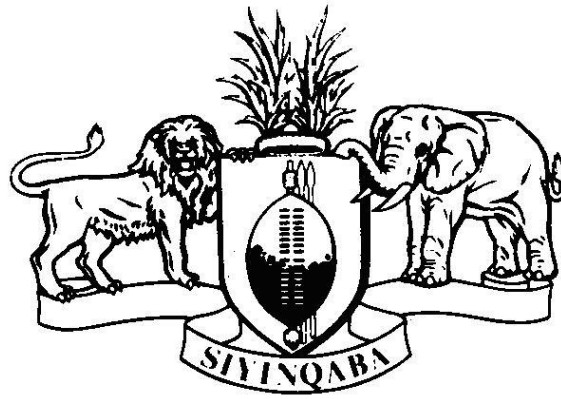


## Peer Education and Support in HIV/AIDS Prevention, Care, and Treatment

A Comprehensive Training Course  
for Expert Clients in the Kingdom of Swaziland





# PEER EDUCATION IN HIV/AIDS PREVENTION, CARE, & TREATMENT:

## A Comprehensive Training Course for Expert Clients in the Kingdom of Swaziland

### Trainer's Manual

Kingdom of Swaziland  
Ministry of Health and Social Welfare  
Swaziland National AIDS Program

August, 2007



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Dear Colleagues,

The Ministry of Health and Social Welfare, Swaziland National AIDS Program (SNAP), is pleased to support a new cadre of Expert Clients at care and treatment sites and primary health units throughout the country. We have confidence that Expert Clients will work successfully as part of multidisciplinary HIV care and treatment teams. We are looking to Expert Clients to improve the uptake of care and treatment and pMTCT-Plus services, as well as increase adherence to these services through the provision of supportive, ongoing counseling to patients and their families. The ultimate success of our efforts to roll out care and treatment throughout the country will be measured by long-term adherence to treatment and prevention of new HIV infections.

The design and implementation of the Expert Client Program was a collaborative effort and we would like to thank all of our partners who helped make the vision of the program into a reality across the country. We give our thanks to the International HIV/AIDS Care and Treatment Program (ICAP) of Columbia University in New York and in Swaziland for their work framing the program and developing the training curriculum and implementation plan in partnership with SNAP, the Swaziland National Network of People Living with HIV and AIDS (SWANNEPHA) and Clinton Foundation. ICAP also provided technical assistance to carry out the training of the first batch of 52 Expert Clients and we thank them for their ongoing efforts with the program. Thanks also go to SWANNEPHA for their review of this curriculum, support for Expert Client trainings, and provision of training facilitators. We would like to graciously thank the Clinton Foundation and SWANNEPHA for their financial support of the Expert Client Program, including funds for the National Expert Client Coordinator and monthly stipends for our Expert Clients. Finally, we would like to thank UNICEF for input in the curriculum development, and offer to support the development of job aides for Expert Clients.

We are counting on continued support from our partners, strong collaboration, and continuous evaluation to support Expert Clients and make the program a success.

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Sincerely,



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## ACRONYMS

ABC	Abacavir
AIDS	Acquired Immunodeficiency Syndrome
ANC	Antenatal Care
ART	Antiretroviral Therapy
ARV	Antiretroviral (drug)
AZT	Zidovudine
CHBC	Community Home-based Care
CTX	Cotrimoxazole
d4T	Stavudine
EC	Expert Client
EFV	Efavirenz
HBC	Home-based Care
HTC	HIV Testing and Counseling
HIV	Human Immunodeficiency Virus
ICAP	International Center for AIDS Care and Treatment Programs
LFT	Liver Function Test
LPV/r	Kaletra
LTFU	Lost to Follow-up
MOHSW	Ministry of Health and Social Welfare
MTCT	Mother-to-Child Transmission (of HIV)
NVP	Nevirapine
OI	Opportunistic Infection
PHU	Primary Health Unit
PLWHA	Person/People Living with HIV/AIDS
pMTCT	Prevention of Mother-to-Child Transmission
pMTCT-Plus	Prevention of Mother-to-Child Transmission, plus care, treatment, and follow up of the mother, the child and the whole family
SNAP	Swaziland National AIDS Programme
STI	Sexually Transmitted Infection
SWANNEPHA	Swaziland National Network of People Living with HIV and AIDS
TB	Tuberculosis
TDF	Tenofovir
3TC	Lamivudine

## INTRODUCTION

The Kingdom of Swaziland ranks among the countries most severely affected by HIV/AIDS, with about 33.4% of adults (aged 15-49) currently living with HIV/AIDS and a life expectancy that has plummeted to 39.4 years. In urban areas in the early 1990s, about 4.3% of women attending antenatal clinics tested positive for HIV. By 1996, a staggering 26.3% of pregnant women tested positive and by 2004, sentinel surveillance data revealed a further increase in the sero-prevalence among pregnant women to 39.2.<sup>1</sup>

### **Prevention of Mother-to-Child Transmission in Swaziland**

The Ministry of Health and Social Welfare (MOHSW) of the Kingdom of Swaziland is committed to providing equitable access to quality HIV/AIDS prevention, care, and treatment information and services throughout the country. A major focus nationally is the prevention of mother-to-child transmission (pMTCT) plus provision of ongoing care and treatment for mothers living with HIV/AIDS and their families (pMTCT-Plus).

Around the world, pMTCT programs started off with the goal to reduce transmission of HIV from mothers to their babies. For a long time, pMTCT programs did not focus on treatment of the mother's HIV or the baby's health after delivery. Based on experience over time, most programs agree that this is too narrow of a focus.

pMTCT-Plus programs include this same goal - to reduce the transmission of HIV from mothers living with HIV/AIDS to their babies - and also emphasize taking care of the mother in her own right, including enrollment in care and treatment programs, careful follow up of HIV-exposed babies, and ongoing support for the whole family. This is why we call it pMTCT-Plus - because the focus is on preventing HIV in the baby PLUS taking care of the mother, the baby, and the whole family over time. pMTCT-Plus programs also include HIV prevention as a key strategy to keep families and babies healthy.

### **The National HIV/AIDS Care and Treatment Program in Swaziland**

The MOHSW launched a national, free HIV/AIDS care and treatment program in 2004. Since then, thousands of people throughout the country, including pregnant women, have accessed care and treatment services, including antiretroviral therapy (ART). Despite national success enrolling patients in treatment, intense stigma, fear of disclosure, and lack of psychosocial and material support remain common, leaving many people without access to the services they need. Once initial barriers to receiving treatment are overcome, one of the biggest challenges is the need for patients to achieve near-perfect adherence to care and treatment for their entire lives. At the time of writing, there was no national tracking system in place for patients enrolled in ART and no formal mechanism to follow-up people lost to follow-up at most ART sites in the country. Adherence is an important part of HIV/AIDS treatment success. Adherence and psychosocial support, as part of a comprehensive care and treatment program, can help people live long, healthy lives, improve the health and well-being of affected families, help decrease stigma and discrimination, and prevent new infections, ultimately slowing the epidemic.

Adherence can be defined as:

*A patient's ability to follow a care and treatment plan in the long term, attend follow-up appointments as scheduled, take medications at prescribed times and frequencies, recognize side effects and seek treatment, and follow instructions regarding food and other medications.*

Proper education and counseling of patients in pMTCT-Plus and general care and treatment programs, particularly before and after the initiation of ART, is vital for adherence success. The engagement of people living with HIV/AIDS (PLWHA) as expert clients (EC) and the continuous involvement of community HIV/AIDS support groups can complement the work of health care providers and play an important role in ensuring access to effective and sustained care and treatment. Experience in Swaziland and from other countries shows that patients' adherence to care and treatment depends on patient preparation with the multidisciplinary care team and at home, counseling and "real life" strategies for adherence and disclosure, an uninterrupted drug supply, regular follow-up at the facility, community, and household levels, and ongoing clinical monitoring and evaluation of patients' conditions.

Human resources are a major challenge for Swaziland's national ART program. There is no national cadre of dedicated care and treatment counselors and facility staff workload is very high. As a major national focus of the MOHSW is pMTCT and provision of care and treatment for mothers, emphasis needs to be placed on ensuring that pregnant women understand pMTCT-Plus and access the services they need to keep themselves, their babies, and their families healthy. Furthermore, a more reliable system to track patients lost to follow-up (LTFU) must be developed and stronger linkages between community- and facility-based HIV/AIDS programs created to ensure a continuum of care and support. To address some of these needs, the MOHSW is creating a national cadre of expert clients, that that will bring new perspectives to prevention, care, and treatment programs.

#### **Peer Education to Increase Access and Adherence to Care and Treatment:**

Peer education, including counseling by expert clients, provides a viable solution to some of the challenges mentioned above.

- Expert clients are a great potential source of practical and psychological support for other patients living with HIV/AIDS, who will probably feel more comfortable sharing feelings, concerns, experiences, and problems with other people who face similar situations.
- Expert clients can help maximize adherence to care (e.g., attending appointments, going to the clinic for tests, following and understanding care instructions, etc.) and can help facility staff follow-up with patients who miss appointments.
- Expert clients can improve treatment literacy among patients by explaining different aspects of treatment in common ways that are easily understood.
- Expert clients can work within the multidisciplinary care team to prioritize pregnant women for care and treatment services by helping overcome myths about treatment during pregnancy and encouraging women to protect themselves and their babies by enrolling in care and treatment.

- Expert clients can help maximize adherence to medications, especially ART, by providing counseling and problem solving for real life challenges to adherence.
- Expert clients can build on their own experience and serve as role models to encourage “positive living” and healthy behaviors among patients, including secondary prevention of HIV.
- Expert clients can undoubtedly serve as effective recruiters for new patients into the program and lighten the workload for clinical staff in terms of counseling, education, preparation for ART, adherence monitoring, and patient tracking. Expert clients can also add an empathetic point of view to the multidisciplinary care team.
- Expert clients can help patients navigate services at health facilities and strengthen between these services, such as between pMTCT, antenatal care (ANC), and care and treatment services.
- Since expert clients come from the communities served by the hospitals and clinics, they can provide a vital link to community-based services, such as nutrition support and home-based care.
- Expert client programs can create positive changes in the lives of the expert clients themselves, help to decrease stigma and discrimination in the community, and encourage community members to access HIV/AIDS services.

### **About this Training Course**

This comprehensive training course was designed to train expert clients working in clinic- and hospital-based pMTCT-Plus, and care and treatment sites in Swaziland. It can also be adapted and used to train other types of lay counselors and peer educators working with PLWHA at the facility, community, and household levels.

**The purpose of this training course** is to empower and ensure greater involvement of people living with HIV/AIDS as active implementers in prevention, care, and treatment programs. The addition of expert clients to multidisciplinary care teams can contribute to increased uptake of care and treatment services, and improved treatment literacy, adherence, and quality of HIV/AIDS services in Swaziland. The course emphasizes the importance of prioritizing pregnant women for care and treatment and the idea that pregnant women are an entry point for care and treatment for other family members.

The breadth and depth of knowledge required to be an expert client is immense. This training course is designed to provide basic training to new cadres of expert clients (phase 1). As expert clients gain skills, confidence, and experience, and as the program matures and changes, refresher and advanced training should be provided at regular intervals. Suggestions for advanced expert client training (phase 2) topics are included and these advanced modules will be developed later from the basic training course, based on experience with the initial expert client program roll-out.

## **Training Objectives**

By the end of the expert client basic training course (phase 1), participants will be able to:

1. Understand the expert client's critical role in comprehensive HIV/AIDS prevention, care, treatment, psychosocial support, and referral linkage activities.
2. Provide basic counseling and practical strategies to patients, especially pregnant women, for understanding and accessing care and treatment (for themselves and their babies), adherence to care and treatment, disclosure, positive living, and prevention.
3. Assist patients and their families to access other services within the hospital, such as ART, pMTCT-Plus, TB diagnosis and treatment, pediatric care and treatment, and others.
4. Assist in patient follow-up through linkages with community-based services and improved tracing mechanisms for patients lost to follow-up (LTFU).
5. Contribute to reducing stigma and discrimination of PLWHA by working as an integral part of the facility multidisciplinary care team and engaging communities in the fight against HIV/AIDS.

## **Suggestions for Advanced Expert Client Training Objectives**

By the end of the expert client advanced training sessions (phase 2 and beyond), participants could also be able to:

1. Organize and lead support groups.
2. Provide advanced counseling and psychosocial support to patients and their families.
3. Train and mentor treatment supporters.
4. Track and counsel patients lost to follow-up in the community.
5. Provide linkages to community-based care and support services to ensure a continuum of care for patients.
6. Organize, generate support for, and educate other PLWHA and community members about comprehensive HIV/AIDS prevention, care, treatment, and support services.

**Trainers:** The training will be facilitated by a core group of trainers from ICAP, MOHSW, and SWANNEPHA. The training relies on the participation of the multidisciplinary care teams providing pMTCT-Plus, care, and treatment services (doctors, nurses, pharmacists, counselors, etc.). Multidisciplinary care team members should be invited as guest facilitators at each training.

**Participants:** The primary participants will be PLWHA who have enrolled in care and treatment at the site, who have shown good adherence to care and treatment, and who have been jointly selected as expert clients, based on agreed upon selection criteria. At least one expert client per site will be a woman who is currently or was previously enrolled in pMTCT-Plus. As mentioned above, the curriculum may be adapted to train other types of community-based workers as well.

**Duration:** The basic training for expert clients (phase 1) includes **16 training units** to be conducted over **6.5 days**. At least the equivalent of 2 full training days should be spent

in supervised practicum at a care and treatment site. This may be done all together over 2 days, or spread out over the week, depending on logistics. Adaptations to the training schedule should be made as needed based on availability of trainers and participants, the training location, availability of time for practicum sessions, and other factors.

**Location:** Expert client training ideally will be conducted on-site where pMTCT-Plus, care, and treatment services are offered. Bringing expert clients from various sites to a central, conveniently located hospital in the region is ideal. This allows expert clients to learn in a practical setting and will facilitate the supervised practicum sessions. On-site training also facilitates involvement of the multidisciplinary care team in the training and inclusion of expert clients as part of the care team. Training should take place in a separate room at the facility that is private, quiet, and big enough for large group discussions and for participants to break into smaller groups.

If on-site training is not possible for the for the full 6 days, the first 4.5 days of the training may be conducted off-site, with the last 2 days spent on-site for the supervised practicum.

**Content:** Expert clients are not meant to become or replace HIV treatment experts working at the facility. However, to complement the work of physicians, nurses, and others and be an active member of the multidisciplinary team, expert clients should know the basics of HIV/AIDS and the issues surrounding prevention, care, and treatment. Content areas for the training are not meant to be exhaustive and modifications should be made based on the specific needs of the program and its patients, as well as the capacity of the expert clients.

**Major content areas included in this expert patient basic training curriculum are:**

- **The Impact of HIV/AIDS**
- **Expert Clients as a Part of Comprehensive HIV/AIDS Programs**
- **HIV/AIDS Basics**
- **Communication and Counseling Skills**
- **HIV/AIDS Care**
- **HIV/AIDS Treatment**
- **pMTCT-Plus**
- **Pediatrics**
- **Adherence to Care and Treatment**
- **Stigma and Disclosure**
- **Positive Living**
- **Referrals and Record Keeping**
- **Linkages to Community Support**
- **Skill-based Practicum**

**Methodology:** Participatory adult learning principles will be employed. The curriculum contains a variety of interactive training methodologies including:

- Observation
- Trainer presentation
- Brainstorming

- Small and large group discussion
- Small group work
- Case studies and role plays
- Games
- Supervised practicum sessions in the classroom and in the clinic

The curriculum authors recognize that there are more participatory activities included than will be possible to conduct in the 6.5 day training period. However, a variety of activities are given so that the trainers can adjust accordingly to the time available and skill levels of participants.

The training is designed to be participant-focused instead of trainer-driven. All people learn and retain more information when they participate fully, actively, and equally in the learning process. The trainer's main task is to facilitate the learning process and encourage active interaction and learning between participants, recognizing the enormous amount of knowledge expert clients have as participants in the HIV/AIDS care and treatment program. The trainer's role is to draw out these experiences, skills, and talents and encourage skill-building, exchange of information, and confidence-building among expert clients as a professional cadre. The trainer and training methods used should serve as a model for how expert clients should communicate with patients in their work. Lectures and trainer-led activities should be minimized as much as possible, with emphasis instead on expert client-led, participatory group activities, with the trainer supplementing information when needed. Trainers will note that most sessions begin by asking participants to give their thoughts and experiences on the topic of discussion, after which the trainer adds key information.<sup>ii</sup>

An African proverb nicely summarizes the participatory learning process:

*"If I give you one egg and you give me one egg,  
We will each have one egg;  
But, if I give you one idea and you give me one idea,  
We will both have two ideas."*

**Language:** While the curriculum is written in English, trainers are encouraged to conduct as much of the training as possible in Si Swati. Trainers should assist participants to be sure they understand the content of case studies, which are written in English.

**A Note on Confidentiality:** The success of expert client training depends on active participation and engagement of each participant. Participants should be encouraged and feel "safe" to share their own personal experiences as PLWHA enrolled in the pMTCT-Plus and/or care and treatment program, including the challenges they have faced at the hospital, in their community, and at home. For example, participants should feel comfortable discussing times when they have struggled with adherence, or with disclosure, or practicing safer sex with their partner. Trainers should remind participants that what is said in the training sessions is confidential and that no one will be judged or stigmatized for their comments or questions.

**Supportive Materials:** Complementary job aides, such as flip charts and posters have been prepared and should be distributed to all expert clients and facilities. Multidisciplinary care teams and program coordinators should be encouraged to seek out other available materials in local languages related to care and treatment, pMTCT-Plus, positive living, nutrition, managing ART side effects, and other key content areas to support expert clients in their work.

**Evaluation:** Informal evaluations will be conducted at the end of each training day through “How did it go” exercises, to ensure that participants understand course content and that trainers can make adjustments to content or methodology if needed. To encourage honest evaluation, trainers can ask participants to note what they liked and didn’t like about the day on pieces of paper (one piece with a happy face to record things they liked about the day and another piece with a sad face to note things that didn’t go well), or on pieces of flip chart. Alternatively, one of the participants can volunteer to lead the days’ “How did it go” exercise, which can be conducted with the trainers out of the room. The participant would then report back to the trainers on how participants viewed the day. This feedback should be reviewed by trainers and modifications made as needed for subsequent training days.

**Timing of Training:** Basic expert client training will be conducted at the outset of the program, but it is important to ensure that skills learned in training are updated and supported through supervision and regular refresher training. As new program needs develop, advanced training sessions should be considered to teach expert clients new skills in the suggested advanced content areas mentioned above, as well as others content areas as needed to best meet the needs of the program and the patients. As turnover tends to be high in volunteer programs, regular training of new expert clients should be planned for from the outset in order to sustain a steady supply of active, skilled providers.

## PRE-TRAINING ACTIVITIES

For training to be effective, a number of planning activities need to be conducted by the training team. The checklist is meant to guide the planning process.

- Recruit Expert Clients** with key stakeholders, according to agreed-upon selection criteria.
- Recruit a training team and orient team members** on the training curriculum and participatory methodology (Training of Trainers). The training team should include members of the multidisciplinary care team if possible.
- Agree on the training agenda** and facilitation assignments. Rotational assignments can be made for facilitation, note-taking, picture-taking, etc.
- Decide on the number of participants.** The ideal number is about 10, and no more than 15, participants.
- Set dates and timing** for the training. These should be sensitive to the competing activities of both trainers and participants.
- Find a venue** for the training, ideally inside the hospital/clinic. The venue should be comfortable and clean, with privacy and limited outside distractions. The space should allow participants to sit in a circle or “U” shape and should also accommodate small group work.
- Arrange for food and drinks.** If participants need to spend the night, plan where they will stay and how they will get to and from the training each day.
- Plan what per diems will be distributed** and who will be responsible.
- Plan the supervised practicum,** site, timing, checklists to be used, assignments of participants to preceptors, orientation of facility staff, etc.
- Decide how the training will be evaluated.** If a training report is to be written, assign someone this responsibility.
- Invite guests** to the training, such as heads of community-based organizations members of multidisciplinary care teams from the sites, PLWHA support group members, and other stakeholders. Plan for the introductory remarks and invite distinguished guests to the opening and closing sessions.
- Plan what equipment and materials are needed,** such as flip charts, markers, tape, paper and pens, name tags, copies of the participants’ manual, etc. Male and female condoms and penis/vagina models are also needed. Each unit includes a “Materials Needed” section at the beginning to assist in trainer preparation. An LCD project may be helpful to present the learning objectives of each Unit, but is not a necessity as these are included in both the trainer’s and participant’s manuals.
- Prepare training completion certificates and t-shirts** to give participants when they successfully complete the training.
- Plan the next steps** - what will happen when the training and practicum are finished? When will site be visited, etc?

## MATERIALS NEEDED

- Trainer's Manual for each trainer/facilitator
- Participant sign in sheet
- Flip charts
- Markers
- Tape or sticky tack
- Index cards or pre-cut small pieces of paper
- Print outs of case studies/role plays on individual index cards or small sheets of paper
- LCD projector
- Laptop computer
- Plug adapters and extension cord, if needed
- Slides of Learning Objectives for each Unit
- Slide of Expert Client Program Key Players
- Camera
- Small ball
- Male and female condoms
- Penis and vaginal models
- Adult and pediatric ARVs and OI drugs (such as Cotrimoxazole tablets and suspension)
- Pill boxes
- Sample pMTCT and facility referral forms
- Expert client reporting forms
- DBS cards and DBS bar codes
- Spoons (one for each participant)
- Training certificates for each participant
- Expert client t-shirts for each participant
- Per diems for participants and facilitators
- Folders for each participant that contain:
  - o Participant manual
  - o Name tag
  - o Notebook
  - o Pen

## SUGGESTED TRAINING AGENDA

This suggested training agenda should be used as a guide. The exact agenda will depend on the days and times of the training and the availability of trainers and participants, as well as the training and practicum venues. This agenda assumes that full-day trainings will be conducted, with about 6.5 hours of total training time per day with a 15 minute morning break, 1 hour lunch break, and 15 minute afternoon break. The first four and a half days are mainly classroom based, and the last two are based at a facility as a supervised practicum.

	Day 1	Day 2	Day 3	Day 4	Day 5	Day 6	Day 7	
8:30-10:00		Unit 4: HIV/AIDS Basics	Unit 7: HIV Treatment	Unit 10: Adherence to Care & Treatment	Unit 12, continued	Unit 15: Supervised Practicum at Facility	Unit 15: Supervised Practicum, continued	
10:00-10:15		<i>TEA BREAK</i>	<i>TEA BREAK</i>	<i>TEA BREAK</i>	<i>TEA BREAK</i>			
10:15-12:00		Unit 4, continued Unit 5: Communication	Unit 7, continued Unit 8: pMTCT-Plus	Unit 10, continued	Unit 13: Referrals & Record Keeping			
12:00-1:00		<i>LUNCH</i>	<i>LUNCH</i>	<i>LUNCH</i>	<i>LUNCH</i>			
1:00-3:00		Unit 5, continued	Unit 8, continued	Unit 11: Disclosure & Stigma	Unit 14: Facility-Community Linkages			Unit 16: Action Planning, Evaluation, & Graduation
3:00-3:15		<i>TEA BREAK</i>	<i>TEA BREAK</i>	<i>TEA BREAK</i>	<i>PRACTICUM PREP HOW DID IT GO? CLOSING</i>			
3:15-4:45	Participants arrive at training venue	Unit 6: HIV Care	Unit 9: Pediatrics	Unit 12: Positive Living				
4:45-5:00		<i>HOW DID IT GO? CLOSING</i>	<i>HOW DID IT GO? CLOSING</i>	<i>HOW DID IT GO? CLOSING</i>				
5:00-7:30	Welcome Unit 1: Introduction Unit 2: Impact of HIV/AIDS Unit 3: EP Role in HIV Programs							

**UNIT 1**  
**INTRODUCTION**  
**(Time: 1 HOUR)**

**LEARNING OBJECTIVES:** By the end of this Unit, participants will be able to:

- Know more about the trainers and other training participants.
- Understand the training agenda, objectives, and “ground rules.”
- Assess their own baseline knowledge about content and skills to be covered during the training.

**PRACTICAL SKILLS:**

- None for this session.

**MATERIALS NEEDED:**

- Flip chart
- Markers
- LCD Projector and Slide of Expert Client Key Players
- Trainer’s Tool 1 and 2

## 1.1: WELCOME, INTRODUCTIONS, AGENDA, AND GROUND RULES

### ACTIVITY:

#### The trainer should:

- **Introduce him/herself** and the other trainers and welcome participants to the training.
- **Introduce keynote speaker(s)** to give brief introductory remarks and welcome.
- **Pass around registration sheet** (see **Trainer's Tool 1**) where participants record their name, address and other contact information. Participants should sign in for each day of the training attended.
- **Introduce the participant's manual** and make sure each person has a copy. Explain that the manual contains the learning objectives and key points for each Unit. Participants should also take notes during the training of key information. A notebook and pen are provided to each participant for this purpose.
- **Lead an introductory activity** so people can introduce themselves and get to know more about one another and the trainers.
  - Ask participants to get in pairs with someone they don't know. Give the pairs 5 minutes to get to know each other (name, family members, what is important to them, how long they have been in the care and treatment program, etc.). After 5 minutes, get the large group back together and ask each person to introduce their partner to the larger group. The trainers should also participate and introduce each other.
  - Use other fun introductory activities as well – choose ones that get all of the participants involved and puts them at ease.
- **Go over the training agenda** that participants should have in the beginning of their participant manuals. Don't forget to mention logistics, such as lunch, start and end times, payment of per diems, transport arrangements, etc. Ask if there are questions or conflicts about the agenda.
- **Lead participants to set "ground rules"** for the training. Record these rules on flip chart and encourage participation from the whole group. Examples include, turn off mobile phones, confidentiality, no judgmental attitudes, no question is a bad question, everyone should be respected when they have the floor, everyone should actively participate, come back from breaks and lunch on time, etc. Keep these "ground rules" posted throughout the training.

## 1.2: REVIEW OF TRAINING OBJECTIVES

### ACTIVITY:

#### The trainer should:

- Go around the room and ask participants, “Why do you want to be an expert client? What skills and information do you hope to learn at this training?” Note answers on flip chart and fill in with content on training objectives below.
- Provide brief background information on the expert client program in Swaziland (how it started, key partners, vision for the future, etc.). Use **Trainer’s Tool 2** as a guide for this discussion.

### CONTENT:

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

1. Understand the expert client’s critical role in comprehensive HIV/AIDS prevention, care, treatment, psychosocial support, and referral linkage activities.
2. Provide basic counseling and practical strategies to patients, especially pregnant women, so they have a better understanding and are able to access care and treatment, adherence, disclosure, positive living, and prevention services.
3. Assist patients and their families to access other services within the hospital, such as ART, pMTCT-Plus, TB diagnosis and treatment, and pediatric care and treatment.
4. Assist in patient follow-up through linkages with community-based services and improved tracing mechanisms for patients lost to follow-up.
5. Contribute to decreasing stigma and discrimination of PLWHA by working as an integral part of facility multidisciplinary care teams and by engaging their communities in the fight against HIV/AIDS.

### 1.3: NEEDS ASSESSMENT

#### ACTIVITY:

##### The trainer should:

- Post a large "TRUE" sign on one side of the room and also a large "FALSE" side on the other side of the room.
- Tell participants that in order to guide the training and make it useful to the participants, the trainers need to have an idea of what people already know and what gaps exist.
- Read out the statements below (or a sub-set of them) and ask participants to move to either the TRUE or the FALSE side of the room – participants can also stand in the middle if they are not sure. Ask a few participants to justify their responses, and allow participants to move their position. Don't worry about explaining the right answers, as all of the topics will be covered in detail during the training.
- After the activity, ask participants how they felt about the questions. "Were the questions easy? Hard?" Again, remind participants that we are all here to learn and that at the end of the training they will be able to answer all of these questions, and many more, with confidence!

#### CONTENT:

##### Questions for needs assessment:

1. Only very sick people need to take ART.
2. If a woman with HIV has a baby, the baby has a 75% chance of getting HIV.
3. Missing one ARV dose per week is ok.
4. Supportive counseling includes telling people what you think is best for them.
5. Before starting ART, you have to disclose your HIV status to someone you trust.
6. A person on ART can still give HIV to another person.
7. If you forget to take your dose of ARVs at 7am, and you realize at 9am, it's too late to take them and you should just wait until the 7pm dose.
8. Cotrimoxazole (Bactrim) can help prevent opportunistic infections.
9. All babies born to women with HIV will at first be HIV-positive.
10. It's safe for pregnant women to take ART.
11. Normally, a person's CD4 count does down when they start ART.
12. Shared confidentiality means that expert clients should tell a person's family that the person has HIV, but not community members.
13. Side effects of ART usually go away in 2-4 weeks.
14. Expert clients are an important part of the multidisciplinary team.
15. Positive living means telling people you are living with HIV.

**UNIT 2**  
**THE IMPACT OF HIV/AIDS**  
**(Time: 30 MINUTES)**

**LEARNING OBJECTIVES:** By the end of this Unit, participants will be able to:

- Describe the impacts of the HIV/AIDS epidemic at individual, family and community, and national levels in Swaziland.

**PRACTICAL SKILLS:**

- None for this Unit.

**MATERIALS NEEDED:**

- Flip chart
- Markers

## 2.1: THE IMPACT OF HIV/AIDS ON INDIVIDUALS, FAMILIES AND COMMUNITIES, & THE NATION

### ACTIVITY:

#### The trainer should:

- Ask participants to break into 3 small groups. Explain that this exercise will help participants understand and communicate the impact of HIV/AIDS at different levels. This will help expert clients see the “big picture” of HIV/AIDS.
- Give each group flip chart paper and assign them one of the following topics:
  - Individual (adults and children)
  - Family and community
  - Nation
- Ask each group to draw a large tree on their piece of flipchart, including roots, a trunk, and many branches on the top.
- Tell each group to think about the impact of HIV/AIDS at the level they have been assigned. They should draw from their own experiences as PLWHA and family and community members. For example, “what happens when a person has HIV/AIDS? How does it impact his/her life? How did it impact my life?” Or, “what happens when HIV/AIDS enters a family, or many members of a community are living with HIV/AIDS?” Or, “what happens when more and more people in Swaziland have HIV/AIDS?”
- It may be helpful for the trainer to draw a sample impact tree on flip chart. For example, if one impact is that the person loses his/her job, this can be written on a branch. Then on a sub-branch, the group can write that the children now have to work, and so on.
- Give groups 15 minutes to discuss HIV/AIDS impacts and write them on different parts of the tree.
- Trainers should walk around the room to help the small groups understand the exercise.
- After 15 minutes, ask each group to present their “impact tree” to the larger group. The group should ask questions and discuss the impact of HIV/AIDS at different levels. Use the content below to add to the discussion as needed (not all items in the lists below need to be mentioned – this should just serve as a guide).
- Ask if there are any positive impacts of HIV/AIDS? For example, that it can bring communities together for a common goal.

### CONTENT:

#### Some of the impacts of HIV/AIDS on individuals:

- Fear of telling others and being stigmatized, hiding
- Weight loss
- More frequent, severe illness
- More trips to the clinic and hospital
- Need to take many pills every day if on treatment
- Loss of job due to illness

- Violence
- Distanced from family and friends
- Property can be taken away
- Feeling hopeless
- Feeling guilty and/or angry
- Pass the virus to other people, such as sexual partners and babies

For children, specifically:

- More frequent, severe illness
- Many trips to the clinic
- Slow growth
- Treated differently by other children, teachers, or family members
- Need to take a lot of pills/syrups every day
- Not able to stay in school

**Some of the impacts of HIV/AIDS on communities and families:**

- Loss of wages and family/community resources due to illness
- Poverty because of increased health care costs
- Increased number of orphans to care for
- Stigma and discrimination, forcing people to hide their status
- Not enough food because people can't raise animals or crops
- Children can't attend school because they are caring for sick relatives or working
- Teachers are sick or taking care of relatives who are sick
- Community health care systems are overstretched

**Some of the impacts of HIV/AIDS on the nation:**

- There are over 220,000 Swazis living with HIV/AIDS.
- Increased health service demand and patient loads, often resulting in reduced quality of services
- Increased health expenses for drugs, equipment, training, supplies, taking away from other health needs
- Reduced teacher and health care worker supply due to illness/death
- Reduced student enrollment and increased drop outs because children may have to work or care for a sick relative
- Decreased life expectancy
- Increased number of orphans that need to be cared for (63,000 orphans estimated in 2005)
- Reduced productive work force (because of deaths, but also absenteeism to attend funerals, care for sick family members, or because of illness)
- Reduced agricultural output and increased food shortages and numbers of hungry families
- Reversed development gains made in past years and increased poverty
- View by others that the country is a "lost cause" because so many people have HIV/AIDS

## 2.2: UNIT SUMMARY

### **ACTIVITY:**

#### **The trainer should:**

- Ask participants what they think are the key points of this Unit. What information will they take away from the Unit?
- Summarize the key points of the Unit, using participant feedback and the content below.
- Ask if there are any questions or clarifications.
- Review the learning objectives with participants and make sure each person is confident in their skills and knowledge in these areas.
- If there are areas in which participants need more help or do not fully understand, go back and review the session before moving to the next Unit.

### **CONTENT:**

#### **The key points of this Unit include:**

- HIV/AIDS impacts not only individual people, but also families, communities, and the nation as a whole.
- HIV does not discriminate in Swaziland, where about 40% of people are living with HIV/AIDS.

## UNIT 3

### THE ROLE OF EXPERT CLIENTS IN COMPREHENSIVE HIV/AIDS PROGRAMS

(Time: 1 HOUR)

**LEARNING OBJECTIVES:** By the end of this Unit, participants will be able to:

- Have a common understanding of the role of expert clients in improving access and adherence to care and treatment in Swaziland.
- Explain who is part of a multidisciplinary HIV/AIDS care team and how the team works together.
- Understand the day-to-day activities and expectations of expert clients as part of the multidisciplinary care team.

**PRACTICAL SKILLS:**

- Communicate with different members of the multidisciplinary care team.

**MATERIALS NEEDED:**

- Flip chart
- Markers
- Trainer's Tool 3
- Copies of Expert Client Job Description for each participant

### 3.1: INTRODUCTION TO PEER EDUCATION

**ACTIVITY:**

**The trainer should:**

- Ask if any participants have worked as a volunteer before, and if yes, to explain their experiences. What made the experience good or bad?
- Ask if any participants have received counseling or other services from a peer educator, expert client, or outreach worker. If yes, ask them to describe these services. What made them good or bad? Were they helpful?
- Use the content below to present information on the expert client program.

**CONTENT:**

**Basic terms:**

- **A peer** is a person who belongs to the same social group as another person or group. The social group may be based on age, sex, sexual orientation, occupation, socio-economic status, health status, or other factors.
- **Education** refers to the development of a person's knowledge, attitudes, beliefs, or behavior, as a result of the learning process.
- **Peer education** is the transfer of knowledge and skills to members of a social group by others within the same group.
- **Expert clients** are a type of peer educator who are themselves enrolled in pMTCT-Plus and/or care and treatment services, who have a good

understanding of HIV/AIDS, care, treatment, pMTCT-Plus and adherence and who have the skills to help other patients with their care and treatment.

#### **Advantages of Peer Education/Expert Client Programs:**

- **Accepted by audience:** patients have the opportunity to discuss their personal circumstances in a safer environment with someone who relates to their situation.
- **Enhance adherence:** expert clients can support clients' adherence to care and treatment.
- **Community participation:** expert clients can play a role in community mobilization, decreasing stigma, and increasing support for PLWHA.
- **Empowering individuals:** can increase people's confidence that they can make good decisions and take action, changing behaviors among expert clients as well as their clients to take care of their own health and that of their families.
- **Job opportunities:** training and work experience may improve the expert clients' job opportunities in the formal economic sector.
- **Improve service quality:** expert clients can help to improve the overall quality and effectiveness of health care programs.
- **Gain access:** expert clients can gain access to groups that are otherwise difficult to reach and encourage them to seek prevention, care, and treatment services. Similarly, expert clients can follow up with patients who have missed appointments.

### **3.2 THE MULTIDISCIPLINARY CARE TEAM**

#### **ACTIVITY:**

##### **The trainer should:**

- Ask participants to list all the people they have come in contact with at the facility when accessing pMTCT-Plus and HIV/AIDS care and treatment services. List these on flip chart, and fill in using the content below if needed.
- Ask participants to discuss why each of the people listed on flip chart is important to providing quality HIV/AIDS services to patients and family members. Remind them to draw on their own experiences.
- Ask participants what they think would happen if one member of the multidisciplinary care team left? How would this impact a patients' care?
- Remind participants that they are going to be an important part of the multidisciplinary care team and that they will COMPLEMENT, not duplicate the other members' roles.

#### **CONTENT:**

##### **The Multidisciplinary Care Team**

No one person, no matter how skilled, can provide all the care and support that a patient needs. We all have different training, skills, and personal strengths. Also, no one person has time to do everything. This is why it's important for HIV/AIDS prevention, care, and treatment programs to have a multidisciplinary team that looks after every patient.

**Multidisciplinary means a mix of different professionals and volunteers – doctors, nurses, counselors, expert clients, and others – working as members of a team.**

Depending on the specific site, members of the team can include:

- **Doctors** (to check on the patients' health status and make a care and treatment plan, to assess if a patient needs to be on ART and if so, which drugs they should take)
- **Nurses** (to provide pMTCT-Plus counseling to women, provide adherence counseling to patients, perform intake and history-taking activities when the patient comes to the clinic, to take blood samples, provide support on positive living, to weight infants and give immunizations)
- **Pharmacists** (to provide patients with medicines and information on how to take them)
- **Lab technicians** (to take blood or other samples from patients, to perform lab tests - like CD4, liver function, etc., to record test results and report them back to the doctor and nurses)
- **Phlebotomists** (to take people's blood for testing at the lab)
- **Counselors or social workers** (to provide counseling after an HIV test, on PMTCT-Plus, on living positively with HIV/AIDS, disclosing HIV status to family members, helping when a patient feels depressed or hopeless or is thinking about suicide, to provide referrals to other supportive services in the community)
- **Peer educators, such as expert clients, and lay counselors** (to provide "real life" advice and psychosocial support to patients, to help them with adherence and disclosure, to talk about HIV/AIDS and care and treatment in understandable terms, to link patients with need facility and community resources, to serve as the link between patients and clinical staff)
- **Data clerks/information officers** (to make sure good records are kept on all patients so the team can give them the best possible care)
- **Site Coordinators or Advisors** (to coordinate inputs at the hospital and make sure people are working together)
- **Community-based workers and organizations** (to provide psychosocial support, material support, home-based care, and nutritional support in the patients' home and community, to mobilize the community to stop stigma and discrimination)
- **Faith-based organizations and spiritual leaders** (to provide support and counseling to the patient and his/her family, and sometimes material and nutritional support)
- **Family members and friends** (to accept the person's status and provide support for him/her to live positively and access and adhere to care and treatment, to practice safer sex and infection prevention in the home, to serve as home-based care providers)
- **The patients themselves** (to be educated and informed consumers of services and be active participants in their own care)

Multidisciplinary care teams need to work together, communicate with one another, and respect each individual's contribution to improving the health and well-being of the patient. If one "link in the chain" is missing, the patient will not get the quality care

they need in the hospital, in the community, or in the home. It's important that multidisciplinary care teams plan ways to work together, such as by meeting regularly to talk about the program and specific patients' care.

### 3.3 ROLES OF EXPERT CLIENTS IN THE MULTIDISCIPLINARY CARE TEAM

#### ACTIVITY:

##### The trainer should:

- *Note: Ideally the National Expert Client Coordinator would lead this session.*
- Review the expert client job description (see **Trainer's Tool 3**) and ask if there are any questions. Pass out copies of the job description to each participant.
- Review the roles of the National Expert Client Coordinator as well as the Site-based Expert Client Coordinator in supervising and supporting the expert clients.

#### CONTENT:

- See **Trainer's Tool 3, Expert Patient Job Description**

### 3.4: UNIT SUMMARY

#### ACTIVITY:

##### The trainer should:

- Ask participants what they think are the key points of this Unit? What information will they take away from the Unit?
- Summarize the key points of the Unit, using participant feedback and the content below.
- Ask if there are any questions or clarifications.
- Review the learning objectives with participants and make sure each person is confident in their skills and knowledge in these areas.
- If there are areas in which participants need more help or do not fully understand, go back and review the session before moving to the next Unit.

#### CONTENT:

##### The key points of this Unit include:

- Expert clients are important givers and receivers of HIV/AIDS prevention, care, and treatment services.
- Expert clients make up an important part of the multidisciplinary care team and complement the work of other team members.
- Expert clients have many day-to-day roles and responsibilities to support patients in accessing and adhering to care and treatment.

**UNIT 4**  
**HIV/AIDS BASICS**  
**(Time: 2 HOURS)**

**LEARNING OBJECTIVES:** By the end of this Unit, participants will be able to:

- Discuss myths and rumors about HIV/AIDS and know which are true and which are false.
- Discuss the difference between HIV and AIDS.
- Discuss how HIV affects the immune system, including the impact of HIV/AIDS on CD4 cells.
- Describe the ways HIV is transmitted.
- Talk about ways HIV can be prevented.
- Understand the major pieces of comprehensive HIV/AIDS care and support and why each is important to PLWHA and their families.
- Understand and incorporate the idea of “family-focused care” into their work as expert clients.

**PRACTICAL SKILLS:**

- Tell people facts about HIV/AIDS
- Explain the difference between HIV and AIDS
- Describe to patients how HIV affects the body
- Discuss the meaning of the CD4 cell count with patients
- Discuss the ways HIV is and is not transmitted and how it can be prevented.
- Recognize all of the services PLWHA and their families may need and provide linkages to these services
- Ask about family members and partners who may also need care and support

**MATERIALS NEEDED:**

- Flip chart
- Markers
- Trainer’s Tool 4

## 4.1: MYTHS AND RUMORS ABOUT HIV/AIDS AND PLWHA

### ACTIVITY:

#### The trainer should:

- Ask participants to think about things they have heard about HIV/AIDS in their communities. Ask some participants to share these things and record them on flip chart. Fill in using the content below.
- Ask participants how these ideas about HIV/AIDS have impacted their own and their families' lives.
- Tell participants that an important part of being an expert client is knowing all the facts about HIV/AIDS and being able to communicate the facts to other people in the clinic and in the community.
- Remind participants that while everyone is entitled to his/her own opinions, knowing the facts about HIV/AIDS will help decrease stigma and discrimination of PLWHA and encourage people to seek prevention, care, and treatment services. This Unit will help expert clients learn the facts.

### CONTENT:

Myths, rumors, and truths about HIV/AIDS and PLWHA:

- Having sex with a virgin can cure AIDS.
- Only promiscuous people get infected with HIV.
- Anyone with TB or pneumonia has HIV/AIDS.
- Although HIV/AIDS is a risk for anyone, women and girls are more vulnerable than men and boys in Swaziland.
- An HIV positive woman must have been sleeping around.
- People over age 40 do not get HIV.
- PLWHA should never have sex again.
- PLWHA should be responsible and tell everyone about their HIV-status as soon as they know they are positive.
- Traditional healers and holy water can cure people with HIV/AIDS.
- A faithful couple that is HIV-positive does not need to use condoms.
- Being diagnosed with HIV is a death sentence.
- You can tell if a person has AIDS by looking at them.
- It is important for PLWHA to visit the clinic regularly, even if they are not on ART.
- ART is only available in rich countries, or for people that have a lot of money.
- ART makes you look better on the outside, but it makes you sick on the inside and may ultimately kill you.
- Feeling better after starting ARV treatment means an HIV-positive person has been cured.
- Being HIV-positive means a woman should never have children.
- All children born to women with HIV/AIDS will get infected with HIV.
- ART is too strong for pregnant women to take, as it will hurt the baby.

## 4.2: THE DIFFERENCE BETWEEN HIV AND AIDS

### ACTIVITY:

#### The trainer should:

- Tell participants that it's important for expert clients to know and be able to explain the difference between HIV and AIDS to other patients and community members.
- Ask participants to give some of the common/slang words for HIV and AIDS in the community and record these on flip chart.
- Ask participants if the difference between HIV and AIDS was explained to them during VCT, pMTCT-Plus, or in the HIV/AIDS clinic. If yes, ask some participants to share how it was explained to them with the group. Ask the group to comment and fill in gaps using content below.
- Ask participants to define what it means when someone is "HIV-infected." What does it mean when someone has "AIDS?"

### CONTENT:

**HIV** stands for *Human Immunodeficiency Virus*.

**H** = Human (refers to us)

**I** = Immunodeficiency (lack of protection from getting sick)

**V** = Virus (a type of germ in the body that can't be cured)

**AIDS**: stands for *Acquired Immune Deficiency Syndrome*.

**A** = Acquire (to get something)

**I** = Immune (the way the body fights disease)

**D** = Deficiency (not enough of something – in this case lack of protection from getting sick)

**S** = Syndrome (a group of symptoms or illnesses)

#### Some basic definitions:

- **HIV** is the virus that gets into the body,
- **HIV-infected** is when HIV has entered a person's body. A person who is HIV-infected might be very healthy and not have any signs of illness for a long time, but they can pass the virus to others. The average time from HIV-infection to developing AIDS can be many years. This is why the only way to tell if a person has HIV is with a blood test, not by looking at them.
- **AIDS** is a group of serious illnesses and opportunistic infections that develop after more and more HIV develops in the body and the body is too weak to fight back.

### 4.3: FROM HIV TO AIDS – WHAT DOES HIV DO IN THE BODY?

#### ACTIVITY:

##### The trainer should:

- Ask participants how a person knows if they have HIV/AIDS. Ask them to reflect on their own experiences if they want to share. Use content below to review the importance of HIV testing (especially for pregnant women) and ongoing clinical and lab tests for PLWHA to monitor health.
- Ask participants to break into 3 small groups. Ask each group to prepare a role play about the way HIV enters the body, and ends up making people sick. They should be sure to include the following:
  - HIV enters the body
  - HIV-positive, lots of CD4 cells, no symptoms
  - HIV-positive, less CD4 cells, with some symptoms and infections
  - AIDS develops, low CD4 cells, many infections attacking the body
- Ask the small groups to present their role play, pretending that the audience is made up of new patients at the HIV/AIDS clinic that just learned they were HIV-positive. Ask the group to comment and ask questions that they think patients would want to know, using examples of question they had when they got their own HIV test results.
- Fill in using content below and refer to **Trainer's Tool 4** to illustrate how HIV affects the immune system.

#### CONTENT:

##### How does a person know if they have HIV or AIDS?

- **HIV infection** can be diagnosed with a simple blood test. This is usually called "HTC" or HIV testing and counseling in Swaziland. Pregnant women are usually given an HIV test as a routine part of antenatal care. Remember, you can't tell if a person has HIV by looking at them!
- **AIDS** is diagnosed by clinical and lab tests, usually with blood samples, done at the hospital. Where these tests are not available, AIDS can be diagnosed by a doctor after examining a person's health and taking a history.

##### What does HIV do to the immune system<sup>iii</sup>?

*Note: See **Trainer's Tool 4** for illustrations of this process*

- The immune system is the body's natural defense against diseases.
- The human body is made up of many tiny cells. Cells are the basic building blocks in our body – they give us energy and keep us healthy and alive.
- In a healthy person, the immune system fights off diseases that enter the body to keep the person healthy. A type of cell called the CD4 cell helps the body fight infections. Some people talk about the CD4 cells as "soldiers" that defend the body.
- HIV enters the blood stream and starts to attack CD4 cells.

- HIV reproduces itself in the CD4 cells. These are the same cells that the body uses to fight infection.
- For a while, the CD4 “soldier” cells keep the HIV virus weak in the body.
- But, after some time, the HIV becomes stronger than the CD4 soldier cells and keeps making more of the virus and attacking more of the CD4 cells. The HIV keeps reproducing and there is more and more of it in the body.
- This makes people more likely to get infections and makes it harder for the body to fight these infections because they don’t have as many CD4 cells.
- Eventually, the HIV attacks so many of the CD4 soldiers, that there aren’t enough to fight back. The body is attacked by infections and germs that the person can’t fight off.
- These infections (called opportunistic infections) are what eventually make people develop AIDS, and without treatment, die.

### Stages of HIV/AIDS:

1. **HIV enters:** Virus enters the body.
2. **HIV-positive, high CD4 count, no major symptoms:** Person carries HIV and can spread it to others, but feels healthy and has a lot of CD4 soldier cells. The person will not know they are HIV-positive unless they get tested. This stage can last up to 10 years in adults, but a much shorter time in children who usually become sick quickly.
3. **HIV-positive, less CD4 cells, some symptoms:** Person is healthy most of the time, but may start losing weight and getting sick more often as they have less and less CD4 soldiers. Also takes longer to feel healthy after being sick.
4. **AIDS, very few CD4 cells, lots of symptoms and infections:** Person has many opportunistic infections and has a hard time getting rid of them, CD4 count drops below 200, and amount of HIV increases in the body.

This process is a bit different for babies and children with HIV, who progress from HIV to AIDS very quickly without treatment. Also, there are different CD4 count cut offs for babies and children than there are for adults.

### Making sense of CD4 test results:

People living with HIV/AIDS should get a blood test to see the levels of CD4 soldiers when they first know they are HIV-positive and then regularly after that time (usually every 6 months). It’s important for expert clients to help other patients, including pregnant women, come back for and understand the CD4 test results.

- Healthy people with good immune systems have CD4 counts between 500-1500 (measured in the unit cells/mm<sup>3</sup>). People do not need to start taking ART when the CD4 count is this high but they should take Cotrimoxazole, when they are advised to do so by health care workers
- When a person’s CD4 count goes below about 500, they may start getting opportunistic infections that the body has trouble fighting.
- When a person’s CD4 count goes below 200 (350 for pregnant women), they will usually become quite sick and now need ART to stay healthy. It’s important to get CD4 tests on a regular basis because usually the CD4 will fall first and then the person will get sick a bit later. If the person knows the CD4 is dropping, he/she can take steps to avoid getting sick, like taking ART.

## 4.4: HIV TRANSMISSION

### ACTIVITY:

#### The trainer should:

- Have all the participants stand up. One-by-one, ask each person to list a body fluid that contains HIV. The person can sit down once a correct answer is given. Write these on flip chart.
- Have everyone stand up again and now ask each person to list a body fluid that does not contain HIV. Record answers on flip chart and have participants sit down once a correct answer is given. Fill in using the content below, if needed.
- Prepare 2 sheets of flip chart, one that says "DOES NOT TRANSMIT HIV" and one that says "DOES TRANSMIT HIV." Now ask participants to think of the ways HIV is and is not transmitted and record on the appropriate flip chart. Fill in using the content below, as needed.
- Close the session by reviewing some of the myths and wrong information in the community about how HIV IS and IS NOT transmitted. Ask expert clients to discuss what they can do to make sure people have the right information and can protect themselves.

### CONTENT:

#### HIV can be transmitted in these body fluids:

- Semen
- Vaginal fluids
- Blood
- Birthing fluids
- Breastmilk

#### HIV is not transmitted in these body fluids (unless there is also blood present):

- Urine
- Feces
- Saliva
- Sweat
- Mucous (snot)

#### Ways HIV is transmitted:

##### Sexual transmission:

- Unprotected sexual intercourse with infected person
- Direct contact with body fluid of infected person (blood, semen, vaginal secretions)
- *Note: sexual transmission accounts for 87% of HIV transmission worldwide*

**Mother-to-child transmission:**

- During pregnancy
- During labor and delivery (*note: most mother-to-child transmission happens at this stage*)
- During breastfeeding

**Blood-to-blood transmission:**

- Transfusion with infected blood
- Direct contact with infected blood/body fluids

**Use of unsafe sharp objects:**

- Injecting drugs and sharing needles with an infected person
- Piercing, tattooing, or cutting with unclean knives or other objects.

**Ways HIV is NOT transmitted:**

- Sharing food or a drinking cup
- Hugging
- Kissing
- Shaking hands
- Coughing or sneezing
- Being near a PLWHA
- Sharing a latrine/toilet
- Using condoms
- Mosquitoes or insect bites – even if they carry human blood, HIV cannot live outside of humans

## 4.5: HIV PREVENTION

### ACTIVITY:

#### The trainer should:

- Tell participants that the next steps after knowing how HIV is passed from person to person, is to know all the ways to prevent HIV and help people practice safe behaviors.
- Break the large group into 4 smaller groups. Ask each group to elect a speaker. Assign each group one of the modes of transmission (sexual, MTCT, blood-to-blood, and sharp object use). Ask each group to come up with 5 key messages to tell patients and other community members about preventing this kind of transmission. Ask groups to write the messages on flip chart.
- After 10 minutes, the chosen speaker for each group should present the 5 key messages to the larger group, as if they are leading a meeting of PLWHA and their families at the hospital. Remind them that they need to speak clearly and slowly and explain each message in common terms. It's best if they can use "real life" examples and experiences. Give each group about 5 minutes to present, ask if there are questions, and fill in with content below.
- Debrief by asking the speakers how they felt presenting in front of the large group. Did they feel comfortable that they knew the right information and could answer questions?

### CONTENT:

Expert clients have an important role to play in teaching people how to prevent HIV for themselves, their families, and in their communities.

#### The ABCs of preventing sexual transmission

- **A:** Abstinence – for young people
  - **B:** Be faithful to one uninfected partner
  - **C:** Consistent and correct condom use (male or female) - every time - for "dual protection" against pregnancy and HIV
  - **D:** Delay sexual debut
  - **E:** Early and complete treatment of sexually transmitted infections (STIs)
  - **F:** Free and open communication between partners about sex
  - **G:** Get to know you HIV status
- 
- Male circumcision can also reduce the risk of sexual transmission, but should not be used as the only risk reduction method. People still need to use condoms and get tested for HIV even if the man is circumcised. Circumcisions should only be done by trained doctors at a health facility.

### **Prevention of mother-to-child transmission (pMTCT)**

- Prevention of unwanted pregnancies in the first place (good family planning and communication about family planning between couples)
- HIV testing before deciding to become pregnant
- Good, early antenatal care
- HIV testing as part of antenatal care
- Counseling for mothers and fathers on pMTCT-Plus
- Safer sex during and after pregnancy
- Family support and reducing stigma against pregnant women with HIV
- ARVs for mother during pregnancy and for the baby when it's born
- Prioritizing pregnant women for ART if they are eligible – during pregnancy and ongoing – because half of pregnant women living with HIV in Swaziland need ART
- Safe, normal delivery at a facility
- Safe infant feeding – exclusive breastfeeding (no other fluids, foods, or herbs at all, including water) for as long as possible - 6 months is best. Then when the baby is 6 months old, giving others foods along with breastmilk
- Prevention and treatment of breast infections
- Regular follow-up of mother and baby

### **Prevention of blood-to-blood transmission**

- Screen all blood and blood products for HIV (and Hepatitis)
- Follow infection prevention procedures at clinics
- Use protective equipment (like apron, gloves, eye shield)
- Throw out needles and other sharp instruments directly in sharps containers (or a can or bottle will work too)
- Clean and disinfect all surfaces with a solution of bleach and water

### **Prevention of unsafe sharp object use**

- Don't share blades or knives in traditional ceremonies involving blood or cuts on the skin.
- Don't inject drugs or share needles. If you have to, be sure to clean them every time with bleach mixed with water.
- Don't share piercing or tattooing tools, or clean them with bleach solution every time.

## 4.6: INTRODUCTION TO COMPREHENSIVE, FAMILY-FOCUSED CARE

### ACTIVITY:

#### The trainer should:

- Ask participants what is meant by “comprehensive care.” Ask why it’s important to provide PLWHA and their families with comprehensive or “holistic” care and support.
- Ask participants to think about what kinds of services and support they have needed to live positively with HIV/AIDS? What about their families? Note responses on flip chart and encourage participants to think beyond individual and medical needs.
- Ask participants to rank which services are the most important to PLWHA and their families. It’s likely that everyone will rank things differently. This is a good time to remind participants that all components are important and they will change from time to time based on a person’s health and social situation.
- Based on participants’ answers, lead a discussion on the importance of comprehensive care for PLWHA and their families, explaining why it’s important for expert clients to think about the whole family and not just the individual. Use the content below to fill in where needed.

### CONTENT:

#### The goals of comprehensive HIV/AIDS care are to:

- Improve the quality of life of PLWHA.
- Improve the lives of families and communities affected by HIV/AIDS.
- Prevent further spread of HIV.

#### Important points to remember about comprehensive care:

- It involves many types of information, resources, and services to address a range of needs – not just medical needs.
- Each PLWHA has different needs at different points in time, depending on the stage of illness and his/her specific circumstances. Remember, HIV/AIDS is a chronic illness that lasts for a person’s whole life.
- A “continuum of care” responds to the range of care and support needs in different places – such as at the hospital, clinic, community, and home – over the course of the person’s life.
- It relies on a coordinated response from people with a variety of skills – such as doctors, nurses, counselors, pharmacists, family members, community health workers, peer educators, other PLWHA, spiritual leaders, and volunteers.

## **Program components for comprehensive care**

Expert clients need to know about all of the aspects of comprehensive care so that they can best help PLWHA and their families to understand and get the services they need. This training covers information and skills related to many pieces of comprehensive care.

### **Comprehensive care includes:**

- Pre- and post-test HIV counseling, HIV testing, and follow-up
- Early infant diagnosis for babies
- Prevention, diagnosis, and treatment of opportunistic infections and other illnesses, such as malaria
- Palliative care, including pain management
- ART (for those who need it)
- pMTCT-Plus, antenatal, and reproductive health services
- Support for exclusive breastfeeding
- Regular immunizations for babies
- Ongoing monitoring of health status (through lab tests and physical exams)
- Ongoing follow-up of babies that have been exposed to HIV
- Hospitalization for those that are very sick
- Counseling on positive living and prevention
- Couples and disclosure counseling
- Referral and follow-up
- Home-based care
- Nutritional support
- Psychological support
- Social and spiritual support
- Material or economic support (money, clothes, food, etc.)
- Legal support
- End of life care, including pain management
- Care and support for family members, including children

### **Family-Focused Care**

Family-focused care means that all members of the multidisciplinary care team, including the expert client, think about the needs of all family members, and not just the patient. It also means thinking about the linkages between the individual patient, that patient's family, and the community as a whole. Expert clients should make it a normal practice to ask patients about their family members and partners and encourage them to bring these people to the clinic for services, if needed.

Remember: People's day-to-day lives include their families, partners, friends, and other community members, so it's important to ask about them at every visit!

Here are some examples of the benefits of a family-focused approach<sup>iv</sup>:

- An expert client may know that a patient's mother-in-law moved into the house and the doctor may know that the patient is getting sick more often. Only when the expert client and the doctor share this information with each other would they be able to see that the patient may be hiding her HIV-status from the mother-in-law and no longer can take medications openly. She may need of help to disclose her status.
- A pregnant woman is seen for antenatal care and she tests HIV-positive. She is given pMTCT-Plus counseling and told to come back to collect her CD4 results. The counselor asks her if she has a partner at home or other children. The woman says that she has a young baby that seems healthy and a partner that's had a high fever and a lot of coughing. The expert client helps the woman figure out how to disclose her status to her partner and try to get him – as well as her baby - into the clinic for testing. Only by asking about the whole family can we identify other people in need of services and help the family as a unit.
- A pediatrician may know that a child isn't growing fast enough, while another doctor might have just found out that the mom has TB. The home-based care provider might have noticed that the mom isn't able to work in the garden anymore because she's too sick and the family doesn't have enough food now. Only by talking together and thinking about the whole family's well-being can they develop a support plan for the mother and the child.

#### 4.7: UNIT SUMMARY

##### **ACTIVITY:**

##### **The trainer should:**

- Ask participants what they think are the key points of this Unit. What information will they take away from the Unit?
- Summarize the key points of the Unit, using participant feedback and the content below.
- Ask if there are any questions or clarifications.
- Review the learning objectives with participants and make sure each person is confident in their skills and knowledge in these areas.
- If there are areas in which participants need more help or do not fully understand, go back and review the session before moving to the next Unit.

##### **CONTENT:**

##### **The key points of this Unit include:**

- Expert clients should know the facts about HIV/AIDS and help dispel myths and rumors among patients and in the community.
- HIV is a virus that enters the body. A person can be healthy and HIV-infected for many years before getting sick and developing AIDS. But they can still spread

HIV to other people so it's important for people to know their HIV-status by getting tested.

- Babies and children with HIV develop AIDS much faster than adults.
- You can't tell if a person has HIV by looking at them. The only way to know is to get an HIV test.
- HIV attacks a person's immune system and makes it hard for the body to stay healthy and fight off diseases and infections.
- HIV attacks the CD4 cells in the body. The CD4 cells are like soldiers that protect the body from attacking illnesses. Eventually, HIV attacks so many of the CD4 soldier cells that the body can't fight infections anymore and develops AIDS.
- The doctors and nurses can tell if someone needs to start ART by looking at the number of CD4 cells they have (through a blood test). The test can also be used to see if the treatment is working (more CD4 cells). Also if a doctor sees a person has some clinical signs and symptoms of AIDS, s/he may start a person on treatment.
- It's very important that expert clients know all the ways HIV can and cannot be passed from person to person and help people prevent infections.
- HIV lives in semen, vaginal and birthing fluids, blood, and breastmilk.
- HIV can be passed through unsafe sex with an infected person, from an infected mother to her child, from blood-to-blood contact, and from sharing needles, knives, and other sharp objects with a PLWHA.
- Even though there are many ways to get HIV, there are many ways to prevent it! Expert clients play a key role with patients and their families and in the community to make sure everyone knows how to practice safe behaviors and prevent new HIV infections.
- Expert clients should know all the pieces of comprehensive care and help patients and their families understand and access the services over time. Remember that needs will change over time.
- HIV is a family and community disease. It doesn't just affect individuals, but rather whole families and communities. It is important for expert clients to always ask about a person's family members and try to get them in for needed services.

**UNIT 5**  
**BASIC COMMUNICATION AND COUNSELING SKILLS**  
**(Time: 3 HOURS)**

**LEARNING OBJECTIVES:** By the end of this Unit, participants will be able to:

- Reflect on their own attitudes, values, and beliefs and discuss how these may affect communication with others.
- Explain the goals of counseling.
- Discuss what is meant by shared confidentiality and why it's important.
- Demonstrate non-verbal communication and active listening skills.
- Demonstrate reflection, goal-setting, and summarizing skills.
- Describe the difference between counseling and group education.

**PRACTICAL SKILLS:**

- Lead one-on-one and couples counseling sessions
- Explain shared confidentiality and reassure patients
- Use non-verbal communication and active listening skills
- Use reflection, goal-setting, and summarizing in counseling sessions
- Lead group education sessions

**MATERIALS NEEDED:**

- Flip chart
- Markers
- Examples of open-ended questions written on index cards for Session 5.3

**5.1: OUR OWN ATTITUDES AND VALUES**

**ACTIVITY:**

**The trainer should:**

- Ask participants to describe a situation in which they could see a health care provider, counselor, or peer educator's negative attitudes and values. For example, a nurse made you feel like you were to blame for having HIV/AIDS, or a counselor made a pregnant woman with HIV/AIDS feel like she was a bad mother.
- Ask participants what some of their own values, attitudes, and prejudices are about HIV/AIDS and PLWHA. Use the content below to explain these terms.
- Remind participants that even though everyone is entitled to his/her own opinions, it's important to be respectful and non-judgmental when working as an expert client and communicating with patients and other community members. Supplement the conversation with the content below.

## CONTENT:

- **Being self-aware** means knowing yourself, how other people view you, and how you affect other people.
- **Attitudes and values** are feelings, beliefs, and emotions about a fact, thing, behavior or person. For example, some people believe that having multiple sexual partners is OK as long as you practice safer sex, while other people believe that this is wrong.
- **Prejudices** are negative opinions or judgments made about a person or group of people before knowing the facts. For example, when a person assumes that a person with HIV/AIDS must be promiscuous or that a truck driver is sleeping around.

### Expert clients should always:

- Think about the issues related to their own attitudes, values, and prejudices and how they affect their ability to help provide effective counseling and support services to patients and community members.
- Be sensitive to the culture, values, and attitudes of their clients, even if they are different from their own.
- Learn some of the main culture, values, and attitudes of the people with whom they are working at the facility and in the community.
- Examine their own values and beliefs in order to avoid prejudice and bias and make all people feel comfortable and that it is “safe” to talk with them openly and honestly.

Remember: Prejudice, stigma, and negative attitudes drive the HIV/AIDS epidemic, so expert clients should avoid them!

## 5.2: WHAT IS COUNSELING?

### ACTIVITY:

#### The trainer should:

- Ask participants to describe a time when they received good counseling from someone (a doctor, nurse, friend, peer educator, spiritual leader, etc.) Ask what made the counseling good? Why was it helpful?
- Ask participants to now describe a time when they received bad counseling from someone. Why did the counseling make them feel badly?
- Facilitate a discussion on the purpose of counseling, what counseling is and is not, using the content below.
- Ask participants why it's important to keep counseling sessions confidential and what is meant by the phrase “shared confidentiality.” Use the content below to fill in as needed.
- Remind participants that this Unit and others are meant to prepare them to be great communicators and counselors.

## **CONTENT:**

- The aim of counseling is not to solve every problem but to improve the client's coping skills.
- Counseling is a two-way communication process that helps individuals examine personal issues, make decisions, and plan how to take action.
- Counseling helps people talk about and explore, and understand their thoughts and feelings. Counseling helps people work out what they want to do and how they will do it.<sup>v</sup>

### **Counseling includes:**

- Establishing supportive relationships
- Having conversations with a purpose (not just chatting)
- Listening attentively
- Helping people tell their stories without fear of stigma or judgment
- Giving correct and appropriate information
- Helping people to make informed decisions
- Exploring options and alternatives
- Helping people to recognize and build on their strengths
- Helping people to develop a positive attitude to life
- Respecting everyone's needs, values, culture, religion, and lifestyle

### **Counseling does not include:**

- Solving someone's problems
- Telling someone what to do
- Making decisions for another person
- Blaming the person
- Interrogating or questioning the person
- Judging the person
- Preaching or lecturing to a person
- Making promises that cannot be kept
- Imposing one's own beliefs on another person

### **Shared confidentiality:**

In order for patients to trust someone with their feelings and problems, it's important for them to know that this information will be kept confidential. This means that the expert client and other members of the multidisciplinary care team will not tell other people what the patient says, that they are HIV-positive, or other information. Confidentiality is especially important in HIV/AIDS programs because of all the stigma around HIV and discrimination against PLWHA in the home, at work and school, and in the community.

Because multidisciplinary teams take care of patients, sometimes they need to discuss a patient's needs and health status with one another to provide the best care possible. Shared confidentiality means that information about a patient is disclosed to another person involved in the patient's care – a member of the multidisciplinary team, a community health worker, a treatment supporter, etc. – *with* the patient's consent.

Expert clients will come from the same community as the recipients of their services. This might make some people who know them uneasy, especially in the beginning. Expert clients need to assure patients that they will not discuss their concerns, health, or problems with people in the community.

### 5.3: ASKING QUESTIONS

#### ACTIVITY:

##### The trainer should:

- *Note: In advance of the session, write examples of closed-ended questions on pieces of paper (one question per piece). Use the examples below if needed.*
- Explain the difference between open- and closed-ended questions to participants, using the content below. Explain why it's best to ask open-ended questions during counseling sessions.
- Ask participants to break up into groups of 2 or 3 and give each group 3 of the pieces of paper that you prepared with closed-ended questions. Ask one member of the group to read one of the closed-ended question out loud, and then ask other members of the group to rephrase it as an open-ended question. Repeat with all of the questions. Trainers should provide support to the small groups.
- Get the large group back together and ask each small group to give an example of how they turned a closed-ended question into an open-ended question.
- Remind participants that good counseling involves asking a lot of open-ended questions.

#### CONTENT:

##### Closed-ended questions:

Closed-ended questions can be answered with a one-word or short answer. Examples of closed-ended questions are, "How old are you?" "What is your CD4 count?" "Do you have children?"

Closed-ended questions are good for gathering basic information at the start of a counseling or group education session. They shouldn't be used too much because they can make it seem that the expert client is being too direct. They are not helpful in getting at how the patient is really feeling.

##### Open-ended questions:

Open-ended questions cannot be answered in one word. People answer open-ended questions with more of an explanation. Examples of open-ended questions are, "Can you tell me more about your relationship with your partner?" "How does that make you feel?"

Open-ended questions are the best kind to ask during counseling and group education sessions. They help patients explain their feelings and concerns and help the expert client get the information they need to help people make decisions.

**Examples:**

Closed-ended question	Open-ended question
Do you have safer sex?	How do you negotiate safer sex with your partner?
Do you have more than one sex partner?	There are a lot of ways to reduce risk for HIV – like not having sex, being faithful to each others, and using condoms. Which would work best for you based on your situation?
Do you use condoms?	What challenges do you have using condoms with your partner?
Do you drink alcohol when you are upset?	What are some of the ways you relieve stress or anger?
Did your partner get tested?	How would you feel about asking your partner to get tested so you can both be as healthy as possible?
Do you want to have children in the future?	How do you feel about having a bigger family? What concerns do you have?
Do you have someone you can talk with about taking your medicines the right way?	Tell me more about the people you have disclosed to and how they could help you remember to take your medicines.
Do you know how to prevent transmission of HIV to your baby?	I want to make sure that I've explained everything well to you – can you tell me what you understand about ways you can protect your baby from HIV?
Do you exclusively breastfeed the baby?	Can you tell me more about how you feed the baby?

## 5.4: NON-VERBAL COMMUNICATION AND ACTIVE LISTENING

### ACTIVITY:

#### The trainer should:

- Ask participants what they think makes a good listener. Ask them to give specific examples of times that they felt someone was listening. What things made them feel this way?
- Explain the difference between non-verbal (not talking) and verbal (talking) communication skills. Remind participants that both are important to being a good expert client.
- Copy the lists of non-verbal communication and active listening skills below onto flip chart and review each bullet to make sure participants understand them.
- Demonstrate bad communication skills in a short role play with one of the participants where the trainer plays the role of expert patient. Ask participants to comment. Repeat, but this time, demonstrate good, active communication skills (verbal and non-verbal). Ask participants to discuss which role play was better and why.
- Ask participants to turn to their neighbor and ask them about something important that's happened to them in the recent past. First, have participants use bad non-verbal communication skills. Ask people to comment on what was wrong with the communication.
- Ask participants to again turn to their neighbor and ask about something bad that's happened recently. Have participants use good non-verbal communication skills this time. Ask people to comment on the differences they experienced while talking and listening.
- Remind participants that they will be using the skills learned in this Unit throughout the training, in their practicum, and every day in their work as an expert client.

### CONTENT:

These are essential skills for actively listening and building trust with your client.

#### Non-verbal communication:

- Make eye contact.
- Face the person.
- Be relaxed and open with your posture.
- Dress neatly and respectfully.
- Use good body language – nod your head, lean forward.
- Smile.
- Don't look at your watch, the clock, or anything other than the person you're talking to.
- Turn your mobile phone off and never take calls during a counseling session.

**Active listening skills:**

- Listen in a way that shows respect, interest, and empathy.
- Show the person you are listening by saying “ok,” or “mmm hmmm.”
- Use a calm tone of voice – not directive.
- Listen to the content of what the person is saying – are there themes?
- Listen to how they are saying it – do they seem worried, angry, etc.?
- Allow the person to express their emotions-for example if they are crying, allow them time for this.
- Never judge a person or impose your own values.
- Keep distractions to a minimum and try to find a private place to talk.
- Don’t do other tasks while talking to a person.
- Don’t interrupt the person.
- Ask questions or gently probe if you need more information.
- Use open-ended questions that can’t be answered with “yes” or “no”. For example, “can you tell me a bit more about that?”

**5.5: REFLECTION, GOAL-SETTING, AND SUMMARIZING SKILLS****ACTIVITY:****The trainer should:**

- Explain to participants that they will now learn how to be an even better communicator by learning reflection, goal-setting, and summarizing skills.
- Demonstrate each of the skill sets in the content below with a participant, where the trainer plays the role of expert client.
- Break the group up into small groups of 3. Have one person play the expert client, the other the patient, and the third an observer. Ask participants to come up with their own role plays, based on their own experiences with counselling. Remind the person playing the expert client to continue practicing good verbal and non-verbal communication, and to add reflecting, goal-setting, and summarizing to the role play.
- Allow enough time for each person to play all 3 roles and then ask one of the groups to perform their skit. Ask the group what skills were used well.
- Remind participants that they will be using the skills learned in this Unit throughout the training, in their practicum, and in their daily work.

**CONTENT:****Reflecting skills:**

- The expert client repeats back to the person the main themes and feelings of what the person communicated to him/her.
- Provides feedback to the person and enables the person to confirm that they have been listened to, understood, and accepted.
- Helps promote discussion.
- Shows understanding of the person’s story.
- Helps the expert client check the clarity of their understanding.

- Provides a good alternative to always responding with questions.
- Can reflect the content of what is being said as well as the feelings the person has about the situation
- For example, after the person talks for awhile about his/her feelings and situation, the expert client can say "So I sense that you feel \_\_\_\_\_ because \_\_\_\_\_." Or, "I'm hearing that when \_\_\_\_\_ happened, you didn't know what to do."

#### **Goal-setting skills:**

- Towards the end of a counseling session, the expert client works with the person to come up with "next steps" to solve their issues in the short- and long-term.
- Should be developed jointly by the expert client and person receiving counseling.
- Can empower people to achieve what they want by agreeing to realistic short- and long-term goals and actions.
- Goals provide direction; and they must be results-oriented.
- Goals must be clear enough to help people measure their own progress; people feel good when they achieve something they've set out to do.
- To start, the expert client could say, "OK, now let's think about the things you will do today based on what we talked about."

#### **Summarizing skills:**

- The expert client summarizes what has been communicated during a counseling session and clarifies the major ideas.
- Can be useful in an ongoing counseling session or in making sure you're clear on important issues raised during a counseling session.
- Best when both the expert client and patient participate and agree with the summary.
- Gives an opportunity for the expert client to encourage the person to examine his/her feelings about the session.
- The expert client could say, "I think we've talked about a lot of important things today. (List main points). And, we agreed that the best next steps are to \_\_\_\_\_. Does that sound right? Let's plan a time to talk again soon..."

## 5.6: THE DIFFERENCE BETWEEN COUNSELING AND GROUP EDUCATION

### ACTIVITY:

#### The trainer should:

- Ask if any of the participants has ever gone to a group education session, either at the ART clinic, in a pMTCT-Plus program, or in the community. Ask them to share their experiences. What made the group session helpful? What could have made it better? What did you take away from the session?
- Remind participants that as expert clients, they will be holding counseling sessions with individuals, couples, or family members and that they will also work with the multidisciplinary care team to conduct group education sessions. These sessions will help people understand HIV/AIDS, help prepare them to take ART, help pregnant women understand pMTCT-Plus and the importance of taking ART, and help people deal with side effects of ART.
- Review the major differences between counseling and group education below and go over some of the key points on leading successful group education sessions. Remind participants that they will be able to practice giving group education session later in the training.

### CONTENT:

Expert clients will be asked to conduct one-on-one counseling as well as lead group education sessions in their work. While many of the good practices used in counseling can also be used in group education sessions, there are a few differences expert clients should be aware of.

In general, these are the major differences between counseling and group education<sup>vi</sup>:

Counseling	Group Education
Confidential (or shared confidentiality)	Not usually confidential within the group
Usually one-one or with couples	With small or large groups of people, who may not know each other
Based on needs of individual patient(s)	Usually has a pre-set curriculum/content areas
Focused on specific actions and feelings of the patient(s)	More general and less personalized

#### Important points to remember when leading group education sessions:

- Hold groups sessions in a quiet, private area.
- Speak loudly enough so everyone can hear you clearly, but so that you are not shouting.
- Start by explaining the goals and content areas for the session and ask if there are any questions.

- Discuss shared confidentiality and encourage participants to keep things discussed during the session confidential. Put participants at ease by saying that we all have tested positive for HIV.
- Lead an introductory activity (have people introduce themselves, or say something about their family) so participants feel more comfortable with one another.
- Interact with participants and engage them by moving around the room, asking questions, and asking people to share personal stories/concerns, etc.
- Acknowledge that the people attending the session will know something about the topic being discussed. Encourage them to share what they know and use it as an opportunity to identify and correct any misconceptions.
- Don't stand behind a desk or other furniture.
- Encourage participants to sit in a circle to make it more comfortable to talk – and less like a classroom. The person leading the session should be part of the circle.
- Make eye contact with all members of the group.
- Check in regularly to make sure participants are engaged and understanding the messages.
- Pay attention to people who seem shy or quiet and emphasize that everybody's personal experiences, questions, and concerns are important.
- Use job aides and avoid lecturing.
- Encourage participants to speak with you in private after the group session if they have concerns they don't want to share with the group.
- Ask group education participants to summarize what they've learned and actions they will take at the end of the session. Re-explain anything that was not understood completely.

## 5.7: TYPES OF HIV/AIDS COUNSELING AND GROUP EDUCATION

### ACTIVITY:

#### The trainer should:

- Remind participants that one of the most important roles of expert clients is to provide good education and counseling to patients about HIV/AIDS prevention, care, and treatment.
- Using the content below, give participants a preview of the types of counseling and group education they will be asked to facilitate during the practicum and in their work as expert clients.

### CONTENT:

These are some of the main types of group education and counseling that expert clients will learn more about in this training:

- **On-on-one pMTCT-Plus counseling or group education** – to help pregnant women get a test for HIV, understand the test results, prevent HIV infection during pregnancy and beyond if they are negative, and get needed services for herself

and the baby if she is positive, including prioritizing pregnant women for ART and infant follow-up.

- **One-on-one adherence counseling or group education** - assists patients to follow a care plan and to take medications consistently and correctly. This is usually done before a person starts ART, but should also be continued over time as people's adherence challenges will change.
- **On-on-one disclosure counseling** – when people are ready to tell another person about their HIV-status, it can help bring the disease out into the open, make it easier for a person and his/her family to seek and adhere to care and treatment, and reduce stigma and discrimination by being a positive PLWHA role model. Disclosure counseling can be with one person or with more than one person, for example a couple.
- **On-on-one supportive counseling or group education** – providing ongoing practical, psychological, and emotional assistance and referrals to people to live positively with HIV/AIDS.
- **Couples counseling** – can be on any of the above subjects, with couples that are both living with HIV/AIDS or with discordant couples, meaning that one is living with HIV/AIDS and the other is not; especially important for women to be supported in seeking pMTCT-Plus and care and treatment services.
- **Care for the carer counseling** – when counselors and educators support each other, listen to difficulties others are having, and solve problems/challenges together, recognizing the enormous mental burden of caring for and counseling people day in and day out.

### Supporting each other

Counseling is not an easy job. It's important that expert clients and other health care providers make a plan to support each other by developing a "care for the carer" plan at the health facility. Expert clients should meet with each other on a regular basis and the multidisciplinary team should meet to support each other and discuss difficult cases.

## 5.8: UNIT SUMMARY

### ACTIVITY:

#### The trainer should:

- Ask participants what they think are the key points of this Unit. What information will they take away from the Unit?
- Summarize the key points of the Unit, using participant feedback and the content below.
- Ask if there are any questions or clarifications.
- Review the learning objectives with participants and make sure each person is confident in their skills and knowledge in these areas.
- If there are areas in which participants need more help or do not fully understand, go back and review the session before moving to the next Unit.

## CONTENT:

### The key points of this Unit include:

- Our own attitudes, values, and prejudices should not be a part of communication and counseling with patients and other community members.
- Counseling is a very important, two-way communication process that expert clients will use every day in their work.
- It is best to limit the use of closed-ended questions and instead use more open-ended questions during counseling.
- It's important for patients to know that what they say will be kept private. Patients should give consent for counselors to talk about their situation with other providers. Expert clients should practice shared confidentiality.
- The best communication includes using good non-verbal communication and actively listening to the other person.
- Skills such as reflecting what the person is saying back to him/her, helping the person set goals and next steps, and summarizing what was discussed in the counseling session are all important skills for expert clients to have.
- Expert clients are expected to be good leaders and facilitators of group education sessions, as well as one-on-one or couples counseling sessions.
- It's important to take care of ourselves and other people giving counseling services, by having a care for the carer plan at each facility.

**UNIT 6**  
**HIV/AIDS CARE**  
**(Time: 1 HOUR, 30 MINUTES)**

**LEARNING OBJECTIVES:** By the end of this Unit, participants will be able to:

- Explain the HIV testing and counseling (HTC) process and how HCT is the entry point to care and treatment.
- Provide support and information to patients during and after post-test counseling and help link them to care and treatment services.
- Understand the difference between care and treatment services and who is eligible for care.
- Describe the components of clinical care to patients, including regular CD4 testing, and why these components are important.
- Motivate patients to return to the clinic for care, even if they are not on ART.
- Explain common opportunistic infections, and how they can be prevented and treated.

**PRACTICAL SKILLS:**

- Provide post-test support to patients.
- Link patients from HIV testing to care and treatment.
- Tell patients about the components of care and why getting care services can help keep them healthy.
- Counsel patients on routine CD4 testing when they are not yet on ART.
- Give patients information on preventing and treating opportunistic infections.
- Help patients understand the connection between TB and HIV and the importance of getting care for both.

**MATERIALS NEEDED:**

- Flip chart
- Markers
- Case study cards to hand out

## 6.1: HIV TESTING AND COUNSELING: THE ENTRY-POINT TO CARE

### ACTIVITY:

#### The trainer should:

- Ask if any participants want to share a personal story about HIV counseling and testing. What was their experience with pre- and post-test counseling?
- Ask participants to list the benefits of HIV testing and counseling and list on flip chart, reminding participants to include their thoughts about the benefits for people who test negative. Ask participants if they think testing and counseling should be recommended by doctors and nurses to all people, some people, or if it should be totally voluntary. Discuss, using the content below to fill in gaps, as needed.

### CONTENT:

#### The need for routine counseling and testing:

In Swaziland, about 40% of adults are living with HIV/AIDS, but many people still don't know their status and therefore cannot access the services and support they need to stay healthy, like care and treatment. 15% of PLWHA in Swaziland need ART, although only 40% of those in need receive it. As we know from the last Unit, 50% (half) of pregnant women living with HIV/AIDS need ART, although only 10% of those in need of ART are getting it.

While HIV tests should be available to all people on a voluntary basis through HTC, HIV testing is also becoming a routine part of clinical care, since so many people are living with HIV/AIDS. For example, all pregnant women, all adults and children admitted to the hospital, and all people with TB should be offered and encouraged to get an HIV test. This is called **provider initiated HIV testing and counseling** because the health care provider actively suggests that the patient get an HIV test, instead of waiting for the person to say they want an HIV test. This is a good strategy to get more people tested and counseled, and to get people who test positive enrolled in care and treatment as soon as possible.

**HIV testing is an entry point to care and treatment**, meaning that it's the first step in getting care and treatment services. We need to know for sure that a person has HIV before we link them with care and treatment.

#### The counseling and testing process:

The HIV counseling and testing process includes three major steps:



Expert clients are not trained as HIV test counselors and should play a supportive role to the nurse or counselor assigned to this task at their site. Expert clients can play an especially important role during and after post-test counseling, especially by encouraging people to enroll in care and treatment and helping them to do this. Information on pre-test counseling is included here so that when expert clients use the family-focused approach they can talk to other family members about getting an HIV test and what to expect.

**Remember: HIV counseling and testing is the ENTRY POINT to care and treatment.**

**In the pre-test counseling session, a trained counselor (usually a nurse) will do the following, in an individual session or in a group session:**

- Introduction and orientation to the session
- Explore options for reducing risk and vulnerability, or if in a group discuss how HIV can be prevented
- Explain the meaning of a positive or a negative result
- HIV test preparation

**During HIV Testing a trained person, usually a nurse, will:**

- Explain the testing procedure and when the results of the test will be ready (usually the same day).
- Draw a small amount of blood. In Swaziland, usually 2 tubes of blood are taken from a vein in the arm. One tube is used for the HIV test and the other is kept so that if the person is positive a CD4 test can be done right away. Only a small amount of blood is needed, so the person doesn't need to worry about feeling weak or tired because of loss of blood.

**During the post-test counseling session, the provider will:**

**For a NEGATIVE test result:**

- Inform the client that the test results are ready.
- Show results clearly and simply.
- Explore the client's reaction to the test results.
- Review the meaning of the results.
- Explain the window period and coming back for another test.
- Discuss risk reduction plan.
- Discuss disclosure and partner referral.

**Expert clients will be most involved during post-test counseling or just after post-test counseling.**

**For a POSITIVE test result:**

- Inform the client that the test results are ready.
- Show results clearly and simply.
- Review the meaning of the result (including an explanation of discordant results and next steps)
- Allow the client time to absorb and react to the meaning of the result.

- Explore the client's understanding of the result.
- Assess how the client is coping with the result.
- Acknowledge the challenges of dealing with a positive result.
- Discuss the meaning of a CD4 count and when and why the person should return to get CD4 test results.
- Discuss pMTCT-Plus strategies and remind the woman that not all babies get HIV from the mom if the woman is pregnant. There is hope for the mom and baby to be healthy.
- Explain ART eligibility and for pregnant women and the benefits of ART for the mom and baby.
- Discuss positive living and care and treatment.

### **Identify Sources of Support**

- Assess whom the client would like to tell about his/her positive test results and when.
- Identify a family member or close friend that can help the client through the processes of dealing with coping, planning, positive living, and follow-up.
- Identify the client's current health care and social resources.
- Address the need for health care providers to know client's test result.
- Identify needed medical and social support referrals.
- Discuss which support groups are available.
- Provide appropriate referrals to support groups, community resources, and care and treatment services, including ART (what, when, where).

### **Discuss Risk Reduction Plan**

- Identify priority of risk-reduction behavior.
- Talk about routine antenatal care, safe delivery, pMTCT-Plus and safer sex if the woman is pregnant or wants to become pregnant.
- Promote exclusive breastfeeding for as long as possible if the woman is pregnant.
- Explore behaviors that the client will be most motivated about.
- Identify reasonable, small steps towards changing the identified behavior.
- Plan risk-reduction into specific and concrete steps.
- Identify barriers to the risk reduction plan and provide support.
- Role-play as needed, for example situation such as condom negotiation.
- Recognize the challenges of behavior change.
- Provide support for the person to share the plan with partner, family, and friends.

### **Discuss Disclosure and Partner Referral**

- Explore client's feelings about telling partner(s) about the HIV-positive test result.
- Remind client that the result does not indicate the partners' HIV status.
- Identify partners that are at risk and need to be informed of their risk of HIV infection.
- Discuss possible approaches to disclosure of sero-status to partners (more on this later in the training).
- Support client to refer partners and children for counseling and testing.
- Practice and role-play different approaches to disclosure.
- Anticipate potential partner reactions.

- Provide the client with ongoing support and linkages to support groups.
- Discuss safer sex and risk reduction with partner(s).

**Expert clients can help people plan next steps after their post-test counseling, such as to:**

- Listen to the patient and provide support, using good communication skills.
- Explain CD4 testing, why it's done, and when and where to pick up results.
- Explain importance of enrolling in care and treatment program and help people to do this.
- Ask about partners and children and encourage them to come for HTC and care services if needed.
- For pregnant women, discuss pMTCT-Plus and the idea that if the woman enrolls in care and treatment she is "saving 2 lives." Also, discuss ANC plan and safe delivery plan, as well as promoting exclusive breastfeeding for all babies.
- Agree on a next visit date, record this in your notebook, and make sure it's recorded in the patient's appointment card. Help identify barriers to coming back and work with patients to come up with solutions.

## **6.2: CARE AND TREATMENT – WHAT IS THE DIFFERENCE?**

### **ACTIVITY:**

#### **The trainer should:**

- Remind participants that they are a critical part of helping people, especially pregnant women, enroll in care and treatment if they receive a positive test result.
- Ask participants what kinds of care they receive at the hospital, in the primary health clinic, or in the community other than ART and record these on flip chart. Why are these services just as important as ART?
- Explain the difference between care and treatment using the content below, emphasizing that all PLWHA should be given care services (OI prevention and treatment, psychological and nutritional support, positive living support, etc.), but not all people in care need to be on treatment.
- Ask participants to discuss where care services (other than ART) are offered at hospitals, PHUs, and clinics and list on flip chart.
- Ask participants what the barriers to accessing these services are and how can expert clients can help people understand the importance of coming back to the hospital or clinic even if they are not on ART?

### **CONTENT:**

There is a lot people with HIV/AIDS can do to stay healthy even if not on ART. All PLWHA should come to the hospital for regular check ups, tests, counseling, and for medicines to help prevent opportunistic infections and stay healthy.

Also, when people come back to the clinic regularly before they are on ART, we can help them to start ART right away when they are eligible to keep them healthier.

One way of saying this is that all PLWHA need care, and a certain number of PLWHA also need treatment with ART. Once a person tests positive for HIV, they should be enrolled in the care program at the hospital and linked to needed community resources. Over time, the person will probably also need to be enrolled in treatment and we want to start treatment as soon as possible once a person is eligible.

### **Who is eligible for care?**

**Everyone who is living with HIV/AIDS** should be enrolled in care, even if they are not eligible for ART. People should return to the clinic at least once every 6 months for a check-up, counseling, and a CD4 test to see if they are eligible for treatment. Babies that have been exposed to HIV should also all be enrolled in care from birth. Babies and pregnant mothers should come back to the clinic even more often.

### **Components of clinical care (other than ART):**

- General health check-up by the doctor and nurse
- Prevention and treatment of opportunistic infections, especially pneumonia, malaria, and TB for adults and children. Cotrimoxazole is one of the most important drugs adults and children can take to prevent OIs.
- Infant diagnosis at under-5 clinics and care for babies exposed to HIV
- CD4 testing to see how much the HIV is affecting the immune system and if ART is needed
- Other lab tests, such as one to test how well the liver is functioning ("LFTs"), especially for people on ART
- Emotional counseling and support
- Positive living counseling and support
- Disclosure counseling and support
- Discussion and referral for testing and care of other family members (like children, partner, etc.)
- Nutrition counseling and support (direct support or through referrals)
- Linkages to support groups and community resources

### **Where is care provided?**

More and more, care is being provided for PLWHA in Swaziland. Care services should be provided at clinics and PHUs as these are easier for patients to come to and less crowded than the ART clinics. At some hospitals care services for PLWHA are provided through the out-patient department. This is a challenge because it's hard to follow up with people in this department and sometimes they will be charged for services outside of the ART clinic. Expert clients should work with the multidisciplinary care team to advocate for all PLWHA to be provided with quality care services at the ART clinic and to encourage good referral linkages.

## 6.3 WHY SHOULD PATIENTS COME BACK FOR CARE IF THEY'RE NOT ON ART?

### ACTIVITY:

#### The trainer should:

- Ask participants to break into groups of 4. Have one person act as the patient, another as the expert client, and the third and fourth as observers.
- Give participants the following case studies, or ask them to come up with their own scenarios based on real world experience. Give each group about 10 minutes to role play the scenarios, changing roles after a couple of minutes if there is time.
- Ask the groups to perform their role play in front of the large group. Give the groups' designated observers a chance to comment on what they thought was done well and what could be improved. Then open it up to the large group for comments.
- Debrief with participants and ask them to share their experiences with the role plays, reinforcing the important role of expert clients in getting all PLWHA enrolled in care.

**Case Study 1:** A woman has just tested HIV-positive and comes back to pick up her CD4 results. Her CD4 count is still quite high and the doctor says she doesn't need to start ART right away. She talks to you afterwards and says she's relieved that she no longer has to come back to the hospital because she is not that sick.

**Case Study 2:** A young man was just referred to you by the nurse at the VCT clinic. He tested positive for HIV, but feels healthy so he doesn't see the need to come to the hospital where people will think he's sick and dying from HIV. He tells you he will come back if he starts getting sick.

**Case Study 3:** A pregnant woman just delivered her baby. She is living with HIV/AIDS, but is not eligible for ART because she has a high CD4 count. She took a short course AZT and Nevirapine during the pregnancy and the baby got a single dose of Nevirapine after it was born. She plans to come back so the child can be immunized and have a check-up, but she doesn't want to be seen at the ART clinic because she hasn't told her family her status. So, she says she doesn't want to come back.

### CONTENT:

Everyone who is living with HIV/AIDS should come back to a clinic or hospital at least every 6 months, even if they are not on ART. It's important to see a health care worker for a check-up and get CD4 tests done to see if ART is needed. Different types of counseling, like positive living and disclosure, are important to all PLWHA, not just those on ART.

**Remember to talk with patients about how important care is and that they should come back to the clinic or hospital often (at least every 6 months, or more for babies and children or as needed for adults) to get:**

- A general health check-up by health care workers (best if this can be done at the primary health clinics).
- Prevention and treatment of opportunistic infections, especially pneumonia, malaria, and TB. It's important that ALL babies exposed to HIV or adults and children living with HIV take Cotrimoxazole.
- CD4 testing to see how much the HIV is affecting the immune system and if ART is needed (then we can start people on ART right away when they are eligible to keep them healthy).
- Early infant testing (if available) to see if HIV-exposed babies have HIV.
- Emotional counseling and support.
- Positive living counseling and support.
- Disclosure counseling and support.
- Nutrition counseling and support (direct support or through referrals).
- Linkages to support groups and community resources.

#### **6.4: PREVENTION AND TREATMENT OF OPPORTUNISTIC INFECTIONS**

##### **ACTIVITY:**

##### **The trainer should:**

- Ask if any of the participants can define the term "opportunistic infection." Ask participants to give examples of OIs and record them on flip chart.
- Ask participants what they know about OIs and how they can be prevented and/or treated. If participants feel comfortable, ask them to share their own stories about OIs. What are participants doing to prevent these infections?
- Review the common OIs and their symptoms, using the content below.
- Organize a game/role play where each participant is assigned an OI from the list below. Ask them to act out how the OI impacts the body or to speak as if they were that OI (for example, "I'm the infection that makes people cough a lot and have a fever. It's easy to pass me from one person to the next especially when in a closed room"). Ask the other participants to guess which OI the person represents (in this case TB) and then lead a discussion about ways it can be prevented and treated.
- Spend a bit of time talking specifically about TB and the connections between TB and HIV, using the content below. Ask participants what expert clients can do to help people prevent or treat TB in the clinic.
- Review the key strategies and medications used to prevent/treat them, using the content below and encouraging participants to share they own experiences taking these medicines and trying to prevent OIs.

## **CONTENT:**

### **Opportunistic infections:**

Opportunistic infections, or OIs, are the infections that make PLWHA sick because the body's immune system is weakened and it cannot fight back. Remember that we discussed the impact of HIV on the CD4 "soldier" cells in the body – when the HIV attacks the CD4 cells, the person has trouble fighting back when a virus or germ enters their body. PLWHA, especially people not on ART, can get a lot of OIs.

One of the best ways to live positively with HIV/AIDS, whether you are on ART or not, is to prevent opportunistic infections from happening in the first place or treating them right away if they do happen. Usually, a doctor or nurse will give PLWHA medicines to prevent these infections from happening. They will also give some medicines to babies born to mothers with HIV/AIDS to help prevent them from getting sick. Eating well, drinking clean water, sleeping enough, and practicing good hygiene also help prevent infections. This is covered more in the Unit on Positive Living.

### **The most common OIs are:**

- Tuberculosis (usually in the lungs; the person will have a bad cough, fever, and will lose weight; easily transmitted from person to person)
- Malaria (given to people by mosquitoes; causes high fever and weakness)
- Pneumonia or PCP (a very bad infection in the lungs that can develop quickly; causes coughing, weakness, shortness of breath; is often is what can kill a person with HIV if it's not treated)
- Meningitis (a deadly disease in the brain, can cause bad headaches)
- STIs (can cause infected sores in the genital area of men and women; can cause unusual discharge, or sometimes have no symptoms; easy to spread through sex and need to be treated right away; PLWHA more likely to get STIs than people without HIV)
- Bad diarrhea (diarrhea that lasts more than a few days and causes dehydration and weight loss; especially dangerous if there is also fever)
- Vomiting (often a sign of other problems, especially if there is also fever and it doesn't go away after a couple of days; causes dehydration)
- Skin problems (like rashes or shingles, warts, or sore lesions; can be caused from fungus and be very uncomfortable)
- Oral sores (very common among PLWHA; can be very painful,
- Others...

### **More about TB**

TB is the most common OI among PLWHA. TB and HIV are like brother and sister – about 50% of PLWHA in Swaziland also have TB and about 79% of people with TB also have HIV. Because TB and HIV are so closely linked, services to prevent and treat both also need to be linked.

TB usually infects the lungs, but it can also infect other areas. Usually people with TB have a bad cough that doesn't go away, fever, and they lose weight.

TB is spread through the air, especially from coughing, sneezing, and being in close quarters with a person with TB. It's made worse when there is not good air circulation – like if there are no open windows. It's VERY easy to spread TB from person to person, and PLWHA are especially likely to get it if they are in contact with a person with TB. Little kids are at high risk for TB when they live with adults who have TB.

**Expert clients should do the following to help patients treat and avoid TB:**

- Counsel PLWHA on the risks of TB. Let them know they have a 50% risk of getting TB if they are exposed to it (like if a family member or someone at work has TB).
- Make sure PLWHA know how to prevent TB infection. This includes avoiding close contact with people who have a known case of TB, making sure there is a lot of fresh and moving air in living and working areas (open windows), and make sure always to always cover the mouth when coughing or sneezing (and ask that other people do the same).
- Go to the hospital or clinic right away if there are symptoms of TB, like a cough that won't go away, fever, or weight loss.
- TB treatment can last as long as 9 months, and as with ART, it's important to take the medicines the right way, every day to make sure they work.
- Explain that it is important to have a TB treatment supporter that can help remind the person to take the drugs every day.
- If a person has TB and HIV, and their CD4 count is very low (below 200), they may take TB drugs and ART at the same time. In people with higher CD4 counts, TB treatment is usually started before the person goes on ART so the body has time to get used to these strong drugs. The doctor and nurse will check for TB during clinic visits.
- Medicines are available in the country to treat opportunistic infections.

## 6.5: UNIT SUMMARY

**ACTIVITY:**

**The trainer should:**

- Ask participants what they think are the key points of this Unit. What information will they take away from the Unit?
- Summarize the key points of the Unit, using participant feedback and the content below.
- Ask if there are any questions or clarifications.
- Review the learning objectives with participants and make sure each person is confident in their skills and knowledge in these areas.
- If there are areas in which participants need more help or do not fully understand, go back and review the session before moving to the next Unit.

## CONTENT:

### The key points of this Unit include:

- HIV testing and counseling is the entry point to care and treatment.
- Expert clients have a key role to play in post-test support, especially pregnant women who test positive.
- Expert clients should counsel all PLWHA to enroll in care services at the clinic or hospital, even if they feel healthy and are not on ART.
- Important components of care that can help all PLWHA include check-ups by health care workers, preventing and treating opportunistic infections, especially by taking Cotrimoxazole; regular CD4 tests to see if ART is needed, early infant testing for babies where available; counseling on positive living, nutrition, disclosure, etc., and referrals to support groups and community support.
- Coming back often for care also means that we can identify and start people on treatment as soon as they are eligible instead of waiting until they are very sick.
- One of the most important parts of HIV clinical care is to get a CD4 test done at least every 6 months, whether the person is on ART or not. If they are not on ART, the CD4 test results can help the team and the patient decide if ART is needed.
- OIs attack the body when the immune system is weak. PLWHA can get many OIs, like skin problems, TB, pneumonia, thrush or sores in the mouth, or bad diarrhea and vomiting.
- One of the best things PLWHA can do to stay healthy is to prevent OIs by living positively and taking certain medicines.
- TB and HIV are like brother and sister. TB is the most common OI among PLWHA and can be very dangerous if not treated right away.

## UNIT 7 HIV/AIDS TREATMENT (Time: 2 HOURS)

**LEARNING OBJECTIVES:** By the end of this Unit, participants will be able to:

- Dispel myths about ART to patients and in the community.
- Explain when a person should start taking ART, including the clinical and social criteria.
- Discuss the goals of ART and the health and social benefits for men and women.
- Know common ART regimens and be able to explain how to take them.
- Help patients recognize, manage, and know when to go to the doctor for ART-related side effects.

**PRACTICAL SKILLS:**

- Explain the facts about ART and why ART myths are not true.
- Explain to patients why they are or are not eligible to take ART based on clinical and social assessment by the multidisciplinary care team.
- Explain to patients that there are a number of steps to go through before they can start taking ART, like group education and one-on-one counseling sessions.
- Tell patients about the goals and benefits of ART for the person and their family.
- Educate patients on the names of their ARVs and other medicines (like Cotrimoxazole), and how and when to take them.
- Talk with patients about common ART side effects and how to manage them.
- Counsel patients to never stop taking their ART without talking with the doctor first – even if they have side effects.

**MATERIALS NEEDED:**

- Flip chart
- Markers
- Common ARVs used in Swaziland, in their original bottles
- True and False index cards for each participant
- Case study cards to hand out

## 7.1: MYTHS AND FACTS ABOUT ART

### ACTIVITY:

#### The trainer should:

- Give each participant a card that says “true” and a card that says “false” on it.
- Go through the myths and facts statements below one by one, mixing up the myths and facts, and ask participants to hold up their “true” card if they think the statement is true or the “false” card if the statement is a myth about ART.
- Ask selected participants why they think a statement is true or false and encourage discussion and debate in the large group.
- Summarize the discussion by reminding participants that there are a lot of myths about ART that can be harmful and prevent people from starting treatment or taking their medicines the right way. All expert clients should know the facts about ART and be able to explain them to other patients and community members.

### CONTENT:

#### Some common myths about ART:

- ART is a last resort and is only good for people that are sick and dying.
- ART cures AIDS.
- ART can kill you on the inside even though it can make you gain weight and look healthy on the outside.
- Without ART, there is nothing PLWHA can do to stay healthy.
- Only rich people can afford to take ART.
- Pregnant women can't take ART because it will hurt the baby.
- People can share ARVs with family members.
- Once you are feeling better on ART, you can stop taking it.
- If you feel well enough on ART, you can have sex without condoms because the HIV won't spread anymore.
- Traditional medicines are just as good as ART.
- There are no ARVs for babies and children.
- There is nothing you can do about side effects of ART.
- If the ARVs make you sick, you should stop taking them.

#### Some facts about ART:

- ART stands for “anti-retroviral therapy” and ARV stands for “anti-retroviral.” If a person is on ART, it means they are taking a combination of ARVs.
- ART should be delivered as part of comprehensive HIV/AIDS care.
- ART is not just for sick and dying people. Even people who look and feel healthy may need ART.
- Only a doctor can tell if you need to take ART by doing a check-up and looking at your CD4 count.

- ART is a life long treatment, because ART is not a cure for AIDS. There is NO CURE for AIDS.
- People can still pass HIV to others while on ART, even if they feel healthy.
- Adherence to care and treatment is needed for success of ART.
- Side effects and the body's reaction to ARVs must be monitored by a doctor or nurse.
- Pregnant women can take ART.
- While some traditional medicines can help people feel better, there is no replacement for ART.
- ART can help the immune system be more active and able to fight illness.
- ART can reduce the number of sicknesses a person has and can improve their quality of life a great deal.
- There are special kinds of ARVs for babies and children, and the dose is based on their weight. Children should not be given adult ARVs unless instructed by a doctor.

## 7.2: WHEN SHOULD PATIENTS START ART?

### ACTIVITY:

#### The trainer should:

- Ask participants who are taking ART to talk about when they started treatment. Why did they start treatment? What reasons did the doctor or nurse give for starting treatment?
- Ask participants what they think is needed for a patient to start taking ART, other than their health status? Use the content below to supplement the discussion.
- Break the group into small groups of 3 and ask each group to role play one of the following scenarios, switching so that each person has a chance to be the expert client, the patient, and the observer.
- Ask some of the groups to perform the scenario for the larger group and discuss how the expert patient explained pre-ART services, the criteria to start ART, etc.

**Case Study 1:** A patient comes out of the clinic upset. He tells you he is angry because he traveled for 2 hours to get to the clinic for treatment, but the doctor wouldn't prescribe any ART. Talk to him about the reasons the doctor may have not prescribed ART and the importance of adherence to the care plan.

**Case Study 2:** You are walking to the market and someone stops you because they know you are an expert client. She tells you she tested positive for HIV and is going to the clinic to get ART because it will help her live longer. Talk to her about the differences between care and treatment and why not everyone that is HIV-positive needs ART.

**Case Study 3:** A patient comes out of the doctor's office very confused. He doesn't feel well and his CD4 count is only 100, but the doctor wouldn't give him ART because he said he had concerns about the patient's ability to adhere to ART because of his mobile lifestyle (he's a mine worker that spends a lot of time away from home and he hasn't told anyone he works with that he's HIV-positive). Talk to him about the non-medical reasons that make someone ready or not ready to be on ART.

**Case Study 4:** A pregnant woman says she is angry with the nurse because she said she has a low CD4 count and needs to start taking ART to keep herself and the baby healthy. She heard from her friends that ART will kill the baby so she isn't going to start until after the baby is born. Talk to her about the need for eligible pregnant women to start taking ART as soon as possible to save 2 lives.

## CONTENT:

Not everyone who is HIV-infected needs ART right away. As we learned in the last session, there are still a lot of things to help keep people healthy and well if they are not on ART. Only a doctor or nurse, with the patient, can make the decision to start ART. For an adult to start ART, they must have an HIV-positive test result and meet these criteria<sup>vii</sup>:

- **Clinical staging** (a check-up by the doctor looking for specific symptoms and signs of HIV):
  - If the person is very ill, losing weight very fast, and has many opportunistic infections, such as bad diarrhea, they can be started on ART, no matter what the CD4 count.
- **CD4 test:**
  - CD4 below 200, even if the person doesn't show any symptoms
  - CD4 below 350, if the person is showing symptoms, such as TB
  - For pregnant women, everyone who has a CD4 count below 350
- **Patient readiness for ART:**

Patients should be part of the decision to take ART. All people getting ready to start ART should participate in at least 2 group education sessions and one-on-one counseling sessions to make a treatment plan and address barriers.

  - Psychosocial barriers to adherence have been addressed
  - Patient ready and comfortable to start ART
  - Patient understands ARV therapy, possible side effects, limitations, adherence schedule and wants treatment, demonstrates readiness
  - Patient actively involved in his/her own care
  - Treatment partner/family/social support available
  - Schedule to take ART and other logistics like picking up and storing pills worked out
  - No psychiatric illness or substance abuse that would impact adherence
  - No recent non-adherence to care or medication

- Rule out other severe health conditions or current treatment (such as for TB, in which case the TB is usually treated before a person starts ART)
- Determine if the patient is pregnant (ART can and should be started in pregnant women, but certain kinds of ARVs should not be used, like Efavirenz)
- See if the patient has already taken ARVs, and assess which ones and adherence issues
- Opportunistic infections are treated and OI prophylaxis is provided

### 7.3: GOALS AND BENEFITS OF ART

#### ACTIVITY:

##### The trainer should:

- Ask if any of the participants can remember what was learned about how HIV affects the body earlier in the training, such as what HIV does to the CD4 “soldier” cells in the body.
- Review how HIV affects the body if needed.
- Lead a discussion on how ART works in the body and why it’s necessary to take a combination of medicines to fight the HIV. Keep it as simple as possible to make sure all participants understand.
- Ask participants to think of some of the goals of ART – both medically and socially – and list these on flip chart.
- Supplement the conversation using the content below, as needed, and reiterate that ART is not a cure for HIV and that HIV can still be passed from person to person even if they are on ART.

#### CONTENT:

##### How does ART work?

As we learned, HIV attacks the body’s immune system and CD4 “soldier” cells. The virus enters CD4 cells and reproduces itself to make more viruses.

ART works by:

- Preventing HIV from entering the CD4 cells.
- Preventing HIV from growing inside the cells.
- Preventing HIV from leaving the cell to infect other cells.

The reason people need to take many ARVs (usually 3) and not just one or two is because the different drugs work in different ways. Some stop the HIV from entering the cell, some prevent the HIV from multiplying in the cell, and others prevent the HIV from leaving the CD4 cell to infect other cells.

When a person takes ART the right way, it helps the CD4 cells fight back against the HIV and the virus doesn’t attack as many cells. This means the person has more and more healthy CD4 cells that can help the body fight attack and infection.

### **Goals of ART**

- Keep the person healthy by increasing the number of healthy CD4 cells.
- Prevent the HIV from reproducing in the person's CD4 cells.
- Prevent the HIV from leaving one cell and infecting other cells.
- Prevent transmission of HIV from a mother to a baby.
- Keep the immune system strong so the body can prevent and fight infections.
- Make a person feel healthier and able to work, take care of self and family, and be an active member in the community.

### **What does ART NOT do?**

- ART does not cure HIV/AIDS. Once a person has HIV, they will have it for their whole life, even if they feel healthy or their CD4 count is very high.
- Being on ART does not prevent the spread of HIV to another person. ART helps keep the HIV under control in a person's body, but they can still pass it to other people. This is why it's important to always practice safer sex!

### **Benefits of ART**

- Less illness.
- Less trips to the hospital or clinic.
- Increased lifespan and less chance of dying young.
- Return to a "normal" lifestyle (working, going to school, taking care of family and household tasks).
- Continue providing financial support to the family.
- Babies born to women living with HIV can be born without HIV.
- People can feel happier and have a sense of freedom from HIV.
- Improved social life including possibilities of marriage, having a family, and living a long, healthy life.

## 7.4: COMMON ART REGIMENS

### ACTIVITY:

**The trainer should:** *Note: before this session, collect the most common ARVs used at the clinic in their original bottles. Also invite a pharmacist to this session.*

- Ask participants if they know the names of the ARVs that they are taking. How often do they need to be taken? Ask if any of the participants have babies or children on ARVs and other medicines that they are giving and how often they are given.
- Ask participants why it's important for them and other PLWHA to know this information.
- Review the common ARV regimens in Swaziland, making sure expert clients know the common names of the drugs, the dosage, and when and how they are to be taken.
- As drug suppliers in Swaziland often change, ask participants if they've had to switch brands of the same drug and how expert clients can make this less confusing for people.
- Pass around the bottles that the drugs come in and make sure participants know what each drug looks like.
- Ask if there are any volunteers to lead a mock group education session on ART, including explaining the ART regimens to people about to start treatment.
- Ask the group to ask questions as if they were new patients in the treatment program, and remind presenters to use good verbal and non-verbal communication skills.
- Debrief by reminding participants that an important job of the expert client is to help people understand which drugs they are taking, how many, how often, etc. This is especially challenging when drug suppliers change, so expert clients should work closely with the facility pharmacist.

### CONTENT:

Expert clients do not need to memorize every ARV that exists, but they should be familiar with the names, and instructions for the most common regimens in Swaziland. Knowing more about the drugs can also help in communicating with the clinical staff, who may use drug names or abbreviations that are not familiar to patients. During group education and one-on-one counseling sessions, expert clients should talk with patients about which medicines they are taking, why they are taking the medicine, and how often and how they take each one.

Sometimes, patients may have to switch brands of the same drugs depending on what is available in the country. This can be difficult for patients as the shape, size, packaging and dosing or their ARVs may change, even though they are still on the same regimen. Expert clients should work with the pharmacist to be up to date on drug changes, and

help people prepare for this change and make sure that adherence is kept up. The next Unit has more information on adherence counseling.

### Common First Line ART Regimens in Swaziland

Regimen	Name and dose		Timing
AZT+3TC+NVP	AZT/ZDV	Zidovudine 300 mg	Twice daily or every 12hr
	3TC	Lamivudine 150 mg	Twice daily or every 12hr
	NVP	Nevirapine 200 mg	Once daily for 14 days, then twice daily
AZT+3TC+EFV	AZT/ZDV	Zidovudine 300 mg	Twice daily or every 12hr
	3TC	Lamivudine 150 mg	Twice daily or every 12hr
	EFV	Efavirenz 600 mg (400mg if <40 kg)	Once daily, at night
D4T+3TC+NVP	D4T	Stavudine 30 mg if < 60Kg 40 mg if >60Kg	Twice daily or every 12hr
	3TC	Lamivudine 150 mg	Twice daily or every 12hr
	NVP	Nevirapine 200 mg	Daily for 14days, then every 12hr
D4T+3TC+EFV	D4T	Stavudine 30 mg if <60Kg 40 mg if >60Kg	Twice daily or every 12hr
	3TC	Lamivudine 150 mg	Twice daily or every 12hr
	EFV	Efavirenz 600 mg (400mg if <40 kg)	Once daily, at night

If these first-line regimens do not work well, a patient will normally switch to a second line regimen.

**According to national guidelines the recommended second line regimen is:**

ddl (Didanosine) + ABC (Abacavir) + LPV/r (Kaletra)

**The alternative second line regimen is:**

TDF (Tenofovir) + ABC (Abacavir) + LPV/r (Kaletra)

There is more information on ARVs for babies and children in Unit 9 of the curriculum.

## 7.5: SIDE EFFECTS OF ART

### ACTIVITY:

#### The trainer should:

- Introduce the session by asking participants on ART what kinds of side effects they have experienced. How did they feel? How long did they last? What did they do?
- Explain that ARVs are strong drugs and that many people will experience some kind of side effects, but that most are not severe and most will go away with time and as the body gets used to the drugs.
- Prepare flip chart papers with the major categories of side effects listed in the content below. Each flip chart paper should have one side effect written along the top (e.g. headache, diarrhea, rash, can't sleep, tired, numbness/tingling). Post the flip chart papers in different places around the room.
- Give out markers. Ask participants to walk around the room, stopping at the flip charts with the names of side effects/symptoms they have experienced. Ask them to write down what helps make the side effect go away on the flip chart papers. For example, if the flip chart title is "HEADACHE" a participant may write, "cool compresses" underneath.
- Once the participants have circulated around the room, review each flip chart and use the content below to help participants learn about side effects, how to help patients with side effects, and when to tell patients to visit the doctor right away about side effects.

### CONTENT:

**One of the hardest parts of starting ART can be dealing with the side effects.** A side effect is a reaction to the medicine in the body – it can be good or bad, expected or unexpected.

- Expert clients play an important role in helping patients to learn about, prepare for, and manage their side effects, as part of the multidisciplinary care team.
- It's important for patients to know that starting ART is not an immediate cure for feeling badly. The ART will help them feel much better over time, but probably not right away.
- Most side effects will go away after a few weeks of starting ART. During this time of initial side effects, the patient needs to take their medicine the right way, every single day.
- There is a difference between minor or mild side effects that will go away (and patient should keep taking the drugs) and more serious side effects that may mean the doctor or nurse will switch the drugs.
- A patient should never make the decision alone to stop taking some or all of the medicines. This should only be done in consultation with health care workers at the ART clinic.

## Some common side effects from ART and how to manage them<sup>viii,ix</sup>

### Nausea and vomiting:

- Usually goes away in 2-4 weeks.
- Expert clients should tell patients to:
  - Take medicines with food.
  - Eat small meals more often.
  - Stay away from fried or greasy and fatty foods.
  - Stay away from really spicy foods.
  - Drink a lot of clean, boiled water, weak tea, and lemon water.
  - Don't drink too much coffee or strong tea.
  - Stop using traditional medicines which may be making things worse.
  - See the doctor or nurse if there is fever, vomiting more than 3 times/day, inability to drink, stomach pains, dehydration, or confusion.

### Headaches:

- Usually goes away in 2-4 weeks.
- Expert clients should tell patients to:
  - Rest in a quiet, dark room.
  - Put a cold cloth over the face and eyes.
  - Stay away from strong tea and coffee.
  - See the doctor or nurse if it doesn't go away with paracetamol; or if there is fever, vomiting, blurry vision, or convulsions.

### Diarrhea:

- Usually will go away 2-4 weeks.
- Expert clients should tell patients to:
  - Eat small meals during the day.
  - Eat soft foods like rice and bananas.
  - Stay away from spicy, greasy, or fatty foods.
  - Drink sips of clean, boiled water, weak tea, oral rehydration salts, or lemon water.
  - See the doctor or nurse if there is blood or mucous in the diarrhea, if there is fever, if diarrhea occurs more than 4-5 times in a day or for 5 or more days in a row, or if the person loses more than 2 kg.

### Rash and skin problems:

- Expert clients should tell patients to:
  - Keep skin clean and dry.
  - Only use mild soaps.
  - Drink a lot of clean, boiled water to keep skin healthy.
  - See the doctor or nurse if the itching is severe, the skin is peeling, looks infected (for example has pus), is blistering, or has open sores; also if the patient has a fever or if the rash is in the eyes and mouth. If taking the drug Nevirapine, come to see the doctor if there is any kind of rash

**Can't sleep or has nightmares:**

- Usually goes away 2-4 weeks (most common with patients taking Efavirenz).
- Expert clients should tell patients to:
  - Take pills at bedtime.
  - Avoid heavy meals before going to sleep.
  - Avoid drugs or alcohol.
  - Avoid foods or drinks with sugar or caffeine before going to sleep.
  - Talk about feelings and worries with expert clients, friends, or family members.
  - See the doctor or nurse if they are really depressed or suicidal.

**Tiredness:**

- This is very common and can be caused by many things.
- Expert clients should tell patients to:
  - Avoid alcohol and drugs.
  - Do light physical activity, like taking a walk.
  - Eat lots of fruits and vegetables and make sure to get enough iron.
  - Take multivitamins.
  - Try to get enough sleep at night and rest during the day if needed.
  - See the doctor or nurse if they have a drug or alcohol problem or feel really depressed.

**Numbness or tingling feelings:**

- Can be caused by taking D4T and DDI, but also other ARVs and TB medicines, or if there are other infections.
- Expert clients should tell patients to:
  - Wear loose socks and shoes to protect the feet.
  - Check the feet to make sure there are no infection or open sores.
  - Keep feet uncovered when in bed.
  - Soak feet in warm water and massage them if this feels good.
  - Keep feet up.
  - Don't walk too much at one time; take breaks.
  - Eat healthy foods and take multivitamins every day.
  - See the doctor or nurse if they can't walk, are in pain, or weak. Also, if they are on d4T, they can visit the clinic as the doctor may want to decrease the dose.

**Remember: Patients should not stop taking their ARVs if they have side effects! Some side effects are common and most will go away with time, but if the patient thinks they are serious, they should call or visit the clinic right away. The decision to stop or change ARVs should be made by the patient and a health care worker together.**

## 7.6: UNIT SUMMARY

### ACTIVITY:

#### The trainer should:

- Ask participants what they think are the key points of this Unit. What information will they take away from the Unit?
- Summarize the key points of the Unit, using participant feedback and the content below.
- Ask if there are any questions or clarifications.
- Review the learning objectives with participants and make sure each person is confident in their skills and knowledge in these areas.
- If there are areas in which participants need more help or do not fully understand, go back and review the session before moving to the next Unit.

### CONTENT:

#### The key points of this Unit include:

- There are a lot of myths about ART in Swaziland. Expert clients need to know the facts and share correct information about ART with others.
- ART is a lifelong commitment, meaning people have to take the drugs every day, at the same time of day, for their whole lives, even if they feel good.
- ART is not a cure for AIDS.
- HIV can still be spread when taking ART.
- Traditional medicines may be able to help with some symptoms, but they are NOT a replacement for ART.
- There are a number of criteria a person must meet to start ART. These include both medical criteria (stage of disease and CD4 count), and non-medical criteria (like their ability to understand and adhere to treatment). Patients should be part of the decision to start ART with the health care team.
- Since HIV affects the body in different ways, different kinds of ARVs need to be taken to fight HIV. At least 3 types of ARVs should be taken at a time to fight HIV.
- There are different types of ART for adults, but the most common regimens for adults in Swaziland are:
  - AZT (Zidovudine) + 3TC (Lamivudine) + NVP (Nevirapine)
  - AZT (Zidovudine) + 3TC (Lamivudine) + EVF (Efavirenz)
  - D4T (Stavudine) + 3TC (Lamivudine) + NVP (Nevirapine)
  - D4T (Stavudine) + 3TC (Lamivudine) + EVF (Efavirenz)
- If there is treatment failure, the most common second line regimens for adults in Swaziland are:
  - ddI (Didanosine) + ABC (Abacavir) + LPV/r (Kaletra)
  - TDF (Tenofovir) + ABC (Abacavir) + LPV/r (Kaletra)
- The ARV's for babies and children are similar to the ones for adults, the difference is that some come in syrups while others are in capsules and tablets that can be broken or crushed.
- Adults, babies, and children on ART should also take Cotrimoxazole to prevent opportunistic infections.

- Some people on ART have side effects that make them feel very badly. Most side effects go away within a few weeks of starting ART or a new drug. Expert clients can help patients prevent and manage side effects.
- Patients should never stop taking their ART without consulting with the doctor.

## UNIT 8 pMTCT-PLUS (Time: 3 HOURS)

**LEARNING OBJECTIVES:** By the end of this Unit, participants will be able to:

- Understand the difference between pMTCT and pMTCT-Plus programs and services.
- Explain key pMTCT-Plus concepts and interventions for before and during pregnancy, during the time of labor and delivery, and after the baby is born – and the expert clients' role in each.
- Provide basic pMTCT-Plus counseling and referrals to patients at Primary Health Units (PHUs), clinics, and hospitals.
- Explain the importance of ART for pregnant women and link women enrolled in pMTCT-Plus to ART services.
- Provide advice to patients on safe infant feeding.
- Counsel patients on needed follow-up and testing of HIV-exposed babies.

**PRACTICAL SKILLS:**

- Provide basic counseling on pMTCT of HIV and ways to reduce the risk of MTCT before pregnancy, during pregnancy, during labor and delivery, and during infant feeding and beyond.
- Explain why ARVs for all pregnant women living with HIV/AIDS are important to "save 2 lives."
- Link women enrolled in pMTCT-Plus to ongoing care and treatment services.
- Link women enrolled in pMTCT-Plus to follow-up care for her baby.

**MATERIALS NEEDED:**

- Flip chart
- Markers
- ARVs given for pMTCT (both for moms and babies)
- Ball
- Case study cards to hand out

## 8.1: INTRODUCTION TO pMTCT-PLUS

### ACTIVITY:

#### The trainer should:

- Ask if any of the participants have received pMTCT-Plus services or know someone who has. What types of services did they receive? What was good about these services? What could have been done better?
- Give a brief presentation about MTCT in Swaziland, the goals of pMTCT-Plus programs, and key pMTCT-Plus concepts, using the content below.
- Ask participants what role they think expert clients can play in helping more women understand and access pMTCT-Plus services for themselves and their babies? Discuss as a large group for about 10 minutes and then move to the next session.

### CONTENT:

**Maternal to Child Transmission (MTCT)** is the transmission of HIV from a woman living with HIV/AIDS to her baby during pregnancy, labor and delivery, or during infant feeding.

#### MTCT in Swaziland

In Swaziland, about 40% of pregnant women are living with HIV/AIDS. This is higher than just about any other country in the world. There are more than 40,000 babies delivered each year and this means that about 17,000 infants exposed to HIV are delivered every year. Without HIV/AIDS services about 30-45% of these babies will become HIV-infected during pregnancy, delivery, and during breastfeeding. About 50% of HIV-infected babies will die before they are 2 years old. The MOHSW started a national pMTCT program in 2003 to reduce the number of babies exposed to and infected with HIV and to keep mothers healthy during and after their pregnancies.

In Swaziland, the national pMTCT program has 4 prongs. In this training, we will focus mainly on Prongs 3 and 4. The 4 prongs include:

1. Primary prevention of HIV among women of childbearing age
2. Prevention of unintended pregnancies among women living with HIV/AIDS
3. Reduction of MTCT among pregnant women living with HIV/AIDS
4. Care, support, and treatment for women and their families living with HIV/AIDS.

#### pMTCT and pMTCT-Plus Program Objectives

Prevention of mother-to-child transmission (pMTCT) programs started off with the goal to reduce transmission of HIV from mothers to their babies. For a long time, pMTCT programs did not focus on treatment of the mother's HIV or the baby's health after delivery. Based on experience over time, most programs agree that this is too narrow of a focus for pMTCT programs.

**pMTCT-Plus programs include this same goal - to reduce the transmission of HIV from mothers living with HIV/AIDS to their babies - and also emphasize taking care of the mother in her own right, including enrollment in care and treatment programs, careful follow up of HIV-exposed babies, and ongoing support for the whole family.**

This is why we call it pMTCT-Plus – because the focus is on preventing HIV in the baby PLUS taking care of the mother, the baby, and the whole family over time. pMTCT-Plus programs also include HIV prevention to keep families and babies healthy.

### **Benefits of pMTCT-Plus**

Providing family-centered, comprehensive HIV/AIDS care, treatment, and support for mothers, babies, and families has a lot of benefits:

- Fewer babies with HIV
- Healthier moms, babies, and families
- Improved care, treatment, and support for all mothers and children
- Stronger families and communities
- Reduced number of orphans and vulnerable children

### **pMTCT-Plus – Key Concepts**

It's important to remember and explain to patients that not all babies born to women living with HIV/AIDS will become HIV-infected. Without any interventions, about 1 in 3 babies of women with HIV/AIDS will get HIV.

**Key Concept 1 – Keep Moms Healthy:** The healthier the mom, and the higher her CD4 count, the less likely it is that the baby will be HIV-infected.

**Key Concept 2 – Reduce Risk at Every Stage:** The risks of passing HIV from the mother to the child are different at different times during and after the pregnancy.

- During pregnancy, about 5-10 out of 100 babies will get HIV if there is no intervention
- During labor and delivery, about 15-20 out of every 100 babies will get HIV with no intervention
- During breastfeeding, about 10-15 out of every 100 babies will get HIV with no intervention (this depends a lot on how the mom breastfeeds, which is covered later on).

It's important to reduce the risk of transmission at all of these stages.

**Key Concept 3 – All Moms Need ARVs:** One of the best ways to lower the amount of HIV in the mother's body and make her healthy and less likely to pass HIV to the baby is for her to get the care and treatment she needs to be as healthy as possible, including ART. All pregnant women with HIV/AIDS need to take ARVs.

- If a mom has a CD4 count below 350, the baby is at high risk of getting HIV. Women with a CD4 count of 350 or lower, she should start ART.
- If a mom has a CD4 count above 350, the baby has a lower risk of getting HIV that if the mom's CD4 count is low. Women with a CD4 count above 350 should take a shorter course of ARVs (AZT and NVP) during the pregnancy, according to national guidelines.

**Key Concept 4 – All Babies of HIV-Infected Moms Need ARVs:** All babies of women living with HIV/AIDS also need treatment. They need to take ARVs at the time of birth and for the first few weeks of life to help prevent them from becoming HIV-infected. If the baby gets tested and is HIV-infected, s/he may also need ART if eligible.

Remember: If the mom and the baby get the care and treatment they need, including ARVs, the risk of MTCT can be lowered from 1 out of every 3 babies to 1 out of every 50 babies.

## 8.2: pMTCT-PLUS STRATEGIES BEFORE AND DURING PREGNANCY

### ACTIVITY:

#### The trainer should:

- *Note: Before this session, collect samples of the various ARVs given during pMTCT-Plus (Nevirapine, AZT, etc. adult and pediatric formulations).*
- Prepare 4 pages of flip chart, each with one of the following headings: Before pregnancy, during pregnancy, during labor and delivery, after the baby is born. *Note: if trainers are short on time, they can prepare the flip chart pages and ask participants to break up into 4 groups to brainstorm about pMTCT-Plus strategies at each stage, ask the groups to present back, and fill in the content as needed from this and the next couple of sessions.*
- Ask participants to brainstorm about what can be done to prevent MTCT before pregnancy. Record ideas on flip chart and fill in using the content below, as needed.
- Then ask participants to discuss what pMTCT-Plus activities happen during pregnancy. Record these on the appropriately labeled flip chart and highlight the fact that all pregnant moms with HIV/AIDS need to take ARVs.
- Pass around AZT, Nevirapine, and 3TC tablets and syrups to the group and explain how they are taken during and after pregnancy by the mom and the baby. This will help expert clients become familiar with the ARVs and help moms take/give them the right way.
- Ask participants what is meant by the phrase “pMTCT-Plus – saving 2 lives.” Record answers on flip chart. Explain to participants that this is the motto of pMTCT-Plus and a message they should share with moms, partners, and the whole community to show how important pMTCT-Plus services are. Have participants turn to the person sitting next to them and role play how they would explain the motto “saving 2 lives” to a mom that just found out she was positive during an ANC visit.

## CONTENT:

### pMTCT-Plus Strategies<sup>x</sup>

#### pMTCT-Plus strategies before pregnancy

- Prevent HIV transmission in the first place – through good prevention programs that promote:
  - Risk reduction
  - Condoms
  - Being faithful
  - Delaying the age that young people have sex for the first time,
  - Making sure all people understand HIV prevention and have access to services, including condoms and HIV counseling and testing
  - Community support to access HIV prevention services.
- Prevent unwanted pregnancies through good family planning and reproductive health programs. Promote “dual protection” against HIV and pregnancy with condoms or other methods.
  - It’s important to remember that all women have the right to have or not have babies, no matter what their HIV-status.
  - Also remember that women on ART should be provided with good family planning services as part of their care.
- Promote HIV counseling and testing, especially before marriage and pregnancy.
- Make sure people know about sexually transmitted infections (STIs) and get treatment for themselves and their partner(s) right away.
- Improve community knowledge about and support for increasing access to HIV prevention services, like counseling and testing and free condoms.

#### pMTCT-Plus strategies during pregnancy

Expert clients should provide counseling on and promote pMTCT-Plus services in this stage, including:

- Antenatal care for all women (at least 3 visits, but more is better).
- HIV counseling and testing for all pregnant women and their partners, including:
  - Group pre-test education and counseling for all women.
  - HIV testing for all pregnant women (unless they specifically opt out).
  - Taking 2 blood samples for each woman – one for the HIV test and another to do the CD4 test right away if the woman is positive (so that she doesn’t have to have more blood taken and can get CD4 results sooner rather than later).
  - One-on-one post-test counseling for all pregnant women, including:
    - For HIV-negative women, messages on how to stay negative and have a healthy pregnancy and baby.
    - For HIV-positive women, messages that the baby does not have to be HIV-infected and that all pregnant women with HIV/AIDS need ARVs (some will need to start ART right away and others will take a shorter course of ARVs during the pregnancy). Also messages around safe delivery, continuous care and follow-up of mom and baby, and regular CD4 testing.

- ARVs for all pregnant women according to national guidelines:
  - **For women not eligible for ART (CD4 more than 350):**
    - The mother gets AZT two times per day from 28 weeks (7 months) of pregnancy and Nevirapine single dose during labor
    - Baby gets Nevirapine syrup and AZT syrup two times every day for either 7 days or 4 weeks (depending on how long the mom took her ARVs during pregnancy)
    - In some settings, the mother gets a single dose of Nevirapine during labor and the baby gets a single dose of Nevirapine after birth.
  - **For women eligible for ART (CD4 less than 350):**
    - The mother gets AZT + 3TC + Nevirapine each day while she's pregnant, during labor, and after the baby is born
    - Baby gets AZT two times every day for 7 days or 4 weeks (depending on how long the mom took ART during pregnancy)<sup>xi</sup>
- Safer sex and condom use during pregnancy
- Nutrition advice and supplements (iron, multi-vitamins)
- Prevention of malaria, TB, and tetanus
- Treatment of STIs
- Planning for a safe delivery.
- Linkages to mother's support groups and other social support in the community.

**Remember to promote the pMTCT-Plus motto of "saving 2 lives"** – the mom's and the baby's - by enrolling in pMTCT-Plus services, taking ARVs, and coming back to the clinic often.

### 8.3: pMTCT-PLUS STRATEGIES DURING LABOR AND DELIVERY

#### ACTIVITY:

##### The trainer should:

- Ask participants to brainstorm about things that can reduce the risk of MTCT during labor and delivery. Note suggestions on the "labor and delivery" flip chart or ask one of the participants to take notes on the flip chart.
- Fill in missing information using the content below, and highlighting that the most important messages at this stage are that:
  - Women should plan to deliver at a health care facility.
  - Women should continue taking ARVs or take them during labor if they haven't started already and be sure the baby gets ARVs within 72 hours of being born.
  - As much as possible, minimize contact between the baby and the mother's blood and placental fluids.

## CONTENT:

### **pMTCT-Plus strategies near to and during labor and delivery**

Most MTCT of HIV happens around the time of labor and delivery. Expert clients need to work with the multidisciplinary team, and providers in the labor and delivery unit, to make sure women understand and access safe delivery care.

Expert clients should help women to understand and access these services:

- Plan to deliver the baby in a health facility with a trained provider. Talk to partners and other family members about how important it is for the mom and baby to have a safe delivery.
- Encourage mothers with unknown HIV-status to get tested right away.
- Encourage mothers who did not start taking ARVs during pregnancy to take them during labor and delivery, according to national guidelines.
  - The mother gets AZT + single dose of Nevirapine as soon as labor starts
  - Baby gets single dose of Nevirapine within 72 hours of birth and AZT (Zidovudine) 2 times every day for 4 weeks
- Promote good infection prevention practices for all births– keep the delivery area clean, washing hands, cleaning instruments, etc.

## **8.4: pMTCT-PLUS STRATEGIES DURING INFANT FEEDING**

### **ACTIVITY:**

#### **The trainer should:**

- Ask participants to discuss “norms” in Swaziland around infant feeding. Has the HIV epidemic changed this at all?
- For expert clients that have gone through pMTCT-Plus programs, ask if they would like to share some of the things that went into their decisions about infant feeding.
- Lead a discussion about exclusive breastfeeding, mixed feeding, and weaning using the content below. Avoid discussion of the “AFASS” approach, as this is not longer recommended by WHO and will be confusing to participants.
- Ask participants to list some of the key messages they think expert clients should tell women and their families about infant feeding. Record on flip chart and reiterate the importance of exclusive breastfeeding for as long as possible, up to 6 months and then giving complimentary foods with breastmilk until the baby stops breastfeeding altogether (around 12-18 months).

## CONTENT:

### **pMTCT-Plus strategies during infant feeding**

There is HIV in breastmilk. It's important to note that most of the HIV transmission during breastfeeding happens when mothers mixed feed their babies and/or when the mothers are very sick with AIDS, have a low CD4 count, and do not take ART.

- Mixed feeding means giving babies breastmilk together with other liquids, like water, herbal mixtures, or juice or other foods like cow's milk, formula milk, or soft porridge.
- Exclusive breastfeeding means only giving the baby breastmilk (or medicines prescribed by a doctor).

**While there is no risk of HIV transmission when babies get only formula or other replacement feeds, they can be at great risk of malnutrition, diarrhea, and infections that will do them more harm than breastfeeding and the risk of HIV. For most mothers in Swaziland, the risk of their babies dying from diarrhea or malnutrition is much higher than the risk of the baby dying from HIV. Also, there is stigma against women who do not breastfeed and it is often very difficult for the mom to prepare replacement feeds.**

**There is much lower transmission from breastmilk if:**

- The mother is healthy
- The mother is on ART, if eligible
- The baby **ONLY** gets breastmilk for as long as possible, up to 6 months (exclusive breastfeeding)
- Breast infections are prevented and treated right away
- Thrush (white spots, yeast) in the baby's mouth is treated right away

Expert clients should support women to make good decisions around infant feeding and help them implement their infant feeding plan, or change the plan if it's not working. Although expert clients are not sufficiently trained to be infant feeding counselors, they can refer mothers to other members of the multidisciplinary care team for counseling and provide basic information to women and their families.

### **Key messages about infant feeding:**

- Breastmilk is healthy, accepted, free, and prevents diseases in the baby like diarrhea and respiratory problems that could be deadly. Breastmilk is the only food babies need until they are 6 months old.
- Women should take ART if they are eligible as this will decrease the amount of HIV in the breastmilk. Women who are not on ART should exclusively breastfeed and come back to the clinic regularly for monitoring.
- In Swaziland, **exclusive breastfeeding for as long as possible up to 6 months** (no other water, juices, or other liquids and no foods like cow's milk, formula milk, or soft porridge – except medicines prescribed by a doctor) is usually the best and healthiest choice for all babies.
- Women should not wean (stop breastfeeding) before 6 months. Early weaning will cause more harm than good to the baby.

- At 6 months, the baby needs to have other foods as well as breastmilk to get the nutrition s/he needs. Women should meet with a nurse to talk about safely preparing other foods for the baby at 6 months.
- The baby can have breastmilk and other foods until it is 12-18 months old and/or the mother stops breastfeeding completely. Moms should not stop breastfeeding if there are not enough healthy foods for the baby to eat.
- Even if the baby is tested and found to be HIV-infected, the mother should keep breastfeeding.
- Women should watch out for breast infections (cracking, sore nipples, strange discharge from nipples, pain, etc.) and come to the clinic right away if this happens.

### 8.5: pMTCT-PLUS STRATEGIES DURING THE POSTNATAL PERIOD

#### ACTIVITY:

##### The trainer should:

- Lead a discussion on postnatal care using the content below, emphasizing that this is often the time when mothers and babies are “lost” and not followed-up. Although mothers bring their babies back for immunizations, the baby isn’t recognized as being HIV-exposed or in need of HIV care and treatment by health care workers.
- Stress that expert clients have a key role to play in making sure women and babies are not “lost” and that they come back to the clinic for regular care and treatment for themselves and the baby. Expert clients can help the mother demand the services she and the baby need by telling all health care workers about her HIV-status and that the baby has been exposed to HIV.
- Ask participants what they think can help reduce the number of lost mothers and babies after delivery. What can help mothers and babies come back to the clinic after delivery and make sure the health care workers know the mother has HIV and the baby has been exposed? What roles do expert clients have in following up mothers and babies in the postnatal period?

#### CONTENT:

All babies born to women with HIV/AIDS are exposed to HIV because they shared blood and fluids with the mother. This does not mean that they will all become HIV-infected. In fact, many babies will escape HIV infection, especially if the mother and baby get care and treatment. It’s important to explain follow-up care to mothers and families very well and make sure that they are not lost after the baby is delivered. There is a lot that can be done to keep the baby healthy when it has been exposed to HIV and there are tests that can be done to tell if the baby itself is HIV-infected.

## **pMTCT-Plus strategies during the postnatal period**

### **For the mom and family:**

- If possible, link women with community health workers who can visit them regularly in their homes in the days/weeks after birth. Women who have heavy bleeding or signs of infection should come back to the hospital or clinic right away. Babies who have a fever, are crying or sleeping all the time, look yellow, or are not eating well should also come back to the hospital/clinic right away.<sup>xii</sup>
- Make sure that women are enrolled in care and treatment programs, have adherence support, and are on/continue taking ART if they are eligible.
- Pregnant women should be advised to get a CD4 count after they deliver the baby, especially to see if they are now eligible for treatment (if not on treatment already).
- Counsel the mom and family on follow-up of the baby, including Cotrimoxazole prophylaxis after the baby is 6 weeks old, importance of routine child care visits for immunizations, etc., and HIV testing options for the baby and the timing and meaning of these tests.
- Help create demand for needed HIV services by encouraging the mom to tell health care workers that she has HIV and that the baby has been exposed.
- Provide emotional support.
- Discuss family planning options.
- Linkages to support groups, nutrition for the mother, and income generating activities.

### **For the baby:**

- Make sure the baby goes for check ups and gets immunizations on schedule.
- Make sure the mother tells all health care workers that the baby has been exposed to HIV.
- Look for and treat oral thrush in the baby.
- Make sure the baby is getting good nutrition and growing well.
- Explain to the mother that the baby needs to start taking Cotrimoxazole at 6 weeks of age. Cotrimoxazole helps prevent infections and keeps the baby healthy.
- Counsel the mom on early infant diagnosis and testing the baby. The baby may need 2 tests:
  - Once the baby is 6 weeks old, a small amount of blood can be taken from the baby's heel and a test conducted to see if the baby is HIV-infected. The test tries to find out which children are HIV-infected as early as possible so they can get the care and treatment they need. Remember, even if the baby is HIV-infected, the mother should continue breastfeeding.
  - The test will have to be repeated later on when the baby is about a year and a half old and is not breastfeeding anymore.

## 8.6: LINKING pMTCT-PLUS AND ART SERVICES

### ACTIVITY:

#### The trainer should:

- Remind participants that one of the best things to prevent MTCT is for the mother to stay healthy, take ART, and adhere to her own care and treatment.
- Ask participants to think about how expert clients can make sure women and their babies are offered pMTCT-Plus, care and treatment, and routine child health care services when they are all in different places in the hospital/clinic and provided by different doctors and nurses. List solutions on flip chart and discuss this important component of the expert client program.
- Mention that multidisciplinary team meetings are a good starting point to link different services and follow-up mothers and babies, as well as actually walking mothers and babies from one point to another in the facility.

### CONTENT:

We've talked about the need for pregnant women to enroll in pMTCT-Plus and be linked to care and treatment. Even though this is important to prevent MTCT and to take care of the mother and family over time, there are many challenges with these linkages at hospitals and clinics in Swaziland.

#### Some of the challenges of linking pMTCT-Plus and ART services include:

- Services are located in different parts of the hospital and it's difficult for women to go to multiple service delivery points on different days.
- Services are given by different providers with no one person coordinating the mother or the baby's care.
- Records don't give information on where else in the hospital a patient has been seen or the results of visits to other hospital services.
- There are no formal referral systems in place from one service to another in the hospital and even if a referral is made, there is no way to follow-up to see if the mother and baby went for other services to which they were referred.
- Mothers and families aren't always given the counseling they need to understand how important it is to enroll in and adhere to care and treatment.

#### Some possible solutions to link pMTCT-Plus and ART services:

- Facilities can strengthen the care portion of services so that women who are not eligible for ART are still seen regularly for care, get medicines like Cotrimoxazole to prevent infections, receive CD4 testing, get counseling, etc.
- Facilities can develop intra-facility referral forms and follow-up systems between pMTCT-Plus, ART, and other services (like TB, family planning, etc.).
- Expert clients can provide quality information and counseling to women on the benefits of pMTCT-Plus and ongoing care and treatment for herself and other family members.

- Expert clients can literally walk with patients from one part of the hospital to another and help them understand why they are being referred and what to expect.
- Expert clients can also work with other multidisciplinary team members to prioritize pregnant women for care and treatment, for example, ensuring that they are not made to wait long hours at the clinic or that there are family care and treatment days where the mom and baby can be seen at the same time by one doctor.
- Expert clients can keep their own records about which women they should follow-up with. For example, they can keep a list of all pregnant women eligible for ART and make sure that each comes to scheduled appointments or that women who are especially sick are prioritized.
- The multidisciplinary team, including expert clients, can hold case discussions about pregnant women and how to get them enrolled in and adhering to care and treatment.

## 8.7 REVIEW OF KEY pMTCT-PLUS MESSAGES

### ACTIVITY:

#### The trainer should:

- *Note: the trainer should be sure to bring a ball to this session.*
- Lead a game to help review the key pMTCT-Plus messages expert clients should understand. Ask participants to stand in a circle. Throw a ball to one participant and ask them to say one of the key pMTCT-Plus messages. When they are done, ask them to throw the ball to another participant who will say another key message. Continue until most of the key messages are reviewed.
- Supplement using the content below if needed.

### CONTENT:

#### Some key pMTCT-Plus messages:

- The pMTCT-Plus motto is "SAVING 2 LIVES" – the mom's and the baby's.
- Not all babies born to women living with HIV/AIDS will be HIV-infected.
- MTCT can happen during pregnancy, during the time of labor and delivery, and during breastfeeding, especially with mixed feeding in the first 6 months.
- Pregnant women should be prioritized for HIV care and treatment with ART if they are eligible.
- Half of pregnant women with HIV/AIDS need ART in Swaziland.
- Most ARVs will not hurt the baby and this is one of the best ways to prevent MTCT.
- For most women in Swaziland, exclusive breastfeeding for as long as possible, up to six months, is best for the baby.
- It's not good to stop breastfeeding before 6 months.
- After 6 months, other foods need to be given as well as breastmilk.
- Mothers should only stop breastfeeding when there is a good, safe supply of replacement foods for the baby (up to 12-18 months).

- All HIV-exposed babies should get follow-up care and take Cotrimoxazole until their HIV status is known for sure.
- There is a test available at some health facilities that can tell if a baby is HIV-infected. A baby can get the test after it's 6 weeks old.
- Women and their babies should keep coming back to the clinic for care and treatment, child health and other services.
- Expert clients should help women receiving pMTCT-Plus services enroll in the care and treatment program, receive follow-up services for themselves, their babies, and other family members; join support groups; and find nutritional and other support services in the community.

## 8.8: CLASSROOM PRACTICUM ON pMTCT-PLUS

### ACTIVITY:

#### The trainer should:

- Ask if there are questions or areas where participants need clarification on knowledge and skills related to pMTCT-Plus.
- Remind participants that they play an important role in promoting these services, preparing people for pMTCT-Plus, and following-up with moms and babies after they receive these services.
- Divide the groups up into smaller groups of 3 and do rotating role plays where one person acts as the pregnant woman, another as the expert client, and the third observes and gives constructive feedback. Use the case studies below or ask participants to write their own case studies based on personal experience.
- The trainers should rotate around the room and provide feedback to the small groups during the activity.
- Have the groups perform some of their role plays to the large group.
- Debrief as a group after the rotating role plays and answer any remaining questions.

### Case Study 1:

A 22-year old woman comes to the ART clinic for a regular appointment. She is doing well on her ART regimen and confides in you that she really wants to have a baby. She has discussed it with her husband, who is also living with HIV/AIDS, but he told her that it's not responsible for them to have a baby because it will definitely be born with HIV. What would you tell her about pMTCT-Plus services, family planning, etc.?

### Case Study 2:

You are sitting next to a pregnant woman on the bus while you are on the way to the hospital. The two of you start talking and you learn that she is about 4 months pregnant. You learn that she has not visited the doctor since she got pregnant, but is going for her first antenatal check up now at the PHU. So far, she has only been taking herbal mixtures from her neighbor. You tell her you are an expert client and she asks you to tell

her more about what to expect at the PHU today. How would you counsel her and prepare her for this visit? What would you tell her about HIV testing and pMTCT-Plus?

**Case Study 3:**

You are talking with a pregnant woman who just received her CD4 test results, which are 150. You sense that she doesn't understand why the CD4 test was done or what the number means. She hasn't disclosed to her partner yet and is very afraid that her baby will have HIV. What things would you talk to her about?

**Case Study 4:**

A woman comes to the hospital with her husband for a regular appointment and to pick up ARV refills. You notice that she is pregnant and start talking with the couple. She was tested for HIV during pMTCT and found out that she is positive, as is her husband. They are both on ART, but don't know much about pMTCT. What types of things would you discuss about her pregnancy, the upcoming delivery, and infant feeding?

**Case Study 5:**

A woman comes to the PHU for her first antenatal care visit. She has an HIV test which is positive. She is very upset because she's certain that she's been cursed and her baby will have HIV for sure. You discuss ARVs with her to protect herself and the baby, but she says that ARVs will kill the baby – they are too strong to take while pregnant. What would you tell her about ART during pregnancy?

**Case Study 6:**

You are worried because you haven't seen a patient in quite a long time. She was enrolled in pMTCT-Plus and came to all of her antenatal care appointments, but you haven't seen her since she delivered the baby. You want to discuss this at the next multidisciplinary team meeting to develop a plan to follow-up and get her back for care and treatment. Prepare what you will say to the group.

**Case Study 7:**

You meet a woman who has just come to the hospital with her 8-week old baby. The mom is living with HIV/AIDS. She wants to know if her baby has HIV. She is worried that her husband and mother-in-law will be very angry with her if the baby is HIV-infected. She feels very lonely and afraid. What would you tell the mother about testing the baby, care for the baby and herself, and safe breastfeeding?

## 8.9: UNIT SUMMARY

### ACTIVITY:

#### The trainer should:

- Ask participants what they think are the key points of this Unit. What information will they take away from the Unit?
- Summarize the key points of the Unit, using participant feedback and the content below.
- Ask if there are any questions or clarifications.
- Review the learning objectives with participants and make sure each person is confident in their skills and knowledge in these areas.
- If there are areas in which participants need more help or do not fully understand, go back and review the session before moving to the next Unit.

### CONTENT:

#### The key points of this Unit include:

- About 40% of pregnant women in Swaziland are living with HIV/AIDS, so pMTCT-Plus services should be the “norm.”
- pMTCT-Plus programs try to reduce risk of HIV to the baby, but also try to give the mother, the baby, and the whole family ongoing care, support, and treatment.
- The pMTCT-Plus motto is “SAVING 2 LIVES” – the mom’s and the baby’s.
- Not all babies born to women living with HIV/AIDS will have HIV. About 1 out of 3 will become HIV-infected if there are no pMTCT-Plus interventions.
- MTCT can happen during pregnancy, around/during labor and delivery, and during breastfeeding, especially with mixed feeding in the first 6 months.
- Most HIV transmission happens during labor and delivery.
- There are many things that can be done to prevent MTCT before pregnancy, during pregnancy, during the time of labor and delivery, and during the postpartum period and infant feeding. Expert clients should be familiar with interventions at each stage and talk to people about the importance of pMTCT-Plus services.
- Pregnant women should be prioritized for HIV care and treatment with ART if they are eligible. Most ARVs will not hurt the baby and this is one of the best ways to prevent MTCT.
- Half of pregnant women living with HIV/AIDS in Swaziland need ART.
- Breastmilk is the only food babies need until they are 6 months old.
- Women should exclusively breastfeed the baby for as long as possible, up to 6 months.
- Stopping breastfeeding before 6 months is not good for the baby.
- At 6 months, the mom should add other foods and continue breastfeeding.
- The mom can give breastmilk and other foods for up to 12-18 months, and should only stop breastfeeding when there is a good supply of other foods available.
- All HIV-exposed babies should be followed-up and given Cotrimoxazole until we know if they are HIV-infected – this can take up to 12-18 months.

- Babies exposed to HIV may need two tests to tell if they are HIV-infected: one when they are 6 weeks or older and another once they are over a year old and have stopped breastfeeding.
- Expert clients should help women receiving pMTCT-Plus services enroll in the care and treatment program, receive follow-up services for themselves and their babies and other family members, join support groups, and find nutritional and other support services in the community.

**UNIT 9**  
**PEDIATRIC CARE AND TREATMENT**  
**(Time: 2 HOURS)**

**LEARNING OBJECTIVES:** By the end of this Unit, participants will be able to:

- Discuss why it's important to give special attention to babies and children with HIV/AIDS in the health facility.
- List different ways HIV-exposed and infected babies and children can be found and brought into care and treatment.
- Understand when and how HIV can be diagnosed in infants and children.
- Help counsel families/caretakers on needed follow-up of babies exposed to HIV during pregnancy and breastfeeding.
- Understand what ART regimens are available for children in Swaziland.

**PRACTICAL SKILLS:**

- Provide information to families/caretakers on HIV testing in babies and children, including early infant diagnosis.
- Talk with families/caretakers about the importance of bringing back HIV-exposed babies to the clinic and keeping them as healthy as possible.
- Help families/caretakers understand the need for and prepare to start giving their children ART.

**MATERIALS NEEDED:**

- Flip chart
- Markers
- DBS cards and bar code labels
- Pediatric ARVs (including Keletra suspension) and supplies to give them (e.g. syringes)
- Spoons for Keletra taste test
- Case study cards to hand out

## 9.1: PEDIATRIC HIV/AIDS IN SWAZILAND

### ACTIVITY:

#### The trainer should:

- Introduce the unit by reminding participants of the goals of pMTCT-Plus programs, which include following-up and caring for babies.
- Explain that there was some information on pediatrics in the last unit, but that this unit will go more in depth into the needs of babies and children infected with HIV/AIDS. Remind participants that expert clients have a key role to play in getting babies and children enrolled in care and treatment (with the whole family if possible) and sticking with the care plan in the long-term.
- Ask participants to discuss why care and treatment is so important for babies and children with HIV/AIDS, highlighting that without ARVs, most will die before their 2<sup>nd</sup> birthday.
- Ask participants to brainstorm the special needs of babies and children with HIV/AIDS, drawing from personal experiences, and record on flip chart.
- Ask participants caring for children with HIV/AIDS what some of the challenges are and record on flip chart, filling in using the content below as needed.

### CONTENT:

There are more than 40,000 babies delivered each year in Swaziland and since so many women are living with HIV/AIDS, this means that about 17,000 infants exposed to HIV are delivered every year. Right now, there are 15,000 babies and children living with HIV/AIDS in Swaziland. But, only 10% of them are getting the care and treatment they need to stay alive.

#### Importance of pediatric care and treatment

- Children are not little adults. Adults can live many years with HIV before they get sick. But, children are not as strong and get sick very quickly once infected with HIV. 50% of babies with HIV will die before their 2<sup>nd</sup> birthday without care and treatment.
- Caring for sick children and having a child die can be very hard emotional experiences for families.
- Children are the future of Swaziland and we need to keep them healthy to build strong communities and a strong nation.
- Babies and children with HIV/AIDS who are in care and take ARVs can live long, healthy lives and grow up to be healthy adults.

#### Challenges to pediatric care and treatment

- Moms in pMTCT-Plus programs don't always bring their babies back to the clinic, or if they do, the health care workers don't know that the baby has been exposed to HIV.
- It's hard to find babies that are in need of care and treatment and waiting too long means the babies will probably die.

- Adult HIV tests don't tell if a baby is infected – they are only useful if the baby is one or more years old.
- Early infant diagnosis is now available in Swaziland, but not in all areas and many moms don't have the facts about early testing.
- Many children with HIV/AIDS may be orphans and without a consistent caretaker and instructions about their care and treatment is given to different people, which makes their follow up difficult.
- Health care workers may not be used to working with children or know about pediatric care and treatment.
- Children have to rely on adults to give their medicines and bring them to the clinic for appointments, which may be a challenge, especially if the caretaker is sick.
- It's hard to talk about HIV with children or tell them their status.
- There aren't many easy to use ART regimens for children in Swaziland.
- Doses of ARVs change all the time for children because they are based on the child's weight. This can make it hard for the caregiver to give the right dose.
- Many caregivers don't want to tell their children, other family members, or people in the community that the child has HIV/AIDS.

## 9.2: HOW TO IDENTIFY BABIES THAT ARE HIV-INFECTED

### ACTIVITY:

#### The trainer should:

- Ask participants to think of places where we can find babies and children that may need HIV/AIDS care and treatment and record on flip chart. Remind participants that while pMTCT services are a good place to start, there are many other places where we can look for sick babies and children and bring them into care and treatment.
- Ask if any of the participants have heard of Dried Blood Spot or DBS. Explain HIV testing in babies and pass around DBS cards and barcode stickers so that participants will recognize them when they are back at their sites.
- Explain that children over 12 months (1 year) of age can be tested with the standard rapid test used on adults, but that special counseling must be given to the caretaker, especially if the child is still breastfeeding.
- Remind participants of the key role of the expert client in finding exposed babies and making sure they are tested, and that the results are picked up and understood by the mom or caretaker.

## **CONTENT:**

(Reminder from Unit 8): All babies born to women with HIV/AIDS are exposed to HIV because they shared blood and fluids with the mom. This does not happen in all pregnancies; therefore many babies will escape HIV infection, especially if the mother and baby get care and treatment. It's important to explain follow-up care to moms and families very well and make sure that they are not lost after the baby is delivered. There is a lot that can be done to keep the baby healthy when it's been exposed to HIV and there are tests that can be done to tell if the baby itself is HIV-infected.

### **Finding babies and children and bringing them into care**

pMTCT programs are one of the best ways to find babies exposed to HIV who should be tested and enrolled in care and treatment. But, there are other places where expert clients should help the multidisciplinary team and community workers find sick babies since not all will get pMTCT services or come back for follow-up, including in:

- Under 5 clinics
- Pediatric inpatient wards
- Adult ART clinics (by asking patients about their children)
- Health centers and hospital outpatient departments where babies and children are taken when they're sick
- Community health workers and community-based organizations, especially those working with orphans
- Traditional healers who may be a first point of contact for sick children

In each of these places, health workers should be trained to recognize symptoms of HIV/AIDS in babies and children and refer them to the ART clinic. Since expert clients will work mainly at the hospitals and health centers, they play a key role in following up with health care teams and families with sick children and getting them in care and treatment. It's important to remember that while most babies and children living with HIV/AIDS in Swaziland were infected through MTCT, others may have been victims of sexual abuse. Expert clients should always turn to a professional counselor or other member of the multidisciplinary care team in these situations.

### **HIV testing in babies and children**

Because most babies born to women with HIV/AIDS will test positive for HIV in the first 12 months of life, it's best to test babies under 12 months using "DNA PCR testing" with Dried Blood Spots, or DBS. This is a new service available in Swaziland so expert clients play a key role in helping mothers and caretakers understand the test and the results. This is the only way to know if a baby under 12 months is actually HIV-infected.

### **For babies under 12 months of age:**

- Counsel the mom on early infant diagnosis and testing the baby. The baby may need 2 tests:
  - Once the baby is 6 weeks old, a small amount of blood can be taken from the baby's heel and a test conducted to see if the baby is HIV-infected. The test tries to find out which children are HIV-infected as early as possible so they can get the care and treatment they need.

- Once the mother is counseled by the nurse and the baby's blood is taken, the sample will be sent out to be tested. It can take up to one month to get the results back.
- Nurses and expert clients should make sure mothers understand that the results will take time and schedule an appointment for the mother and baby to return to the clinic to pick up results.
- If the result of the test is positive, the baby is HIV-infected and many babies should start ARVs right away (depending on the stage of HIV/AIDS and their CD4%). If the result of the test is negative and the mom is still breastfeeding, she should keep breastfeeding and then retest the baby 3 months after she's stopped breastfeeding completely.
- Some moms are scared to have their babies tested because of lack of information about what services will be available to the baby if the test is positive. Expert clients need to explain to moms (and other caretakers) that there is help available for the baby and that the sooner they know the baby's HIV-status the more quickly the baby can take medicines to avoid being sick.
- During counseling, expert clients should help the mom think about her support system - who will help her look after the baby if the baby is HIV-infected? Who will help come to clinic appointments? These people can be their treatment supporter when the baby starts taking medicines.
- You can tell if a baby has had a DBS test because there should be a bar code on the file kept at the clinic. Expert clients should look for these bar codes and follow-up to see if the mom or caretaker has picked up the results. If not, they should encourage her to know her to get her results.

**For children over 12 months (1 year) of age:**

- Once children are over 1 year old, they can be tested for HIV with the standard rapid test used on adults.
- If the child is still breastfeeding, they should be retested once the mother has completely stopped breastfeeding.
- There are special consent issues for HIV testing in children and caregivers need to be given special pre- and post-test counseling focusing on pediatric issues. After counseling, the caregiver can give consent to have the child tested. Both parents do not need to give consent to have the baby tested. Any main caretaker of the child (mom, dad, auntie, others...) can give consent, even if it is not the mom or dad.

### 9.3: CARING FOR BABIES EXPOSED TO HIV

#### ACTIVITY:

##### The trainer should:

- Present the content below about caring for babies exposed to HIV and record key points on flip chart. Encourage participants to ask questions.
- Ask if any participants are caring for children that take Cotrimoxazole and have volunteers share their understanding of why it's important to keep babies healthy, how often it's given to the baby, in what dose, etc.
- Ask participants why it's important to weigh and measure all babies, and especially babies that may have HIV.
- Review the 5 key points on caring for babies exposed to or infected with HIV:
  - Come back often
  - Early HIV testing
  - Cotrimoxazole every day
  - Weigh and measure at every visit
  - Focus on the whole family

#### CONTENT:

The most important thing for babies exposed to HIV and babies and children with HIV/AIDS is that they **come back to the clinic very often** to see the doctor. Babies with HIV will get sick very quickly and they need to be seen at the clinic more often than adults with HIV. Expert clients should counsel moms and other caretakers about bringing the baby back to the clinic every month for a check-up and whenever they are sick.

#### Caring for babies exposed to HIV/AIDS

Right away after the baby is delivered to a mom with HIV/AIDS:

- The baby should get a single dose Nevirapine within 72 hours of birth and AZT (Zidovudine) 2 times every day for 4 weeks (or 7 days if the mom took ART during pregnancy or 1 month or more of AZT)

At 6 weeks of age:

- All exposed babies should start taking Cotrimoxazole. This is one of the best ways to keep babies healthy and prevent illness. Babies exposed to HIV or with confirmed HIV infection should take Cotrimoxazole EVERY DAY.
- The dose of Cotrimoxazole will depend on the baby's weight. This is one reason why it's important for the mom or caretaker to bring the baby to the clinic every month – so the baby can be weighed and the dose changed to have the best impact on the baby's health.
- Where available, babies should get early infant diagnosis with DBS as soon as possible after 6 weeks of age as explained in the last section.

Ongoing:

- If the baby has been tested and is HIV-infected, a CD4 test needs to be done. This is similar to the test done with adults, but instead of an actual number, the

test for babies gives a CD4%. It's important for expert clients to understand the difference between adult and pediatric CD4 test results and help explain to parents and caretakers. CD% will be interpreted by the health care workers.

- Babies should keep taking Cotrimoxazole until it's definite that they are not HIV-infected and they are no longer breastfeeding.
- Make sure the baby goes for check ups and gets immunizations on schedule.
- Health care providers should look for and treat opportunistic infections.
- Make sure the baby is getting good nutrition and growing well. The doctors or nurses will **weigh, measure, and examine the baby at every visit** to see if it is growing and developing normally. The baby's height, weight, and head measurement should be recorded on a growth chart at each visit. This is one of the best ways to see if a baby is healthy and changes in the baby over time. Expert clients may be asked to help weigh and measure babies and will have a chance to do so in the practicum.

### **Family-focused care**

Having a sick baby and/or knowing that the baby may have HIV can be a very hard thing for parents and caretakers. It's important for expert clients to spend time talking with the family about how they are feeling and making sure they understand what is happening with the baby (tests, medicines, side effects, etc.) in easy to understand terms. Remember, HIV is a family disease and parents of sick babies will often themselves be sick and in need of care and treatment and support to adhere, disclose to others, or seek community support services. Parents and caretakers should be active in the baby's care and monitoring as they often know best when "something isn't right" with the baby (the baby is crying all the time, the baby isn't eating, the baby isn't sitting up or playing, etc.). Whenever the baby isn't doing well, parents and caretakers should be encouraged to trust their instinct and bring the baby to the clinic right away.

Expert clients should also ask about all caretakers of the baby, as they often change. All caretakers should know what's going on with the child's health and care and treatment plan.

### **5 key points about caring for babies exposed to or infected with HIV/AIDS**

- Come back often
- Early HIV testing
- Cotrimoxazole every day
- Weigh and measure at every visit
- Focus on the whole family

## 9.4: PEDIATRIC ART

### ACTIVITY:

#### The trainer should:

- *Note: Before the session the trainer should collect all pediatric ARVs available and supplies to give the medicines, such as syringes to draw up and measure syrups.*
- Ask participants if they think ARVs for children are the same as ARVs for adults, and if not to list some of the differences.
- Ask participants caring for children with HIV/AIDS what ARVs they give, how much, how often, and some of the challenges in giving medicines to children every day. Encourage participants to ask questions of others that have first hand experience with pediatric ART.
- Review the common ART regimens for babies and children in Swaziland, stressing that the doses always depend on the child's weight.
- Work with the guests from the multidisciplinary care team to demonstrate how pediatric ARVs are given and give participants a chance to practice drawing up specific amounts of syrups, crushing and dissolving pills, etc.
- Debrief by asking participants what was difficult and what challenges parents and caretakers of children with HIV/AIDS may face. Discuss what the expert client can do to help with pediatric ART patients and their families.

### CONTENT:

As with adults, the use of ART with babies and children with HIV/AIDS can keep them healthy, strong, and able to live a whole lifetime. But, the use of ART in babies and children is not always easy and is more complicated than ART in adults. Pediatric ART regimens are not always available and can be more difficult than for adults, children depend on caregivers to give their ART and take them to the clinic, and doses and regimens change often with children depending on their age and weight.

Expert clients need to be advocates for access to pediatric ART in Swaziland and help babies, children, families, and other caregivers get the services they need.

#### Key issues for pediatric ART

- Success depends on teamwork and the relationship between a child and the caregiver(s). There are often many caregivers in a child's life – like the “committee of aunts” involved with the child on a daily basis. All members of the family and all caretakers must be prepared to give the child ART at the same time every day. The child must cooperate and be involved in their treatment as well.
- There are many barriers to adherence with pediatric ART. Children may not want to take the medicines, they may be away at school for many hours of the day, or caretakers may be at work or not always with the child when the medicines need to be given.

- Caregivers may also be living with HIV/AIDS themselves. If the parent or caregiver has not disclosed their HIV-status it makes it hard to tell people about the child's HIV-status. The family or other caregivers will not know what kinds of care and treatment the child needs if they do not know the child's status.
- ART preparation and support is very important for pediatric ART before the child starts the ART and ongoing.
- Pediatric ARVs aren't always available in syrup form, so pills may need to be crushed or dissolved in water or juice, adding extra time to the caretakers' day.
- Some of the pediatric ARV syrups taste very bad.
- The dose of different ARVs will change often in children because it depends on their weight. It can be hard for caretakers to remember the right dose to give since it changes as the child grows.

### When to start ART

Only a doctor can decide if a pediatric patient is eligible for ART through exams and tests, like the CD4%. Most babies and children with HIV/AIDS will need ART since they get sick quickly and are at great risk of illness and death. Once the doctor decides the patient is eligible, the caretakers need to be well-prepared for the challenges ahead. Expert clients can help caretakers understand pediatric HIV and make an ART adherence plan with the multidisciplinary care team. Success with pediatric ART depends on a partnership among the caregiver(s), the child, and the multidisciplinary care team.

### Common pediatric ART regimens in Swaziland

There are special types of ARVs for babies and children in Swaziland – some are in the form of syrups and some are pills that need to be broken and crushed or mixed with water. Adult ARVs should not be used in children unless the doctor says it's ok to do so. Remember, all babies and children with HIV/AIDS should also take Cotrimoxazole. The dose of each ARV depends on the child's weight, so there is no "standard" dose like in adults. The only way to know the right dose is to visit the clinic often so the child can be examined and weighed to decide on the right dose.

Pediatric ARV regimens are changing all the time in Swaziland, but the table below includes the most common first- and second-line regimens used. Hopefully, more regimens, and ARVs that are easier for children to take, will become available in Swaziland soon.

Regimen	Full Name (dose depends on child's weight)	
<i>First-line:</i> <b>d4T+3TC+NVP</b>	D4T	Stavudine
	3TC	Lamivudine
	NVP	Nevirapine
Notes:		
<ul style="list-style-type: none"> <li>○ If family does not have cold storage for d4T, give AZT instead of d4T</li> <li>○ Children over 3 years old can also take EFV</li> </ul>		
<i>Second line:</i> <b>ABC+ddI+LPV/r</b>	ABC	Abacavir
	ddI	Didanosine
	LPV/r	Kaletra

Just like with babies and children in care, the most important thing for pediatric ART is that people come back to the clinic often to see the doctor! Like with adults, it's very important that ARVs are taken the right time, the right way, at the same time every day!

## 9.5: PREPARING FAMILIES FOR PEDIATRIC ART

### ACTIVITY:

#### The trainer should:

- Ask if any of the participants have children on ART or if they know anyone who does. Ask what the challenges are of helping children adhere to their care and treatment plan?
- Conduct a taste test with Kaletra (ensuring participants that it is safe just to taste a small amount). Note participants' reactions to the taste and ask how it must be for moms to give this to their baby 2 times each day. How might the taste impact adherence?
- Fill in any missing information using the content below and remind participants that issues of adherence and disclosure for adults and children will be discussed in the next Units of the training.

### CONTENT:

Adherence can be difficult for children and their caretakers. Pediatric ARVs may be hard to give (measuring syrups or breaking pills) and the doses change over time, based on the child's weight and development. Telling a child that s/he is living with HIV/AIDS can also be really hard for a parent or caretaker. There is more about pediatric disclosure in Unit 11. Even though there are many challenges, more and more babies and children in Swaziland have access to the HIV/AIDS care and treatment they need to live longer and be healthy.

#### Expert clients can help caregivers and children on ART in many ways:

- Help counsel and educate families on HIV/AIDS, adherence, why it's important, treatment plans, and how important it is to ask the doctor, nurse, expert client or other member of the team if they don't completely understand something.
- Help prepare the child and caretakers for ART and give peer support (mothers support groups are really helpful in some places). Work with the multidisciplinary care team to help the family find answers to questions such as:
  - **Who will give the child the medicines?** Ideally, many people should be trained to give the child medicine, not just the mother for example. But, this might be hard if the mother has not disclosed her own or the child's HIV-status.
  - **Which medicines will be given?** Help the family with medicine identification, storage, measuring, and giving it to the child.
  - **When will the medicines be given?**
  - **How will the medicines be given?** How are syrup doses measured? Do pills need to be broken or crushed? Does one of the medicines taste really

bad? Should they be taken at the same time? What if the child spits out the medicine?

- **Ask about adherence at every visit and work as part of the multidisciplinary care team to support adherence.** Children may have different issues with adherence over time, as they grow. For example, an infant may easily swallow syrup, but then when they get older refuse to swallow a pill because it tastes bad. Remember to always treat patients and their families with respect and never to judge.
- **Offer counseling, psychosocial support, and linkages** to community resources (like nutrition support and educational support for children) at each visit.

## 9.6: CLASSROOM PRACTICUM ON PEDIATRIC CARE AND TREATMENT

### ACTIVITY:

#### The trainer should:

- Ask if there are questions or areas where participants need clarification on knowledge and skills related to pediatric care and treatment.
- Remind participants that they play an important role in promoting these services, preparing children, parents and other caregiver for care and treatment, and following-up.
- Divide the groups up into smaller groups of 3 and do rotating role plays where one person acts as the mother/caregiver, another as the expert client, and the third observes and gives constructive feedback. Use the case studies below or ask participants to write their own case studies.
- The trainers should rotate around the room and provide feedback to the small groups during the activity.
- Ask some of the groups to perform their role play in front of the large group and discuss.
- Debrief and answer any remaining questions.

### Case Study 1:

Muzi is 3 months old. His mother is HIV-positive and has brought him to the clinic. The mother says that she is breastfeeding the baby but complains that he does not feed well, cries a lot, and she is thinking of adding other foods so that the baby can get full and stop crying. When you talk to the mother, she says her partner has bought her formula which she will give in addition to breastfeeding and her mother suggested that she should add some porridge so that the baby can be full and stop crying. You also notice that the baby has got sores in the mouth.

### Case Study 2:

Ncobile is a 5 year-old child who has been on ART for the past 8 months. A caregiver has brought him to the ART clinic. The pharmacist is concerned that there is too much medication left than there should be if the medication was given properly. On speaking to the caregiver, she seems to be unclear about how much medication Ncobile takes or how he takes it. You figure out that she is not the same caregiver who brought the child to the ART clinic last time and therefore, does not know much about what should be happening.

### **Case Study 3:**

A 28 year-old mother has brought her 5 month old baby to the child welfare clinic for immunization. The mother is living with HIV/AIDS and is exclusively breastfeeding the baby. The baby is on Cotrimoxazole prophylaxis. The mother is happy with the child's growth and development as indicated on the child's Road to Health Card. She has also brought along her other son who is 22 months old. However, there is not much information about this child. Talk to the mother about testing for both children.

## **9.7: UNIT SUMMARY**

### **ACTIVITY:**

#### **The trainer should:**

- Ask participants what they think are the key points of this Unit. What information will they take away from the Unit?
- Summarize the key points of the Unit, using participant feedback and the content below.
- Ask if there are any questions or clarifications.
- Review the learning objectives with participants and make sure each person is confident in their skills and knowledge in these areas.
- If there are areas in which participants need more help or do not fully understand, go back and review the session before moving to the next Unit.

### **CONTENT:**

#### **The key points of this Unit include:**

- Children are not "little adults" and children with HIV/AIDS have different medical, social, and psychological needs than adults with HIV/AIDS.
- Without treatment, most children with HIV/AIDS will die before their 2<sup>nd</sup> birthday.
- With care and treatment, children with HIV/AIDS can become healthy, productive adults.
- HIV makes babies and children sick quickly, so we need to identify them early and get them enrolled in care and treatment as soon as possible.
- pMTCT programs are a good place to find exposed and infected babies. We also need to look for sick children in under 5 clinics, adult ART clinics, inpatient wards, outpatient departments, and by reaching out in the community.
- The only way to tell if a baby under 12 months (1 year) of age is HIV-infected is through DNA PCR testing, which can be done when the baby is 6 weeks old.
- Adult HIV tests only work in children over 12 months (1 year) old.

- The 5 key points to remember with following exposed and infected children are:
  - Come back to the clinic often
  - Early HIV testing
  - Cotrimoxazole every day (to prevent infections)
  - Weigh and measure at each visit
  - Focus on the whole family
- Only a doctor can decide that a child is eligible for ART – this is done by examining the child and doing a test to see the CD4%.
- Pediatric ART depends on a partnership among the caretaker(s), the child, and the multidisciplinary care team.
- There are special ARVs for babies and children in Swaziland. They should not be given adult ARVs unless prescribed by the doctor.
- The first line regimen for children is normally:
  - D4T (Stavudine) + 3TC (Lamivudine) + NVP (Nevirapine).
  - If d4T is not available in a fixed dose, and the patient does not have refrigeration, AZT (Zidovudine) can be given instead.
  - Children over 3 years old can also take EVF (Efavirenz)
- The second line regimen for children is:
  - ABC (Abacavir) + ddl (Didanosine) + LPV/r (Kaletra)
- The type and dose of ARVs for children depends on age and weight. This will change often over time so patients need to come back to the clinic regularly.
- Expert clients play a key role in helping caretakers prepare to give ART to babies and children and adhere to the care and treatment plan in the long term. Adherence will be discussed more in the next Unit.
- Expert clients can also provide emotional support to caretakers, as caring for sick children and/or giving children medicine every day is not easy.
- Disclosure is an important part of pediatric adherence to care and treatment and will be discussed more later in the training.

## UNIT 10

### ADHERENCE TO HIV/AIDS CARE AND TREATMENT

(Time: 3 HOURS)

**LEARNING OBJECTIVES:** By the end of this Unit, participants will be able to:

- Define adherence to care and treatment.
- Describe why adherence is important for patients in HIV/AIDS care and treatment.
- Define non-adherence and tell patients about what can happen when they are non-adherent.
- Identify common barriers to adherence and work with patients and the multidisciplinary team to come up with practical strategies.
- Help patients understand and adhere to their care and treatment plan.
- Follow up with patients who do not come to the clinic for appointments.
- Prepare people to start taking ART through group education and one-on-one counseling sessions.
- Ask patients about adherence at every visit.
- Give advice on what to do about missed doses.
- Work with patients to come up with and implement practical and personalized strategies to improve and maintain adherence.
- Provide ongoing adherence support to all patients enrolled in care and treatment.

**PRACTICAL SKILLS:**

- Explain what adherence means and why it is important.
- Explain to patients what can happen if they are not adherent.
- Assess some of the potential barriers to adherence for specific patients.
- Work with patients to come up with specific, practical adherence strategies for their care and treatment plan.
- Co-facilitate group adherence education/ART preparation sessions with members of the multidisciplinary team.
- Counsel patients (by phone or in person) when they have missed an appointment or have not been adhering to their treatment.

**MATERIALS NEEDED:**

- Flip chart
- Markers
- Case study cards to hand out
- Pill boxes
- Ball

## 10.1: ADHERENCE BASICS

### ACTIVITY:

#### The trainer should:

- Ask participants what is meant by the term “adherence.” Record on flip chart. Ask participants what the difference is between “adherence” and “compliance,” using local words if possible.
- Ask a participant or two to volunteer to speak about why adherence is important to living positively with HIV/AIDS. Ask another two participants to share more about what adherence means to them, in their own lives.
- Supplement the discussion using the content below.

### CONTENT:

Adherence is the word used to describe how faithfully a person sticks to their care and treatment plan.<sup>xiii</sup>

#### Adherence:

- Includes active participation of the patient in his/her care plan.
- Implies understanding, consent, and partnership with the health care delivery system and different levels of people, including expert clients.
- Includes adherence both to care and to treatment/medicines.
- Depends on a shared decision-making process between the patient and health care providers.

Some people use the word “compliance,” but we prefer to use the word “adherence” as it indicates more than just following orders from the doctor. Adherence means that the patient is an active participant in developing and sticking with his/her own care plan.

#### Adherence to care means:

- Entering into and continuing on a care and treatment plan.
- Taking medicines to prevent and treat opportunistic infections.
- Participating in ongoing education and counseling.
- Attending appointments and tests (like regular CD4 tests) as scheduled.
- Picking up medications when scheduled and before running out.
- Modifying lifestyle and avoiding risk behaviors.
- Making a commitment to preventing new HIV infections.

#### Adherence to treatment means:

- Taking ART medications correctly, as prescribed, for the person’s whole life, even if the person feels healthy.
- Missing any doses is risky – patients should aim for 95-100% adherence to their ART and not take “treatment holidays” (stop taking the drugs for short or long periods of time).

### Why is adherence important?

- To lower the amount of HIV in a person's body.
- To avoid the body becoming resistant to certain medicines (meaning the medicines don't work in the body the way they are supposed to).
- To increase the CD4 soldier cells and decrease the amount of HIV virus in the body.
- To make sure the person gets all the benefits that OI medicines and ARVs have to offer (feeling better, not getting OIs, etc.).
- To prevent mother-to-child transmission of HIV.
- To monitor the person's health and also help them find community support resources for themselves and their family.
- To keep the person looking and feeling good so they can get back to normal life.

**Remember, a person should not take ARVs without adherence assessment and support at every visit! Expert clients have a key role to play in helping people to adhere to their care and treatment plans.**

## 10.2: NON-ADHERENCE

### ACTIVITY:

#### The trainer should:

- Admit that no one is perfect and everyone has problems with adherence at some point in their care and treatment. Ask participants what is meant by "non-adherence."
- Discuss the implications of non-adherence (such as drug resistance) and explain that expert clients have a key role in communicating the negative effects of non-adherence to patients.

### CONTENT:

#### Non-adherence means:

- Missing one or many appointments at the hospital or health center, lab, or pharmacy.
- Not following the care plan.
- Missing a dose or doses of medicine.
- Stopping medicine for a day or many days (a "break").
- Taking medicines at the wrong times.
- Taking medicines without following instructions about food or diet.
- Not reducing risk taking behavior (e.g. not practicing safe sex or using drugs and alcohol).

It's important not to judge patients if they are non-adherent. Instead, expert clients should try to uncover the root causes of non-adherence and help find ways to resume good adherence as soon as possible.

### **What happens when a person doesn't adhere?**

- The levels of drugs in the body drop and HIV keeps multiplying and spreading. When we take ARVs, it pushes back the virus, so we need to keep constant levels of the drugs in our bodies to keep the virus back.
- The person can develop "resistance" to one or all of the drugs, meaning that the drugs won't work anymore, even if they are taken correctly again. We can say that HIV is a very "smart" virus – it only takes a couple of missed doses for it to take over the body again, multiply, and learn how to be stronger than the ARVs.
- The CD4 count will drop and the person will start getting more opportunistic infections.
- The person may have to start taking a different kind of ARVs, but in Swaziland there aren't many kinds of ARVs available so it's best to avoid any resistance through perfect adherence.

**Remember: Development of drug resistance must be avoided at all costs. There are not many other drug options in Swaziland if a person develops resistance to the drugs they are started on!**

## **10.3: BARRIERS TO ADHERENCE**

### **ACTIVITY:**

#### **The trainer should:**

- Post 4 sheets of flip chart on the wall. Write "Access" on one, "Patient's life" on another, "Medicines" on another and "Health Services" on the last.
- Break participants into 4 groups and assign a flip chart paper to each group. Ask them to think about reasons that make it hard for a person to adhere to care and treatment that have to do with access, the patient's life, the medicines themselves, and the HIV/AIDS program services depending on which group they are in. Ask participants to pay special attention to barriers for pregnant women. Encourage participants to think about their own difficulties with adherence.
- After about 10 minutes, ask each group to present their ideas to the larger group and facilitate discussion.
- Remind participants that there are many factors that impact adherence other than the person's individual behaviors and desires.
- Finally, ask the group to brainstorm – for each item on the lists, what can the expert clients and/or multidisciplinary care team do to help the person overcome this barrier? Record these on the flip charts.

## **CONTENT:**

There are many possible barriers to adherence. Some are listed below.<sup>xiv</sup>

### **Barriers related to access**

- Transportation problems
- Can't get out of work to go to the clinic
- Lack of partner/family support to go to the clinic
- Haven't disclosed and partner/family doesn't understand/support many trips to the clinic
- Stigma – don't want to be seen at the ART clinic
- Not enough money to get to the clinic or pay for services
- No food to take medicines with
- No one to watch children or take care of daily activities while at the clinic

### **Barriers related to the patient's life**

- Patient doesn't understand HIV or adherence and has doubts about ART
- Patient is in denial
- Patient doesn't think they can do anything to help themselves (low self-efficacy)
- Patient doesn't feel well enough to get to the clinic
- Bad adherence counseling given because of lack of time
- No treatment buddy
- Patient doesn't know how to take medicines the right way
- No social support from friends or family
- Pressure from family to share medications with sick partner or children
- Pressure from partner not to take ART (because partner doesn't believe in ART or thinks it's dangerous)
- Keeping HIV a secret/stigma
- Other things to do – work, kids, cooking
- Forgetfulness
- Unhealthy habits, like drinking too much alcohol or doing drugs
- Travel or being away from home
- Changing schedules or routines
- Fear of treatment

### **Barriers related to the medicine**

- Doesn't understand medicines
- Side effects
- Too many pills to take
- Too many doses to take
- Hard to swallow pills
- Developing new symptoms that a patient thinks is caused by the ART and means they should stop taking it

### **Barriers related to health service provision**

- Have to wait a long time at the clinic
- Pregnant women don't want to go to the ART clinic and find it hard to get services in multiple places
- Bad attitudes and stigma among providers at the clinic
- Lack of training of providers and perceived low quality of services
- Lack of confidentiality and fear of disclosure to others
- Clinic hours are not convenient
- No place for children at the clinic
- Shortage of supplies at the health clinic (like not enough lab supplies or medicines)

## **10.4: HELPING PEOPLE ADHERE TO CARE**

### **ACTIVITY:**

#### **The trainer should:**

- Ask participants what helps them adhere to care. What helps them get to the clinic for appointments – reminders, support, outreach, etc.?
- Follow up by asking how expert clients can help patients adhere to care. Lead a discussion, using the content below to supplement the conversation as needed.
- Stress the importance of the green take-away books, as well as appointment and patient record systems at the sites. Expert clients should become familiar with these as soon as they return to their sites.

### **CONTENT:**

There are many things that can be done to support people to adhere to care.

#### **Good care setting**

- Welcoming and comfortable environment (waiting time isn't too long, there is a place to wait in the shade, convenient hours, expert clients and staff are welcoming).
- Pregnant women are given priority treatment when they come for care where they are allowed to go before other patients.
- Easy to access and services are "co-located," meaning that a patient can get many health needs taken care of in one visit, or that his/her child can also be seen during the visit.
- Child care facilities at clinic.

#### **Good communication**

- Follow good communication and active listening skills.
- Ask open-ended questions about adherence to help patient sharing, for example, "some people find it hard to come to the hospital every month because they have so much to do at home. How has this been for you?"
- Restate answers to ensure understanding (reflective listening).

- Show concern and respect.
- Never judge someone that you are counseling.

### **Shared confidentiality**

- Make sure all patients understand that what is said at the clinic is confidential.
- Assure that HIV status will not be disclosed without consent.
- Remind patients that they might see other community members at the clinic and help them prepare for this.
- Remind patients that care and treatment information may be shared among the multidisciplinary care team, but not beyond it (shared confidentiality).

### **Patient education and peer support**

- The expert client program can help patients understand their illness and help them adhere to care and treatment.
- Support groups and one-on-one counseling sessions are good for adherence support.

### **Strong outreach and follow up**

- Develop tracing systems when patients miss appointments – plan ahead with the team.
- Keep contact information updated and organized.
- Respect patients' wishes about how they prefer to be contacted.

**Remember, it is NOT ethical to disclose a person's HIV status without his/her consent!**

## **10.5: FOLLOWING UP WHEN PATIENTS DON'T RETURN TO THE CLINIC**

### **ACTIVITY:**

#### **The trainer should:**

- Ask participants what the consequences are of missing appointments at the clinic. Ask for ideas about what expert clients can do to help patients come for their appointments on the right day and time.
- Read out the following case studies and discuss next steps as a large group.
- Discuss how expert clients can help follow up with patients when they don't return to the clinic, using the content below, as needed

### **Case Study 1:**

A young man comes to the clinic for his first visit. You have a chance to talk with him before he sees the nurse and doctor. He is very scared that people in the community will find out he's HIV-positive. Using good listening and communication skills, talk to him about keeping appointments and how he wants to be contacted if he misses an appointment (by phone, home visit, contacting treatment buddy, etc.).

### Case Study 2:

A young, pregnant woman missed her appointment at the clinic and no one has heard from her in over one month. She does not have a phone and didn't give any contact information other than her address. What steps would you take?

### Case Study 3:

A patient missed his appointment and the multidisciplinary team asks you to try and call him. You call him but he says he can't talk because he's at work. What would you do and say?

### Case Study 4:

You call a woman who hasn't come back to the ART clinic to pick up her drugs. She says she hasn't come back to the clinic because she's feeling great and the ART must have worked. She thanks you for helping her and says she's just fine now. What would you say?

### CONTENT:

An important role of expert clients is to help clinical staff follow up on patients who miss appointments for consultation, lab tests, or to pick up medicines.

**At a patient's first visit at the clinic**, the nurse or another team member should take down the following information and make sure it's updated and kept in a safe place:

- Full name and address, including the physical address, for example, area, river, mountain, shop, dip tank, etc.
- If available, phone number for patient and/or friends or neighbors
- Name, address, and phone for close family and friends
- Name, address, and phone of person's workplace or other place where they spend time
- Contact information of patient's community health worker and treatment buddy if they have one
- How the patient wants to be contacted. By phone? Is it ok to be visited at home? Can the care providers contact a friend or family member if needed? Remember, it's important to keep things confidential.

### If a patient misses an appointment:

- If s/he hasn't contacted the clinic to reschedule or come to the clinic within one week of the appointment, the patient should be called if they have a phone or contacted as otherwise arranged.
- If there is no way to reach the person by phone, the expert client should conduct a home visit, **only if that was agreed upon in advance** by the patient. Patients who have not consented to home visits should not receive home visits. Also, expert clients should consult with the multidisciplinary team before doing any home visiting. Note that home visiting is not expected of all expert clients and should only be done if this is the policy of the specific site.
- During the home visit, try to talk with the patient about why s/he missed the appointment, what makes it hard to come to appointments, and how they can come back to the clinic as soon as possible. Also give adherence counseling.

- If the patient still can not be located during a home visit, do not give up. They might be traveling and eventually come back to the clinic. Keep following up through calls and home visits even if the first try isn't a success.
- Discuss patients who miss appointments often at the multidisciplinary team meetings. How can the team work together to help the patient come to their appointments?
- Discuss missed appointments and adherence with patients when they do return to the clinic for care.

## 10.6: PREPARING PEOPLE TO TAKE ART

### ACTIVITY:

#### The trainer should:

- Ask what participants did to get ready to take ART?
- For participants that attended group education sessions before starting ART, ask what information they received. Was the information enough to prepare them to start ART? Were they able to ask questions and have them answered during the group sessions? What was good and what will you do differently as an expert patient giving the adherence sessions?
- Review the national protocol for initiating ART, including that people are expected to attend at least 2 group education sessions and have at least 1 one-on-one counseling sessions with providers.
- Review the content below, reminding participants that they can help patients prepare for ART and succeed once they've started treatment. All participants should know the "Six Basic Rules for ART Success."

### CONTENT:

Once the doctor and nurse decide a person is ready to take ART, and the person agrees that they want to start ART, the expert client can help them prepare for treatment and make an adherence plan with the multidisciplinary team and the patient. Patients planning to start ART should participate in at least **2 group education sessions and one-on-one counseling sessions** at the clinic. The expert client and care team will lead these sessions together.

#### Topics covered in pre-ART session 1:

- Understanding of HIV/AIDS and their own health status
- Develop a trusting relationship between patients and the multidisciplinary care team.
- Explain the process of care and treatment, or the "patient pathway to care and treatment" (include the steps like what happens during care, when is blood drawn and why, when people should come back to the clinic, etc.)
- Importance of attending one health care facility until the person is stable and has established a good adherence pattern
- Help disclosing status

- Identify sources of social support, including a treatment buddy and support groups
- Beliefs and attitudes about treatment and ART

**Topics covered in pre-ART session 2:**

- Understand the treatment plan (what medicines need to be taken, how many times per day/week, at what time, with food or without, etc.)
- Possible side effects from different ARVs and what to do if the person has side effects or problems taking ART.
- Possible barriers to adherence and problem solving
- How will the person remember to take pills (alarm, buddy, pillbox, diary, and explaining the small blue booklet given to patients in Swaziland, etc.)
- Help find ways to make care and treatment plan a part of every day life
- What to do if the person misses pills and how late is too late to take a missed dose
- Access to support services, such as income generation and nutrition, if needed

These sessions should be adapted as needed, for example for the special needs of pregnant women living with HIV/AIDS.

Adherence planning is not something that happens only once. Expert clients and other members of the multidisciplinary care team should always be asking patients about adherence, changing the plan as needed, and helping patients to overcome old and new challenges.

**Six Basic Rules for ART Success<sup>xv</sup>:**

1. **Take your ARVs every day**
2. **Take your ARVs at the same time**
3. **Take your ARVs for your whole life**
4. **See the doctor or nurse if you have ongoing side effects**
5. **Never share ARVs with other people**
6. **You can still pass HIV to others even when on ART and if you feel well, so remember to use a condom every time you have sex.**

## 10.7: HELPING PEOPLE ADHERE TO TREATMENT

### ACTIVITY:

#### The trainer should:

- Write the phrase “every dose, every day, for life” on a flip chart in the front of the room.
- Ask participants to stand up in a circle. Toss a ball to one of the participants and ask him/her to say one way that expert clients can help patients stick to treatment “Every dose, every day, for life.” Ask that participant to throw the ball to another participant who should come up with another idea. Keep the game going until everyone has had a chance to speak.
- Give a short talk on adherence strategies, using the content below.
- Ask participants what advice they would give other PLWHA on good ways to remember to take medicines at the right times in the right ways, based on their own experiences. Ask what kind of reminders or tools they use (like pillboxes or cell phones) and if anyone has a treatment buddy. Are the reminders or the treatment buddy helpful in following the treatment plan?
- Pass around pill boxes so that all participants can see how they work and what the labels mean (morning dose, evening dose, etc.). If pill boxes are not available at the clinic or in the community, discuss what other tools would be useful.
- If a participant keeps a medicine diary, ask him/her if he/she would be willing to show it to the other participants. Pass it around the room and lead a discussion on different ways to keep a medicine diary, paying special attention to helping patients with limited literacy keep a diary.
- Read the following case studies out loud and ask the group to discuss what they would do as expert clients to help these people adhere to their care and treatment plan.

### Case Study 1:

A male patient comes to the clinic for a regular check up and to get more medicines. You spend some time with him in the waiting area before he sees the doctor. How would you ask about his adherence? What advice would you give him when you learn he usually misses his morning dose because he has to go to work really early?

### Case Study 2:

A mother comes to the clinic with her 3 children. She has been on ART for about 6 months, but now that one of her children is not feeling well, her husband makes her share her ART with the child. How can you help this woman to adhere to her own treatment plan?

### CONTENT:

The goal of ART is >95% adherence. This is because even a couple of missed doses each month can make ART less effective or can increase the chances of drug resistance and getting very sick.

## **The adherence motto is “EVERY DOSE, EVERY DAY, FOR LIFE!”**

Expert clients should talk with patients about adherence at every visit. They play an important role by helping patients plan for adherence, stick to their treatment plan, stay positive and focused, and by answering any questions they or their caretakers and families have. Expert clients can also help patients avoid side effects or know how to manage them if they happen, as discussed in the last unit.

### **How should expert clients ask patients about adherence?**

- Make adherence a normal part of every session.
- Don't judge a person, make them feel comfortable.
- Share that everyone has problems taking medicines the right way all the time.
- Build a trusting relationship and ask people to be completely honest with you about adherence.

### **Examples of questions an expert client can ask about missed doses:**

- Many patients taking these medications, including me, find it difficult from time to time. What has your experience been?
- How many doses have you missed in the past day? Week? Month?
- On an average a week, how often do you miss your medications? How often are you late?
- Do you ever share your medicines with sick family members, like your husband/wife or kids?

### **What to do when a dose is missed:**

- Take the missed dose if your next dose is scheduled for more than 6 hours away. For example, if you normally take your medicine at 7am, and you remember at 1pm you should still take the dose when you remember.
- Don't take the missed dose if your next dose is scheduled for less than 6 hours away for twice a day medicines. For example, if you normally take your medicine at 7am and you only remember at 2pm, you should just wait until the next dose at 7pm.
- For medicines taken once per day, such as EFV, take the missed dose if you remember within 12 hours of the schedule dose time.
- Never take a double dose (2 doses at a time).

### **Examples of question an expert client can ask about challenges to adherence:**

- When/why is it most difficult to remember your medications (e.g. side effects, fears, hard to pick them up from the hospital)?
- It is not easy to take medicine every day. What kinds of problems make it hard to take your pills?
- It's not easy to take medicines every day. What things help you to take your pills?
- It's great that you are feeling better now that you started ART. What things make it hard to remember to take your medicines now that you're feeling better?

## **Strategies to promote adherence to treatment<sup>xvi</sup>**

### **Strengthen patient counseling/education:**

- Make sure the medicine plan fits the patient's lifestyle.
- Give a lot of detailed information about how to take medications, including timing, food, restriction, drugs interactions, etc.
- Come up with ways to help patients remember to take medications, including daily cues (like when they eat breakfast and dinner), reminders (like a watch or alarm clock), partners, support groups, and others.
- Come up with a plan to handle side effects.
- Remember family-focused care and encourage the person to bring his/her partner and children to the clinic for testing and treatment, if needed. This will lower the chance that the patient shares their medicines with family members.

### **Easy access to a reliable medicine supply:**

- Make sure patients understand where, when, and how to obtain medicines.
- Help patients plan how to store their medicines safely at home.

### **Make it easy to remember when to take medicines**

- Help patients learn to use pill boxes or blister packs (if available).
- Help patients set up daily charts, calendars, or diaries to plan when and which drugs to take. They can be ticked off when each dose is taken.
- Come up with medication "reminders" linking to daily activities, timers, beepers, alarm clocks.
- Work with the patient and their treatment "buddy." A treatment "buddy" is a friend, family member, or community health worker that agrees to help the person take his/her medication on time, gives support, helps the person keep appointments at the clinic, etc.
- Organize treatment support groups if possible.

## 10.8: CLASSROOM PRACTICUM ON ADHERENCE COUNSELING

### ACTIVITY:

#### The trainer should:

- Provide a quick review of the content covered in the Unit so far and ask if there are questions or areas where participants don't yet feel comfortable and need more help. It may be helpful to ask participants to volunteer to summarize each of the sub-sections with the group since this is a large Unit. The trainer should fill in and go back to sub-sections to review as needed.
- Explain that this classroom practicum session will have 2 parts: practicing group education and practicing one-on-one counseling.
- Divide participants into 3 groups. Assign one group Pre-ART group session 1, the second group Pre-ART group session 2, and the last group Pre-ART group session for pregnant women. Give participants about 15 minutes to prepare their group education sessions based on what was learned in this unit. Ask each group to give a brief 10-minute group education session and have other participants act as patients who are about to start ART.
- Debrief the group education sessions as a large group, discussing what was covered well, what was missed, etc.
- Next, move on to the one-on-one case studies below. Break participants into groups of 3 or 4. Do rotating role plays where one person acts as the patient, another as the expert patient, and others observe and give constructive feedback.
- The trainers should rotate around the room and provide feedback to the small groups during the activity.
- If there is time, ask some of the groups to perform their role play in front of the larger group and lead a discussion summarizing the skills learned in the Unit on supporting patients to adhere to care and treatment plans.

### Case Study 1:

One of the patients that you talk to every time he comes to the clinic is going to start taking ART. He knows from talking to you that you are on ART. He asks you what you do to help remind yourself to take the medicines at the right time every day and in the right amount. He heard this is important with ART and wants to know what you think.

### Case Study 2:

A young man has been on ART for 2 years and is doing really well and feeling good. He was taking the doses on a set schedule and is almost never late. But, he just changed jobs and now is a bus driver. He is working different hours and far from home. Some days he starts work at 6 in the morning and sometimes at noon. Since starting this new job, the young man forgot to take his pills with him to work two different times and has to wait until he gets back home to take them. He doesn't want anyone at work to know he is HIV-positive.

**Case Study 3:**

A 35 year-old woman was diagnosed with HIV about 5 years ago. For the past year she has been getting sicker and sicker with TB and other infections. The nurse wants to talk with her more about starting ART. In the waiting area, she tells you that she feels nervous and asks you to tell her more about getting ready to take ART.

**Case Study 4:**

A 26 year-old woman tested positive for HIV 6 months ago. She is caring for a sick husband and has 5 children. She is so busy that she has missed a couple of appointments at the ART clinic. Her husband is the only one that knows she is HIV-positive, and he himself has not been tested. She comes to the clinic because she thinks she might be pregnant and you meet her in the waiting area.

**Case Study 5:**

A 27 year-old woman comes to the clinic because she is in a lot of pain, is losing weight, and has a high fever. She said she started taking ART about a year ago and felt really good within about 3 months. She admits that once she was feeling better she didn't always take her ART every day because it was just a reminder that she had HIV. She wants to know why her ART isn't working like it used to and why she's getting sicker and sicker even though she's taking the ART at the right time every day again.

**Case Study 6:**

A patient at the clinic started ART 2 months ago. She came to the hospital because she was told to come back if she had any bad symptoms. Now she has diarrhea and a bad rash all over her body and wants to stop taking the ART. She tells you that she's missed 3 doses in the last month but thinks that taking the doses most of the time is good enough. She is worried about being a burden on her family, so she doesn't talk to them about the medicines, but they do know she's HIV-positive.

**Case Study 7:**

A pregnant woman you meet at the PHU said she's been living with HIV for about 4 years. She said the doctor thinks it's time to start ART, but she has heard that it's very complicated to take. She works as a midwife in the community and is very afraid that people will find out she is HIV-positive and she will lose all of her business. She is even nervous to talk to the doctor and nurse at the ART clinic because she thinks they are going to tell people that she is HIV-positive and that she shouldn't be having a baby. Talk to her about ART, adherence, and confidentiality.

## 10.9: UNIT SUMMARY

### ACTIVITY:

#### The trainer should:

- Ask participants what they think are the key points of this Unit. What information will they take away from the Unit?
- Summarize the key points of the Unit, using participant feedback and the content below.
- Ask if there are any questions or clarifications.
- Review the learning objectives with participants and make sure each person is confident in their skills and knowledge in these areas.
- If there are areas in which participants need more help or do not fully understand, go back and review the session before moving to the next Unit.

### CONTENT:

#### The key points of this Unit include:

- Adherence means how faithfully a person sticks to the care and treatment plan.
- Adherence support is most successful when it's provided by a number of people on the multidisciplinary care team in partnership with the patient. Adherence support should be part of every visit because adherence barriers and strategies will change over time.
- Adherence includes active understanding and participation of the patient in his/her care and treatment plan.
- Adherence to care is important to make sure a person stays healthy, understands how to live positively, knows when to start ART, and gets psychosocial support at the clinic and in the community.
- Adherence to treatment is important to lower the amount of HIV in a person's body and make sure the person gets all the benefits that OI medicines and ARVs have to offer (feeling better, not getting OIs, etc).
- At least 95% adherence is needed for ART to work the right way and keep a person healthy.
- Non-adherence means missing one or many doses, not following the care plan or returning for appointments at the clinic, taking medicines the wrong way, etc.
- Non-adherence to treatment can lead to drug resistance, preventing the ART from working and making the person very sick.
- Expert clients should counsel patients to do all they can to avoid resistance.
- There are many barriers and challenges to good adherence, including things related to the patient's life, things related to the medicines, and things related to the health care system and HIV/AIDS program.
- Before starting ART, patients need to attend group education and one-on-one counseling sessions to understand the treatment plan and identify strategies to overcome adherence barriers.
- Expert clients should ask patients about adherence at every visit.
- Encourage patients to be honest about their adherence, even when it's not perfect. Never judge someone about missing doses or appointments.

- Involve friends or family members (if the patient is comfortable with this). Social support and disclosure are very important to adherence.
- Coordinate with the clinical team to follow up when patients miss appointments.
- Expert clients can help patients and caretakers find practical solutions to adherence, like pill boxes, medicine diaries, or having a treatment buddy.
- Expert clients should tell everyone about the 6 Basic Rules for ART Success:
  - **Take your ARVs every day**
  - **Take your ARVs at the same time**
  - **Take your ARVs for your whole life**
  - **See the doctor or nurse if you have ongoing side effects**
  - **Never share ARVs with other people**
  - **You can still pass HIV to others even when on ART and if you feel well, so remember to use a condom every time you have sex.**

## UNIT 11

### STIGMA AND DISCLOSURE

(Time: 2 HOURS)

**LEARNING OBJECTIVES:** By the end of this Unit, participants will be able to:

- Understand the different types of stigma.
- Describe how stigma negatively affects access and adherence to PMTCT-Plus, care, and treatment services for adults and children.
- Implement strategies to overcome different forms of stigma at the individual and programmatic levels.
- Explain the advantages and disadvantages of disclosure.
- Explain the difference between partial and full disclosure.
- Work as part of the multidisciplinary team to provide ongoing disclosure counseling and support to other PLWHA.

**PRACTICAL SKILLS:**

- Recognize different types of stigma and how they affect people.
- Help patients overcome stigma in their own lives and in their children's lives.
- Work with the multidisciplinary team to make sure that HIV/AIDS services aren't stigmatizing.
- Counsel patients about the advantages of disclosure, and explore with them the possible disadvantages.
- Counsel patients on partial and full disclosure, and help them decide who to disclose to at different points in time using disclosure circles.
- Help patients plan for disclosure to other adults and to children, including through disclosure role plays.

**MATERIALS NEEDED:**

- Flip chart
- Markers
- Case study cards to hand out
- Blank index cards or small pieces of paper

## 11.1: OUR OWN EXPERIENCES WITH STIGMA

### ACTIVITY:

#### The trainer should:

- *Note: Since the word "stigma" does not always translate well to other languages, it's important that expert clients can explain the term in everyday words and phrases.*
- Ask participants to think quietly to themselves about a time they were stigmatized. This may or may not have to do with HIV/AIDS. To explain stigma a bit more, ask participants to think about a time in their lives that they felt isolated or rejected because they were thought to be different than others. Ask participants to think about what happened and how this made them feel.
- Now, ask participants to share their experience with another participant.
- After about 5 minutes, bring participants back to the large group and ask if anyone would like to share their story. People should only share if they feel comfortable.
- Next, ask participants to again think quietly again to themselves, but now about a time when they isolated or rejected someone because they thought they were different. Again, this may or not be related to HIV/AIDS. What happened and how did they behave as someone who was stigmatizing someone else?
- Ask participants to write down thoughts, feelings, or words that they associate with stigma and to read this list out loud to the larger group if they feel comfortable doing so.
- Lead a discussion on stigma using the content below.

### CONTENT:

#### Defining stigma

We have all felt rejected or isolated at some point in our lives and we have all probably rejected or isolated another person because we perceive them as different.

To stigmatize someone means to label them and to see them as inferior (less than, below) because of something about them. A lot of times people stigmatize other people because they don't have the right information and knowledge and/or because they are afraid.

We know that stigma is one of the biggest challenges to living with HIV/AIDS or being affected by HIV/AIDS all over the world, including in Swaziland. Stigma is a big reason why people don't access HIV testing, pMTCT-Plus, care and treatment, and community-based services, such as food support.

Expert clients need to help other patients understand and deal with stigma. They can work with the multidisciplinary team and the community to fight stigma and make sure people have access to the services they need.

**There are different kinds of stigma:**

- **Stigma towards others**
  - Rejecting or isolating other people because they are different or perceived to be different.
- **Self-stigma**
  - People take cruel and hurtful views placed upon them by other people as their own views of themselves. Often self-stigma can lead to isolating oneself from the family and the community.
- **Secondary stigma**
  - People, such as NGO workers, doctors and nurses at the HIV clinic, children of parents with HIV, and caregivers and family members are stigmatized by their association with PLWHA.

**11:2: HOW DOES STIGMA AFFECT HIV/AIDS SERVICES?**

**ACTIVITY:**

**The trainer should:**

- Ask participants to discuss how they think stigma can affect HIV prevention, HIV testing, pMTCT-Plus, pediatric, care, and treatment services? Note responses on flip chart.
- Ask probing questions about stigma in the family, in the community, in church, at the health facility, etc. that may affect access to HIV-related services.
- Discuss and fill in using the content below, as needed.

**CONTENT:**

Stigma prevents good access to HIV prevention, care, and treatment services for many people. For example:

- Stigma keeps people from getting an HIV test.
- Stigma makes it hard for people to tell their partner(s) their test result.
- Stigma makes it hard for parents to disclose to their children.
- Stigma keeps PLWHA from accessing care, treatment, counseling and community support services because they want to hide their status.
- Stigma discourages pregnant women from taking ARVs or accessing other pMTCT-Plus services.
- Stigma prevents people from caring for PLWHA.<sup>xvii</sup>

### How can stigma affect care and treatment?

- When stigma prevents someone from knowing their HIV status, enrolling in care, or getting a CD4 test, then less people have access to ART.
- Stigma can cause feelings of hopelessness and depression (covered more in the next Unit), that can make it hard for people to start or adhere to ART.
- People may fear that if they take ART, more people will know they are living with HIV/AIDS.
- If a person can't disclose their status because of stigma, they will have to keep their ART a secret, and this will impact their adherence and the amount of support they receive.
- Children with HIV cannot get the care and treatment they need if there is stigma attached to their illness or if the family has not disclosed to caretakers and teachers.
- Stigma can cause people to be isolated from friends and family, which means they won't get support to take ART and adhere to care and treatment.
- Women—especially pregnant women—and young people, are often the most stigmatized. This makes it even harder for these groups to access and adhere to care and treatment.
- Stigma among health care providers can result in low quality services at health facilities, making people less likely to access the care they need.
- Stigma can extend to caregivers of PLWHA as well – making it less likely that people will want to care for PLWHA or seek services themselves.<sup>xviii</sup>

Expert clients and all PLWHA have an important role to play in reducing stigma among individuals, at the health care facility, and in the community. Being a positive role model is one of the best ways to fight stigma! Making sure everyone knows about and has access to quality, affordable pMTCT-Plus, care, and treatment services also helps fight stigma.

### 11.3: STRATEGIES TO DEAL WITH STIGMA

#### ACTIVITY:

##### The trainer should:

- Break participants into pairs and give each group 10-15 index cards or small sheets of paper that you've cut in advance.
- Ask the pairs to "card storm" – thinking of all the ways they or people they know use to deal with stigma. Ask what we as members of a pMTCT-Plus and HIV/AIDS care and treatment program can do to fight stigma. Have the pairs write one individual or program strategy on each card.
- After about 10 minutes, collect the cards and bring the large group back together. Post the cards on the wall, arranging them in logical categories.
- Ask the group which strategies they think are most helpful in dealing with stigma. At the individual level? For children? At the program level?
- Supplement using the content below.

## CONTENT:

### **Some common individual strategies for dealing with stigma<sup>xix</sup>:**

- Talk back
- Educate people
- Be strong and prove yourself
- Talk to people you feel comfortable with
- Ignore people who stigmatize you
- Join a support group
- Try to explain the facts
- Avoid people that you know will stigmatize you

### **Some strategies for dealing with different forms of stigma:<sup>xx</sup>**

#### **At the health facility:**

- Allow health care workers, including expert clients, to talk about their own attitudes, feelings, fears, and behaviors in an open way. Help them to address their fears and to avoid burnout.
- Encourage health care workers to be open about their status and for every one to support one another.
- Implement an HIV/AIDS workplace policy that includes non-discrimination and access to prevention, care, and treatment services for all staff.
- Teach counseling and communication skills.
- Work with the multidisciplinary team to develop standard operating procedures (SOPs) about confidentiality and behavior of staff at the workplace.
- Provide in-service training on different HIV-related topics, including stigma reduction.
- Get feedback from expert clients and other clients about the services and attitudes at the facility and use these to make improvements.

#### **In the community:**

- Get community and NGO leaders involved in the fight against HIV/AIDS.
- Promote PLWHA as role models and active community participants.
- Organize community meetings and activities related to HIV/AIDS.
- Conduct community sensitization and education on HIV/AIDS, involving PLWHA.
- Get the community to support orphans and other children affected by or infected with HIV.
- Improve linkages between health facilities and the community.
- Conduct community education on caring for someone with HIV/AIDS and being a treatment buddy.

#### **With faith-based and religious groups:**

- Use churches, mosques, etc. to discuss stigma.
- Get people to recognize their own stigmatizing behavior and correct it.
- Help religious leaders to lead efforts in stigma reduction and tolerance.
- Work with religious leaders to provide counseling that is non-stigmatizing and non-judgmental, such as pre-marital counseling.
- Support religious leaders living with HIV/AIDS to be open about their status.

## 11.4: INTRODUCTION TO DISCLOSURE

### ACTIVITY:

#### The trainer should:

- Ask participants what is meant by the term “disclosure.” How does this translate into the local language? Record on flip chart.
- Ask participants the advantages and disadvantage of disclosure in their own lives and in the lives of other PLWHA they know. Record answers on flip chart.
- Supplement the discussion using the content below and drawing on participants’ experiences as much as possible.

### CONTENT:

#### What is disclosure?

- Disclosure is when a person tells one or more people about their HIV-status.
- Disclosure is an ongoing process – meaning that a person may first want to disclose to only one person and then over time disclose to others. It is not a one-time event and PLWHA need ongoing support on disclosure.

#### Advantages of disclosure may include:

- Avoiding the burden of secrecy and hiding.
- Avoiding anxiety about accidental or unwanted disclosure.
- Access to emotional and practical support.
- Ability to talk about symptoms and concerns.
- Easier access to health care.
- Enhance adherence to care and medication, and ultimately make the person healthier and able to live positively with HIV/AIDS.
- Ability to discuss safer sex and family planning choices with one’s partners.
- Ability to refer partner and children for HIV counseling and testing, and to care and treatment if needed.
- For pregnant women, ability to get support for safer infant feeding from family members and friends, and linkages to food support programs when the mom wants to wean the baby.
- Freedom to ask a friend or relative to be a treatment buddy.
- Access to patient support groups and community organizations.
- Can serve as a role model for other people on disclosure.

#### Disadvantages of disclosure may include:

- Blame by partner or family for “bringing HIV into the household.”
- Distancing, fear, rejection, or abandonment by partner, family, or friends.
- Loss of economic/subsistence support from a working partner.
- Discrimination in the community.
- Discrimination at work, including possible loss of job.
- Assumptions made about sexuality, promiscuity, or lifestyle choices.
- Rejection of children at school or in the community.
- Reluctance on the part of partner to have more children.
- Physical violence.

## 11.5: PARTIAL VS. FULL DISCLOSURE

### ACTIVITY:

#### The trainer should:

- Ask participants if they disclosed their HIV status to someone or many people. If they did, when, how, and to whom they disclosed? Did they have any help preparing for disclosure from a peer educator, community health worker, counselor, or other person? What was their experience with disclosing?
- Discuss the differences between partial and full disclosure using the content below, reminding participants that disclosure is a process – not a one-time event.
- Explain “circles of disclosure” using the content below.

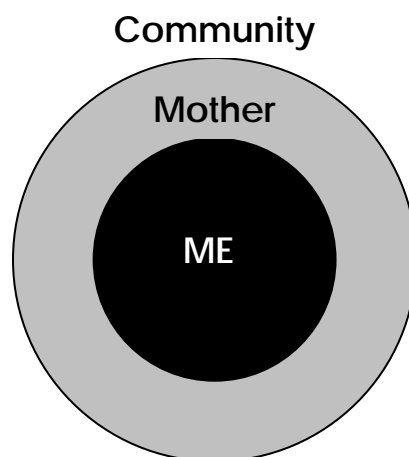
### CONTENT:

#### Deciding about disclosure

A good way to understand disclosure and help people decide who they will disclose to is by creating “disclosure circles.”<sup>xxi</sup>

- The center of the circle is the person him/herself.
- The next circle out is a person or people the PLWHA is very close to, such as their mother or a partner.
- The next circle includes larger groups of people that the PLWHA is not as close to, such as people at work or others in the community.
- There can be many layers to the circles of disclosure.

Here is an example of a disclosure circle<sup>xxii</sup>:



## Partial and full disclosure

Disclosure is a process and not a one time event. Disclosure to one or many people usually works the best when it is planned and the person feels comfortable and able to deal with any reaction.

- Partial disclosure means telling your HIV-status to one or a few people, but not to everyone. Most people opt for partial disclosure as a first step. For example, a person may want to tell their close family members about their HIV-status, but not people at work or in the community.
- Full disclosure means being open with everyone about your HIV-status. People who fully disclose their status can have a big impact on reducing stigma and advocating for other PLWHA, but there are also risks and people shouldn't fully disclose unless they are well-prepared and feel a lot of support.

## 11.6: DISCLOSURE COUNSELING

### ACTIVITY:

#### The trainer should:

- Ask participants how they felt about disclosing their status. What were their fears? What techniques did they use to disclose?
- Have participants break into pairs and ask them to role play about disclosing to a family member. Ask one participant to come up with a scenario that each pair will discuss or use the example below. The pair should switch roles after 5 minutes.
  - Sample scenario: Patience found out she was HIV-positive during an antenatal check-up. She sits down with her mother one evening to tell her she is HIV-positive and that she needs to go to the hospital regularly to make sure she and her baby are healthy, but she isn't ready to tell her partner. Patient's Mom is shocked and at first accuses her daughter of sleeping around, but then starts understanding that she needs to give her daughter support and accept her status.
- Debrief the role play by asking how each person felt when playing Patience. Ask what strategies the person disclosing used to tell the other person. How did participants feel when they were playing the role of Patience's mom?
- Ask participants what they think are the key components of disclosure counseling, reminding them that expert clients will be able to help people plan for disclosure. Record answers on flip chart and supplement the discussion using the content below.

### CONTENT:

#### Disclosure counseling:

- Should not include pressure for someone to disclose.
- Is a confidential conversation that assists a patient to work through the issues related to telling others about his/her HIV status.

- Is important to reduce stigma, enhance adherence to care and treatment, and reduce secondary HIV infection.
- Is intended to promote informed decisions about whether or not to disclose HIV status and if so to whom.
- Assists and supports someone who has decided to disclose their status.
- Enhances coping strategies following disclosure.

**General approach to disclosure counseling:**

- Use good communication and counseling skills (e.g. good body language, ask open-ended questions, summarize and reflect, etc.).
- Discuss the advantages and disadvantages of disclosure specific to the person's life.
- Help the person to identify barriers and fears about disclosure.
- Explore possible options to overcome barriers.
- Encourage the patient to take the time needed to think things through.
- Talk about sexual partners who need protection from HIV infection.
- Identify sources of support.
- Support the person to make his/her own decisions about disclosure.
- Keep in mind that disclosure to children depends on what stage of development they are in. For example, a young child may only need to know that they are sick and have to go to the doctor and take medicines to feel better, whereas an older child should know that they have HIV, understand the disease and the medications, and actively participate in their own care and treatment.
- Prepare patients who choose to disclose by:
  - Helping to decide whether partial or full disclosure is best, using the disclosure circles exercise above.
  - If partial disclosure is chosen, helping to decide whom to tell first, when, where and how to tell them.
  - For parents or caretakers, decide what type of information is most understandable for a child given the child's age and development.
  - Plan for a good place and time to have the conversation, for example, when the children are asleep and when no one else can hear.
  - Assisting the patient to anticipate likely responses.
  - Practicing disclosure through role plays with the expert client, including how they will start the conversation. For example, "I wanted to talk to you about something because I know you can help and support me." Or, "I went to the clinic today for a check-up and they talked to me about how it's important for everyone to get an HIV test because you can't tell if someone has it by looking at them."
  - Providing practical suggestions, ongoing support, and reassurance.
  - Planning the next steps and scheduling the next session.

## 11.7: CLASSROOM PRACTICUM ON STIGMA AND DISCLOSURE COUNSELING

### ACTIVITY:

#### The trainer should:

- The first part of the classroom practicum will be a start-stop drama. Ask for 3 volunteers. Assign each a role to play, based on the scenario below (or one that you come up with). Give each actor a few minutes to prepare for his/her role, and then ask the group to get started with the drama. The trainer should stop ("freeze") the actors from time to time and the group should discuss what's going on. Then the drama should resume.
- Ask participants to divide into groups of 3 and do rotating role plays using the case studies below, or using situations that participants come up with based on their experiences. One person should act as a patient, another as the expert client providing disclosure support, and the third as an observer.
- Guide the groups during the drama and role play and provide positive feedback.
- Ask if there are questions or discussion points before moving on.

### Scenario 1 for Start-Stop drama:

A pregnant woman wants to disclose her status to her mother and sister. She sits them down one evening after they've cleaned up the house and the other children are asleep. Her boyfriend is out at a bar with his friends.

The pregnant woman is scared that her baby will be HIV-positive. She wants her mother and sister to help her stay healthy during the pregnancy. She isn't sure if she should tell her partner about her status and wants support and advice from her mother and sister.

The mother will not accept her daughter's status. She says that the doctors are wrong and she should just take herbal medicines and she will feel better. She is completely in denial.

The sister knows a bit more about HIV than the mother, but is worried about her sister taking ART during pregnancy because she thinks it will kill the baby. She's also worried because she's a teacher at the community school and she's afraid she might lose her job if everyone knows there is HIV in the family.

### Case Study 1:

A 25 year old woman named Sibongile is a counselor at the local HIV testing center. She is good at her work and takes pride in helping other people. About one year back, Sibongile decided to test herself and found out she is HIV-positive. Since then, she hasn't enrolled in the care and treatment program because she doesn't want anyone to know she's positive. She's feeling well, but has started losing weight lately and thinks some of her fellow counselors might be talking about how she has HIV. She feels so badly about herself and thinks she should have known better than to have unsafe sex. Sibongile comes to you for advice. What would you tell her?

**Case Study 2:**

A married man named Sipha with 2 children (aged 7 and 3) tested positive for HIV last week after having pneumonia and being referred for HIV counseling and testing. He wants to know if he has AIDS and he has not told anyone about his status because he's worried about their reactions. He started using condoms, but his wife is acting suspicious. He came to the ART clinic for his first appointment and meets you while he is waiting. Sipha wants to talk about disclosure with you. What would you talk to him about? Lead him through a disclosure role play.

**Case Study 3:**

A pregnant woman named Bongwiwe comes to talk with you. She is physically quite well, but just tested positive for HIV during pMTCT services. She is scared to tell anyone and doesn't think she wants to go to the ART clinic or take any ARVs because someone might see her there and tell her family. Her husband can be violent when he gets upset, and she thinks he gave her HIV because he's the only person she's had sex with without condoms. Bongwiwe turns to you for help. How would you counsel her?

**Case Study 4:**

A 19 year-old man tested positive for HIV about 2 years ago, but takes good care of himself and feels fine. He got tested because his girlfriend at that time found out she was HIV-positive. He has since changed girlfriends and has not told his new girlfriend about his HIV-status. He comes to the clinic for his regular appointment, but wants to talk with you about how to tell his girlfriend that he is living with HIV. He doesn't know how to use condoms and is afraid that if he starts using them with his girlfriend she will know he has HIV. How would you try and counsel this young man?

**Case Study 5:**

A woman named Hope has been caring for her HIV-infected child for the last 6 years. The child is now ready to start school, but she is afraid to tell the teacher that he has HIV. She is afraid he will be stigmatized in the school, but also that he will learn about his HIV status from schoolmates or the teacher. What would you talk with her about in terms of disclosing to her child and to the teacher at school?

**11.8: UNIT SUMMARY****ACTIVITY:****The trainer should:**

- Ask participants what they think are the key points of this Unit. What information will they take away from the Unit?
- Summarize the key points of the Unit, using participant feedback and the content below.
- Ask if there are any questions or clarifications.
- Review the learning objectives with participants and make sure each person is confident in their skills and knowledge in these areas.
- If there are areas in which participants need more help or do not fully understand, go back and review the session before moving to the next Unit.

## CONTENT:

### The key points of this Unit include:

- Stigma is one of the biggest challenges to living with HIV/AIDS or being affected by HIV/AIDS.
- Stigma comes in many forms – it can be from one person to another, a person stigmatizing him/herself, or stigma by association. Programs can also stigmatize people, as well as communities and religious groups.
- Stigma at all levels makes it hard for people to accept, access, and adhere to prevention, care, and treatment services.
- Expert clients have an important role to play as positive role models, reducing stigma among individuals, at the health care facility, and in the community.
- Expert clients can work with the multidisciplinary care team to reduce stigma at the health care facility.
- Expert clients can help patients deal with stigma in their own lives.
- Disclosure can help a person access care, treatment and support; improve adherence to care and treatment; help reduce stigma and discrimination by bringing HIV/AIDS out into the open; help slow the spread of HIV by helping people protect themselves and their partners; and help normalize HIV/AIDS prevention, care, and treatment services.
- Expert clients can help people weigh the advantages and disadvantages of disclosure and be a supportive counselor throughout the process.
- Partial disclosure to a small number of trusted people is usually a good first step in the disclosure process.
- Disclosure with children is also important, and the amount and level of information that a child should be told about HIV depends on the child's age and development.

**UNIT 12**  
**POSITIVE LIVING**  
**(Time: 2 HOURS, 30 MINUTES)**

**LEARNING OBJECTIVES:** By the end of this Unit, participants will be able to:

- Understand the “recipe” for positive living.
- Provide support to patients to keep their minds and bodies healthy.
- Help patients and their partners practice safer sex.
- Demonstrate male and female condom use.
- Work with patients to advocate for themselves and encourage “self care” as a part of positive living.

**PRACTICAL SKILLS:**

- Explain the recipe for positive living to patients.
- Recognize signs of anxiety and depression and provide counseling.
- Refer serious cases of anxiety and depression to the doctor.
- Counsel patients on things they can do to keep their bodies healthy.
- Counsel patients on things they should avoid to stay healthy.
- Counsel patients (and their partners) on safer sex – why it’s important and what it means.
- Explain the risks of re-infection to patients.
- Show patients how to use male and female condoms.
- Give patients strategies for negotiating condom use with their partner(s).

**MATERIALS NEEDED:**

- Flip chart
- Markers
- Ball
- Male and female condoms
- Penis and vagina models
- Case study cards to hand out

## 12.1: WHAT IS POSITIVE LIVING?

### ACTIVITY:

#### The trainer should:

- Write the “recipe for positive living” on flip chart.  
**KNOWLEDGE + DETERMINATION TO LIVE**  
with actions for a  
**HEALTHY MIND + HEALTH BODY + HEALTHY SOUL**  
  
**= A LONG, HEALTHY LIFE**
- Ask participants to discuss the different “ingredients” in the “recipe.”
- Ask participants to discuss how they live positively with HIV/AIDS in their own lives. Ask what participants do to take care of their minds, bodies, and souls to stay strong and live a healthy life.
- Fill in the conversation using the content below and by explaining that expert clients can be role models to help patients live positively with HIV/AIDS.

### CONTENT:

- Positive living means having a positive outlook to living and life. It also means living responsibly with HIV/AIDS.
- People with HIV can live full and healthy lives if they take care of themselves, access treatment and support, and feel supported to make healthy choices.
- Positive living includes:
  - Preventing illnesses.
  - Adhering to care and treatment.
  - Keeping the mind healthy.
  - Keeping the body healthy.
  - Keeping the soul healthy.
- Expert clients play a key role in helping other PLWHA live positively and following the “**recipe for positive living:**”<sup>xxiii</sup>

**KNOWLEDGE + DETERMINATION TO LIVE**

with actions for a

**HEALTHY MIND + HEALTH BODY + HEALTHY SOUL**

**= A LONG, HEALTHY LIFE**

## 12.2: HEALTHY MIND

### ACTIVITY:

#### The trainer should:

- Write the words "anxiety" and "depression" (discuss the local words for this that make more sense) on two separate sheets of flip chart. Ask participants what they have heard about these words. Since these are clinical terms, participants may not know them, although they will know many of the signs and symptoms. Explain using the content below.
- Ask participants if they or anyone they know have had anxiety or depression. How did it make them feel? What were the signs? What helped them to feel better?
- Write the signs of anxiety and depression on the flip chart papers and discuss what expert clients can do to help patients have a healthy mind and live positively with HIV/AIDS. Use the content below to supplement the discussion.

### CONTENT:<sup>xxiv</sup>

Expert clients can help people deal with their feelings after learning they are living with HIV/AIDS (after receiving test results, for example) or help them cope with disclosure. These are important times for expert clients to provide emotional support, but ongoing support is also needed to help people live positively with HIV/AIDS in the long term.

Sometimes patients may need your help when they feel anxious or depressed.

- **Anxiety** is when you feel nervous, have a lot of fear, or don't want to do things that you normally enjoy. Sometimes people also use the word "stress" to describe their feelings of anxiety.
- **Depression** is when you feel very sad and hopeless.

These are common reactions to living with HIV/AIDS, especially when a person isn't feeling well and doesn't get the support they need from family, friends, and the community. Our mental health and our physical health are closely related – this is why helping people deal with anxiety and depression can help with positive living.

#### Signs of anxiety:

- Can't eat
- Can't breathe
- Shaking and sweating
- Heart pounding fast
- Tingling in the hands or feet
- Can't sleep
- Can't concentrate on anything
- Feel "jumpy" or "stressed"
- Feel worried about many things

**Signs of depression:**

- Feel like you just don't know what to do (helpless or hopeless)
- Really tired with no energy
- Can't find good in anything
- Don't enjoy the things you used to
- Sleep too much or not enough
- Get angry for no reason
- Can't eat or eat too much
- Don't feel like being social with friends or family
- Don't feel like having sex
- Talk about running away
- Think about suicide

**What to do:**

- Talk with the multidisciplinary care team about the patient's symptoms.
- Provide continuous supportive counseling to the patient so they feel "heard." Use good communication skills, such as reflection.
- Encourage the patient to join a support group to meet other people living positively with HIV/AIDS.
- Link the patient with support services like groups that provide spiritual support, counseling, home care, or nutritional support.
- Remind patients that they shouldn't use alcohol or drugs because this will only make things worse.
- Make a plan with the person to stay hopeful and get feel good again.
- Encourage the person to continue any religious or spiritual practices that make them feel peaceful.
- Talk with family members – they may be discouraged and need support too. Remind them to provide ongoing support and love to the person.
- Remind the patient that his/her feelings are normal and that they will feel better.

**When the expert client needs to make a referral**

Each member of the multidisciplinary care team needs to help take care of a patient's mental health. Expert clients should look for danger signs that anxiety and depression may be out of control and consult with the clinic doctors, nurses, community-based counselors and spiritual advisors immediately. Expert clients should seek help from the team right away when:

- The patient might hurt him/herself or another person.
- The depression is so bad that the person is thinking about killing him/herself.
- The family cannot cope with the person anymore and wants to throw them out.
- The patient can't eat or sleep (may be due to side effects of ART like Efavirenz, but may also be anxiety or depression).
- There is any kind of emotional crisis.

**Expert clients can help people find hope and joy, accept their situation, and want to live for the future!**

## 12.3: HEALTHY BODY

### ACTIVITY:

#### The trainer should:

- *Note: you will need a small ball for this activity.*
- Ask the group to stand in a circle. Explain that positive living includes practicing certain behaviors and actions and staying away from others. Throw the ball to one person in the group and ask them to say one thing PLWHA can do to stay healthy. Have them throw the ball to another participant who will say another way PLWHA can stay healthy. Continue this until participants run out of answers. Start the game over, but this time, ask participants to name unhealthy things that PLWHA should stay away from.
- After the game, ask participants to sit down and summarize the answers they gave on two pieces of flip chart paper with the titles, "Healthy practices for PLWHA" and "Unhealthy practices PLWHA should stay away from."
- Ask expert clients what challenges they have faced keeping good behaviors and how they think they can best help other PLWHA.
- Supplement using the content below.

### CONTENT:<sup>xxv</sup>

#### Healthy behaviors:

There are many things PLWHA can do to keep their bodies healthy and live positively with HIV/AIDS, including:

- Use condoms and practice safer sex, every time!
- Get STIs treated right away and tell your partner to get them treated too.
- Get a TB test and treat TB right away.
- Use a family planning method if they want to limit or space children.
- Go to the hospital or clinic for check-ups, lab tests, and to pick up medicines. Never miss an appointment!
- Take medicines the right way (at the right time, the right number, etc.).
- Tell the nurse and doctor if there are any changes, even small ones, in your health.
- Stay busy and active.
- Get enough rest.
- Get sunlight and breathe fresh air every day.
- Join a support group and talk about things openly.
- Eat enough good food and take multivitamins.
- Exercise or stretch every day to stay healthy. If bedridden, have a family member help do stretches to keep blood flowing and prevent bedsores.
- Stay clean – wash regularly and wash hands often, especially after going to the toilet and before making food.
- Boil drinking water to make sure it's clean.
- Eat enough food. PLWHA need more calories to help their bodies fight the virus.
- Cook food well to get rid of germs.
- Wash raw fruits and vegetables well – with clean water.

- Keep the house and compound clean, including getting rid of any still water and garbage.
- Use a germ-killing bleach solution (like Jik, Barakina, or GV) diluted with water to keep surfaces clean.

**Unhealthy behaviors:**

Expert clients should talk about avoiding practices or behaviors that are not healthy. These include:

- Drinking too much alcohol.
- Using drugs.
- Smoking.
- Sharing medicines or stopping them without talking to the doctor.
- Having unsafe sex without condoms.
- Avoiding social contact.
- Missing appointments at the clinic.
- Taking local treatments that you haven't discussed with the doctor.
- Eating too many sugary or fatty foods.
- Not eating enough.

**12.4: SAFER SEX**

**ACTIVITY:**  
**The trainer should:**

- Ask participants what is meant by the term "safer sex" and why it's an important part of living positively with HIV/AIDS.
- Start a discussion by saying the following statement and asking participants to discuss: "People with HIV/AIDS have the right to a healthy sexual life."
- Remind participants that everyone has a right to safer sex and that it's really important for everyone to practice safe sex all the time, every time.
- Discuss what people can do to practice safer sex, using the content below.

**CONTENT:**

**What is safer sex?**

Safer sex is any kind of sex that reduces the risk of passing STIs or HIV from one person to another. Safer sex should prevent infected fluids from being passed between partners. These include: semen, fluid from the vagina, and blood.

To be safe, these fluids should not enter the vagina, the anus, or the opening of the penis. They should not enter open sores, cuts, or broken skin anywhere on the penis, in the mouth, on the vagina, in the anus, or anywhere else on the body.

**Why is safer sex important to living positively?**

- So HIV isn't spread to a person's partner(s).
- So PLWHA do not expose themselves or their partner(s) to STIs.
- So PLWHA or their partner(s) do not have an unintended pregnancy.

- So PLWHA do not expose themselves or their partner(s) to new, more harmful strains of the HIV virus.

#### **Ways to practice safer sex:**

- Stay in a relationship where both partners are HIV-negative and faithful to one another.
- Reduce the number of partners and use condoms all the time.
- Masturbate (alone or together), touching, massage, kissing, and hugging.
- Use a condom for all kinds of sex (vaginal, anal, oral).
- Don't put products or herbs in the vagina before sex.
- Don't have sex if you or your partner have an STI or any kind of sore in the genital area.
- Do not have sex at all.
- Never force another person to have sex.

### **12.5: MALE AND FEMALE CONDOMS**

#### **ACTIVITY:**

##### **The trainer should:**

- *Note: male and female condoms and penis and vaginal models are needed for this activity. Some participants may be uncomfortable touching and talking about condoms. But, it's important that all expert clients know about condoms and can tell people and show people how to use them. Condoms are one of the best ways to prevent HIV.*
- Tape male and female condoms on the wall and hand out small sheets of paper to participants. Ask them to write common myths about condoms on the papers and to tape them on the wall. Discuss why people have these myths and what expert patients can do to make sure people have the correct information about condoms.
- Ask if anyone in the class can demonstrate male condom use on a penis model. Ask the participant to describe the steps out loud, from how to store and open the condom package to throwing the condom away after it's been used. The trainer may need to demonstrate the steps first.
- Ask the same for the female condom. Ask a participant to demonstrate and say the steps out loud. Correct as needed until the demonstration is correct.
- Remind participants that condoms are effective in preventing HIV, STIs, and unwanted pregnancies. Even if 2 people both are HIV-positive they should still use condoms to prevent the risk of getting infected with a different, stronger strain of the virus.
- Ask participants, if two HIV-positive people have sex do they need to use condoms? Explain that condoms help prevent all kinds of STIs, unwanted pregnancy, and re-infection with different strains of the virus.
- Ask participants to break into groups of 3 and practice demonstrating male and female condom use, making sure to explain each step along the way, as if they were working with a patient.

## CONTENT:

### Myths about condoms:

- They break all the time.
- They actually give someone HIV.
- They are only for sex workers.
- They make sex feel bad.
- They are too small.
- You only use condoms with people you don't trust.
- Using condoms means you are not faithful.
- Condoms aren't for married people.
- Sex without condoms means you are in love.
- Condoms are only for sex outside of marriage.

### Safer sex using condoms:

Not having sex at all is one way to be completely safe. But this is not practical or enjoyable for most people. Using condoms is one reliable way to practice safer sex – see the list above for other ways. There are a lot of myths about condoms, such as that they are only for sex workers or that they make sex feel less good. Some people think that if both partners are HIV-positive then they don't need to use condoms at all. We know this isn't true because there are different types of HIV that can still be passed from one PLWHA to another. A lot of people in Swaziland also think that married people don't use condoms – that they are only for sex outside of marriage.

Part of the expert client's job is to spread the truth about condoms and help people learn how to use them to protect themselves and their partners from HIV, a new strain of HIV, STIs, and unwanted pregnancy.

### The male condom:

These are the basic steps you should know for using, and demonstrating how to use, a male condom. If penis models are not available, you can use a bottle, banana, or corn. Only condoms made out of latex protect against HIV.

- Look at the condom package and check the date to make sure it's still good and that the package doesn't have any damage.
- Open the packet on one side and take the condom out. Don't use your teeth to open the package.
- Pinch the tip of the condom to keep a little space at the tip. This will hold the semen and prevent the condom from breaking.
- Hold the condom so that the tip is facing up and it can be rolled down the penis.
- Put it on the tip of an erect (hard) penis (only use condoms with erect penis) and unroll it down to the bottom of the penis.
- After sex, hold the rim of the condom while the man removes his penis without spilling the semen. The penis must be removed while it's still hard to make sure the condom doesn't fall off.
- Remove the condom and tie it in a knot to avoid spilling. Throw it away in a latrine or bury it.
- Use a new condom every time!

**Also, it's important to:**

- Use only lubricants made out of water (not oils).
- Store condoms in a cool, dry place, out of the sun. Don't keep them in a wallet.
- Do not use condoms that seem to be sticky, a strange color, or damaged in any way. Throw them away.

**The female condom:**

Some women really like the female condom because it gives them more control over their own bodies and over sex. Some men like it too because they don't have to use a male condom. The female condom is becoming more affordable and available to women in Swaziland. These are the main steps for using a female condom. If no vaginal model is available to demonstrate its use to people, you can use a box with a round hole cut in it, or your hand.

- Open the packet – do not use teeth.
- Find the inner ring at the bottom, closed end of the condom. The inner ring is not attached to the condom.
- Squeeze the inner ring between the thumb and middle finger.
- Guide the inner ring all the way into the vagina with your fingers. The outer ring stays outside the vagina and covers the lips of the vagina.
- When you have sex, guide the penis through the outer ring. It has to be INSIDE the ring.
- After sex, before the woman stands up, squeeze and twist the outer ring to keep the semen inside the pouch and pull the pouch out.
- Put the used condom in a latrine or bury it. Don't put it in a flush toilet.

## 12.6: CONDOM NEGOTIATION

**ACTIVITY:**

**The trainer should:**

- Ask participants what makes it difficult for people to talk about condoms with their partners. What makes it hard for women? Young people? What about men?
- Explain that expert clients need to help patients and their families feel comfortable talking about safer sex. A good way to do this is to practice what the person is going to say beforehand with the expert client.
- Break the group into small groups of 2 and ask each group to come up with one reason that people say they don't want to use condoms. Ask the group to role play, with the expert patient helping the person come up with responses to tell their partner who doesn't want to use condoms. For example, one group could discuss what to say when the person's partner says "condoms always break. They're not big enough." The expert client should help the person learn how to use condoms the right way so they don't break. Or, "If you love me, we don't need condoms." The expert client should suggest that the person say, "I do love you and I want us to be safe so we can be happy together."
- Ask some of the groups to perform the scenario for the larger group and discuss, using the content below.

## CONTENT:

It's very hard for most people to talk about condoms openly with their partners. Part of the expert client's job is to teach patients how to use condoms to protect themselves and their partners, and how to talk to their partners about condoms. Even when a person decides that s/he wants to use condoms, s/he still needs to talk about condoms with the partner, which can be tough.

Expert clients can:

- Promote condom use every time, but especially with irregular partners or partners who don't know his/her HIV status. Pregnant women and their partners should also use condoms every time to protect the woman and the baby.
- Help people practice what they are going to say about condoms to their partners.
- Suggest that the person focus on safety issues instead of trust issues. For example, "it's good for us to use condoms because I don't want to give you HIV. It's not because I don't trust you."
- Use other people practicing safer sex as examples. So, "I know that so and so in the community decided they should use condoms, even though they are faithful to one another."
- Suggest that the person bring their partner to talk with the expert client.
- Tell people that you use your whole body to have sex – not just the penis, vagina, anus, or mouth. Only a small part of the body is covered by a condom so it shouldn't take away from the experience.
- Help people make condoms fun and pleasurable, for example suggesting that a woman help a man put on a condom or reminding people that a man with a condom on may take a longer time to ejaculate (cum), so it can mean more pleasure for his partner!<sup>xxxvi</sup>

## 12.7: PROMOTING SELF-CARE AS PART OF POSITIVE LIVING

### ACTIVITY:

#### The trainer should:

- Ask participants to discuss how much they have been involved in their own care and treatment decisions.
- What are the challenges in working in a partnership with the clinical team? What makes them feel supported as partners in their own care and treatment?
- Ask the group to brainstorm ways that expert clients can help patients get involved and stay involved in their own care and treatment. Use the content below to add to the conversation as needed.

## CONTENT:

### What is self-care?<sup>xxvii</sup>

Expert clients should always try to leave the patient in charge of his/her own care as much as possible. This is called self-care.

People can take responsibility for taking their medication. They can make positive choices about their diet, exercise, and other lifestyle issues that protect their health and help them to live positively.

Patients need to be educated, motivated, and supported in order to take care of themselves. This gives them a better sense of control, makes them feel better about their situation, and helps them be more successful in caring for themselves.

Promoting self care includes developing a good relationship between the care team and the patient. Self care also depends on the support of family, friends, and the community – without stigma and discrimination. It's hard to practice healthy behaviors when these behaviors aren't supported by others (for example a woman who wants to use condoms needs her partner's support).

### How can people be more involved in their own care and treatment? Expert clients should encourage them to:

- **Be involved:** Be a part of every decision that is made about your health.
- **Think ahead:** When you talk to your health care providers about your health BEFORE problems happen, you will get the best possible care.
- **Ask questions:** If you do not understand something that the doctor, nurse or pharmacist tells you, always ask questions. If you do not understand the answer, ask your question again. You can also ask an expert client, family member, a friend or caregiver to be there with you.
- **Learn more about your health and treatment:** Collect as much information as you can about HIV/AIDS and your treatment. Ask your health care worker about the tests and treatment you need, and how to get the treatment. Also know the risks and side effects of the treatment and what will happen if you do not get the treatment.
- **Understand which medicines you are taking:** Make a list of all the prescription medicine, traditional medicine, and anything else you are taking or doing for your treatment. Make sure you write down if you are allergic to any drugs. Before you take any medicines, make sure you ask a health care provider about:
  - How to use the medicine.
  - How you might feel when you are on the medicine (side effects).
  - What other medicines you should NOT take when using the medicine.
  - How long you will need to take the medicine.
- **Get the results of every test:** Ask for the results of the tests you are taking. Ask what the results mean for your health and for your treatment.
- **Ask for more information about referrals:** Ask the doctor, nurse, or expert client:
  - Why am I being referred? Is it necessary?

- How quickly do I need to go to the clinic/hospital? Will I have to wait a long time?
- Will they be familiar with my case so I don't have to explain everything?
- Is there a referral form to take?
- What will happen to me if I do NOT go?
- Will I have to pay for treatment? How much will it cost?
- **Understand the treatment plan:** Before you leave the hospital, ask your health care workers to explain the treatment plan you will use at home. Know what you need to bring back to your health care worker. Also make sure you understand your follow-up care plan, and what medicines you must continue to take. Expert clients are always available to help!

## 12.8: CLASSROOM PRACTICUM ON POSITIVE LIVING COUNSELING

### ACTIVITY:

#### The trainer should:

- Provide a quick review of the content covered in the Unit so far and ask if there are questions or areas where participants don't yet feel comfortable and need more help.
- This classroom practicum session will have 2 parts. The first part will be done as a large group. Lead the group in a storytelling exercise. Ask one participant to start the story by saying one sentence in the language that they feel comfortable, such as "Mary was diagnosed with HIV yesterday during her antenatal check up." Then the person seated next to them continues the story, and the person next to them continues it further. Keep going, and remind participants to discuss issues of adherence, stigma, disclosure, and positive living discussed during the training.
- Now move on to small group case studies (you don't have to do them all, select which ones you think would be most useful for the group). Divide the groups up into smaller groups of 3 or 4. Do rotating role plays where one person acts as the patient, another as the expert patient, and others observe and give constructive feedback. Use the case studies below or ask participants to write their own case studies and exchange them with others.
- The trainers should rotate around the room and provide feedback to the small groups during the activity.
- If there is time, ask one of the groups to perform their role play in front of the larger group and lead a discussion summarizing the skills learned in the Unit.

### Case Study 1:

A 40 year-old married man who tested positive for HIV 2 weeks ago comes to his first appointment at the ART clinic. He knows he should use condoms to prevent HIV from spreading, but is embarrassed to talk about them with his wife and fears she will think he's cheating on her. He told his wife that he is HIV-positive, but hasn't discussed condoms with her, and doesn't know how to use condoms. He asks you for advice.

**Case Study 2:**

On a visit to the clinic, a pregnant woman tells you she is having trouble breathing sometimes and feels like her heart might jump out of her body because she is so scared her baby will die. She can't sleep and is having trouble eating. How would you help her?

**Case Study 3:**

A patient misses an appointment so you stop by his house on the way home for a visit because he said home visits are ok and the multidisciplinary team asked you to see what's happening. He is there completely alone, in dirty clothes, lying on a dirty blanket on the floor. He says he is so angry about having AIDS that he doesn't care if he lives or dies anymore and isn't going to come to the clinic ever again. He tells you to leave his home right away. What would you say?

**Case Study 4:**

A young mother of 3 children just started coming to the ART clinic. She is worried about her children and wants to stay as healthy as she can to take good care of them. What would you tell her about living positively with HIV/AIDS? What should she do? What should she avoid?

**Case Study 5:**

A 25 year-old man that's on ART and is feeling good comes to the clinic. He is healthy and wants to have sex with his wife. She is also on ART and feeling really good. He wants to know if he needs to use condoms because they are both HIV-positive and both on ART and doing well. He also says he can't afford condoms and doesn't like how they feel. Counsel him on safer sex and condom use.

**Case Study 6:**

You learn that a patient at the clinic can often be found at the local bar drinking and smoking into the morning hours. You worry that he may be hurting himself and missing doses because he is drunk when he gets home. What would you say to him about positive living and adherence next time he's at the clinic?

**Case Study 7:**

A pregnant woman comes to you and says her husband refuses to wear a condom. He thinks they are only for sex workers and doesn't see the point because she's already pregnant. She is worried that she and the baby will get HIV from him because he tested positive, even though she is still negative. Help her prepare to discuss condoms again with her husband and tell her more about female condoms.

**Case Study 8:**

A young man comes to the clinic and tells you that he recently had sex with another man at University. He wants to keep it a secret, but wants to be safe. He asks you how he can be safe and protect himself. Tell him about safer sex and be sure not to be judgmental of his actions.

### Case Study 9:

A patient comes to you and says she doesn't care about her treatment any more. It's so confusing and they are just referred from one place to the next. She doesn't have time to wait anymore and feels angry that she doesn't know why she had to come to the clinic today in the first place, just to wait around for the nurse. Help her be an advocate for her own care and treatment.

### Case Study 10:

A 24 year-old pregnant woman tested HIV-positive during her antenatal check-up. She has been attending her clinic appointments and the doctor says she should start ART because her CD4 count is low. She goes to counseling sessions and starts ART. On her next visit she tells you that she isn't taking the ART because her partner won't let her take it. She doesn't want to go against his wishes, because if he leaves her she won't have any financial support. How would you counsel her on positive living and ART?

## 12.9: UNIT SUMMARY

### ACTIVITY:

#### The trainer should:

- Ask participants what they think are the key points of this Unit. What information will they take away from the Unit?
- Summarize the key points of the Unit, using participant feedback and the content below.
- Ask if there are any questions or clarifications.
- Review the learning objectives with participants and make sure each person is confident in their skills and knowledge in these areas.
- If there are areas in which participants need more help or do not fully understand, go back and review the session before moving to the next Unit.

### CONTENT:

#### The key points of this Unit include:

- People with HIV can live full and healthy lives if they take care of themselves, access treatment and support, and feel supported to make healthy choices.
- Expert clients play a key role in helping other PLWHA live positively and following the "recipe for positive living:"

**KNOWLEDGE + DETERMINATION TO LIVE**  
with actions for a  
**HEALTHY MIND + HEALTHY BODY + HEALTHY SOUL**

**= A LONG, HEALTHY LIFE**

- Expert clients should know the signs of anxiety and depression and help people overcome them. They should also alert the clinical care team if they think someone is anxious, depressed, or wants to end his/her life.

- Expert clients can help people keep their minds and bodies healthy by practicing safer sex, eating well, staying clean and avoiding infections, and keeping active (among other things).
- Expert clients should help people stay away from unhealthy things, like alcohol, smoking, unsafe sex, eating sugary and fatty foods, and being isolated from other people.
- PLWHA and their partners should be counseled on safer sex to avoid spreading HIV and/or STIs, avoid re-infection with a different strain of HIV, and to avoid unwanted pregnancy.
- Safer sex means avoiding passing of semen, vaginal fluids, and blood from one person to another.
- One of the best ways to have safer sex is to use male or female condoms, the right way, every time.
- Expert clients should be comfortable demonstrating how to use male and female condoms.
- Expert clients can help people negotiate condom use with their partners and be safer sex role models.
- Expert clients can help other patients be in charge of their own health care as much as possible and support them to do so.
- Expert clients can help other patients advocate for themselves, be involved and understand their treatment, ask questions to providers, understand referrals, and other aspects of their care.

## UNIT 13 REFERRALS AND RECORD KEEPING (Time: 1 HOUR)

**LEARNING OBJECTIVES:** By the end of this Unit, participants will be able to:

- Understand the expert clients' role in referring patients from service to service and among hospitals, PHUs, and health centers.
- Explain the importance of record keeping in HIV/AIDS and expert client programs.
- Understand the different forms used in pMTCT-Plus, care, and treatment services in Swaziland.
- Fill out forms and reports used by the expert client program.

**PRACTICAL SKILLS:**

- Make and follow-up on referrals.
- Fill in expert client recording and reporting forms.

**MATERIALS NEEDED:**

- Flip chart
- Markers
- Expert client recording and reporting forms
- Sample pMTCT cards and facility referral forms

### 13.1: MAKING REFERRALS

**ACTIVITY:**

**The trainer should:**

- *Note: Collect and photocopy expert patient recording and reporting forms developed by the MOHSW and make sure every participant has copies.*
- Lead a discussion on referrals using the content below. Using examples, explain the difference between internal and external referrals.
- Ask participants to share their experiences with referrals. What happens when you are referred from one place to another within the hospital or from the PHU to the hospital? Or from the hospital to the clinic? What makes it hard? Why don't people go when they are referred some place? Ask what they think expert clients can do to make referrals easier for patients.
- Tell participants that for now, the group is going to focus on internal referrals – those from one place to another within the hospital or clinic. There is more information on linkages to the community in a later unit. Tell participants that part of the practicum will be to walk with people from place to place at the hospital or clinic, ensuring that they understand the referral services.

## CONTENT:

No one person or organization can provide a person and his/her family with all the comprehensive care and support services they need. That is why it's important to have a strong referral system in place.

Making a referral means that you formally send a person and/or family members to another place in the hospital, another health facility, or another organization for services. There are 2 basic kinds of referrals:

- **Internal:** Referrals from one part of the health facility to another part of the health facility, for example from the PHU to the ART clinic, from the VCT clinic to the ART clinic or from the ART clinic to the TB clinic.
- **External:** Referrals from the facility to a community organization or from a community organization to the health facility. For example, an expert client refers a patient to a faith-based organization providing food supplies for PLWHA or a home-based care worker refers a patient to the hospital to get a CD4 test.

The "referral network" should include organizations and people in a defined geographical area that provide services and support needed by PLWHA, their caregivers, and their families. Expert clients play an important role in both types of referrals.

### **Helping people get from place to place in the hospital/health facility:**

Many times a person will need different services at the hospital or health facility on the same visit. This can be very overwhelming for someone who isn't familiar with where things are, how to get from place to place, or if they are not feeling well or have to wait a long time at each place. A key role of the expert client is to help people get from one place to another in the hospital as easily as possible.

Here are some steps:

- Make sure you know where each service is at the hospital and how to get there the fastest way. It's helpful to walk around the hospital alone first and then you will be able to better help patients.
- Make sure you know which days and which hours during the day different services are offered.
- Make sure you know where the patient is being referred and why. What services do they need when they get there? For example, if someone is being referred to the lab, what tests do they need?
- It's best if there is a referral form, where the doctor or nurse writes exactly why the person is being referred. Expert clients should be familiar with any forms used at the hospital.
- Expert clients should help the patient understand why they are being referred and why it's important to get these services. A lot of times, people don't understand why they are referred and they might just leave. This is common with referrals from PMTCT-Plus services to ART services.
- **WALK WITH THEM** to the other part of the hospital and make sure they have a comfortable place to wait.

- Expert clients should wait with the person at the referral point. This is a good time to provide counseling and support and ask about the needs of other family members.
- Expert clients should help the patient tell staff that they are waiting and talk with the doctor or nurse to try and get the patient seen as soon as possible to minimize waiting – especially for pregnant women. One of the biggest reasons that people don't get care is because they don't want to wait a long time, many times, during the day. Some facilities give pregnant women "red carpet treatment," meaning they don't have to wait to be seen. This is similar to what happens in banks or on the bus.
- If the person needs other services or gets more referrals, stay with them until they leave the hospital. Continue to explain why each service is important and walk them from place to place.
- If needed, help the person plan follow-up actions and visits to the hospital and provide needed referrals to community-based organizations.

## 13.2: THE IMPORTANCE OF RECORD KEEPING

### ACTIVITY:

#### The trainer should:

- Ask participants if they can list all of the people they talked to in the last 3 weeks. Since most will not be able to recall this information, make the point that if we don't write things down, we often don't remember them.
- Ask participants what kind of records they keep in their daily lives (e.g. medicine diary, calendar, child's health/immunization records, etc.). Why do we keep these records?
- Discuss why it's important for expert clients to keep records and do monthly reports. Fill in the discussion using the content below.

### CONTENT:

Records are important because they can help us:<sup>xxviii</sup>

- Remember things
- Plan
- See what we've done
- See what we can do better
- Report to other people (like a boss) what we've done
- See what the gaps are and fill them.

It's important for expert clients to understand the records that are kept in PMTCT-Plus and care and treatment programs and to fill in your own reports each month because:

- They will show what you've done in the month (e.g. how many people you've counseled, how many group education sessions you've led, how many pregnant woman you've taken to the ART clinic, etc.)
- They will show your supervisor what you've done.
- They will help plan the next month.

- They will help follow-up on patients from month-to-month.
- They will help show how effective expert clients can be in helping PLWHA when all of the reports are combined across the country.

### 13.3: TYPES OF RECORDS KEPT FOR pMTCT-PLUS AND CARE AND TREATMENT SERVICES

#### ACTIVITY:

##### The trainer should:

- Pass our common forms seen in the pMTCT-Plus and care and treatment clinics. Note that many facilities use the national forms, and have also developed their own forms. Expert clients should become familiar with all of the forms used at their facilities during the practicum and when they return from the training.
- Ask participants to look through the forms and discuss why the forms are used and what is the major information recorded in the forms.
- Look at the pMTCT-Plus form specifically and ask if participants know what the coding system means (see content below). Do you think patient know what these codes mean? What are the effects of codes on stigma and access to services?

#### CONTENT:

##### Things to know about the national ART and pMTCT registers/forms in Swaziland:

The MOHSW has national forms and registers for pMTCT services. Each facility should have patient files and registers, but they will differ from place to place.

##### Coding system for pMTCT in Swaziland:

The national pMTCT registers use a common coding system to tell what women have been tested, the results, and if Nevirapine or ART was given. The abbreviations are:

C= counseled  
 T= tested  
 R = result  
 MD = mother dose  
 ID = infant dose  
 A = ART

If the code is circled, it means the mother received that service. If CT and R are circled, the woman is probable HIV-negative. It can also mean that the mother is HIV-positive but has not yet gotten her Nevirapine dose. Health care workers and expert clients should always ask the mom to confirm the results of her HIV test. Some facilities will circle C, T, and R and write MD 28/40 to indicate that the mother is HIV-positive but has not yet gotten the Nevirapine doses. If MD is circled, it means the mom is HIV-positive for sure.

These codes can be very confusing or can be written the wrong way, so it's very important that moms are asked about their HIV-status when visiting the clinic. Also, many women are afraid that they will be stigmatized if other people see their patient records and know what the codes mean. Remember, it's important to keep all registers and patient files confidential so that no one outside of the health care team sees them.

#### 13.4 EXPERT CLIENT RECORD KEEPING AND REPORTING

##### **ACTIVITY:**

##### **The trainer should:**

- *Note: Ideally, the National Expert Client Coordinator should lead this session.*
- Pass out the expert patient recording and reporting forms and orient participants on the different information they are expected to collect and give scenarios so they can practice filling out the forms.
- Encourage participants to work with the Expert Client Coordinator at their site to set up a reporting system each month.

##### **CONTENT:**

##### **Types of information recorded by expert clients each day:**

- The numbers of group sessions held and the number of men and women at each
- The numbers of one-on-one counseling sessions held, and how many were with men, women, or for pediatric or pregnant patients
- The number and type of adherence counseling provided, for example pre-ART, at the 2-week visit, or on-going.
- Any additional information, such as questions, challenges, successes should be recorded by expert clients in their notebook and included in their monthly reports.

##### **Reporting your work to the National Expert Client Coordinator:**

- Expert clients should submit their monthly reports to the Site Expert Client Coordinator each month.
- The Site Expert Client Coordinator should submit monthly reports to the National Expert Client Coordinator.
- In addition to the numbers and types of patients reached by expert clients, the report can also include bullet points about challenges faced, areas that need refresher training, or solutions to problems that may be replicated in other sites.

## 13.5: UNIT SUMMARY

### ACTIVITY:

#### The trainer should:

- Ask participants what they think are the key points of this Unit. What information will they take away from the Unit?
- Summarize the key points of the Unit, using participant feedback and the content below.
- Ask if there are any questions or clarifications.
- Review the learning objectives with participants and make sure each person is confident in their skills and knowledge in these areas.
- If there are areas in which participants need more help or do not fully understand, go back and review the session before moving to the next Unit.

### CONTENT:

#### The key points of this Unit include:

- Referrals within the hospital setting, and from one health facility to another, and between community and facility-based services, are a key part of comprehensive care.
- Each hospital and clinic will have different referral systems and forms so it's important for expert clients to become familiar with these when they return to their assigned facility after the training.
- Expert clients play a key role in referring patients for services, helping them understand why they are being referred, and taking them to the referral point when possible.
- It's important for expert clients to keep good records of their work and report every month to the Site Expert Client Coordinator.

**UNIT 14**  
**LINKAGES TO COMMUNITY SUPPORT SERVICES**  
**(Time: 2 HOURS)**

**LEARNING OBJECTIVES:** By the end of this Unit, participants will be able to:

- Identify what community-based care and support services PLWHA and their families may need.
- Understand why PLWHA and their families may need home-based care, access to associations and support groups, nutrition support, income-generating activities, and legal support.
- Return to their facilities and work with the multidisciplinary team to map and link with community-based organizations.

**PRACTICAL SKILLS:**

- Assess which community services patients could benefit from.
- Counsel patients on the range of community services available to them and their family.
- Provide referrals to community-based services, such as home-based care, support groups, nutrition support, and legal support.

**MATERIALS NEEDED:**

- Flip chart
- Markers
- Facility-community referral forms (if available)

## 14.1: REVIEW OF COMPREHENSIVE HIV/AIDS CARE AND SUPPORT

### ACTIVITY:

#### The trainer should:

- *Note: Trainers should invite community groups and community health workers to the training in advance. In the interest of time, the activity can be structured as a panel session with panelists representing the different kinds of community support services available. Be sure to explain the goals of the expert client program to each invited speaker in advance.*
- Ask participants what they recall about the pieces of comprehensive HIV/AIDS care. Ask participants to name some of the elements of comprehensive care and write them on flip chart, filling in as needed from the content below.
- Remind participants that part of their work as expert clients is to provide referrals to patients and help patients get the services to which they've been referred. This Unit will focus on external referrals to community-based activities and organizations.
- Ask participants which of the comprehensive care services listed below are mainly community-based? Note these on flip chart. Ask participants to brainstorm which organizations offer these kinds of services in their communities (can be PLWHA groups, faith-based organizations, NGOs, etc.).
- Record these local, community resources on flip chart and fill in as needed based on local knowledge of organizations providing HIV/AIDS-related support services. Go over any referral forms that are available.
- Remind expert clients that part of their job is to work with the multidisciplinary care team at their site to link to community resources and keep up-to-date on the services being offered in the community to best serve the needs of patients at the hospitals and health centers.

### CONTENT:

Comprehensive HIV/AIDS care can include:

- Pre- and post-test HIV counseling and testing and follow-up
- Prevention, diagnosis, and treatment of opportunistic infections and other illnesses, such as malaria
- Palliative care, including pain management
- PMTCT-Plus, antenatal, and reproductive health services
- ART (for those who need it)
- Ongoing monitoring of health status (through lab tests and physical exams)
- Hospitalization for those that are very sick
- Counseling on positive living and prevention
- Couples and disclosure counseling
- Referral and follow-up
- Home-based care
- Nutritional support

- Psychological support
- Social and spiritual support
- Economic support
- Legal support
- End of life care, including pain management
- Care and support for family members, including children

Remember, not any one person or organization can provide all of the services and support PLWHA need. They must work together to provide a quality continuum of care and support!

## 14.2: HOME-BASED CARE (HBC)

### ACTIVITY:

#### The trainer should:

- Invite home-based care workers to this session of the training. Ask them to give a brief overview of the services they offer to PLWHA and their families, which specific communities they work in, and whether or not there is a referral system from the facility to the HBC workers or from the HBC workers to the facility. If there is not, the training is a good time to develop one.
- To start the discussion and get a sense of what people already know, ask participants why many PLWHA receive HBC services. What value does HBC bring to people's lives? What kinds of services do HBC workers provide? How do they complement the services people get at the health facility? Add to the discussion using the content below.
- Allow participants to ask questions of the HBC teams and encourage the group to think more about how they can work together to best provide a continuum of care and support to patients – in the facility and in their homes (e.g. referral systems and forms, regular meetings between the groups of HBC providers and expert patients).
- Remind expert clients that when they return to their facility they will work with the multidisciplinary team to learn more about community resources and services, like home-based care.

### CONTENT:

**Home-based care** programs usually involve trained health workers visiting PLWHA in their homes to provide care and support services to the patient and the family. In many places, HBC has evolved to include community-wide prevention and mobilization activities in addition to care activities in the home. Sometimes this is called community home-based care, or CHBC.

#### HBC is needed because:

- Facility-based health services can not cope with an increasing demand and increased numbers of patients. In many places, over 50% of hospital beds are occupied by PLWHA.

- Many people prefer to receive ongoing care in their homes, have too many responsibilities at home to visit the facility (children, getting water, cooking, farming), or live long distances from health facilities.
- It supports existing, longstanding family and community structures in Swaziland, whereby family members take care of each other.
- It ensures a continuum of care to patients with both at the home and health facility levels.
- It can empower PLWHA to take care of each other and themselves when they are trained as HBC providers.
- It provides support and training to caretakers and family members, not just the patient.
- It can promote HIV prevention and can reduce stigma and discrimination in the whole community by bringing HIV/AIDS out into the open.

#### Kinds of HBC programs:

- Some HBC programs are **extensions of facility-based services**. In these types of programs, it is usual trained nurses or nurses aides that do home visits on certain days of the week, often focusing visits on the sickest patients or those who cannot come to the facility.
- Other HBC programs are **based in the community** and run by community-based organizations. These programs often train volunteer community health workers to provide HBC services in homes and mobilization activities in the community.
- The best HBC services **help patients learn self-care** and train family members/caretakers how to provide basic care.

#### Components of HBC

Depending on the care providers' level of skill and training, the following services are considered a part of home-based care.

- **Basic nursing care:** (training patients and caregivers to give bed bath, mouth care, nail care, turn patient in bed, pressure area prevention and care, wound care, physical therapy, prevention and treatment of opportunistic infections)
- **Treatment of HIV/AIDS-related conditions:** (ART adherence support, recognizing and treating ART side effects or referring to the facility, preventing and treating opportunistic infections, supporting TB treatment, basic pain management and symptom relief)
- **Care for the environment:** (changing soiled bedding, handing soiled clothes, cleaning of house and compound, malaria prevention)
- **Nutrition services:** (preparing food, training the caretakers and patient how to prepare locally available nutritious foods, serving and feeding the patient, supporting infant feeding)
- **Preventing infections:** (infection prevention for example in handling body fluids, cooking food safely, ensuring safe water, personal hygiene, making sure the house compound is clean, proper waste disposal)
- **Referral for medical services** (identifying and referring pregnant women for pMTCT, encouraging family members to seek VCT or care and treatment, following up with patients who have missed appointments at the facility)
- **Other support services:** (Social, spiritual, emotional, economic, and nutritional support for patient and family members, often through referral linkages)

- **Education/counseling:** (adherence to care/ treatment, condom use, safer sex and condom distribution, hygiene, nutrition, infection prevention, symptom relief, positive living, and others).

### 14.3: PLWHA ASSOCIATIONS AND SUPPORT GROUPS

#### ACTIVITY:

##### The trainer should:

- Invite PLWHA Association leaders and members to this session of the training (there may already be PLWHA Association members in the training). Ask them to give a brief overview of the services they offer to PLWHA and their families, which specific communities they work in, and whether or not there is a referral system from the HIV/AIDS services at the facility (ART, pMTCT, HTC) to the Association or from the Association to the facility.
- To start the discussion and get a sense of what people already know, ask participants if they belong to a PLWHA Association. What have their experiences been and how has being a member benefited them? What activities do they do with the Association? How can PLWHA Associations complement the services people get at the health facility? Add to the discussion using the content below, as needed.
- Allow participants to ask questions of the PLWHA Association members and encourage the group to think more about how they can work together to best provide a continuum of care and support to patients.
- Remind expert clients that when they return to their facility they will work with the multidisciplinary team to learn more about the PLWHA group in their area and link with support groups or start their own. Expert patients will also be trained on setting up and leading support groups during their advanced training.

#### CONTENT:

We learned about support groups in the last Unit and why they are important for PLWHA and their families. Many times, support groups are run by PLWHA associations. PLWHA associations can offer many services, including:

- Ongoing support through individual or group counseling.
- Support groups for PLWHA and their families.
- Financial or nutritional support to PLWHA and their families.
- Support for children to enroll in or stay in school (formal or non-formal education).
- Income-generating activities or micro-credit schemes for PLWHA and their families.
- Advocacy for PLWHA to receive the services they have a right to. This can be at the community, regional, national, and international levels.
- Community sensitization and advocacy to reduce stigma and discrimination.
- Sensitization/training for health care providers on providing quality care to PLWHA, drawing on members' own perspectives and experiences.

- Help with legal support when a person is discriminated against because of their HIV-status (in the home, at work, in the community).
- Linkages to the national and local PLWHA Associations.

#### 14.4: NUTRITION SUPPORT

##### ACTIVITY:

##### The trainer should:

- Invite nutritional support organizations to this session of the training. There may be international associations such as World Food Program, Heifer International, or CARE providing this kind of support to the whole community or just focused on PLWHA, and/or there may be local organizations providing these services. Ask them to give a brief overview of the services they offer to PLWHA and their families, which specific communities they work in, and whether or not there is a referral system from the facility to the nutrition program or from the nutrition outreach program to the facility.
- To start the discussion and get a sense of what people already know, ask participants why nutrition is so important for PLWHA. What are the connections between eating well and living positively with HIV/AIDS? What kinds of food should PLWHA eat? What should they avoid? Add to the discussion using the content below.
- Allow participants to ask questions of the nutrition workers and encourage the group to think more about how they can work together to best provide a continuum of care and support to patients – in the facility and in their homes (e.g. referral systems and forms, regular meetings between the groups of nutrition providers and expert clients).
- Remind expert clients that when they return to their facility they will work with the multidisciplinary team to learn more about community nutrition resources and services.

##### CONTENT:

There is a strong relationship between nutrition and HIV/AIDS. PLWHA need to pay attention to how much they eat, what they eat, and how often they eat.

##### Good nutrition can:

- Make muscles, skin, and bones healthy
- Provide energy
- Protect against infections
- Prevent weight loss
- Improve overall well-being
- Help medicines absorb into the body and prevent side effects from some ARVs

Even if a person does not feel sick, PLWHA need more energy and food than people without HIV. The body needs more energy to fight off the virus and help the person stay healthy. Eating enough good foods can help PLWHA fight off opportunistic infections

and stay healthy longer. Expert clients should help patients understand nutrition and link them to organizations that can help them get enough healthy foods to eat.

### **Challenges to good nutrition:**

Even though most people know it's good to eat healthy foods and lots of them, sometimes PLWHA don't eat enough. This can be because:

- They lose their appetite or ARVs change the way food tastes.
- They have sores in their mouth or are nauseous and it's hard to eat.
- They feel tired or depressed and don't want to eat.
- There is not enough money to buy food or the person is too sick to farm, fish, garden or prepare food.

### **The basic food groups:**

No one food or group of foods has all the nutrients we need. That's why it's important for expert clients to help patients learn to eat many kinds of foods and link them to groups that can help.

- **"GO" foods** give us energy. These include rice, bread, pasta, and other grains.
- **"GROW" foods** provide protein and help build our bodies and keep muscles strong. These include meat, fish, eggs, beans, and dairy.
- **"GLOW" foods** provide vitamins and minerals to help the immune system stay strong and fight off infections. These include all kinds of fruits and vegetables.
- **Fats and sugars** can help give energy, help us gain weight, and can make foods taste better, but they should be eaten with other healthy foods and in moderation. "Good fats" include things like avocados, nuts, and palm oil.

### **Ways expert clients can work with community-based organizations to help PLWHA and their families get enough good foods to eat:**

- Link with nutrition support programs.
- Make sure patients take multivitamins.
- Provide counseling and education to patients and family members on nutrition, as well as storing and preparing food (like washing hands and not leaving food out in the sun).
- Help families learn to make sack gardens or start community gardens.
- Organize market workers, restaurant and store owners to donate food to households affected by HIV/AIDS.
- Organize community members to help take care of other people's gardens when they are ill or need to go to the facility for an appointment.
- Organize food banks through community and faith-based organizations.

## 14.5: LEGAL SUPPORT

### **ACTIVITY:**

#### **The trainer should:**

- Invite legal organizations and advocacy groups to this session of the training. Ask them to give a brief overview of the services they offer to PLWHA and their families, which specific communities they work in, and whether or not there is a referral system from the facility to the legal organization or from the legal organization to facility-based HIV/AIDS services. If there is not, the training is a good time to develop one.
- To start the discussion, ask participants what types of legal services PLWHA and their families may need. Fill in using the content below, as needed.
- Allow participants to ask questions of the legal services organization and encourage the group to think more about how they can work together to best provide support to patients.
- Remind expert clients that when they return to their facility they will work with the multidisciplinary team to learn more about legal services available to patients in that area.

### **CONTENT:**

People with HIV/AIDS and their families often have their rights violated and may need legal support services. Some organizations provide these services for free or at reduced cost to PLWHA, often through PLWHA Associations. Expert clients should be aware of what kinds of legal services patients and their families need and who provides these services in the community.

#### **Types of legal support can include:**

- Inheritance rights for widows
- Support for women or children who experience violence in the home or community
- Inheritance rights and access to schooling and community services for children, including orphans, affected by HIV/AIDS
- Fighting discrimination in the workplace, at health facilities, or in the community
- Access to HIV testing and other HIV/AIDS services, especially for children with no legal guardian
- Access to social support and welfare services, regardless of HIV-status.

## 14.6: UNIT SUMMARY

### ACTIVITY:

#### The trainer should:

- Ask participants what they think are the key points of this Unit. What information will they take away from the Unit?
- Summarize the key points of the Unit, using participant feedback and the content below.
- Ask if there are any questions or clarifications.
- Review the learning objectives with participants and make sure each person is confident in their skills and knowledge in these areas.
- If there are areas in which participants need more help or do not fully understand, go back and review the session before moving to the next Unit.

### CONTENT:

#### The key points of this Unit include:

- Referrals to community-based services are a key part of the continuum of HIV/AIDS care and support. No one person or group can provide PLWHA and their families with all the services they need. People must work together.
- There are many community-based services in most places, but often groups don't know about each or make formal plans to work together. Without this collaboration, patients won't be able to access the full continuum of care and support.
- Expert clients can provide a vital link for patients to these community-based services through collaboration, referral, and follow-up.
- Once the training is completed, expert clients should go back to their sites and work together and with other members of the multidisciplinary team to identify and link with community-based organizations. If there is time, a good exercise is to do community mapping.
- Expert clients should assess patients' needs for community-based services and provide referrals and follow-up for:
  - Home-based care and support
  - PLWHA Association membership and links to support groups and income generating activities
  - Nutritional education and food support
  - Legal support
- Expert clients should identify and meet regularly with community-based groups in their areas to make formal referral systems, improve the ways facility and community-based groups work together, avoid overlap, identify gaps in services and come up with solutions to fill them, and better serve the needs of patients and their families.

**UNIT 15**  
**SUPERVISED PRACTICUM**  
**(TIME: 2 DAYS)**

**LEARNING OBJECTIVES:** By the end of this Unit, participants will be able to:

- Apply skills learned in training in the clinic.
- Provide one-on-one and group education to patients about care and treatment, PMTCT+, adherence, and positive living.

**PRACTICAL SKILLS:**

- All of the skills covered in the classroom portion of the training will be applied in the facility practicum.

**MATERIALS NEEDED:**

- Trainer's Tool 5 (one practicum checklist should be completed by preceptors for each participant)

## 15.1 FACILITY-BASED PRACTICUM

### ACTIVITY:

#### WORK TO DO IN ADVANCE OF THE PRACTICUM:

- Select sites for the practicum, ideally a busy care and treatment site and a facility that also provides pMTCT-Plus services. Depending on the number of participants and preceptors, it's best to split up the group so that preceptors have no more than 3 participants each during the practicum.
- Meet with facility leadership and staff to discuss the Expert Client program, the training, and the supervised practicum.
- Get a sense of daily activities at the site, and how participants may be able to observe and practice applying the skills they've learned.
- If possible, orient some of the facility staff to be preceptors during the practicum and orient them on the key skills taught in training, the roles of expert clients at the site, and the practicum checklist.
- Preceptors may also need orientation on methods of coaching and mentoring if they are new to this type of training. Ideally, preceptors would be pre-selected and able to participate in some/all of the classroom training.
- Decide how the practicum will be structured. How will participants practice each skill set on the checklist? How will participants be assigned to preceptors? For example, if participants are to practice giving a group session on adherence, this must be arranged in advance and patients must be present, a space for the talk identified, etc.
- Also arrange for transport to and from the site and lunch for participants and preceptors. It's best to bring all participants back together at a site for the final session after the practicum.
- Prepare a practicum checklist for each participant (**Trainer's Tool 5**), that will be filled out by preceptors throughout the course of the Supervised Practicum.

#### JUST BEFORE THE PRACTICUM:

- Introduce the practicum to participants and tell them that this is the time they will get to put all of the information and skills they have learned and practice them at a care and treatment and PHU, with real patients, and working as a member of the multidisciplinary team.
- Go over the major skills that will be conducted during the practicum, using the checklist as a guide. Also go over the logistics and assignment of preceptors. Allow participants to ask questions.
- Remind participants that at each stage of the practicum, constructive feedback will be given on what was done well and what could be improved. Participants will also be asked to do a self-assessment of their skills, and patients and providers at the facility will also give feedback.
- Finally, remind participants that the practicum is a great chance to apply all that they have learned in the training – and make improvements where needed so they can be the best expert clients possible!

**UNIT 16**  
**ACTION PLANNING, EVALUATION, AND GRADUATION**  
**(Time: 2 HOURS)**

**LEARNING OBJECTIVES:** By the end of this Unit, participants will have:

- Agreed on next steps when expert clients go back to their respective facilities.
- Completed a final needs assessment.
- Completed a training evaluation.
- Graduated from the expert client training.

**PRACTICAL SKILLS:**

- None for this Unit

**MATERIALS NEEDED:**

- Flip chart
- Markers
- Training completion certificates
- Expert client t-shirts
- Copies of a group photo taken during the training, if available

**16.1: NEXT STEPS**

**ACTIVITY:**

**The trainer should:**

- *Note: It's best if the National Expert Client Coordinator leads this session.*
- First debrief from the practicum days and allow participants and preceptors to share their thoughts on what went well, what was challenging, and what was learned.
- Review the tasks of expert clients in the expert client job description presented at the beginning of the training. Ask participants if they feel confident that they can complete each of these tasks after the training?
- Talk about what will happen when expert clients go back to their sites (e.g. work with multidisciplinary team to establish space for expert clients, review tasks of expert clients, visits by National Expert Client Coordinators, explanation of when/how stipends are received, etc).
- Ask if participants have any additional questions about the program, or their roles at the sites. Clarify any outstanding programmatic or logistical issues.

## CONTENT:

- See Trainer's Tool 3, Expert Client Job Description

### Next steps for expert clients:

- Expert clients will return to their assigned sites.
- Supervised practicum period at sites in coordination with the multidisciplinary team, Site Expert Client Coordinator, and National Expert Patient Coordinator, as well as organizations that support the site.
- Expert clients will become a part of the multidisciplinary team at their sites, with the help of the organization that is supporting the site and the MOHSW.
- Ideally, all members of the multidisciplinary care team would be trained on adherence and psychosocial support, similar to the training you received in this area during expert client training.
- Expert clients will contribute to one-on-one counseling sessions and group education sessions at their sites, using the skills learned in this training.
- Each month, expert clients will send their reporting forms to the Site Expert Client Coordinator.
- Expert clients will be provided with regular supportive supervision at their site, as well as monthly stipends.
- Each quarter (every 3 months or so), all of the expert clients will be brought together for review meetings and refresher trainings to see what we've done well and what we can improve.

## 16.2: FINAL NEEDS ASSESSMENT

### ACTIVITY:

#### The trainer should:

- Tell participants that they will now repeat the needs assessment exercise that was conducted at the beginning of the training.
- Remind participants that this is not a test, but a way for participants to evaluate what they have learned and for trainers to note where more mentoring is needed at the site level.
- Place large "TRUE" and "FALSE" signs on opposite sides of the room, and read the statements below. Ask participants to move to the side of the room depending on whether they think the statement is true or false. Ask some participants to justify their answers.
- Remind participants how much they have learned in the past week and congratulate them on a job well done!
- Debrief by asking participants to compare how they felt about their knowledge and skills on the first day of training vs. how they feel now on the last day of training. Ideally, the final needs assessment should be a time for participants to feel confident in the skills and knowledge they have learned during the training.

## CONTENT:

### Questions for final needs assessment:

1. Only very sick people need to take ART.
2. If a woman with HIV has a baby, the baby has a 75% chance of getting HIV.
3. Missing one ARV dose per week is ok.
4. Supportive counseling includes telling people what you think is best for them.
5. Before starting ART, you have to disclose your HIV status to someone you trust.
6. A person on ART can still give HIV to another person.
7. If you forget to take your dose of ARVs at 7am, and you realize at 9am, it's too late to take them and you should just wait until the 7pm dose.
8. Cotrimoxazole (Bactrim) can help prevent opportunistic infections.
9. All babies born to women with HIV will at first be HIV-positive.
10. It's safe for pregnant women to take ART.
11. Normally, a person's CD4 count does down when they start ART.
12. Shared confidentiality means that expert clients should tell a person's family that the person has HIV, but not community members.
13. Side effects of ART usually go away in 2-4 weeks.
14. Expert clients are an important part of the multidisciplinary team.
15. Positive living means telling people you are living with HIV.

## 16.3: TRAINING EVALUATION

### ACTIVITY:

#### The trainer should:

- Review the course learning objectives with participants, referring to the piece of flip chart prepared on the first day of training (or by rewriting the learning objectives on flip chart). Ask participants if they think each learning objective has been met or which they feel need more attention and practice during refresher trainings.
- Go around the room and ask each participant two things they will do better now as a result of the training.
- Tell participants that all of the trainers are going to leave the room. Ask the group to select two note takers.
- Post 2 pieces of flip chart paper, one labeled with a happy face and the other labeled with a sad face. Ask participants to be very honest in evaluating what was good and not-so-good about the overall training. The nominated note takers should record participants' answers on the appropriate flip charts (when the trainers are out of the room) and then the trainers should read them **after** the training ends. Have the participants roll up the pieces of flip chart and call the trainers back into the room when the evaluation exercise is complete.
- The trainers should meet after the training to debrief, review what they think went well and what could be improved, discuss plans for refresher/ongoing training, and review the participants' training evaluations.

## CONTENT:

At the beginning of the training, we agreed on the following learning objectives. Participants will be able to:

1. Understand the expert client's critical role in comprehensive HIV/AIDS prevention, care, treatment, psychosocial support, and referral linkage activities.
2. Provide basic counseling and practical strategies to patients, especially pregnant women, on understanding and accessing care and treatment, adherence to care and treatment, disclosure, positive living, and prevention.
3. Assist patients and their families to access other services within the hospital, such as ART (for women enrolled in pMTCT-Plus), TB diagnosis and treatment, pediatric care and treatment, and others.
4. Assist in patient follow-up through linkages with community-based services and improved tracing mechanisms for patients lost to follow-up.
5. Contribute to reduced stigma and discrimination of PLWHA by working as an integral part of the facility multidisciplinary team and by engaging communities in the fight against HIV/AIDS.

## 16.4: CLOSURE AND GRADUATION

### ACTIVITY:

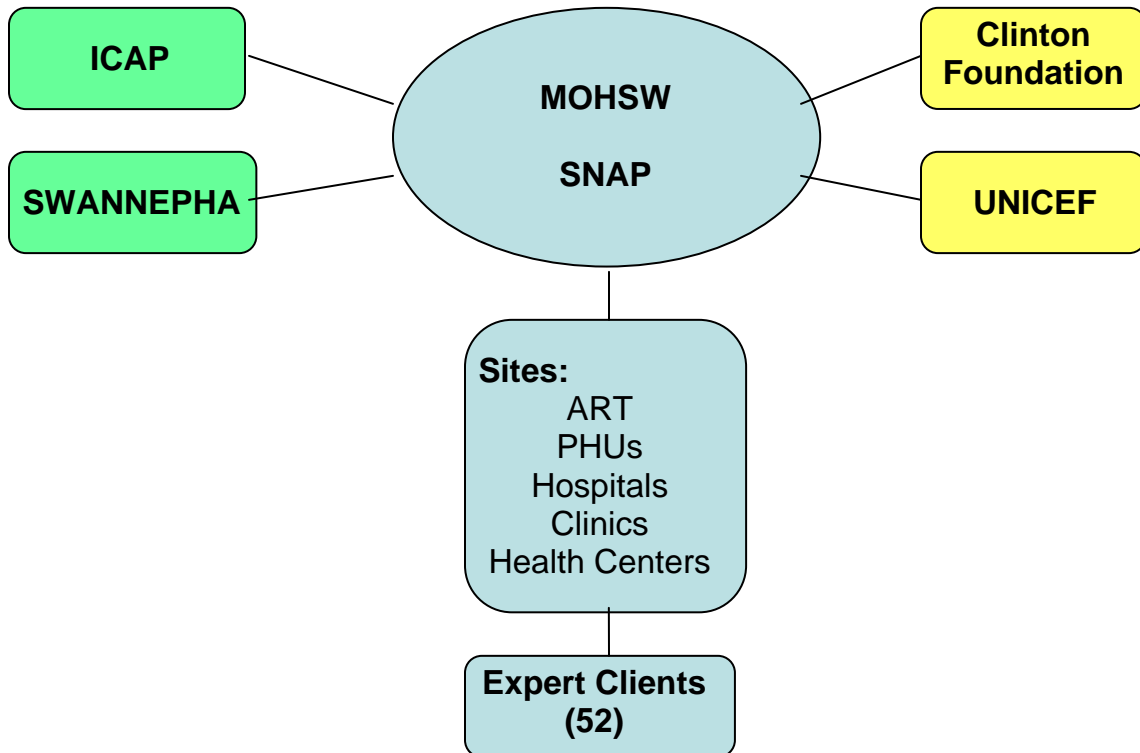
#### The trainer should:

- Arrange the expert client graduation ceremony in advance. Consider:
  - Location, date, and time
  - Invited guest speakers and attendees (Medical Officer, etc.)
  - Inform local press
  - Preparing training completion certificates and t-shirts
- Congratulate expert clients on a job well done and officially present them with training certificates and their expert client t-shirts.

# TRAINER'S TOOLS



## Swaziland Expert Client Program Key Players



### **Trainer's Tool 3: Expert Client Job Description**

#### **Key Responsibilities of Expert Clients working at ART Clinics, Clinics, and PHUs:**

1. Participate as an active member of the multidisciplinary care team at ART clinics, MCH clinics, and PHUs, including attending multidisciplinary team meetings.
2. Conduct group education sessions, in coordination with other members of the multidisciplinary care team, including:
  - Pre-ART sessions 1 and 2
  - pMTCT+ sessions
  - Others, as decided by the site
3. Conduct one-on-one counseling sessions with patients, caretakers, and treatment supporters on the following topics:
  - HIV/AIDS Basics
  - Understanding care and treatment
  - Adherence to care and treatment
  - Preventing mother-to-child transmission and the importance of treatment for mothers and follow-up care for babies (pMTCT+)
  - Disclosure
  - Positive living and risk reduction
  - On-going psychosocial support
4. Work as part of the multidisciplinary care team to prioritize pregnant women for care and treatment services, and follow-up mothers and babies after delivery.
5. Help patients with referrals, including walking them to the referral point, explaining why the referral was made and what services will be given at the referral point, and making sure the patient is seen in a timely manner at the referral point.
6. Act as a link between patients and the multidisciplinary care team, including presenting common concerns of patients/adherence challenges faced by patients in multidisciplinary team meetings.
7. Implement family-focused care by asking all patients about family members and encouraging them to come for HIV testing and counseling, care and treatment.
8. Work as part of the multidisciplinary care team to identify and follow-up with patients who do not return to the clinic for appointments, CD4 or other tests (and results), and medication refills.
9. Lead support group meetings.
10. Link patients and caretakers with community-based care and support services.
11. Keep basic records and compile monthly reports.

## Trainer's Tool 4: How Does HIV Impact the Body<sup>xxix</sup>?

- The CD4 cell is a kind of white blood cell.
- The CD4 is the friend of our body



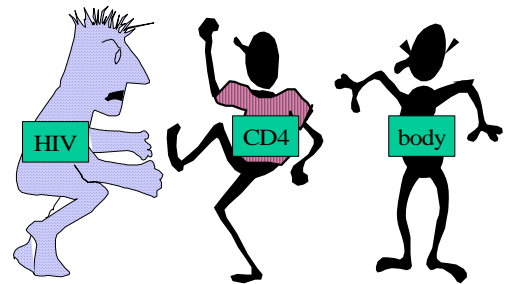
Diseases like cough try to attack our body, but the CD4 fights them to defend the body, his friend



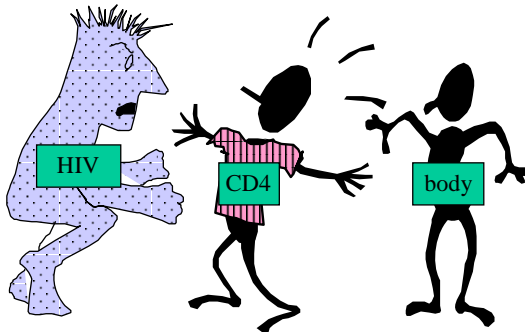
Diseases like diarrhoea try to attack our body, but the CD4 fights them to defend the body



Now, HIV enters and starts to attack the CD4



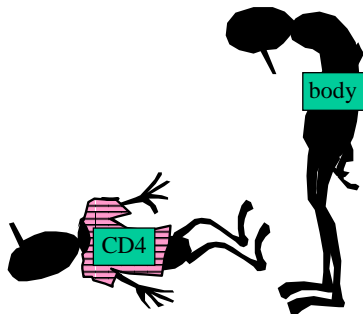
The CD4 notices he cannot defend himself against HIV!



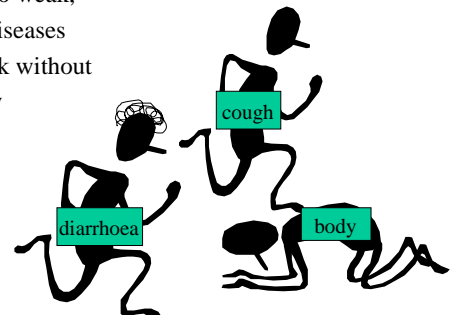
Soon, CD4 loses it's force against HIV



CD4 loses the fight. The body remains without defense.



In the end, the body is so weak, that all diseases can attack without difficulty



### Trainer's Tool 5: Expert Client Practicum Checklist

Preceptors should complete one checklist for each expert client during supervised practicum. First, introduce expert clients to the multidisciplinary team. Remind participants that the practicum is a chance to put all the knowledge and skills they have learned together. It is not a test, but a way to practice what they have learned and make improvements!

Name of Expert Client: \_\_\_\_\_

Name of Preceptor(s): \_\_\_\_\_

Dates of Practicum Session: \_\_\_\_\_

Practicum Site(s): \_\_\_\_\_

Key Activity	Demonstrated during Practicum (yes/no)	Comments (use back side if needed)
Pre-ART Group Education Session #1		
Pre-ART Group Education Session #2		
Pre-ART Group Education Session with Pregnant Women		
One-on-One Counseling Session (1)		
One-on-One Counseling Session (2)		
One-on-One Counseling Session (3)		
Helping Clients with Referrals (Walk with them, explain reason for referral, etc.)		
Filling out Record Keeping Forms		
Other (list): _____		

## REFERENCES

Abrams, E , El Sadr, W. & Rabkin, M. 2005. The Columbia Clinical Manual: Pediatric care and treatment of HIV/AIDS in resource limited settings. The International Center for AIDS Care and Treatment Programs. New York, NY. Columbia University, Mailman School of Public Health.

The CHANGE Project & ICRW. 2003. Understanding and challenging HIV stigma: Toolkit for action. Washington, DC. The CHANGE Project, Academy for Educational Development.

Colton, T., Dillow, A., Hainsworth, G., Israel, E., & Kane, M. 2006. Community home-based care for people and communities affected by HIV/AIDS: A comprehensive training course for community health workers. Watertown, MA: Pathfinder International.

Fayorsey, R. & Abrams, E. 2006 (draft). Pocket guide: Pediatric HIV/AIDS care and treatment. The International Center for AIDS Care and Treatment Programs. New York, NY. Columbia University, Mailman School of Public Health.

Family Health International/IMPACT Project. Peer-to-peer: HIV & AIDS peer educators trainers' guide for IMPACT implementing agencies. Arlington, VA: FHI.

Family Health International/AIDSCAP. 1997 (?). How to create an effective peer education project: Guidelines for AIDS prevention projects. Arlington, VA: FHI/AIDSCAP.

Federal Ministry of Health (FMOH), Disease Prevention and Control Department. 2004. AIDS in Ethiopia: Fifth report. Addis Ababa, Ethiopia: FMOH.

Federal Ministry of Health (FMOH). 2005 (draft). Trainer's manual on provider-initiated HIV counseling and testing. Addis Ababa, Ethiopia, FMOH.

Federal Ministry of Health (FMOH). 2004. Participants manual for training course in HIV voluntary counseling and testing. Addis Ababa, Ethiopia, FMOH.

Horizons/Population Council, International Centre for Reproductive Health, Coast Province General Hospital, Mombasa. 2004. Adherence to ART in adults: A guide for trainers. Nairobi, Kenya. Population Council.

The International HIV/AIDS Alliance. 2006. Trainer's manual: Community engagement for antiretroviral treatment. Participatory tools and activities for civil society organizations working with people with HIV. International HIV/AIDS Alliance.

Kingdom of Swaziland. Ministry of Health and Social Welfare. 2006. Prevention of mother to child transmission of HIV guidelines, 2<sup>nd</sup> edition. Kingdom of Swaziland, Ministry of Health and Social Welfare.

Orr, N. 2004. Positive health. Cape Town, South Africa: Double Story Books.

Rabkin, M, El-Sadr, W. & Abrams, E. 2005. The Columbia Clinical Manual. The International Center for AIDS Care and Treatment Programs. New York, NY. Columbia University, Mailman School of Public Health.

Swaziland National AIDS Program (SNAP), Ministry of Health and Social Welfare, Kingdom of Swaziland. 2005. ARV Treatment Literacy Training Course, Trainee's Manual. Swaziland MOHSW.

The AIDS Support Organization (TASO) Training Centre. (draft). Peer education and counseling: Greater involvement of PLWHA (GIPA). Kampala, Uganda: TASO.

UNAIDS. 2003. Handbook on access to HIV/AIDS-related treatment: A collection of information, tools, and resources for NGOs, CBOs, and PLWHA groups. Geneva, Switzerland: UNAIDS.

World Health Organization. 2003. Scaling up antiretroviral therapy in resource-limited settings: Treatment guidelines for a public health approach. Geneva, Switzerland: WHO.

World Health Organization. 2005. HIV care and ART: A course for physicians. Reference manual for trainers. Geneva, Switzerland: WHO.

World Health Organization. 2005 (draft). Participant manual for the WHO basic ART clinical training course, based on chronic HIV care with ARV therapy module. Addis Ababa, Ethiopia: WHO.

World Health Organization and Food and Agriculture Organization. 2002. Living well with HIV/AIDS: A manual on nutritional care and support for people living with HIV/AIDS. Geneva, Switzerland: WHO/FAO.

## ENDNOTES

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<sup>i</sup> Kingdom of Swaziland. Ministry of Health and Social Welfare. 2006.

<sup>ii</sup> Family Health International/IMPACT Project. Peer-to-Peer: HIV&AIDS peer educators trainers' guide for IMPACT implementing agencies. FHI/Nigeria.

<sup>iii</sup> Swaziland National AIDS Program (SNAP), Ministry of Health and Social Welfare, Kingdom of Swaziland. 2005. ARV Treatment Literacy Training Course, Trainee's Manual. Swaziland MOHSW.

<sup>iv</sup> Rabkin, M, El-Sadr, W. & Abrams, E. 2005. The Columbia Clinical Manual. The International Center for AIDS Care and Treatment Programs. New York, NY. Columbia University, Mailman School of Public Health.

<sup>v</sup> Swaziland National AIDS Program (SNAP), Ministry of Health and Social Welfare, Kingdom of Swaziland. 2005. ARV Treatment Literacy Training Course, Trainee's Manual. Swaziland MOHSW.

<sup>vi</sup> Swaziland National AIDS Program (SNAP), Ministry of Health and Social Welfare, Kingdom of Swaziland. 2005. ARV Treatment Literacy Training Course, Trainee's Manual. Swaziland MOHSW.

<sup>vii</sup> Rabkin, M, El-Sadr, W. & Abrams, E. 2005. The Columbia Clinical Manual. The International Center for AIDS Care and Treatment Programs. New York, NY. Columbia University, Mailman School of Public Health.

<sup>viii</sup> Horizons/Population Council, International Centre for Reproductive Health, and Coast Province General Hospital, Mombasa- Ministry of Health, Kenya. 2004. Adherence to antiretroviral therapy in adults: A guide for trainers. Nairobi, Kenya: Population Council

<sup>ix</sup> Rabkin, M, El Sadr, W, & Abrams, E. 2005. The Columbia clinical manual: Care and treatment of HIV/AIDS in resource-limited settings. New York, NY: The International Center for AIDS Care and Treatment Programs. New York, NY. Columbia University, Mailman School of Public Health.

<sup>x</sup> Colton, T., Dillow, A., Hainsworth, G., Israel, E., & Kane, M. (2006). Community home-based care for people and communities affected by HIV/AIDS: A comprehensive training course for community health workers. Watertown, MA: Pathfinder International.

<sup>xi</sup> Kingdom of Swaziland. Ministry of Health and Social Welfare. 2006. Prevention of mother to child transmission of HIV guidelines, 2<sup>nd</sup> edition. Kingdom of Swaziland, Ministry of Health and Social Welfare.

<sup>xii</sup> Colton, T., Dillow, A., Hainsworth, G., Israel, E., & Kane, M. (2006). Community home-based care for people and communities affected by HIV/AIDS: A comprehensive training course for community health workers. Watertown, MA: Pathfinder International.

---

<sup>xiii</sup> The International HIV/AIDS Alliance. 2006. Trainer's manual: Community engagement for antiretroviral treatment. Participatory tools and activities for civil society organizations working with people with HIV. International HIV/AIDS Alliance.

<sup>xiv</sup> Rabkin, M, El-Sadr, W. & Abrams, E. 2005. The Columbia Clinical Manual. The International Center for AIDS Care and Treatment Programs. New York, NY. Columbia University, Mailman School of Public Health.

Horizons/Population Council, International Centre for Reproductive Health, Coast Province General Hospital, Mombasa, Ministry of Health, Kenya. 2004. Adherence to antiretroviral therapy in adults: A guide for trainers. Nairobi, Kenya: Population Council.

The International HIV/AIDS Alliance. 2006. Trainer's manual: Community engagement for antiretroviral treatment. Participatory tools and activities for civil society organizations working with people with HIV. International HIV/AIDS Alliance.

<sup>xv</sup> Swaziland National AIDS Program (SNAP), Ministry of Health and Social Welfare, Kingdom of Swaziland. 2005. ARV Treatment Literacy Training Course, Trainee's Manual. Swaziland MOHSW.

<sup>xvi</sup> Adapted from WHO. 2005 (draft). Participant manual for the WHO basic ART clinical training course, based on chronic HIV care with ARV therapy module. Geneva, Switzerland: WHO.

<sup>xvii</sup> The CHANGE Project & ICRW. 2003. Understanding and challenging HIV stigma: Toolkit for action. Washington, DC. The CHANGE Project, Academy for Educational Development.

<sup>xviii</sup> The International HIV/AIDS Alliance. 2006. Trainer's manual: Community engagement for antiretroviral treatment. Participatory tools and activities for civil society organizations working with people with HIV. International HIV/AIDS Alliance.

<sup>xix</sup> The CHANGE Project & ICRW. 2003. Understanding and challenging HIV stigma: Toolkit for action. Washington, DC. The CHANGE Project, Academy for Educational Development.

<sup>xx</sup> The CHANGE Project & ICRW. 2003. Understanding and challenging HIV stigma: Toolkit for action. Washington, DC. The CHANGE Project, Academy for Educational Development.

<sup>xxi</sup> The CHANGE Project & ICRW. 2003. Understanding and challenging HIV stigma: Toolkit for action. Washington, DC. The CHANGE Project, Academy for Educational Development.

<sup>xxii</sup> The CHANGE Project & ICRW. 2003. Understanding and challenging HIV stigma: Toolkit for action. Washington, DC. The CHANGE Project, Academy for Educational Development.

<sup>xxiii</sup> Orr, N. 2004. Positive health. Cape Town, South Africa: Double Story Books.

<sup>xxiv</sup> Colton, T., Dillow, A., Hainsworth, G., Israel, E., & Kane, M. (2006). Community home-based care for people and communities affected by HIV/AIDS: A comprehensive training course for community health workers. Watertown, MA: Pathfinder International.

<sup>xxv</sup> Colton, T., Dillow, A., Hainsworth, G., Israel, E., & Kane, M. (2006). Community home-based care for people and communities affected by HIV/AIDS: A comprehensive training course for community health workers. Watertown, MA: Pathfinder International.

<sup>xxvi</sup> Colton, T., Dillow, A., Hainsworth, G., Israel, E., & Kane, M. (2006). Community home-based care for people and communities affected by HIV/AIDS: A comprehensive training course for community health workers. Watertown, MA: Pathfinder International.

<sup>xxvii</sup> World Health Organization. 2005 (draft). Participant manual for the WHO basic ART clinical training course, based on chronic HIV care with ARV therapy module. Addis Ababa, Ethiopia: WHO.

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<sup>xxviii</sup> Colton, T., Dillow, A., Hainsworth, G., Israel, E., & Kane, M. (2006). Community home-based care for people and communities affected by HIV/AIDS: A comprehensive training course for community health workers. Watertown, MA: Pathfinder International.

<sup>xxix</sup> Swaziland National AIDS Program (SNAP), Ministry of Health and Social Welfare, Kingdom of Swaziland. 2005. ARV Treatment Literacy Training Course, Trainee's Manual. Swaziland MOHSW.