



USAID
FROM THE AMERICAN PEOPLE

**HEALTH POLICY
INITIATIVE**



COMMUNITY TREATMENT LITERACY: RECOGNIZING GENDER ISSUES IN ADHERING TO HIV TREATMENT

WORKSHOP MANUAL

AUGUST 2010

This publication was produced for review by the U.S. Agency for International Development (USAID). It was prepared by staff of the Health Policy Initiative, Task Order I.

Suggested citation: USAID | Health Policy Initiative, Task Order I. 2010. *Community Treatment Literacy: Recognizing Gender Issues in Adhering to HIV Treatment, Workshop Manual*. Washington, DC: Futures Group International, Health Policy Initiative, Task Order I.

The USAID | Health Policy Initiative, Task Order I, is funded by the U.S. Agency for International Development under Contract No. GPO-I-01-05-00040-00, beginning September 30, 2005. Task Order I is implemented by Futures Group International, in collaboration with the Centre for Development and Population Activities (CEDPA), White Ribbon Alliance for Safe Motherhood (WRA), and Futures Institute.

COMMUNITY TREATMENT LITERACY: RECOGNIZING GENDER ISSUES IN ADHERING TO HIV TREATMENT

WORKSHOP MANUAL

AUGUST 2010

The views expressed in this publication do not necessarily reflect the views of the U.S. Agency for International Development or the U.S. Government.

CONTENTS

Acknowledgments	v
Abbreviations	vi
Introduction	1
Day 1	2
Session 1: Workshop Introduction.....	2
□ Welcome.....	2
□ Activity 1: Participant Introductions	2
□ Activity 2: Workshop Agenda.....	3
Session 2: Exploring HIV and AIDS.....	3
□ Activity 1: Understanding HIV and AIDS	4
□ Activity 2: Preventing HIV through Sexual Transmission.....	6
□ Activity 3: Obstacles to Preventing HIV Infection through Blood	7
□ Activity 4: Prevention of Parent-to-Child Transmission (PPTCT)	8
Session 3: HIV Treatment and Adherence	9
□ Activity 1: Antiretroviral Therapy.....	10
□ Activity 2: HIV/AIDS Treatment Adherence.....	12
□ Activity 3: Identifying Factors Affecting Adherence.....	13
□ Activity 4: Facilitating HIV/AIDS Treatment Adherence.....	15
Day 2	16
Session 4: Introduction to Gender and Health.....	16
□ Activity 1: Sex and Gender	16
□ Activity 2: Defining Gender and Related Terms	17
□ Activity 3: Gender and the Health System	18
Session 5: Gender and HIV	20
□ Activity 1: Understanding the Human Face of HIV/AIDS in Households.....	20
□ Activity 2: Gender-Related Vulnerability to HIV	21
Day 3	24
Session 6: HIV and AIDS Status Disclosure.....	24
□ Activity 1: Defining HIV Serostatus Disclosure	24
□ Activity 2: Advantages and Disadvantages of HIV Serostatus Disclosure.....	26
□ Activity 3: Disclosure of HIV Serostatus and Gender.....	26
□ Activity 4: Disclosure and Adherence.....	27
□ Activity 5: Legal and Ethical Issues and Disclosure	27
Session 7: Gender and Adherence to HIV Treatment.....	28
□ Activity 1: Gender Issues Related to HIV Treatment.....	29
□ Activity 2: Exploring/Identifying Gender Issues Related to Adherence	29
□ Activity 3: Overcoming the Problems	30
Day 4	31
Session 8: Workplan and Closing.....	31
□ Activity 1: Prioritizing Strategies for Overcoming the Problem	31
□ Activity 2: Presentation of Group Workplans and Discussion	32
□ Activity 3: Evaluation and Closing	32
Annex A: Sample Workshop Agenda.....	33
Annex B: Pre- and Post-training Assessment	35
Annex C: Glossary.....	36
Annex D: Gender Definitions and Terms	39
Annex E: Human Faces of HIV/AIDS.....	40

Annex F: Human Faces Questions.....	42
Annex G: Disclosure of HIV Serostatus	43
Annex H: He Has HIV/She Has HIV.....	44
Annex I: Gender Issues Related to Adherence	45
Annex J: Becoming a Treatment Buddy to a Woman/Man on ART	46
Annex K: Workplan.....	48
Annex L: Evaluation.....	49
References.....	50

ACKNOWLEDGMENTS

The USAID | Health Policy Initiative would like to thank the following staff members for drafting, reviewing, and piloting this workshop manual: Britt Herstad, Dorothy Odhiambo, Mary Kincaid, Lydia Rwechungura, Millicent Obaso, Tito Coleman, Anita Bhuyan, and Lori Merritt. We would also like to thank Tanzania-based consultants Franco Mpangala, Dr. Jaiving Kazitanga, and Susan Bisanda for their leadership and participation in the pilot workshop. The workshop would not have been possible without the partnership with the National Network of Tanzanian Women with HIV (NETWO+), including Chairperson Mpendwa Abinery Chihimba, Upendo Mchatta, Kant Baraka, and Omary Ally. Many thanks for their support in undertaking the workshop and bringing together the network's representatives from the Morogoro region of Tanzania. Last, a heartfelt thank you to all of the participants of the two workshops. Your participation enriched the development of this workshop manual, and the workshop can now be replicated in other regions.

ABBREVIATIONS

AIDS	acquired immunodeficiency syndrome
ART	antiretroviral treatment
ARV	antiretroviral
CTC	care and treatment centers
DNA	deoxyribonucleic acid
ECSA	Eastern, Central, and Southern Africa
ELISA	enzyme-linked immunosorbent assay
HAART	highly active antiretroviral therapy
HBC	home-based care
HIV	human immunodeficiency virus
HPI	Health Policy Initiative
ICW	International Community of Women with HIV/AIDS
MTCT	mother-to-child transmission
NACP	National AIDS Control Program
NETWO+	National Network of Tanzanian Women with HIV
NNRTI	non-nucleoside reverse transcriptase inhibitor
NRTI	nucleoside reverse transcriptase inhibitor
NtRTI	nucleotide reverse transcriptase inhibitor
OI	opportunistic infection
PI	protease inhibitor
PLHIV	people living with HIV/AIDS
PMTCT	prevention of mother-to-child transmission
PPTCT	prevention of parent-to-child transmission
PTCT	parent-to-child transmission
RNA	ribonucleic acid
STIs	sexually transmitted infections
VCT	voluntary counseling and testing

INTRODUCTION

Stigma, discrimination, and gender inequality are recognized as major impediments to effective HIV and AIDS care, treatment, and prevention efforts. As treatment programs are rolled out and scaled up, stigma and discrimination and gender inequality can adversely affect adherence in different ways for HIV-positive women and HIV-positive men. An International Community of Women with HIV/AIDS (ICW) report (Rwechungura and Kayitare, 2006) identifies factors impeding HIV-positive women’s full access to antiretrovirals (ARVs), such as the financial and time costs of traveling to service points, lack of confidentiality, and the need for permission from partners to access services. Similar data for men’s gender barriers have not been well researched or discussed.

This workshop manual was designed as part of a USAID | Health Policy Initiative, Task Order 1 pilot activity to address gender issues in relation to adherence to HIV/AIDS treatment in Tanzania. The USAID | Health Policy Initiative strives to improve the enabling environment for health, especially family planning/reproductive health, HIV and AIDS, and maternal health. The initiative assists countries in devising strategies for responding to issues that cut across technical areas and hinder service quality and access, such as gender. Initial discussions with HIV-positive networks in Dar es Salaam led to a partnership with the National Network of Tanzanian Women with HIV/AIDS (NETWO+) that focuses on integrating gender into its existing treatment literacy training program and piloting it with one group of women and one group of men. NETWO+ identified a particular need to involve men in such programs.

This curriculum is structured as a three- and one-half-day program. It is designed for people living with HIV/AIDS (PLHIV) who are involved with a PLHIV network and who plan to engage in awareness-raising or support activities with other PLHIV in their own communities. It may be adapted to meet the priorities and needs of different participants and varying contexts. The workshop manual was piloted with subdistrict representatives of NETWO+ and HIV-positive men from the same subdistricts in the Morogoro region of Tanzania.

Workshop Objective

The overall workshop objective is to raise awareness among HIV-positive women and men about gender issues related to adherence to HIV treatment, so they can effectively address and act on adherence issues in their communities. At the end of the workshop, participants will

- Demonstrate a heightened awareness and knowledge of gender issues related to HIV treatment adherence;
- Feel comfortable discussing the issues with community- and home-based care providers, HIV-positive women and men, and others;
- Be familiar with materials, techniques, and exercises on gender issues related to HIV/AIDS treatment adherence; and
- Be able to discuss differences between men and women with respect to gender adherence issues.

Sample Workshop Agenda

Day 1 Workshop Introduction Exploring HIV and AIDS HIV Treatment and Adherence	Day 3 HIV and AIDS Status Disclosure (continued) Gender and Adherence to HIV Treatment
Day 2 Introduction to Gender and Health Gender and HIV HIV and AIDS Status Disclosure	Day 4 (half day) Workplan and Closing

DAY I

Workshop Objective

Raise awareness among PLHIV of gender issues related to adherence to HIV treatment, so that PLHIV can effectively share and act on information about the issues in their communities.

SESSION I: WORKSHOP INTRODUCTION (45 MINUTES)

Learning Objectives

At the end of this session, participants should be better able to:

- Understand the purpose and objectives of the workshop
- Demonstrate knowledge of participants, facilitators, and organizers and their backgrounds

Preparation

- Write workshop objective and Day 1 agenda on a flipchart
- Write instructions for introductions on a flipchart
- Photocopy Annex A and Annex B

Materials

- Flipchart
- Markers
- Handout: Workshop Agenda (Annex A)
- Handout: Pre-assessment (Annex B)

❖ Welcome (10 minutes)

1. Training organizers and/or training facilitators should introduce themselves, welcome participants, introduce the activity and the work they do, and thank participants for attending the training.

❖ Activity I: Participant Introductions (20 minutes)

1. Introduce the activity—review the following instructions written on the flipchart:
 - Name (the name they prefer to be called)
 - Where they come from
 - How they work on HIV issues in their community
 - Two expectations for the workshop
2. Ask participants to find someone they do not know and make that person their partner. Ask them to undertake a brief interview with each other.
3. Monitor time and make sure partners have equal time.
4. After 10 minutes, invite partners to introduce each other to the group and share their expectations.

5. Record participants' expectations on the flipchart and let them know that you will discuss expectations shortly.

❖ **Activity 2: Workshop Agenda (15 minutes)**

1. If necessary or relevant, provide information on how the training fits into a larger initiative, project, or context. For example, in this pilot workshop, the Health Policy Initiative's mandate and work in Tanzania should be explained. The work of NETWO+ should also be explained if participants are not familiar with it.
2. Review the workshop objective and agenda, displaying the flipchart.
3. Review participant expectations listed on the flipchart. Any expectations outside the scope of the workshop should be written on the flipchart under the heading "parking lot." Explain that these issues will not be addressed in the workshop but may be discussed during break times.
4. Ask participants if they have any questions on the workshop's objective or agenda.
5. Ask participants to share any ground rules for the workshop. Write them on the flipchart, and remind participants that you will all hold each other accountable to the rules. Post the ground rules on the wall in a place that is visible to all participants throughout the workshop.
6. Explain to participants that they will now fill out a pre-workshop assessment (distribute Annex B). Ask them to read each statement and answer true or false. The assessment will be repeated at the end of the workshop to see what participants have learned.

Facilitator's Note: It is important for the facilitator and participants to have the same understanding of the workshop's objectives. Otherwise, participants may be frustrated if they expect an outcome that is outside the scope of the workshop.

SESSION 2: EXPLORING HIV AND AIDS (3 HOURS)

Learning Objectives

At the end of this session, participants should be better able to:

- Explain the meaning of HIV and AIDS, including differences
- Explain modes of HIV transmission
- Explain how HIV can be prevented

Preparation

- Create two signs, one reading "correct" and the other "incorrect" and attach them to the wall

Materials

- Flipchart
- Markers
- Bowl
- Cards (different colors)
- Signs reading "correct" and "incorrect"

❖ **Activity I: Understanding HIV and AIDS (60 minutes)**

1. Explain to participants that you will now begin discussing HIV and AIDS. While everyone will be knowledgeable of HIV and AIDS, the discussion will serve as a fact check.
2. Distribute cards of different colors, if possible. Ask participants to write down modes of HIV transmission on one color of card; how HIV is diagnosed on another color of card; and information related to the history of HIV and AIDS (general or country-specific) on another color of card. Give participants 10 minutes.
3. Deliver a brief lecture on HIV and AIDS, with the following information (20 minutes):

Facilitator's Information

HIV: Human Immunodeficiency Virus

- HIV is a retrovirus. A virus containing genetic RNA material rather than DNA. For the virus to replicate itself within an infected cell, its ribonucleic acid (RNA) must be converted to deoxyribonucleic acid (DNA). It does so by using an enzyme known as reverse transcriptase.
- HIV attacks the immune system, which helps defend the body against infections. Over time, the virus overwhelms the immune system. The body is then not able to defend itself from opportunistic infections.
- The virus targets a cell known as the T4 lymphocyte (more commonly known as a CD4 cell), which is a special type of germ- or disease-fighting cell. Over the course of a lifetime, starting from infancy, we are all subjected to infections that are held in check by our immune system. When HIV suppresses a person's immune system, infections such as tuberculosis can manifest themselves while others may never cause disease unless the immune system is weakened (e.g., cytomegalovirus (CMV) retinitis). Infections that move a patient from HIV status to AIDS are referred to as opportunistic infections.
- HIV may be isolated from blood, semen, and secretions that include cervical and vaginal secretions, breast milk, saliva, tears, and urine. A certain viral load is necessary for the infection to be transmitted. Viral load is the amount of HIV per milliliter of blood.

AIDS: Acquired Immunodeficiency Syndrome

- AIDS is a life-threatening condition that is characterized by the destruction of certain cells, mainly the cells of the immune system—CD4 cells. This leads to opportunistic infections, which are severe and ultimately fatal.
- The length of time from when a person is infected with HIV to the development of AIDS varies from person to person. People can remain healthy for any time from a few years to more than 10 years before developing any AIDS-related symptoms.
- If a blood test shows that a person has HIV, the person does not necessarily have AIDS.

(SAfAIDS, 2005; Cain et al., 2006; AVERT, n.d.a)

Modes of Transmission

- Sexual intercourse with an infected partner
- Parent-to-child transmission
- Blood transfusion with infected blood
- Sharing of infected needles for injecting drugs intravenously

HIV cannot be transmitted by:

- Casual, everyday contact (e.g., shaking hands, hugging, kissing, coughing, sneezing)
- Donating blood
- Using common swimming pools or public toilet seats; sharing bed linen, eating utensils, food, and so forth
- Animals, mosquitoes, and other insects

(SAfAIDS, 2005; Cain et al., 2006; UNIFEM, 2000)

Origin and History

- The first cases of HIV/AIDS in Tanzania were reported in 1983, although HIV began to surface in the late 1970s in sub-Saharan Africa.
- In 1985, the HIV epidemic was confirmed in Tanzania; by 1986, all regions had reported AIDS cases to the National AIDS Control Programme (NACP).
- The epidemic has evolved from a rare and new disease to a common household problem that has affected many Tanzanian families.
- In 2003, Tanzania's mainland was estimated to have about 1,840,000 people living with HIV (860,000 males and 980,000 females). A total of 16,430 AIDS cases was reported to the NACP from 21 regions during 2004, translating into a cumulative 192,532 reported cases since 1983.

(Ministry of Health and Social Welfare, National AIDS Control Programme, 2008)

Diagnosis

- The presence of HIV antibodies indicates HIV infection. These antibodies can be detected through an HIV antibody test between roughly 1–2 months after infection.
- The period during which antibodies are not yet detected is called the window period; transmission of infection can take place during this period.
- Diagnosis of HIV requires two tests: a screening test and a confirmatory test. Screening involves an HIV antibody test, such as a rapid test or a lab-based ELISA test (Enzyme-Linked Immunosorbent Assay) that indirectly tests for the presence of HIV. If the screening test result is positive, it is followed by a confirmatory test, such as a Western Blot or nucleic acid test that looks for the presence of HIV genetic material rather than antibodies.
- The incubation period of AIDS is the time between infection and the onset of symptoms and varies from person to person.

(AVERT, n.d. b; UNIFEM, 2000 ; WHO and CDC, 2005 ; WHO, 2007)

4. Following the lecture, gather all the cards in a bowl. Referring to places on the wall marked “correct” or “incorrect,” invite participants to take a card from the bowl and place it on the wall, indicating whether it is correct or incorrect (10 minutes).
5. Facilitate a discussion of the cards (20 minutes), noting what is correct and what is incorrect and why. Discuss how widespread the misperceptions may be in communities and why. Ask participants if women and men have different knowledge of HIV. Facilitate a brief discussion of the reasons for any differences in knowledge. Explain that participants will be exploring these reasons in detail in the following days.

❖ **Activity 2: Preventing HIV through Sexual Transmission (60 minutes)**

1. Affirm that it is possible to eliminate or reduce the risk of HIV infection during sex and through contact with infected blood or other bodily fluids, as well as during pregnancy, at birth, and during breastfeeding.
2. Ask participants to sit in groups of five. Give each group a flipchart and markers. Ask each group to discuss how to prevent HIV through sexual contact. Encourage participants to discuss and clarify some of the existing myths around the use of male and female condoms and other prevention strategies. Ask the groups to list on their flipchart up to three issues and one myth related to HIV prevention.
3. Use the information below to ensure that participants cover most of the issues as well as some of the barriers to prevention strategies. Record barriers on the flipchart. Ask participants why the strategies have not succeeded.

Facilitator’s Information

Someone can eliminate or reduce the risk of HIV infection during sexual contact through the following:

- Abstain from sex or delay first sexual contact/relationship
- Be faithful to one uninfected partner
- Use male or female condoms consistently and correctly

The use of media campaigns, social marketing, peer education, and small group counseling can encourage and educate people to adopt safe sexual behavior. Such activities should suit the needs, conditions, and context of the target groups. For example, information targeting women and girls and men and boys should be based on context and prevention needs. For young people in general, comprehensive sex education should be an essential part of HIV prevention and should include life skills, how to negotiate healthy sexual relationships, and accurate and explicit information about how to practice safe sex.

Condoms, if used consistently and correctly, are highly effective in preventing HIV infection and other sexually transmitted infections (Department of Health and Human Services and Centers for Disease Control and Prevention, n.d.). Strong evidence is also emerging that male circumcision reduces the risk of transmission from women to men by 50 percent (Centers for Disease Control and Prevention, 2008). However, circumcision does not reduce the likelihood of male-to-female transmission, and the effect on male-male transmission is not yet known.

Some Obstacles to Preventing Sexual Transmission of HIV

- People have difficulty in sustaining changes in sexual behavior.
- Young people have difficulty remaining abstinent.
- Women in male-dominated societies may be unable to negotiate condom use, let alone abstinence.
- Many people are compelled to engage in unprotected sex in order to have children, even when they know their status.
- Many people associate condoms with promiscuity.
- Many African communities find it difficult to discuss issues of sex openly, especially with young people.
- For moral or religious reasons, authorities in many African countries limit what constitutes sex education and what should be discussed in classrooms or in a public information campaign.

4. Ask the groups to hang their flipchart on the wall. Invite participants to go for a gallery walk and read all the flipcharts and discuss any controversial issues emerging from the group discussions. Correct any myths and misconceptions that may arise relative to prevention of HIV and other sexually transmitted infections (STIs).

❖ Activity 3: Obstacles to Preventing HIV Infection through Blood (30 minutes)

1. Explain to participants that HIV transmission is possible through several ways. This activity will discuss preventing HIV infection through blood.
2. Ask participants as a single group to brainstorm about obstacles that may affect prevention of HIV infection through blood.
3. Conduct a discussion with all participants, ensuring that the following points are mentioned:
 - Many poor and resource-constrained countries lack facilities for rigorously screening blood supplies. Some authorities oppose needle exchange programs.
 - Many countries have trouble recruiting blood donors; some have resorted to importing blood or paying citizens to donate blood.
 - In most sub-Saharan countries, lack of resources compromises the safety of medical procedures.

Facilitator's Information

Prevention of Transmission through Blood and Other Bodily Fluids

- Infection through blood occurs when people are transfused with infected blood or share sharp objects or devices such as needles, circumcision knives, and razor blades and toothbrushes, and so forth.
- People who inject drugs may be put on drug treatment programs and provided with methadone maintenance to help eliminate withdrawal and reduce the urge to inject drugs (WHO, 2005a).

- Initiation of needle exchange programs by provision of clean needles has been shown to reduce the number of new infections among injecting drug users without encouraging drug use. Safe needle disposal should be encouraged.
- Screening of all blood supplies is essential; transfusion of infected blood or blood products is the most efficient means of transmitting HIV.
- Even though screening of blood may not be 100 percent foolproof, interventions such as restricting and screening those eligible to donate blood and reducing the number of unnecessary transfusions can reduce the risk of HIV transmission.
- Health workers who come into contact with blood and other bodily fluids should practice universal precautions such as wearing gloves and putting on protective barriers for direct contact with bodily fluids.

(NAM, n.d.; Global HIV Prevention Working Group, 2006)

❖ **Activity 4: Prevention of Parent-to-Child Transmission (PPTCT) (45 minutes)**

1. Explain to participants that HIV can be transmitted from a mother to her baby during pregnancy, at labor, during delivery, and after birth through breastfeeding. Generally, the first step to reduce the number of children infected with HIV is to prevent unintended pregnancies and HIV infection in women of child-bearing age. Nevertheless, once a woman knows her positive status, it is imperative for her to take steps to prevent transmission to the baby.
 - Remind participants that when using the phrase “parent-to-child transmission” (PTCT), it is important to keep in mind that men cannot biologically transmit HIV to the baby. Similarly, men and women *cannot* transmit HIV to babies through hugging, kissing, or holding the baby. The term “PTCT” is used to encourage male involvement and highlight the role that men can play in preventing transmission of HIV to the baby, in partnership with the mother of the baby.
2. Discuss with participants how PTCT can be prevented. Record key points on a flipchart labeled “prevention strategies.” Ask if any participants would like to share any experiences related to a successful PPTCT process.
3. List the strategies suggested by participants and ask them to describe any barriers to successful PPTCT. Note “barriers” on a separate flipchart. Participants should note some of the following strategies:
 - Providing a course of antiretrovirals (ARVs) during pregnancy and birth and to the newborn can greatly reduce the chances that the child will become infected.
 - If the mother is eligible for ARVs as treatment for her own health, ensuring that she receives combination ARV after delivery. Also, mothers may receive ARVs as a prophylaxis during breastfeeding. .
 - A Caesarean section—an operation to deliver a baby through the mother’s abdominal wall—reduces the baby’s exposure to its mother’s bodily fluids. The procedure lowers the risk of HIV transmission and is beneficial if the mother has high levels of HIV in the blood.

- Mothers known to be HIV positive (and whose infants are HIV negative or of unknown HIV status) should exclusively breastfeed their infants for the first six months of life, introducing appropriate complementary food thereafter, and continuing breastfeeding for the first 12 months of life (WHO, 2009).
 - Breastfeeding should then only stop once a nutritionally adequate and safe diet without breastmilk can be provided (WHO, 2009).

Facilitator's Information

Obstacles to PPTCT

- Lack of ARVs (along with a lack of access to ARVs) in many poor countries, especially in sub-Saharan Africa, limits opportunities to prevent infection.
- Caesarean section is often expensive and impractical in the absence of trained medical personnel.
- Many women in Africa lack the resources needed to avoid breastfeeding and cannot buy formula or other options for replacement feeding.
- Limited male involvement in PPTCT can create difficulties for women trying to access and adhere to prevention strategies. Encouraging and enabling men to participate in PPTCT efforts can greatly improve PPTCT outcomes.
- HIV-related stigma is a major obstacle to preventing PPTCT. HIV-positive women are afraid to attend clinics and pick up their ARVs or to give their babies formula because doing so reveals their HIV status.

(Teasdale and Besser, 2008)

SESSION 3: HIV TREATMENT AND ADHERENCE (3 HOURS AND 30 MINUTES)

Learning Objectives

At the end of this session, participants should be better able to

- Describe the goals and benefits of ART;
- Explain the benefits of antiretroviral drugs;
- Identify when to start ARVs;
- Discuss criteria for ARV use; and
- Identify reasons for changing or stopping ARVs.

Preparation

- Write ARV, ART, and HAART on the flipchart
- Photocopy Annex C

Materials

- Flipchart
- Markers
- Handout: Glossary (Annex C)

❖ Activity 1: Antiretroviral Therapy (60 minutes)

1. Ask participants to define the following acronyms written on the flipchart: ARV, ART, and HAART.

Facilitator's Note: Spend 10 to 15 minutes on steps 1 through 3.

2. Reveal the flipchart with the following written on it:

- ARV = Antiretroviral
- ART = Antiretroviral Therapy
- HAART = Highly Active Antiretroviral Therapy

3. Briefly discuss what the terminologies mean and the differences between them. Share the following information with participants even if they mention it:

Facilitator's Information

How ART Works

- Standard antiretroviral therapy (ART) consists of the use of at least three antiretroviral (ARV) drugs to maximally suppress the HIV virus and stop the progression of HIV disease.
- ART stops the progress of viral replication, preventing further disease progression and damage to the immune system.
- With ART, the body's defense (immune system) gets a chance to recover and defend against opportunistic infections.
- When people take ART, they get sick less often and feel better for longer periods of time.

(United Republic of Tanzania Ministry of Health and Social Welfare, 2007; WHO, n.d.)

Facilitator's Note: The terms ART and HAART tend to be used synonymously for a combination of therapy of at least three drugs used to treat HIV infection, while ARV means a specific ARV drug. ART and HAART involve several pills taken every day. They all work together to slow HIV infection—they do not work individually (FHI Ghana, 2004). It is important to note that antiretroviral drugs do not cure HIV infection.

4. Explain that HIV is a retrovirus; therefore, medications are mainly antiretroviral. Treatment is a three-drug combination therapy. List the following four drugs on a flipchart and present the following definitions to participants (5 minutes):

Facilitator's Information

- **NRTIs/NtRTIs: Nucleoside/Nucleotide Reverse Transcriptase Inhibitors**—These include nucleoside/nucleotide reverse transcriptase inhibitors. Common NRTIs/NtRTIs are stavudine, lamivudine, zidovudine, abacavir, tenofovir, and didanosine. NRTIs/NtRTIs are converted into a form similar to nucleotides, the building blocks of DNA (nucleotides), and as such are “mistakenly” incorporated into the DNA chain produced by the reverse transcriptase.
- **NNRTIs: Non-Nucleoside Reverse Transcriptase Inhibitors**—Reverse Transcriptase is an enzyme that changes the HIV in a way that enables it to become part of the nucleus of a target cell, thereby allowing it to make copies of itself. NRTIs and NNRTIs inhibit (slow down) the action of this enzyme. If the enzyme does not do its job properly, HIV cannot take over and start making new copies of itself.
- **PI: Protease Inhibitors**—These slow the enzyme protease, which works on HIV after it comes out of the nucleus of the cell. Protease acts like a pair of chemical scissors by cutting up the long chains of HIV proteins into smaller pieces so that HIV can make active new copies of itself. Protease Inhibitors gum up (block) the protease scissors.

Prophylactic Medications—These help prevent opportunistic infections when the immune system becomes weak, e.g., Foscarnet and Ganciclovir to treat Cytomegalovirus Eye infections, Fluconazole to treat yeast and other fungal infections, and menengitis, TMP/SMX or Pentamidine to treat Pneumocystis Carinii Pneumonia.

(NAM, 2010; UNIFEM, 2000)

5. Tell participants that you will now briefly discuss the benefits and goals of ARVs (15 minutes). Ask participants to raise their hand and share any benefits or goals. Record their comments on a flipchart. If any participants would like to share their experiences, ask them to do so. Use the following information as a guide and bring up any issues they may have missed:

Facilitator's Information

Benefits of ARVs

- Prolong life and improve quality of life
- Reduce parent-to-child transmission
- Increase number of people seeking voluntary counseling and testing
- Increase awareness in the community as more people take the test
- Increase motivation of health workers; they feel they can do more for HIV patients
- Fewer resources spent to treat opportunistic infections and provide palliative care
- Decrease in number of orphans
- Businesses and households remain intact

Goals of ART

- ART stops the progress of viral replication, thus preventing further disease progression and immune system damage.

- The body's defense (immune) system gets a chance to recover and can defend against opportunistic infections; however, antiretroviral drugs do not cure HIV.
- The virus can never be eradicated completely; therefore, a person must take ART drugs forever, even if symptoms disappear.
- Since the virus cannot be eradicated, safe sex is essential even during treatment and even if the virus is no longer seen in the blood (undetectable viral load).

(United Republic of Tanzania Ministry of Health and Social Welfare, 2007)

6. Conclude the activity with a brief discussion of eligibility for ART (10 to 15 minutes). Ask participants to name the major factors that determine when someone should begin HIV treatment. Use the information below to facilitate a brief discussion on eligibility for ART and then conclude the activity. Distribute the Glossary (Annex C) for participants' reference throughout the rest of the workshop.

Facilitator's Information

Eligibility for ART

The decision to begin treatment should be based on the following major factors:

- The degree of HIV-related disease (WHO staging).
- The degree of HIV-related immunosuppression (CD4 count). HIV attacks CD4 cells—the infected CD4 cell first produces many new copies of the virus, and then dies. This cycle continues, depleting one's number of CD4 cells (cells of the immune system).
- A solid adherence plan and a working relationship with the health care system; the patient must express preparedness and be ready to start therapy for life.
- If a patient begins treatment but does not adhere, he or she may develop resistance to the first set of drugs. Once resistance has occurred, treatment options become more difficult. The first line offers the best chance for success. Therefore, if someone is not mentally, emotionally, or socially prepared to adhere to treatment, it is often best to refrain from initiating treatment until he or she is prepared.

Adult and adolescent patients in the following categories are eligible for ART:

- All patients in WHO stage 4 clinical criteria regardless of CD4 cell count
- All patients in WHO stage 3 with a CD4 count <350 cells /mm³ as an indicator of their progression to AIDS
- All patients with a CD4 count < 200 cells/mm³ regardless of clinical symptoms

(United Republic of Tanzania Ministry of Health and Social Welfare, 2007; WHO, 2010)

❖ Activity 2: HIV/AIDS Treatment Adherence (30 minutes)

1. Tell participants that an important component of HIV/AIDS treatment is adherence. Ask participants if they have heard this word before and if they can define it (5 minutes). Record participants' responses on a flipchart.
2. Deliver a brief lecture or presentation on adherence. Use the following information:

Facilitator's Information

What is adherence?

- Adherence means that you take your drugs exactly as prescribed, at the right time, and in the right doses.
- Adherence also means that you follow any special dietary restrictions.
- Missing even a few doses can cause your drugs to fail, and there's good evidence that adherence levels of over 90 to 95 percent are needed for you to get the best response.
- In other words, you should not miss more than one dose a month if you are on once-a-day therapy or two doses a month if you are taking anti-HIV drugs twice a day.

Adherence to most drug regimens is poor across all populations and all diseases.

- Adherence is poor in the case of diabetes, TB, and heart disease.
- One-fifth to 100 percent of patients (average: 50 percent) fail to take medication as prescribed.
- For most chronic diseases, greater than 80 percent adherence is considered successful (United Republic of Tanzania Ministry of Health and Social Welfare, 2007)

(Treatment Action Campaign, 2006)

Why is adherence to HIV treatment important?

- HIV drugs work only if you keep a constant minimum level of each drug in your body at all times.
- If the level drops below the minimum level, then your virus can develop resistance to the drugs, and the drugs will stop working.
- A little HIV medication is dangerous—with HIV, you need to take all or nothing. You need to develop a routine to ensure that you take your drugs as prescribed, even if you take only one pill twice a day.
- It is very important to take medication exactly on time. You usually have leeway of about an hour on either side of the exact time; some drugs have longer leeway than others. Because the leeway can differ for different drugs, it is still best to aim for the same time every day.
- It is important to pay attention to dietary restrictions for different drug combinations; ignoring the restrictions can be like taking only half a dose. You will not absorb enough of the drug for it to work properly.
- Missing one or two doses a week can have a big impact on the chances of successful treatment. If you take every dose, you will get much better results.

(Treatment Action Campaign, 2006)

3. After presenting the information above, ask participants if they have any questions. Ask if their healthcare providers or someone else has already shared this adherence information with them. Conduct a brief discussion on adherence if participants want to discuss it further.

❖ Activity 3: Identifying Factors Affecting Adherence (60 minutes)

1. Divide participants into groups of five.

2. Ask participants to discuss the following questions in small groups (write the questions on a flipchart):
 - What are some of the factors that influence a person’s ability to adhere to a treatment regimen?
 - What factors *facilitate* adherence or *create* barriers to adherence for women and men?
3. Give participants three categories of factors, including the following:
 - Social
 - Individual
 - Structural (health services/facilities)

Briefly introduce the categories and provide details and examples if participants are unsure of the categories.

4. Assign each group a category and ask it to come up with answers to the questions, focusing on the assigned category and giving reasons for women and men separately. Ask groups to record their responses on a flipchart. Give participants an example, such as a social factor (e.g., readiness to take ART) or a health services factor (e.g., distance to clinic). After 15 minutes, bring the groups together and ask them to report on the three factors. Ask each group to post its flipchart on the wall so all participants can view the responses for the three factors at the same time. Note any factors that need to move to another category (e.g., items designated as social factors that are structural factors).

Facilitator’s Information		
Facilitators and Barriers to Adherence		
Social	Individual	Structural
<ul style="list-style-type: none"> • Fear of stigma and discrimination • Misconceptions/rumors about ART • Others’ opinions of ART • Social influence of family members (e.g., husbands not allowing wives to take ART) • Misunderstanding of behaviors interacting with treatment (such as drinking, sex, and so forth) • Emotional and/or material support from family, friends • Side effects 	<ul style="list-style-type: none"> • Depression • Alcohol/substance abuse • Belief in ability to take one’s medication as instructed (self-efficacy) • Understanding viral resistance and adherence • Previous adherence • Did not have medication at time of the dose • Forgot to take it • Too busy to take it • Ran out of medication • Difficulty understanding regimen • Didn’t want to take medication in front of others • Didn’t want to be reminded of HIV/AIDS • Beliefs about causes of HIV/AIDS • Side effects 	<ul style="list-style-type: none"> • Relationship with health care provider • Location of clinic or facility • Work obligations • Provision of free services/medication • Adherence training • Treatment partners • Access to resources (food, money, transportation) <p>(Roura et al., 2009; Anderson, 2005)</p>

❖ **Activity 4 : Facilitating HIV/AIDS Treatment Adherence (60 minutes)**

1. Ask participants for *practical* suggestions for how people living with HIV can improve their adherence, keeping in mind the factors discussed in the previous activity.
2. List participants' suggestions on the flipchart. Add suggestions from the list below (Treatment Action Campaign 2006):
 - Before starting treatment, get all the information on what you will need to help ensure adherence. How many tablets? How big are they? How often do you need to take them? How precise do you have to be with timing?
 - Do you have food/dietary requirements? Restrictions on storage of drugs?
 - Use a daily chart to plan a timetable and practice using it to get used to the routine. For the first few weeks, mark off each dose and the time you take it.
 - Make sure you tell your health care provider or clinic if you have difficulties with side effects. Your provider or clinic can prescribe additional medication to help alleviate side effects or even change treatment.
 - Divide up your drugs each morning or, if you use a pill box, each week. You can always check the pill box to see if you missed a dose.
 - Use a pill beeper, alarm watch, or your cell phone's alarm for both morning and evening doses.
 - Learn always to carry a few doses of your medication with you.
 - Try to take your pills in the same place every time. If possible, avoid a morning dose at work and take the evening dose at home.
 - Take extra pills if you go away for a few days.
 - Keep a small supply of pills where you may need them in an emergency, as in a cool place at work or at a friend's house.
 - Get friends to help you remember difficult dose times. Ask them to remind you to take your pills when you are in social situations. If you have not disclosed your status to anyone, seek assistance in doing so.
 - Ask friends who are already on treatment what they do to ensure adherence. Ask them how they manage.
 - Most treatment centers can arrange for you to talk to someone who is already on the same treatment.
 - It is best to visit your clinic when you first experience side effects such as nausea and diarrhoea, which are the most common side effects.

DAY 2

SESSION 4: INTRODUCTION TO GENDER AND HEALTH¹ (2 HOURS AND 30 MINUTES)

Learning Objectives

At the end of this session, participants should be better able to:

- Define gender terms
- Discuss health systems and how gender affects women’s and men’s experiences with healthcare

Preparation

- Write out gender definitions and terms on flipcharts
- Photocopy Annex D

Materials

- Flipchart
- Markers
- Colored cards
- Handout: Gender Definitions and Terms (Annex D)

❖ Activity 1: Sex and Gender² (45 minutes)

1. Provide each participant with two cards—one marked with an “S” for sex and one with a “G” for gender. It is best to use different-colored cards for sex and gender to make them easy to identify.
2. Tell participants that you will read a series of statements and that you would like them to hold up the card that fits the statement, indicating whether the statement refers to sex or gender. Ask participants to explain their answer and encourage discussion between those who disagree. Use a few of the following statements:
 - Women give birth to babies, men do not.
 - Little girls are gentle, boys are tough.
 - Most drivers in Tanzania are men.
 - Women have long hair, men have short hair.
 - Men do not need tenderness and are less sensitive than women.
 - Women should have no experience in relationships when they marry, and men need to be experienced when they get married.
 - Women have weaker sexual needs than men.

¹ Adapted from the USAID Interagency Gender Working Group “Gender and Reproductive Health 101” training module, available at www.igwg.org.

² Adapted from the Introductory Gender Analysis and Gender Planning Training Module for UNDP Staff, available at <http://www.undp.org/women/docs/GenderAnalysisTrainModule.pdf>.

3. Summarize the discussion of ideas about gender and sex, making a statement about the differences.

Facilitator's Note: It is important to have an accurate translation of the terms sex and gender in the local language to ensure that people are clear on the terms' meaning.

❖ **Activity 2: Defining Gender and Related Terms (45 minutes)**

1. Divide participants into five groups. Provide each group with a list of roles/professions. Ask all groups to draw a picture of each role/profession: doctor, teacher, nurse, driver, and soldier.
2. Ask the groups to paste their drawings on the wall. Each group should explain how it conceptualized each role and why. For example, if a group's drawing of a nurse depicts a woman, the group should explain why. Discuss how participants perceive gender roles based on the drawings.
3. Split the groups again into pairs. Assign each pair one of the following terms:
 - Sex
 - Gender
 - Gender equality
 - Women's empowerment
4. Tell the pairs to take five minutes and define the term. Ask them to write the definition on a piece of flipchart paper and tape it to the wall.
5. Ask participants to assemble around each term, ask the pairs read their definition, and ask participants for their thoughts on how each term was defined. Clear up any incorrect information.
6. Display flipchart pages with the definitions of each gender term (below). Explain to participants that gender is defined in many ways, as displayed by their words, but that, for today's purposes, we will use these definitions (below). Continue through each definition.

Facilitator's Information

Sex refers to the biological differences between males and females. Sex differences are concerned with male and female physiology.

Gender refers to the economic, social, political, and cultural attributes and constraints and opportunities associated with being a woman or a man. The social definitions of what it means to be a woman or a man vary among cultures and change over time; thus, gender is learned. Gender is a socio-cultural expression of particular characteristics and roles that are associated with certain groups of people with reference to their sex and sexuality.

Gender equality is the state or condition that affords women and men equal enjoyment of human rights, socially valued goods, opportunities, and resources.

Women's empowerment means improving the status of women to enhance their decisionmaking capacity at all levels, especially as it relates to their sexuality and reproductive health.

7. Distribute the handout with these terms as a reference sheet (Annex D). Ask participants if they have further questions and/or comments.

Facilitator's Note: Participants who have not before been exposed to gender information may find the definitions difficult to comprehend. In particular, “gender equality” and “women’s empowerment” might require an in-depth discussion.

❖ **Activity 3: Gender and the Health System³ (60 minutes)**

1. Tell participants that we are going to discuss health systems and ask them to volunteer a definition of “health system.”
2. Ask participants what a good health system would address or achieve?
3. Use the following WHO definition to guide participants’ responses:

Facilitator’s Information

A health system is the sum total of all the organizations, institutions, and resources whose primary purpose is to improve health. A health system needs staff, funds, information, supplies, transport, communications, and overall guidance and direction. It needs to provide services that are responsive and financially fair, while treating people decently.

A good health system improves people’s lives tangibly every day. A mother who gets a letter reminding her that her young son is due for immunization against a life-threatening illness is benefiting from a health system. The same holds true for a family finally able to access clean water at a carefully tended pump in its village because of a government-sponsored sanitation project; or for a person with HIV who gets ART, nutritional counseling, and regular check-ups at an affordable clinic.

The ultimate responsibility for the overall performance of a country’s health system lies with government, but good stewardship by regions, municipalities, and individual health institutions is also vital.

Strengthening health systems and making them more equitable are recognized as key strategies for fighting poverty and fostering development.

(WHO, 2005b)

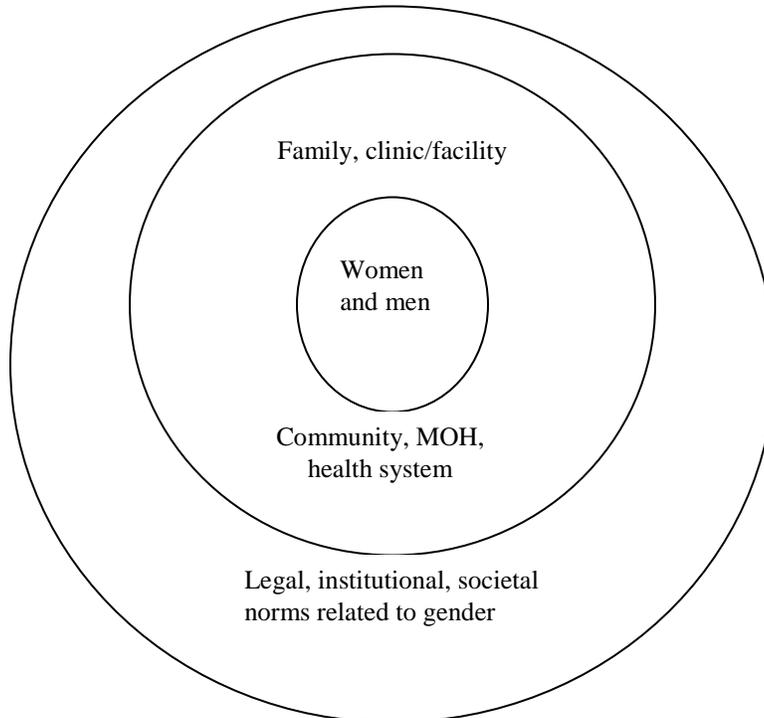
4. Divide participants into four small groups (depending on number of participants). Ask each group to discuss one of the following questions and prepare an answer to be shared with all participants:
 - How does the health system stereotype women and men in access to treatment services? Why?
 - How are women treated? How are men treated? Is one sex favored over the other?
 - How does the family/community affect women’s and men’s access to the health system?

³ Adapted from the Medical Women’s International Association’s *Training Manual for Gender Mainstreaming in Health*, available at <http://www.fmwc.ca/docs/TrainingManualonGenderMainstreaminginHealth%5B1%5D.pdf>.

- How do other related institutions affect their access (i.e., health institutions, Ministries of Health, legal, and so forth)?

Facilitator's Note: To illustrate ways in which institutions differentiate between women's and men's access to health services, you can draw a set of concentric circles with the following labels: women/men (in the middle); family, community, clinic/facility, MOH/health system; and legal, institutional, societal norms related to gender.

For example:



5. Bring participants together and ask for their responses to each question. Record responses on a flipchart, with one page for responses related to women and one page for those related to men. Compare participants' responses/lists to the list below, adding anything that may have been overlooked. Ask a participant to circle the responses that relate to both women and men on each flipchart.

The health system has affected women by

- Focusing on reproductive health or child-maternal issues;
- Ignoring women through health research or education materials;
- Treating women the same way as men when it is inappropriate to do so; and
- Treating women differently when it is not appropriate to do so.

The health system has affected men by

- Ignoring the effects of the social meaning of masculinity on men's health;
- Avoiding research and practice in men's emotional health; and
- Not reaching men in providing services for their health needs.

Facilitator's Note: If time allows, ask participants what role healthcare workers play in women's and men's access to healthcare services. Do healthcare providers need to be sensitized on any relevant attitudes or practices?

SESSION 5: GENDER AND HIV (2 HOURS AND 45 MINUTES)

Learning Objectives

At the end of this session, participants should be better able to

- Recognize how HIV-related stigma affects men and women; and
- Identify ways in which women and men are vulnerable to HIV.

Preparation

- Photocopy Annex E
- Photocopy Annex F

Materials

- Flipchart
- Markers
- Handout: Roles for Faces exercise, cut ins trips as indicated (Annex E)
- Handout: Human Faces Questions (Annex F)

❖ Activity 1: Understanding the Human Face of HIV/AIDS in Households⁴ (2 hours)

1. Tell participants that the exercise will bring HIV and AIDS to life from many perspectives. We are going to look at individuals, their issues, and their concerns.
2. Divide participants into small groups.
3. Pass out the envelopes with roles (Annex E). Mix male and female roles and ages in each small group where possible. Distribute Human Face Questions (Annex F) to each participant and state the following:
 - We want you to play a different role today, to understand what it might be like to be this person, who may have a different point of view or life circumstances from you. Give your person a name. Write your name and role at the top of the "Question" page.
 - Take about 15 minutes to think about your role. Build your story by answering the questions and thinking about other details. What is your tribe, your occupation, your religion? Have you migrated from somewhere else? Are you from a rural or urban area?
 - Write your answers to the questions on the sheets in bulleted form. After we share our stories with others, we will post the sheets.
 - Any questions?

⁴ Adapted from the USAID Interagency Gender Working Group "Gender and HIV" training module, available at www.igwg.org.

4. Review Annex F with participants.
5. Tell participants that they have about 10 minutes to prepare their own story and then 5 minutes per person to tell their stories in their small groups. After everyone has told a story, ask participants to think about which story (stories) moved them the most or gave them new insights. Allow about 45 minutes.
6. Select one to two people to remain in their roles and tell their stories to all participants.
7. Bring all participants together and ask:
 - How was this experience for everyone?
 - Let's hear some of the stories. As you begin, tell us your name and age, and I will write the information on the flipchart. After each story, I will ask if anyone has any comments or other points to make.

Facilitator's Note: Make sure to devote sufficient time to issues of tribe, sexual orientation, socioeconomic status, and so forth. Bring out additional facts as needed. Encourage participants to see how additional information affects the community as a whole.

8. After participants have shared stories related to their role, ask them about their own stories:
 - Did anything strike you about these stories? Did any themes surface?
 - What were some things that you never thought about before?
 - Did anyone experience the stigma of HIV? Were there any striking similarities or differences among the types of stigma and discrimination experienced by different characters? Why? How does gender relate to differences in stigma and discrimination?
 - (*Optional question depending on time*) What were the common concerns among different people? What were the differences? Why do you think these differences exist?
 - Did any of these stories suggest something different that could be done in your HIV work?

❖ **Activity 2: Gender-Related Vulnerability to HIV⁵ (45 minutes)**

1. Prepare four flipcharts by writing “Vulnerability to HIV/AIDS” at the top and then write “Women” on one, “Girls” on another, “Men” on the third, and “Boys” on the fourth.

Facilitator's Note: As you go through each chart, leave enough time for participants to copy the responses or tell them that you will post the charts later.

2. Tell participants that we will focus on four sets of people (women, girls, men, and boys) and will summarize what we have learned, keeping in mind the discussions from the previous activity. Ask participants the following:
 - What are the gender norms, roles, and relations that affect women's and men's vulnerability to HIV/AIDS?
 - What makes women and girls **vulnerable** to HIV/AIDS? What about men and boys? What have we learned? Have we left anything out?
3. Use the following information to discuss vulnerability:

⁵ Adapted from the USAID Interagency Gender Working Group “Gender and HIV” training module, available at www.igwg.org.

Facilitator's Information

Women are biologically vulnerable:

- As a receptive partner, women have a larger mucosal surface exposed during sexual intercourse.
- Semen has a far higher concentration of HIV than does vaginal fluid.
- Women run a greater risk of acquiring HIV, more so if intercourse takes place at an early age when the mucosal surface is still tender or when it is damaged as a result of rituals and practices such as infibulations, early marriage, rape, and so forth.

Men are also vulnerable to HIV due to gender norms:

- Ideas and attitudes about masculinity encourage men's involvement with several sexual partners and participation in risk-taking behaviors. Other ideas of masculinity such as drinking and/or drug use also put men at risk.
- Men generally do not seek health services as often as women and have fewer opportunities for provider-initiated HIV testing.
- Cultural practices such as polygamy and wife inheritance increase men's risk.
- Stigma and discrimination against men who have sex with men hinders promotion of safe sexual practices.

Women are epidemiologically vulnerable:

- Women tend to marry or have sex with older men who may have had more sexual partners and are more likely to be infected.
- Violence against women with intimate partners during war and in peace increases women's vulnerability.
- Women frequently require blood transfusions during childbirth and abortions, as the prevalence of anemia among pregnant women in developing countries is usually very high.

(UNIFEM, 2000)

4. Now, let's look at how HIV affects each sex differently according to gender roles. Conduct a discussion around the following questions:
- How does HIV *affect* women and girls? Think about all the roles that women played in the Human Faces exercise.
 - How does HIV *affect* men and boys? Think about all the family configurations and age groups.
 - What strikes you most about the differences in impact?
 - Any questions about what we have covered?

Facilitator's Information

Women

- Risk-taking and vulnerability to infection are increased
 - By norms that make it inappropriate for women to know about sexuality or suggest condom use;
 - The common link between substance abuse and the exchange of sex for drugs or money; and
 - By women's need, especially migrants and refugees, to resort to sex work.

- Women's inability to negotiate safe sex and question their partner's infidelity adds to their vulnerability.
- Where HIV is seen as a sign of sexual promiscuity, HIV-positive women often face greater stigmatization and rejection than men.

Men

- Risk and vulnerability are heightened by norms that make it hard for men to acknowledge gaps in their knowledge about sexuality; by the link between socializing and alcohol use; by the frequency of drug abuse, including by injection; and by predominantly male occupations (e.g., truck-driving and military enlistment) that involve mobility and family disruption.
- Men often tend to have more sex partners than women, including more extramarital partners, thereby increasing their and their partner's risk of contracting HIV.

(UNIFEM, 2000)

DAY 3

SESSION 6: HIV AND AIDS STATUS DISCLOSURE (2 HOURS AND 30 MINUTES)

Learning Objectives

At the end of this session, participants should be better able to:

- Define HIV status disclosure and learn about a process for disclosing HIV status
- Identify advantages and disadvantages of disclosing HIV status
- Explain the relationship between disclosure and HIV treatment adherence
- Explain barriers and challenges to disclosure
- Explain legal and ethical issues around disclosure

Preparation

- Write definition of disclosure and disclosure process on a flipchart
- Photocopy Annex G

Materials

- Flipchart
- Markers
- Handout on disclosure (Annex G)

❖ Activity 1: Defining HIV Serostatus Disclosure (30 minutes)

1. Stress with participants that the session is meant to help people, particularly PLHIV, to think through the process of disclosing their HIV status, so as to receive appropriate care and support and to improve adherence for those already taking HIV treatment.
2. Ask participants to define what they understand by the term disclosure. Write all suggestions on a flipchart and use the responses to generate discussion on the meaning of the concept of disclosure, along with the process involved in disclosing. Participants should be able to differentiate between disclosure and going public.
3. Use the following information to discuss the concept of disclosure and the process involved in disclosing:

Facilitator's Information

Definition of Disclosure (UNAIDS and WHO, 2000):

The act of revealing HIV status to somebody else—a group or an individual. Disclosure of HIV serostatus is a difficult and emotional task that requires preparation and support. In the context

of HIV and AIDS , WHO and UNAIDS encourage beneficial disclosure, which is disclosure that is voluntary, respects autonomy and dignity of the affected individuals and family, leads to greater openness in the community about HIV, and meets ethical requirements to maximize good for the infected and affected.

To encourage beneficial disclosure, it is essential to create an environment in which people are willing and able to be tested for HIV and empowered and encouraged to change their behavior.

Lack of disclosure often lies with denial and stigma and discrimination around HIV and AIDS.

4. Ask one participant who has successfully disclosed his or her status to discuss the process of disclosing. Remind participants that disclosure is a voluntary process and that it is vital to ask the following questions before disclosing:
 - Whom do I want to tell? Why do I want to disclose to those individuals?
 - How much information do I want to reveal?
 - How will disclosing my status affect me and the people around me?
 - Where do I want to disclose and when? (It is important to disclose where support is readily available.)
 - Am I fully prepared and ready to disclose?
 5. Mention that disclosure is an important public health practice.
 - Disclosure may motivate sexual partners to seek testing, change behavior, and ultimately decrease transmission of HIV. For example, women who disclose are likely to participate in a PMTCT program.
 - Disclosure may lead to accessing various support services, including treatment.
- Use the following notes on the steps and process of disclosing to fill in the experience discussed by participants (write the notes on a flipchart as you talk about them, or prepare a flipchart in advance to use as a speaking aid):
- There is a useful framework to describe the decision-making process for disclosure in six steps (Kimberly, 1995 in Maman and Medley, 2004):
 - **Step 1—Adjustment to the diagnosis.** Individuals may need help adjusting to the new diagnosis and accepting the status.
 - **Step 2—Review personal disclosure skills.** Individuals need to evaluate whether they have the relevant skills to tell others.
 - **Step 3—Check the appropriateness or need to disclose to a potential recipient.** Support the individual in deciding whom to tell, how, where, and when.
 - **Step 4—Evaluate the circumstances for disclosure.** Certain circumstances may prohibit disclosure to certain individuals, e.g., workmates or colleagues.
 - **Step 5—Anticipate the reactions of potential recipients.** Support individuals as they deal with any reaction against the anticipated benefits of disclosure.
 - **Step 6—Help individuals identify their motive for disclosure to each recipient.**
6. Inform participants that several factors influence the decision to disclose, such as:
 - Individuals' psychological state
 - Personal communication skills and pattern
 - Anticipated reaction and individuals' motivation for disclosure.
 7. Distribute Annex G to participants as a wrap-up.

❖ **Activity 2: Advantages and Disadvantages of HIV Serostatus Disclosure (30 minutes)**

1. Reflect on the experiences shared by those who have disclosed their status. Emphasize that disclosure can be beneficial but, at the same time, traumatic and stressful if not well managed. It is important to be prepared for any possibility. While family members may show love and support, others may not be as accepting. It is important to have someone to support you during and after the difficult process of disclosing.
2. Remind participants that disclosure can also affect those around the person disclosing and that these people also need support in dealing with the information. Family members may face (or feel) higher levels of stigma and discrimination than the person who has disclosed. Children should be supported in dealing with the effect of disclosure of a person close to them.
3. Ask participants to break into groups of three. Ask the groups to list the advantages and disadvantages of disclosure. Guide participants in discussing their findings Use the information in the table below to inform and complement the discussion:

ADVANTAGES	DISADVANTAGES
<ul style="list-style-type: none"> • Reduced anxiety about transmission of HIV, making sexual contact comfortable and relaxed • Increased opportunity for important social support from family • Improved quality of support to the person disclosing • Increased self-esteem and reduced level of depression • Can lead to support that facilitates initiation of and adherence to HIV treatment • Prevention of HIV transmission and increased social support for PLHIV • Opportunities to plan for the future carefully and thoughtfully 	<ul style="list-style-type: none"> • Possible complication of personal matters • Timing—if done relatively early, potential disruption of relationships and family stability • Possible rejection, stigma and discrimination, and violence, especially for women • Disclosure to certain people possibly burdensome, e.g., disclosing at the workplace can result in job loss • Possible loss of economic support, blame, abandonment, physical and emotional abuse, and disruption of family relationships • Children may face violence or abandonment as a result of parental disclosure <p>(WHO, 2004; Maman and Medley, 2004)</p>

4. Help participants appreciate that, for women, the individual benefits of sharing HIV status with a partner should be weighed carefully against potential risks.

❖ **Activity 3: Disclosure of HIV Serostatus and Gender (30 minutes)**

1. Divide participants into groups of five and ask them to brainstorm how the benefits and risks associated with disclosure differ for men and women. Ask participants to make separate lists for men and women under the headings of benefits and risk.

2. Ask groups to designate one person from each group to present the group findings to all participants. Below are some of the issues to be considered.
3. Summarize the presentations and add what is missing, focusing on gender issues and allowing for a few minutes (5 minutes) of discussion on gender.

Facilitator's Information

Gendered Dimensions of Disclosure

- Women often disclose to several categories of people.
- Thirteen of 14 studies conducted in developing countries with women reported that fear of abandonment and loss of economic support posed major barriers to disclosing HIV status to sexual partners.
- Fear of violence and/or divorce prevents many women from disclosing positive status.
- HIV-infected women with a serodiscordant sexual partner may be at increased risk for violence following disclosure.
- For men who have sex with men, disclosure is both a source of stress and a source of social support.
- HIV-infected women fear accusations of infidelity and conflict within the family as a result of disclosure.

(Maman and Medley, 2004; Medley et al., 2004)

❖ Activity 4: Disclosure and Adherence (30 minutes)

1. In the same five-person groups as above, ask each group to discuss how disclosure may affect adherence.
2. Inform participants that several studies (Stirrat et al., 2006; Mills et al., 2006) have shown that PLHIV who disclose their status to others often enhance their ability to adhere to HIV treatment. Interventions to improve ART adherence should address the role of serostatus disclosure by developing skills in how to maintain adherence in contexts of non-disclosure and how to make informed choices regarding selective disclosure.
3. Ask each group to present its findings. Support participants in their discussions of outcomes.

❖ Activity 5: Legal and Ethical Issues and Disclosure (30 minutes)

1. Explain to participants that disclosure involves some legal and ethical issues that must be observed and addressed as part of the process of disclosing.
2. Ask participants to brainstorm about legal and ethical issues; record on a flipchart.
3. Review participants' responses in light of the information in the table below, ensuring that all information is covered.

Legal Issues	Ethical Issues
<ul style="list-style-type: none"> • Laws requiring people to disclose HIV status, especially to sexual partners or those sharing injecting needles • Laws making it a crime for a person to engage in certain high-risk behaviors without disclosing HIV status • Awareness that HIV status may not be accurate, especially if testing occurs during the acute stage of HIV infection (window period, during which a person is highly infectious even though tests reveal negative anti-body results) • No policies on disclosure for people providing support services; counselors, clinicians, and programs need to be sensitive to the complexity of disclosure • Understanding that disclosure is not for all people in all contexts 	<ul style="list-style-type: none"> • Who, where, how, and when to disclose • Confidentiality of disclosed information • Shared confidentiality • Belief that there is no need for disclosure if one engages in protected sex • Encouraging disclosure further stigmatizes HIV-positive persons • People may use disclosure as a way to limit their partners only to persons of the same serostatus (HIV-positive or HIV-negative, know as sero-sorting) <ul style="list-style-type: none"> ○ Success of sero-sorting as a preventive strategy depends on honest and accurate disclosure on the part of any two sexual partners <p>(University of California San Francisco, 2007)</p>

SESSION 7: GENDER AND ADHERENCE TO HIV TREATMENT (4 HOURS)

Learning Objectives

At the end of this session, participants should be better able to

- Describe the importance of adherence and the consequences of non-adherence;
- Identify how gender affects HIV treatment adherence; and
- Discuss strategies to promote adherence success.

Preparation

- Write definitions of adherence on flipchart
- Photocopy handouts—Annexes H through J

Materials

- Flipchart
- Markers
- Handout: He Has HIV/She Has HIV (Annex H)
- Handout: Gender and Adherence Issues (Annex I)
- Handout: Becoming a Treatment Buddy to a Woman/Man on ART (Annex J)

❖ **Activity 1: Gender Issues Related to HIV Treatment (2 hours)**

1. Divide participants into three or four groups and distribute He Has HIV/She Has HIV (Annex H).⁶ Assign each group one of the rows on the handout and ask it to read the paper and enact a role play depicting the scenario presented. Encourage groups to use the given scenarios as a guide, and use their own experiences/imaginings in developing the role plays. They will have 20 minutes to plan their performance.
2. Ask each group to perform its role play before all participants.
3. Following the role plays, sum up the areas participants identified as examples of gender-based discrimination related to adherence to HIV treatment. Ask participants if they can think of other examples.

❖ **Activity 2: Exploring/Identifying Gender Issues Related to Adherence (1 hour)**

1. Discuss how gender relates to HIV treatment adherence.
2. Explain that the Health Policy Initiative undertook an initial assessment by meeting with PLHIV networks in Dar es Salaam to ask them about gender issues related to HIV treatment adherence. Distribute the Gender and Adherence Issues (Annex I). On separate flipcharts (one for men and one for women), present the following list of issues that came out of the assessment:

Women

- Women who are HIV positive may be perceived as sex workers.
- Women may not disclose to partners out of fear of abandonment or violence.
- Women lack financial resources to travel to clinics, especially in rural areas. The number of service delivery sites is inadequate to meet the needs of rural women.
- Women often need to request money (for transportation or other costs) or support from their partner to seek treatment. When male partners are not supportive, they may flush medications down the toilet.
- Women face serious financial constraints to nutrition because many have been divorced/abandoned upon disclosing their positive status. Some women stop taking ARVs because they have no food to eat with their medication; they return the ARVs to the clinic saying they can't take them without food.
- Women often discover their HIV status through PMTCT programs. There is little follow-up with women on HIV treatment once they return home; they often do not have the resources to return to health facilities, and they must care for a newborn.
- Women may adhere to HIV treatment better than men because of greater concern for their health, better access to healthcare (in comparison with men), and the desire to take care of the family.

Men

- Men who are HIV positive are perceived as weak for carrying a women's disease.
- Men may not disclose because they do not want to change their lifestyle.

⁶ Adapted from UNIFEM's *Gender, HIV, and Human Rights: A Training Manual*, available at http://www.unifem.org/materials/item_detail.php?ProductID=5.

- Men are often reluctant to leave work to get treatment out of fear of losing their job or income, which is associated with men's roles as providers and with masculinity; the need to take medication is associated with weakness. Men may not want to take treatment at work for fear of disclosure. Conversely, men may prefer to take treatment at work to keep their partners or families from discovering their status.
 - Men are often reluctant to seek HIV testing. In some cases, men share their partner's medication without knowing their own status. Some men force their female partner to share her ARVs, compromising her ability to adhere properly to the regimen; as a result, neither partner takes a full dose.
 - Men's responsibility to the family is often equated with providing financial support rather than taking care of their health.
3. Ask participants if they have any other issues to be added to the list; write them on the appropriate flipcharts. The following issues could be included:
 - HIV-affected women are more likely to suffer from depression than men, and depression can affect their ability to adhere to their treatment regime.
 - Men's and women's use of drugs and alcohol can affect their ability to adhere.
 - Medication side effect can include pain, numbness, tingling, fevers, rashes, nausea, vomiting, and pain while urinating. Women are usually less tolerant of side effects than men.
 - Men may have more economic, social, and educational resources and, as a result, may be more likely to adhere.
 4. Ask all participants to rank the issues separately for men and women, with each issue's ranking written next to the issue. Compare differences and similarities in the rankings for men and women.
 5. Wrap up with observations and discussions on the exercise. Do women and men face different or similar barriers to adherence?

❖ **Activity 3: Overcoming the Problems (1 hour)**

1. Begin discussing how to overcome the gender issues raised in the previous activity.
2. Refer to the rankings and ask participants to group the issues based on the easiest to change and the most difficult to change.
3. Next, discuss who can make change happen, such as individuals, institutions, community members, etc.; be as specific as possible.
4. Ask participants what are the most realistic short-, medium-, and long-term goals? Write the goals along an axis that represents the timeframe for the various goals. Ask participants to agree on where they can take action in relation to their role as community educators or peer counselors, etc. Discuss options for what they can do, such as becoming a treatment buddy and/or helping others with disclosure (evidence shows that those who disclose their status are more likely to adhere to treatment) [distribute Annex J]. Finally, what is the role of healthcare providers?

DAY 4

SESSION 8: WORKPLAN AND CLOSING (3 HOURS)

Learning Objectives

At the end of the session, participants should be better able to:

- Prioritize activities that they can implement on their own at the community level
- Develop a three-month workplan for implementation

Preparation

- List of strategies for overcoming the problem generated in Session 7, Activity 3
- Photocopy Annex K

Materials

- Flipchart
- Markers
- Handout: Workplan framework (Annex K)
- Handout: Post-assessment (Annex B)
- Handout: Evaluation (Annex L)

❖ **Activity 1: Prioritizing Strategies for Overcoming the Problem (75 minutes)**

1. Ask participants to form groups based on where they come from—districts, wards, and so forth. Once participants are settled in groups, provide each group with a list of strategies it generated the previous day. Ask each group to study the list and to prioritize the interventions that it is able to implement on its own when group members return home.
2. Ensure that each group prioritizes at least three intervention strategies. Ask each group to generate related activities for each strategy, such as supporting PLHIV in adhering to treatment.
3. Circulate among the groups to ensure they generate practical interventions that are implementable by individuals and community members with limited resources.
4. Once activities are clear and group members are in agreement, provide all groups with a flipchart and instruct them to draw the workplan template by using the following headings: Issue, Activity, By whom, When, and Resources needed.
5. Allow each group to fit in its activities against the identified strategies or issues.

❖ **Activity 2: Presentation of Group Workplans and Discussion (75 minutes)**

1. Ask each group to present its workplan while the others listen and make comments on proposed interventions.
2. Allow each group time after all the presentations to amend its workplan based on the feedback from all participants.
3. Inform participants that their progress on implementing the proposed activities will be monitored after the second month and that they will be required to make reports based on challenges and achievements in implementing gender and adherence activities.

❖ **Activity 3: Evaluation and Closing (30 minutes)**

1. Ask participants if they have final questions or comments. Ask them what key points they learned from the workshop and generate responses.
2. Make final remarks and ask participants to complete the workshop evaluation (Annex L) and post-training assessment (Annex B) before they leave. Distribute the evaluations and collect them as participants leave.
3. Thank participants for their enthusiasm, energy, and participation.

ANNEX A: SAMPLE WORKSHOP AGENDA

Day 1	Time
Session 1: Workshop Introduction	8.30am–9.15am
Session 2: Exploring HIV and AIDS	9.15am–10.15am
Tea Break	10.15am–10.45am
Session 2 (continued)	10.45am–12.45pm
Lunch	12.45pm–1.45pm
Session 3: HIV Treatment and Adherence	1.45pm–3.15pm
Tea Break	3.15pm–3.45pm
Session 3 (continued)	3.45pm–5.45pm

Day 2	Time
Session 4: Introduction to Gender and Health	9.00am–10.30am
Tea Break	10.30am–11.00am
Session 4 (continued)	11.00am–12.00pm
Lunch	12.00pm–1.00pm
Session 5: Gender and HIV	1.00pm–3.00pm
Tea Break	3.00pm–3.30pm
Session 5 (continued)	3.30pm–3.45pm
Session 6: HIV and AIDS Status Disclosure	3.45pm–4.45pm

Day 3	Time
Session 6 (continued)	9.00am–10.30am
Tea Break	10.30am–11.00am
Session 7: Gender and Adherence to HIV Treatment	11.00am–12.30pm
Lunch	12.30pm–1.30pm
Session 7 (continued)	1.30pm–3.00pm
Tea Break	3.00pm–3.30pm
Session 7 (continued)	3.30pm–4.30pm

Day 4	Time
Session 8: Workplan and Closing	9.00am–10.00am
Tea Break	10.00am–10.30am
Session 8 (continued)	10.30am–12.30pm

ANNEX B: PRE- AND POST-TRAINING ASSESSMENT

True or False

1. _____ Gender and sex have the same meaning.
2. _____ Everyone who is HIV positive should be on ART.
3. _____ Adherence means taking your drugs exactly as they are prescribed.
4. _____ If I am taking ARVs, I do not need to practice safe sex.
5. _____ Women and men face exactly the same stigma for being HIV positive.
6. _____ Women and men have different reasons for not adhering to HIV treatment.
7. _____ HIV drugs will work only if you keep a constant minimum level of each drug in your body at all times.
8. _____ I should take my HIV medication at the same time every day.
9. _____ Women find it easier to adhere to HIV treatment than men.
10. _____ There is nothing I can do to help my friends and family adhere to HIV treatment.

ANNEX C: GLOSSARY⁷

Adherence—With ART, adherence involves taking medications in the correct amount, at the correct time, and in the way they are prescribed.

AIDS—Acquired Immunodeficiency Syndrome. AIDS is the name given to a group of serious illnesses in HIV-positive people. AIDS develops when PLHIV are no longer able to fight off infections because of lowered immunity.

Antibodies—Special proteins produced by the body in response to an infection. HIV antibodies are specific proteins produced to show that the body has reacted to HIV infection.

Antiretroviral (ARV) medicines—Medicines that interfere with or disturb the life cycle of HIV by slowing or stopping the processes by which HIV makes copies of itself and increases in the body.

Antiretroviral treatment—The process of taking the ARV medicines that fight HIV.

Asymptomatic—A stage of a disease during which you show no signs of the disease and do not feel sick. It may be referred to as the “latent phase.”

CD4 cell count—A blood test to tell how well the immune system is doing by determining the number of CD4 cells in your body.

CD4 cells—A CD4 cell is a type of cell (lymphocyte) in the body that plays an important part in helping your immune system stay strong and fight infection-causing diseases. CD4 cells are killed by HIV at a very fast rate.

Disclosure

Full disclosure—A person publicly reveals his or her HIV status to a person or organization, for example, a family member, friend, support group, or the media. Before clients disclose their HIV status, a counselor can assist in exploring whom to tell, how, and when. In this way, clients remain in control of what to say and how to say it.

Involuntary disclosure—A person reveals someone’s HIV status without the latter’s approval or knowledge. Involuntary disclosure can also occur when a person is forced to reveal his or her HIV status for workplace or international travel requirements.

Non-disclosure—A person does not reveal his or her HIV status to anyone.

Partial disclosure—A person tells only tell certain people about his or her HIV status, for example, a spouse, relative, counselor, or friend. Before disclosure, counselors need to assist clients in thinking carefully about and preparing them for the range of possible outcomes. PLHIV may not be able to control what happens once they have disclosed their status. Most cases of involuntary disclosure arise from situations where clients decide on partial disclosure of their status without knowledge that the information is made public by an individual or organization.

⁷ Adapted from SAfAIDS, 2005.

Voluntary disclosure— A person shares information about his or her HIV status with other people. Disclosure may be partial or full (see above). A counselor should help the client identify the possible impacts of his or her decision.

Discrimination—A term used to describe unfair or different treatment because of a person’s HIV-positive status.

First-line treatment or regimen—The first set of ARV drugs given as part of ART. Usually, the set is a combination of three antiretroviral medicines aimed at increasing CD4 counts and decreasing viral load while preventing resistance.

Highly Active Antiretroviral Therapy (HAART)—A combination of three antiretroviral medicines used to fight HIV and AIDS.

HIV—Human Immunodeficiency Virus, a virus that weakens the human immune system.

Immune system—A combination of the different parts of our body—chemicals, cells, tissues, and organs that protect the body from germs. The immune system can tell the difference between what does and does not belong to the body. It is sometimes called the body’s defense system. When your immune system is strong, you are able to fight foreign bodies that enter your body and avoid illness. HIV makes our immune system weak. If you are infected with HIV, over time you begin to get sick more often and for longer periods.

Informed consent—The basis of voluntary counseling and testing, whereby the decision to take an HIV test is made entirely by the individual to be tested.

Life cycle—The different times in a person’s life. People at different stages in the life cycle have different needs, concerns, and ways of coping with problems.

Non-adherence—The failure or inability of PLHIV to stick to their ARV regimen.

Opportunistic infections (OI) —Diseases caused by bacteria, fungi, or viruses that take advantage of the weakened immune system in people infected with HIV.

Parent to Child Transmission (PTCT) —Transmission occurs when HIV-positive parents pass HIV to their baby during pregnancy, at birth, or after delivery. Because the virus comes directly from the mother, transmission is also called mother-to-child transmission (MTCT) or vertical transmission. It is now called PTCT because we know that a baby’s HIV status is the responsibility of both parents.

Pill burden—ART regimens that involve many doses of pills each day with specific food and fluid intake instructions. High pill burden is associated with decreased levels of adherence.

Pill count—A method for measuring adherence to ART that involves counting the number of pills taken and comparing that number against how many pills should be taken for 100 percent adherence.

Positive living—Steps taken by people living with HIV or AIDS to enhance their lives and improve their health.

Provider-initiated testing and counseling (PITC)—HIV testing and counseling that occurs within health facilities (i.e., antenatal care centers, tuberculosis clinics, and outpatient clinics) and is recommended by a provider as a standard component of medical care. PITC enables specific clinical

decisions and/or medical services to be offered that would not be possible without knowledge of a person's HIV status.

Resistance—The ability of HIV to change its structure so that ARV medicines become less effective. The fewer antiretroviral medicines a person takes, the greater is the chance that HIV will have not the opportunity to change. Resistance is the reason why ARVs are usually prescribed as a combination of three medicines.

Safer sex—Sexual practices that prevent possible contact with and mixing of infected sex fluids. Practices include intercourse using a female or male condom, oral sex, non-penetrative sex, and mutual masturbation.

Second-line treatment regimen—A second line of ARV medications given to individuals who have developed resistance to first-line ARV regimens or have experienced treatment failure.

Sero conversion—The time after the window period when a person's body begins to make antibodies to fight HIV.

Shared confidentiality—Sharing certain information with people chosen by the patient.

Stigma—Negative attitudes toward people who are HIV positive, who belong to a particular group, or who have different characteristics than others.

Support network—People in your life whom you can talk to openly and honestly about things that trouble you. A support network often includes people whom you feel understand you and what you are facing.

Syndrome—A collection of signs and symptoms that together give a picture of a particular disease or abnormal health condition.

Treatment failure—The failure of ARV medicines to continue preventing opportunistic infections and/or to improve CD4 levels. Treatment failure requires a change in ARV regimen.

Viral load—The amount of HIV in the blood.

Virological failure—The inability of ARV medicines to keep the viral load suppressed in PLHIV. Virological failure is associated with poor adherence.

Voluntary counseling and testing (VCT) [also referred to as client-initiated testing and counseling]—Testing and counseling that involves individuals actively seeking HIV testing and pre- and post-test counseling that includes a risk assessment, risk reduction management, and linkages to care, treatment, and prevention interventions as required. Client-initiated testing and counseling occurs in a range of settings, including health facilities, mobile units, door-to-door interventions, and workplaces.

Window period—Time from infection with HIV until the body is able to make antibodies to fight HIV. The window period lasts approximately 6 to 12 weeks. A person may test negative for HIV during this time.

ANNEX D: GENDER DEFINITIONS AND TERMS⁸

Sex refers to the biological differences between males and females. Sex differences are concerned with male and female physiology.

Gender refers to the economic, social, political, and cultural attributes and constraints and opportunities associated with being a woman or a man. The social definitions of what it means to be a woman or a man vary among cultures and change over time. Gender is a sociocultural expression of particular characteristics and roles that are associated with certain groups of people with reference to their sex and sexuality.

Gender equality is the state or condition that affords women and men equal enjoyment of human rights, socially valued goods, opportunities, and resources.

Women’s empowerment means improving the status of women to enhance their decision-making capacity at all levels, especially as related to their sexuality and reproductive health.

⁸ Adapted from the USAID Interagency Gender Working Group “Gender and Reproductive Health 101” training module, available at www.igwg.org.

ANNEX E: HUMAN FACES OF HIV/AIDS⁹

Cut these names into strips and distribute to participants as needed.

Mother

Girl Child in Family

Father

Teen Son of a Single Mother

Wife

Orphaned Female Teen with Siblings

Husband

Adult Woman in Extended Family

Man Having Sex with Men

Young Teen Daughter of a Single Mother

Young Single Male

⁹ Adapted from the USAID Interagency Gender Working Group “Gender and HIV” training module, available at www.igwg.org.

Woman Having Sex with Women

Mother-in-Law

Male Sex Worker

Young Single Female

Single Mother

Grandfather

Orphaned Male Teen with Siblings

Grandmother

Female Sex Worker

Boy Child in Family

ANNEX F: HUMAN FACES QUESTIONS¹⁰

Learning about HIV/AIDS

1. Where do you get your information about HIV/AIDS?
2. What misconceptions might you have?
3. Whom do you feel comfortable asking about HIV/AIDS, inside or outside the family?

Fears about HIV/AIDS

4. What are your greatest personal fears about HIV/AIDS?
5. How vulnerable do you think you are? Why?
6. When you think about HIV/AIDS in your family or community, what are you most afraid of?

Consequences of HIV/AIDS

7. If you get HIV/AIDS, how will that affect your role and responsibilities? How would your life change?
8. How would it affect your housing, your access to food, your economic situation? Your daily life? How you spend your daily hours?
9. If someone in your family gets HIV/AIDS, how will that affect your role and responsibilities?
10. How would your life change? How would it affect your housing, your access to food, your economic situation? Your daily life? How you spend your daily hours?

¹⁰ Adapted from the USAID Interagency Gender Working Group “Gender and HIV” training module, available at www.igwg.org.

ANNEX G: DISCLOSURE OF HIV SEROSTATUS

You will need someone or some people within your circle of friends or family to support and encourage you. It is therefore important for you to tell someone—a family member or a friend—about your HIV status as well as the treatment you are receiving. Telling someone about your status is called “disclosing.” To ensure appropriate and adequate support from family members and caregivers, you need to disclose your status to people you trust.

Why do you need to disclose your status?

- Disclosure can help you accept your status and reduce the stress of coping on your own. “A problem shared can be a problem halved.”
- After you have disclosed your status, you will no longer need to hide the fact that you are taking ARVs. You will be better able to adhere to your treatment.
- Disclosure can help you protect yourself and others when, for example, negotiating for sex.
- Once you have disclosed, you may influence others to avoid infection.
- People may accept your HIV status, particularly if you are showing symptoms of AIDS. Disclosure can put an end to rumors.

As more people disclose their HIV status, they will help reduce the stigma, discrimination, and denial associated with HIV and AIDS, decreasing the transmission of new infections in your community.

ANNEX H: HE HAS HIV/SHE HAS HIV¹¹

Scenario	He Has HIV	She Has HIV
You tell your spouse that you are starting ARVs	You should not fall sick. I will be by your side. I will do what I can to help you take your medication.	If you have HIV, you must have given me HIV. I do not want to go to the clinic to find out. I will take your medication, too.
Your family finds ARVs in the home	You have brought us shame. It is better that we keep the family's honor by dissociating ourselves from you. Please leave the house. Take your wife and children with you.	We did not know that we were sheltering a whore in this household. Leave the children here and before the sun rises tomorrow we do not want to see you here.
The community sees you going to the clinic	It is unfortunate that this has happened to him. After all, men will be men. They do go around sometimes, but such misfortune does not strike everybody. It is his destiny. In any case, a bull is not a bull without scars.	The kind of activities she has indulged in, she has got away lightly by just being thrown out. In our times, she would have been branded so as to be a lesson for other girls to keep away from base activities.
You ask your employer for time off to pick up medication at the clinic	Why should I give you time off to do something personal? Where do you need to go? Maybe I should just ask someone else to come and do your job!	Before learning their HIV status, none of the women had held jobs. After they were kicked out of their homes, the women looked for work with little success. There is a deep fear of rejection.
The clinic tells you to adhere strictly to nutritional guidelines	My family has used all our savings so I must seek work to pay for medication. I am even eating less and giving the children less food so my husband can eat well with his medication.	I don't know how I can eat properly with my medication...I'm not sure I can even continue taking the medication, as I must find a new home for my family.

¹¹ Adapted from UNIFEM's *Gender, HIV, and Human Rights: A Training Manual*, available at http://www.unifem.org/materials/item_detail.php?ProductID=5.

ANNEX I: GENDER ISSUES RELATED TO ADHERENCE

Women

- HIV-positive women may be perceived as sex workers.
- Women may not disclose their status to partners out of fear of abandonment or violence.
- Women lack the financial resources needed to travel to clinics, especially in rural areas. The number of service delivery sites is inadequate to meet the needs of rural women.
- To seek treatment, women often must ask their partner for money (for transportation or other costs) or support. When male partners are not supportive, they may flush medications down the toilet.
- When women disclose their status, they often face divorce/abandonment and thus serious financial constraints to nutrition. Some women stop taking ARVs because they have no food to eat with their medication; they return the ARVs to the clinic, saying they can't take the medications without food.
- Women often discover their HIV status through PMTCT programs. However, the programs fail to follow up with women on HIV treatment once they return home, and the women often lack the resources to return to the health facilities and must care for a newborn.
- Given greater concern for their health, better access to healthcare, and the desire to take care of the family, women may adhere to HIV treatment better than men.

Men

- HIV-positive men are perceived as weak for carrying a woman's disease.
- Men may not disclose their status because they do not want to change their lifestyle.
- Men are often reluctant to leave work to get treatment for fear of losing their job or income, which is associated with men's roles as providers. Men associate the need for medication with weakness. In addition, men may refuse to take treatment at work for fear of disclosure. Conversely, men may prefer to take treatment at work to keep their partners or families from discovering their status.
- Men are often reluctant to seek HIV testing. In some cases, men share their partner's medication without knowing their own status. Some men force a female partner to share her ARVs, compromising her ability to adhere to the regimen; as a result, neither takes the prescribed dose.
- Men's responsibility to the family is often equated with providing financial support rather than taking care of their own health.

ANNEX J: BECOMING A TREATMENT BUDDY TO A WOMAN/MAN ON ART¹²

Who can be a buddy?

A buddy is anyone who is willing to be a source of support and feels that he or she has information and experiences worth sharing. You may or may not be HIV positive. You may or may not be on ART. At times, women on ART appreciate hearing about the experiences of other women on ART. They look for practical solutions to potential problems with ART and are interested in learning how others coped or dealt with a problem. The buddy has to identify as much as possible with the person he or she is supporting in terms of the same social class, same language, and same cultural sensitivities.

To be an effective buddy, you may need some training so that you can provide total support. As a buddy, you will mainly offer moral support and therefore need appropriate knowledge and skills and a good attitude.

Knowledge

Knowledge is an understanding of information and ideas. An ART buddy should be familiar with most of the following issues:

- Alcohol abuse
- Sex
- HIV and AIDS
- Positive living
- ARV medicines
- Opportunistic infections
- Nutrition
- Violence
- Suicide

Skills

A skill is knowing how to do something well. A good buddy should have the following skills:

- Asking questions
- Listening
- Ensuring that people understand
- Planning, managing care, support, follow-up, and referral
- Training or teaching skills
- Counseling skills

Attitude

Attitude is how an individual views issues and others. A good buddy should have an attitude that shows:

- Compassion
- Respect
- Honesty
- Common sense
- Equality
- Positive and encouraging behavior
- Acceptance

¹² Adapted from SAfAIDS, 2005.

What does a buddy do?

- Shares own experiences
- Accompanies the person on ART to visit clinics
- Talks about life in general
- Goes for a walk—just spends time together
- Prays together
- Listens—allows the person on ART to talk while you listen
- Keeps secrets
- Knows where to get help—referrals
- You can think of many more ways to help

ANNEX K: WORKPLAN

ISSUE	ACTIVITY	ACTORS	TIME	RESOURCES

ANNEX L: EVALUATION

1. Were the workshop materials clear and easy to understand?
2. Please tell us what you found most useful in the workshop and why.
3. How will you use the knowledge and skills gained from the workshop?
4. How might we improve the workshop in the future?
5. Additional comments or suggestions:

REFERENCES

- Anderson, Jean R. ed. 2005. *A Guide to the Clinical Care of Women with HIV—2005 Edition*. Rockville, MD: U.S. Department of Health and Human Services, Health Resources and Services Administration, HIV/AIDS Bureau. Accessed online at <http://hab.hrsa.gov/publications/womencare05/>, June 3, 2010.
- AVERT. N.d.a “HIV Structure and Life Cycle.” Available online at: www.avert.org/hiv-virus.htm.
- AVERT. N.d.b “HIV Testing.” Available online at: <http://www.avert.org/testing.htm>.
- Cain Michael, Hans Damman, Robert Lue, and Carol Kaesuk Yoon. 2006. “Life Cycle of HIV, a Retrovirus.” *Discover Biology*. Second Edition. New York, New York: Sinauer Associates and W. W. Norton & Co. Available online at: <http://www.sumanasinc.com/webcontent/animations/content/lifecyclehiv.html>.
- Centers for Disease Control and Prevention. 2008. *TB and HIV/AIDS Factsheet*. Atlanta: Centers for Disease Control and Prevention. Available online at: <http://www.cdc.gov/hiv/resources/factsheets/hivtb.htm>.
- Family Health International (FHI)/Ghana. 2004. *Basic Facts about Antiretroviral Therapy (ART)*. Ghana: FHI.
- Global HIV Prevention Working Group. 2006. *Proven HIV Prevention Strategies: Factsheet*. Global HIV Prevention Working Group.
- Joint United Nations Programme on HIV/AIDS (UNAIDS) and WHO. 2000. *Opening Up the HIV/AIDS Epidemic, Guidance on Encouraging Beneficial Disclosure, Ethical Partner Counselling and Appropriate Use of HIV Case-reporting*. Geneva: UNAIDS.
- Kimberly, Judy, Julianne Serovich, and Kathryn Greene. 1995. “Disclosure of HIV-positive Status: Five Women’s Stories.” *Family Relations* 44: 316–323.
- Maman, Suzanne and Amy Medley. 2004. *Gender Dimensions of HIV Status Disclosure to Sexual Partners: Rates, Barriers, and Outcomes. A Review Paper*. Geneva: World Health Organization.
- Medical Women’s International Association. 2002. *Training Manual for Gender Mainstreaming in Health*. Medical Women’s International Association. Available online at: <http://www.fmwic.ca/docs/TrainingManualonGenderMainstreaminginHealth%5B1%5D.pdf>.
- Medley, Amy, Claudia Garcia-Moreno, Scott McGill, and Suzanne Maman. 2004. “Rates, Barriers, and Outcomes of HIV Serostatus Disclosure among Women in Developing Countries: Implications for Prevention of Mother-to-Child Transmission Programmes.” *Bulletin of the World Health Organization* 82 (4):299-307.
- Mills, Edward, Jean Nachega et al. 2006. “Adherence to Antiretroviral Therapy in sub-Saharan Africa and North America: A Meta-Analysis.” *Journal of the American Medication Association* 296 (6):679-690.
- Ministry of Health and Social Welfare, National AIDS Control Programme. 2008. HIV/AIDS in Tanzania. Available online at: http://www.nacp.go.tz/about_us/HIV_AIDS_in_Tanzania.php.

- NAM. 2010. *HIV Treatment*. Available online at: <http://www.aidsmap.com/page/1044497/>.
- NAM. N.d. *How Transmission Occurs*. Available online at: <http://www.aidsmap.com/page/1320672/>.
- Roura, Maria, Joanna Busza, Alison Wringe, Doris Mbata, Mark Urassa, and Basia Zaba. 2009. "Barriers to Sustaining Antiretroviral Treatment in Kisesa, Tanzania: A Follow-Up Study to Understand Attrition from the Antiretroviral Program." *AIDS Patient Care and STDs* 23 (3):1-8.
- Rwechungura, Lydia and Frank Kayitare. 2006. *Mapping of Experiences of Access to Care, Treatment, and Support—Tanzania*. London: International Community of Women Living with HIV/AIDS (ICW).
- Southern Africa HIV/AIDS Information Dissemination Service (SAfAIDS). 2005. *Women's Treatment Literacy Toolkit*. Harare, Zimbabwe: SAfAIDS.
- Stirrat, Michael J. et al. 2006. "The Role of HIV Serostatus Disclosure in Antiretroviral Medication Adherence." *AIDS and Behavior* 10 (5):483-493.
- Teasdale, Chloe and Mitchell Besser. 2008. "Enhancing PMTCT Programmes through Psychosocial Support and Empowerment of Women: The mothers2mothers Model of Care." *The Southern African Journal of HIV Medicine* Summer 2008: 60–64.
- Treatment Action Campaign. 2006. *ARVs in Our Lives: A Handbook for People Living with HIV and Treatment Advocates in Support Groups, Clinics, and Communities*. South Africa: Treatment Action Campaign.
- United Nations Development Programme (UNDP). 2002. "Introductory Gender Analysis and Gender Planning Training Module for UNDP Staff." *Gender Training Kit*. New York: UNDP. Available online at: <http://www.undp.org/women/docs/GenderAnalysisTrainModule.pdf>.
- United Nations Fund for Women. 2000. *Gender, HIV, and Human Rights: A Training Manual*. New York: UNIFEM. Available online at: http://www.unifem.org/materials/item_detail.php?ProductID=5.
- United Republic of Tanzania Ministry of Health and Social Welfare. 2007. *Module 1: Participants Manual. Basic Training Course for Comprehensive Management of HIV/AIDS*. Dar es Salaam, Tanzania: United Republic of Tanzania Ministry of Health and Social Welfare.
- U.S. Department of Health and Human Services and Centers for Disease Control and Prevention. N.d. *Condoms and STDs: Fact Sheet for Public Health Personnel*. Available online at: <http://www.cdc.gov/condomeffectiveness/latex.htm>.
- University of California San Francisco. 2007. *How Does Disclosure Affect HIV Prevention?* San Francisco: University of California. Available online at: <http://www.caps.ucsf.edu/pubs/FS/disclosure.php>.
- USAID Interagency Gender Working Group (IGWG). "Gender and HIV" training module. Washington, DC: IGWG. Available online at <http://www.igwg.org>.
- USAID IGWG. "Gender and Reproductive Health 101" training module. Washington, DC: IGWG. Available online at <http://www.igwg.org>.

Watt, Melissa, Suzanne Maman, Jo Anne Earp, Eugenia Eng, Philip Setel, Carol Golin, and Mark Jacobson. 2009. “‘It’s All the Time in My Mind’: Facilitators of Adherence to Antiretroviral Therapy in a Tanzanian Setting.” *Social Science & Medicine* 68: 1793-1800.

World Health Organization (WHO). 2010. *Antiretroviral Therapy for HIV Infection in Adults and Adolescents: Recommendations for a Public Health Approach—2010 Revision*. Geneva: WHO.

WHO. 2009. *Rapid Advice: Revised WHO Principles and Recommendations on Infant Feeding in the Context of HIV*. Geneva: WHO.

WHO. 2007. *Guidance on Provider-initiated HIV Testing and Counselling in Health Facilities*. Geneva: WHO.

WHO. 2005b. *Online Q&A What is a health system?* Available online at:
<http://www.who.int/features/qa/28/en/index.html>.

WHO. 2005a. *Policy and Programming Guide for HIV/AIDS Prevention and Care among Injecting Drug Users*. Geneva: WHO.

WHO. 2004. *HIV Status Disclosure to Sexual Partners: Rates, Barriers, and Outcomes for Women. WHO Document Summary*. Geneva: WHO. Available online at:
http://www.who.int/gender/documents/en/VCTinformationsheet_%5B92%20KB%5D.pdf.

WHO. n.d. *Antiretroviral Therapy*. Available online at:
<http://www.who.int/hiv/topics/treatment/en/index.html>

WHO and Centers for Disease Control (CDC). 2005. *Guidelines for Assuring the Accuracy and Reliability of HIV Rapid Testing*. Geneva: WHO.

Health Policy Initiative, Task Order I
Futures Group
One Thomas Circle, NW, Suite 200
Washington, DC 20005 USA
Tel: (202) 775-9680
Fax: (202) 775-9694
Email: policyinfo@futuresgroup.com
<http://ghiqc.usaid.gov>
<http://www.healthpolicyinitiative.com>