mother-to-child transmission of HIV
- ❖ Antiretroviral treatment

The guide provides facilitators and trainers with information about how to facilitate discussion sessions with people who have watched the accompanying *Tsha Tsha* DVD thematic compilations.



TSHA TSHA DVD DISCUSSION GUIDE

Tsha Tsha

DVD DISCUSSION GUIDE

Strategies towards the effective management of HIV

- ❖ HIV risk and having many sexual partners
- ❖ Orphans and vulnerable children
- ❖ Prevention of mother-to-child transmission of HIV
- ❖ Antiretroviral treatment



The objective of the *Tsha Tsha* guide and DVDs is to facilitate engagement with four key areas in the management of HIV. In some instances this refers to minimising the risk of HIV infection, and in others, to managing treatment for AIDS. The guide is aimed at encouraging conversation and debate about individual perceptions of risk to HIV infection. The guide may be used by a variety of audiences, in different contexts and for various purposes. It is suitable for youth audiences and adults who are interested in learning about the prevention, mitigation and management of HIV/AIDS. Each theme presented in this guide can be explored in conjunction with a 15 – 24 minute DVD thematic compilation put together from the last 26 episodes of *Tsha Tsha*. The DVD with the four compilations can be found in the back cover of this guide.



Tsha Tsha

DISCUSSION GUIDE DVD: STRATEGIES TOWARDS

THE EFFECTIVE MANAGEMENT OF HIV

TSHA TSHA

DISCUSSION GUIDE DVD



Tsha Tsha

DVD DISCUSSION GUIDE

Strategies towards the effective management of HIV

- ◆ HIV risk and having many sexual partners
- ◆ Orphans and vulnerable children
- ◆ Prevention of mother-to-child transmission of HIV
- ◆ Antiretroviral treatment

Researched and written by
Helen Hajiyanis





© CADRE 2008

Acknowledgements

The President's Emergency Plan for AIDS Relief (PEPFAR) through the United States Agency for International Development (USAID)¹ for financial support, with technical support from the Health Communication Partnership (HCP) based at the Johns Hopkins Bloomberg School of Public Health Centre for Communication Programs, and Johns Hopkins Health and Education in South Africa (JHHESA).

Published by

CADRE, PO Box 30829, Braamfontein, Johannesburg, 2017, South Africa
Website URL: www.cadre.org.za

Print design and printing by

The Library
Website URL: www.lib.co.za

¹ The opinions expressed herein are those of the author(s) and do not necessarily reflect the views of the United States Agency for International Development.

Introduction	1
About Tsha Tsha	1
About this guide	3
Overall objective	4
Who the guide and DVD are designed for	5
How to use the guide with the DVD	5
Notes for facilitators	7
Technical preparation	8
Key principles for facilitating effective discussion groups	8
 Section one: HIV risk and having many sexual partners	 11
Educational objectives	12
Key concepts	12
Key points in relation to HIV/AIDS	13
Behaviours that increase the risk for HIV infection	15
Story outline	15
Discussion questions	17
 Section two: Orphans and vulnerable children	 19
Educational objectives	20
Key concepts	20
Key points in relation to HIV/AIDS	21
Behaviours that increase the risk for HIV infection	23
Story outline	23
Discussion questions	25

Section three: Prevention of mother-to-child transmission of HIV 27

Educational objectives. 28

Key concepts 29

Key points in relation to HIV/AIDS 30

Factors that increase the risk for HIV infection 32

Story outline 33

Discussion questions 35

Section four: Antiretroviral treatment 37

Educational objectives. 38

Key concepts 38

Key points in relation to HIV/AIDS 39

Factors that decrease the effectiveness of antiretroviral treatment 41

Story outline 42

Discussion questions 43

Appendix one 45

The National Patients’ Rights Charter 45

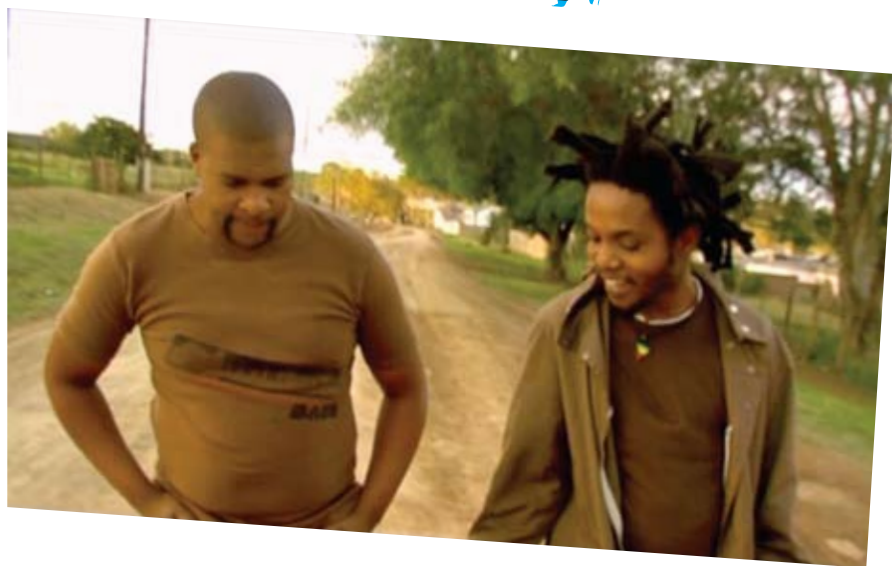
The South African Bill of Rights 47

Abbreviations and acronyms

ANC	Antenatal care
AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral treatment/therapy
ARV	Antiretroviral
AZT	Zidovudine
CADRE	Center for AIDS Development, Research and Evaluation
CF	Complementary feeding
CTX	Cotrimoxazole
EBF	Exclusive breastfeeding
EFF	Exclusive formula feeding
HAART	Highly active antiretroviral therapy
HCP	Health Communication Partnership
HIV	Human Immunodeficiency Syndrome
JHHESA	Johns Hopkins Health and Education in South Africa
MTCT	Mother-to-child transmission
NVP	Nevirapine
OVC	Orphans and vulnerable children
PEPFAR	US President's Emergency Plan for AIDS Relief
PLHA	Person living with HIV or AIDS
PMTCT	Prevention of mother-to-child transmission
PNC	Postnatal care
SABC	South African Broadcasting Corporation
sdNVP	Single-dose Nevirapine
STI	Sexually Transmitted Infection
TB	Tuberculosis
USAID	United States Agency for International Development
VCT	Voluntary Counselling and Testing
WHO	World Health Organisation



Tsha Tsha



Introduction

Tsha Tsha is a multi-part entertainment education television drama series that was first commissioned by the South African Broadcasting Corporation (SABC) in 2001. The series was developed and produced by the Centre for AIDS Development, Research and Evaluation (CADRE) and Curious Pictures and a total of 78 episodes were broadcast in South Africa during primetime between 2003 and 2006. Support was provided by Johns Hopkins Health and Education in South Africa (JHHESA) and Johns Hopkins Center for Communication Programs in Baltimore. CADRE, Curious Pictures and JHHESA continue to develop post-broadcast materials.

About *Tsha Tsha*

Tsha Tsha is a youth-oriented television drama series that focuses on young people living in a world affected by HIV/AIDS and the challenges they face as they negotiate their way to adulthood. Although originally produced for a youth target audience, the series has drawn viewers across age and language groups.

Set in the fictional rural town of Lubusi, *Tsha Tsha* allows for the exploration of issues relating to community life, including the marginalisation of youth and the challenges of personal and social transformation. The rural setting sets the drama series apart from the predominantly urban orientation of most South African television youth dramas.

HIV/AIDS issues include prevention, treatment, care and support and rights. Situations portrayed include: HIV infection risk and prevention; the complexities of Voluntary Counselling and Testing (VCT); learning one's HIV status; living with HIV/AIDS; disclosure of HIV status; the personalisation of HIV risk of infection; caring for sick family members; the impact of HIV/AIDS on families and communities; and individual and community responses to the epidemic. Other themes include relationships, sexuality, life skills and problem solving, which include a focus on gender relations, parent-child relationships, coping skills, alternatives to violence, entrepreneurship and community mobilisation.

Ballroom dancing is used as an organising concept in the drama and a ballroom dance club provides a background for exploring relationships, mutual respect and intimacy.

The *Tsha Tsha* television drama series is informed by extensive research, including the scoping of the external environment to determine the current issues within the HIV/AIDS and communication fields, as well as talking to people on the ground – people living in urban and rural communities, service providers and people living with HIV/AIDS (PLHA). In this way, the current challenges that act as barriers to effective individual and community responses to HIV/AIDS are identified. The series is thus grounded in the issues and concerns embedded in the daily realities of young South Africans.

The research-driven approach towards the development of characters and storylines contributes strongly to the series' realism and viewers' ability to identify with the characters and events that take place.

Tsha Tsha's approach to entertainment education is based on nine key principles, including promoting the following concepts: identification with characters and events; advocating a problem-solving approach; developing self-efficacy; living humanely and having empathy for others; using lessons rather than messages as a way of modelling learning; creative thinking to address problems; challenging norms, conventions and stereotypes; understanding change as a complex process; and naming or showing things in order to identify and address problems.

About this guide

This guide and the accompanying DVD form part of a strategy to broaden the reach of *Tsha Tsha* to non-broadcast environments. The guide supports the use of *Tsha Tsha* in contexts where the visual material is used to facilitate discussion, reflection, debate and learning. It provides facilitators and trainers with information about how to facilitate discussion sessions with people who have watched the *Tsha Tsha* DVD thematic compilations.

This training guide presents a selection of key themes from series four that highlight strategies towards the effective management of HIV/AIDS.

The key themes are

- ◆ HIV risk and having many sexual partners
- ◆ Orphans and vulnerable children
- ◆ Prevention of mother-to-child transmission of HIV
- ◆ Antiretroviral treatment

Each theme presented in the guide can be explored in conjunction with a 15 – 24 minute DVD thematic compilation put together from the last 26 episodes of *Tsha Tsha*². The DVD with the four compilations can be found in the back cover of the guide.

Overall objective

The overall objective of the guide is to facilitate engagement with four key areas in the management of HIV. In some instances this refers to minimising the risk of HIV infection, and in others, to managing treatment for AIDS.

The guide is aimed at encouraging conversation and debate about individual perceptions of risk to HIV infection in relation to sexual partnerships, care and support for orphans and vulnerable children,

² Though some of the most relevant issues pertaining to each theme are presented, it must be kept in mind that a compilation does not fully capture the depth of characters, the complexities of problems, and the accompanying processes inherent to problem solving and change.

minimising the risk of mother-to-child transmission of HIV, and antiretroviral treatment.

Who the guide and DVD are designed for

The guide may be used by a variety of audiences, in different contexts and for various purposes. It is suitable for youth audiences and adults who are interested in learning about the prevention, mitigation and management of HIV/AIDS.

How to use the guide with the DVD

The discussion guide and DVD are resources that may be used to facilitate group discussions – either as a direct educational tool or as a training tool.

Small groups of around six to eight people, or larger groups of up to twenty people, may be brought together to view one of the compilations on the DVD, followed by a discussion. The length of the discussion will depend on the broader purpose of the group's meeting, the specific goals of using the *Tsha Tsha* resource, as well as on the size of the group.

The facilitator or trainer of the group should have group facilitation skills and be familiar with various aspects of the HIV epidemic. Facilitators and trainers are not expected to have all the 'answers' to group members' questions, though good facilitation skills and knowledge



of HIV/AIDS resources and referral systems are essential³. In South Africa, the AIDS Helpline is a 24 hour tollfree number that facilitators should be familiar with for their own information and to refer people to when necessary. The Helpline offers information, counselling and referral services.

The facilitator or trainer should be familiar with the *Tsha Tsha* material prior to facilitating or training a group. This means watching the DVD prior to the group viewing, as well as reviewing the guide in order to be familiar with the story outline and main educational content.

A participatory interactive approach to using the materials is recommended, where facilitators, trainers and group members interact with each other and discuss issues that spontaneously emerge from the process. It is through the exchange of information, ideas and opinions that individuals engage with alternate perspectives and learn new things or interrogate their own frames of reference.

3 For information on facilitation skills and how to run groups, see Hajjiyannis, H & Jugbaran, N. (2005). *Tsha Tsha: A Facilitator's Guide to Series One*. Johannesburg: CADRE.

Participatory approaches to learning are an alternate approach to formal didactic methods⁴. Various methods may be incorporated into these discussions in order to facilitate interaction between group members and engagement with various issues⁵.

Notes for facilitators

Facilitators or trainers must prepare for the discussion group. This includes:

- ◆ Being clear about the overall objective of the intervention.
- ◆ Being informed about the key issues in relation to the theme to be discussed.
- ◆ Knowing about the group to be worked with in relation to age, gender, culture, religion and other specific characteristics of the participants.
- ◆ Developing a structure for the intervention within a timeframe, including group activities that will facilitate and contribute to discussions, such as icebreakers, energisers and games or tasks that are linked to the thematic content being discussed.

4 For information about participatory approaches, see International HIV/AIDS Alliance (2001). *A Facilitator's Guide to Participatory Workshops with NGOs/CBOs Responding to HIV/AIDS*. Brighton, United Kingdom: International HIV/AIDS Alliance.

5 For additional exercises for groups, see International HIV/AIDS Alliance (2002). *101 ways to energise groups: Games to use in workshops, meetings and the community*. Brighton, United Kingdom: International HIV/AIDS Alliance.

Technical preparation

The facilitator or trainer must ensure that:

- ◆ A suitable venue is identified that has adequate space to meet viewing and discussion needs.
- ◆ That viewing equipment is available and in working order. This includes setting up equipment such as DVD players and television sets and testing to see that they are working prior to commencing a discussion group.

Key principles for facilitating effective discussion groups

- ◆ Set ground rules for the group process. These may include: respecting fellow group members, not interrupting each other, respecting individuals' rights to privacy and confidentiality, switching off cell phones etc.
- ◆ The facilitator should adopt an attitude of openness to the group process and the emerging content that is discussed, be non-judgmental, and respect group members, including being culturally and gender sensitive.

◆ The facilitator should exhibit the skills of active listening – reflection, probing, and summarising - as well know how to manage group dynamics and processes, in particular, knowing how to manage conflict situations or participants who may become upset or worried during a discussion group.

◆ Be prepared with an alternative plan or structure for facilitating the group in case the selected format is not well-received by participants, participation is low, or if there is more or less time available than was planned for. A back-up plan is also important in case equipment does not work or there is a power failure.

Additional information for facilitators that outlines patients' rights and the laws in South Africa as they apply to people living with HIV/AIDS can be found in appendix one. In the following sections, each of the selected themes and accompanying DVDs are described. The same structure is used for each theme:

- ◆ Educational objective(s)
- ◆ Key concepts
- ◆ Key points in relation to HIV/AIDS
- ◆ Behaviours / factors that increase the risk for HIV infection
- ◆ Story outline
- ◆ Discussion questions



Section one: HIV risk and having many sexual partners

"I can't afford to fall pregnant."



"Pregnancy isn't the only risk of unprotected sex. Do you know his status?"



"No, I was drunk."



Section 1: HIV risk and having many sexual partners

Educational objectives

- ❖ Link the practice of having multiple sexual partnerships to the risk for HIV infection.
- ❖ Link the practice of having concurrent (overlapping) sexual partnerships to the risk for HIV infection.
- ❖ Highlight the risk of HIV infection as a result of a high number of sexual partners.
- ❖ Emphasise the importance of correct and consistent condom use.

Key concepts⁶

- ❖ **Gender** – both men and women engage in sexual relationships with many partners – including having more than one partner in the same month. It is not true that these sexual behaviours are mostly attributable to men.
- ❖ **Alcohol and drug consumption** – increase the likelihood of casual sex (which is usually unprotected sex).

⁶ Key notes and key points on multiple sexual partners are taken from: Parker, W., Makhubele, B., Ntlabati, P. and Connolly, C. (2007). *Concurrent sexual partnerships amongst young adults in South Africa: Challenges for HIV prevention communication*. CADRE, Johannesburg.

- ❖ **Sexual networks** – two people may have sex, but those same two people may have sexual relationships with other people. This is very risky for HIV infection.
- ❖ **'Main' and 'other' partners** – in instances where people have many sexual partners over time, overlapping sexual partnerships and/or casual sex, partners may be referred to as 'main' or 'other' partners. The 'main' partner is the person who is cared for and loved, whilst there are few emotional ties to the 'other' partner. A 'main' partner is often described as the person one has chosen as a longer-term partner.
- ❖ **Sex and faithfulness** – in the context of having many overlapping sexual partnerships, faithfulness is often not understood as being monogamous (i.e. having a sexual relationship with only one person), but may be used to explain the process of protecting one's 'main' sexual partner from knowing about the other sexual partners.

Key points in relation to HIV/AIDS

- ❖ Multiple and concurrent sexual partnerships⁷ are one of the biggest drivers of the HIV epidemic in South and Southern Africa.
- ❖ 'Concurrent' partners refer to having overlapping sexual relationships – that are sustained over time - with two or more partners.

7 For definitions and more information about multiple and concurrent sexual partnerships see Parker, W., Makhubele, B., Nlabati, P., & Connolly, C. (2007). *Concurrent sexual partnerships amongst young adults in South Africa: Challenges for HIV prevention communication*. Johannesburg, CADRE.

◆ 'Casual sex' or 'one-night stands' can take place within the context of an already existing longer-term sexual partnership or as a pattern of having many partners over time.

◆ Sexual networks are important for understanding why different types of sexual partnerships sharply increase the risk of infection with HIV. This is because multiple and concurrent sexual partnerships, including casual sex, involve more than the two people who

are together at a specific time. Each partner may have another sexual partner – and those people in turn may have other sexual partners – thus increasing the risk.

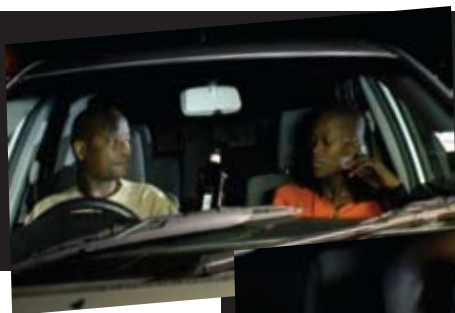
Sexual networks sharply increase the risk for HIV infection. Sexual networks involve more than two people who are together at a specific time. Each partner may have another sexual partner – and those people in turn may have other sexual partners – thus increasing the risk.

Behaviours that increase the risk for HIV infection

- ◆ Having a high total number of sexual partners.
- ◆ Having casual sex and 'one-night stands'.
- ◆ Changing sexual partners frequently and having two or more sexual partners in one year.
- ◆ Having more than one sexual partner in the same month.
- ◆ Having overlapping sexual partnerships.
- ◆ Having a 'main' partner as well as having 'other' partners.

Story outline

Zukiswa arrives back in Lubusi after spending a few years working elsewhere. Raised by her mother, Zukiswa has never known who her father is. She has suffered from her mother's alcoholism from early childhood, and taking care of her without complaint. Her behaviour around men causes a stir in the small town of Lubusi. Zukiswa is not in a stable sexual relationship; instead, she has casual sex with many different partners. She believes that she is in full control of her sex life, as she always uses condoms. However, she is forced to confront the possibility of being HIV positive after she gets drunk and has unprotected sex. We follow Zukiswa as she confronts this reality and starts to personalise her vulnerability to HIV infection.



Discussion questions

- ◆ What are some of the reasons why people have many different sexual partners?
- ◆ Zukiswa thought that she was in control of her life, including her sex life. How did Zukiswa come to realise that her behaviour and choices were putting her at risk for HIV infection?
- ◆ What are some of the risks of having many sexual partners in one's lifetime or over a short space of time?
- ◆ Why is it important to use a condom every single time one has sex, even when having sex with the same partner?
- ◆ What are the differences between women who have many sexual partners and men who have many sexual partners?
- ◆ Why do people sometimes have sexual relationships with more than one person at the same time?
- ◆ What does 'casual' sex mean? How is this different to sex that takes place between two people who are in a committed relationship?
- ◆ How can a person who is faithful to their sexual partner still be at risk for HIV infection?
- ◆ What are the key messages or lessons from this story?



Section two: Orphans and vulnerable children



"It's all too much. Looking after my brothers and now this baby, how will I cope? How will I manage another mouth to feed?"



Section 2: Orphans and vulnerable children

Educational objectives

- ◆ Identify the contexts and risks for HIV infection among orphans and vulnerable children.
- ◆ Highlight the impact of HIV/AIDS on child-headed households and ways of managing this impact.

Key concepts

- ◆ **Gender roles** – male and female children living in child-headed households may take on roles that are largely determined by society and or culture. Young boys or men may thus feel responsible for the economic survival of the family, whereas girls or young women may take on what are seen as traditional ‘female’ roles, such as cooking, cleaning the house and taking care of the emotional needs of the family.
- ◆ **Psychosocial support** – this refers to the provision of care and support from individuals, groups, communities and state

The provision of psychosocial support is one of the factors that helps to reduce the impact of HIV/AIDS on individuals, families and communities.

institutions. The provision of psychosocial support is one of the factors that helps to reduce the impact of HIV/AIDS on individuals, families and communities.

- ◆ **Psychological symptoms** – experiences of loss and trauma affect people emotionally in many ways. Some children may have behavioural problems such as aggressiveness or ‘skipping’ school, while others may complain of physical symptoms such as stomach aches and headaches. These kinds of symptoms are possible signs of underlying stress.

Key points in relation to HIV/AIDS

- ◆ Children who are vulnerable to HIV/AIDS include those who are children whose parents have HIV/AIDS, refugees and displaced persons, children who are living in poverty and those who are sexually abused.
- ◆ The emotional demands of HIV/AIDS on children are high. Having an ill parent who is dying places enormous stress on children. On a psychological level, children may become anxious about their future and this will impact on their daily functioning.
- ◆ The death of a parent or caregiver from HIV/AIDS affects children’s emotional and physical wellbeing. The death of a parent(s) leads to the loss of love, protection and emotional and material support. In some instances, children are left to take care of themselves, usually with an older sibling taking responsibility for the family. These are known as child-headed households.

- ◆ Left without the family's breadwinner, children and adolescents find themselves in situations where they are vulnerable to exploitation and abuse. In order to meet basic needs of food and shelter, children may leave or not attend school because they cannot afford to pay for education or because necessity demands that their time is spent looking after younger siblings, cleaning and cooking, and 'working' to survive.
- ◆ HIV/AIDS can have a negative longer term effect on children: leaving school prematurely in order to raise money to survive may create a situation where the child has less access to opportunities in future because of lower education; children or adolescents may become involved in sexual partnerships in exchange for money or goods, significantly increasing the risk of HIV infection; children that are living with HIV/AIDS in child-headed households may not have access to care and support because of their circumstances.
- ◆ Behavioural problems often occur as a product of the grief, loss and sense of being overwhelmed that orphans and vulnerable children experience. It is the responsibility of adults and community members to know how to identify and understand these behaviours and to offer their support.
- ◆ Children have a right to protection, education, and health care and to be treated with dignity. It is important for communities and institutions, such as churches, businesses, community organisations, to respond to the psychosocial and economic needs of orphans and vulnerable children.
- ◆ Community and government action can help in providing the care and support that children need. Volunteering time or physical

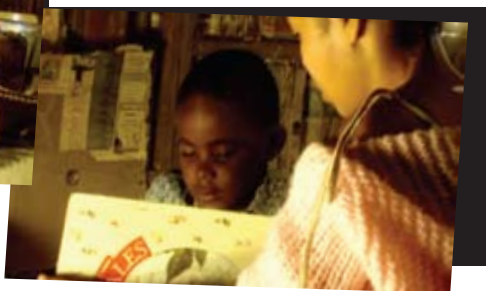
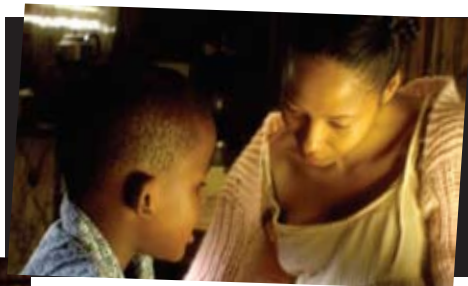
resources or working with government agencies and other organisations to provide care for children enriches communities.

Behaviours that increase the risk for HIV infection

- ◆ Living in a home/place without adult supervision.
- ◆ Having sexual relationships in exchange for money or goods.
- ◆ Having older sexual partners.

Story outline

Nobuntu and her two siblings, Loyiso and Zolile, are orphans and live on their own. Nobuntu is the head of the household and is responsible for the financial and emotional care of her siblings. She is pregnant and living with HIV as a result of a relationship with a sugar daddy (an older man) to support her family. Left to fend for themselves, Nobuntu ekes out a living selling vegetables from the community garden. She discovers that Loyiso is skipping school and has become involved with a group of petty criminals in order to access money for his family. We come to understand some of the challenges faced by orphans and vulnerable children as a direct result of HIV/AIDS. Nobuntu has to find a way to look after herself and her family by drawing on internal resources and external support, while Loyiso has to realise that he is a child and not responsible for the wellbeing of his family.



Discussion questions

- ◆ What are some of the challenges facing orphans and vulnerable children?
- ◆ How can these challenges be managed to minimise negative impacts?
- ◆ How/why are orphans and vulnerable children at increased risk for HIV infection?
- ◆ What can communities do to support child-headed households?
- ◆ In a child-headed household where there are males and females, how should the various responsibilities of looking after the household (e.g. caring for children, generating an income, taking care of the home) be allocated? Why?
- ◆ What are the key messages or lessons from this story?





Section three: Prevention of mother-to-child transmission of HIV



"I know what it's like to be worried when you don't know what's going to happen."



"But you must start looking after yourself. You are no good to your baby, your brothers or yourself if you are sick."



Section 3: Prevention of mother-to-child transmission of HIV

Educational objective

- ◆ Living with HIV and preventing HIV transmission between mother to child.

Background to antiretroviral treatment

Antiretroviral treatment for the prevention of mother-to-child transmission has been available in South Africa from government service points since 2002.

The original PMTCT policy and guidelines made provision for two antiretroviral treatment regimes to prevent mother-to-child transmission of HIV: (i)

Mother takes a four-week dose of AZT (Zidovudine) prior to delivery or (ii) Mother takes a single dose of Nevirapine as she goes into labour followed by administering a single dose of Nevirapine syrup to the newborn within 72 hours after birth.

In 2008, there was a change to the treatment policy and guidelines. However, the treatment approaches described above may still be followed while the new PMTCT policy is being rolled out and implemented (see next page).

In 2008 there was a change to the PMTCT treatment policy and guidelines in South Africa with the introduction of dual antiretroviral treatment as an option to prevent mother-to-child transmission of HIV

Key concepts

- ◆ **PMTCT** – this is an abbreviation for prevention of mother-to-child transmission of HIV and refers to prevention methods and procedures that can be taken by HIV positive mothers to reduce the risk of transmitting HIV to their children.
- ◆ **Transmission** – HIV positive women can transmit HIV to their baby during pregnancy, childbirth or through breastfeeding.
- ◆ **New South African PMTCT policy in 2008 ⁸** – recognises that in order to prevent HIV among women and children, the four elements of PMTCT are integral. These are: (i) Preventing HIV among women of childbearing age; (ii) Providing contraceptive options to avoid unintended pregnancy among women living with HIV; (iii) Preventing HIV transmission from mother to child, and (iv) Providing appropriate treatment, care and support to women living with HIV and their children and families.
- ◆ **Antiretroviral treatment** – according to the new policy, dual antiretroviral treatment is promoted in South Africa to prevent mother-to-child transmission of HIV. This means that two types of antiretrovirals are taken by the mother before, during and after labour and by the infant after birth as part of PMTCT: (i) Pregnant women living with HIV take AZT (Zidovudine) from 28 weeks of pregnancy; (ii) Mother takes a single dose of Nevirapine (sdNVP) as she goes into labour, followed by administering a single dose of

8 The South African National Department of Health changed its PMTCT policies and guidelines in March 2008. These may be found in: National Department of Health (2008). *Policy and guidelines for the implementation of the PMTCT programme*. <http://www.doh.gov.za/docs/policy/pmtct-f.html>

Nevirapine syrup to the newborn as soon as possible and not later than within 72 hours after birth; (iii) Infants take AZT for seven or 28 days after birth (length of time is determined by a registered health professional).

- ◆ **Infant feeding practices** – these vary between exclusive breastfeeding (EBF) and exclusive formula feeding (EFF) for six months. It is important never to mix the two feeding approaches. Health workers should confirm the mother's infant feeding choice and advise her accordingly.
- ◆ **Post-natal care** – a health care worker will determine the treatment for the child. A test is done after **six weeks** to see if the child is HIV positive.
- ◆ **Maternal and child health** – it is important for the mother to take care of herself and to be healthy so that she is able to look after her baby. In cases where mothers-to-be or mothers have a CD4 count of 200 or less antiretroviral treatment (ART) may be started.
- ◆ **Psychosocial support** – it is important to get support from family or other people to deal with the natural anxieties and concerns that arise when having a baby, as well as to deal with anxieties that are HIV/AIDS-related.

Key points in relation to HIV/AIDS

- ◆ **During pregnancy**, interventions used to reduce the risk of mother-to-child transmission include: (i) HIV testing to learn one's status and (ii) Antiretroviral treatment for HIV-positive expectant

mothers to prevent HIV transmission to her unborn child. A dual treatment regime is promoted in South Africa – mother taking a drug called AZT (Zidovudine) from 28 weeks of pregnancy and a single dose of a drug called Nevirapine as she goes into labour. Other practices include: (iii) Regular antenatal checkups, (iv) Prevention of other sexually transmitted infections, and (v) Mothers taking antiretroviral treatment for their own health. (vi) It is also important for uninfected mothers to be informed of the risk of HIV infection to themselves and to their unborn child and be educated on safer sex practices especially if the status of the partner is unknown.

- ◆ **During childbirth**, interventions used to reduce the risk of mothers passing on HIV to their infants include the promotion of delivery practices that reduce the likelihood of HIV being transmitted during child birth.
- ◆ **After birth**, interventions used to reduce the risk of HIV transmission to newborn babies include: (i) Giving the newborn a single dose of Nevirapine as soon after birth as possible (maximum within 72 hours of birth) and (ii) AZT for seven or 28 days after birth (the course to be followed must be determined by a doctor), and (iii) Exclusive breastfeeding (EBF) or exclusive formula bottle feeding (EFF). However, in cases where milk formula is not available or there is no continuous access to clean water, the following is recommended: exclusive breastfeeding to take place for four to six months with no other substitute feeding (no other fluids, including water, tea, juice and no alternate food). Most importantly, breastfeeding and bottle feeding should never be mixed.

- ❖ Milk formula is available for free for six months from all South African government HIV service points.

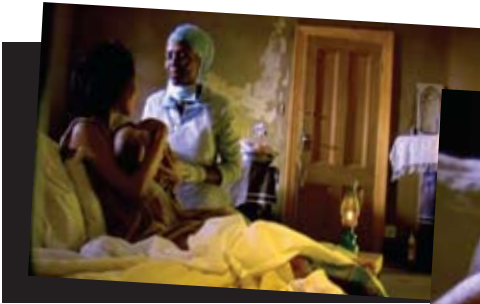
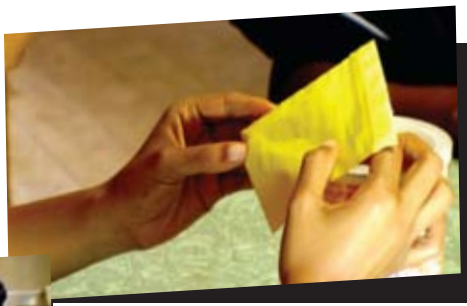
Factors that increase the risk for HIV infection

- ❖ Not knowing one's HIV status.
- ❖ Not knowing the risks of transmitting HIV to the baby.
- ❖ Not going for regular antenatal checks.
- ❖ Not being aware about the option of antiretroviral drugs.
- ❖ Having unprotected sex during pregnancy and when breastfeeding (a woman who is HIV negative may be infected with HIV during pregnancy or after childbirth).
- ❖ Having many sexual partners during pregnancy.
- ❖ Not treating other sexually transmitted infections.
- ❖ Not taking care of mother's health, including not taking antiretroviral treatment if this is necessary for the mother's health.

Story outline

Nobuntu has been the head of her household since her parents died, and became involved in a sexual relationship with an older man in order to get money and food to support her younger siblings. As a result of having unprotected sex with him, Nobuntu is pregnant and living with HIV. She has dropped out of school and is confronted with the challenges of being a caregiver to her siblings, as well as her own anxieties about becoming a mother. We follow Nobuntu as she learns to take responsibility for her family and for the wellbeing of her unborn child. We see how with social and community support, Nobuntu is better able to manage the impact of HIV on herself and her family. Some of the challenges Nobuntu confronts in reducing the risk of transmitting HIV to her baby are raised and we follow how she deals with these.





Discussion questions

◆ What are some of the ways that mothers can transmit HIV to their babies?

◆ Why is it important to know one's HIV status when one is pregnant?

◆ What are some of the things that women who are living with HIV can do to reduce the risk of transmitting HIV to their children?

◆ Why might a woman **not** take precautions to reduce the risk of transmitting HIV to her baby? (Probes: explore individual, social and cultural reasons).

◆ How can men support efforts to reduce the risk of mother-to-child transmission?

◆ Are antiretrovirals given to children immediately after birth to cure them from HIV or to reduce the risk of them getting HIV? Discuss. (Note for facilitators: there is no cure for AIDS and this needs to be stressed during discussions. The question asks about 'cures' because this is a belief that exists among some people).

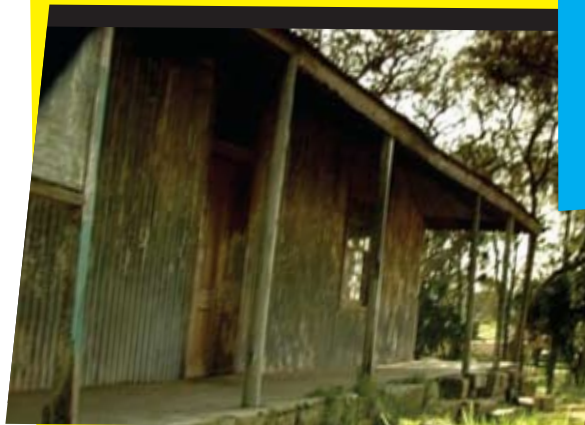
◆ What steps can mothers living with HIV/AIDS take in order to be healthy?

◆ What feeding practices are recommended for children born to mothers living with HIV/AIDS in order to reduce the risk of HIV transmission?

◆ What are the key messages or lessons from this story?

Section four: Antiretroviral treatment

"I never really thought how I would feel. I know it's not a death sentence. But it still feels like one. And now I'm on these drugs for the rest of my life, whether I want to be or not".



Section four: Antiretroviral treatment

Educational objectives

- ◆ Highlight the role of antiretroviral treatment in the management of HIV/AIDS.
- ◆ Highlight when antiretroviral treatment is indicated and some challenges this raises for the management of HIV/AIDS.

Key concepts

- ◆ **ART** – this stands for antiretroviral treatment. This is a treatment using medicine that prolongs and improves the quality of life for people living with AIDS. ART is not a cure for AIDS, but one of the ways of managing and treating it.

ART is a medicine that prolongs and improves the quality of life for people living with AIDS. ART is not a cure for AIDS, but one of the ways of managing and treating it.

- ◆ **CD4 cell count test** – this is a test which indicates the strength of the immune system by measuring the number of CD4 cells in the blood. CD4 cells are important because they fight HIV. ART prevents the HIV virus from multiplying and in this way decreases the amount of HIV in the blood.

- ◆ **Indications** – ART is started when a person's CD4 count falls below 200.
- ◆ **Adherence** – ART must be taken for life. Once ART is started, it should not be stopped unless under the direction of a doctor. Antiretrovirals need to be taken at the same time every day.
- ◆ **Side effects** – there are some side effects from taking ART; these include diarrhea and vomiting. These effects can be managed and ART should not be stopped unless under the instruction of a doctor.
- ◆ **Opportunistic infections** – these are illnesses that take advantage of a person's immune system when it is weakened by HIV. Most sickness associated with HIV occurs as a result of other diseases taking advantage of a weakened immune system – for example tuberculosis (TB) and pneumonia.
- ◆ **Vitamins** – can be taken with ART, but are not a substitute for ART.

Key points in relation to HIV/AIDS

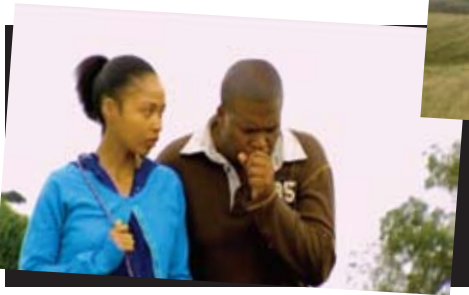
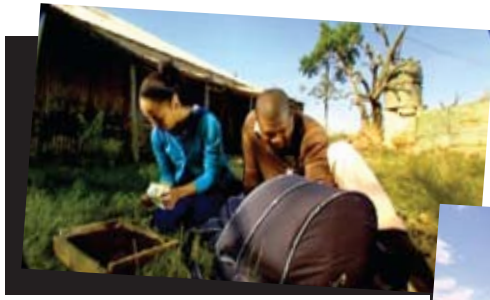
- ◆ The decision to start ART is usually guided by the CD4 cell count and the viral load in the body. As the CD4 cell count decreases, the HIV viral load increases in the body.
- ◆ According to the World Health Organisation (WHO) guidelines, which are also used by the South African government, people should start taking ART once their CD4 cell count falls below 200

cells/mm³ or if they have life threatening opportunistic infections that are associated with the later stages of AIDS.

- ❖ Important issues to think about prior to starting ARVs include:
 - (i) What other therapies you are taking, such as traditional and alternative medicines, and how these may have a negative interaction when used with ART; (ii) Whether you have disclosed your status to anyone and have the support of a family member or close friends (as this will provide the necessary support to help you take your medication) and (iii) Participating in an ART programme, which includes information on positive living, HIV/AIDS, opportunistic infections, antiretroviral treatment regimes, side effects and adherence.
- ❖ Evidence that the ART is working includes: feeling better; gaining weight; fewer opportunistic infections; higher CD4 count and lower viral load. This is why it is important to know your status and to have regular check ups to monitor CD4 cell count and viral load.
- ❖ In order to get maximum benefit from ART, it is important that the treatment is started when the CD4 is 200 and not much lower.
- ❖ ART is available for free from South African government HIV service points. Some workplaces and private practitioners also provide this service.
- ❖ In South Africa a disability grant is available for people who are living with AIDS who are unable to work.

Factors that decrease the effectiveness of antiretroviral treatment

- ◆ Not knowing one's HIV status and therefore not starting treatment in time.
- ◆ Not taking the medicines every day as instructed by the doctor or health worker e.g. missing or changing doses.
- ◆ Having previously been on antiretrovirals and having stopped taking them.
- ◆ Taking traditional or alternative medicines that may have a negative impact on the usefulness of the ART.
- ◆ Not living healthily and positively e.g. not eating nutritiously, drinking alcohol and smoking tobacco, not exercising, having a poor outlook on life and a lack of psychosocial support.
- ◆ A lack of psychosocial support has been shown to have negative effects on a person's mental health as well as on overall physical wellbeing. Symptoms that have been linked to the absence of psychosocial support include depression, anxiety, stress, and substance abuse, and these may all contribute to a weakened immune system.

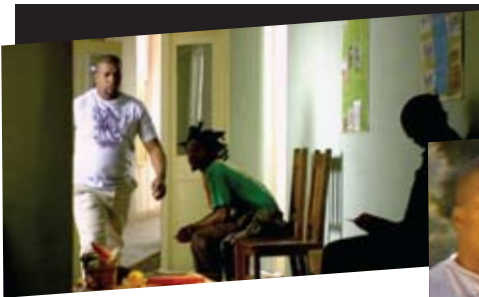


Story outline

Tyson is living positively with HIV. He is an active member of the community, eats healthily, exercises, is surrounded by friends as well as attending an HIV support group. He is especially close to Nobuntu, taking on a brotherly or fatherly role towards her as he supports her coming to terms with the reality that she is HIV positive and pregnant. Tyson starts to display symptoms of being ill, but dismisses these as a sign of the flu or tiredness from hard work. As Tyson becomes more ill, he has to confront the challenges that come with learning that one has AIDS. He also has to make choices about how he wants to manage his illness within the broader context of what it means to him to have AIDS and the treatment options that are available.

Discussion questions

- ◆ Where can ARVs be accessed?
- ◆ When does a person start to take ARVs?
- ◆ What are some of the individual, social and cultural challenges that taking antiretroviral treatment present?
- ◆ How can some of these challenges be addressed?
- ◆ How can friends, families, communities assist/support people living with HIV/AIDS in caring for their health?
- ◆ What can a person do if they are treated badly or poorly at the clinic or by a health worker?
- ◆ What do you think of alternative treatments for AIDS besides ART?
- ◆ What are the key messages or lessons from this story?



Appendix one

It is important to be familiar with the laws and guidelines governing patients' rights and what these rights may mean for people living with HIV/AIDS.

The National Patients' Rights Charter⁹

The South African Constitution gives every person in South Africa the right of access to health care services (Act No 108 of 1996). The National Patients' Rights Charter was launched by the National Department of Health in 1999. The Charter is not a law, but it sets out the rights and duties of all patients attending government clinics or government hospitals. The Department of Health uses The Charter as a standard for the realisation of the right to health care services.

According to The Patients' Charter, all people have a right to:

- ◆ **A healthy and safe environment** that will ensure physical and mental health and wellbeing.
- ◆ **Participation in decision-making** at the level of health policies and in decisions affecting one's health.
- ◆ **Access to health care** that includes treatment, information and counselling.

9 Adapted for use from the government website <http://www.doh.gov.za/docs/legislation/patientsright/charterere.html> and from *HIV/AIDS and the Law: A Resource Manual (3rd Ed)*, 2003. AIDS Law Project and the AIDS Legal Network.

- ◆ **Knowledge of one's health insurance/medical aid scheme** and opportunities to challenge their decisions if necessary.
- ◆ **Choice of health services** in relation to which health care provider and which health facility to get treatment from, within existing service delivery guidelines.
- ◆ **Know the name of the health care provider treating you** and as such must be treated by a clearly identified health worker.
- ◆ **Confidentiality and privacy** concerning one's health or treatment and that the details thereof may only be shared with others where there is informed consent, except when required by law or by an order of the court.
- ◆ **Informed consent** which involves being given full details about the diagnostic procedures to be used and subsequent diagnosis, proposed treatment, and costs involved in order that a person may make an informed decision with regards to his or her care.
- ◆ **Refusal of treatment** as long as that refusal does not endanger the health of others.
- ◆ **Get a referral to another doctor** for a second opinion.
- ◆ **Continuity of care** from a health care provider or health facility that initially took responsibility for one's health.
- ◆ **Complain about poor health services by health care workers**, to have these complaints investigated and to receive feedback about the investigation.

- ❖ In South Africa, if you are treated poorly by a health care worker or are refused treatment at a government health facility, you can report it to the **Public Prosecutor**, to the **High Court** or to the **Human Rights Commission**.

The South African Bill of Rights¹⁰

The South African Bill of Rights contains a list of fundamental rights that are applicable to all people living in South Africa. The table below explains some of these and what these may mean for people living with HIV/AIDS.

Right	Meaning for people living with HIV/AIDS
Human dignity	A person or institution may not insult or damage any person's self-respect by their words or actions.
Freedom and security of the person	A person has the right to take their own decisions e.g. about medical treatment, pregnancy, HIV testing etc. This includes the right not to be treated in a cruel or degrading manner by any person or institution.

¹⁰ Taken from *HIV/AIDS and the Law: A Resource Manual (3rd Ed)*, 2003. AIDS Law Project and the AIDS Legal Network.

Right	Meaning for people living with HIV/AIDS
Privacy	To keep one's HIV status to one's self. An employer or institution cannot force disclosure or force a blood test.
Freedom of expression	To ensure that people have a right to access information about HIV prevention in schools and correctional facilities.
Freedom of association	All people have the right to join any organisation and not to be forcefully separated from other people.
Freedom of movement and residence	A person living with HIV/AIDS is free to move around the country and may not be forced to live separately from others.
Freedom of trade, occupation and profession	People living with HIV/AIDS can choose what work they want to do and cannot be told that they are barred from certain jobs or professions.
Labour relations	No person may be unfairly discriminated against at work.

Right	Meaning for people living with HIV/AIDS
Environment	This is the right to an environment that promotes physical and mental health, and applies to people living with HIV/AIDS who reside in state institutions such as psychiatric hospitals and correctional facilities.
Housing	People living with HIV/AIDS may not be refused a loan or a subsidy to purchase a house, nor may they be evicted from their place of residence because of their HIV status.
Health care, food, water and social security	No person living with HIV/AIDS may be refused emergency medical treatment; people living with HIV/AIDS who are too sick to support themselves or their families qualify for social security grants.
Education	People with HIV/AIDS have the same rights to education as all South Africans; an educational institution may not refuse to educate someone who is living with HIV/AIDS.

Right	Meaning for people living with HIV/AIDS
Access to information	All people have the right to information that is being used to discriminate against them in the public and private sphere e.g. access to own medical records, policies etc. The right extends to the provision of information about HIV/AIDS in state institutions.
Just administrative action	If a person feels/believes that they are being refused a social service (e.g. house or education) for unjust administrative reasons, it is their right to receive these reasons in writing.
Arrested, detained and accused persons	Incarcerated offenders or those in police custody who are living with HIV/AIDS may not be unfairly discriminated against.