



PSYCHOSOCIAL & ADHERENCE **Counseling Support Training** FACILITATOR MANUAL



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REFERENCES

In addition to the national PMTCT guidelines (South Africa National Department of Health (NDoH) 2010), this training curriculum draws from a number of existing resources on PMTCT and adherence and psychosocial support developed by ICAP, including those listed below:

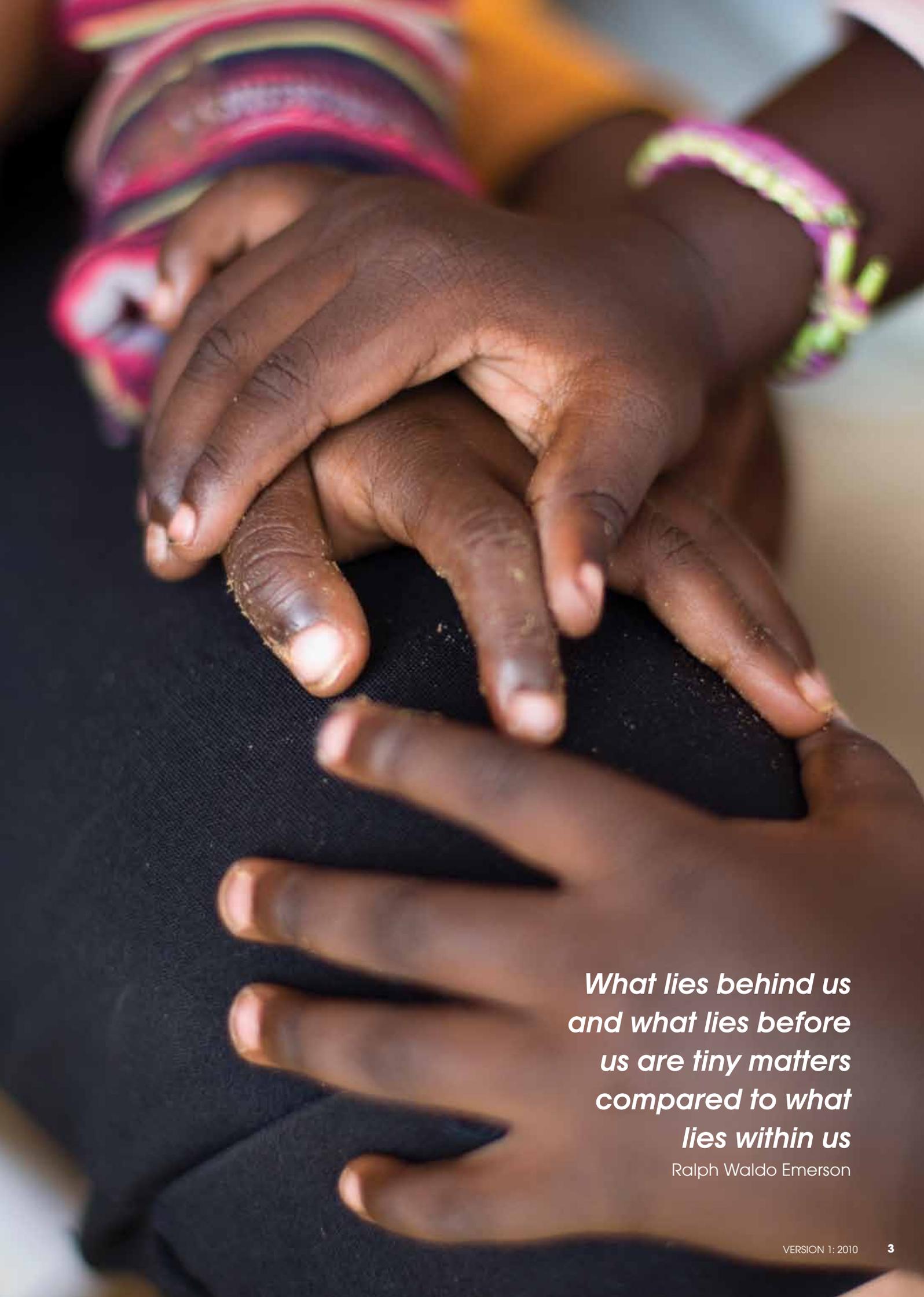
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*What lies behind us
and what lies before
us are tiny matters
compared to what
lies within us*

Ralph Waldo Emerson

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INTRODUCTION

In 2006, an estimated 38 000 South African children acquired HIV from their mothers around the time of birth and an additional 26 000 were infected during the breastfeeding period (National Department of Health (NDoH) 2007). This accounts for more than 90% of all new infections in children annually. Without interventions, there is a 20 - 45% chance that a baby born to an HIV infected mother will become infected. In response to the urgent need to expand and strengthen Prevention of Mother-To-Child Transmission (PMTCT) services for pregnant women living with HIV/AIDS and their families, South to South Partnership for Comprehensive Family HIV Care & Treatment Programme has developed a comprehensive training curriculum entitled, *Improving Psychosocial and Adherence Counselling and Support in PMTCT Programmes: A Training Curriculum for Lay counsellors and Social Workers*, to help support PMTCT services within public sector health facilities in South Africa.

The South to South Programme, with technical assistance from International Centre for AIDS Care and Treatment Programmes (ICAP) at Columbia University's Mailman School of Public Health, has developed this training curriculum to support and improve the skills of health care workers in PMTCT settings in South Africa. ICAP is an important partner in the global effort to expand access to quality PMTCT and HIV care and treatment services, who supports the design, development, and implementation of a diverse range of initiatives providing HIV prevention, care, and treatment services in resource-limited settings. To better assist clients and their families, ICAP has increasingly emphasized the importance of adherence and psychosocial support as an integral part of PMTCT and HIV care and treatment programmes

It is South to South's hope that availability of these resources will help bring us one step closer to our goal of eliminating the public health scourge of Mother-to-Child Transmission of HIV/AIDS and will contribute to the good health and well-being of women and families affected by HIV/AIDS throughout South Africa.

BACKGROUND ON THE NATIONAL PMTCT PROGRAMME IN SOUTH AFRICA

Despite significant challenges, the recent global expansion of prevention of mother-to-child transmission of HIV (PMTCT) and HIV care and treatment programmes, particularly in sub-Saharan Africa, has been dramatic. In South Africa, 90% of all pregnant women attend antenatal care (ANC) services, with many women accessing these services through the country's 3,000 primary health clinics (PHCs) nationwide. According to the National Antenatal Sentinel HIV and Syphilis Prevalence Study (2008), the HIV prevalence rate among pregnant women in South Africa is 29.3%. Of the estimated 1,065,000 deliveries occurring annually in the country (Statistics South Africa. Mid-year population estimates 2010), approximately 312,000 are among pregnant women living with HIV. The Department of Health prioritized the scale-up of PMTCT services nationwide, with more than 90% of Primary Health Care Clinics (PHCs) and all

public hospitals in the country now offering PMTCT services (NDOH, 2008). With this impressive expansion of services, however, also comes the need to develop innovative and responsive programmes to support clients to adhere to clinical care and to medication regimens during pregnancy, in the postpartum and infant feeding periods, and in the long-term.

In efforts to further reduce mother-to-child transmission of HIV, promote HIV free survival among infants, decrease maternal and child mortality, and increase life expectancy, The National Department of Health of South Africa and the South African National AIDS Council issued revised clinical guidelines for PMTCT, HIV Counselling and Testing, Adult, Adolescent, and Paediatric HIV Care and Treatment in 2010. Among other changes, the revised PMTCT guidelines call for early initiation of lifelong ART among pregnant women living with HIV who have CD4 counts below 350, prophylactic ARV treatment of pregnant women with CD4 counts above 350 starting at 14 weeks gestation, expanded use of ARVs for women not taking lifelong ART during labour and delivery, and recommend that women living with HIV can safely breastfeed their infants for up to 12 months, provided that the child is taking ARVs throughout the duration of breastfeeding. Extended ARV prophylaxis for breastfeeding infants promotes greater emphasis on safer infant feeding practices that protect HIV exposed infants from the risk of childhood infections and death associated with inappropriate and unsafe formula feeding, while promoting child survival, growth, and development.

Given the expanded access to ART for pregnant women living with HIV, HIV exposed and HIV infected infants, issues of adherence to both the mother's and the infant's care and medications are paramount to successful roll out and implementation of the revised clinical guidelines. Further, an important measure of success of any HIV related programme is patient's adherence to both care and medications over time.

Adherence and Psychosocial Support in PMTCT and HIV Care and Treatment Programmes

Despite national success in enrolling clients in PMTCT and care and treatment programmes, continued stigma, fear of disclosure, fears of testing and treatment for children, and lack of psychosocial and material support remain common problems that leave many people without access to the services they need.

Even once these barriers to receiving PMTCT and HIV care are overcome, the significant challenge remains in ensuring that clients achieve near-perfect adherence to care and treatment throughout pregnancy, labour and delivery, and breastfeeding, – as well as HIV infected children and women on lifelong ART, for their entire lives. Adherence and psychosocial support, as a part of comprehensive PMTCT and HIV care and treatment programmes, 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, thereby ultimately slowing the epidemic.

Proper education and counselling of PMTCT and ART clients and their family members, and consistent and routine follow-up on adherence needs and challenges, are vital for programme quality and success. Experience shows that clients' adherence to PMTCT and HIV care and treatment depends on adequate and tailored preparation and ongoing counselling and planning for "real life" adherence and disclosure strategies. Further, an uninterrupted drug supply, regular follow-up at the facility, community, and household levels, ongoing clinical monitoring, and provision of, or linkages to, material and support services, as well as strong linkages between community- and facility-based HIV programmes, could also assist in ensuring a continuum of care and improved adherence and psychosocial well-being for clients and their families.

The Role of Lay counsellors in PMTCT Settings in South Africa

Shortages of health care workers (HCWs) and exhausted and overstretched human resources have been a bottleneck in PMTCT and ART roll out in resource-limited settings. In South Africa, as elsewhere, new cadres of health care workers have been developed to provide patient education, counselling, adherence support, and community outreach. Lay counsellors conduct group and individual sessions for PMTCT and HIV care and treatment clients, including as part of the HIV counselling and testing process, provide health education on HIV prevention, care, treatment, tuberculosis prevention and treatment, and living positively, provide psychosocial counselling and support, and offer adherence counselling as part of the multidisciplinary care team.

Lay counsellors also conduct community and home visits to trace patients who have missed appointments or to provide adherence support; they provide a critical link to the community on issues of disclosure, safer sex, stigma reduction, and improving adherence to care and treatment. Lay counsellors often are also persons living with HIV/AIDS (PLHIV), often taking ART and/or enrolled in PMTCT services themselves, contributing to the meaningful involvement of PLHIV principle. With national efforts to increase uptake of PMTCT and HIV counselling and testing services, and with implementation of the new PMTCT and PICT guidelines by the National Department of Health, lay counsellors now also have the expanded role of conducting finger pricks for rapid testing.

As a result, the training needs and obligations of lay counsellors must be adequately addressed. This training curriculum was designed to strengthen the knowledge base of these critical multidisciplinary care team members and ideally strengthen the overarching health care system, as the knowledge and process from the trainings will ultimately be diffused to other staff at the facility. It is our hope that this curriculum will help prepare and equip lay counsellors and social workers to better support their clients and their families' psychosocial counselling and adherence needs, as they wrestle with so many difficult issues such as stigma, loss, and coping with their HIV status, care and treatment.

*An effort made for the
happiness of others
lifts us above ourselves*

Lydia M Child



HOW TO USE THIS TRAINING CURRICULUM

This training curriculum was designed to provide lay counsellors and social workers with the knowledge and skills necessary to provide PMTCT clients with quality adherence and psychosocial support – throughout the PMTCT care spectrum. The training curriculum could also be modified and adapted for use with other cadres of HCW, including peer educators, nurses, pharmacists, doctors, and others working in PMTCT settings.

Notes on the Training Agenda and Location

The curriculum consists of 8 sequential Modules that build upon one another. The training is meant to be conducted one Module at a time (with the exception of Modules 1 and 2, which should be conducted on the same day), with ample time between Modules. This will give participants the opportunity to actively practice the specific skills covered in each Module, and will allow time for participants to receive on-site mentoring to reinforce the knowledge and skills learned before moving onto the next Module. When feasible, training should be conducted at the clinic level to allow for direct mentoring, keep training costs low, and avoid taking lay counsellors away from their work for extended periods. If training is conducted off-site, it is advised that each training not be longer than 1-2 days so that participants can practice specific new skills and receive mentoring and so that they are not removed from the clinic for long periods of time, which compromises the quality of services and is costly.

General Notes on the Training Methodology

The training curriculum is designed to acknowledge and build upon the knowledge and experience that lay counsellors and social workers already have. The training course is highly participatory and based on principles of adult learning. By using the suggested participatory training methodologies, participants will be able to share their thoughts and experiences openly, and will learn from one another as much as they learn from trainers. The training methods used should serve as a model for how participants should communicate with clients in their work. Lectures and trainer-led activities should be minimized as much as possible, with emphasis instead on participatory activities, with the trainer supplementing information as needed. Most Modules contain a classroom practicum session, whereby participants can apply information and skills learned in the training to real world case studies they may encounter in their daily work with clients in the clinic. In some cases, easy-to-use summary checklists are provided to guide lay counsellors, social workers, and supervisors in their own counselling sessions and/or when mentoring others.

The key information covered in the training is intended to be practical and interesting to participants. Additionally, all Modules use simple, non-clinical language and participatory activities so that they are accessible to the intended target audience, namely lay counsellors, and social workers as well as to trainers with varying experience and comfort with facilitation.

The experiences, baseline knowledge, and literacy levels of participants will vary, so trainers should make adaptations as needed. As mentioned above, the training can also be adapted for use with other cadres and may be helpful to guide refresher and update trainings with a range of HCWs.

The participatory training methodologies used in the curriculum include:

- Interactive trainer presentation
- Large group discussion
- Large group work
- Small group discussion
- Small group work
- Brainstorming
- Guest speakers
- Classroom practicum sessions
- Case studies
- Role play

THE TRAINING CURRICULUM DESIGN

There are 2 parts to the curriculum – a **Trainer’s Manual** and a **Participant’s Manual**. Each Module of the Trainer’s Manual begins with the following information, followed by step-by-step trainer instructions and key content information for each Session:

	<p>DURATION</p> <p>The approximate time it will take to facilitate the training Module.</p>
	<p>LEARNING OBJECTIVES</p> <p>The expected knowledge and skills participants will gain by the end of the Module.</p>
	<p>KEY CONTENT AREAS</p> <p>A list of the Sessions within the Module.</p>
	<p>METHODOLOGIES</p> <p>An overview of the training methods used in the Module.</p>
	<p>MATERIALS NEEDED</p> <p>A list of materials the trainer should collect and prepare before the training sessions, such as flip chart, markers, tape or Bostik, etc.</p>
	<p>WORK FOR THE TRAINER TO DO IN ADVANCE</p> <p>Key preparatory activities for the trainers to do before facilitating the Module.</p>
	<p>KEY POINTS</p> <p>A summary of key points, at the end of each Module.</p>

STEP-BY-STEP TRAINER INSTRUCTIONS

Each Session begins with a shaded box, listing the training methodologies used in that Session, followed by suggested step-by-step guidance for trainers. The training is designed to be participant-focused instead of trainer-driven. Adults 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 significant experience that lay counsellors and social workers already have working with PMTCT clients. The trainer's role is to draw out these experiences and encourage skills-building, exchange of information, and confidence-building among participants.

KEY INFORMATION

The key content information for each Session follows the step-by-step trainer instructions. All trainers should be familiar and comfortable with the updated national PMTCT, HIV Counselling and Testing, and Paediatric HIV Care and Treatment National Guidelines in advance of trainings with lay counsellors and social workers. Trainers should adapt the key information as needed for their particular setting and on the baseline knowledge of participants (for example, sometimes it will be useful to cover all of the key information, but in other cases, when participants already know a good deal about the topic, trainers may just want to review some parts of the key information). Most of the Modules also contain Appendices that will be useful for trainers and participants. Some of the Appendices also include helpful checklists and tools that lay counsellors and social workers can use in their work.

THE PARTICIPANT'S MANUAL

The Participant Handouts for each Module (see the Participant's Manual) contain a simplified version of the Key Information in the Trainer's Manual, as well as relevant Appendices and tools (e.g. checklists, counselling cue cards). Trainers should encourage participants to refer to their Handouts during the training and to take their own notes as needed. The Participant's Manual also serves as a useful reference for participants after the training and can be used in follow-up mentoring sessions with lay counsellors at health facility level.

EVALUATING THE TRAINING

Because the training is intended to be conducted only one Module at a time (with the exception of Modules 1 and 2), an evaluation form has been included at the end of each Module to help trainers gather and assess participant feedback, and make adjustments for subsequent trainings. Trainers should photocopy the relevant Module evaluation form for each participant in advance of the training session.

SOME USEFUL TIPS FOR TRAINERS

How to be an Effective Training Facilitator

Trainers should always keep the following “do’s and don’ts” in mind.

DO’S:

- Maintain good eye contact
- Prepare in advance
- Involve participants and ask open-ended questions
- Use visual aids
- Speak clearly
- Speak loud enough
- Encourage questions
- Recap at the end of each Session
- Connect one topic to the next and consecutive Modules with each other
- Encourage everyone to actively participate by asking questions, engaging quiet participants, and affirming contributions
- Discourage domination by one or a handful of participants
- Write clearly and boldly
- Summarize after each Session and Module
- Use logical sequencing of topics
- Use good time management
- K.I.S. (Keep It Simple)
- Give feedback
- Position visuals so everyone can see them
- Avoid distracting mannerisms and distractions in the room
- Be aware of the participants’ body language
- Be aware of the participants’ energy levels and use energizers as needed
- Keep the group focused on the task
- Provide clear instructions
- Check to see if your instructions are understood
- Evaluate as you go
- Be patient

DON'TS:

- Talk to the flip chart
- Block the visual aids
- Stand in one spot-move around the room
- Ignore the participants’ comments and feedback (verbal and non-verbal)
- Read from the curriculum
- Shout at the participants
- Assume everyone has the same level of baseline knowledge
- Assume everyone can write at the same level

A Note on Confidentiality

The success of this training depends on the active participation and engagement of each participant. Participants should be encouraged and be made to feel “safe” to share their own personal experiences. Trainers should remind participants that what is said in the training sessions is confidential (they should respect this rule themselves), and that no one will be judged or stigmatized for their comments or questions.

***Dare to reach out your
hand into the darkness, to pull
another hand into the light***

Norman B Rice



MODULE 1

Introduction to Psychosocial & Adherence Support Training



MODULE 1

Introduction to Psychosocial and Adherence Support Training



CONTENT

Session 1.1: Welcome and Introductory Activity

Session 1.2: Learning Objectives, Agenda, and Ground Rules

Session 1.3: Examining Our Own Attitudes and Values



DURATION

70 minutes (1 hour, 10 minutes)



LEARNING OBJECTIVES

By the end of this Module, participants will be able to:

- Know more about the trainers and other training participants
- Understand the learning objectives, agenda, and “ground rules”
- Examine their own attitudes and values related to HIV, people living with HIV, and psychosocial and adherence support



PREVIOUS TRAINING/KNOWLEDGE REQUIRED FOR THIS MODULE

- Basic knowledge about PMTCT protocols and guidelines
- Experience in HIV counselling and testing (e.g., VCT and PICT), PMTCT, and ARV/ART education/counselling



METHODOLOGIES:

- Interactive Trainer Presentation
- Small Group Work
- Large Group Work
- Large Group Discussion
- Brainstorming



MATERIALS NEEDED

- Flip chart and stand
- Markers/Khoki's
- Tape or Bostik
- Nametags
- Pens and notebooks (for each participant)
- Copies of the Participant Folder and inserts (for each participant)
- Large "AGREE" and "DISAGREE" signs (can be made on flip chart)
- Copy of *Appendix 1A*



WORK FOR THE TRAINER TO DO IN ADVANCE

- Read through the entire Module and make sure you are familiar with the training methodologies and content.
- Write the overall training objectives on flip chart or prepare an overhead slide.
- Finalize all training logistics and ensure that the training room is set up, all materials for the training are available, logistics are arranged for participants, etc.
- Make 1-2 copies (depending on the number of participants) of *Appendix 1A: Sample Training Registration Form*.
- Choose which introductory activity you will use for Session 1.1.
- Prepare large "AGREE" and "DISAGREE" signs for the values clarification activity in Session 1.3.

***If you judge people you have
no time to love them***

Mother Teresa



SESSION 1.1

WELCOME AND INTRODUCTORY ACTIVITY (20 MINUTES)



TRAINER INSTRUCTIONS

Methodologies: Interactive Trainer Presentation, Small Group Work, Large Group Discussion

Step 1: As participants arrive, give each person a nametag. Also, pass around a registration sheet (see *Appendix 1A* for a sample) and ask participants to record their name, profession and how long in that profession, facility where they work, organization to which they belong (if applicable), contact information, and any HIV related or counselling training that they have received.

Step 2: Once all participants have arrived, officially open the workshop. Introduce yourself and the other trainers and welcome participants to the training.

Step 3: Lead an introductory activity so people can get to know more about one another and the trainers. You can choose one of the sample introductory activities given below, or you can use your own. Adjust the activity depending on the size of the group and how well participants already know one another.

NOTE: Participant registration and an introductory activity should be conducted at the start of each separate training programme with lay counsellors and social workers.

KEY INFORMATION

Here are some sample introductory activities, or feel free to choose your own.

Introductory activities to choose from:

- Ask participants to get in pairs with someone they do not 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 a lay counsellor or social worker, etc.). After 5 minutes, bring the large group back together and ask each person to introduce his or her partner to the larger group. The trainers should also participate and introduce one another.
- In addition to stating their name and how long they have been a lay counsellor or social worker, ask participants to state two true things about themselves and one lie (not necessarily in this order). Encourage participants to be creative and share things that co-workers may not know about them. The other participants should then guess which statement is the lie.

- In addition to stating their name and how long they have been a lay counsellor or social worker, ask participants to choose two items that they have with them or that they are wearing that mean something special to them, and to briefly explain why.
- In addition to stating their name and how long they have been a lay counsellor or social worker, ask participants to say three things that motivate them – either at home, in the community, or at work.



***Never look down on anybody
unless you're helping him up***

Jesse Jackson

SESSION 1.2

LEARNING OBJECTIVES, AGENDA AND GROUND RULES (20 MINUTES)



TRAINER INSTRUCTIONS

Methodologies: Interactive Trainer Presentation, Brainstorming, Large Group Discussion

- Step 1:** Discuss why we are doing a training on psychosocial and adherence support for lay counsellors and social workers, and the importance of these services as part of PMTCT; ongoing care for mothers, families, and babies. Review the overall objectives of the workshop, referring to the pre-prepared flip chart or slide.
- Step 2:** Highlight the specific objectives and Modules that will be covered in the day's session, noting that other Modules and objectives will be introduced and covered over time. Go over the training agenda for the day/training session. In some cases, the training will only be for a single afternoon, and in others it may be for multiple afternoons or days in a row. Do not forget to mention logistics, such as lunch or breaks, start and end times, payment of per diems, and transport arrangements, if applicable.
- Step 3:** After reviewing the objectives and agenda, ask participants to quickly brainstorm some of their expectations for this workshop by asking:
What do you hope to take away from this workshop today?
- Step 4:** Introduce the Participant Folder and make sure each person has a copy. Explain that for each Module, the trainers will give participants the key points of that Module, as well as background information and paper for notetaking. Participants should keep and add to their Folders over time. The Folder can also be used as a reference after the training. Encourage participants to take their own notes in their Participant Folder during the training.
- Step 5:** Lead participants to quickly 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, keep what is said confidential, 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 on time, etc.
- Step 6:** Allow participants time to ask questions about the objectives, agenda, logistics, or other concerns.

KEY INFORMATION

Overall goals and objectives of the training:

This multi-part, on-site training for lay counsellors and social workers is intended to improve knowledge, skills, and confidence in providing psychosocial and adherence support services within PMTCT programmes. Ultimately, we hope to improve the scope and quality of psychosocial and adherence support services for our clients, their families, and their children.

After completing the different Modules in this training, participants will be able to:

1. Define psychosocial and adherence support in the context of PMTCT programmes
2. Understand the importance of psychosocial and adherence support to meet the needs of women and families enrolled in PMTCT services
3. Understand the important roles of lay counsellors and social workers in providing pregnant and postpartum women and families with ongoing psychosocial and adherence support services
4. Identify strategies to improve psychosocial and adherence support within PMTCT programmes
5. Use improved communication and counselling skills with clients and family members
6. Improve pre- and post-test counselling services for pregnant women, family members, and children
7. Conduct a psychosocial assessment and document key points and next steps, as well as make necessary referrals
8. Conduct ongoing, supportive counselling for pregnant women and their family members on: having a health pregnancy, planning a safe labour and delivery, adhering to the PMTCT care plan, adhering to ARV/ART regimens, and making safe infant feeding decisions
9. Conduct ongoing, supportive counselling for postpartum women and their family members on: postpartum care for the mother, caring for an HIV exposed infant, adhering to the baby's care and medications, safely feeding the baby, making future childbearing and family planning decisions, testing infants for HIV, and caring for an HIV infected child
10. Provide supportive disclosure preparation and follow-up counselling
11. Use tools, such as counselling cue cards, to improve the quality of counselling

THE TRAINING COURSE IS BROKEN DOWN INTO 8 MODULES.

Each Module covers a different topic and has its own specific learning objectives.

Module 1: Introduction to Psychosocial and Adherence Support Training

Module 2: Introduction to Psychosocial and Adherence Support in PMTCT Programmes

Module 3: Basic Counselling and Communication Skills

Module 4: Improving HIV Counselling and Testing for Pregnant Women

Module 5: Conducting a Psychosocial Assessment and Providing Referrals and Linkages to Social Support

Module 6: Providing Supportive PMTCT Counselling – During Pregnancy

Module 7: Providing Supportive PMTCT Counselling – After the Baby is Born

Module 8: Providing Disclosure Counselling

SESSION 1.3

EXAMINING OUR OWN ATTITUDES AND VALUES (30 MINUTES)



TRAINER INSTRUCTIONS

Methodologies: Large Group Work and Discussion, Interactive Trainer Presentation, Values Clarification

- Step 1:** Post the pre-prepared flip chart papers that say “AGREE” and “DISAGREE” on opposite sides of the training room. Ideally, they should be posted in an open space where participants are able to move back and forth between the signs.
- Step 2:** Ask participants to stand up and move to the open space in the room where the “AGREE” and “DISAGREE” signs are posted. Tell participants that you will read some statements out loud and that, after each statement, they should move to the “AGREE” or the “DISAGREE” sign, based on their opinions. If participants are not sure whether they agree or disagree with the statement, they can stand somewhere between the two signs.
- Step 3:** Read each of the sentences listed below out loud. Allow participants a few seconds to move to the side of the room that reflects their opinion. Ask a few participants to tell the group why they “AGREE” or “DISAGREE” with the statement. Allow participants to change their answer after these explanations, if desired. Do not worry about explaining the “right” answers, as all of these topics will be topics which will be discussed during the workshops.
- Step 4:** Once you have read all of the statements below, or 20 minutes have passed, ask participants to return to their seats. Debrief the activity reminding participants that it’s important for us to remember that we ALL bring certain values and attitudes to our work, but that it is important not to let these values and attitudes influence the quality of care we provide to clients.
- Step 5:** Write the words “SELF-AWARE,” “ATTITUDES AND VALUES,” and “PREJUDICES” on 3 individual pieces of flip chart. Ask participants what these phrases mean and to give some examples. Record answers on the flip charts and fill in using the definitions below
- Step 6:** Close the session by asking participants to think silently to themselves about one value, attitude, or prejudice that they have about pregnant women living with HIV. Ask them to write down this thought in their Participant Folder and to commit themselves to being self-aware in letting this thought influence the way they provide care to clients.

Emphasize how important it is for participants to think about their own values, attitudes, and prejudices and how may these affect their work as lay counsellors or social workers – both positively and negatively.

KEY INFORMATION

STATEMENTS FOR VALUES CLARIFICATION EXERCISE:

1. It is irresponsible for a woman who knows she has HIV to get pregnant.
2. The biggest reason pregnant women do not adhere to their ARVs is because they are forgetful.
3. Pregnant women living with HIV should be required to take ARVs.
4. We can't do much if a pregnant woman decides not to come back for her appointments.
5. It bothers me when women living with HIV breastfeed their babies.
6. HIV infected children are victims.
7. It is a waste of time to talk about condoms – men here will never use them.
8. It is usually a waste of time to provide counselling to our clients – they don't listen.
9. Psychosocial support means linking clients to social grants.
10. It is the lay counsellor's job to know which services exist for pregnant women in the community.
11. Supportive counselling includes telling people what you think is best, in a nice way.
12. It is immoral for people who know they are HIV positive to not disclose their status to their sexual partners.
13. If I see that a client is acting irresponsibly, it's my job to correct that behaviour.

KEY TERMS

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, behaviour, or person.

- For example, some people believe that having multiple sexual partners is okay 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 health care worker assumes that a person with HIV must be promiscuous or assuming that a minor is sleeping around when parents are away.

LAY COUNSELLORS AND SOCIAL WORKERS SHOULD ALWAYS:

- Think about the issues related to their own attitudes, values, and prejudices, and how these affect their ability to help provide effective counselling and support services to pregnant and postpartum women, families, and children

- 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
- Examine their own values and beliefs in order to avoid prejudice and bias make participants feel comfortable and encourage them to talk openly and honestly

REMEMBER: Prejudice, stigma, and negative attitudes drive the HIV epidemic, so we all need to work hard to provide quality, fair, equal, and non-judgmental services to all of our clients!



Be kind, for everyone you meet is fighting a hard battle

Plato

APPENDIX 1A

SAMPLE TRAINING REGISTRATION FORM



***Children are one
third of our population
and all of our future***

Select Panel for the
Promotion of Child Health, 1981

MODULE 2

Introduction to Psychosocial & Adherence Support in PMTCT Programmes



MODULE 2

Introduction to Psychosocial and Adherence Support in PMTCT Programmes



CONTENT

- Session 2.1:** Psychosocial and Adherence Support Basics
- Session 2.2:** Psychosocial and Adherence Support Needs of Pregnant and Postpartum Women
- Session 2.3:** Improving Psychosocial and Adherence Support in PMTCT Programmes
- Session 2.4:** Classroom Practicum
- Session 2.5:** Module Summary and Evaluation



DURATION

195 minutes (3 hours, 15 minutes)



LEARNING OBJECTIVES

By the end of this Module, participants will be able to:

- Define the terms “psychosocial support” and “adherence”
- Understand the importance of psychosocial and adherence support in PMTCT programmes
- Understand the adherence and psychosocial support needs of pregnant and postpartum women, their families, and children
- Identify strategies to improve psychosocial and adherence support within PMTCT programmes



PREVIOUS TRAINING/KNOWLEDGE REQUIRED FOR THIS MODULE

- Basic knowledge about PMTCT protocols and guidelines
- Experience in HIV counselling and testing (e.g., VCT and PICT), PMTCT, and ARV/ART education/counselling



METHODOLOGIES:

- Interactive Trainer Presentation
- Brainstorming
- Large Group Discussion
- Small Group Discussion
- Small Group Work
- Case Studies
- Role Play



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- Interactive Trainer Presentation
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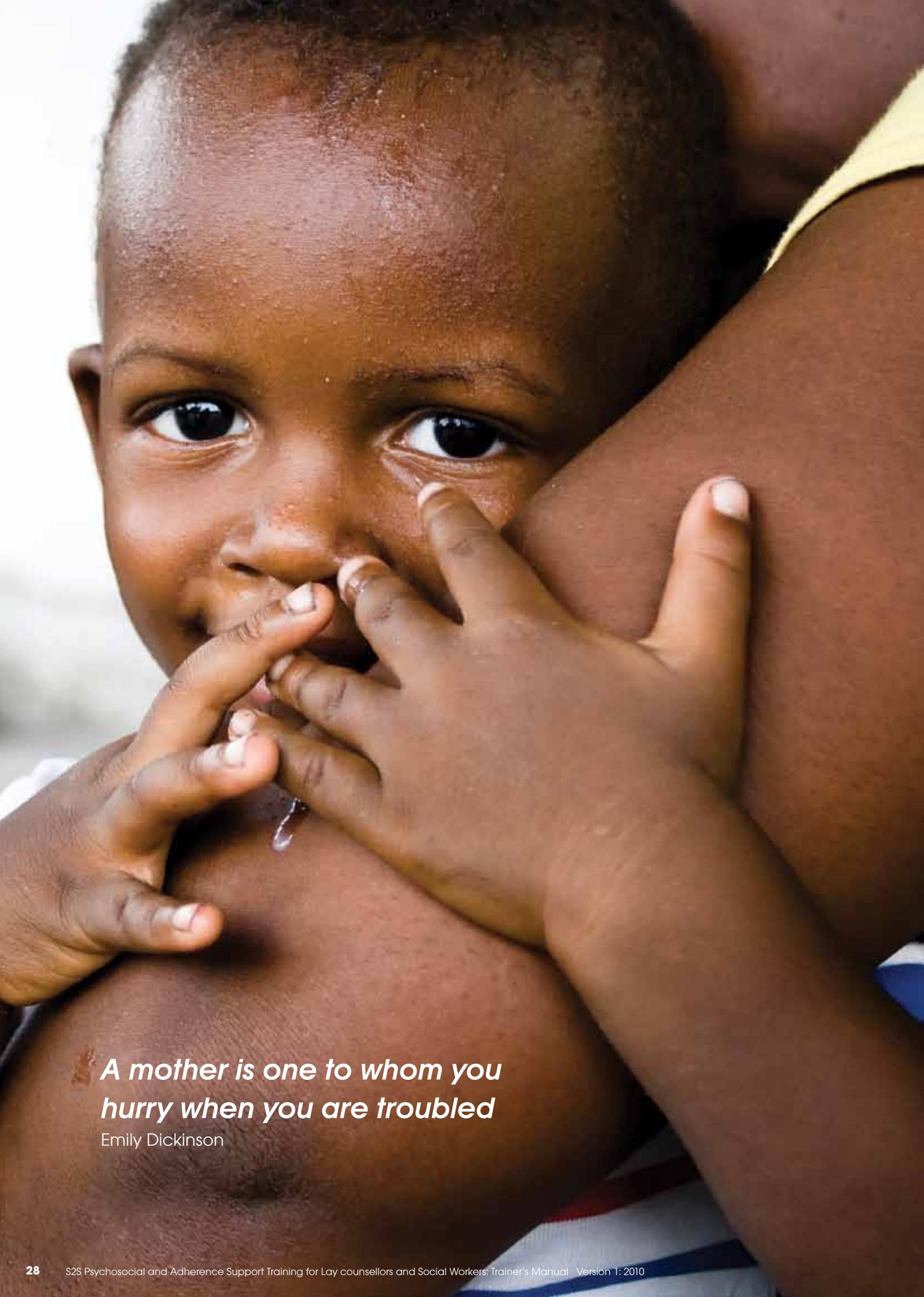
MATERIALS NEEDED

- Flip chart and stand
- Markers/Khoki's
- Tape or Bostik
- Copies of *Appendix 2A*
- Pens and notebooks (for each participant)
- Participant Handouts for Module 2
(to be inserted into the Participant Folder)



WORK FOR THE TRAINER TO DO IN ADVANCE

- Read through the entire Module and make sure you are familiar with the training methodologies and content.
- Write the Module learning objectives on the flip chart or list them on a Powerpoint slide
- Review the case studies in Session 2.4
- Make a copy of *Appendix 2A* for each participant



*A mother is one to whom you
hurry when you are troubled*

Emily Dickinson

SESSION 2.1

PSYCHOSOCIAL AND ADHERENCE SUPPORT BASICS

(35 MINUTES)



TRAINER INSTRUCTIONS

Methodologies: Interactive Trainer Presentation, Brainstorming, Large Group Discussion, Small Group Discussion

Step 1: Review the Module learning objectives and ask if there are any questions.

Step 2: Ask participants:

- *What do we mean by psychosocial support?*

Allow the group about 5 minutes to brainstorm and record responses on flip chart

Step 3: Present the definition of psychosocial support, building on participant responses and using the content below. Next, discuss why it is important to provide psychosocial support services to pregnant and postpartum women, drawing first on the input of participants and then filling in using the content below.

Step 4: Ask participants to discuss times when they have provided psychosocial support services to clients in the PMTCT programme, including times they have referred clients for other clinical services or for support services in the community. Record on flip chart. Remind participants that psychosocial support includes much more than counselling clients in the clinic – for example, it also includes ongoing care and referrals for clients in the community.

Step 5: Ask participants:

- *What do we mean by adherence?*
- *How is psychosocial support and adherence related?*

Allow the group about 5 minutes to brainstorm and record responses on flip chart.

Step 6: Present the definition of adherence and the key concepts about adherence, especially in the context of PMTCT services, using the content below.

Step 7: Write “ADHERENCE TO PMTCT and HIV CARE” on one piece of flip chart and “ADHERENCE TO MEDICATIONS” on another. Ask participants to list what we mean by each of these phrases. Record participants’ answers on flip chart and fill in using the information below.

Step 8: Write “NON-ADHERENCE” on a piece of flip chart and ask participants to discuss what this phrase means. Record participants’ responses on the flip chart and fill in using the content below.

Step 9: Ask participants to turn to the person seated next to them and spend a few minutes discussing these questions in pairs (you may want to write the questions on flip chart):

- *Why is it important to offer ongoing psychosocial support services to PMTCT clients?*
- *Why is adherence to care important for pregnant and postpartum women living with HIV and their children?*
- *What is the relationship between psychosocial support and adherence?*
- *Why is near-perfect adherence to ARVs, ART, and other medicines important for pregnant and postpartum women and their children?*
- *What happens when a pregnant or postpartum woman does not adhere to care? To treatment?*

After a few minutes, reconvene the large group and ask participants to share some of their ideas. Record these on flip chart and fill in using the content below. Close the session by reminding participants that psychosocial and adherence support are ongoing – not one-time events – and that the entire multidisciplinary team is responsible for providing these services – not just lay counsellors and social workers.

KEY INFORMATION

Definition of psychosocial support:

Psychosocial support addresses the ongoing psychological and social concerns and needs of people living with HIV, their partners, their family, and caregivers of children living with HIV. In the context of PMTCT services, psychosocial support addresses the psychological, social, and adherence needs of pregnant and postpartum women, their partners and families, and children, throughout the PMTCT care spectrum.

REMEMBER: Since pregnancy is a relatively short period of time, it is very important to assess and support pregnant women's psychosocial support needs as soon as they are enrolled in ANC and PMTCT services.

It is important to provide psychosocial support to pregnant women and family members because:

- HIV affects all dimensions of a person's life: physical, psychological, social, and spiritual.
- A woman who has just learned her HIV status during prenatal HIV testing may need support in understanding and adjusting to this information, as well as planning what is going to happen next.
- It can help clients and caregivers cope more effectively with HIV and enhance their own and their children's quality of life.

- It can help facilitate the disclosure process.
- It can create opportunities to provide pregnant women and their families with needed information, specific to their situation.
- It can help clients gain confidence in themselves and their skills (coping with chronic illness, dealing with stigma or discrimination, adhering to the care and treatment plan, dealing with taking/giving medications every day, caring for an HIV exposed or HIV infected child, etc.).
- It can help build a trusting relationship between the client and the lay counsellor, as well as other health care workers.
- It can sometimes prevent more serious mental health issues from developing (like anxiety, depression, or withdrawal).
- Psychosocial well-being is related to better adherence to PMTCT and HIV care and treatment.
- Mental health is closely linked to physical health and well-being.
- It can provide people (or link people) with needed social, housing, and legal services.
- It can help people mentally and practically prepare for difficult circumstances, like ill-health, having an HIV infected baby, etc.
- When people can come together to solve problems and support one another, movements for change, acceptance, and advocacy are born.

DEFINITION OF ADHERENCE:

The standard clinical definition of adherence has been taking at least 95% of medications the right way, at the right time. Over time, this definition has been broadened to include more factors related to continuous care, such as following a care plan, attending scheduled clinic appointments, picking up medicines on time, and getting regular CD4 tests.

Adherence describes how faithfully a person sticks to and participates in her or his HIV prevention, care, and treatment plan.

Adherence support is an important part of psychosocial support services; PMTCT and HIV clinical service.

KEY CONCEPTS OF ADHERENCE:

Adherence:

- Is not the same as compliance in that it includes much more than following the doctor's orders
- Is a part of psychosocial support and clinical services
- Includes active participation of the client in her care plan
- Depends on a shared decision-making process between the client and health care providers
- Includes adherence to both care and medicines
- Determines the success of PMTCT and HIV care and treatment programmes
- Changes over time

Adherence to PMTCT and HIV care includes:

Entering into and continuing on a care and treatment plan

- Taking medicines to prevent and treat opportunistic infections
- Planning for/having a safe delivery in a health facility
- Practicing safer infant feeding practices
- Bringing the baby back often for checkups and for HIV testing at 6 weeks
- Participating in ongoing education and counselling
- Attending appointments and tests (such as antenatal and postnatal appointments and regular CD4 tests) as scheduled
- Picking up medications for herself and the child when scheduled, and before running out
- Adopting a healthy lifestyle and avoiding risk behaviours
- Recognizing when there is a problem or a change in health and coming to the clinic for care and support

All pregnant women living with HIV in South Africa need to take ARVs during pregnancy and in the postpartum period. Some women need to take ART for their own health, for their whole lives, and other women need to take ARVs only during pregnancy and breastfeeding to prevent HIV transmission to their baby.

REMEMBER: ALL PREGNANT WOMEN LIVING WITH HIV NEED TO TAKE ARVs, THE RIGHT WAY, EVERY DOSE, EVERY DAY!

Adherence to HIV treatment includes:

- Taking ARVs correctly, as prescribed, even if the person feels healthy
- For women who are eligible for ART, taking ARVs as prescribed for their entire life
 - every pill, every day, for life
- Taking other medicines, such as cotrimoxazole, as prescribed
- Giving medications, including ARVs and cotrimoxazole, to HIV exposed and HIV infected babies and children as prescribed
- Not taking any breaks from treatment

Non-adherence to care and treatment includes:

- Missing one or many appointments at the hospital or health centre, lab, or pharmacy – for herself or her baby
- Not following the care plan – for self or baby
- Missing one or more doses of medicine, or not giving the baby doses on time
- Sharing medicines with other people
- Stopping medicine for a day or many days (taking a treatment “break”)
- Taking or giving medicines at the wrong times
- Taking or giving medicines without following instructions about food or diet
- Not reducing risk-taking behaviour (for example, not practicing safer sex or not delivering a baby with a trained health care provider)

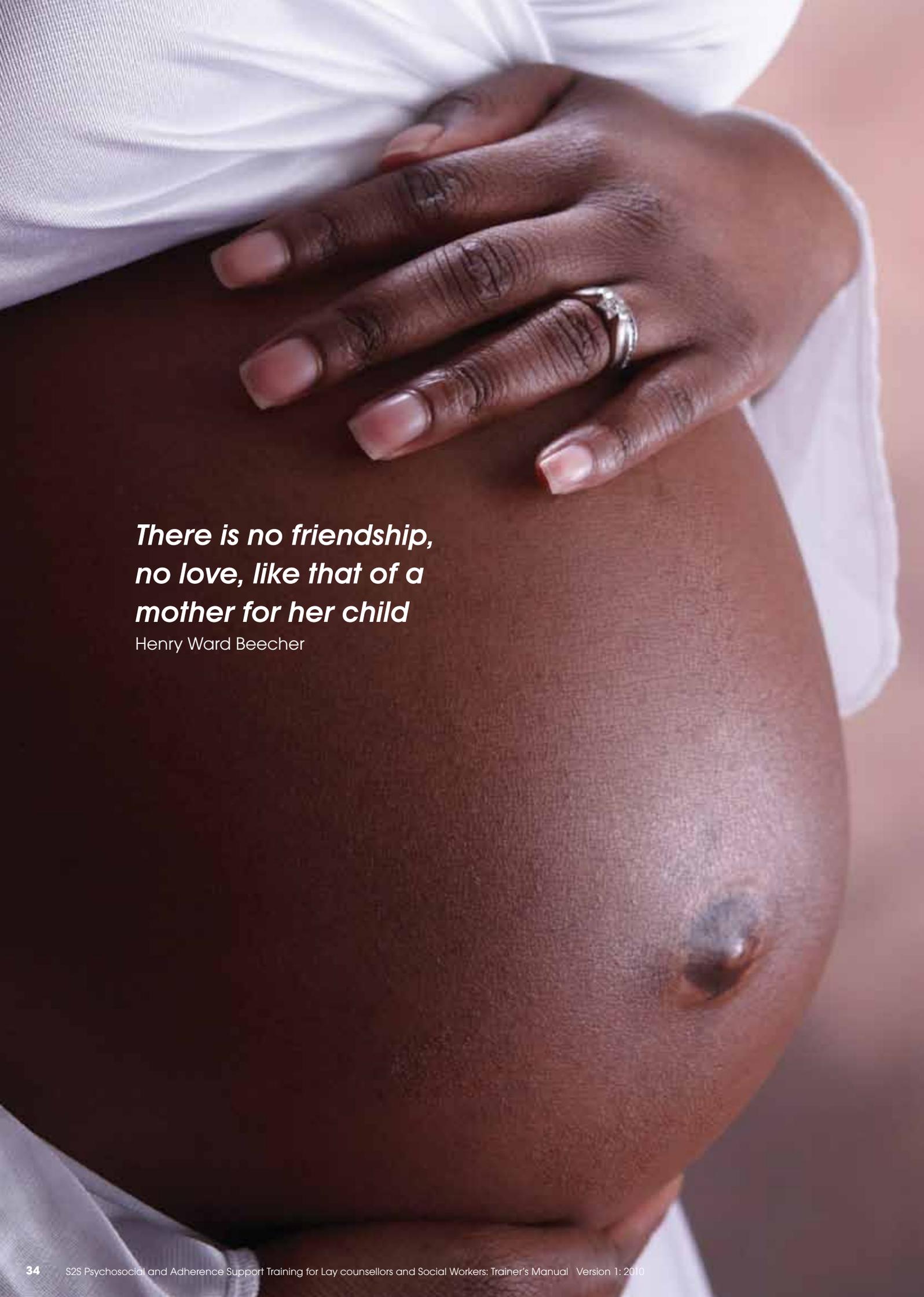
REMEMBER: No one is perfect. It is important not to judge clients if they are non-adherent. Instead, we should try to uncover the root causes of non-adherence and help find ways to resume good adherence as soon as possible.

Why is near-perfect adherence to PMTCT and ART medications important?

- To reduce the chance of MTCT at all stages (e.g. during pregnancy, during labour and delivery, during breastfeeding)
- To ensure that ART and other medications do their job and keep clients healthy
- To increase the CD4 cells and decrease the amount of HIV in the body
- To avoid the body becoming resistant to certain medicines
- To make sure the person gets all the benefits that ARVs and other medicines have to offer, such as feeling better, not getting opportunistic infections, etc.
- To monitor the person's health and also help her find community support resources for herself and her family
- To keep the person looking and feeling good so she can get back to normal life breastfeeding
- To keep families, communities, and our nation healthy and productive

What happens when a person doesn't adhere to his or her care and treatment plan?

- The levels of drugs in the body drop and HIV keeps multiplying
- A baby is more likely to acquire HIV from his or her mother during pregnancy, delivery, or breastfeeding
- The CD4 count will drop and the person will start getting more opportunistic infections
- Children, in particular, will become ill very quickly
- It is more likely that the person will pass HIV to others (during unprotected sex, for example)
- The person might become depressed or de-motivated due to illness or physical deterioration
- The person can develop resistance to one or all of the drugs, meaning that the drugs will not 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 learn how to be stronger than the ARVs, to multiply, and take over the body again
- The person may have to start taking a new regimen or second-line ARVs. In South Africa, there aren't many kinds of ARVs available for free, so poor adherence can decrease future treatment options



***There is no friendship,
no love, like that of a
mother for her child***

Henry Ward Beecher

SESSION 2.2

PSYCHOSOCIAL AND ADHERENCE SUPPORT NEEDS OF PREGNANT AND POSTPARTUM WOMEN (40 MINUTES)



TRAINER INSTRUCTIONS

Methodologies: Interactive Trainer Presentation, Large Group Discussion, Small Group Work

Step 1: Introduce the session by reminding participants that psychosocial and adherence support are multi-dimensional because every person is different, every person's health/life/family situation is different, and people's needs change over time. There are many things that can affect adherence and psychosocial well-being.

Step 2: Facilitate an interactive discussion on the key factors affecting adherence and psychosocial well-being for people living with HIV, and specifically for pregnant and postpartum women, using the content below. Discuss factors at the following levels and record on flip chart:

- Things about an individual person
- Things about our community and culture
- Things about health services
- Things about medicines

Step 3: Break participants into 3 small groups. Once participants have moved into their groups, ask each group to select a note-taker and a facilitator/presenter. Give each group a piece of flip chart paper and markers.

Assign one of the following discussion questions to each of the 3 groups:

- *What are the most common psychosocial and adherence support needs of pregnant women, regardless of their HIV status?*
- *What are the most common psychosocial and adherence support needs of pregnant women living with HIV?*
- *What are the most common psychosocial and adherence support needs for women living with HIV and their babies in the post-partum period (e.g. until the baby is one year old)?*

Step 4: Allow the small groups about 15 minutes to discuss their question, and then reconvene the large group. Ask the facilitator of each group to present back a summary of their small group discussion to the larger group. Fill in, as needed, from the content below.

Step 5: Conclude the discussion by emphasizing the following points:

- Providing quality counselling includes acknowledging and responding to the factors in a client's life that can affect her own, or her child's, adherence and psychosocial well-being
- We often blame clients for not adhering to care and treatment, but research tells us that access is often the biggest barrier to adherence. Also, a client's adherence is often affected by the level and quality of social support she receives
- While we, as lay counsellors and social workers, are not always able to address all of the root causes and barriers, there are many factors that we can address in order to support clients' adherence and psychosocial well-being
- Psychosocial and adherence support are not only the work of lay counsellors and social workers – the whole multidisciplinary team must work together to provide these services to clients and their families

KEY INFORMATION

FACTORS AFFECTING PSYCHOSOCIAL WELL-BEING AND ADHERENCE

Indicators of psychosocial well-being and adherence:

A. Individual based

- How well they think they can adhere
- Acceptance of their HIV status
- Ability to disclose
- Having a treatment supporter
- Understanding the benefits of HIV care and treatment and PMTCT services
- Quality of life while on treatment
- How sick or well they feel
- Travel and migration
- Health status
- Mental illness, like depression
- Drug or alcohol abuse
- Concern for their family's well-being

B. Community based

- Poverty
- Lack of food
- Stigma

- Social support at home and in the community
- Lack of childcare to attend clinic
- Ability to take time off work to attend clinic
- Family structure and decision-making
- Gender inequality
- Violence
- Forced migration
- Distrust of the clinic/hospital
- Use of traditional medicine
- Political instability or war
- Physical environment, e.g., mountainous terrain, seasonal flooding, etc.

C. Health provider based

- The cost of health services or medicines
- Drug stock-outs
- Distance to the clinic/transportation costs
- Convenience of clinic hours
- Patient record and tracking systems
- Number and type of health care workers
- Provider attitudes
- Provider language
- Youth-friendliness of services
- Waiting times
- Space for private counselling
- Linkages between different services
- Referral systems
- Linkages to social and material support in the community
- Linkages to home-based care services
- Support groups
- PLHIV involvement

D. Treatment based

- Side effects
- Number of pills in regimen
- Dose timing
- Availability of reminder cues – pill boxes, calendars, alarms, etc.
- Taste
- Changing paediatric doses
- Changes in drug supplier – labeling, pill size, color, formulation

PSYCHOSOCIAL AND ADHERENCE SUPPORT NEEDS OF PREGNANT AND POSTPARTUM WOMEN

Common psychosocial support needs among all pregnant and postpartum women, regardless of HIV status:

- Discussing their feelings and concerns about their pregnancy and being/becoming a mother
- Understanding the processes of pregnancy, delivery, and infant feeding
- Specific information concerning the pregnancy, infant feeding options, and the health and developmental needs of the baby
- Acceptance and support from partner and family members throughout the pregnancy, delivery, and postpartum period
- Discussing fears of delivering and/or taking care of the baby (physically, emotionally, financially, etc.)
- Support to have a safe pregnancy and delivery
- Support to practice safer sex during and after the pregnancy
- Support to feed the baby properly and successfully
- Support to bring the baby back to the clinic for routine checkups and growth monitoring
- Access to social, nutritional, legal, spiritual, and other support services in the community

Common psychosocial support needs among pregnant and postpartum women living with HIV:

- Discussing their feelings and concerns about their HIV status and the effects it has on their own and their family's lives
- Discussing fears of passing HIV to the baby
- Empathy and acceptance from partner and family members
- Support in understanding and coming to terms with their HIV status
- Support to have a safe pregnancy and delivery
- Support to continue their own care and treatment after the baby is born
- Support to safely feed the baby
- Support to bring the baby for follow-up care, testing, and treatment
- Peer support from other pregnant women and mothers
- Strategies to disclose their HIV status to their partner and other family members, as well as to children living with HIV
- Strategies to encourage their partner and other family members to test and, if appropriate, enroll into care and treatment programmes
- Strategies and support for positive living
- Strategies and support for positive prevention, including in discordant couples
- Access to community-based organizations and support groups
- Access to nutrition support for self and family
- Access to social grants and income-generating activities
- Spiritual support and referrals to spiritual counselling

- Knowledge about their legal issues and rights
- Support for mental health, including anxiety and depression
- Substance abuse management

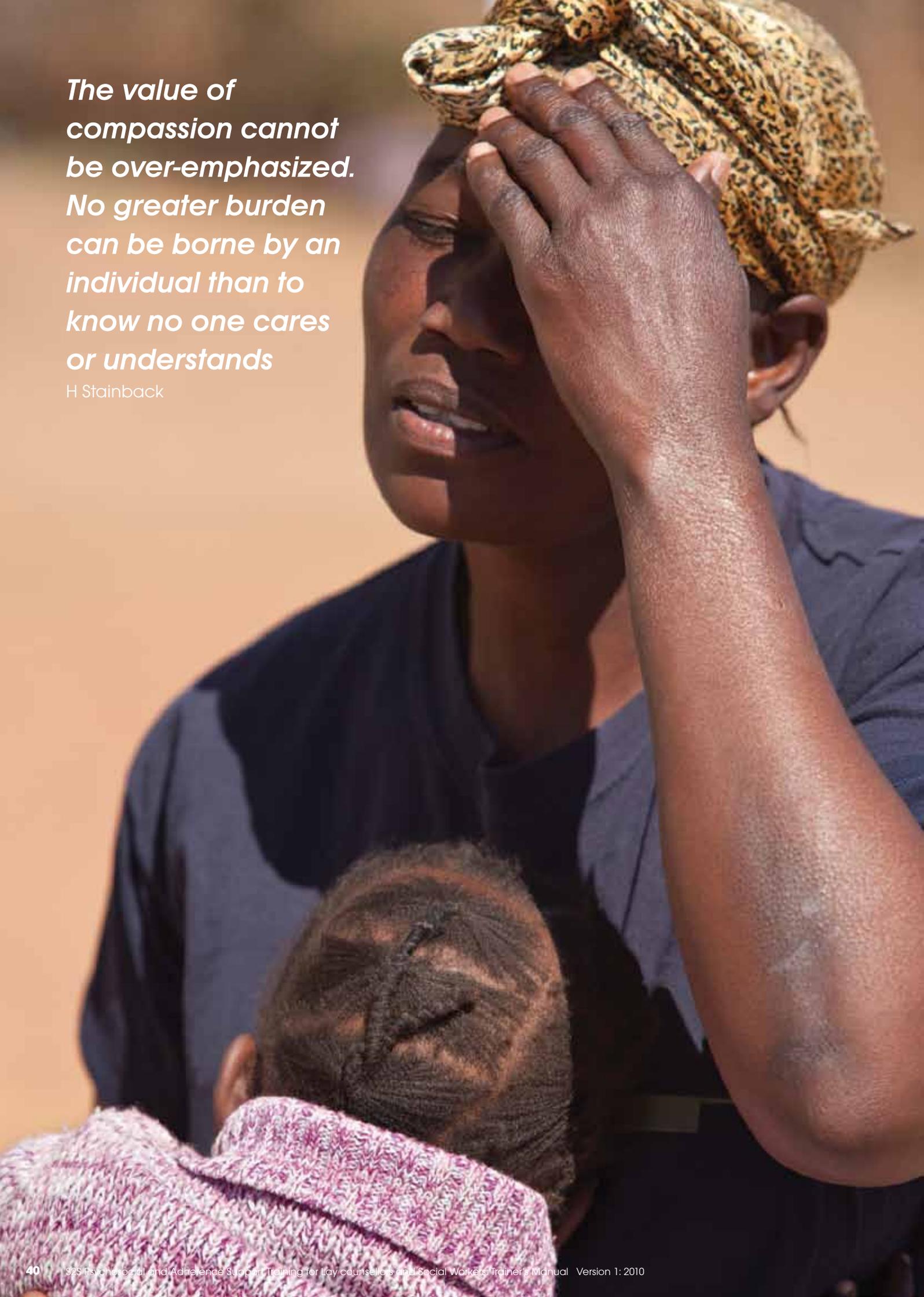
Common adherence support needs among pregnant and postpartum women living with HIV:

- Discussing their commitment to, and understanding of, their own and their child's care and treatment plan
- Making an adherence plan for their own and their baby's care and treatment, including anticipation of barriers and challenges and solutions to overcome them
- Discussing challenges to attending appointments and tests at the clinic, including routine follow-up of the baby after delivery and early infant diagnosis
- Discussing views about taking medication during pregnancy – including the fact that many pregnant women are not “sick,” which impacts their views on taking and adhering to medication and coming to the clinic for ongoing care
- Discussing views about giving a baby medication
- Discussing challenges to taking their medicine the right way, every day, and giving the baby medicines the right way, every day
- Strategies to help them remember to take/give their medicine the right way, every day
- Discussing challenges to picking up their own and the baby's medicines before running out
- Support in overcoming any challenges to adherence, which will change over time



*The value of
compassion cannot
be over-emphasized.
No greater burden
can be borne by an
individual than to
know no one cares
or understands*

H Stainback



SESSION 2.3

IMPROVING PSYCHOSOCIAL AND ADHERENCE SUPPORT IN PMTCT PROGRAMMES (40 MINUTES)



TRAINER INSTRUCTIONS

**Methodologies: Large Group Discussion,
Interactive Trainer Presentation, Brainstorming**

Step 1: Introduce the session by reminding participants that psychosocial and adherence support need to be ongoing – they are not one-time events. As a way to remind participants of all of the points where psychosocial and adherence support can be offered, present the PMTCT care spectrum (refer participants to their Participant Folder and/or present the spectrum on a slide).

Step 2: Using the PMTCT care spectrum below as a guide, lead an interactive discussion on the ways psychosocial and adherence support are currently provided to clients, and the ways we can improve support to clients at different stages in the PMTCT care spectrum. You may want to record what we are doing now above the diagram, and what we can do better below the diagram.

Ask participants to answer the following questions for each of the stages of PMTCT care listed below, and record on flip chart (and encourage participants to take notes in their Folder):

- *What psychosocial and adherence support services do we currently offer to clients at this step of PMTCT care?*
- *How do we document these services?*
- *What kinds of referrals do we make?*
- *What can we do better at this step in the future to improve psychosocial and adherence support services?*
 - *When a woman comes in for her first antenatal visit?*
 - *When she comes back for her ANC visits?*
 - *When she is referred to the ART clinic?*
 - *When she delivers the baby?*
 - *When the baby is 0-8 weeks old?*
 - *When the baby is 2-6 months old?*
 - *When the baby is 6-12 months old?*
 - *When the baby is 12-18 months old?*

Step 3: Summarize and close the session by reminding participants that psychosocial and adherence support are ongoing processes, throughout the spectrum of PMTCT care, for mothers, babies, and families. Emphasize the importance of documentation of psychosocial and adherence support activities and the rationale for doing so (e.g. to provide quality, continuous care to clients and to provide client-centred counselling), as well as the importance of referrals (to clinical and community-based services).

KEY INFORMATION

PMTCT CARE SPECTRUM from Pregnancy to 18months Post Partum

ANTEPARTUM	INTRAPARTUM	1 - 6 wks	6wks - 6 mths	6 - 9 mths	9 -12 mths	12 - 18 mths
						
<ul style="list-style-type: none"> • Routine HIV test in ANC • WHO staging & CD4 testing • Commence AZT at 14 weeks • ART Initiation • Screening for TB, STI & Pap smear • Comprehensive Counselling • Repeat HIV test at 32 wks for Neg women 	<ul style="list-style-type: none"> • Status unknown - Routine HIV test in L&D • Sd-NVP with TDF + FTC • AZT 3-hourly • FP Counselling • NVP infant dose • Comprehensive Counselling including Infant Feeding Support 	<ul style="list-style-type: none"> • Maternal postnatal check-up • Maternal CD4 & Pap smear if not done • Enrollment into Wellness/CCMT • FP & Infant Feeding Counselling • NVP for all HIV Exposed Infants (HEIs) • PCR testing at 6 wks • CTX Initiation • Growth Monitoring 	<ul style="list-style-type: none"> • Catch up missed PCR testing • Repeat maternal CD4 at 6 mths • Growth monitoring • CTX + NVP continuation IF breastfeeding • HIV infected infants: ART initiation • Infant Feeding Counselling 	<ul style="list-style-type: none"> • Growth monitoring • CTX + NVP continuation IF breastfeeding • Infant Feeding Counselling • Repeat PCR 6wks after weaning 	<ul style="list-style-type: none"> • Growth monitoring • CTX + NVP continuation IF breastfeeding • PCR testing 6wks after weaning • Infant Feeding Counselling & Support 	<ul style="list-style-type: none"> • PCR testing: 6wks after weaning • Antibody testing for all HIV negative infants at 18 months • Final infection status known • Child discharged from PMTCT programme

SESSION 2.4

CLASSROOM PRACTICUM (60 MINUTES)



TRAINER INSTRUCTIONS

Methodologies: Small Group Work, Case Studies and Role Play, Large Group Discussion

- Step 1:** Break participants into small groups of 3. Refer to the case studies written in the Participant Folder and assign a case study to each group. Ask the groups to assign one person to play the role of a lay counsellor, one the role of the client, and another the role of observer.
- Step 2:** Ask the small groups to read through their case study and the discussion questions, and then to role play the case study (changing roles so that everyone has the chance to play the role of the lay counsellor).
- Step 3:** After about 30 minutes, ask each small group to present back the key points of their case study to the large group for discussion. If time allows, some groups can also do a short role play of their case study for the large group. Go over the key points and considerations of each case study, using the content below as a guide (note that the suggested key points in italics below are not included in the Participant handouts).

KEY INFORMATION

CASE STUDY 1:

Patience is 18 years old, pregnant, and tested positive for HIV during her first ANC visit. During your counselling session, she discloses that it will be difficult for her to take medicines because she can't disclose to anybody. She expresses her fears of her boyfriend throwing her out of the house and not supporting her, but she really wants to protect her unborn baby.

QUESTIONS:

- **What are the most important issues for Patience right now?**

(She needs to enroll in PMTCT services, including taking ARVs; understanding the importance of PMTCT services for herself and her baby, including ARVs; disclosure to someone she trusts – perhaps her boyfriend; planning how she can adhere to care and treatment)

- **What kind of psychosocial support do you think Patience needs?**

(Suggestions of where she can get support – perhaps a support group – and help identifying support within her own family and friendship circles; disclosure counselling; help coping with her situation at home and planning next steps – highlighting the opportunity of future counselling sessions)

- **What kind of adherence support does Patience need?**

(Help understanding of the importance of adherence to care and medicines for herself and her baby; discussion of adherence challenges and solutions; making an adherence plan that fits her life situation)

- **What would your plan be for the current session with Patience? What would you discuss?**

(Praise her for caring for her baby; make sure she understands the importance of PMTCT care, including ARVs for her own and the baby's health; assess her home situation and discuss where she may be able to seek support; assess her ability/willingness to disclose to her boyfriend and her fears and concerns; discuss couples counselling and partner testing; plan next steps; plan a follow-up session)

- **How would you document your session and the next steps you agree upon with Patience?**

(Record key psychosocial and adherence issues in her file, as well as key points discussed, agreed upon next steps, and when she will come back for a follow-up appointment; also any referrals to support groups, etc.)

- **What is your role as a lay counsellor in helping Patience? What about other health care workers in the clinic?**

(To help her explore her fears and concerns about disclosing her status and coming for PMTCT services and taking medication; to reiterate how she wants to take care of her baby and that, to do so, she needs to take care of herself, including taking ARVs during and after the pregnancy; to motivate her so as to begin encouraging and facilitating adherence; to help her come up with concrete next steps to find support – either from her boyfriend or someone else she trusts; to link her to other women in similar situations – for example to a Mother Mentor or support group)

- **Would you provide any referrals for Patience? If yes, describe. How would you document this and find out if she went where she was referred?**

(possible referral to ART clinic (if CD4 count 350 or below); other referrals based on her specific psychosocial needs – could include referral for social grant, to Mother Mentor, mothers support group, PLHIV association in the community, or other services. Referrals should be documented in the patient file, a referral slip should be filled out and given to her, and at the next visit the lay counsellor should follow-up to see if she went to the referral service)

CASE STUDY 2:

Nancy is married and has 4 children. She is 5 months pregnant and at her last ANC visit she was referred to the ART clinic because her CD4 count was 200. She missed her next ANC visit, but returns to the clinic a few weeks later. When you meet with her, Nancy says that she went to the ART clinic, but left because there was a long queue and people were gossiping about her. She decided she does not want to take any ARV medications and is feeling fine.

QUESTIONS:

- **What are the most important issues for Nancy right now?**

(She needs to start ART and come back to the clinic for all ANC appointments; understanding the need for PMTCT and lifelong ART for her own health and her baby's health – even if she does not feel sick; adherence to care challenges since she is missing appointments; help overcoming access barriers to ART, such as long waiting time)

- **What kind of psychosocial support do you think Nancy needs?**

(Need to explore her understanding of HIV, PMTCT, and ART; need to assess her support system and home situation with her husband and children, including if they know about her HIV status and are supportive of her care and treatment; help to deal with stigma and discrimination from other patients at the clinic and in the community)

- **What kind of adherence support does Nancy need?**

(Help understanding the importance of coming to all scheduled ANC appointments; help understanding the importance of taking lifelong ART for her own health and for her unborn baby's health, so she can stay healthy and be able to take care of her family; explore the adherence challenges she's mentioned, such as long wait time and gossip, as well as other potential challenges at home; make an adherence plan that fits her life situation; try and fast-track her at the ART clinic so she doesn't have to wait)

- **What would your plan be for the current session with Nancy? What would you discuss?**

(Her understanding of HIV and PMTCT and the importance of coming to all appointments and lifelong ART for her own and her baby and family's health; her home situation, including if she has disclosed and if she has any support from her husband or friends and family; discuss challenges she faces in coming to appointments and try and come up with solutions; physically walk her to the ART clinic and help her enroll (if possible); empathize with her negative experience at the ART clinic and try to plan a way so that she will not have to wait; make a follow-up appointment for her at the ART clinic; discuss potential challenges to adherence and solutions that fit her situation; plan next steps; plan a follow-up counselling session)

- **How would you document your session and the next steps you agree upon with Nancy?**

(Record key psychosocial and adherence issues in her file as well as key points discussed, agreed upon next steps, and when she will come back for a follow-up appointment; also record any referrals to the ART clinic, etc.)

- **What is your role as a lay counsellor in helping Nancy? What about other health care workers in the clinic?**

(To help her understand the importance of regular clinic care and ART for her own health and the health of her baby; to explore any challenges, feelings, fears, or concerns she is having about coming for ANC services or about going to the ART clinic and taking ART; to explore her home situation and support network; to help her come up with concrete next steps, including planning for her next ANC appointment and another visit to the ART clinic)

- **Would you provide any referrals for Nancy? If yes, describe. How would you document this and find out if she went where she was referred?**

(She should be referred to the ART clinic and, if possible, not be made to wait while she is there; depending on her psychosocial needs, she also may want referrals to a Mother Mentor or a mother's support group, as well as a referral to social services, via a social worker, for a possible social grant. Referrals should be documented in the patient file, a referral slip should be filled out and given to her, and at the next visit the lay counsellor should follow-up to see if she went to the referral service)

CASE STUDY 3:

Mpho delivered her baby, a girl, 9 weeks ago. Mpho took ARVs during her pregnancy and delivered at a health facility. Mpho missed her 6-week postpartum visit, but comes to the clinic a couple of weeks later for a well-child visit. You meet her for a counselling session. The baby was given ARVs at birth, but Mpho said she has not been able to give the baby medications at home because she doesn't want her family to be suspicious that something is wrong. Right now, neither the baby nor Mpho is taking any medications. The baby doesn't seem to be gaining very much weight even though Mpho says she breastfeeds often.

QUESTIONS:

- **What are the most important issues for Mpho right now?**

(The baby probably did not benefit from ARVs postpartum; the baby should be taking CTX; Mpho should be evaluated for ART eligibility; the baby is not gaining weight; the baby needs to be tested for HIV; understanding the importance of coming back to the clinic for all appointments for her own and the baby's health; adherence to her own and the baby's care; disclosure of her HIV status at home and finding support to care for herself and the baby)

- **What kind of psychosocial support do you think Mpho needs?**

(Need to explore her home and family situation and where she can get support to care for herself and her baby; disclosure counselling and discussion of fears/concerns that her family will find out her HIV status or that of the baby)

- **What kind of adherence support does Mpho need?**

(Help understanding the importance of coming to all appointments for herself and for the baby; help understanding the importance of ARVs and CTX for the baby's health, explore her specific adherence challenges and make an adherence plan that fits her life situation)

- **What would your plan be for the current session with Mpho? What would you discuss?**

(Praise her for taking ARVs during her pregnancy and delivering at a health facility; make sure she has an appointment with the doctor since the baby is not well; help her understand the importance of continued care and ARVs for herself and the baby now; refer the baby for HIV testing; explore her home situation and challenges to disclosure and adherence; explore her social support needs and who might be able to support her to come back to the clinic and follow her own and the baby's care plan; explore how she is feeding the baby and address any challenges; plan next steps; plan a follow-up counselling session)

- **How would you document your session and the next steps you agree upon with Mpho?**

(Record key psychosocial and adherence issues in her file, as well as key points discussed, agreed upon next steps during the session, and when she will come back for a follow-up appointment; also record any referrals)

- **What is your role as a lay counsellor in helping Mpho? What about other health care workers in the clinic?**

(Help her understand that the baby is sick now and needs care and treatment to get better and to prevent the baby from getting sicker; help her explore her fears and concerns about disclosing her status, giving the baby ARVs, and coming back for appointments; reiterate how she took steps during the pregnancy to take care of her baby and that she needs to continue these steps now that the baby is born; encourage and motivate her and emphasize the possibility of having her baby be healthy again; help her come up with concrete next steps to find support from someone she trusts; link her to other women in similar situations – for example, to a Mother Mentor or support group)

- **Would you provide any referrals for Mpho? If yes, describe. How would you document this and find out if she went where she was referred?**

(The baby needs to see the doctor immediately because she is not gaining weight; refer for early infant diagnosis; refer for/provide infant feeding support; refer to Mother Mentor or mothers' support group, etc.)

*A baby is born with a
need to be loved and
never outgrows it*



SESSION 2.5

MODULE SUMMARY AND EVALUATION (15 MINUTES)



TRAINER INSTRUCTIONS

Methodologies: Large Group Discussion, Interactive Trainer Presentation

Step 1: Ask participants what they think are the key points of this Module.

What information will they take away from the Module?

Step 2: Summarize the key points of the Module using participant feedback and the content below. Review the learning objectives with participants and make sure all are confident with their skills and knowledge in these areas.

Step 3: Ask if there are any questions or clarifications.

Step 4: Ask each participant to share with the group one thing he or she will do differently in his or her work as a lay counsellor or social worker, based on the information and skills learned in this Module.

Step 5: Hand out a Module evaluation form to each participant (see *Appendix 2A*), and ask that they take about 5 minutes to fill it out and to return it to the trainers. Remind participants that they do not need to put their name on the form.



THE KEY POINTS OF THIS MODULE INCLUDE:

- Psychosocial support addresses the ongoing psychological and social concerns and needs of people living with HIV, their family, and caregivers of children living with HIV.
- Adherence means how faithfully a person sticks to, and participates in, her or his HIV prevention, care, and treatment plan.
- Adherence support is an important part of psychosocial support and clinical care.
- Adherence to PMTCT and HIV care is important to make sure women and babies stay healthy, get the ongoing care they need, understand how to live positively, know when and how to start ARVs or ART, and get psychosocial support.
- Adherence to medications is important to lower the amount of HIV in the body, to lower the chances that the baby will acquire HIV, and to make sure women and babies get all the benefits that ARVs and other medicines have to offer for their own health.

- There are many barriers and challenges to good adherence and psychosocial programme, and to the medicines themselves.
- Quality PMTCT services include acknowledging and recognizing the specific factors in a woman's life that affect her psychosocial well-being and adherence to her own, and her baby's, care and treatment over time.
- Psychosocial and adherence support are important services in PMTCT programmes and throughout the PMTCT care spectrum – from the time before a woman gets pregnant, through her pregnancy and delivery, in the postpartum period, and ongoing as the child grows.
- The entire multidisciplinary team, including but not limited to lay counsellors, is responsible for providing psychosocial and adherence support to pregnant and postpartum women.
- It is critical to document the psychosocial and adherence issues of the client and the support that is given, in order to follow-up and provide a continuum of support over time.
- Referrals are an important part of psychosocial and adherence support, as one person or clinical team cannot provide all of the support a woman needs.
- Adherence and psychosocial support are interrelated and a client's adherence is often affected by the level and quality of social support she receives.



APPENDIX 2A

MODULE 2 EVALUATION FORM

APPENDIX 2A

MODULE 2 EVALUATION FORM

Name (optional): _____ Health Facility: _____ Position: _____

Please note the following statements on a scale of 1 to 5:

	 Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	 Strongly Agree
1. The module objectives were clear	1	2	3	4	5
2. This module met my expectations	1	2	3	4	5
3. The technical level of this module was appropriate	1	2	3	4	5
4. The pace of speed of this module was appropriate	1	2	3	4	5
5. The facilitators were engaging and informative	1	2	3	4	5
6. The information I learned in this module will be useful to my work	1	2	3	4	5

How helpful were each of the workshop sessions to you and your work?

You can write extra comments on the back.

	 Not Helpful				 Very Helpful
Adherence and Psychosocial Support Basics	1	2	3	4	5
Adherence and Psychosocial Support Needs of Pregnant and Postpartum Women	1	2	3	4	5
Improving Adherence and Psychosocial Support for Pregnant and Postpartum Women	1	2	3	4	5
Classroom Practicum	1	2	3	4	5

What was the BEST THING about this Module?

What was NOT USEFUL about this Module?

Do you have other comments (use the back of the page if needed)?



*We can do no great things,
only small things with great love*

Mother Teresa

***We must care
about the world of
our children and
grandchildren, a
world we may
never see.***

Bertrand Russell



MODULE 3

Basic Counselling & Communication Skills



MODULE 3

Basic Counselling and Communication Skills



CONTENT

- Session 3.1:** Communication and Counselling Basics
- Session 3.2:** Key Listening and Learning Skills - # 1-3
- Session 3.3:** Key Listening and Learning Skills - # 4-7
- Session 3.4:** The Counselling Session
- Session 3.5:** Classroom Practicum
- Session 3.6:** Module Summary and Evaluation



DURATION

520 minutes (8 hours, 40 minutes - split over 2 training days)



LEARNING OBJECTIVES

By the end of this Module, participants will be able to:

- Describe the importance of effective communication and counselling skills in PMTCT care and treatment settings
- Reflect on their own attitudes, values, and beliefs and discuss how these may affect the quality of counselling
- Discuss the basic principles of counselling and challenges to putting these principles into practice
- Discuss what is meant by shared confidentiality and why it is important
- Avoid common counselling mistakes
- Demonstrate the 7 key listening and learning skills
- Understand the main components of a counselling session
- Apply strategies to help clients solve their problems



PREVIOUS TRAINING/KNOWLEDGE REQUIRED FOR THIS MODULE

- Basic knowledge about PMTCT protocols and guidelines
- Experience in HIV counselling and testing (e.g., VCT and PICT), PMTCT, and ARV/ART education/counselling



METHODOLOGIES:

- Interactive Trainer Presentation
- Large Group Discussion
- Small Group Work
- Values Clarification
- Brainstorming
- Role Play
- Review Exercise
- Case Studies



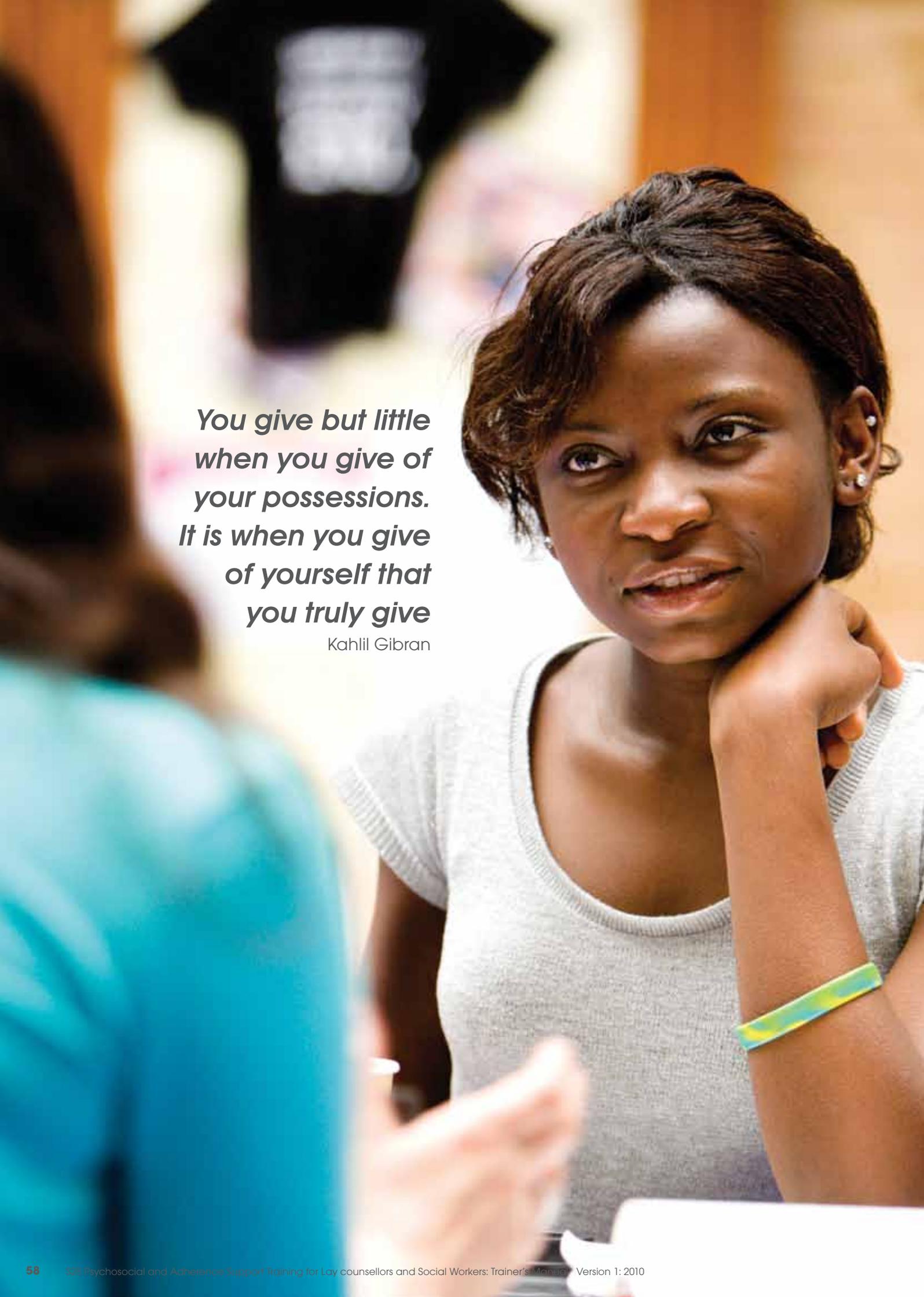
MATERIALS NEEDED

- Flip chart and stand
- Markers/Khoki's
- Tape or Bostik
- Copies of *Appendix 3A* and *3B* for each participant
- Participant Handouts for Module 3 (to be inserted into the Participant Folder)



WORK FOR THE TRAINER TO DO IN ADVANCE

- Read through the entire Module and make sure you are familiar with the training methodologies and content.
- Write the Module learning objectives on flip chart or list them on a PowerPoint slide.
- Review all of the role plays in Sessions 3.2 and 3.3.
- Review the case studies in Session 3.5.
- Review the *Appendices*, including the listening and learning skills checklist.
- Make large "AGREE" and "DISAGREE" signs on flip chart.
- Make sure there are at least 2 extra chairs in the front of the room that can be used when the trainers role play the demonstrations in Sessions 3.2 and 3.3.
- Make a copy of *Appendices 3A* and *3B* for each participant.



*You give but little
when you give of
your possessions.
It is when you give
of yourself that
you truly give*

Kahlil Gibran

SESSION 3.1

COMMUNICATION AND COUNSELLING BASICS (90 MINUTES)



TRAINER INSTRUCTIONS

Methodologies: Large Group Discussion, Interactive Trainer Presentation, Small Group Work, Values Clarification

Step 1: Review the Module learning objectives and ask if there are any questions.

Step 2: Start by asking participants to reflect on a time when they received good counselling – from a friend, a colleague, a lay counsellor, etc. Ask some participants to share their experiences.

Step 3: Write **“What is Counselling?”** on top of flip chart. Ask participants to brainstorm possible answers. Write participants’ responses on flip chart. Fill in using the content below.

Step 4: Write **“Why do we do Counselling?”** on top of flip chart. Ask participants to brainstorm possible answers. Write participants’ responses on flip chart. Fill in using the content below.

Step 5: Write **“Confidentiality and Shared Confidentiality”** on top of flip chart. Ask participants to brainstorm what is meant by these terms. Write participants’ responses on flip chart. Fill in using the content below.

Step 6: Break participants into groups of 4. Give each group flip chart and a marker. Ask each group to discuss one of the following questions and to record their ideas on flipchart:

- *What characteristics or skills does a person need to be a good lay counsellor?*
- *How can we ensure that the environment we are working in is safe and conducive for counselling?*
- *What are some common counselling mistakes we should avoid?*
- *Even though we know what good counselling is, why don’t we always provide good counselling?*

After 15 minutes, have each small group present their ideas to the larger group and discuss. Fill in, as needed, using the content below.

Step 7: Remind participants that lay counsellors should be aware of their own strengths and weaknesses, as well as their fears or anxiety about HIV. By thinking about their own skills, beliefs, and attitudes, lay counsellors can become more self-aware, thereby improving their ability to counsel clients well.

Step 8: Post the pre-prepared flip chart papers that say “AGREE” and “DISAGREE” on opposite sides of the training room.

Ask participants to stand up and move to the open space in the room where the “AGREE” and “DISAGREE” signs are posted. Tell participants that you will read some statements out loud and that, after each statement, they should move to the “AGREE” or the “DISAGREE” sign, based on their opinions. If participants are not sure whether they agree or disagree with the statement, they can stand somewhere between the two signs.

Step 9: Read each of the sentences listed below (“Statements for Values Clarification Exercise”) out loud. Allow participants a few seconds to move to the side of the room that reflects their opinion. Ask a few participants to tell the group why they “AGREE” or “DISAGREE” with the statement.

Once you have read all of the statements below, or 20 minutes have passed, ask participants to return to their seats.

Debrief the activity by reminding participants that although we ALL bring certain values and attitudes to our work, we must not let these values and attitudes affect the quality of counselling we provide to clients. By striving to be self-aware, lay counsellors can make sure they are equally supportive of all of their clients.

Step 10: Close the session by summarizing the key points discussed, including the definitions of counselling and confidentiality, the qualities of a good lay counsellor, challenges to counselling, and common counselling mistakes to avoid.

KEY INFORMATION

WHAT IS COUNSELLING?

- Counselling is a two-way communication process that helps people look at their personal issues, make decisions, and plan how to take action

COUNSELLING INCLUDES:

- Establishing supportive relationships
- Having conversations with a purpose (not just chatting)
- Listening carefully
- 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 toward life and to become more confident
- Respecting everyone's needs, values, culture, religion, and lifestyle

COUNSELLING DOES NOT INCLUDE:

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

WHY DO WE DO COUNSELLING?

- To help people talk about, explore, and understand their thoughts and feelings
- To help people work out what they want to do and how they will do it
- To provide people with information and referrals that might assist them

CONFIDENTIALITY:

In order for clients to trust lay counsellors with their feelings and problems, it is important for them to know that anything they say will be kept confidential. This means that lay counsellors, social workers, and other members of the multidisciplinary care team will not tell other people any information about the client, anything the client says, or that the client is HIV positive. Confidentiality is especially important in HIV programmes because of the stigma surrounding HIV and discrimination against PLHIV in the home, at work, at school, and in the community.

Because multidisciplinary teams take care of clients, sometimes they need to discuss a client's needs and health status with one another to provide the best care possible.

Shared Confidentiality

Shared confidentiality means that information about a client is disclosed to another person involved in the client's care – a member of the multidisciplinary team, a community health worker, a treatment supporter, etc. – with the client's permission (consent).

COMMON COUNSELLING MISTAKES

The principles of good counselling and communication are easy to learn but difficult to apply. Some common counselling mistakes include:

- Controlling the discussion, instead of encouraging the client's open expression of feelings and needs
- Judging the client—making statements that show that the client does not meet the lay counsellor's standards, for example: "you never should have trusted that guy, now you have created a big problem for yourself."
- Preaching to the client—telling the client how she should behave or lead her life, like saying: "if your husband is treating you that way, you should leave him."
- Labeling the client instead of finding out her individual motivations, fears, or anxieties.
- Reassuring the client without even knowing her health status—for example, telling a client, "you have nothing to worry about."
- Not accepting the client's feelings—saying "you shouldn't be upset about that."
- Advising the client before the client herself has collected enough information or taken enough time to arrive at a personal solution.
- Interrogating the client or asking accusatory questions. Questions that start with "why...?" can sound accusatory.
- Encouraging dependence—increasing the client's need for the lay counsellor's presence and guidance.
- Persuading or coaxing—trying to get the client to accept new behaviour by flattery or fakery. "I know you are a smart girl and you will take the medicines every day, just like I told you."

SELF-AWARENESS

Listening and counselling require that the lay counsellor be aware of his or her strengths and weaknesses, as well as his or her fears or anxiety about HIV. All lay counsellors should strive to be self-aware and to understand how others affect them as well as how they affect others.

STATEMENTS FOR VALUES CLARIFICATION EXERCISE:

1. I expect clients to do everything in their power to protect their health.
2. Sometimes I feel uncomfortable discussing HIV with clients.
3. Many people living with HIV have made irresponsible decisions in their lives.
4. It is a good idea to encourage HIV positive women NOT to become pregnant.
5. People who have unprotected sex with many different partners deserve to get HIV.
6. It is sometimes hard for me to keep quiet when I disagree with what a client is saying.
7. Some clients do not know what is best for them.

SESSION 3.2

KEY LISTENING AND LEARNING SKILLS - #1 - 3 (90 MINUTES)



TRAINER INSTRUCTIONS

Methodologies: Interactive Trainer Presentation, Large Group Discussion, Role Play, Small Group Work, Brainstorming

Step 1: Tell participants that in this and the next session, we will learn the 7 key listening and learning skills needed to be a good communicator and lay counsellor.

Ask participants to turn to the person sitting next to them. One person will talk about the best day of his/her life and the other will just listen, without saying anything.

After 3 minutes, ask the pairs to switch roles. Debrief by asking how it felt to be the speaker and how it felt to be the listener.

Step 2: Write **“Skill 1: Use helpful non-verbal communication”** on flip chart and ask participants to brainstorm what this means, thinking about the last activity. Record responses on flip chart and fill in using the content below.

With a co-trainer, perform the role play under Skill 1 below. Ask:

- *What were some examples of unhelpful non-verbal communication?*
- *What were some examples of helpful non-verbal communication?*

Ask participants to turn to the person sitting next to them again. This time, one person will talk about one of the hardest days of his/her life and the other will just listen, without saying anything, but applying helpful non-verbal communication skills.

After 3 minutes, ask the pairs to switch roles. Debrief by discussing what types of non-verbal communication were used and what was most effective.

Step 3: Write **“Skill 2: Actively listen and show interest in the client”** on flip chart and ask participants to brainstorm what this means. Record answers on flip chart and fill in using the content below.

With a co-trainer, perform the role play under Skill 2 below. Ask:

- *What did the lay counsellor do to show he/she was actively listening to the client?*
- *Why was it important that the lay counsellor apply active listening skills in this example?*
- *How can you as a lay counsellor improve your own active listening skills with clients?*

Ask participants to turn to the person sitting next to them again. This time, one person will talk about their favorite family traditions and the other will use active listening skills. After 3 minutes, ask the pairs to switch roles. Debrief by discussing how the listener practiced active listening and what was most effective.

Step 4: Write **“Skill 3: Ask open-ended questions”** on flip chart and ask participants to brainstorm what this means, using examples. Record answers on flip chart and fill in using the content below.

With a co-trainer, perform the role play under Skill 3 below. Ask:

- *What were the differences in the ways the lay counsellor asked questions?*
- *Why was it important to use open-ended questions in this example?*
- *How can you as a lay counsellor improve the way you ask questions of clients?*

Ask participants to change close-ended questions into open-ended questions using the examples below. If additional practice is needed, lead a “round robin” exercise where participants go around the room with one saying a closed-ended question and the next person changing it to an open-ended question.

Step 5: Summarize the session by reviewing the first 3 listening and learning skills. Ask if there are any questions and remind participants that they will get more practice with these skills throughout the training.

KEY INFORMATION

LISTENING AND LEARNING SKILLS

There are 7 essential skills that lay counsellors and social workers should practice and use in their work:

SKILL 1: Use helpful non-verbal communication.

SKILL 2: Actively listen and show interest in the client.

SKILL 3: Ask open-ended questions.

SKILL 4: Reflect back what the client is saying.

SKILL 5: Empathize—show that you understand how the client feels.

SKILL 6: Avoid words that sound judging.

SKILL 7: Help the client set goals and summarize each counselling session.

SKILL 1: USE HELPFUL NON-VERBAL COMMUNICATION

- Make eye contact.
- Face the person.
- Be relaxed and open with your posture.
- Sit squarely facing the person. Do not sit behind a desk!
- Dress neatly and respectfully.
- Use good body language – nod your head and lean forward.
- Smile.
- Make the client feel that you have time, greet the client warmly, and wait for the client to talk when she is ready.
- Do not look at your watch, the clock, or anything other than the person you are counselling.
- Try not to write during a counselling session unless you are recording key information for the client to take home or for your records. Turn your mobile phone off and never take calls during a counselling session.

Role Play: Non-verbal Communication

WHAT NOT TO DO Unhelpful non-verbal communication	WHAT TO DO Helpful non-verbal communication
(Client walks in)	(Client walks in)
Lay counsellor: Hello. My name is _____(name) (Lay counsellor is filling in the register form behind a desk)	Lay counsellor: Hello. My name is _____(name) (Lay counsellor ikeeps filling in the register)
Client: I have some questions about my risk of HIV	Client: I have some questions about my risk of HIV
Lay counsellor: Please sit down (speaking in a hurried fashion). What were your questions? (Lay counsellor still looking at the register)	Lay counsellor: (Looks at client, stops writing in the register, and moves chair so that it is not behind the desk). Please sit down. What were your questions? (Leans forward, not crossing legs).
Client: Well, I think my husband might be infected	Client: Well, I think my husband might be infected
Lay counsellor: (No response and still filling in the register)	Lay counsellor: (Looks warmly, yet with concern at client. Optional: demonstrate appropriate touch)
Client: (Clears throat to get lay counsellor's attention)	–
Lay counsellor: Oh sorry (she finally stops writing and looks at watch). You said that you are concerned that your sister might be infected? (Lay counsellor's hands are folded, legs crossed and facing away from client, looking across the room with expression suggesting disinterest.	Lay counsellor: You look concerned, why do you think he might be infected? (Lay counsellor looks at client, leaning forward and not crossing legs)
Client: Well no, actually it was my hus. . . , actually it's okay. Don't worry, sorry to have bothered you.	Client: Proceeds to tell her story

SKILL 2: ACTIVELY LISTEN AND SHOW INTEREST IN THE CLIENT

It is important for the client to know that she has the whole attention of the lay counsellor. Feeling that the lay counsellor is actively listening will encourage the client to share more about her situation.

Active listening skills:

- Listen in a way that shows respect, interest, and empathy.
- Show the client you are listening by saying “mm-hmm” or “aha.”
- Use a calm tone of voice.
- Listen to what the client is saying – do you notice any themes?
- Listen to how client is saying it – do they seem worried, angry, etc.?
- Allow the client to express her emotions. For example, if she is crying, allow her time to do so.
- Never judge or impose your own values on a client.
- Find a private place to talk and keep distractions, such as phone calls or visitors, to a minimum.
- Do not do other tasks while counselling a client.
- Do not interrupt the client.
- Ask questions or gently probe if you need more information. For example, if a client says, “I can’t exclusively breastfeed my baby,” you could ask, “In what way is exclusive breastfeeding a concern for you?”
- Use open-ended questions that can’t be answered with “yes” or “no.” For example, “Can you tell me a bit more about that?”
- Summarize key points made so far during the counselling session.

Role Play: Active Listening

WHAT TO DO Gestures and responses that show interest
Lay counsellor: How do you think your partner will react if you invite him to come to the clinic for an HIV test?
Client: Actually, I’m really very worried about it. I was hoping you wouldn’t ask, to tell you the truth.
Lay counsellor: Mm-hmm. (nods sympathetically)
Client: I think my husband will accuse me of being HIV infected if I’ve been tested, even if I don’t have my result yet.
Lay counsellor: He’ll accuse you of being infected?
Client: Well, mostly because he’ll be angry that I went ahead and agreed to be tested without telling him first.
Lay counsellor: Mm-hmm.
Client: Last time I was sick and went to the clinic without asking him, he got angry with me for spending the money to see the doctor and get some tests done. I think he’s going to react the same way.
Lay counsellor: So, really, it seems like it’s not that he minds you getting an HIV test, it’s that he minds that you did so without consulting with him first. So, would you prefer not to get the HIV test today and instead wait until the next visit?

SKILL 3: ASK OPEN-ENDED QUESTIONS

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?”* and *“Do you have children?”*

Closed-ended questions are good for gathering basic information at the start of a counselling or group education session. They should not be used too much because they can make it seem like the lay counsellor is being too direct. They are not helpful in getting at how the client 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?”* or *“How does that make you feel?”*

Open-ended questions are the best kind to ask during counselling and group education sessions because they encourage the client to talk openly and they lead to further discussion. They help clients explain their feelings and concerns, and also help lay counsellors get the information they need to help clients make decisions.

Examples of closed- and open-ended questions

CLOSED-ENDED QUESTION	OPEN-ENDED QUESTIONS
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 your partner, and using condoms. Which would work best for you based on your situation
Do you use condoms?	What challenges do you have in using condoms with your partner?
Do you drink alcohol when you are upset?	What are some of the ways you cope with 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 our baby?	I want to make sure that I have 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 your baby?	Can you tell me more about how you feed your baby?

Role play: Open-ended questions

WHAT NOT TO DO Closed-ended questions	WHAT TO DO Open-ended questions
(Client walks in)	(Client walks in)
<p>Lay counsellor: Hi, how are you? I'm _____ (name). Today, as part of your ANC visit, I will be discussing with you HIV, HIV testing, and ways you can protect your health, the health of your baby, and your family</p>	<p>Lay counsellor: Hi, how are you? I'm _____ (name). I am a lay counsellor. Today, as part of your ANC visit, I will be discussing with you HIV, HIV testing, and ways you can protect your health, the health of your baby, and your family</p>
<p>Client: OK</p>	<p>Client: OK</p>
<p>Lay counsellor: Do you know how HIV is transmitted?</p>	<p>Lay counsellor: Tell me, how do you think HIV is transmitted?</p>
<p>Client: Yes, I think so</p>	<p>Client: Well, I'm not sure, but I think you get it from sex</p>
<p>Lay counsellor: OK, great. And do you know how HIV is passed from mother to baby?</p>	<p>Lay counsellor: Yes, that's right. How else do you think it is transmitted?</p>
	<p>Client: By kissing and blood transfusions</p>
	<p>Lay counsellor: You are correct in saying that HIV is transmitted by blood transfusions - if the blood is not screened. However, since blood is screened, the chance of HIV transmission through transfusions is very, very low. But HIV isn't actually transmitted by kissing. The reason is</p>
	<p>Client: Hmm. That's very interesting.</p>
	<p>Lay counsellor: What have you heard about mother-to-child-transmission of HIV?</p>
	<p>Client: Well, I've heard that HIV is transmitted from mom to baby So I guess if I'm HIV positive, that means that me baby will be positive too, right?</p>
	<p>Lay counsellor: Not necessarily. A mother with HIV can pass HIV to her baby during pregnancy, labour and delivery, or breastfeeding. But not all women who have HIV will pass it to their babies. It is important that you and your baby get care and treatment here at this clinic to stay healthy and lower the chances that your baby will get HIV.</p>

SESSION 3.3

KEY LISTENING AND LEARNING SKILLS - #4 - 7 (120 MINUTES)



TRAINER INSTRUCTIONS

Methodologies: Interactive Trainer Presentation, Large Group Discussion, Role Play, Small Group Work, Brainstorming

Step 1: Tell participants that in this session, we will learn 4 more key listening and learning skills needed to be a good communicator and lay counsellor.

Step 2: Write **“Skill 4: Reflect back what the client is saying”** on flip chart and ask participants to brainstorm what this means, using examples of how to reflect feelings and paraphrase content. Record responses and fill in using the content below. Go over the different formulas for reflection (e.g. “you feel _____ because _____,” and others).

With a co-trainer, perform the role play under Skill 4 below. Ask:

- *How did the lay counsellor use reflection in this session?*
- *Why was it important for the lay counsellor to use reflection?*
- *How can you as a lay counsellor better use reflection in your sessions with clients?*

Break participants into pairs. Have one person play the role of the lay counsellor and the other the role of a client. Ask the client to talk about a challenge he/she faces or has faced in life. Have the lay counsellor respond using reflection. After a few minutes, switch roles. Debrief by discussing what was easy or difficult about reflecting. If additional reflection practice is needed, lead a “round robin” exercise where participants go around the room with one saying a feeling statement and the next person reflecting back the feelings and paraphrased content of the previous person’s statement.

Step 3: Write **“Skill 5: Empathize—show that you understand how the client feels”** on flip chart and ask participants to brainstorm what this means, and how empathy is different from sympathy. Record responses on flip chart and fill in using the content below.

With a co-trainer, perform the role play under Skill 5 below. Ask:

- *In which role-play was the client sympathizing?*
- *How did the lay counsellor show empathy for the client?*
- *Why was it important for the lay counsellor to show empathy?*
- *How can you as a lay counsellor better empathize with clients, and avoid sympathizing?*

Step 4: Write “**Skill 6: Avoid words that sound judging**” on flip chart and ask participants to brainstorm what this means as well as examples of judging words in the local language(s). Record responses on flip chart and fill in using the content below.

With a co-trainer, perform the role play under Skill 6 below. Ask:

- *Which words did you think were judging?*
- *How might these words make a client feel?*
- *How can you as a lay counsellor avoid using judging words with clients?*

Step 5: Write “**Skill 7: Help your client set goals and summarize each counselling session**” on flip chart and ask participants to brainstorm what this means. Discuss why it is important to work with clients to set goals and plan next steps, and then summarize the session. Record responses on flip chart and fill in using the content below.

Break participants into pairs again. One should play the role of the lay counsellor and the other person should begin by telling the lay counsellor his or her plans to incorporate these 7 listening and learning skills into his or her work with clients.

After about 5 minutes, the lay counsellor should help the client set goals and summarize the session. Then participants should switch roles so each has a chance to practice goal setting and summarizing. If time allows, ask some of the pairs to perform their role play in front of the large group and discuss.

Step 6: Summarize the session by reviewing the 7 listening and learning skills. Point participants to *Appendix 3A*, which is a checklist summarizing the 7 key skills. Discuss how lay counsellors can use this checklist in their work, in mentoring other lay counsellors, and in the Classroom Practicum.

Go around the room and ask each participant to name 2 things they will do, starting tomorrow, to improve their listening and learning skills with clients. Ask if there are any questions and remind participants that they will get more practice with these skills in the next session.

KEY INFORMATION

SKILL 4: REFLECT BACK WHAT THE CLIENT IS SAYING

Reflecting skills:

The lay counsellor repeats back to the client the main feelings and themes that the client has just expressed.

Reflecting:

- Provides feedback to the client and lets her know that she has been listened to, understood, and accepted
- Encourages the client to say more
- Shows that the lay counsellor has understood the client's story
- Helps the lay counsellor check that he or she has understood the client's story
- Provides a good alternative to always answering with another question
- Can reflect the client's feelings and include a summary of the content of what the client has said (sometimes called paraphrasing)
- For example, the lay counsellor can use the following formulas for reflecting:
 - "You feel _____ because _____."
 - "You seem to feel that _____ because _____."
 - "You think that _____ because _____."
 - "So I sense that you feel _____ because _____."
 - "I'm hearing that when _____ happened, you didn't know what to do."
- When reflecting back, try to say it in a slightly different way. Do not just repeat what the client said. For example, if a client says, "I can't tell my partner about my HIV test result," the lay counsellor could say, "Talking to your partner about your result sounds like something that you are not comfortable doing." Then say, "Let's talk about that."

Role play: Reflecting skills

WHAT NOT TO DO Reflecting back
Lay counsellor: What do you think about telling your partner about your HIV status? Maybe he could be your treatment supporter?
Client: Well, I honestly don't think I could ever bring up the subject to him. I think he'd get really angry and say that I have been sleeping around.
Lay counsellor: It sounds like disclosing to your husband is something that you would actually be hesitant, maybe even afraid, to do right now.
Client: Yes, that's right.....

SKILL 5: EMPATHIZE—SHOW THAT YOU UNDERSTAND HOW THE CLIENT FEELS

Empathy or empathizing:

- Is a skill used in response to an emotional statement
- Shows an understanding of how the client feels and encourages the client to discuss the issue further
- Is different than sympathy. When you sympathize, you feel sorry for a person and look at the situation from your own point of view. For example, if the client says: *“My baby wants to feed very often and it makes me feel so tired,”* the lay counselor can show empathy by saying: *“You are feeling very tired all the time then?”* However, if the lay counselor responds by saying, *“I know how you feel. My baby also wanted to feed often and I was exhausted!”*, this is sympathizing because the attention is on the lay counselor and her experiences instead of on the client.

Role play: Showing empathy vs. sympathy

WHAT NOT TO DO Sympathizing	WHAT TO DO Empathizing
Lay counsellor: What do you think about asking your partner to use condoms?	Lay counsellor: What do you think about asking your partner to use condoms?
Client: I'd be really afraid that he might hit me, or even worse.	Client: I'd be really afraid that he might hit me, or even worse.
Lay counsellor: Yes, I know what you mean, that happened to my sister. She actually did ask her husband to use condoms and you know what? He hit her then he made her leave the house. He didn't let her come back for two full days.	Lay counsellor: It sounds like you're afraid of your husband's response.
Client: So did your sister go back?	Client: Yes, I am. It's not just about asking him to use condoms. I'm also scared that he'll be upset if dinner is late, if the house isn't tidy, if the children aren't behaving well, and for a lot of other reasons.

SKILL 6: AVOID WORDS THAT SOUND JUDGING

Judging words are words that can include:

- “right” – You should do the right thing.
- “wrong” – That is the wrong way to feel.
- “badly” – Why are you behaving badly and missing appointments?
- “good” – Be a good girl and tell your boyfriend to use condoms.
- “properly” – Why don’t you take your medicine properly?
- “these people” or “those people” (referring to people living with HIV for example) - Those people are irresponsible and should not have children.

If a lay counsellor uses these words when asking questions, the client may feel that she is wrong, or that there is something wrong with her actions or feelings. Sometimes, however, lay counsellors need to use the “good” judging words to build a client’s confidence.

Role Play: Avoid judging words

WHAT NOT TO DO Using judging words	WHAT TO DO Avoid words that sound judging
Lay counsellor: What do you think about asking your partner to use condoms?.	Lay counsellor: What do you think about asking your partner to use condoms?
Client: Honestly I don’t feel comfortable with it.	Client: Honestly I don’t feel comfortable with it.
Lay counsellor: (Surprised) Really? That’s the wrong way to feel! Have you had a good conversation about condoms?	Lay counsellor: Mm-hmm
Client: No, not really	Client: It came up once many years ago before we got married. He said that condoms were uncomfortable and will give him kidney problems.
Lay counsellor: He’s stupid isn’t he? I hope you are a good girl and have a good conversation about condoms and how condoms prevent HIV, STIs and pregnancy.	Lay counsellor: I’ve heard other women say that as well. Have you ever had a talk with him about using condoms to protect the baby’s and your health? Also, condoms definitely won’t cause any kidney problems – that is a myth.
Client: Yes, I will.	Client: That’s a good idea, maybe I’ll try that.

SKILL 7: HELP THE CLIENT SET GOALS AND SUMMARIZE EACH COUNSELLING SESSION

Goal-setting

Toward the end of a counselling session, the lay counsellor should work with the client to come up with “next steps” to solve their issues in the short and long term.

Next steps and goals:

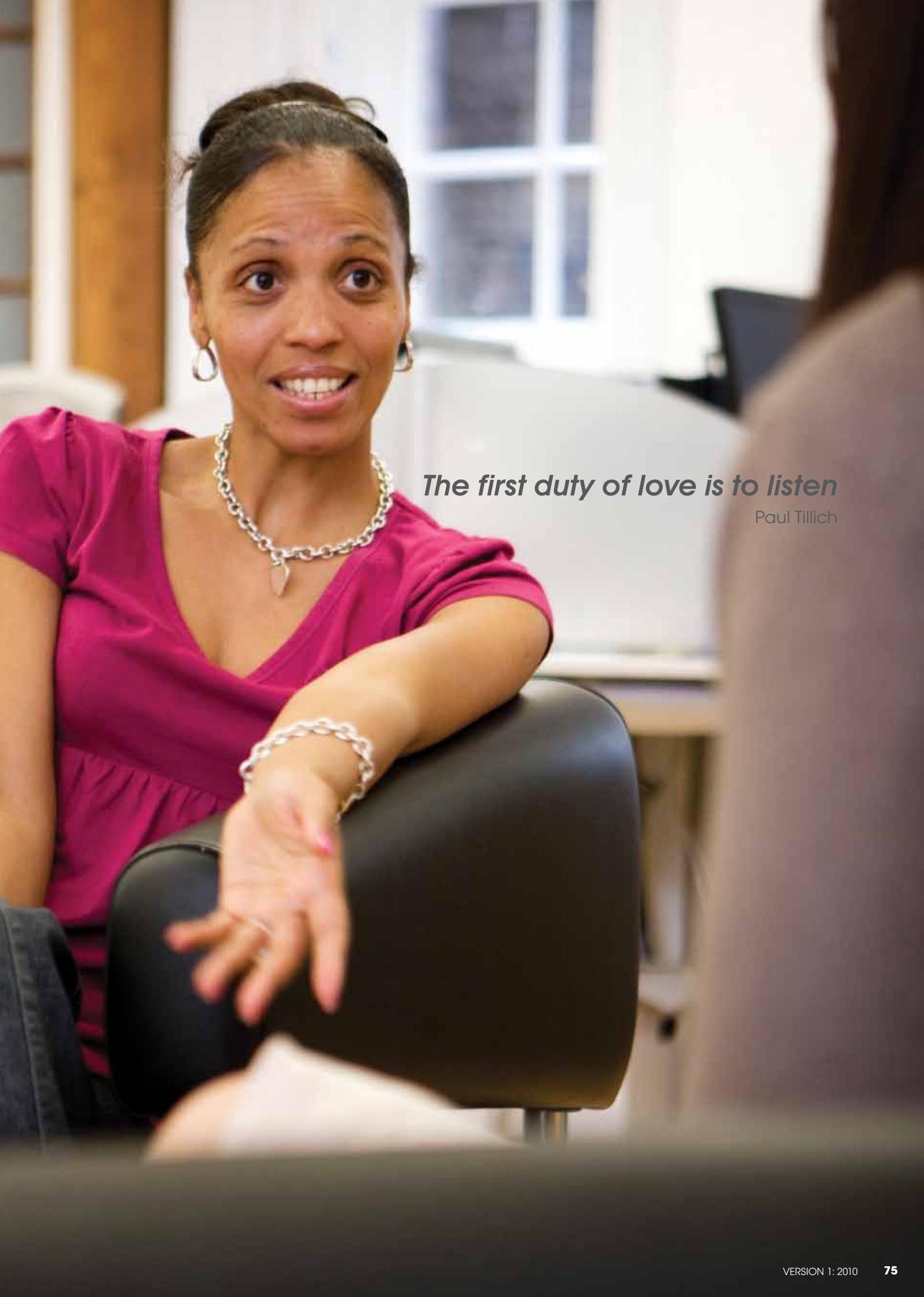
- Should be developed by the lay counsellor and client together
- Can empower the client to achieve what she wants by agreeing to realistic short- and long-term goals and actions
- Provide direction and must be results-oriented
- Must be clear enough to help the client measure her own progress (people feel good when they achieve something they have set out to do)
- To start, the lay counsellor could say, *“Okay, now let’s think about the things you will do this week based on what we talked about.”*

Summarizing:

The lay counsellor summarizes what has been said during a counselling session and clarifies the major ideas and next steps.

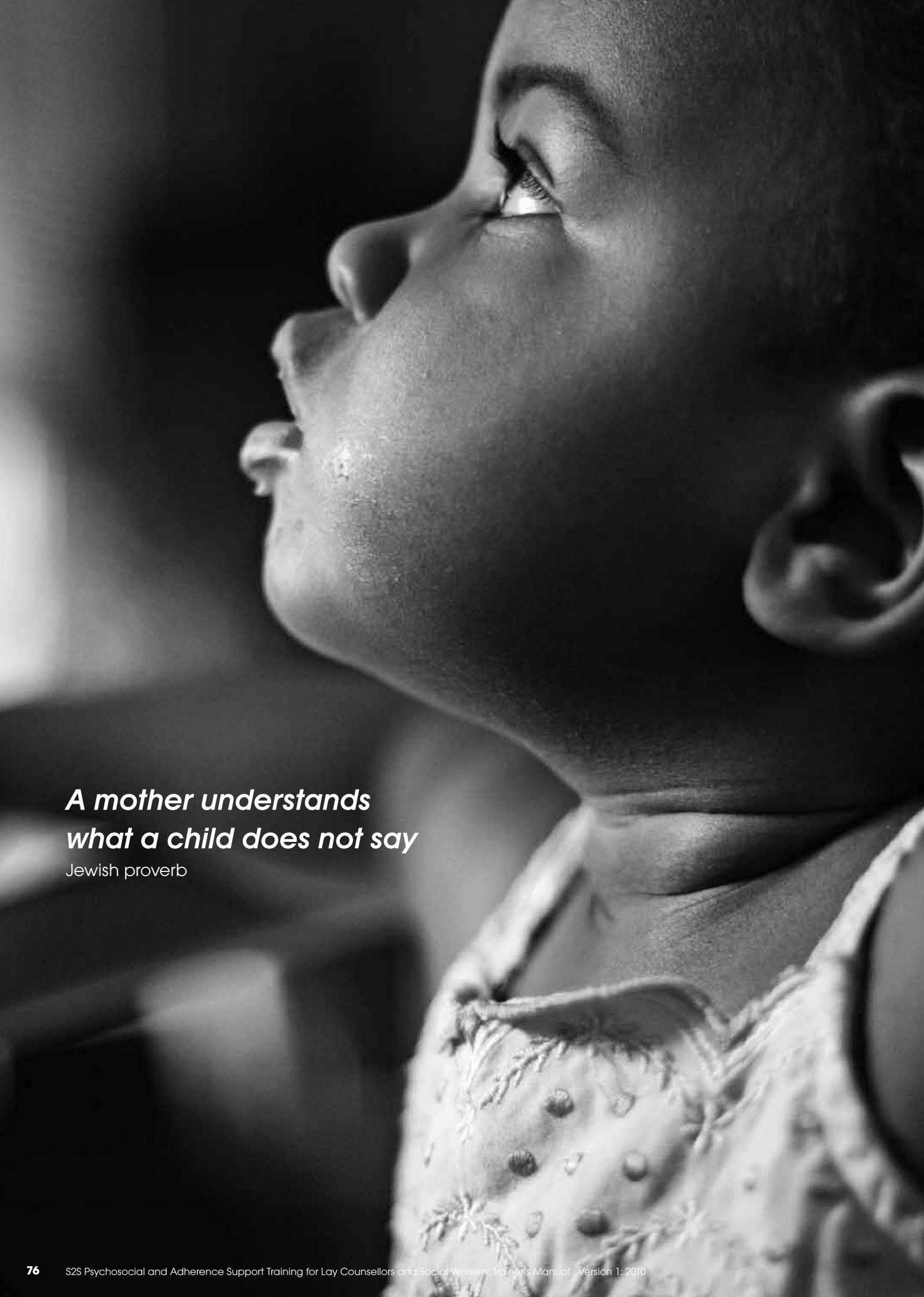
Summarizing:

- Can be useful in an ongoing counselling session or in making sure you are clear on important issues raised during a counselling session
- Is best when both the lay counsellor and client participate and agree with the summary
- Provides an opportunity for the lay counsellor to encourage the client to examine her feelings about the session
- The lay counsellor could say, *“I think we’ve talked about a lot of important things today. (List main points.) We agreed that the best next steps are to _____. Does that sound right? Let’s plan a time to talk again soon.”*



The first duty of love is to listen

Paul Tillich



***A mother understands
what a child does not say***

Jewish proverb

SESSION 3.4

THE COUNSELLING SESSION (60 MINUTES)



TRAINER INSTRUCTIONS

Methodologies: Large Group Discussion, Interactive Trainer Presentation, Small Group Work, Brainstorming

Step 1: Begin the discussion by asking participants to reflect on previous counselling sessions, and to brainstorm about the different phases of a counselling session.

Ask participants:

- *How do you normally structure your counselling sessions?*
- *What do you do at the beginning of a session? Why?*
- *Then what happens next during the session?*
- *How do you normally end your counselling sessions?*

Review the 4 main phases of any counselling session, filling in using the content below.

Step 2: Write **“1. Establish the Relationship”** on flip chart. Ask participants to discuss the ways they establish relationships with their clients at the beginning of a counselling session. Ask what challenges they face. Reiterate the importance of this stage in building trust and rapport with the client, which will set the stage for the entire counselling session.

Review the ways that a lay counsellor can establish a relationship with the client (e.g. ensuring privacy, introductions, explaining confidentiality, opening with a question), using the content below, and recording key points on flip chart. Ask participants to turn to the person next to them and to role play the beginning of a counselling session, establishing a relationship with the client. Ask some pairs to perform their role play in front of the large group and discuss.

Step 3: Write **“2. Understand the Client’s Problem”** on flip chart and explain that this is the 2nd phase of a counselling session. Ask participants what they can do to understand the client’s problems and issues. Write responses on flip chart and fill in using the content below.

Step 4: Write **“3. Support the Client’s Decision-Making”** on flip chart. Ask participants how lay counsellors can best support a client’s decision-making during the counselling session. Record responses on flip chart and fill in using the content below. Reiterate that the lay counsellor’s role is to support the client to make her or his own decisions.

Step 5: Write “**4. End the Session**” on flip chart. Ask participants how lay counsellors should end a session and, drawing on their own experiences, why the end of the session is important. Record responses on flip chart and fill in using the content below. Reiterate the importance of closing the counselling session by summarizing, reviewing next steps, making referrals if needed, and setting up a return appointment.

Step 6: Note: The next activity and related content on helping clients solve problems is optional. Trainers should assess if participants are comfortable with the key counselling and communication skills, as well as the phases of a counselling session. If participants need more time to practice these skills, the content on problem solving can be postponed until a future training. Lead a large group brainstorming and discussion on the different steps in helping a client solve problems, including actual things the lay counsellor can say, using the content below.

Step 7: Summarize the session by reviewing the key phases of a counselling session and the importance of structuring counselling sessions in this way. Recap the ways lay counsellors can help clients solve problems if this content was covered during the session (Step 6).

KEY INFORMATION

4 Phases of a Counselling Session

1. Establishing the Relationship
2. Understanding the Problem
3. Supporting Decision-Making
4. Ending the Session

1. Establishing the Relationship

- The room should be a quiet place that has doors that close and where there will be no interruptions.
- Introduce yourself: Say your name and explain your role and the length of time you have together (i.e. half an hour or 45 minutes).
- Ask the client to introduce herself or himself.
- Explain that what is discussed will be kept confidential.
- Ways to begin a counselling session:
 - *Can you tell me why you came here today?*
 - *Where would you like to start?*

2. Understanding the Problem

- Let the client talk about the thoughts, feelings, and actions around her or his issues or problems.
- Use the 7 essential counselling skills.
- Help the client decide which issues or problems are the most important to talk about during the session.

3. Supporting Decision-Making

- Support the client to make her or his own decisions on next steps.
- The lay counsellor can help the client explore the options, but it is ultimately the client's decision to make.

4. Ending the Session

- Summarize what was discussed during the session.
- Review the client's next steps.
- Give the client a chance to ask questions.
- Make referrals, if needed.
- Discuss when the client will return and make sure she or he has an appointment.

STEPS IN PROBLEM SOLVING AND EXAMPLES OF WHAT THE LAY COUNSELLOR CAN SAY

UNDERSTANDING THE CLIENT'S PROBLEM

1. Help your client define the problem

- *What would you like to discuss today?*
- *What do you see as the main problem?*
- *How are things different from the way you want them to be?*
- *What are the challenges you are facing?*

2. Help your client analyze the problem

- *How does this problem affect you?*
- *How does it affect other people?*
- *How do you manage now?*
- *What do you think are the causes of the problem?*

SUPPORTING THE CLIENT WITH DECISION-MAKING

3. Help your client set goals

- *What do you want to see happen?*
- *What is your goal related to solving this problem?*

4. Help your client come up with solutions

- *What do you think are some solutions?*
- *What do you think are next steps that you could take?*
- *How have you managed similar situations in the past?*
- *How have other people you know managed similar situations in the past?*
- *Do you think these solutions are realistic for you?*
- *What do you think some of the challenges will be?*
- *What do you think some of the consequences will be?*

5. Summarize the session

- *We've talked about a lot today. But, we've identified your main problem as being...*
- *You have spoken about some ways that you can address the problem. Some of the solutions we talked about are...*
- *You suggested that you would try to doas a next step.*
- *I will check in with you at your next appointment to see how things are going. Or, you can always come back to talk anytime.*

6. During follow-up sessions: Continue to support your client to implement solutions and follow-up on how things are going

- *Tell me about how things are going for you now.*
- *What happened since we last talked?*
- *You should be very proud that you took these steps and tried to solve these problems.*
- *Tell me about how you approached the problem.*
- *What was the outcome?*
- *Did you get what you wanted?*
- *How do you feel now?*

SESSION 3.5

CLASSROOM PRACTICUM (145 MINUTES)



TRAINER INSTRUCTIONS

Methodologies: Review Exercise, Large Group Discussion, Small Group Work, Case Studies, Role Play,

Step 1: Note: Trainers should conduct a review exercise on the start of the 2nd day of training. The review exercise is included here in Session 3.5, but it may also be done before Session 3.4, depending on the training agenda and division of training days.

Lead participants through a review exercise to recap key information and skills learned on the previous training day. In the large group, take about 45-60 minutes to go through the 10 review questions/exercises below. Review any areas that require more practice.

Step 2: Break participants into small groups of 4. Refer the small groups to the case studies in the Participant Handouts. Ask each group to read all 4 case studies. Ask the groups to assign one person to play the role of the lay counsellor, one to play the role of the client, and the others to play the role of observers. Explain that each small group will go through each of the 4 case studies, with group members shifting roles so that each person has the chance to play the role of the lay counsellor.

Refer participants again to *Appendix 3A* and review the listening and learning skills checklist with participants, giving each participant an extra copy to use during the Practicum. The observers can use this checklist to observe and record the different skills demonstrated. The checklist can also be used for self-assessment and mentoring at any time after the training.

Step 3: Ask the groups to start their first role play. The client should spend 10 minutes talking to the lay counsellor about her concerns. The lay counsellor will practice as many of the listening and learning skills possible in the time given.

After 10 minutes, stop the exercise and ask the observers to provide feedback on each of the skills and techniques observed, using the checklist as a guide.

Ask the groups to change roles and move on to the second case study. Continue until all of the small groups have worked through each case study. The trainers should participate in the small groups if possible.

Step 4: Bring participants back to the large group and ask the groups to report on the things they saw the lay counsellor doing to improve his or her counselling. If time allows, ask some of the small groups to present one of their role plays.

Summarize by pointing out strengths observed and possible ways to improve listening and learning skills. Remind participants that improving counselling skills takes practice, as well as continuous self-exploration.

KEY INFORMATION

STATEMENTS AND QUESTIONS FOR REVIEW EXERCISE:

1. Why is non-verbal communication important?

What are some ways to show good non-verbal communication?

2. Why is active listening important?

What are some ways a lay counsellor can show she or he is actively listening to the client?

3. What is the difference between closed- and open-ended questions?

4. Change the following into open-ended questions:

- Do you use condoms?
- Did you take all of your medicines?
- Did you tell someone about your HIV test results?
- Do you have support at home to give the baby medicines?
- Are you having any side effects?
- Do you know you need to come back to the clinic in 4 weeks time?
- Did you get your CD4 test results?
- Are you breastfeeding?

5. Why is reflection important? What are some of the formulas for reflection?

6. Reflect back the following statements:

- I missed a lot of my pills this month and I feel hopeless.
- My boyfriend does not know my test results – I'm scared to tell him.
- I feel like a bad mother because my baby does not want to suckle from me.
- My husband would just get angry if I asked him to use a condom, so I am not going to ask.
- My husband thinks it's dangerous to give the baby medicines and I am afraid of disobeying him.
- I am worried because my mother-in-law will assume I am living with HIV if I don't give the baby herbs.

- I feel so happy that my baby is growing well.

7. What is the difference between showing empathy and showing sympathy?

8. How would you use reflection and show empathy if your client said the following:

- I am so dizzy and weak since I started taking these pills. I am going to stop.
- My milk looks so thin. I am worried it isn't enough for the baby.
- I am really scared to tell my boyfriend I have HIV.
- I will be so sad if my baby has HIV.
- I have to hide my medicines so it is hard for me to remember to take them at the right times.

9. What are the key parts or phases of a counselling session?

10. What are the steps in helping clients solve their own problems?

Give specific examples of what you might say for each step (optional).

CASE STUDY 1:

Mpho is at the ANC for the first time. She is 16 and lives with her aunt. Mpho is still in school, and just found out that she is pregnant and HIV positive. She is concerned that being pregnant and having HIV will mean giving up her dream of becoming a nurse.

CASE STUDY 2:

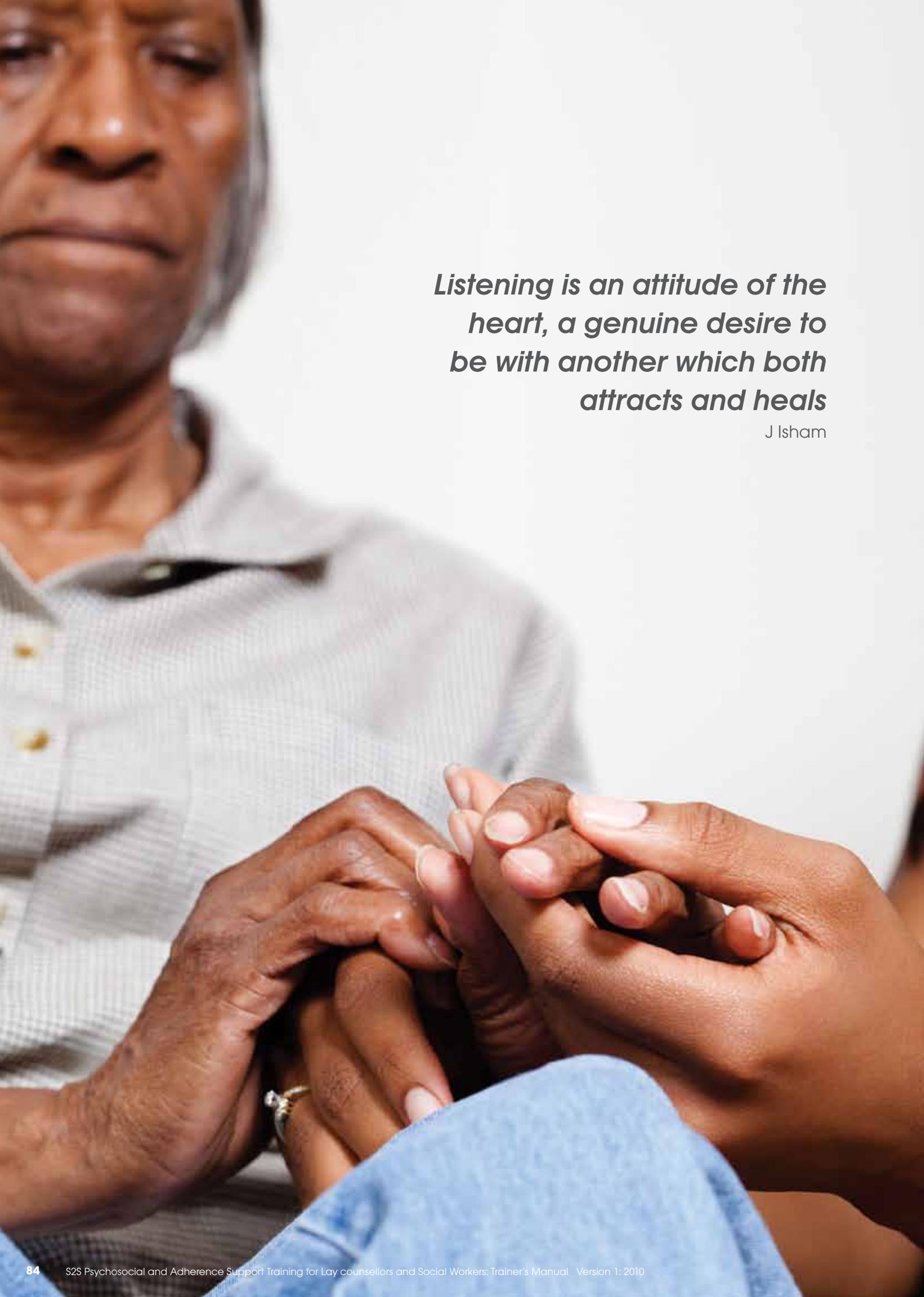
Puleng is pregnant with her first baby and has found out she has HIV. Puleng's husband is the boss of the house. She says she is so frightened that her husband might find out when he sees the medicines from the clinic.

CASE STUDY 3:

Dineo is enrolled in the PMTCT programme and started taking ART about 4 months ago. She starts crying because she was not able to get enough money to pay for the bus to the clinic last month, so she has stopped taking her ARVs. Dineo is very worried because she has no job, no money, and now she is feeling unwell.

CASE STUDY 4:

Lerato is living with HIV. She is enrolled in the PMTCT programme and had her second child about 7 weeks ago. Her first child is HIV negative. She comes to the clinic today to get her new baby tested for HIV. She is very worried that the baby is HIV infected because he is sick a lot of the time.



***Listening is an attitude of the
heart, a genuine desire to
be with another which both
attracts and heals***

J Isham

SESSION 3.6

MODULE SUMMARY AND EVALUATION (15 MINUTES)



TRAINER INSTRUCTIONS

Methodologies: Large Group Discussion, Interactive Trainer Presentation

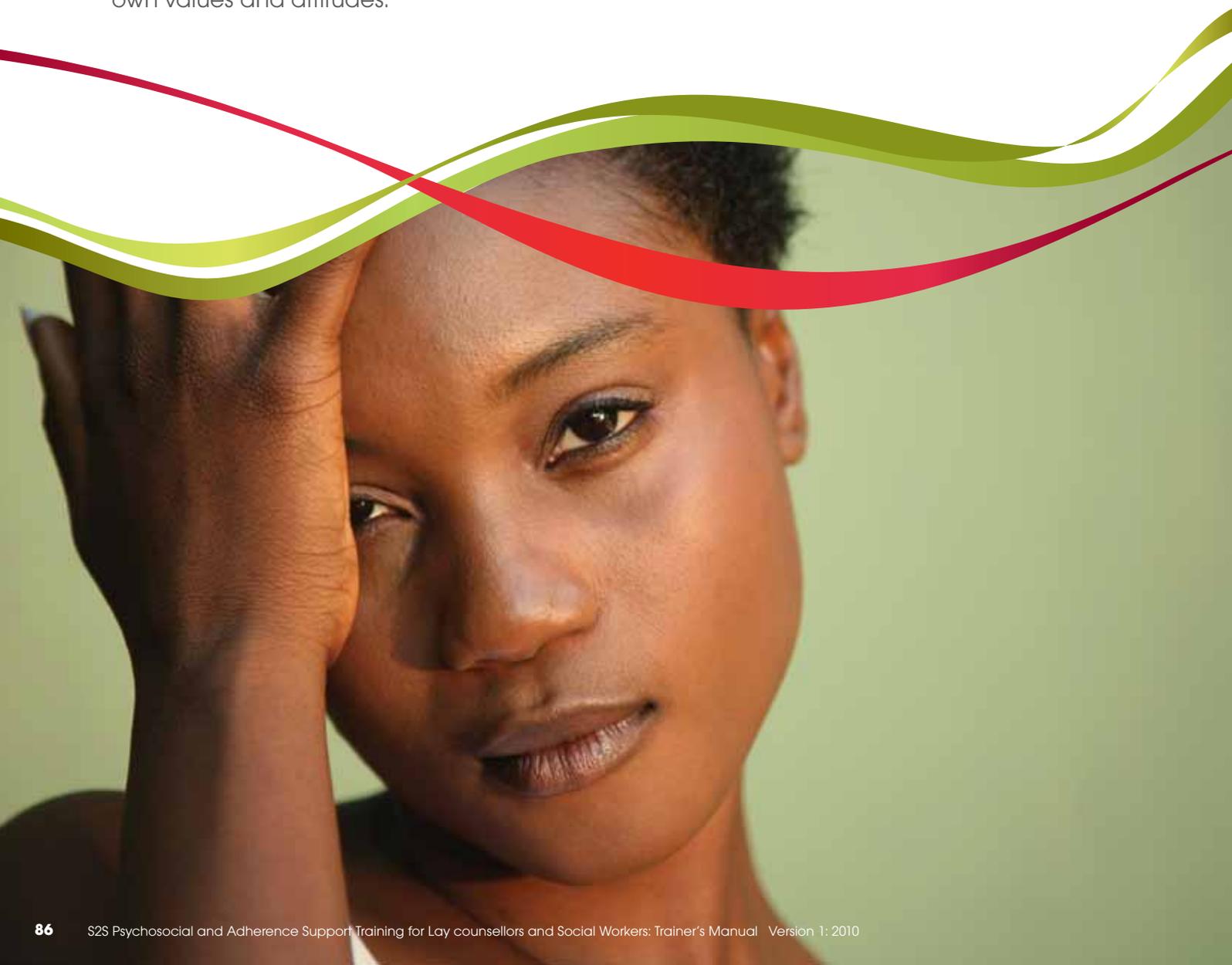
- Step 1:** Ask participants what they think are the key points of this Module. What information will they take away from the Module?
- Step 2:** Summarize the key points of the Module using participant feedback and the content below. Review the learning objectives with participants and make sure all are confident with their skills and knowledge in these areas.
- Step 3:** Ask if there are any questions or clarifications.
- Step 4:** Ask each participant to share with the group one thing he or she will do differently in his or her work as a lay counsellor, based on the information and skills learned in this Module.
- Step 5:** Hand out a Module evaluation form to each participant (see *Appendix 3B*), and ask that they take about 5 minutes to fill it out and to return it to the trainers. Remind participants that they do not need to put their name on the form.



THE KEY POINTS OF THIS MODULE INCLUDED:

- Our own attitudes, values and prejudices should not be a part of communication and counselling with clients and other community members.
- Counselling is a way of working with people to understand how they feel and of helping them decide what they think is best to do in their situation.
- Lay counsellors are not responsible for solving all of the client's problems.
- The role of lay counsellors is to support and assist the client's decision-making process.
- There can be many challenges to providing quality counselling in PMTCT and ART clinics, including lack of time and lack of private counselling space.
- It is important for clients to know that what they say will be kept private. Lay counsellors and social workers should practice shared confidentiality.
- Lay counsellors and social workers should work with the multidisciplinary care team to ensure that there is private counselling space available and that counselling sessions are not interrupted for any reason.

- These are the 7 key listening and learning skills lay counsellors and social workers should always use:
 - Use helpful non-verbal communication.
 - Actively listen and show interest in the client.
 - Ask open-ended questions.
 - Reflect back what the client is saying.
 - Empathize - show that you understand how the client feels.
 - Avoid words that sound judging.
 - Help the client set goals and summarize each counselling session.
- There are 4 main phases of a counselling session:
 - Establishing the relationship.
 - Understanding the problem.
 - Supporting decision-making.
 - Ending the session.
- Lay counsellors can work with clients to define and analyze their problems, set goals, and come up with realistic solutions. Lay counsellors can help clients by summarizing next steps and following up at the next clinic visits.
- Improving counselling skills takes practice, as well as continuous self-exploration of our own values and attitudes.



APPENDIX 3A

COUNSELLING AND COMMUNICATION CHECKLIST

APPENDIX 3A:

COUNSELLING AND COMMUNICATION CHECKLIST

SKILL	SPECIFIC STRATEGIES, STATEMENTS, BEHAVIOURS	TICK
Establish a relationship with the client	• Ensure privacy (make sure others cannot see or hear).	
	• Introduce yourself (name and role).	
	• Ask the client to introduce herself (or himself) to you.	
	• Ensure client about confidentiality / explain shared confidentiality	
	• Start the session with an open-ended question (" <i>Where would you like to start?</i> " or " <i>Tell me more about why you came today.</i> ")	
SKILL 1: Use helpful non-verbal communication	• Make eye contact.	
	• Face the person (sit next to her or him) and be relaxed and open with posture.	
	• Use good body language (nod, lean forward, etc.).	
	• Smile.	
	• Do not look at your watch, the clock or anything other than the client.	
	• Do not write during the session.	
	• Other (specify)	
SKILL 2: Actively listen and show interest in your client	• Nod and smile. Use encouraging responses (such as " <i>yes,</i> " " <i>okay</i> " and " <i>mm-hmm</i> ").	
	• Use a calm tone of voice that is not directive.	
	• Allow the client to express emotions.	
	• Do not interrupt.	
	• Other (specify)	
SKILL 3: Ask open-ended questions	• Use open-ended questions to get more information.	
	• Ask questions that show interest, care and concern.	
	• Other (specify)	
SKILL 4: Reflect back what your client is saying	• Reflect emotional responses back to the client.	
	• Other (specify)	
SKILL 5: Show empathy, not sympathy	• Demonstrate empathy: show an understanding of how the client feels.	
	• Avoid sympathy.	
	• Other (specify)	
SKILL 6: Avoid judging words	• Avoid judging words such as " <i>bad,</i> " " <i>proper,</i> " " <i>right,</i> " " <i>wrong,</i> " etc.	
	• Use words that build confidence and give support (e.g., recognize and praise what a client is doing right).	
	• Other (specify)	
SKILL 7: Help your client set goals and summarize each counselling session	• Work with the client to come up with realistic "next steps."	
	• Summarize the main points of the counselling session.	
	• Make a next appointment date with the client and reassure her or him that you, or someone else at the clinic, are always available.	

Note: This checklist was adapted from: WHO & CDC. (2008) Prevention of Mother-to-Child Transmission of HIV Generic Training Package: Trainer Manual.

APPENDIX 3B

MODULE 3 EVALUATION FORM

APPENDIX 3B:

MODULE 3 EVALUATION FORM

Name (optional): _____ Health Facility: _____ Position: _____

Please note the following statements on a scale of 1 to 5:

	 Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	 Strongly Agree
1. The module objectives were clear	1	2	3	4	5
2. This module met my expectations	1	2	3	4	5
3. The technical level of this module was appropriate	1	2	3	4	5
4. The pace of speed of this module was appropriate	1	2	3	4	5
5. The facilitators were engaging and informative	1	2	3	4	5
6. The information I learned in this module will be useful to my work	1	2	3	4	5

How helpful were each of the workshop sessions to you and your work?

You can write extra comments on the back.

	 Not Helpful				 Very Helpful
Communication and Counselling Basics	1	2	3	4	5
Listening and Learning Skills # 1 - 3	1	2	3	4	5
Listening and Learning Skills # 4 - 7	1	2	3	4	5
The Counselling Session	1	2	3	4	5
Classroom Practicum	1	2	3	4	5

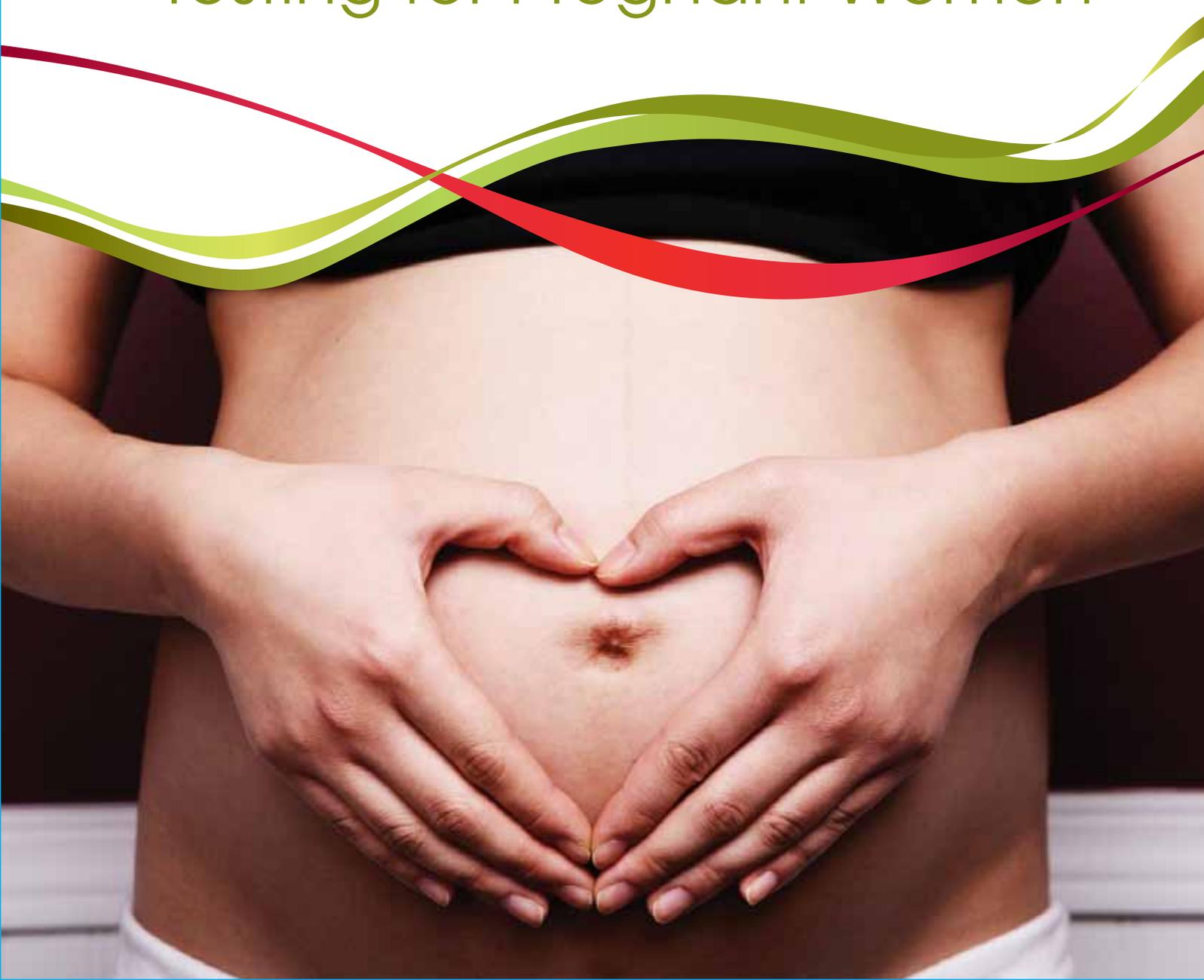
What was the BEST THING about this Module?

What was NOT USEFUL about this Module?

Do you have other comments (use the back of the page if needed)?

MODULE 4

Improving HIV Counselling & Testing for Pregnant Women



MODULE 4

Improving HIV Counselling and Testing for Pregnant Women



CONTENT

- Session 4.1:** The HIV Counselling and Testing Process
- Session 4.2:** Conducting the Group Information Session
- Session 4.3:** Conducting the Individual Information Session and Obtaining Informed Consent
- Session 4.4:** Providing Post-Test Counselling for Pregnant Women
- Session 4.5:** Module Summary and Evaluation



DURATION

310 minutes (5 hours, 10 minutes)



LEARNING OBJECTIVES

By the end of this Module, participants will be able to:

- Recall and improve upon skills learned in previous HIV counselling and testing trainings
- List the steps in provider-initiated HIV counselling and testing for pregnant women
- Counsel a group information session on HIV testing and PMTCT
- Conduct an individual pre-test information session
- Obtain verbal consent for HIV testing and provide follow-up counselling for women who decline testing
- Conduct post-test counselling with pregnant women who test negative, using a counselling checklist
- Conduct post-test counselling with pregnant women who test positive, using a counselling checklist



PREVIOUS TRAINING/KNOWLEDGE REQUIRED FOR THIS MODULE

- Basic knowledge about PMTCT protocols and guidelines
- Experience in HIV counselling and testing (e.g., VCT and PICT), PMTCT, and ARV/ART education/counselling
- Completion of Modules 1-3 of this lay counsellor training curriculum



METHODOLOGIES:

- Interactive Trainer Presentation
- Brainstorming
- Large Group Discussion
- Small Group Work
- Role Play
- Case Studies



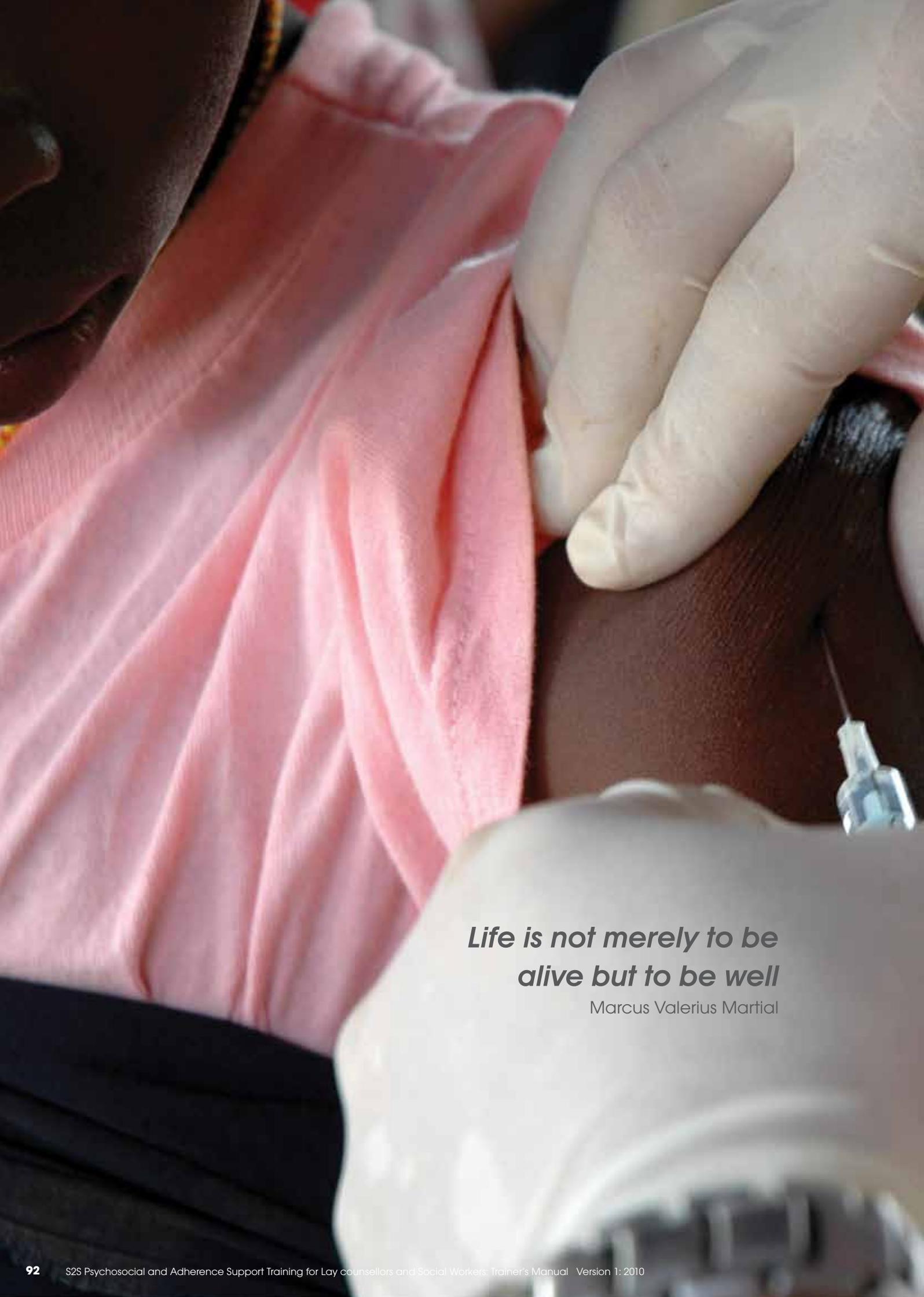
MATERIALS NEEDED

- Flip chart and stand
- Markers/Khoki's
- Tape or Bostik
- Copies of *Appendix 4A, 4B* and *4C* for each participant
- Participant Handouts for Module 4 (to be inserted into the Participant Folder)



WORK FOR THE TRAINER TO DO IN ADVANCE

- Read through the entire Module and make sure you are familiar with the training methodologies and content.
- Write the Module learning objectives on flip chart or list them on a PowerPoint slide.
- Carefully review the case studies in Session 4.4.
- Review the HIV counselling and testing section of the National PMTCT Guidelines.
- Make a copy of *Appendices 4A, 4B, and 4C* for each participant.



***Life is not merely to be
alive but to be well***

Marcus Valerius Martial

SESSION 4.1

THE HIV COUNSELLING AND TESTING PROCESS (40 MINUTES)



TRAINER INSTRUCTIONS

Methodologies: Interactive Trainer Presentation, Brainstorming, Large Group Discussion

Step 1: Review the Module learning objectives and ask if there are any questions.

Step 2: First, ask participants to brainstorm what is meant by the phrase, “**provider-initiated counselling and testing**” and how this applies to pregnant women. Discuss the definition and fill in, as needed, using the content below. Stress that HIV counselling and testing is a routine part of antenatal care for all women, unless they specifically opt out of testing.

Step 3: Next, ask participants to list the steps in HIV counselling and testing for pregnant women. Record responses on flip chart and fill in, as needed, using the content below. Refer participants to the Figure summarizing the steps in the Participant Handouts.

Step 4: Ask participants to get into groups of 3 and to discuss the following questions (you may want to write them on flip chart or on a slide):

- *What have been your experiences with HIV counselling and testing at your clinic?*
- *What are some of the challenges conducting quality HIV counselling and testing?*
- *What are some of the solutions to these challenges?*

After about 15 minutes, reconvene the large group and discuss the above questions.

Step 5: Close the session by telling participants that we will review all of the HIV counselling and testing steps in this Module in order to refresh and improve our skills. Tell participants that while lay counsellors are being trained to conduct the actual rapid HIV test on clients, these skills will not be covered in this Module. Other trainings will be held specifically on the rapid testing procedure.

KEY INFORMATION

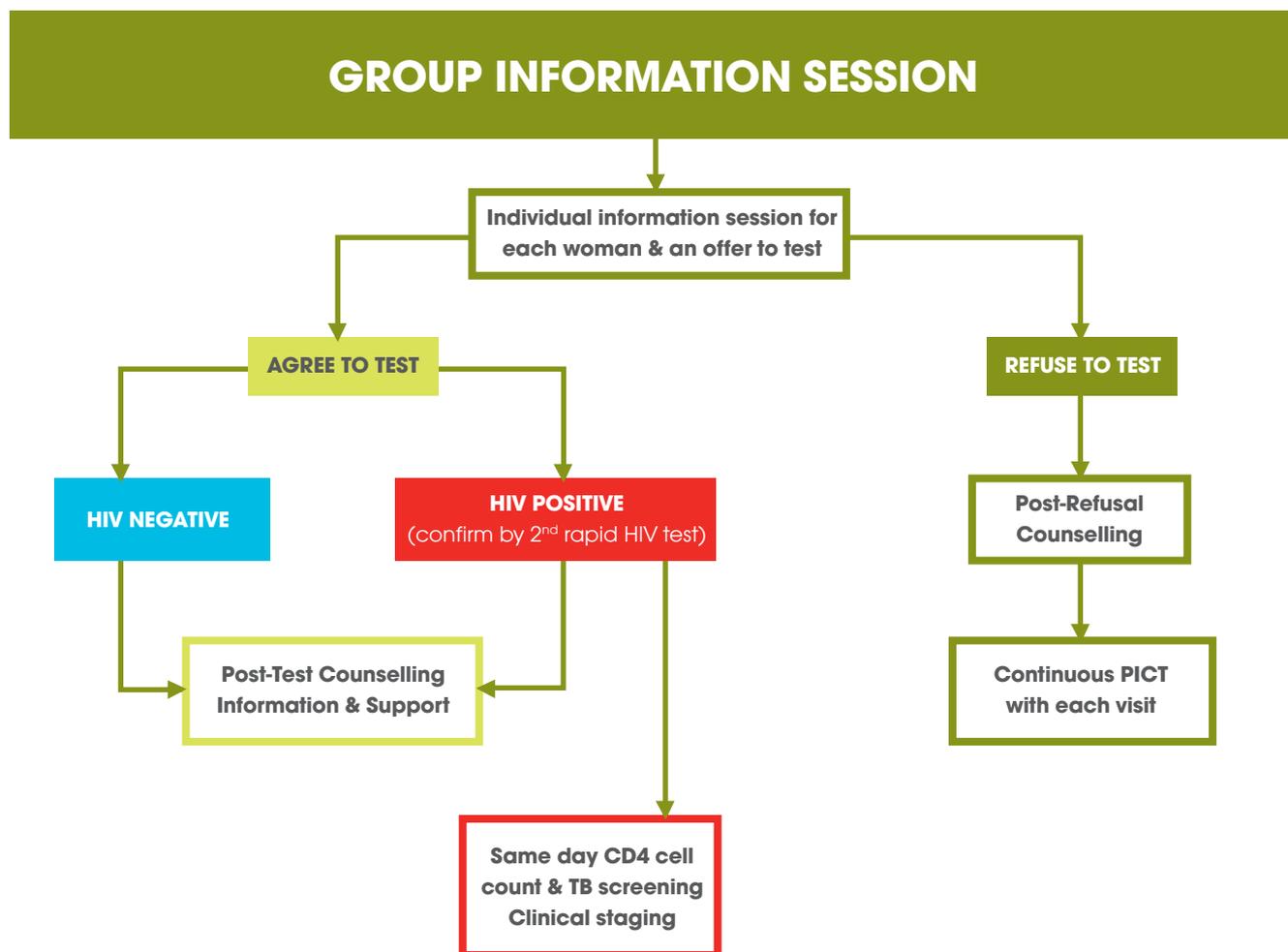
The Department of Health gives clear recommendations on HIV counselling and testing for pregnant women in the 2010 Guidelines for PMTCT.

- HIV counselling and testing should be provider-initiated.
- This means that ALL women attending ANC (both first-time attendees coming to book and women attending follow-up visits) should be given routine information about HIV testing and the PMTCT programme (by a lay counsellor, nurse, social worker, etc.).
- Women may “opt out” or refuse an HIV test. Unless a woman specifically refuses to be tested for HIV, HIV counselling and testing should be considered a routine part of ANC care.

These are the steps in the HIV counselling and testing process for pregnant women:

1. All women are given routine information about HIV testing and the PMTCT programme.
2. Initial information on HIV and its transmission is given in a Group Information Session.
3. All women who have not previously been tested or those who require retesting meet with a lay counsellor, nurse, or midwife for a one-on-one Individual Information Session.
 - During this session, each woman is informed of the routine HIV testing procedure and then is offered an HIV test.
 - She is asked to give verbal consent to the testing.
 - She may refuse the HIV test (opt out).
 - Women who refuse (opt out) of HIV testing should be offered ongoing counselling to explore her reasons for this choice, to address misunderstandings, and to encourage her to reconsider her decision not to test – without applying pressure. These women should be offered routine HIV testing at their future clinic visits.
4. Information is offered before the testing procedure and counselling is offered after the test results are provided.
5. All women who test HIV positive should receive a 2nd confirmatory HIV test.
6. Post-test counselling should be offered to both HIV positive and HIV negative women.

Summary diagram of the provider-initiated counselling and testing process with pregnant women in South Africa:



Note: For more information, see: *Clinical guidelines: PMTCT (prevention of mother-to-child transmission)*, (2010). National Department of Health, South Africa; South African National AIDS Council.

*In prosperity, our friends
know us; in adversity, we
know our friends*

John Churton Collins



SESSION 4.2

CONDUCTING THE GROUP INFORMATION SESSION (75 MINUTES)



TRAINER INSTRUCTIONS

Methodologies: Large Group Discussion, Brainstorming, Interactive Trainer Presentation, Small Group Work, Role Play

Step 1: Spend about 15 minutes leading a large group discussion.

Ask participants to discuss how the group information sessions work at their clinics (who conducts the session, where does it take place? How often does it take place? etc.). Next, ask participants to share their experiences conducting the group education sessions with pregnant women (what is working well, what are the challenges, etc.).

Step 2: Ask participants to brainstorm the topics to be covered in the group education session. Record these on flip chart and fill in, as needed, using the content below (adapted from the National PMTCT guidelines). Refer participants to the group education session checklist in *Appendix 4A*. Lay counsellors should use this checklist as a guide when conducting group education sessions.

Step 3: Ask participants to think back to the counselling and communication skills they learned in Module 3. Ask them to brainstorm what the most important points are about communicating to groups. Fill in, as needed, using the content below on tips for communicating with groups.

Step 4: Break participants into groups of 5. Ask each group to prepare a group information session for pregnant women at the clinic. Remind participants that, as they prepare their session, they should use the checklist in *Appendix 4A* as well as the counselling and communication skills that have been discussed.

Step 5: After about 15 minutes, ask some of the small groups to role play their group information session. If time is short, one small group can start the session and another can pick up where they left off on the content. Encourage participants to use the group information session checklist as they observe the role plays. Discuss the group sessions, including what went well and what could have been done differently.

Step 6: Debrief the activity by asking participants:

- *How did it feel to speak in front of a group?*
- *What information did you find difficult to convey during the group session?*
- *What information do you think clients would have a hard time understanding?*
- *How can lay counsellors address these difficulties and make sure we give information clearly, in a way that clients can understand?*

KEY INFORMATION

Health care workers (including lay counsellors) should conduct a general group information session on HIV and PMTCT-related issues for ALL women coming for first or repeat ANC visits.

The group information session should include discussion of the following (see Appendix 4A):

- HIV basics, transmission, and prevention for individuals and couples
- HIV testing as a routine part of ANC and a necessary step for enrollment in the PMTCT programme
- Benefits of testing for the woman
 - Importance of early access to ART for the mother's own health and ARVs for PMTCT
 - Importance of knowing client's HIV status and CD4 count for clinical decision making
 - Importance of adherence to care and medicines
 - High maternal and infant mortality due to HIV/AIDS
 - PMTCT as a way to prevent maternal death and illness
- Benefits of testing for the fetus and infant
 - Information about MTCT and ways to reduce MTCT
 - PMTCT as a way to prevent infant and childhood death and illness
 - Ways to keep HIV exposed babies healthy, such as ARVs and CTX
 - Information on early infant diagnosis at 6 weeks and the benefits
 - Importance of adherence to care and medicines
- The testing process, including confidentiality
- Partner testing and discordance
- The PMTCT programme and having a safe pregnancy
- HIV and STI prevention and risk reduction

KEY SKILLS FOR SPEAKING TO GROUPS

While many of the good practices used in counselling can also be used in group education sessions, there are a few additional points to remember when speaking in front of a group, such as during a group information session:

- Be sure to plan the group session ahead of time and practice what you are going to say.
- Use notes or a checklist to remember the key points and the order of topics you will discuss with the group.
- It is best to conduct group sessions in a quiet room that offers some privacy. They should not be conducted in waiting areas or other public areas if possible.
- Do not stand behind a desk or other furniture.
- Encourage participants to sit in a semi-circle to make it more comfortable to talk and less like a classroom. The person leading the session should be part of the semi-circle. Make sure you can make eye contact with everyone and that no one is staring at your back.
- Speak loudly enough so everyone can hear you clearly, but so that you are not shouting.
- Start by introducing yourself and explaining the goals and content areas of your discussion; ask if there are any questions before starting.
- Interact with participants and engage them by moving around the room, asking questions, and asking people to share personal stories/concerns, etc. if they feel comfortable. Sharing a personal anecdote (about yourself) often helps make others feel comfortable too.
- Acknowledge that the people attending will know something about the topic being discussed. Encourage them to share what they know and to use this as an opportunity to identify and correct any misconceptions.
- 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 everyone's personal experiences, questions, and concerns are important.
- Use visual aids, if available, and avoid lecturing.
- Encourage participants to speak with you in private afterward if they have concerns they do not want to share with the group.
- At the end, ask group participants to summarize what they have learned and actions they will take following the session.
- Always leave time for questions and review anything that was not understood completely.



***Nothing in life is to be feared.
It is only to be understood***

Marie Curie

SESSION 4.3

CONDUCTING THE INDIVIDUAL INFORMATION SESSION AND OBTAINING INFORMED CONSENT (60 MINUTES)



TRAINER INSTRUCTIONS

Methodologies: Brainstorming, Interactive Trainer Presentation, Large Group Discussion, Role Play

Step 1: Ask participants to brainstorm why they think an individual information session needs to be conducted with each woman after the group information session. Record responses on flip chart and discuss the importance and purpose of the individual session, using the content below.

Step 2: Ask participants to turn to the person next to him or her and to spend about 10 minutes discussing the methods they use to conduct the individual information session with their clients, using these questions as a guide (you may want to write the questions on flip chart or on a slide):

- *Where do you conduct the individual session?*
- *How do you start the individual session? Then what comes next?*
- *What do you talk about in the individual session with your clients?*
- *What are some of the challenges you have faced conducting individual information sessions with clients?*
- *What do you think are some solutions to these challenges?*

Reconvene the large group and ask participants to share key points of their small group discussions. Review the checklist in *Appendix 4A* again, and remind participants that the information covered in the group information session should be touched upon again in the individual session to ensure understanding, to answer specific questions, and to clarify any misunderstandings the client may have.

Step 3: Ask participants how lay counsellors obtain consent for HIV testing and what their experiences have been with obtaining consent. Use these questions to guide the discussion:

- *What are the specific questions that you can ask clients about consent to testing?*
- *Where do you document that the client has given consent for testing?*
- *Why might a client decline testing?*
- *What do you do when a client declines testing?*

Lead a discussion on consent for testing and what to do if a client declines testing, using the information below.

Step 4: Ask participants to form groups of 3 and to spend 10 minutes role playing how they would conduct the individual information session with a client, rotating so

that each person has a chance to play the role of lay counsellor, client, and observer. Remind participants to use the 7 key counselling and communication skills from Module 3. For the first role play, assume that the client gives consent for testing. Then, after about 10 minutes, ask the pairs to switch roles and to have the new lay counsellor conduct an individual information session with the client. This time the client will refuse testing. After 10 more minutes, ask the small groups to switch roles again, this time assuming that the client consents to testing.

Step 5: Bring the large group back together and ask some of the pairs to perform their role play. Encourage the group to comment on what was done well and what could have been differently in the role plays.

Step 6: Close the session by reviewing the steps lay counsellors should take when a client declines HIV testing. Remind participants about the importance of the individual pre-test information session and the importance of providing client-centred and compassionate information and counselling to each woman that comes into the clinic

KEY INFORMATION

Conducting the individual information session:

Following the group education session, an individual information session should be conducted with all pregnant women.

This individual session should include:

- An assessment of understanding of the information provided in the group information session
- Answers to any remaining questions the client has and clarification of misunderstandings
- A discussion of the way forward and next steps, including PMTCT care if positive
- Obtaining verbal consent for HIV testing
- Providing post-refusal counselling to clients that opt out of testing (see below)

What to do if your client declines testing:

Clients are entitled to decline HIV testing. Although HIV testing is strongly recommended for pregnant women, the clients' decision should be respected. If the HIV test is declined, the lay counsellor should provide additional, individual counselling to:

- Explore her concerns about testing
- Encourage her to reconsider testing
- Refer to the social worker for further counselling (remember to discuss the referral with the client prior to setting up an appointment)

Exploratory questions to consider include:

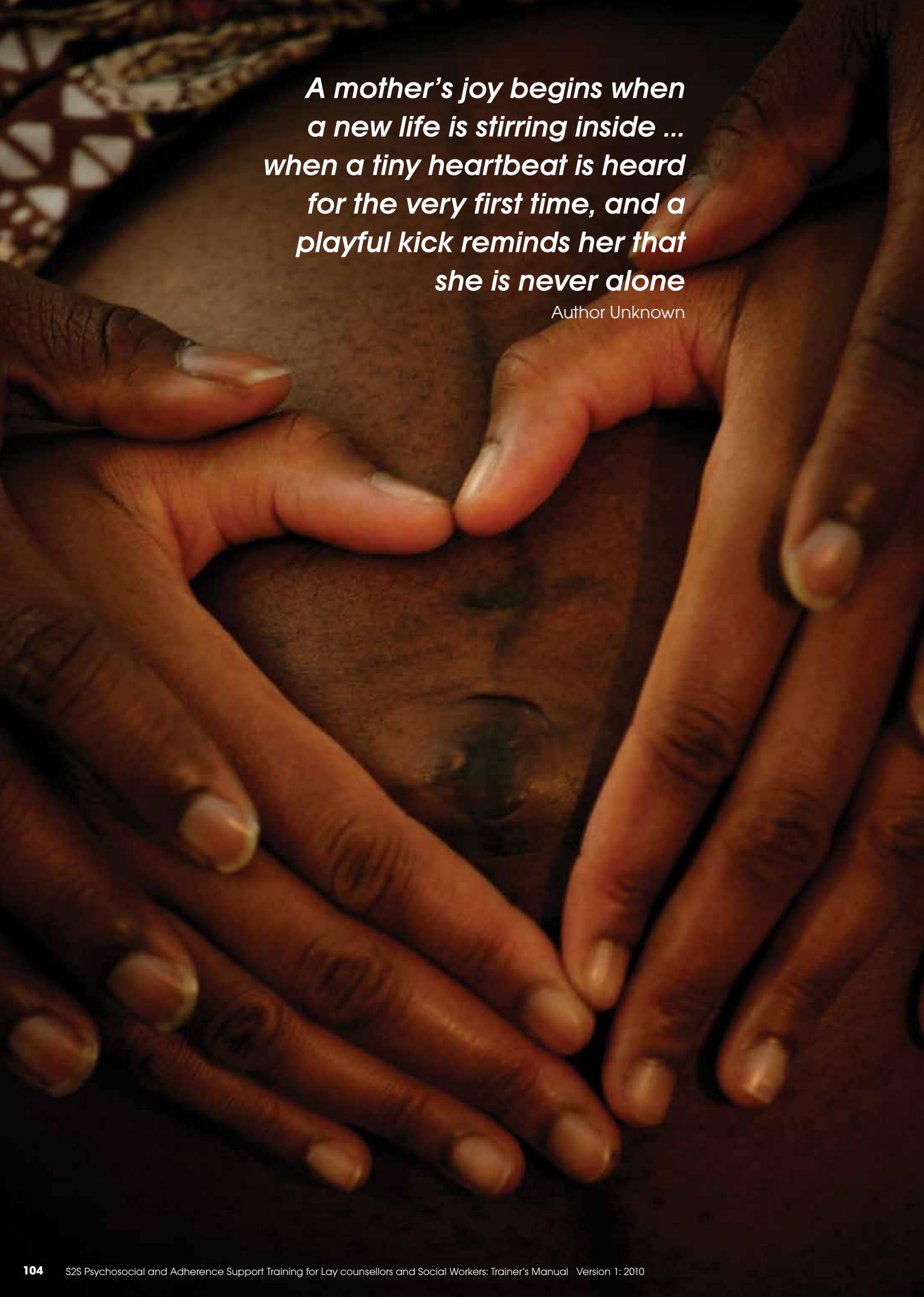
- *Would you be willing to share your reasons for deciding not to have an HIV test today?*
- *What do you know about the benefits of knowing your HIV status – both for yourself and your baby?*
- *What would have to change before you would accept to have an HIV test?*

Continue providing individual information and counselling. If HIV testing is still declined:

- Let the client know your door is open, and that she can decide to have an HIV test anytime.
- Provide written information materials for her to take home, if available.
- Arrange for further counselling at her next visit and offer HIV counselling and testing again.
- Explore referral to the social worker, when needed.

REMEMBER: Stay positive during the individual session and make the client feel that you are accepting and on her side!





***A mother's joy begins when
a new life is stirring inside ...
when a tiny heartbeat is heard
for the very first time, and a
playful kick reminds her that
she is never alone***

Author Unknown

SESSION 4.4

PROVIDING POST-TEST COUNSELLING FOR PREGNANT WOMEN (120 MINUTES)



TRAINER INSTRUCTIONS

Methodologies: Large Group Discussion, Brainstorming, Interactive Trainer Presentation, Case Studies, Role Play

Step 1: Start the Session by asking participants to share some of their experiences providing post-test counselling to clients. Use these questions as a guide:

- *What is the process for post-test counselling in your clinic? Who? Where? How?*
- *Why is post-test counselling important for all pregnant clients? What about specifically for HIV positive clients? HIV negative clients?*
- *What are some of the challenges you or other lay counsellors face providing quality post-test counselling? What are some solutions to these challenges?*

Step 2: Ask participants to brainstorm about some of the key strategies for providing post-test counselling to all clients. Give an example to get the discussion started. Record responses on flip chart and fill in, as needed, using the content below.

Step 3: Ask participants to think about post-test counselling for HIV negative clients. Ask them to brainstorm the key topics that should be covered in a post-test session with a client who has just tested HIV negative. Record responses on flip chart. Refer participants to *Appendix 4B* (the first of the 2 checklists). Explain that this is a checklist lay counsellors can use to guide their post-test counselling sessions with HIV negative women. Go through the key points to cover during post-test counselling with an HIV negative client and, for each key topic area, ask participants why this is important to cover and also ask them to brainstorm what they would actually say to a client about this topic.

Step 4: Ask participants to think about post-test counselling for HIV positive clients. Ask participants to brainstorm the key topics that should be covered in a post-test session with a client who has just tested HIV positive. Record responses on flipchart. Remind participants that post-test counselling is not a one-time event – often, clients need time to reflect and cope and should return for follow-up counselling sessions.

Refer participants to *Appendix 4B* (the second of the 2 checklists). Explain that this is a checklist lay counsellors can use to guide their post-test counselling sessions with HIV positive women. Go through the key points to cover during

post-test counselling with an HIV positive client and, for each key topic area, ask participants why this is important to cover and also ask them to brainstorm what they would actually say to a client about this topic.

Step 5: Discuss how lay counsellors can use the checklists to guide their post-test sessions. Remind them that counselling is always a two-way conversation and that each woman is unique, so each session will be different. Remind participants to always use the 7 key counselling and communication skills from Module 3 in all post-test counselling sessions.

Step 6: Break participants into small groups of 4. Refer to the case studies written in the Participant Folder. Spend a few minutes discussing how participants should use and expand upon the case studies during this exercise (and throughout the training when case studies are used), bringing in their own experiences working with clients. Remind participants that the case studies are to be used as a guide for the role play, encourage creativity while working on case studies as they role play.

Ask the groups to assign one person to play the role of a lay counsellor, one the role of the client, and the others the role of observer. Explain that each small group will go through each of the 4 post-test counselling case studies, with group members shifting roles so that each person has the chance to play the role of the lay counsellor.

One of the observers should use the post-test counselling checklists in *Appendix 4B* to ensure that all key counselling messages are covered. The other observer should use the Counselling and Communication checklist in *Appendix 4C* to ensure that the person playing the lay counsellor is using the key skills covered in Module 3. The trainers should join the small groups to provide guidance and feedback.

Step 7: Ask the small groups to role play the first case study. After about 10 minutes, ask the observers to give feedback (on the content and key messages covered as well as on counselling and communication skills used in the role play). Ask the groups to change roles and move on to the second case study. Continue until all of the small groups have worked through each case study.

Step 8: If time allows, some groups can also do a role play of their case study for the large group. Go over the key points and considerations of each case study as a large group and be sure to answer any questions.

Allow participants time to give feedback, using these questions:

- *What are the main issues for this client?*
- *What did the lay counsellor do well?*
- *What other points do you think the lay counsellor could have discussed with the client?*
- *How did the lay counsellor use the checklist during the role play? What was easy? What was challenging?*

Close the session by reminding participants that post-test counselling is one of the most important times to help mothers understand HIV and PMTCT and the steps they can take to either stay HIV negative or to live positively, take care of their own health, get the care and treatment they need, and prevent MTCT.

KEY INFORMATION

ALL clients, regardless of their test result, must receive individual post-test counselling

Post-test counselling for ALL clients includes

- Providing HIV test results as soon as possible after testing
- Post-test counselling should always be done in an individual session and never in a group
- Ensuring visual and auditory privacy and no interruptions in the counselling room
- Giving the test results clearly and in a way that does not cause the client to be afraid or anxious
- Giving the client time to react to the test results and to explore her feelings about the result, whether positive or negative
- Providing information on having a healthy pregnancy
- Encouraging partner testing and testing of children at home
- Discussing support systems for the mother and baby
- Encouraging the client to ask questions
- Providing referrals and take-home information, if needed
- Offering ongoing and follow-up counselling at any time

For specific key post-test counselling messages for HIV positive and HIV negative women, see the checklists in Appendix 4B.

POST-TEST COUNSELLING CASE STUDIES

CASE STUDY 1:

Thandi has come to the clinic for her first ANC appointment. She is 20-years old and has a steady boyfriend. During the individual information session, you learn that this is her first child and that she is looking forward to having a baby. She consented to HIV counselling and testing and her results are negative. Provide post-test counselling to Thandi.

CASE STUDY 2:

Lucy has come to make a booking at the ANC clinic. She is about 3 months pregnant and this will be her 3rd child. She is married, but her husband is working in another province and only comes home every 2 months. During the individual information session, you notice that Lucy is very concerned about her HIV status and that said she isn't going to talk about the test with her husband. Lucy consents to having an HIV test and her results are positive. Provide post-test counselling to Lucy.

CASE STUDY 3:

Salome is 6 months pregnant. She comes for her routine ANC visit. At first, Salome refused to be tested for HIV, but now she says she wants to have the test because she is worried that her boyfriend is not being faithful during her pregnancy. She has left him and is now living with her sister. Her test results are positive. Provide post-test counselling to Salome.

CASE STUDY 4:

Prudence is a 30-year old woman from a rural area quite far away. She comes to make a booking at the ANC clinic. This will be her 4th child. In the individual information session, she tells you she is worried about her own health and that she is feeling badly during this pregnancy – more so than during her last 3 pregnancies. She wonders how she will be able to take care of another child and says she does not have much help at home. When she first came in and participated in the information sessions, Prudence did not know very much about HIV or PMTCT. Prudence consents to an HIV test, which is positive. Provide post-test counselling to Prudence.

SESSION 4.5

MODULE SUMMARY AND EVALUATION (15 MINUTES)



TRAINER INSTRUCTIONS

Methodologies: Large Group Discussion, Interactive Trainer Presentation,

- Step 1:** Ask participants what they think are the key points of this Module. What information will they take away from the Module?
- Step 2:** Summarize the key points of the Module using participant feedback and the content below. Review the learning objectives with participants and make sure all are confident with their skills and knowledge in these areas.
- Step 3:** Ask if there are any questions or clarifications.
- Step 4:** Ask each participant to share with the group one thing he or she will do differently in his or her work as a lay counsellor or social worker, based on the information and skills learned in this Module.
- Step 5:** Hand out a Module evaluation form to each participant (see *Appendix 4D*), and ask that they take about 5 minutes to fill it out and to return it to the trainers. Remind participants that they do not need to put their name on the form.



THE KEY POINTS OF THIS MODULE INCLUDE:

- HIV counselling and testing for ALL pregnant women should be provider-initiated, and should therefore be considered a routine part of ANC unless a client decides to opt out.
- The new national PMTCT guidelines state that verbal consent needs to be obtained from the client for HIV testing.
- The decision of women to opt out of HIV testing should be respected; however, these women should also be offered follow-up counselling.
- The group information session on HIV testing and PMTCT offers an important opportunity to provide pregnant women with specific information before the individual pre-test information session.
- Lay counsellors and social workers should practice the special skills needed to speak effectively in front of groups.

- The individual pre-test information session provides an opportunity to begin to build a relationship with the client and prepares both the client and lay counsellor for the post-test session.
- When counselling, it is always important to use the 7 key counselling and communication skills from Module 3.
- Lay counsellors should make sure there is enough time to conduct post-test counselling, using a counselling checklist, with all pregnant women regardless of their test's outcome.
- It is important to provide information and support to clients who test negative in order to help them reduce their HIV risk and to help them keep themselves and their families healthy
- The post-test counselling session for women who test positive should include information on PMTCT and the ways they can keep themselves and their babies healthy throughout the PMTCT care spectrum. This information may need to be revisited at various stages of the spectrum.

APPENDIX 4A

GROUP AND INDIVIDUAL INFORMATION SESSION CHECKLIST

APPENDIX 4A

GROUP AND INDIVIDUAL INFORMATION SESSION CHECKLIST

Client's Name: _____ Client's File# _____

TOPIC	TICK
1. Introduce yourself and give an overview of the session	
2. Review HIV basics, transmission, and prevention	
- What is HIV, what is AIDS, how HIV affects the body, etc.	
- Modes of HIV transmission and prevention, including MTCT and PMTCT	
3. Talk about benefits of HIV testing	
- Everyone should learn their HIV status, especially pregnant women	
- HIV testing is a part of routine care and offered to all pregnant women	
- If a pregnant woman has HIV, she can pass it to her baby	
- There are many things we can do to keep mothers living with HIV healthy and to lower the chances of babies becoming HIV infected, including taking ARVs and ART.	
- Without care and treatment, HIV/AIDS can lead to maternal and infant illness and even death. With PMTCT services and medicines, we can help prevent this.	
4. Explain the HIV testing process	
- Confidentiality and shared confidentiality	
- Client's right to refuse, will not affect care	
- Process of HIV testing	
- Meaning of test results	
5. Talk about discordance and partner testing	
- One partner can be living with HIV while the other is HIV negative	
- Encourage partner testing and couples counselling	
6. Talk about HIV prevention and HIV/STI risk reduction	
- High risk of MTCT if she becomes HIV infected during pregnancy or breastfeeding	
- Practice safer sex (mutual faithfulness, always using condoms, abstinence)	
- Condoms, challenges to using condoms	
- STI prevention, signs, and treatment	
7. Talk about PMTCT and having a safe pregnancy	
- Ways to reduce MTCT, including getting CD4 results and early initiation of ART/ARVs	
- HIV testing and early treatment for herself, the baby, partner, and family members	
- Attend all antenatal care appointments and adhere to care and medicines	
- Deliver baby at a health facility	
- Exclusive breastfeeding (or formula) for 6 months or as long as possible up to 6 months. Then introducing complementary foods at 6 months.	
- Bring the baby back to the clinic for appointments (immunization, weighing, checkups)	
- Family planning to prevent or space future pregnancies	
8. (during individual education session) Offer the client an HIV test	
- If she agrees, obtain verbal consent and perform HIV test	
- If she refuses, encourage her to think about why and to come back if she has more questions or changes her mind; set up a return visit date	
9. Provide referrals for ongoing counselling or other support, as needed	
10. Ask if she has any questions or concerns	
11. Summarize the session and next steps	

APPENDIX 4B

POST-TEST COUNSELLING CHECKLISTS

POST-TEST COUNSELLING CHECKLIST FOR HIV POSITIVE PREGNANT WOMEN

Client's Name: _____ Client's File# _____

TOPIC	TICK
1. Provide test results and give client time to react, give emotional support	
2. Discuss PMTCT basics	
- Not all babies will become HIV infected	
- Can lower the chances that baby will be HIV infected by getting care at the clinic, taking ARVs, and safely feeding the baby	
3. Counsel on staying healthy and PMTCT during the pregnancy	
- Come back to the clinic for all appointments during pregnancy and after delivery	
- Importance of emotional support from family and friends, dealing with stigma	
- CD4 testing and meaning of results	
- Early initiation of ARVs for PMTCT or lifelong ART and importance of adherence	
- Disclosure - Who will she share the results with? When? How?	
- Partner testing, testing other children	
- Safer sex during and after pregnancy (mutual faithfulness, condoms, abstinence)	
- Preventing and early treatment of opportunistic infections, including TB screening	
- Nutrition and hygiene	
4. Counsel on safe delivery	
- Plan to deliver at a health facility	
- Tell the health care worker your HIV status and medicines you are taking	
- ARVs for mom and baby during labour and delivery	
5. Counsel on infant feeding and help her choose an appropriate feeding method	
- Exclusive breastfeeding for 6 months or as long as possible up to 6 months	
- Exclusive formula feeding for 6 months	
- Dangers of mixed feeding in the first 6 months	
- Avoid early weaning	
- Add complementary foods at 6 months	
6. Counsel on plans for her own and baby's care	
- Mom needs lifelong HIV care (and some will be on lifelong ART)	
- Importance of getting support from someone she trusts	
- Family planning	
- Bring the baby back to the clinic (immunization, weighing, checkups)	
- ARVs for baby, starting at birth; mom or baby on ARVs for duration of breastfeeding	
- Early infant diagnosis and CTX for baby at 6 weeks	
- Care and treatment if the baby is HIV infected	
7. Provide appropriate referrals and take-home information	
8. Ask if she has any questions or concerns she wants to discuss	
9. Summarize the session and next steps, including the next clinic appointment	

Notes:

Date of next counselling session/clinic appointment: _____

Lay counsellor's signature: _____ Date: _____

APPENDIX 4C

COUNSELLING AND COMMUNICATION CHECKLIST



APPENDIX 4C

COUNSELLING AND COMMUNICATION CHECKLIST

SKILL	SPECIFIC STRATEGIES, STATEMENTS, BEHAVIOURS	TICK
Establish a relationship with the client	• Ensure privacy (make sure others cannot see or hear).	
	• Introduce yourself (name and role).	
	• Ask the client to introduce herself (or himself) to you.	
	• Ensure client about confidentiality / explain shared confidentiality	
	• Start the session with an open-ended question (" <i>Where would you like to start?</i> " or " <i>Tell me more about why you came today.</i> ")	
SKILL 1: Use helpful non-verbal communication	• Make eye contact.	
	• Face the person (sit next to her or him) and be relaxed and open with posture.	
	• Use good body language (nod, lean forward, etc.).	
	• Smile.	
	• Do not look at your watch, the clock or anything other than the client.	
	• Do not write during the session.	
	• Other (specify)	
SKILL 2: Actively listen and show interest in your client	• Nod and smile. Use encouraging responses (such as " <i>yes,</i> " " <i>okay</i> " and " <i>mm-hmm</i> ").	
	• Use a calm tone of voice that is not directive.	
	• Allow the client to express emotions.	
	• Do not interrupt.	
	• Other (specify)	
SKILL 3: Ask open-ended questions	• Use open-ended questions to get more information.	
	• Ask questions that show interest, care and concern.	
	• Other (specify)	
SKILL 4: Reflect back what your client is saying	• Reflect emotional responses back to the client.	
	• Other (specify)	
SKILL 5: Show empathy, not sympathy	• Demonstrate empathy: show an understanding of how the client feels.	
	• Avoid sympathy.	
	• Other (specify)	
SKILL 6: Avoid judging words	• Avoid judging words such as " <i>bad,</i> " " <i>proper,</i> " " <i>right,</i> " " <i>wrong,</i> " etc.	
	• Use words that build confidence and give support (e.g., recognize and praise what a client is doing right).	
	• Other (specify)	
SKILL 7: Help your client set goals and summarize each counselling session	• Work with the client to come up with realistic "next steps."	
	• Summarize the main points of the counselling session.	
	• Make a next appointment date with the client and reassure her or him that you, or someone else at the clinic, are always available.	

APPENDIX 4D

MODULE 4 EVALUATION FORM



APPENDIX 4D

MODULE 4 EVALUATION FORM

Name (optional): _____ Health Facility: _____ Position: _____

Please note the following statements on a scale of 1 to 5:

	 Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	 Strongly Agree
1. The module objectives were clear	1	2	3	4	5
2. This module met my expectations	1	2	3	4	5
3. The technical level of this module was appropriate	1	2	3	4	5
4. The pace of speed of this module was appropriate	1	2	3	4	5
5. The facilitators were engaging and informative	1	2	3	4	5
6. The information I learned in this module will be useful to my work	1	2	3	4	5

How helpful were each of the workshop sessions to you and your work?

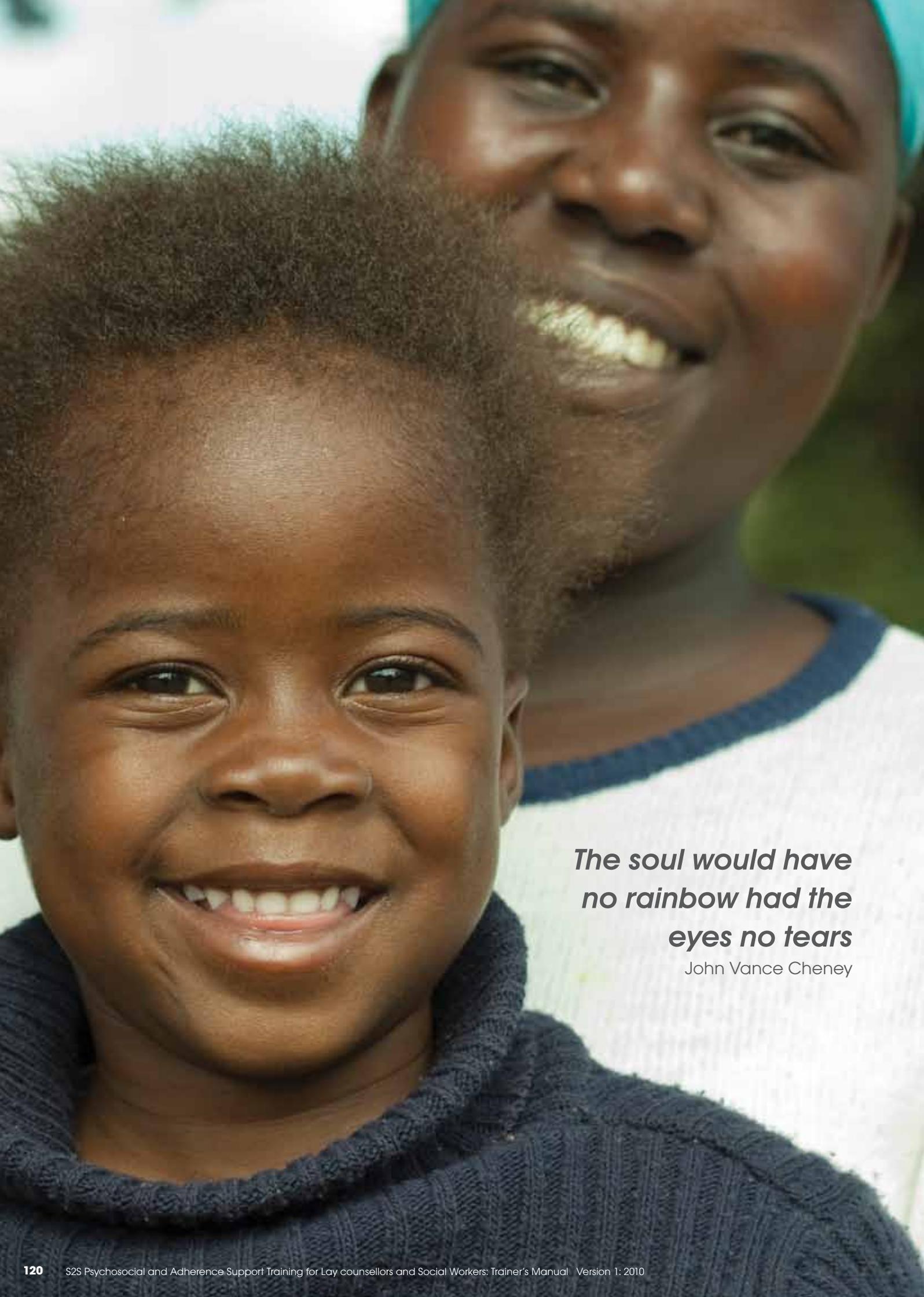
You can write extra comments on the back.

	 Not Helpful				 Very Helpful
Conducting the Group Information Session	1	2	3	4	5
Conducting Individual Pre-Test Counselling and Obtaining Informed Consent	1	2	3	4	5
Providing Post-Test Counselling for Pregnant Women	1	2	3	4	5
Encouraging Family and Partner Testing	1	2	3	4	5
Classroom Practicum	1	2	3	4	

What was the BEST THING about this Module?

What was NOT USEFUL about this Module?

Do you have other comments (use the back of the page if needed)?



*The soul would have
no rainbow had the
eyes no tears*

John Vance Cheney

MODULE 5

Conducting a Psychosocial Assessment & Providing Referrals & Linkages to Social Support



MODULE 5

Conducting a Psychosocial Assessment and Providing Referrals and Linkages to Social Support



CONTENT

- Session 5.1:** Why Conduct a Psychosocial Assessment?
- Session 5.2:** Using the Psychosocial Assessment Guide and Reporting Form
- Session 5.3:** Providing Referrals and Linking Clients to Social Support Services
- Session 5.4:** Developing a Referral Directory
- Session 5.5:** Classroom Practicum
- Session 5.6:** Module Summary and Evaluation



DURATION

375 minutes (6 hours, 15 minutes)



LEARNING OBJECTIVES

By the end of this Module, participants will be able to:

- Understand the importance of conducting a psychosocial assessment with PMTCT clients
- Conduct a psychosocial assessment, using the psychosocial assessment guide and reporting form
- Record key information from the psychosocial assessment
- Identify clients' specific needs and make referrals/link them to social support services
- Use referral forms
- Create and use a community referral directory for their clinic



PREVIOUS TRAINING/KNOWLEDGE REQUIRED FOR THIS MODULE

- Basic knowledge about PMTCT protocols and guidelines
- Experience in HIV counselling and testing (e.g., VCT and PICT), PMTCT, and ARV/ART education/counselling
- Completion of Modules 1-4 of this lay counsellor training curriculum



METHODOLOGIES:

- Interactive Trainer Presentation
- Brainstorming
- Role Play
- Guest Speakers (optional)
- Large Group Discussion
- Demonstration
- Small Group Work
- Case Studies



MATERIALS NEEDED

- Flip chart and stand
- Markers/Khoki's
- Tape or Bostik
- Copies of referral forms used at the health facility
- Copies of any existing directories of community- and clinic- based HIV and pregnancy - related services in the district
- Copies of *Appendix 5A, 5B and 5C*
- Participant Handouts for Module 5 (to be inserted into the Participant Folder)



WORK FOR THE TRAINER TO DO IN ADVANCE

- Read through the entire Module and make sure you are familiar with the training methodologies and content.
- Write the Module learning objectives on flip chart or list them on a PowerPoint slide.
- Invite guest speakers from community-based organizations for Session 5.3 and 5.4 (optional).
- Carefully review the case studies in Session 5.5.
- Obtain copies of the specific forms used to refer patients to social support services at the health facility where the training takes place (for use in Session 5.3).
- Collect copies of any existing directories of organizations/ services for pregnant women and people living with HIV in the district or clinic catchment area (for use in Session 5.4).

Make a copy of *Appendices 5A, 5B, and 5C* for each participant.

Adversity is the first path to truth

Lord Byron



SESSION 5.1

WHY CONDUCT A PSYCHOSOCIAL ASSESSMENT? (40 MINUTES)



TRAINER INSTRUCTIONS

Methodologies: Interactive Trainer Presentation, Large Group Discussion, Brainstorming

Step 1: Review the Module learning objectives and ask if there are any questions.

Step 2: Ask participants to think back to Module 2 and to share with the group any of the common psychosocial support needs of PMTCT clients that they remember. Fill in, as needed, using the content below.

Step 3: Introduce the concept of a psychosocial support assessment. Ask participants what we mean by “psychosocial support assessment” and record on flip chart. Emphasize that this type of assessment can help lay counsellors and social workers learn more about a client’s particular situation and where she may need additional psychosocial support – both from health care workers at the clinic and in the community, as well as at home.

Tell participants that lay counsellors should conduct a psychosocial assessment with all clients after they test positive for HIV (e.g. when they book in ANC and are tested, or when they are repeat tested at 32 weeks, etc.) and when their life situation changes in a significant way (for example, after giving birth, after moving to a new location, when there is a major change in their household situation). Remind participants that while all pregnant and postpartum women have psychosocial needs and issues, lay counsellors should prioritize psychosocial assessments with pregnant women living with HIV.

Step 4: Ask participants to brainstorm key topics that they think should be discussed during a psychosocial support assessment, filling in using the content from the box below. Then ask participants to brainstorm how each of these issues could affect a client’s psychosocial well-being and adherence to PMTCT care and treatment.

Step 5: Summarize the session by emphasizing that without the proper support from family, friends, and health care workers in the facility and in the community, it can be very difficult for clients to feel emotionally well and to adhere to their care and treatment. Answer any questions participants may have.

KEY INFORMATION

PSYCHOSOCIAL AND ADHERENCE SUPPORT NEEDS OF PREGNANT AND POSTPARTUM WOMEN (NOTE: THIS IS A REVIEW FROM MODULE 2)

Common psychosocial support needs among all pregnant and postpartum women, regardless of HIV status:

- Discussing their feelings and concerns about their pregnancy and being/becoming a mother
- Understanding the processes of pregnancy, delivery, and infant feeding
- Specific information concerning the pregnancy, infant feeding options, and the health and developmental needs of the baby
- Acceptance and support from partner and family members throughout the pregnancy, delivery, and postpartum period
- Discussing fears of delivering and/or taking care of the baby (physically, emotionally, financially, etc.)
- Support to have a safe pregnancy and delivery
- Support to practice safer sex during and after the pregnancy
- Support to feed the baby properly and successfully
- Support to bring the baby back to the clinic for routine checkups and growth monitoring
- Access to social, nutritional, legal, spiritual, and other support services in the community

Common psychosocial support needs among pregnant and postpartum women living with HIV:

- Discussing their feelings and concerns about their HIV status and the effect it has on their own and their family's lives
- Discussing fears of passing HIV to the baby
- Empathy and acceptance from partner and family members
- Support in understanding and coming to terms with their HIV status
- Support to have a safe pregnancy and delivery
- Support to continue their own care and treatment after the baby is born
- Support to safely feed the baby
- Support to bring the baby for follow-up care, testing, and treatment
- Peer support from other pregnant women and mothers
- Strategies to disclose their HIV status to their partner and other family members, as well as to children living with HIV
- Strategies to encourage their partner and other family members to test and, if appropriate, enroll into care and treatment programmes
- Strategies and support for positive living

- Strategies and support for positive prevention, including in discordant couples
- Access to community-based organizations and support groups
- Access to nutrition support for self and family
- Access to social grants and income-generating activities
- Spiritual support and referrals to spiritual counselling
- Knowledge about their legal issues and rights
- Support for mental health, including anxiety and depression
- Substance abuse management

WHY, WHEN, AND HOW TO CONDUCT A PSYCHOSOCIAL ASSESSMENT:

- **WHY:** It helps to learn more about each client's specific situation, to prioritize needs, and to give direction to ongoing counselling and psychosocial support. This includes referrals for needed community and home-based services.
- **WHEN:** A psychosocial assessment should be conducted with **each client after she tests positive for HIV**. For many pregnant women, this will be when they come to book at ANC and receive an HIV test, after which clients who test positive will be enrolled in PMTCT. A psychosocial assessment should also be conducted with clients who initially test negative and then test positive, either during retesting at 32 weeks or at any other point in the continuum of care. Lay counsellors may want to conduct another follow-up psychosocial assessment or revisit specific psychosocial issues when a client's situation changes in a significant way, such as after a client gives birth.
- **HOW:** Remember to always respect client confidentiality and to conduct sessions in a space that offers visual and auditory privacy. Allow at least 30 minutes to conduct an initial psychosocial assessment – but more time is better.
 - Key information from the psychosocial assessment should be recorded on the form and kept in the client's file. A template to record follow-up counselling notes is also included (see *Appendix 5A*).
 - Completed psychosocial assessment forms should be kept in the client's file and referred to during follow-up visits.
 - Lay counsellors should allow time at each follow-up visit to offer counselling and follow-up on psychosocial and adherence issues. Key points of counselling sessions should be recorded, kept in the patient's file, and referred to at follow-up visits.

KEY TOPICS TO ADDRESS DURING A PSYCHOSOCIAL ASSESSMENT WITH A PMTCT CLIENT

- The client's coping
- The client's support system
- Disclosure
- Actual or potential risk of stigma, discrimination, and/or violence at home and in the community
- Sources of income and other material support
- Plans for the client's own care
- Plans for the baby's care
- Partner testing and, if necessary, enrollment in care and treatment
- Testing all children in the home and, if necessary, enrollment in care and treatment
- Referrals to other clinical, as well as community- and home-based, services



SESSION 5.2

USING THE PSYCHOSOCIAL ASSESSMENT GUIDE AND REPORTING FORM (90 MINUTES)



TRAINER INSTRUCTIONS

Methodologies: Interactive Trainer Presentation, Large Group Discussion, Demonstration, Role Play

Step 1: Refer participants to the psychosocial assessment guide and reporting form in *Appendix 5A*. Hand out an additional copy of the guide to each participant. Facilitate a discussion of the different sections of the form, asking participants to take turns reading the questions out loud, one section at a time, and then to discuss the purpose of the section and how to approach it.

Step 2: Ask for one participant to volunteer to participate in a role play, playing the role of a client. Then use the psychosocial assessment guide in *Appendix 5A* to demonstrate how to conduct a psychosocial support assessment.

Step 3: Emphasize the importance of writing down the main points of a client's answer for each question on the psychosocial assessment form. This documentation will allow all members of the multidisciplinary team to easily review the client's specific psychosocial needs and challenges, and is an important part of providing quality, continuous counselling over time.

Step 4: Ask participants to break into pairs. One person should play the role of the lay counsellor and the other the role of the client. Those playing clients can make up their answers for this exercise. Give the pair about 15 minutes to practice conducting a psychosocial support assessment using the guide.

For this activity, participants do not have to write responses on the form, but instead should focus on becoming familiar with the questions used during a psychosocial assessment. Additionally, participants should focus on following the phases of the counselling session (e.g. introductions, reminder about confidentiality, framing the session etc.) and using the 7 key listening and learning skills covered in Module 3 (review these, if needed). Then have participants switch roles and start the role play over again. The trainers should circulate around the room to observe and mentor participants. If time allows, ask some of the small groups to present to the larger group.

Step 5: Ask participants to brainstorm challenges and possible solutions to documenting psychosocial assessments with PMTCT clients at their particular health facility

Step 6: Remind participants they will have more chance to practice conducting psychosocial assessments later on in the session

KEY INFORMATION

See *Appendix 5A: The PMTCT Psychosocial Assessment Guide and Reporting Form*

EXPLANATION OF KEY SECTIONS OF THE PSYCHOSOCIAL ASSESSMENT GUIDE AND REPORTING FORM

Basic information:

- At the beginning of the counselling session, the lay counsellor should be sure to write down the client's name and file number.
- At the end of each session, the lay counsellor should be sure to sign and date the form and ensure that the form is kept in the client's clinic file.

Questions to ask the client/caregiver:

- The questions in these sections allow the lay counsellor to discuss and assess the client's psychosocial issues and needs.
- Different questions are suggested for different topic areas, including:
 - Coping, support system, and disclosure
 - Plans for her own and baby's care
 - Follow-up on partner and family testing
- It is important to allow time for the client to respond to each question.
- Clients should always be made to feel comfortable expressing psychosocial challenges and should never be judged or punished.
- The lay counsellor should write down any important information from their responses, as this will help decide on effective next steps and important areas for follow-up, and in supporting the client's psychosocial well-being over the long term.

Questions, summary, and next steps:

- The lay counsellor should ensure that the client has time to ask questions and that the lay counsellor has time to summarize the session as well as agreed upon next steps.
- Key next steps should be recorded in the space provided.

Additional notes:

- The lay counsellor should write any additional notes about the session, the client's psychosocial needs, or next steps in the space provided.

Referrals made:

- Linkages and referrals to psychosocial support services are important elements of quality PMTCT programmes and the ongoing support of clients and their families.
- Each clinic should have an up-to-date list of community support services (such as social grants, mother's support groups, home-based care programmes, adherence supporters, PLHIV associations, food support, legal support, etc.) and formal two-way referral systems to these organizations and services.

- Clients with severe psychosocial and psychological issues (such as depression, use of drugs and alcohol, feeling suicidal) will require careful follow-up and immediate referrals and linkages to ongoing professional counselling and other services.
- Lay counsellors should record any referrals made to the client in the space provided. At the next session, the lay counsellor should follow-up to determine if the client has accessed these referral services.

Date of next counselling session/clinic appointment:

- The lay counsellor should schedule a follow-up counselling appointment with the client and record this date, as well as any clinic appointments, in the space provided.



*Although the world is full of suffering,
it is full also of the overcoming of it*

Helen Keller



SESSION 5.3

PROVIDING REFERRALS AND LINKING CLIENTS TO SOCIAL SUPPORT SERVICES (55 MINUTES)



TRAINER INSTRUCTIONS

Methodologies: Interactive Trainer Presentation, Brainstorming, Large Group Discussion

Step 1: Remind participants that a key component of being a lay counsellor or social worker is encouraging strong linkages between health facilities and the community. In order to provide a continuum of care and support to clients and their families, we must actively help them get the services they need - at the health facility, in the community, and at home.

Ask participants to discuss these questions:

- *What are some of the challenges to having good facility-community linkages in your clinic?*
- *What are some of the specific ways we can improve facility-community linkages?*

Step 2: Tell participants that no one person, organization, or clinic can provide all the services and support clients and families need. This is why it is important to have strong referral systems in place. Ask participants to discuss these questions and fill in as needed:

- *What is a referral?*
- *What is the difference between a formal and an informal referral?*
- *What is the difference between an internal and an external referral?*
- *What do we mean by two-way referral?*
- *What do we mean by referral follow-up? Why is it important to follow-up on referrals? How can one follow-up on a referral?*

Step 3: Ask participants to share what they know about the referral processes used to link clients with social support services (including forms used) at their clinic and in the surrounding community. Ask them to describe the specific steps in making a referral, including what can be done to follow-up the referral. If possible, provide specific examples of community referral forms used at the particular health facility, explain how they are used, and give participants a chance to practice using them.

Step 4: Ask participants to brainstorm common support needs of pregnant and post-partum women living with HIV that are provided in the community or in the home.

Record responses on flip chart. Some examples are provided below. Ask participants to identify the top 6 most important community support needs from the list. Circle these on the flip chart and discuss why each is important.

Step 5: Close the session by reminding participants that lay counsellors and social workers should think about all of the support needs clients and their families may have, and work to link them to available community- and home-based services.

KEY INFORMATION

Examples of strategies to improve facility-community linkages:

- Always ask about clients' community and family situations, any specific barriers to adherence, and any psychosocial support needs during the psychosocial assessment and at follow-up visits.
- Meet with community leaders to talk with them about PMTCT and HIV care and treatment services and why they are important. Also try to clarify common myths about HIV, PMTCT, and ARVs in the community.
- Invite community organizations, community health workers, and community leaders to the hospital for a tour, to meet the health care workers, and to learn more about the services that are provided there.
- Health care workers, including lay counsellors, can participate in community meetings and community gatherings to discuss HIV, PMTCT, and care and treatment.
- Existing community health workers can be trained to identify community members and refer them for testing, PMTCT, care, and treatment. They can also be trained to provide basic adherence and psychosocial support to community members and to follow-up with clients who have missed appointments.
- Learn what community organizations and services are available in the areas where clients live and meet with these organizations to set up a formal "two-way" referral system. This means that the hospital can refer people to the community organization and the community organization can refer people to the hospital.
- Involve community outreach workers with home-based follow-up of clients who have missed appointments at the hospital.
- Involve health care workers and community members openly living with HIV to strengthen facility-community linkages.
- Start a support group at the health facility, if this would be convenient and acceptable to potential members. Invite health care workers to the support group meetings to provide guidance and information.

Examples of common support needs of pregnant and postpartum women living with HIV and their families in the community and at home:

- Support groups
- Disclosure support
- Nutritional and food support
- Spiritual guidance and support
- Transportation to get to the clinic
- Education and counselling for family members
- PLHIV Associations
- Social grants
- Income-generating activities and savings and loan programmes
- Home-based care
- Home-based adherence support
- Home-based infant feeding support
- Legal advice and support
- Others...

REMEMBER, no one person or organization can provide all of the services and support PMTCT clients need. We must work together to provide a continuum of ongoing care and support in the health facility, in the community, and at home!

*A bend in the road is not the end
of the road, unless you fail to
make a turn*

Author Unknown



SESSION 5.4

DEVELOPING A REFERRAL DIRECTORY (100 MINUTES)



TRAINER INSTRUCTIONS

Methodologies: Guest Speakers (optional), Interactive Trainer Presentation, Large Group Discussion, Small Group Work

Step 1: Note: If time allows, trainers may want to invite guest speakers to this session, such as support group leaders, M2M supervisors, home-based care workers, income-generation or community banking leaders, food support organizations, or legal service organizations. Be sure to prepare the guest speakers in advance and ask each to spend about 5 minutes discussing their programme. Invited guests can also join the small groups for these sessions.

Step 2: Remind participants that a key component of being a lay counsellor or social worker is encouraging strong linkages between health facilities and the community, as discussed in the last session. In order to provide a continuum of care and support to clients and their families, we must actively help them get the services they need - at all levels.

Step 3: Ask if any participants use a community referral directory at their clinic. Allow time for experience sharing. Tell participants that, in order to provide effective referrals, it is all of our roles to be up to date on the services available in the community. A good way of knowing where to refer clients is for each health facility to develop a list of community resources – this makes it easier to refer clients based on their specific needs.

Pass out and review any existing service directories from the district/community and ensure that each participant has a copy.

Explain that, in this session, we will create a community resource directory and refer participants to *Appendix 5B*. Explain how to fill in the Community Services Directory.

Step 4: Break participants into small groups. Participants working at the same health facility/clinic should be grouped together. Write the following questions on flip chart or prepare a slide, Ask each small group to discuss the questions and to begin creating a community referral directory for their clinic, using the template in *Appendix 5B*. Participants can draw upon information in any existing service directories that have been passed out.

- *What support groups exist in the community for women/mothers living with HIV? Write information about these groups in the community directory.*
- *What social grants and income generating activities exist for pregnant and postpartum women living with HIV? Write information about these groups in the community directory.*
- *What food and nutritional support is available to pregnant and postpartum women in the community? Write information about these services in the community directory.*
- *What home visiting services exist in the community for pregnant and postpartum women living with HIV? Write information about these groups in the community directory.*
- *What PLHIV Associations exist in the community? Write information about these Associations in the community directory.*
- *What legal support services are available to women living with HIV in the community? Write information about these services in the community directory.*
- *What other support services are available to pregnant and postpartum women living with HIV in the community? Note these in the community directory.*
- *What is being done now to link clients with these groups and organizations?*
- *What could be done to improve referral linkages with the groups and organizations listed in the directory?*
- *How can lay counsellors and social workers help link clients with these services? Be specific!*

Step 5: After about 40 minutes, bring the large group back together. Give each of the small groups about 5 minutes to present their community referral matrix and how they will introduce and use the matrix at their clinic.

Step 6: Close the session by reiterating the importance of facility-community referrals and of having an up-to-date community referral directory in each clinic. Explain that the trainers will type up the community referral directories developed during the session and return them to participants within one week.

Note: Facilitators should compile the community organization matrixes, enter them into a computer, and provide printed, laminated copies to participants and clinic managers/in-charges within one week of the training.

KEY INFORMATION

See Appendix 5B: Community Referral Directory Template

SESSION 5.5

CLASSROOM PRACTICUM (75 MINUTES)



TRAINER INSTRUCTIONS

Methodologies: Small Group Work, Case Studies, Role Play, Large Group Discussion,

Step 1: Divide the participants into groups of 3 by counting off. Assign each group one of the case studies below, and refer participants to their Participant Handouts where the case studies are written. Provide extra copies of *Appendix 5A* to each participant. Ask each group to read their case and then to select one person who will play the role of the lay counsellor, another who will play the role of the “client,” and one who will act as an observer.

Step 2: Ask the groups to start their role plays. The lay counsellor should spend 10-15 minutes beginning to conduct a psychosocial assessment with the client. The lay counsellor should use the psychosocial assessment guide during the role play, recording key information on the form. Remind participants to use their best counselling and communication skills from Module 3. Following the role play, ask the observers to provide feedback.

Repeat this exercise until everyone has had an opportunity to practice the role of the lay counsellor. To be sure that participants have practice with all sections of the assessment guide, ask the lay counsellors to pick up where the last lay counsellor left off with the client (given that a comprehensive psychosocial assessment will take more than the 10 minutes allotted for each person’s turn with the role play). The trainers should participate in the small groups to provide mentoring and feedback.

Step 3: After about 40 minutes and when all participants have had a chance to play the role of the lay counsellor, bring participants back to the large group and ask each group to present their role play, to report on the particular psychosocial needs of their client, and to describe which social support services they would link their clients to and how. Answer any questions that participants have.

Step 4: Debrief the activity by asking participants about their experiences using the psychosocial assessment guide and recording form (e.g. What was easy? What was challenging?). Close by reminding participants how important it is to learn more about our clients and to understand the psychosocial needs of each of our clients. Emphasize that using the psychosocial assessment guide and recording form can provide an effective starting point. Finally, review how the form will be incorporated into lay counsellors’ work at the clinic once the training is finished.

KEY INFORMATION

CASE STUDY 1:

Sipho has just enrolled in the PMTCT programme. She is pregnant with her third child and is living with her boyfriend's family in a township. No one in her family knows that she is living with HIV and she says she struggles to get enough food to eat. She requests help on how to talk to her boyfriend about her HIV status. Conduct a psychosocial assessment and provide counselling and referrals to Sipho.

CASE STUDY 2:

Nkomane is a PMTCT client who will deliver her baby sometime in the next month. She just transferred to your clinic. She tells you she is very concerned about having support to care for her baby and to bring him or her back to the clinic. She also has concerns about how she will exclusively breastfeed her baby. She wishes there were more women she could talk to who have gone through the same experiences, especially because she is new in the area. She has disclosed to her husband and sister, who have been supportive so far. Conduct a psychosocial assessment and provide counselling and referrals to Nkomane.

CASE STUDY 3:

Lungi is a domestic worker. The woman she works for brought her to the clinic after she started getting sick a lot. Lungi says she was tested for HIV even though she didn't want to be. The test results were positive. Now Lungi is pregnant and she comes to the clinic on her own to book. She is frightened to tell the family she works for that she is pregnant because they already said they were thinking about firing her because they don't want someone with HIV around their children. Lungi feels frightened and alone, and she is worried about not having any money if she loses her job. Conduct a psychosocial assessment and provide counseling and referrals to Lungi.

SESSION 5.6

MODULE SUMMARY AND EVALUATION (15 MINUTES)



TRAINER INSTRUCTIONS

Methodologies: Large Group Discussion

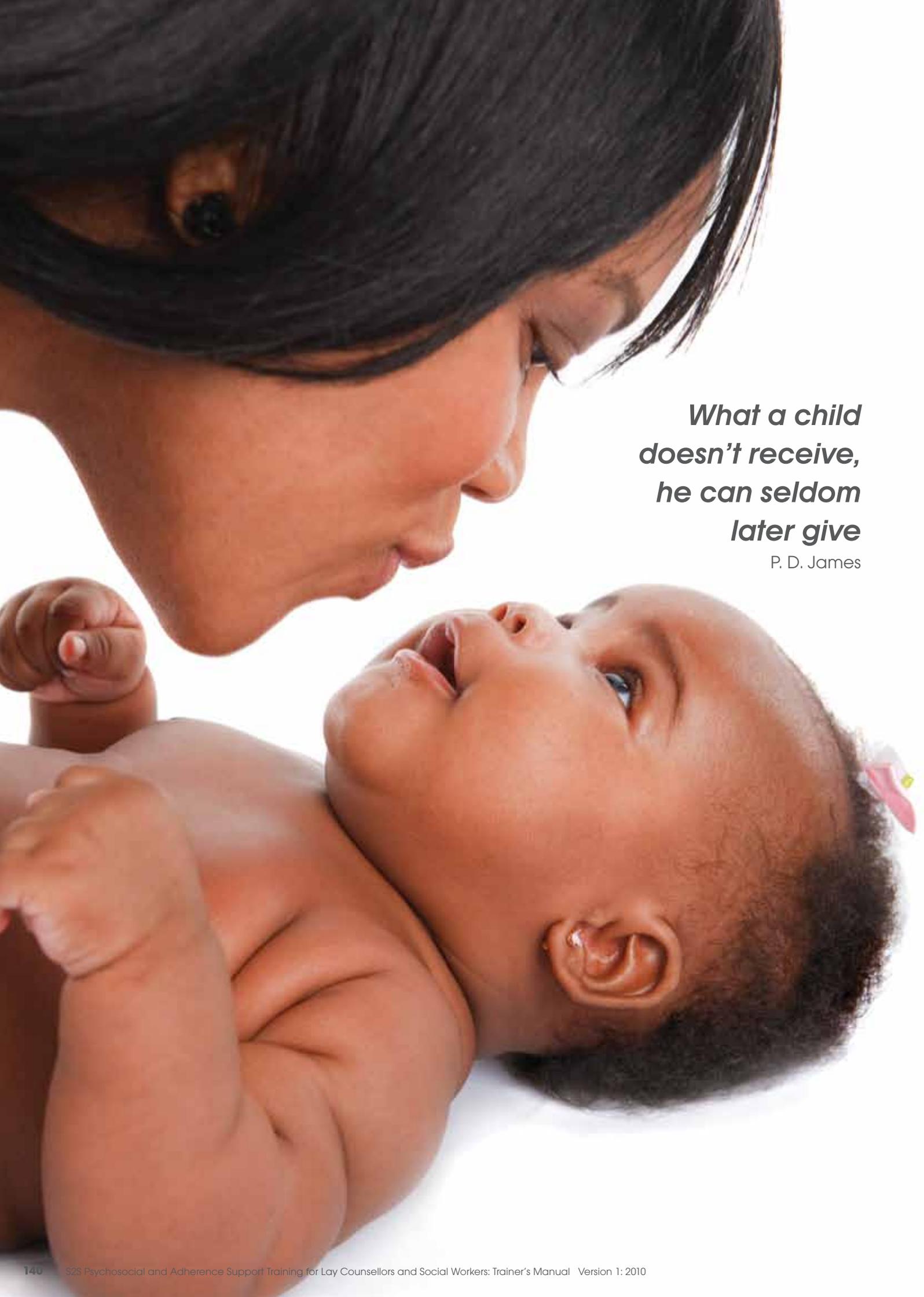
Interactive Trainer Presentation

- Step 1:** Ask participants what they think are the key points of this Module. What information will they take away from the Module?
- Step 2:** Summarize the key points of the Module using participant feedback and the content below. Review the learning objectives with participants and make sure all are confident with their skills and knowledge in these areas.
- Step 3:** Ask if there are any questions or clarifications.
- Step 4:** Ask each participant to share with the group one thing he or she will do differently in his or her work as a lay counsellor or social worker, based on the information and skills learned in this Module.
- Step 5:** Hand out a Module evaluation form to each participant (see *Appendix 5C*), and ask that they take about 5 minutes to fill it out and to return it to the trainers. Remind participants that they do not need to put their name on the form.



THE KEY POINTS OF THIS MODULE INCLUDE:

- A psychosocial assessment is an individual assessment of a client's support system, coping strategies, and plans for her own and her baby's care.
- Psychosocial assessments can help lay counsellors and social workers learn more about a client's particular situation and where she may need additional psychosocial support or facility and community services.
- A psychosocial assessment should be conducted with all clients when they test positive for HIV (this could be during the initial ANC booking, during retesting at 32 weeks, etc.).
- Without the proper support from family, friends, and health care workers, it can be very difficult for clients to adhere to their care and treatment.
- It is important to write down the main points of a client's answer for each question on the psychosocial assessment form, as well as key points of follow-up counselling sessions.
- It is important to think about all of the support clients and their families need, and to work to link them to available community- and home-based services.
- It is important to have a formal two-way referral process between facility- and community-based services and to follow-up on all referrals made.
- All health facilities should have an up-to-date community services referral directory.



***What a child
doesn't receive,
he can seldom
later give***

P. D. James

APPENDIX 5A

PMTCT PSYCHOSOCIAL ASSESSMENT GUIDE AND
RECORDING FORM

APPENDIX 5A:

PMTCT PSYCHOSOCIAL ASSESSMENT GUIDE AND RECORDING FORM

(to be used with all pregnant and postpartum women after testing positive for HIV)

Client's Name: _____ Client's File# _____

COPING	
1. What feelings or concerns do you have, now that you know your HIV status?	
2. Can you tell me how things have been going since you learned your HIV status?	
FAMILY, CHILDREN, AND PARTNER	
3. Who lives with you at home? <i>Counsel on family-testing, care and treatment</i>	Name: Age: Relationship: Name: Age: Relationship: Name: Age: Relationship: Name: Age: Relationship: Name: Age: Relationship:
4. For the children who live with you, can you tell me if each has been tested for HIV and their status? <i>Counsel on HIV testing for all children, even if they seem well, and importance of early care and treatment for HIV infected children</i>	Name: Age: Tested: Yes/No/? Result: pos/neg If positive, in care and tx: Yes/No Name: Age: Tested: Yes/No/? Result: pos/neg If positive, in care and tx: Yes/No Name: Age: Tested: Yes/No/? Result: pos/neg If positive, in care and tx: Yes/No
5. Has your partner been tested for HIV? <i>Counsel on partner testing and discordance</i>	Yes No Don't know
5a. If yes, what was the result?	Positive Negative Don't know If positive, in care and treatment? Yes No Don't know
5b. If no, do you think he would be willing to come for an HIV test?	Yes No Don't know
DISCLOSURE	
6. Have you disclosed your HIV status to anyone? <i>Follow-up on pre-test counselling. Counsel on full and partial disclosure</i>	Yes No
6a. If yes, to whom? What was their reaction?	
6b. If no, how do you feel about disclosing to someone you trust? What support do you need?	
SUPPORT SYSTEM	
7. Who can you go to for emotional support? <i>Counsel on importance of social support</i>	
8. Do you belong to a community organization, support group, or religious group? <i>Refer to support group, if needed</i>	Yes No Name and location of organization or group:
8a. Would you be willing to join a support group at this clinic (if applicable)? <i>Give information about the support group</i>	Yes No
9. How will you remember when to come back to the clinic for your appointments? Is there someone who can help you? <i>Counsel on adherence to care</i>	
10. How will you remember to take your medicines? Is there someone who can help you? <i>Counsel on adherence to medicines</i>	

SUPPORT SYSTEM continued

<p>11. Who will help you take care of the baby and give the baby medicines? <i>Counsel on importance of bringing baby back often and adherence to care and medications</i></p>	<p>Name(s) and relationship(s):</p>
<p>11a. If you cannot bring the baby back to the clinic, who else will be able to bring the baby?</p>	<p>Name and relationship:</p>
<p>12. Would it be ok if we call you (or someone you trust) if you miss an appointment at the clinic?</p>	<p>Yes No Phone number: Own phone or other's?:</p>
<p>13. Have you experienced or do you fear discrimination or violence? <i>Counsel and refer for more support</i></p>	<p>Yes No Details:</p>
<p>13a. If you experience stigma, discrimination, or violence, or if you are afraid, what do you think you will do? <i>Counsel on available support services, including at the clinic</i></p>	
<p>14. Do you have a regular source of income or do you receive help, such as social grants, food parcels, or others? <i>Counsel and refer to social worker and community-level support</i></p>	<p>Yes No Sources of income/support: Receiving social grant? Yes No</p>

PLANS FOR HER OWN AND BABY'S CARE

<p>15. What are you going to do to stay well during and after your pregnancy and to reduce the chance that your baby will be HIV infected? <i>Counsel on BANC and PMTCT during and after pregnancy including ARVs/ART</i></p>	
<p>16. How do you plan to feed your baby? Do you have any questions or concerns? <i>Counsel on infant feeding choices, safer infant feeding</i></p>	<p>Exclusive breastfeeding Exclusive formula Not sure Final infant feeding choice:</p>
<p>17. What do you think are the most important things you can do to care for your new baby? <i>Counsel on care for HIV exposed infants, including ARVs, CTX, and testing at 6 weeks, and on bringing the baby back often for all clinic appointments</i></p>	

QUESTIONS, SUMMARY, AND NEXT STEPS

<p>18. What other questions or concerns do you want to discuss today?</p>	
<p>19. Summarize the session and review immediate plans and next steps, including the next clinic visit date</p>	<p>Note next steps here and in the space below:</p>

Additional notes:

Referrals made:

Date of next counselling session/clinic appointment: _____

Lay counsellor's signature: _____ Date: _____

PMTCT COUNSELLING FOLLOW-UP NOTES

Client's File# _____

Client's Name: _____

Date of counselling session: _____

Key issues and concerns discussed: _____

Next steps and areas for follow-up: _____

Lay counsellor's signature: _____

Date of counselling session: _____

Key issues and concerns discussed: _____

Next steps and areas for follow-up: _____

Lay counsellor's signature: _____

APPENDIX 5B

COMMUNITY REFERRAL DIRECTORY TEMPLATE

APPENDIX 5B: COMMUNITY REFERRAL DIRECTORY TEMPLATE

District Name: _____ Clinic Name _____ Date _____

NAME OF ORGANIZATION	SERVICES PROVIDED	COMMUNITIES/AREAS COVERED	CONTACT PERSON	PHONE NUMBER AND ADDRESS
1.				
2.				
3.				
4.				
5.				
6.				
7.				

NAME OF ORGANIZATION	SERVICES PROVIDED	COMMUNITIES/AREAS COVERED	CONTACT PERSON	PHONE NUMBER AND ADDRESS
8.				
9.				
10.				
11.				
12.				
13.				
14.				

APPENDIX 5C

MODULE 5 EVALUATION FORM



APPENDIX 5C

MODULE 5 EVALUATION FORM

Name (optional): _____ Health Facility: _____ Position: _____

Please note the following statements on a scale of 1 to 5:

	 Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	 Strongly Agree
1. The module objectives were clear	1	2	3	4	5
2. This module met my expectations	1	2	3	4	5
3. The technical level of this module was appropriate	1	2	3	4	5
4. The pace of speed of this module was appropriate	1	2	3	4	5
5. The facilitators were engaging and informative	1	2	3	4	5
6. The information I learned in this module will be useful to my work	1	2	3	4	5

How helpful were each of the workshop sessions to you and your work?

You can write extra comments on the back.

	 Not Helpful				 Very Helpful
Why Conduct a Psychosocial Assessment?	1	2	3	4	5
Using the Guide to Conduct a Psychosocial Assessment	1	2	3	4	5
Providing Referrals and Linking Clients to Social Support Services	1	2	3	4	5
Developing a Referral Directory	1	2	3	4	5
Classroom Practicum	1	2	3	4	5

What was the BEST THING about this Module?

What was NOT USEFUL about this Module?

Do you have other comments (use the back of the page if needed)?

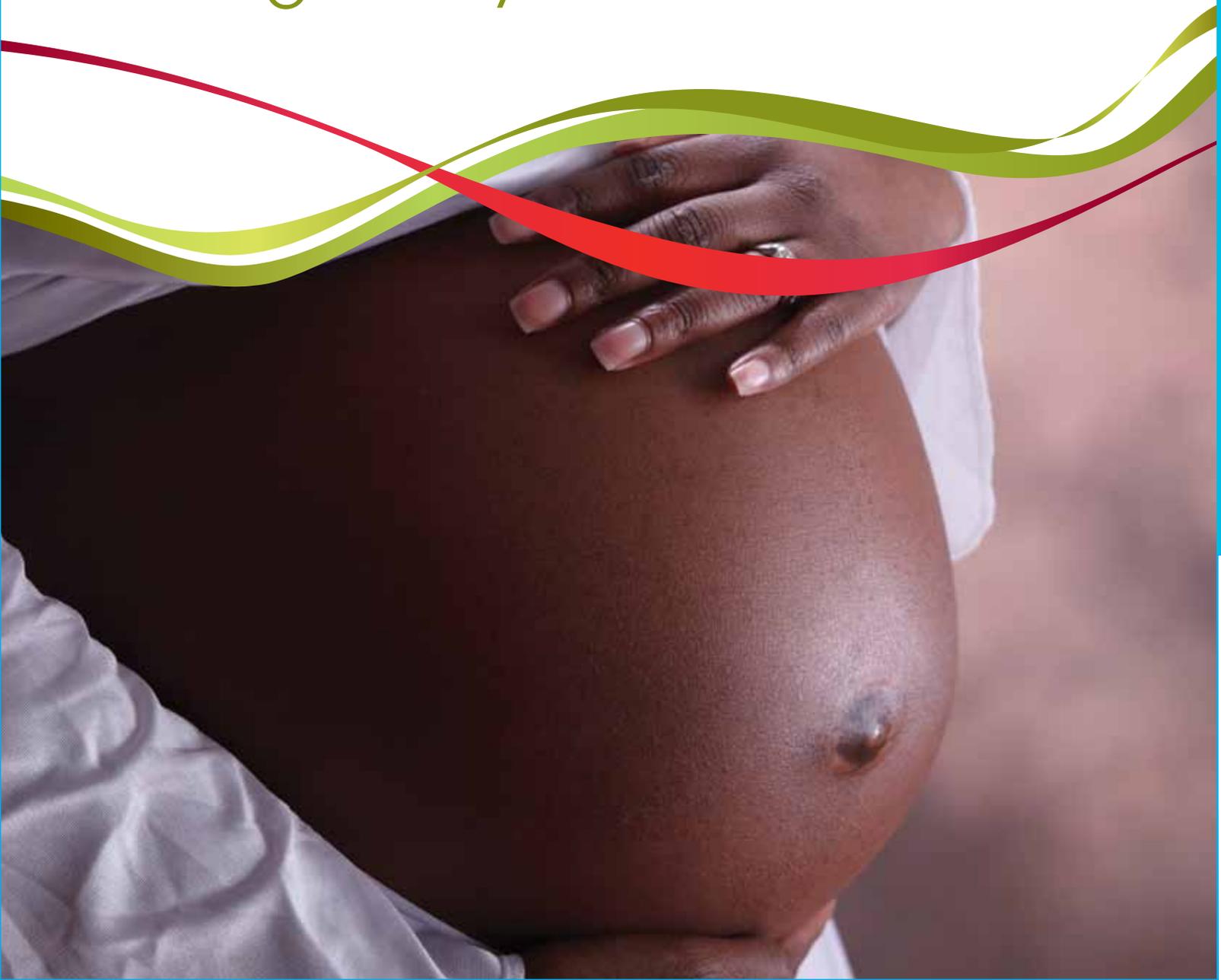
*In each family a story
is playing itself out,
and each family's story
embodies its hope
and despair.*

Auguste Napier



MODULE 6

Providing Supportive PMTCT Counselling - During Pregnancy



MODULE 6

Providing Supportive PMTCT Counselling - During Pregnancy



CONTENT

- Session 6.1:** The Counselling and Support Needs of Pregnant Women Living with HIV
- Session 6.2:** Staying Healthy During Pregnancy
- Session 6.3:** Adhering to the PMTCT Care Plan
- Session 6.4:** Adherence Preparation and Follow-Up for Pregnant Women on the PMTCT Regimen or ART
- Session 6.5:** Planning a Safe Labor and Delivery
- Session 6.6:** Preparing to Safely Feed the Baby
- Session 6.7:** Classroom Practicum
- Session 6.8:** Module Summary and Evaluation



DURATION

405 minutes (6 hours, 45 minutes)



LEARNING OBJECTIVES

By the end of this Module, participants will be able to:

- Counsel clients on PMTCT basics
- Counsel clients on ways to stay healthy during pregnancy
- Counsel clients on adherence to their PMTCT care plan
- Prepare clients to start the PMTCT regimen or start/continue lifelong ART
- Conduct ongoing adherence counselling with clients
- Counsel clients on safe labor and delivery planning
- Counsel and prepare clients for safe infant feeding
- Use cue cards to guide counselling sessions on the above topics



PREVIOUS TRAINING/KNOWLEDGE REQUIRED FOR THIS MODULE

- Basic knowledge about PMTCT protocols and guidelines
- Experience in HIV counselling and testing (e.g., VCT and PICT), PMTCT, and ARV/ART education/counselling
- Completion of Modules 1 - 5 of this lay counsellor training curriculum



METHODOLOGIES:

- Interactive Trainer Presentation
- Brainstorming
- Large Group Discussion
- Small Group Work
- Case Studies
- Role Play



MATERIALS NEEDED

- Flip chart and stand
- Markers/Khokí's
- Tape or Bostik
- Extra copies of *Appendices A-H for each participant*
- Participant Handouts for Module 6 (to be inserted into the Participant Folder)



WORK FOR THE TRAINER TO DO IN ADVANCE

- Read through the entire Module and make sure you are familiar with the training methodologies and content.
- Write the Module learning objectives on flip chart or list them on a PowerPoint slide.
- Carefully review the case studies in all of the sessions.
- Make extra copies of *Appendices A-H* for each participant

***Being a mother means that
your heart is no longer yours;
it wanders wherever your
children do***

Author Unknown



SESSION 6.1

THE COUNSELLING AND SUPPORT NEEDS OF PREGNANT WOMEN LIVING WITH HIV (60 MINUTES)



TRAINER INSTRUCTIONS

Methodologies: Interactive Trainer Presentation, Brainstorming, Large Group Discussion, Small Group Work

- Step 1:** Review the Module learning objectives and ask if there are any questions. Explain that, in this Module, we will learn more about the specific counselling messages and the information to discuss in sessions with pregnant women living with HIV. Explain that we will also become more familiar with counselling cue cards - job aides that lay counsellors can use as tools to guide their sessions.
- Step 2:** Present the PMTCT care spectrum to participants (review from Module 2). Ask participants to think back to Modules 2 and 5, and also to their past experiences as lay counsellors. Ask participants to brainstorm what they think are the most important counselling and support needs for women living with HIV DURING PREGNANCY. Record on flip chart.
- Step 3:** Next, ask participants to brainstorm the key counselling messages for PMTCT – or the “PMTCT Basics” – focusing on general messages all PMTCT clients need to know. Based on participant responses, fill in as needed and present the key PMTCT Basics counselling messages, found below and in the PMTCT Basics counselling cue card in *Appendix 6A*. Note that it may be useful for lay counsellors to cover the PMTCT BASICS as part of post-test counselling.
- Step 4:** Ask participants how they could use this cue card (and others) in their work. Review how lay counsellors can best use the cue cards to guide their counselling sessions, using the content below. Emphasize that they are to be used as a guide, not as a script.
- Step 5:** Break the participants into 5 small groups. Assign each group one of the following topics:
- Staying healthy during pregnancy
 - Adhering to the PMTCT care plan
 - Adhering to the ARV/ART regimen
 - Planning a safe labour and delivery
 - Preparing to safely feed the baby

Ask each group to think about their topic area and to discuss the following questions, noting main points on flip chart:

- What are some of the challenges pregnant women face related to this topic?
- What are the key counselling messages you would focus on for this topic?

Step 6: After about 20 minutes, bring the large group back together and explain that, throughout the day, the small groups will be presenting back the key points of their discussions.

Step 7: Remind participants of the 7 key communication and counselling skills (from Module 3). Conduct a short review of the skills, as needed, and tell participants that they will continue to apply these skills in this Module, as they learn more about counselling pregnant and postpartum women living with HIV.

KEY INFORMATION

Note: This is a review from Modules 2, 3 and 5

PMTCT CARE SPECTRUM from Pregnancy to 18months Post Partum

ANTEPARTUM	INTRAPARTUM	1 - 6 wks	6wks - 6 mths	6 - 9 mths	9 -12 mths	12 - 18 mths
						
<ul style="list-style-type: none"> • Routine HIV test in ANC • WHO staging & CD4 testing • Commence AZT at 14 weeks • ART Initiation • Screening for TB, STI & Pap smear • Comprehensive Counselling • Repeat HIV test at 32 wks for Neg women 	<ul style="list-style-type: none"> • Status unknown - Routine HIV test in L&D • Sd-NVP with TDF + FTC • AZT 3-hourly • FP Counselling • NVP infant dose • Comprehensive Counselling including Infant Feeding Support 	<ul style="list-style-type: none"> • Maternal postnatal check-up • Maternal CD4 & Pap smear if not done • Enrollment into Wellness/CCMT • FP & Infant Feeding Counselling • NVP for all HIV Exposed Infants (HEIs) • PCR testing at 6 wks • CTX Initiation • Growth Monitoring 	<ul style="list-style-type: none"> • Catch up missed PCR testing • Repeat maternal CD4 at 6 mths • Growth monitoring • CTX + NVP continuation IF breastfeeding • HIV infected infants: ART initiation • Infant Feeding Counselling 	<ul style="list-style-type: none"> • Growth monitoring • CTX + NVP continuation IF breastfeeding • Infant Feeding Counselling • Repeat PCR 6wks after weaning 	<ul style="list-style-type: none"> • Growth monitoring • CTX + NVP continuation IF breastfeeding • PCR testing 6wks after weaning • Infant Feeding Counselling & Support 	<ul style="list-style-type: none"> • PCR testing: 6wks after weaning • Antibody testing for all HIV negative infants at 18 months • Final infection status known • Child discharged from PMTCT programme

COMMON PSYCHOSOCIAL SUPPORT NEEDS AMONG PREGNANT WOMEN LIVING WITH HIV:

- Discussing their feelings and concerns about their HIV status and the effects it has on their own and their family's lives
- Discussing fears of passing HIV to the baby
- Empathy and acceptance from partner and family members
- Support in understanding and coming to terms with their HIV status
- Support to have a safe pregnancy and delivery
- Support to continue their own care and treatment after the baby is born
- Peer support from other pregnant women and mothers
- Strategies to disclose their HIV status to their partner and other family members, as well as to children living with HIV
- Strategies to encourage their partner and other family members to test and, if appropriate, enroll into care and treatment programmes
- Strategies and support for positive living
- Strategies and support for positive prevention, including in discordant couples
- Access to community-based organizations and support groups
- Access to nutrition support for self and family
- Access to social grants and income-generating activities
- Spiritual support and referrals to spiritual counselling
- Knowledge about their legal issues and rights
- Support for mental health, including anxiety and depression
- Substance abuse management

COMMON ADHERENCE SUPPORT NEEDS AMONG PREGNANT WOMEN LIVING WITH HIV:

- Discussing their commitment to, and understanding of, their own and their child's care and treatment plan
- Making an adherence plan for their own and the baby's care and treatment, including anticipation of barriers and challenges and solutions to overcome them
- Discussing challenges to attending appointments and tests at the clinic, including routine follow-up of the baby after delivery and early infant diagnosis
- Discussing views about taking medication during pregnancy – including the fact that many pregnant women are not "sick," which impacts their views on taking and adhering to medication and coming to the clinic for ongoing care
- Discussing views about giving a baby medication
- Discussing challenges to taking their medicine the right way, every day, and giving the baby medicines the right way, every day
- Strategies to help them remember to take/give their medicine the right way, every day
- Discussing challenges to picking up their own and the baby's medicines before running out
- Support in overcoming any challenges to adherence, which will change over time

KEY COUNSELLING MESSAGES

– PMTCT BASICS (SEE APPENDIX 6A)

It is important for clients to know that:

- Not all babies born to women living with HIV will become HIV infected.
- If the woman, her partner, and baby all get the care and medicines that are needed, she can lower the chances that the baby will become HIV infected.
- We can save 2 lives – the mom's and the baby's - if the client get services and takes medicines to help her stay healthy and to help prevent passing HIV to the baby.

There are many things clients can do to keep themselves and their babies healthy:

- **All pregnant women living with HIV need to take medicines called ARVs** – even if they do not look or feel sick. Starting ARVs early in pregnancy and taking them the right way throughout pregnancy will lower the chances that the baby will become HIV infected. Taking ARVs can also improve the woman's health.
- **All babies born to mothers living with HIV also need to take ARVs.** ARVs will help lower the chances that the baby will become HIV infected.
- It is important that clients come back to the clinic for all of their appointments – both during pregnancy and after the baby is born.
- It is important that clients plan to have a safe delivery at a health facility.
- We can also plan how clients will feed their baby safely to lower the chance that the baby will become HIV infected after he or she is born.
- Pregnant women also need emotional support – from partners, family, and friends.
- If possible, it is important for clients to tell someone they trust about their HIV status so this person can help care for the pregnant woman and her baby.

Together, we can lower the chances that the baby will become HIV infected:

- There are many things women can do to lower the chances of passing HIV to their baby. We can help clients learn more about the steps they can take during pregnancy, labour, and delivery, as well as after the baby is born.
- If clients come back to the clinic for all appointments and make sure they and the baby take medicines the right way, it will help the woman stay healthy and lower the chances that the baby will become HIV infected.
- If the baby is HIV infected, there is a lot we can do to keep him or her healthy. By coming to the clinic and following the client's and the baby's care plan, we can make sure the baby has the chance to grow up to be a healthy child and adult.

HOW TO USE THE PMTCT COUNSELLING CUE CARDS:

- This set of counselling cue cards was developed to support a range of providers, including lay counsellors, who work with pregnant women living with HIV and their families.
- It may be helpful to translate the cards into the local languages spoken by clients.
- Each of the cue cards focuses on a specific topic important to the care and support of pregnant women living with HIV, their children, and families across the PMTCT continuum of care.
- Lay counsellors may use the cue cards as job aides and reminders of key information to cover during initial post-test and ongoing counselling sessions with pregnant women and newly delivered mothers, their partners, family members, and supporters.
- The cue cards are just a guide. Each counselling session will be different depending on the client's specific needs.
- Lay counsellors should not read directly from the cue cards, but instead should use them as a guide and a reminder of the key points to cover on specific topics.
- The cue cards do not have to be used in sequence, but instead should be used according to the client's specific needs and concerns during the session.
- Good counselling and communication skills, such as active listening, being attentive to the client's questions and specific needs, and avoiding lecturing and one-way communication, should always be used, no matter what the counselling topic.

PLEASE NOTE:

- The cue cards have **2 columns**. The column on the left-hand side gives the lay counsellor guidance on the major subjects to discuss about the specific topic. The column on the right-hand side gives specific questions for the lay counsellor to ask, and specific points about the topic area to be covered. Remember, this is just a guide and each counselling session will depend on the client's specific situation.
- **Key questions** are included in italics, and may be used to initiate discussions, learn more about what the client already knows and her specific concerns, and to gauge understanding and elicit follow-up questions.
- **Notes to guide lay counsellors** are also included in italics.

REMINDER OF KEY COUNSELLING AND COMMUNICATION SKILLS (*FROM MODULE 3*):

There are 7 essential skills that lay counsellors and social workers should practice and use in their work:

Skill 1: Use helpful non-verbal communication.

Skill 2: Actively listen and show interest in the client.

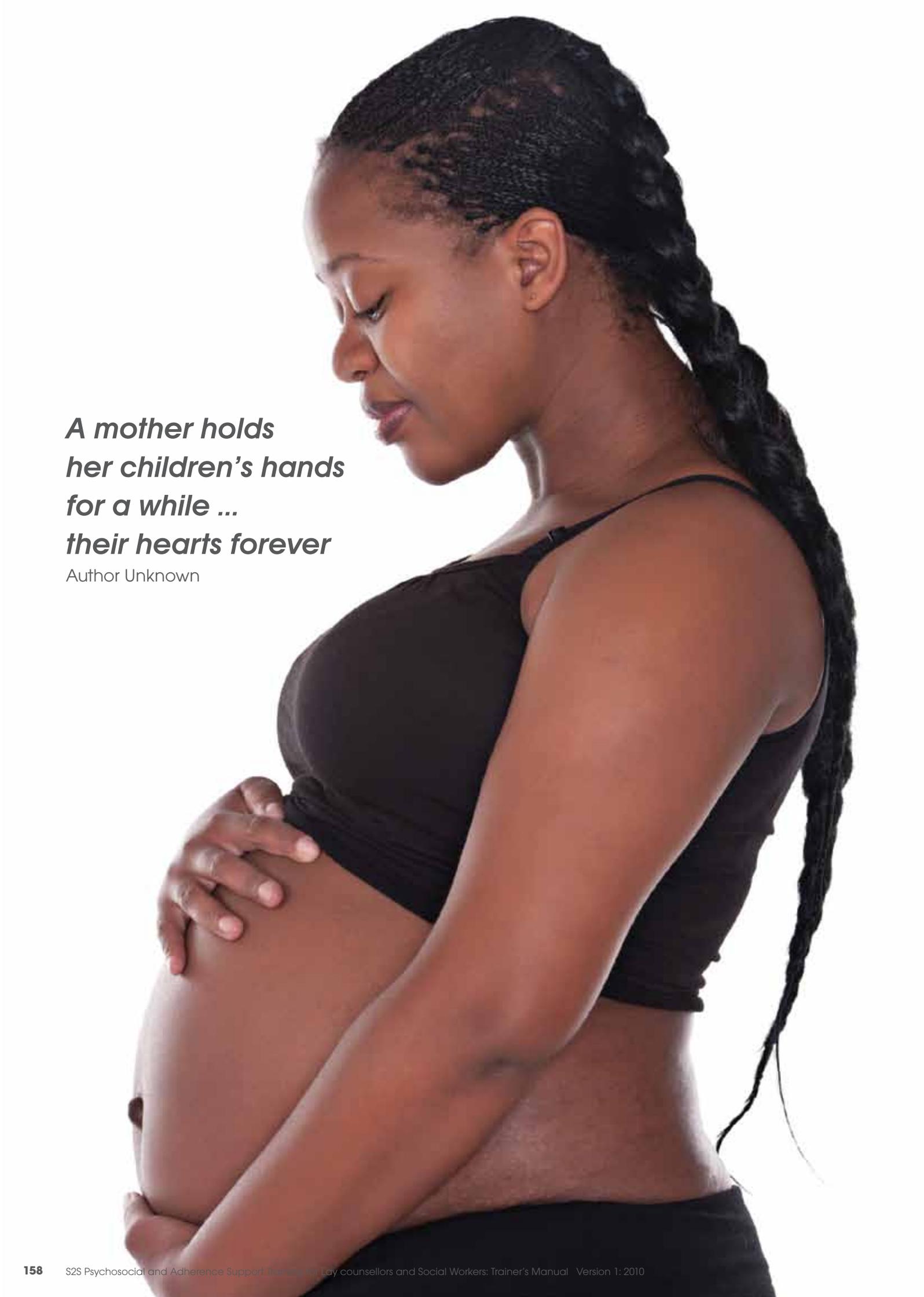
Skill 3: Ask open-ended questions.

Skill 4: Reflect back what the client is saying.

Skill 5: Empathize - show that you understand how the client feels.

Skill 6: Avoid words that sound judging.

Skill 7: Help the client set goals and summarize each counselling session.

A side-profile photograph of a pregnant woman with long, dark braids. She is wearing a black, sleeveless top and is gently cradling her belly with both hands. Her eyes are closed, and she has a serene expression. The background is plain white.

***A mother holds
her children's hands
for a while ...
their hearts forever***

Author Unknown

SESSION 6.2

STAYING HEALTHY DURING PREGNANCY (50 MINUTES)



TRAINER INSTRUCTIONS

**Methodologies: Interactive Trainer Presentation, Small Group Work
Large Group Discussion, Case Studies, Role Play**

- Step 1:** Introduce the session by stating that, now, we will focus on the key counselling messages to help clients stay healthy during their pregnancy.
- Step 2:** Ask the small group assigned to this topic (in *Session 6.1*) to present the main points of their discussion back to the large group, focusing on common challenges women face in having a healthy pregnancy and key counselling messages on having a healthy pregnancy. Give the group about 10 minutes to present and then open up the discussion to the large group.
- Step 3:** Using the content in the counselling cue card called **STAYING HEALTHY DURING YOUR PREGNANCY** in *Appendix 6B*, review the key counselling messages on this topic, building on the small group presentation. Write key messages on flip chart or present them on slides. Refer participants to the counselling cue card in *Appendix 6B* and remind them how they can use the cue card in their work.
- Step 4:** Allow time for discussion and for participants to ask questions about the key messages, providing any updates on the national PMTCT guidelines, as needed.
- Step 5:** Break participants into groups of 3. Assign each small group one of the case studies below and ask one person to play the role of the lay counsellor, another to play the role of the client, and the third to play the role of observer. Remind participants that they should be creative and expand upon the information given in the case study. Hand out extra copies of the cue cards to each participant. Encourage participants to use the counselling cue card to help guide the session and their key messages when they are playing the role of the lay counsellor. When they are playing the role of observer, they should use the cue card as a checklist. After about 10 minutes, stop the role plays and ask the observers to give feedback. Then, ask the pairs to switch roles and to conduct another role play. Do this until everyone has a chance to play each role. The trainers should circulate and provide assistance as needed.

Step 6: Once everyone has had a chance to play the role of the lay counsellor, bring participants back to the large group and, as time allows, ask some of the small groups to present their role play to the large group. Allow participants time to give feedback and debrief the activity using these questions:

- *What did the lay counsellor do well?*
- *What other points do you think the lay counsellor could have discussed with the client about having a healthy pregnancy?*
- *How did you use the counselling cue card during the role play? What was easy? What was challenging?*
- ***How do you think you can use this counselling cue card in your work?***

KEY INFORMATION

See Appendix 6B: Counselling Messages on Staying Healthy During Your Pregnancy

CASE STUDIES

CASE STUDY 1:

Thando booked in the clinic last week, where she learned that she is HIV positive. She comes back to the clinic today. Talk with her about the key things she needs to know about PMTCT and staying healthy during her pregnancy.
(see *PMTCT Basics and Staying Healthy During Your Pregnancy cue cards*).

CASE STUDY 2:

Mpho is 20 weeks pregnant and just booked at the clinic. Her HIV test results are positive. The nurse refers Mpho to you and asks that you counsel her on PMTCT and having a healthy pregnancy.
(see *PMTCT Basics and Staying Healthy During Your Pregnancy cue cards*)

SESSION 6.3

ADHERING TO THE PMTCT CARE PLAN (60 MINUTES)



TRAINER INSTRUCTIONS

**Methodologies: Interactive Trainer Presentation, Small Group Work
Large Group Discussion, Case Studies, Role Play**

- Step 1:** Introduce the session by stating that, now, we will focus on the key counselling messages to help clients understand and adhere to their PMTCT care plan. If needed, review the definition of adherence to PMTCT care from Module 2 with participants.
- Step 2:** Ask the small group assigned to this topic (in *Session 6.1*) to present the main points of their discussion back to the large group, focusing on common challenges women face in adhering to the PMTCT care plan and key counselling messages on adherence to care. Give the group about 10 minutes to present and then open up the discussion to the large group.
- Step 3:** Using the content in the counselling cue card called **ADHERING TO YOUR PMTCT CARE PLAN** in *Appendix 6C*, review the key counselling messages on this topic, building on the small group presentation. Write key messages on flip chart or present them on slides. Refer participants to the counselling cue card in *Appendix 6C* and remind them how they can use the cue card in their work.
- Step 4:** Allow time for discussion and for participants to ask questions about the key messages, providing any updates on the national PMTCT guidelines, as needed.
- Step 5:** Break participants into groups of 3. Assign each small group one of the case studies below and ask one person to play the role of the lay counsellor, another to play the role of the client, and the third to play the role of observer. Remind participants that they should be creative and expand upon the information given in the case study. Encourage participants to use the extra copies of the counselling cue card to help guide the session and their key messages when they are playing the role of the lay counsellor. When they are playing the role of observer, they should use the cue card as a checklist. After about 10 minutes, stop the role plays and ask the observers to give feedback. Proceed as in the last session, where everyone gets the chance to play each role. The trainers should circulate and provide assistance as needed.

Step 6: Once everyone has had a chance to play the role of the lay counsellor, bring participants back to the large group and, as time allows, ask some of the small groups to present their role play to the large group.

Allow participants time to give feedback and debrief the activity using these questions:

- *What did the lay counsellor do well?*
- *What other points do you think the lay counsellor could have discussed with the client about adherence to her PMTCT care plan?*
- *How did you use the counselling cue card during the role play? What was easy? What was challenging?*
- **How do you think you can use this counselling cue card in your work?**

KEY INFORMATION

Note: This is a review from Module 2

Definition of adherence

Adherence describes how faithfully a person sticks to and participates in her or his HIV prevention, care, and treatment plan.

Adherence support is an important part of psychosocial support services and PMTCT and HIV clinical service.

KEY CONCEPTS OF ADHERENCE:

Adherence:

- Is not the same as compliance and includes much more than following the doctor's orders
- Is a part of psychosocial support and clinical services
- Includes active participation of the client in her care plan
- Depends on a shared decision-making process between the client and health care providers
- Includes adherence to both care and to medicines
- Determines the success of PMTCT and HIV care and treatment programmes
- Changes over time

Adherence to PMTCT and HIV care includes:

- Entering into and continuing on a care and treatment plan
- Taking medicines to prevent and treat opportunistic infections
- Planning for/having a safe delivery in a health facility
- Practicing safer infant feeding practices
- Bringing the baby back often for checkups and for HIV testing at 6 weeks

- Participating in ongoing education and counselling
- Attending appointments and tests (such as antenatal and postnatal appointments and regular CD4 tests) as scheduled
- Picking up medications for self and the child when scheduled, and before running out
- Adopting a healthy lifestyle and avoiding risk behaviours
- Recognizing when there is a problem or a change in health and coming to the clinic for care and support

See Appendix 6C: Key Counselling Messages on Adhering to the PMTCT Care Plan

CASE STUDIES

CASE STUDY 1:

Thandiwe returns to the clinic to collect her CD4 results. While she is waiting for her results, talk to her about adhering to her PMTCT care plan.

(see Adhering to Your PMTCT Care Plan cue card)

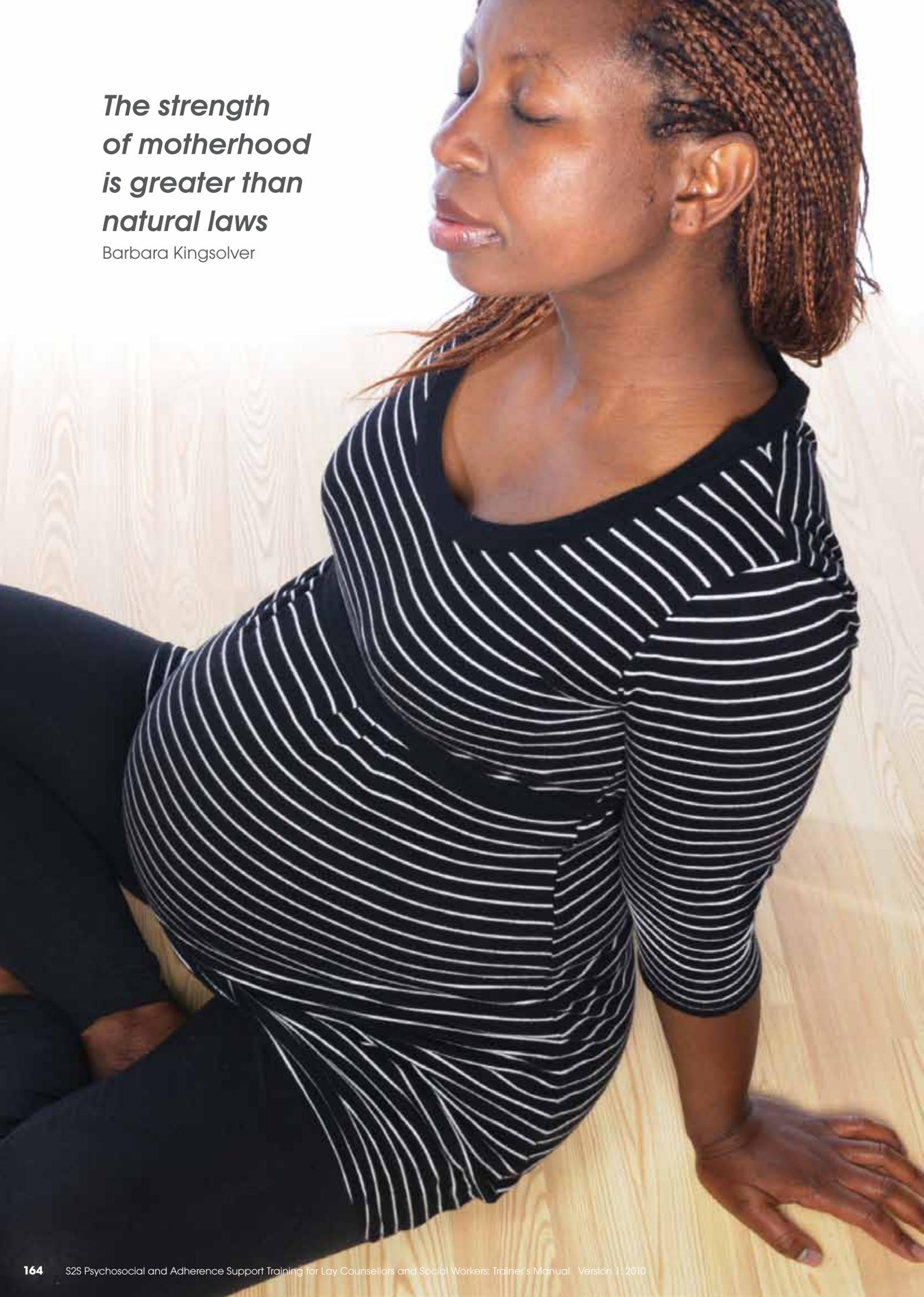
CASE STUDY 2:

Sipho missed her 2nd antenatal care visit. The PMTCT nurse asks you to counsel her on adherence to her PMTCT care plan.

(see Adhering to Your PMTCT Care Plan cue card)

***The strength
of motherhood
is greater than
natural laws***

Barbara Kingsolver



SESSION 6.4

ADHERENCE PREPARATION AND FOLLOW-UP FOR PREGNANT WOMEN ON THE PMTCT REGIMEN OR ART (60 MINUTES)



TRAINER INSTRUCTIONS

Methodologies: Interactive Trainer Presentation, Small Group Work Large Group Discussion, Case Studies, Role Play

- Step 1:** Introduce the session by stating that, now, we will focus on the key counselling messages to help clients adhere to their PMTCT regimen or ART. If needed, review the definition of adherence to medications from Module 2.
- Step 2:** Ask the small group assigned to this topic (in Session 6.1) to present the main points of their discussion back to the large group, focusing on common challenges women face in adhering to PMTCT care and medications and key counselling messages on adherence. Give the group about 10 minutes to present and then open up the discussion to the large group.
- Step 3:** Using the content in the counselling cue cards called **PREPARING TO START AND ADHERE TO THE PMTCT REGIMEN; PREPARING TO START AND ADHERE TO LIFELONG ART; and CONTINUING AND ADHERING TO ART DURING YOUR PREGNANCY** in *Appendix 6D*, review the key counselling messages on these topics, building on the small group presentation. Write key messages on flip chart or present them on slides. Refer participants to the 3 counselling cue cards in *Appendix 6D* and remind them how they can use the cue cards in their work.
- Step 4:** Allow time for discussion and for participants to ask questions about the key messages, providing any updates on the national PMTCT guidelines, as needed. Make sure that counselling messages for women already on ART who become pregnant are discussed.
- Step 5:** Lead a discussion on the importance of early ARV/ART initiation for pregnant women, stressing the point that the sooner women start, the more effective the medicines are in PMTCT. Make the point that adherence preparation needs to be fast-tracked for pregnant women (it should be done in one session and ARVs should be given the same day, unlike for non-pregnant adults where there are often 3-4 separate adherence preparation sessions) and that it is important to minimize any barriers to initiation. Lay counsellors play a key role in preparing women to start ARVs/ART, and, most importantly, in providing ongoing adherence assessment, education, and follow-up at subsequent visits.

Step 6: Break participants into groups of 3. Assign each small group one of the case studies below and ask one person to play the role of the lay counsellor, another to play the role of the client, and the third to play the role of observer. Ask a member of each small group to read their case study out loud. Remind participants that they should be creative and expand upon the information given in the case study.

Encourage participants to use the extra copies of the counselling cue cards to help guide the session and their key messages when they are playing the role of the lay counsellor. When they are playing the role of observer, they should use the cue card as a checklist. After about 10 minutes, stop the role plays and ask the observers to give feedback. Proceed as in the last session, where everyone gets the chance to play each role. The trainers should circulate and provide assistance as needed.

Step 7: Once everyone has had a chance to play the role of the lay counsellor, bring participants back to the large group and, as time allows, ask some of the small groups to present their role play to the large group. Allow participants time to give feedback and debrief the activity using these questions:

- *What did the lay counsellor do well?*
- *What other points do you think the lay counsellor could have discussed with the client about adherence?*
- *How did you use the counselling cue card during the role play?*
- *What was easy? What was challenging?*
- ***How do you think you can use this counselling cue card in your work?***

KEY INFORMATION

Note: This is a review from Module 2.

Adherence to HIV treatment includes:

Taking ARVs correctly, as prescribed, even if the person feels healthy

- For women who are eligible for ART, taking ARVs as prescribed for her entire life – every pill, every day, for life
- Taking other medicines, such as cotrimoxazole, as prescribed
- Giving medications, including ARVs and cotrimoxazole, to HIV exposed and HIV infected babies and children as prescribed
- Not taking any breaks from treatment

Non-adherence to care and treatment includes:

- Missing one or many appointments at the hospital or health centre, lab, or pharmacy – for herself or her baby

- Not following the care plan – for self or baby
- Missing one or more doses of medicine, or not giving the baby doses on time
- Sharing medicines with other people
- Stopping medicine for a day or many days (taking a treatment break)
- Taking or giving medicines at the wrong times
- Taking or giving medicines without following instructions about food or diet
- Not reducing risk-taking behaviour (for example, not practicing safer sex or not delivering a baby with a trained health care provider)

REMEMBER: No one is perfect. It is important not to judge clients if they are non-adherent. Instead, we should try to uncover the root causes of non-adherence and help find ways to resume good adherence as soon as possible.

Why is near-perfect adherence to PMTCT and ART medications important?

- To reduce the chance of MTCT at all stages (e.g. during pregnancy, during labour and delivery, during breastfeeding)
- To ensure that ART and other medications do their job and keep clients healthy
- To increase the CD4 cells and decrease the amount of HIV in the body
- To avoid the body becoming resistant to certain medicines
- To make sure the person gets all the benefits that ARVs and other medicines have to offer, such as feeling better, not getting opportunistic infections, etc.
- To monitor the person's health and also help her find community support resources for herself and her family
- To keep the person looking and feeling good so they can get back to normal life
- To keep families, communities, and our nation healthy and productive

See Appendix 6D: Key Counselling Messages on:

- ***Preparing to Start and Adhere to the PMTCT Regimen***
- ***Preparing to Start and Adhere to Lifelong ART***
- ***Continuing and Adhering to ART During Your Pregnancy***
(for women already on ART who become pregnant)

CASE STUDIES:

CASE STUDY 1:

Funeka is 14 weeks pregnant and her CD4 count is 650, so she will be starting the PMTCT regimen. The nurse asks you to counsel and prepare Funeka on adherence to her care and ARVs, that she will be given today.

(see Adhering to Your PMTCT Care Plan and Preparing to Start and Adhere to the PMTCT Regimen cue cards)

CASE STUDY 2:

Stephina is pregnant and started lifelong ART last week. She returns one week later and the nurse asks you to follow-up and counsel her on adherence to her care and ART.
(see Adhering to Your PMTCT Care Plan and Preparing to Start and Adhere to Lifelong ART cue cards)

CASE STUDY 3:

Paulina books at the clinic. She has been taking ART for the last 3 years and is excited to have a baby. Counsel her on adherence to ART during her pregnancy and for life.
(see Adhering to Your PMTCT Care Plan and Continuing and Adhering to Your ART During Pregnancy cue cards)

SESSION 6.5

PLANNING A SAFE LABOUR AND DELIVERY (50 MINUTES)



TRAINER INSTRUCTIONS

**Methodologies: Interactive Trainer Presentation, Small Group Work
Large Group Discussion, Case Studies, Role Play**

- Step 1:** Introduce the session by stating that, now, we will focus on the key counselling messages to help clients plan for and have a safe labour and delivery.
- Step 2:** Ask the small group assigned to this topic (*in Session 6.1*) to present the main points of their discussion back to the large group, focusing on common challenges women face related to having a safe labour and delivery and key counselling messages on labour and delivery. Give the group about 10 minutes to present and then open up the discussion to the large group.
- Step 3:** Using the content in the counselling cue cards called **HAVING A SAFE Labour AND DELIVERY** in *Appendix 6E*, review the key counselling messages on this topic, building on the small group presentation. Write key messages on flip chart or present them on slides. Refer participants to the counselling cue card in *Appendix 6E* and remind them how they can use the cue card in their work.
- Step 4:** Allow time for discussion and for participants to ask questions about the key messages, providing any updates on the national PMTCT guidelines, as needed.
- Step 5:** Break participants into groups of 3. Assign each small group one of the case studies below and ask one person to play the role of the lay counsellor, another to play the role of the client, and the third to play the role of observer. Remind participants that they should be creative and expand upon the information given in the case study. Encourage participants to use the extra copies of the counselling cue card to help guide the session and their key messages when they are playing the role of the lay counsellor. When they are playing the role of observer, they should use the cue card as a checklist. After about 10 minutes, stop the role plays and ask the observers to give feedback. Proceed as in the last session, where everyone gets the chance to play each role. The trainers should circulate and provide assistance as needed.
- Step 6:** Once everyone has had a chance to play the role of the lay counsellor, bring participants back to the large group and, as time allows, ask some of the small groups to present their role play to the large group.

Allow participants time to give feedback and debrief the activity using these questions:

- *What did the lay counsellor do well?*
- *What other points do you think the lay counsellor could have discussed with the client about having a safe labour and delivery?*
- *How did you use the counselling cue card during the role play? What was easy? What was challenging?*
- ***How do you think you can use this counselling cue card in your work?***

KEY INFORMATION

See Appendix 6E: Key Counselling Messages on Having a Safe Labour and Delivery

CASE STUDIES

CASE STUDY 1:

Seipati is 6 months pregnant. The nurse refers her to you because she has missed some of her clinic appointments and says that it is difficult for her to get to the clinic.

Seipati plans to deliver her baby with a midwife at home. Counsel her on having a safe labour and delivery.

(see Adhering to Your PMTCT Care Plan and Having a Safe Labour and Delivery cue cards)

CASE STUDY 2:

Mary is taking ART and wants to deliver her baby at the clinic, but her mother thinks it's better to follow family tradition and stay home for the birth. Mary is also worried her husband won't allow her to have transport money to go to the clinic.

Counsel Mary on having a safe labour and delivery and on talking to her family about why this is important.

(see Adhering to Your PMTCT Care Plan and Having a Safe Labour and Delivery cue cards)

SESSION 6.6

PREPARING TO SAFELY FEED THE BABY (50 MINUTES)



TRAINER INSTRUCTIONS

**Methodologies: Interactive Trainer Presentation, Small Group Work
Large Group Discussion, Case Studies, Role Play**

Step 1: Introduce the session by stating that, now, we will focus on the key counselling messages to help clients safely feed their babies. Remind participants that this session does not serve as an infant feeding training, and that lay counsellors should work closely with nurses in the clinic to provide infant feeding counselling.

Step 2: Ask the small group assigned to this topic (*in Session 6.1*) to present the main points of their discussion back to the large group, focusing on common challenges women face safely feeding their babies and key counselling messages on safe infant feeding. Give the group about 10 minutes to present and then open up the discussion to the large group.

Step 3: Using the content in the counselling cue card called **SAFELY FEEDING YOUR BABY** in *Appendix 6F*, review the key counselling messages on this topic, building on the small group presentation. Write key messages on flip chart or present them on slides. Refer participants to the counselling cue card in *Appendix 6F* and remind them of how the cue card can be used in their work.

Step 4: Allow time for discussion and for participants to ask questions about the key messages, providing any updates on the national PMTCT infant guidelines, as needed (e.g. the expanded emphasis on exclusive breastfeeding, the importance of mother or baby taking ARVs for the entire duration of breastfeeding, etc.)

Step 5: Break participants into groups of 3. Assign each small group one of the case studies below and ask one person to play the role of the lay counsellor, another to play the role of the client, and the third to play the role of observer. Remind participants that they should be creative and expand upon the information given in the case study. Encourage participants to use the extra copies of the counselling cue card to help guide the session and the key messages when they are playing the role of the lay counsellor. When they are playing the role of observer, they should use the cue card as a checklist.

After about 10 minutes, stop the role plays and ask the observers to give feedback. Proceed as in the last session, where everyone gets the chance to

play each role. The trainers should circulate and provide assistance as needed.

Step 6: Once everyone has had a chance to play the role of the lay counsellor, bring participants back to the large group and, as time allows, ask some of the pairs to present their role play to the large group. Allow participants time to give feedback and debrief the activity, using these questions:

- *What did the lay counsellor do well?*
- *What other points do you think the lay counsellor could have discussed with the client about safely feeding her baby?*
- *How did you use the counselling cue card during the role play? What was easy? What was challenging?*
- **How do you think you can use this counselling cue card in your work?**

KEY INFORMATION

See Appendix 6F: Key Counselling Messages on Safely Feeding Your Baby

CASE STUDIES

CASE STUDY 1:

Nellie is taking the PMTCT regimen and plans to breastfeed her baby. She comes to you for advice because she heard that it's safest to stop breastfeeding after 4 months so that the baby isn't exposed to HIV for too long. Counsel her on safely breastfeeding her baby. (see *Safely Feeding Your Baby – Breastfeeding cue card*)

CASE STUDY 2:

Xoliswa is giving her 4-week old baby formula, but he is sick a lot of the time. Counsel her on safely giving the baby formula. (see *Safely Feeding Your Baby – Formula Feeding cue card*)

SESSION 6.7

CLASSROOM PRACTICUM (60 MINUTES)



TRAINER INSTRUCTIONS

Methodologies: Small Group Work, Large Group Discussion, Case Studies, Role Play

- Step 1:** Break participants into small groups of 4. Refer to the case studies written in the Participant Folder. Ask the groups to assign one person to play the role of the lay counsellor, one the role of the client, and the others the role of observers. Explain that each small group will go through each of the 4 case studies, with group members shifting roles so that each person has the chance to play the role of the lay counsellor. Encourage participants to use the extra copies of the counselling cue cards to help guide the session and the key messages when they are playing the role of the lay counsellor. One of the observers should use the extra copies of the counselling cue cards as a checklist to ensure that all key messages are covered. The other observer should use the Counselling and Communication Checklist in *Appendix 6G* to ensure that the person playing the lay counsellor is using the key skills covered in Module 3.
- Step 2:** Ask the small groups to role play the first case study. After about 10 minutes, ask the observers to give feedback (on the content and key messages covered, as well as on the counselling and communication skills used during the role play). Ask the groups to change roles and move on to the second case study. Continue until all of the small groups have worked through each case study.
- Step 3:** If time allows, some groups can also do a short role play of their case study for the large group. Go over the key points and considerations of each case study as a large group and be sure to answer any questions. Debrief the activity by reminding participants that lay counsellors should be comfortable discussing the key counselling messages and information during sessions with pregnant women enrolled in PMTCT. The counselling cue cards can serve as a useful reminder of these key messages.



***There is no finer
investment for
any community
than putting milk
into babies***

Winston Churchill

KEY INFORMATION

CASE STUDIES

CASE STUDY 1:

Lumka is 14 weeks pregnant and just booked at the clinic. You deliver the news that her HIV test was positive and provide post-test counselling. After talking with her, you sense that she does not have very much information on PMTCT. Counsel Lumka on the key things she needs to know about PMTCT and having a healthy pregnancy.

(see PMTCT Basics, Staying Healthy During Your Pregnancy, and Adhering to Your PMTCT Care Plan cue cards)

CASE STUDY 2:

Janet is enrolled in the PMTCT programme and will begin the PMTCT regimen now that she is 14 weeks pregnant. Counsel her on adherence to her PMTCT care plan and the PMTCT regimen. Also talk with her about planning to have a safe labour and delivery.

(see Adhering to Your PMTCT Care Plan, Preparing to Start and Adhere to the PMTCT Regimen, and Having a Safe Labour and Delivery cue cards)

CASE STUDY 3:

Lungi is enrolled in the PMTCT programme. She began taking ART about one month ago, but complains that she is not feeling well and says that she wants to stop taking the medicine. Counsel Lungi on having a healthy pregnancy, on why ART is important, and on how she can adhere to her care plan and ART.

(see Adhering to Your PMTCT Care Plan, Preparing to Start and Adhere to Lifelong ART, and Staying Healthy During Your Pregnancy cue cards)

CASE STUDY 4:

Thandi has been on ART for about 3 years and her CD4 count is high. You meet her at the ANC clinic, where she is enrolled in the PMTCT programme. She is worried that the ART she has been taking will hurt her baby. Counsel Thandi on adherence to her PMTCT care plan and ART, and also on how she can safely breastfeed her baby once he or she is born.

(see Adhering to Your PMTCT Care Plan, Continuing and Adhering to Your ART During Pregnancy, and Safely Feeding Your Baby – Breastfeeding cue cards)



*The world is as many times
new as there are children
in our lives*

Robert Brault

SESSION 6.8

MODULE SUMMARY AND EVALUATION (15 MINUTES)



TRAINER INSTRUCTIONS

Methodologies: Large Group Discussion, Interactive Trainer Presentation

- Step 1:** Ask participants what they think are the key points of this Module. What information will they take away from the Module?
- Step 2:** Summarize the key points of the Module using participant feedback and the content below. Review the learning objectives with participants and make sure all are confident with their skills and knowledge in these areas.
- Step 3:** Ask if there are any questions or clarifications.
- Step 4:** Ask each participant to share with the group one thing he or she will do differently in his or her work as a lay counsellor or social worker, based on the information and skills learned in this Module
- Step 5:** Hand out a Module evaluation form to each participant (see *Appendix 6H*), and ask that they take about 5 minutes to fill it out and to return it to the trainers. Remind participants that they do not need to put their name on the form.



THE KEY POINTS OF THIS MODULE INCLUDE:

- Lay counsellors should be up-to-date and knowledgeable about the revised national PMTCT guidelines.
- Pregnant and postpartum women often have a number of psychosocial and adherence support needs. Their needs will depend on their specific situation and may also change over time.
- Lay counsellors can use cue cards to help remember key counselling messages for pregnant and postpartum women living with HIV and their families.
- When counselling, it is always important to use the 7 key counselling and communication skills from Module 3.
- It is important to counsel clients about PMTCT basics – starting during post-test counselling and over time. The PMTCT basics include important things about PMTCT and things clients can do to stay healthy and lower the chances that their baby will be HIV infected.
- The PMTCT motto is: You can save two lives – your own and your baby's!

- All pregnant women living with HIV need to take ARVs
- All babies born to mothers living with HIV need to take ARVs.
- Lay counsellors can help clients understand how they can have a healthy pregnancy, including coming to all clinic appointments, finding emotional support, getting a CD4 test and picking up the results, taking ARVs, getting their partner tested, practicing safer sex, preventing and treating STI and TB, eating enough nutritious foods, planning a safe delivery, and staying away from smoking, drugs and alcohol.
- Lay counsellors can help clients understand adherence to their PMTCT care plan, including coming to all clinic appointments (her own and her baby's), understating the reasons why these appointments are important, and making an adherence plan.
- Lay counsellors can help prepare clients to start taking the PMTCT regimen or lifelong ART and can provide follow-up adherence support over time. Lay counsellors should be able to explain why these medicines are important, that they are safe, how and when they are taken, and why adherence is important.
- Lay counsellors can help clients make an adherence plan that fits with their lives.
- Lay counsellors can help clients know what to do if they have side effects or miss ARV doses.
- Lay counsellors can help clients already on ART who become pregnant understand the importance of continuing ART during and after the pregnancy, and how ART helps the woman's health and PMTCT.
- Remember: It is important that lay counsellors follow-up with clients about adherence at EVERY clinic visit.
- Lay counsellors can help clients and their families plan on having a safe labour and delivery at a health facility and can help them understand that the mother and the baby need to take ARVs during this time.
- Lay counsellors can help clients decide the safest way to feed their baby, noting that the Department of Health in South Africa recommends exclusive breastfeeding for 6 months. They can also counsel clients on safely breastfeeding or formula feeding.

APPENDIX 6A

KEY COUNSELLING MESSAGES - PMTCT BASICS

PMTCT BASICS

Open the session and gather information

- *I would like to talk with you about how you can keep yourself and your baby healthy.*
 - *What concerns do you have for your baby?*
 - *What concerns do you have for your own health and well-being?*
-

These are some important things to know about your own and your baby's health

- Not all babies born to women living with HIV will become HIV infected.
 - If you, your partner, and your baby all get the care and medicines that are needed, you can lower the chances that your baby will become HIV infected.
 - **You can save 2 lives - your own and your baby's -** if you get services and take medicines to help you stay healthy and to help prevent passing HIV to your baby.
-

There are many things you can do to stay healthy and prevent your baby from becoming HIV infected

- **All pregnant women living with HIV need to take ARVs.** Taking ARVs will lower the chances that your baby will become HIV infected and can also improve your health.
 - All babies born to mothers living with HIV need to take ARVs. ARVs will help lower the chances that your baby will become HIV infected.
 - **Come back to the clinic for all of your appointments.**
 - Have a **safe delivery** at a health facility.
 - Plan how you will **feed your baby safely** to lower the chance that your baby will become HIV infected after he or she is born.
 - Try and find **emotional support**.
 - **Tell someone you trust about your HIV status** so they can help.
-

Together, we can lower the chances that your baby will be HIV infected

- We can help you learn more about the steps you can take during your pregnancy, delivery, and after your baby is born.
 - Be sure to come back to the clinic for all appointments and make sure you and your baby take medicines the right way.
 - If your baby is HIV infected, there is a lot we can do to keep him or her healthy.
-

Check understanding and plan next steps

- *How do you think you can stay healthy during your pregnancy and lower the chances that your baby will be HIV infected?*
- *How do you feel about talking to someone you trust about your HIV status?*
- *What questions do you have?*
- *Let's set up a time for your next appointment.*

APPENDIX 6B

KEY COUNSELLING MESSAGES -
STAYING HEALTHY DURING YOUR PREGNANCY

STAYING HEALTHY DURING YOUR PREGNANCY

Open the session and gather information

- *Many people living with HIV are healthy and able to live productive and fulfilling lives. Many pregnant women living with HIV are also able to stay healthy and prevent HIV infection in their babies.*
- *What are some of the things you think you can do to stay healthy during your pregnancy and to lower the chances that your baby will be HIV infected?*

Come to the clinic for all appointments during your pregnancy and after you deliver

- Come to the clinic for **at least 3 antenatal care visits**.
- Come back to the clinic **within 3-7 days of birth**.
- The next visit for you and your baby will be at **4-6 weeks after birth**.

Try and find the emotional support you need

- It is important that you have support to take care of yourself and your baby.
- Try to remember that you are not alone and that there are people who can support you.
- If you are feeling very anxious or like you have too much stress, or if you feel very down or depressed, it is important that you speak with a lay counsellor, nurse, or other health care provider.
- You may want to join a mother's support group to talk with other women going through a similar situation.

Make sure you get a CD4 test and that you come back to learn your CD4 test results

- The CD4 cells are the soldiers in our bodies that help us fight infections.
- HIV attacks the CD4 cells and it becomes more and more difficult for our bodies to fight infections.
- To know how many CD4 cells you have, the nurse will take a sample of blood from your arm and send it to the lab.
- It is very important that you pick up your CD4 test results.
- The higher your CD4 count, the better.

Take medicines called ARVs and give your baby ARVs

- All pregnant women living with HIV need to take ARVs.
- ARVs are safe for you and your baby.
- The type of ARVs that you take, and for how long, depends on your CD4 count and how advanced your HIV is.
- It is important to start taking ARVs early in pregnancy.
- All babies born to women living with HIV also need to take ARVs.
- The type of ARVs your baby will take, and for how long, depends on your CD4 count, how advanced your HIV is, which ARVs you take during pregnancy, and how you feed the baby.
- ARVs do not cure HIV. There is no cure for HIV.

Take medicines called ARVs and give your baby ARVs

- You will also need to take a medicine called cotrimoxazole every day to prevent infections.
- It is important that you always take your medicines at the same time, every day.
- Never share your medicines with other people.

Ask your partner to get an HIV test too

- If you want, we can talk about ways to get your partner to come for an HIV test.

Practice safer sex

- Always use a new male or female condom every time you have sex.
- Even though it can be hard, it is good to talk to your partner about using condoms.

Prevent and treat sexually transmitted infections (STIs)

- If you or your partner has signs of STIs, like itching, a rash, strange discharge, or sores around the genitals, come to the clinic.
- Many times women do not have any of these signs, so it is important that we test you for STIs to know for sure.
- If either you or your partner has an STI, both of you need to get treatment.

Prevent and treat tuberculosis (TB)

- Make sure you have a lot of fresh air in your home.
- Cover your mouth when you cough or sneeze.
- If you are living with someone who has TB, try to avoid very close contact, protect yourself, and support that person to get treatment at the clinic.
- If you have signs of TB, like coughing, night sweats, fever, or if you lose a lot of weight, come to the clinic right away.

Eat enough nutritious foods and get enough rest

- Eat more healthy foods than normal.
- Drink lots of fluids. Avoid alcohol.
- Take the vitamin and iron tablets that you get at the clinic.
- Try and get plenty of rest, especially in the last months of pregnancy.

Plan to deliver your baby safely

- Plan on having a safe delivery in the clinic.
- Talk with your partner and family members about how you will get to the clinic and why it is important to deliver your baby there.

Stay away from smoking, alcohol, and drugs

- Smoking, alcohol, and drugs will only hurt your own health and your baby's health and development.
- If you are having trouble quitting smoking, drinking alcohol, or taking drugs, we can help you or refer you for professional help to quit.

Check understanding and plan next steps

- **Can you tell me what you think are the most important things you can do to have a safe pregnancy – for yourself and your baby?**
- **How often will you come back to the clinic during your pregnancy? How about after you deliver?**
- **How is your pregnancy going so far?**
- **What questions do you have?**

APPENDIX 6C

KEY COUNSELLING MESSAGES - ADHERING TO YOUR PMTCT CARE PLAN

ADHERING TO YOUR PMTCT CARE PLAN

Open the session and gather information

- *It is very important that you come back to the clinic for all of your appointments – during the pregnancy and after your baby is born.*
 - *How do you think coming back to the clinic often during and after your pregnancy will help you and the baby stay healthy?*
-

Adherence means how faithfully you stick to and participate in your care plan

This includes:

- Coming to all of your clinic, lab, and pharmacy appointments.
 - Taking all of your medications and giving your baby medications the right way, at the right time, every day.
 - Following advice about how to take care of yourself and your baby during pregnancy and after the baby is born.
-

It is important that you come to all of your own and your baby's clinic appointments

- Come to the clinic for at least 4 antenatal care visits.
 - Come back to the clinic within 3-7 days of birth.
 - The next visit for you and your baby will be at 4-6 weeks after the birth.
 - Your baby should be seen every month until we know for sure if he or she is HIV infected or not.
-

All of these clinic visits are important

- The nurse will give you a check-up and may also take blood. This is to make sure that you are healthy and that your baby is doing well.
 - If something is wrong, the doctors and nurses will be able to quickly get you (or your baby) the treatment that is needed.
 - You will get the medicines and vaccinations that you and your baby need.
 - You will have a chance to have one-on-one counselling.
 - If you are feeling sick or have questions, you should come to the clinic even if you do not have an appointment.
-

It is important to make an adherence plan that fits with your life.

Here are some tips:

- Get support from people you trust.
 - If you cannot keep an appointment, call the clinic and then come as soon as possible.
 - Be sure to come back to the clinic before your or your baby's medicines run out.
 - If you are planning to be away, we can give you extra medicines.
 - Plan ahead if you will need money for transport to the clinic.
 - Write down the dates of your appointments and ask someone to help remind you.
 - Join a mothers' support group.
-

Check understanding and plan next steps

- *Can you tell me why you think it is important to come back to the clinic for all of your appointments?*
- *What will help you remember to come back for appointments? What challenges do you think there will be?*
- *What questions do you have?*

APPENDIX 6D

KEY COUNSELLING MESSAGES -
ADHERING TO THE PMTCT REGIMEN OR LIFELONG ART



PREPARING TO START AND ADHERE TO THE PMTCT PROGRAMME

Open the session and gather information

- *Because your CD4 count is over 350 and you do not have advanced HIV or AIDS, we would like you to start taking AZT 2 times every day (starting at 14 weeks of pregnancy) and to continue taking it throughout your pregnancy to help lower the chances that your baby will be HIV infected.*
- *How do you feel about taking AZT every day during your pregnancy?*

We recommend that you start taking a medicine called AZT at 14 weeks of pregnancy

- ARVs are medicines that help lower the amount of HIV in the body.
- This medicine is safe for you and your baby.
- We will give you AZT during your pregnancy to help protect your baby from HIV.
- It is important to start taking AZT right away when you are 14 weeks pregnant.
- You should take AZT twice a day, until you give birth.
- It is important to keep taking your AZT during your labour and delivery. Bring your medicines with you wherever you deliver.
- The nurse or doctor will also give you other ARVs during your labour and right after the baby is born.
- Your baby will also need to take ARV syrup once every day until you stop breastfeeding to lower the chances that he or she will be HIV infected (or for 6 weeks if not breastfed).

Adherence means how faithfully you stick to and participate in your care and treatment plan

- Coming to all of your clinic, lab, and pharmacy appointments – during and after the pregnancy - and ongoing.
- Taking medicines to prevent and treat infections.
- Taking your ARVs the right way, every day, for as much time as the doctor says. For AZT, this means taking your doses every morning and every evening, every day during your pregnancy.

Why adherence to your care and AZT is important

- Coming to all of your clinic appointments will help you get the care, tests, and medicines you need.
- If you take your AZT the right way, every day, there is a much lower chance that your baby will become HIV infected.
- AZT protects your baby from HIV.

Check understanding

- *What do you think are some things that will help you remember to come back to the clinic and to take your AZT every day?*
- *Who is closest to you in your family? How do you feel about talking to him or her about your care and medicines?*

It is important to make an adherence plan that fits with your life.

Here are some tips:

- Try and talk with someone you trust so you have support to come to the clinic and to take your medicines.
- Make sure you understand your care and treatment plan.
- Be sure to ask me or another health care worker here at the clinic if you have a question.
- Come to all of your appointments at the clinic. If you cannot keep an appointment, call the clinic, and then come as soon as possible.
- Take your AZT the right way, at the same time, every day.
- Try to make your medicine a part of everyday life by fitting it in with things you do normally (like eating breakfast, putting the children to bed, praying, etc.)
- Use reminders, such as a mobile phone, watch, pill box, or medicine calendar.
- Pick up your medicines on time, before they run out.
- Plan ahead if you will need to take your AZT when you are away from home, including during your labour and delivery.
- Join a support group to talk with other women in the same situation.
- All of us at the clinic are also here to help and support you.

What to do about AZT side effects

- Side effects from AZT are usually not serious and most go away after a couple of weeks.
- Keep taking your AZT, even if you have some side effects at first.
- Some side effects caused by AZT are nausea, vomiting, headache, and diarrhoea. These are usually not serious.
- **Come to the clinic right away** if you have a red rash, high fever, problems breathing, a bad headache, numbness in your hands or feet, or very bad vomiting or diarrhoea.
- It is important to keep taking your iron pills while you take AZT to prevent anemia.
- Never make the decision alone to stop taking your AZT. Instead, come to the clinic right away to talk with the nurse or doctor.

What to do about missed AZT doses

- If you miss a dose of AZT, take the missed dose if your next dose is scheduled for more than 6 hours away.
- Do not take the missed dose if the next dose is less than 6 hours away.
- Never take 2 doses at the same time.
- If you are not sure, call or come to the clinic to ask the nurse.

Check understanding and plan next steps

- *Why is it important to take your AZT twice a day every day during your pregnancy?*
- *Who or what will help you remember to take your AZT every day and to come back to the clinic for your appointments?*
- *What challenges do you think you will face taking your medicines every day?*
- *What will you do if you have side effects?*
- *What questions do you have about your care plan or your medicines?*

APPENDIX 6E

KEY COUNSELLING MESSAGES -
PREPARING TO START AND ADHERE TO LIFELONG ART



PREPARING TO START AND ADHERE TO LIFELONG ART

Open the session and gather information

- *Because your CD4 count is below 350 (or your exam showed that you have advanced HIV or AIDS), we recommend that you start taking ART now, and keep taking it during your pregnancy and for your whole life.*
 - *Starting ART now and taking ART for your whole life will help lower the chances that your baby will be HIV infected and help you live longer and stay well.*
 - *How do you feel about taking ART during pregnancy? For your whole life?*
-

We recommend that you start taking medicines called ART

- ARVs are medicines that help lower the amount of HIV in the body. When we take different ARVs at the same time (usually 3), we call this antiretroviral therapy, or ART.
 - These medicines are safe for you and your baby.
 - People with HIV can live long, healthy lives.
 - It is important to start ART early in pregnancy.
 - Taking these medicines for your whole life will lower the chance that your baby will be HIV infected and help keep you healthy.
 - You should take your ART twice a day, this usually means taking pills in the morning and in the evening for your whole life.
 - It is important to keep taking your ART during your labour and delivery. Bring your medicines with you wherever you deliver.
 - Your baby will also need to take ARV syrup every day for 6 weeks after he or she is born to lower the chances of HIV infection.
-

Adherence means how faithfully you stick to and participate in your care and treatment plan

- Coming to all of your clinic, lab, and pharmacy appointments – during and after the pregnancy - and ongoing.
 - Taking medicines to prevent and treat infections.
 - Taking your ART the right way, every day, during pregnancy and for your whole life.
-

Why adherence to your care and ART is important

- Coming to all of your clinic appointments will help you get the care, tests, and medicines you need.
- If you take your ART the right way, for your whole life, you will feel better and not get sick as often.
- There is also a much lower chance that your baby will become HIV infected.

Check understanding

- *What do you think are some things that will help you remember to come back to the clinic and to take your ART every day?*
 - *Who is closest to you in your family? How do you feel about talking to him or her about your care and medicines?*
-

It is important to make an adherence plan that fits with your life.

Here are some tips.

- Try and talk with someone you trust so you have support to come to the clinic and to take your medicines.
 - Make sure you understand your care and treatment plan. Be sure to ask me or another health care worker here at the clinic if you have a question.
 - Come to all of your appointments at the clinic. If you cannot keep an appointment, call the clinic, and then come as soon as possible.
 - Take your ART the right way, at the same time, every day.
 - Try to make your medicine a part of everyday life by fitting it in with things you do normally (like eating breakfast, putting the children to bed, praying, etc.)
 - Use reminders, such as a mobile phone, watch, pill box, or medicine calendar.
 - Pick up your medicines on time, before they run out.
 - Plan ahead if you will need to take your ART when you are away from home, including during your labour and delivery.
 - Join a support group to talk with other women in a similar situation.
 - All of us at the clinic are also here to help and support you.
-

What to do about ART side effects

- Side effects from ARVs are usually not serious and most go away after a couple of weeks.
 - Keep taking your ARVs, even if you have some side effects at first.
 - Some side effects caused by ARVs are nausea, vomiting, headache, and diarrhoea. These are usually not serious.
 - **Come to the clinic right away** if you have a red rash, high fever, problems breathing, a bad headache, numbness in your hands or feet, or very bad vomiting or diarrhoea.
 - It is important to keep taking your iron pills while you take ART to prevent anemia.
 - Never make the decision alone to stop taking your ART. Instead, come to the clinic right away to talk with the nurse or doctor.
-

What to do about missed ART doses

- If you miss a dose of ART, take the missed dose if your next dose is scheduled for more than 6 hours away.
 - Do not take the missed dose if the next dose is less than 6 hours away.
 - Never take 2 doses at the same time.
 - If you are not sure, call or come to the clinic to ask the nurse.
-

Check understanding and plan next steps

- *Why is it important to take your ART twice a day during your pregnancy? For your whole life?*
- *Who or what will help you remember to take your ART every day and to come back to the clinic for your appointments?*
- *What challenges do you think you will face taking your medicines every day during your pregnancy? For your whole life?*
- *What will you do if you have side effects?*
- *What questions do you have about your care plan or your medicines?*

APPENDIX 6F

KEY COUNSELLING MESSAGES - CONTINUING AND
ADHERING TO YOUR ART DURING PREGNANCY

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CONTINUING AND ADHERING TO YOUR ART DURING PREGNANCY

(For women on ART who become pregnant)

Open the session and gather information

- *How long have you been taking ART? Which ARVs do you take?*
 - *Now that you are pregnant, we will review some of the basics about ART and why it is important to continue taking ART while you are pregnant, after the baby is born, and for your whole life.*
 - *How have you felt taking ART so far? How do you feel about taking ART every day during your pregnancy?*
-

Taking ART helps lower the chances that your baby will be HIV infected and helps you live longer and stay well

- ARVs are medicines that help lower the amount of HIV in the body. When we take different ARVs at the same time (usually 3 kinds), we call this antiretroviral therapy, or ART.
 - These medicines are safe for you and your baby.
 - People with HIV can live long, healthy lives. ART does not cure HIV, but it can make you stay healthy and live a long life.
 - You should continue to take ART during your pregnancy and for the rest of your life to lower the chance that your baby will be HIV infected and to help keep yourself healthy.
 - You will take the same ARVs during your pregnancy that you were taking before, unless you were taking a drug called efavirenz. (show new ARVs if regimen will change)
 - You should continue to take your ART at the same time every day. This usually means taking pills in the morning and in the evening for your whole life. (review dosing)
 - It is important to keep taking your ART during your labour and delivery. Be sure to bring your medicines with you wherever you deliver.
 - Your baby will also need to take ARV syrup for 6 weeks after birth.
-

Adherence means how faithfully you stick to and participate in your care and treatment plan

- Coming to all of your clinic, lab, and pharmacy appointments – during and after the pregnancy - and ongoing.
 - Taking medicines to prevent and treat infections.
 - Taking your ART the right way, every day, during pregnancy and for your whole life.
-

Why adherence to your care and ART is important

- Coming to all of your clinic appointments will help you get the care, tests, and medicines you need.
- If you take your ART the right way, for your whole life, you will feel better and not get sick as often.
- There is also a much lower chance that your baby will become HIV infected.

Check understanding

- *Can you tell me about any adherence challenges you have had so far?*
 - *Do you think there will be new challenges now that you are pregnant?*
 - *What helps you remember to come to the clinic and take your medications?*
 - *Do you have support to take care of yourself and adhere to your care and medicines?*
-

It is important to make and adherence plan that fits with your life.

Here are some tips.

- Try and talk with someone you trust so you have support to come to the clinic and to take your medicines.
 - Make sure you understand your care and treatment plan. Be sure to ask me or another health care worker here at the clinic if you have a question.
 - Come to all of your appointments at the clinic. If you cannot keep an appointment, call the clinic, and then come as soon as possible.
 - Take your ART the right way, at the same time, every day.
 - Try to make your medicine a part of everyday life by fitting it in with things you do normally (like eating breakfast, putting the children to bed, praying, etc.)
 - Use reminders, such as a mobile phone, watch, pill box, or medicine calendar.
 - Pick up your medicines on time, before they run out.
 - Plan ahead if you will need to take your ART when you are away from home, including during your labour and delivery.
 - Join a support group to talk with other women in a similar situation.
 - All of us at the clinic are also here to help and support you.
-

What to do about ART side effects

- Side effects from ARVs are usually not serious and most go away after a couple of weeks.
 - Keep taking your ARVs, even if you have some side effects at first.
 - Some side effects caused by ARVs are nausea, vomiting, headache, and diarrhoea. These are usually not serious.
 - Come to the clinic right away if you have a red rash, high fever, problems breathing, a bad headache, numbness in your hands or feet, or very bad vomiting or diarrhoea.
 - It is important to keep taking your iron pills while you take ART to prevent anemia.
 - Never make the decision alone to stop taking your ART. Instead, come to the clinic right away to talk with the nurse or doctor.
-

What to do about missed ART doses

- If you miss a dose of ART, take the missed dose if your next dose is scheduled for more than 6 hours away.
 - Do not take the missed dose if the next dose is less than 6 hours away.
 - Never take 2 doses at the same time.
 - If you are not sure, call or come to the clinic to ask the nurse.
-

Check understanding and plan next steps

- *Why is it important to continue taking your ART the right way, every day, throughout your pregnancy and for your whole life?*
- *Who/what will help you remember to take your ART and come back to the clinic?*
- *What challenges do you think you will face taking your medicines every day?*
- *What will you do if you have side effects?*
- *What questions do you have about continuing your care and treatment plan?*

APPENDIX 6G

KEY COUNSELLING MESSAGES -
HAVING A SAFE LABOUR AND DELIVERY

HAVING A SAFE LABOUR AND DELIVERY

Open the session and gather information

- *There is a chance that HIV will be passed from a mother living with HIV to her baby during labour and delivery.*
 - *What are some of the things you think you can do to lower this chance?*
 - *Can you tell me more about your plans for your baby's birth, such as where you plan to deliver?*
 - *Are there any traditional customs you will follow during or after your baby's birth?*
-

Have a safe delivery in a health care facility

- Deliver your baby in a clinic. Any woman can have complications during delivery, and health care workers know how to take care of you in case of these complications.
 - Plan where you want to give birth to your baby, and how you will get there.
 - Find someone you trust who can give you emotional support during labour and delivery.
 - Bring your health card and ARVs to the clinic. Tell the health care worker of your HIV status and any medicines, such as ARVs, you have taken.
-

You will need to take ARVs during labour and delivery

- If the nurse gave you a **single dose of nevirapine** during an antenatal visit, take it as soon as you go into labour.
 - If you are taking **ART** during your pregnancy, be sure to bring your medicines to the clinic and keep taking them.
 - If you are taking **AZT during your pregnancy**, continue taking the AZT during labour. You will be given one other medicine to take at delivery and after the baby is born.
 - If you haven't taken any ARVs during your pregnancy, the doctor or nurse will give you ARVs to take.
-

Your baby needs to take ARVs right after he or she is born, and for some time after that

- ARVs are **safe** and will help protect your baby from HIV.
 - Your baby needs to take **nevirapine syrup as soon as possible after birth - within 72 hours (3 days) of delivery.**
 - Your baby will also need to take **ARVs for some time after he or she is born.**
-

Taking care of yourself and your baby after the delivery

- What babies need most after delivery is to be loved. Spend as much time as you can with the baby skin-to-skin on your chest. Cuddle, sing, and talk to the baby.
 - Your baby will need to eat within one hour of being born.
 - Be sure to take care of yourself by resting (with your baby, if possible), drinking lots of fluids, and eating healthy foods.
-

Check understanding and plan next steps

- *Can you tell me how you plan to have a safe labour and delivery?*
- *What questions do you have?*

APPENDIX 6H

KEY COUNSELLING MESSAGES -
SAFELY FEEDING YOUR BABY

SAFELY FEEDING YOUR BABY

BREASTFEEDING

Open the session and gather information

- *Breast milk is the best food for all babies.*
- *There are many things you can do to safely feed your baby.*
- *Can you tell me how you plan to feed your baby?*
- *In your family, are there any special foods given to babies or traditional customs related to babies?*

It is important for you to exclusively breastfeed your baby for as long as possible, up to 6 months

- Exclusive breastfeeding means giving your baby ONLY breast milk and no other liquids or foods, like water, herbal mixtures, juice, porridge, or cow's milk.
- It is okay to give the baby medicines that you get from the doctor or nurse.
- Breast milk is the only food your baby needs until he or she is 6 months old.
- Breast milk is healthy, free, and prevents your baby from being exposed to diseases that can cause diarrhoea or even death.
- Babies should start breastfeeding within one hour of birth.
- Babies should breastfeed at least 8 times every day (per 24 hours, this means about every 3 hours).
- It is important that your baby has a good latch onto your breast so that you are comfortable and so that he or she gets enough milk.

You can lower the chances of passing HIV to your baby through breast milk

- If you are on ART while you are breastfeeding, take your medicines every day at the same time. This will lower the chance of passing HIV to your baby.
- If you are not on ART while you are breastfeeding, your baby needs to take ARVs every day for protection against HIV. Give your baby nevirapine syrup once every day – at the same time every day - for as long as you are breastfeeding.
- Make sure your baby does not have any other liquids or foods other than breast milk and medicines for the first 6 months.
- If you have cracked, sore, or painful nipples, come to the clinic.
- If you see white spots in the baby's mouth, come to the clinic.

Your baby will need foods in addition to breast milk after 6 months

- Once your baby is 6 months old, he or she will need to have other foods to get the nutrition he or she needs to grow and develop.
- Your baby can have both breast milk and other foods until he or she is 1-2 years old.
- It is important for your baby to continue taking ARVs as long as you are breastfeeding.
- You should only stop breastfeeding if you have enough healthy foods and milk to feed your baby.
- If your baby is HIV infected, breast milk will help keep him or her healthy.
- When you want to stop breastfeeding, slowly wean your baby. Stopping quickly can be painful for you and bad for the baby.

Check understanding and plan next steps

- *Can you tell me how you plan to safely breastfeed your baby?*
- *What challenges do you think you will face with exclusive breastfeeding?*
- *How do you think you will deal with these challenges?*
- *What questions do you have about safely breastfeeding your baby?*

FORMULA FEEDING

Formula feeding is only safe for you and your baby if all of the following are true

- You and your family will accept that the baby is formula fed.
- You have the time to prepare the formula and feed your baby as many as 12 times in 24 hours.
- You can afford everything that you need to prepare the formula for as long as your baby needs it (bottles/cups, formula, way to boil water, brushes to clean bottles/cups)
- You will have access to all that you need to safely prepare the formula for as long as your baby needs it.
- AND you have access to clean water and a way to boil it.

It is important for you to exclusively formula feed your baby up to 6 months

- Exclusive formula feeding means giving your baby **ONLY** formula and no other liquids or foods, like herbal mixtures, juice, porridge, or cow's milk.
- It is okay to give the baby medicines you get from the doctor or nurse.
- It is important that you do not breastfeed your baby - not even one time.
- Giving the baby both formula and breast milk increases the chance that your baby will become HIV infected.

It is important to prepare the formula safely every time to prevent your baby from getting sick: (demonstrate safe preparation of formula)

- Always get the water from a safe source, like a faucet.
- Always boil the water and allow it to cool before mixing the formula.
- Always put the cooled water in a clean bottle or cup first, and then add the formula powder.
- To add the powder, use the scoop that comes inside the tin. Make sure you use the correct amount of formula powder for each feeding.
- In order to completely clean the bottle and teat or feeding cup so you can use them again, first use soap and a cleaning brush. Then put the bottles in a pot of water and boil them for at least 5 minutes. Then cover and store the bottles in a clean place so they do not get dirty before using them again.

After 6 months, your baby needs foods in addition to formula:

- Once your baby is 6 months old, he or she will need to have other foods to get the nutrition he or she needs.
- Your baby can have both formula and other foods until 1-2 years old.
- You should only stop giving formula if you have enough other healthy foods and milk to feed your baby.

Check understanding and plan next steps

- *Can you tell me how you plan to safely feed your baby with formula?*
- *What challenges do you think you will face exclusively formula feeding your baby?*
- *How do you think you will deal with these challenges?*
- *What questions do you have about safely feeding your baby with formula?*

APPENDIX 6I

COUNSELLING AND COMMUNICATION CHECKLIST



APPENDIX 6I

COUNSELLING AND COMMUNICATION CHECKLIST

SKILL	SPECIFIC STRATEGIES, STATEMENTS, BEHAVIOURS	TICK
Establish a relationship with the client	• Ensure privacy (make sure others cannot see or hear).	
	• Introduce yourself (name and role).	
	• Ask the client to introduce herself (or himself) to you.	
	• Ensure client about confidentiality / explain shared confidentiality	
	• Start the session with an open-ended question (" <i>Where would you like to start?</i> " or " <i>Tell me more about why you came today.</i> ")	
SKILL 1: Use helpful non-verbal communication	• Make eye contact.	
	• Face the person (sit next to her or him) and be relaxed and open with posture.	
	• Use good body language (nod, lean forward, etc.).	
	• Smile.	
	• Do not look at your watch, the clock or anything other than the client.	
	• Do not write during the session.	
	• Other (specify)	
SKILL 2: Actively listen and show interest in your client	• Nod and smile. Use encouraging responses (such as " <i>yes,</i> " " <i>okay</i> " and " <i>mm-hmm</i> ").	
	• Use a calm tone of voice that is not directive.	
	• Allow the client to express emotions.	
	• Do not interrupt.	
	• Other (specify)	
SKILL 3: Ask open-ended questions	• Use open-ended questions to get more information.	
	• Ask questions that show interest, care and concern.	
	• Other (specify)	
SKILL 4: Reflect back what your client is saying	• Reflect emotional responses back to the client.	
	• Other (specify)	
SKILL 5: Show empathy, not sympathy	• Demonstrate empathy: show an understanding of how the client feels.	
	• Avoid sympathy.	
	• Other (specify)	
SKILL 6: Avoid judging words	• Avoid judging words such as " <i>bad,</i> " " <i>proper,</i> " " <i>right,</i> " " <i>wrong,</i> " etc.	
	• Use words that build confidence and give support (e.g., recognize and praise what a client is doing right).	
	• Other (specify)	
SKILL 7: Help your client set goals and summarize each counselling session	• Work with the client to come up with realistic "next steps."	
	• Summarize the main points of the counselling session.	
	• Make a next appointment date with the client and reassure her or him that you, or someone else at the clinic, are always available.	

APPENDIX 6J

MODULE 6 EVALUATION FORM



APPENDIX 6J

MODULE 6 EVALUATION FORM

Name (optional): _____ Health Facility: _____ Position: _____

Please note the following statements on a scale of 1 to 5:

	 Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	 Strongly Agree
1. The module objectives were clear	1	2	3	4	5
2. This module met my expectations	1	2	3	4	5
3. The technical level of this module was appropriate	1	2	3	4	5
4. The pace of speed of this module was appropriate	1	2	3	4	5
5. The facilitators were engaging and informative	1	2	3	4	5
6. The information I learned in this module will be useful to my work	1	2	3	4	5

How helpful were each of the workshop sessions to you and your work?

You can write extra comments on the back.

	 Not Helpful				 Very Helpful
The Counselling and Support Needs of Pregnant Women Living with HIV	1	2	3	4	5
Staying Healthy During Pregnancy	1	2	3	4	5
Adhering to the PMTCT Care Plan	1	2	3	4	5
Preparing Women to Start and Adhere to the PMTCT Regimen or Lifelong ART	1	2	3	4	5
Planning a Safe Labour and Delivery	1	2	3	4	5
Preparing to Safely Feed the Baby					
Classroom Practicum					

What was the BEST THING about this Module?

What was NOT USEFUL about this Module?

Do you have other comments (use the back of the page if needed)?



*Let us be grateful
to the people who
make us happy, they
are the charming
gardeners who make
our souls blossom*

Marcel Proust

MODULE 7

Providing Supportive PMTCT Counselling - After the Baby is Born



MODULE 7

Providing Supportive PMTCT Counselling - After the Baby is Born



CONTENT

- Session 7.1:** The Counselling and Support Needs of Postpartum Women and Caregivers
- Session 7.2:** Postpartum Care for the Mother
- Session 7.3:** Caring for an HIV - Exposed Baby and Adhering to Care and Medicines
- Session 7.4:** Supporting Safe Infant Feeding
- Session 7.5:** Testing the Baby or Child for HIV
- Session 7.6:** Caring for an HIV - Infected Child
- Session 7.7:** Classroom Practicum
- Session 7.8:** Module Summary and Evaluation



DURATION

410 minutes (6 hours, 50 minutes)



LEARNING OBJECTIVES

By the end of this Module, participants will be able to:

- Understand the key counselling messages for postpartum women living with HIV and their HIV - exposed infants
- Counsel clients on their own postpartum care
- Counsel clients on caring for an HIV - exposed infant
- Counsel clients on adherence to care and medicines for HIV - exposed infants
- Counsel clients on safer infant feeding, including complementary feeding starting at age 6 months
- Counsel clients on early infant HIV diagnosis
- Counsel clients/caregivers on caring for an HIV - infected child
- Use cue cards to guide counselling sessions on the above topics



PREVIOUS TRAINING/KNOWLEDGE REQUIRED FOR THIS MODULE

- Basic knowledge about PMTCT protocols and guidelines
- Experience in HIV counselling and testing (e.g., VCT and PICT), PMTCT, and ARV/ART education/counselling
- Completion of Modules 1-6 of this lay lay counsellor training curriculum



METHODOLOGIES:

- Interactive Trainer Presentation
- Brainstorming
- Large Group Discussion
- Small Group Work
- Case Studies
- Role Play



MATERIALS NEEDED

- Flip chart and stand
- Markers/Khokí's
- Tape or Bostik
- Extra copies of *Appendices 7A-G* for each participant
- Participant Handouts for Module 7 (to be inserted into the Participant Folder)



WORK FOR THE TRAINER TO DO IN ADVANCE

- Read through the entire Module and make sure you are familiar with the training methodologies and content.
- Write the Module learning objectives on flip chart or list them on a PowerPoint slide.
- Carefully review the case studies in all of the sessions.
- Make extra copies of *Appendices 7A-G* for each participant

*Every child begins
the world again*

Henry David Thoreau



SESSION 7.1

THE COUNSELLING AND SUPPORT NEEDS OF POSTPARTUM WOMEN AND CAREGIVERS (45 MINUTES)



TRAINER INSTRUCTIONS

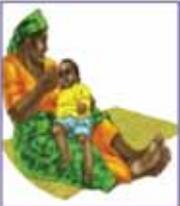
Methodologies: Interactive Trainer Presentation, Brainstorming, Large Group Discussion, Small Group Work

- Step 1:** Review the Module learning objectives and ask if there are any questions. Explain that, in this Module, we will learn more about the specific counselling messages and the information to discuss in sessions with postpartum women living with HIV and with caregivers of children living with HIV. Explain that we will also become more familiar with the counselling cue cards that can be used to guide counselling sessions with postpartum women and caregivers (similar to Module 6).
- Step 2:** Present the PMTCT care spectrum to participants (review from Module 2). Ask participants to think back to Modules 2 and 5, and also to their experiences as lay counsellors. Ask participants to brainstorm what they think are the most important psychosocial support needs of women living with HIV **AFTER THEY HAVE A BABY**. What about adherence support needs after the baby is born? Record on flip chart.
- Step 3:** Next, break the participants into 5 small groups. Assign each group one of the following topics:
- Postpartum Care for the Mother
 - Caring for an HIV Exposed Baby and Adhering to Care and Medicines
 - Supporting Safe Infant Feeding
 - Testing the Baby or Child for HIV
 - Caring for an HIV Infected Child
- Ask each group to think about their topic area and to discuss the following questions, noting main points on flip chart:
- *What are some of the adherence and psychosocial challenges postpartum women and/or caregivers face related to this topic?*
 - *What are the key counselling messages you would focus on for this topic?*
- Step 4:** After about 20 minutes, bring the large group back together and explain that, throughout the day, the small groups will be presenting back the key points of their discussions.

Step 5: Remind participants of the 7 key communication and counselling skills (from Module 3). Conduct a short review of the skills by asking participants to give examples of each of the 7 skills. Tell participants that they will continue to apply these skills in this Module, as they learn more about counselling postpartum women living with HIV and caregivers of HIV exposed and HIV infected children.

KEY INFORMATION

Note: This is a review from Modules 2, 3 and 5.

PMTCT CARE SPECTRUM from Pregnancy to 18months Post Partum						
ANTEPARTUM	INTRAPARTUM	1 - 6 wks	6wks - 6 mths	6 - 9 mths	9 -12 mths	12 - 18 mths
						
<ul style="list-style-type: none"> • Routine HIV test in ANC • WHO staging & CD4 testing • Commence AZT at 14 weeks • ART Initiation • Screening for TB, STI & Pap smear • Comprehensive Counselling • Repeat HIV test at 32 wks for Neg women 	<ul style="list-style-type: none"> • Status unknown - Routine HIV test in L&D • Sd-NVP with TDF + FTC • AZT 3-hourly • FP Counselling • NVP infant dose • Comprehensive Counselling including Infant Feeding Support 	<ul style="list-style-type: none"> • Maternal postnatal check-up • Maternal CD4 & Pap smear if not done • Enrollment into Wellness/CCMT • FP & Infant Feeding Counselling • NVP for all HIV Exposed Infants (HEIs) • PCR testing at 6 wks • CTX Initiation • Growth Monitoring 	<ul style="list-style-type: none"> • Catch up missed PCR testing • Repeat maternal CD4 at 6 mths • Growth monitoring • CTX + NVP continuation IF breastfeeding • HIV infected infants: ART initiation • Infant Feeding Counselling 	<ul style="list-style-type: none"> • Growth monitoring • CTX + NVP continuation IF breastfeeding • Infant Feeding Counselling • Repeat PCR 6wks after weaning 	<ul style="list-style-type: none"> • Growth monitoring • CTX + NVP continuation IF breastfeeding • PCR testing 6wks after weaning • Infant Feeding Counselling & Support 	<ul style="list-style-type: none"> • PCR testing: 6wks after weaning • Antibody testing for all HIV negative infants at 18 months • Final infection status known • Child discharged from PMTCT programme

Common psychosocial support needs among postpartum women living with HIV:

- Discussing their feelings and concerns about their HIV status and the effects it has on their own and their family's lives
- Discussing fears of passing HIV to the baby
- Empathy and acceptance from partner and family members
- Support in understanding and coming to terms with their HIV status
- Support to continue her own care and treatment
- Support to safely feed the baby
- Support to bring the baby for follow-up care, testing, and treatment
- Peer support from other mothers
- Strategies to disclose their HIV status to their partner and other family members, as well as to children living with HIV
- Strategies to encourage their partner and other family members to test and, if appropriate, enroll into care and treatment programmes
- Strategies and support for positive living
- Strategies and support for positive prevention, including in discordant couples
- Access to community-based organizations and support groups
- Access to nutrition support for self and family
- Access to social grants and income-generating activities
- Spiritual support and referrals to spiritual counselling
- Knowledge about their legal issues and rights
- Support for mental health, including anxiety and depression
- Substance abuse management

Common adherence support needs among postpartum women living with HIV

- Discussing their commitment to, and understanding of, their own and their child's care and treatment plan
- Making an adherence plan for their own and the baby's care and treatment, including anticipation of barriers and challenges and solutions to overcome them
- Discussing challenges to attending appointments and tests at the clinic, including routine follow-up of the baby and early infant diagnosis
- Discussing views about giving a baby medication
- Discussing challenges to taking their medicine the right way, every day, and giving the baby medicines the right way, every day
- Strategies to help them remember to take/give their medicine the right way, every day
- Discussing challenges to picking up their own and the baby's medicines before running out
- Support in overcoming any challenges to adherence, which will change over time

Reminder of Key Counselling and Communication Skills (from Module 3):

There are 7 essential skills that lay counsellors and social workers should practice and use in their work:

Skill 1: Use helpful non-verbal communication.

Skill 2: Actively listen and show interest in the client.

Skill 3: Ask open-ended questions.

Skill 4: Reflect back what the client is saying.

Skill 5: Empathize—show that you understand how the client feels.

Skill 6: Avoid words that sound judging.

Skill 7: Help the client set goals and summarize each counselling session.



SESSION 7.2

POSTPARTUM CARE FOR THE MOTHER (60 MINUTES)



TRAINER INSTRUCTIONS

Methodologies: Interactive Trainer Presentation, Small Group Work, Large Group Discussion, Case Studies, Role Play

- Step 1:** Introduce the session by stating that, now, we will focus on the key counselling messages to help clients take care of themselves after their babies are born.
- Step 2:** Ask the small group assigned to this topic (in *Session 7.1*) to present the main points of their discussion back to the large group, focusing on common challenges women face in taking care of themselves after their babies are born and key counselling messages on postpartum care. Give the group about 10 minutes to present and then open up the discussion to the large group.
- Step 3:** Using the content in the counselling cue card called **TAKING CARE OF YOURSELF AFTER YOUR BABY IS BORN** in *Appendix 7A*, review the key counselling messages on this topic, building on the small group presentation. Write key messages on flip chart or present them on slides. Refer participants to the counselling cue card in *Appendix 7A*.
- Step 4:** Ask participants how they could use this cue card (and others) in their work. Review how lay counsellors can best use the cue cards to guide their counselling sessions, using the content below, emphasizing that they are to be used as a guide, not as a script.
- Step 5:** Allow time for discussion and for participants to ask questions about the key messages. Be sure to review relevant changes in the national PMTCT guidelines.
- Step 6:** Break participants into groups of 3. Assign each small group one of the case studies below and ask one person to play the role of the lay counsellor, another to play the role of the client, and the third to play the role of observer. Remind participants that they should be creative and expand upon the information given in the case study.

Hand out extra copies of the cue cards to each participant. Encourage participants to use the counselling cue card to help guide the session and their key messages when they are playing the role of the lay counsellor. When they are playing the role of observer, they should use the cue card as a checklist.

Remind participants of the key counselling messages for antenatal care discussed in Module 6 (including the need for the mother to continue taking ARVs or ART postpartum) and encourage them to weave these messages into the role plays, as appropriate.

After about 10 minutes, stop the role plays and ask the observers to give feedback. Then, ask the small groups to switch roles and to conduct another role play. Do this until everyone has had a chance to play each role. The trainers should circulate and provide assistance as needed.

Step 7: Once everyone has had a chance to play the role of the lay counsellor, bring participants back to the large group and, as time allows, ask some of the small groups to present their role play to the large group. Allow participants time to give feedback and debrief the activity using these questions:

- *What did the lay counsellor do well?*
- *What other points do you think the lay counsellor could have discussed with the client about taking care of herself after her baby is born?*
- *How did you use the counselling cue card during the role play? What was easy? What was challenging?*
- **How do you think you can use this counselling cue card in your work?**

KEY INFORMATION

See Appendix 7A: Taking Care of Yourself after Your Baby is Born

How to Use the PMTCT Counselling Cue Cards

- This set of counselling cue cards was developed to support a range of providers, including lay counsellors, who work with pregnant women living with HIV and their families.
- It may be helpful to translate the cards into the local languages spoken by clients.
- Each of the cards focuses on a specific topic important to the care and support of pregnant women living with HIV, their children, and families across the PMTCT continuum of care.
- Lay counsellors may use the cue cards as job aides and reminders of key information to cover during initial post-test and ongoing counselling sessions with pregnant women and newly delivered mothers, their partners, family members, and supporters.
- The cue cards are just a guide. Each counselling session will be different depending on the client's specific needs.
- Lay counsellors should not read directly from the cue cards, but instead should use them as a guide and a reminder of the key points to cover on specific topics.

- The cue cards do not have to be used in sequence, but instead should be used according to the client's specific needs and concerns during the session.
- Good counselling and communication skills, such as active listening, being attentive to the client's questions and specific needs, and avoiding lecturing and one-way communication, should always be used, no matter what the counselling topic.

Please note:

- The cue cards have **2 columns**. The column on the left-hand side gives the lay counsellor guidance on the major subjects to discuss about the specific topic. The column on the right-hand side gives specific questions for the lay counsellor to ask and specific points about the topic area to be covered. Remember, this is just a guide and each counselling session will depend on the client's specific situation.
- **Key questions** are included in *italics*, and may be used to initiate discussions, learn more about what the client already knows and her specific concerns, and to gauge understanding and elicit follow-up questions.
- **Notes to guide lay counsellors** are also included in *italics*.

CASE STUDIES

CASE STUDY 1:

Palesa found out she was HIV positive during her pregnancy, and just gave birth to her baby this morning. Talk with her about the key things she needs to know in order to stay healthy now that her baby is here.

(see Taking Care of Yourself After Your Baby is Born cue card)

CASE STUDY 2:

Relebohile found out she was HIV positive during her most recent pregnancy, and just gave birth to her fifth child. The nurse refers Relebohile to you and asks that you counsel her on how to stay healthy now that her baby is here.

(see Taking Care of Yourself After Your Baby is Born cue card)

*Act as if what you do
makes a difference.*

It does.

William James



SESSION 7.3

CARING FOR AN HIV EXPOSED BABY AND ADHERING TO CARE AND MEDICINES (60 MINUTES)



TRAINER INSTRUCTIONS

Methodologies: Interactive Trainer Presentation, Small Group Work, Large Group Discussion, Case Studies, Role Play

- Step 1:** Introduce the session by stating that, now, we will focus on the key counselling messages to help clients and caregivers care for HIV exposed babies and adhere to the baby's care and medicines.
- Step 2:** Ask the small group assigned to this topic (in *Session 7.1*) to present the main points of their discussion back to the large group, focusing on common challenges women or caregivers face in caring for HIV exposed babies and adhering to care and medicines, and the key counselling messages addressing these issues. Give the group about 10 minutes to present and then open up the discussion to the large group.
- Step 3:** Using the content in the counselling cue card called **CARING FOR YOUR HIV EXPOSED BABY AND ADHERING TO CARE AND MEDICINES** in *Appendix 7B*, review the key counselling messages on this topic, building on the small group presentation. Write key messages on flip chart or present them on slides. Refer participants to the counselling cue card in *Appendix 7B* and remind them how they can use the cue card in their work.
- Step 4:** Allow time for discussion and for participants to ask questions about the key messages. Be sure to review relevant changes in the national PMTCT guidelines, including ARVs for the mom or baby for the duration of breastfeeding.
- Step 5:** Break participants into groups of 3. Assign each small group one of the case studies below and ask one person to play the role of the lay counsellor, another to play the role of the client, and the third to play the role of observer. Remind participants that they should be creative and expand upon the information given in the case study.

Hand out extra copies of the cue cards to each participant. Encourage participants to use the counselling cue card to help guide the session and their key messages when they are playing the role of the lay counsellor. When they are playing the role of observer, they should use the cue card as a checklist.

Remind participants of the key counselling messages for antenatal care discussed in Module 6 and encourage them to weave these messages into the role plays, as appropriate.

After about 10 minutes, stop the role plays and ask the observers to give feedback. Then, ask the pairs to switch roles and to conduct another role play. Do this until everyone has had a chance to play each role. The trainers should circulate and provide assistance as needed.

Step 6: Once everyone has had a chance to play the role of the lay counsellor, bring participants back to the large group and, as time allows, ask some of the small groups to present their role play to the large group. Allow all participants time to give feedback and debrief the activity using these questions:

- *What did the lay counsellor do well?*
- *What other points do you think the lay counsellor could have discussed with the client or caregiver about taking care of the HIV exposed child and adhering to care and treatment?*
- *How did you use the counselling cue card during the role play? What was easy? What was challenging?*
- ***How do you think you can use this counselling cue card in your work?***

KEY INFORMATION

See Appendix 7B: Taking Care of HIV Exposed Baby and Adhering to Care and Medicines

CASE STUDIES

CASE STUDY 1:

Mapaseka found out that she is HIV positive several years ago. She enrolled in the PMTCT programme and started lifelong ART. She recently gave birth to her first child. Talk with her about the key things she needs to know in order to take care of her HIV exposed baby and adhering to care and medicines.

(see Caring for Your HIV Exposed Baby and Adhering to Care and Medicines cue card)

CASE STUDY 2:

Lebohang's sister recently died of AIDS, and Lebohang is now the person taking care of her sister's 4-month old child. The nurse refers Lebohang to you and asks that you counsel her on taking care of the HIV exposed child and on adhering to care and medicines.

(see Caring for Your HIV Exposed Baby and Adhering to Care and Medicines cue card)

SESSION 7.4

SUPPORTING SAFE INFANT FEEDING (60 MINUTES)



TRAINER INSTRUCTIONS

Methodologies: Interactive Trainer Presentation, Small Group Work, Large Group Discussion, Case Studies, Role Play

Step 1: Introduce the session by stating that, now, we will focus on the key counselling messages to help clients and caregivers practice safe infant feeding.

Step 2: Ask the small group assigned to this topic (in *Session 7.1*) to present the main points of their discussion back to the large group, focusing on common challenges women or caregivers face safely feeding their infants and the key counselling messages on safe infant feeding. Give the group about 10 minutes to present and then open up the discussion to the large group.

Step 3: Using the content in the counselling cue cards called **EXCLUSIVELY BREASTFEEDING YOUR BABY; EXCLUSIVELY REPLACEMENT/FORMULA FEEDING YOUR BABY; and INTRODUCING COMPLEMENTARY FOODS TO YOUR CHILD AT 6 MONTHS** in *Appendix 7C*, review the key counselling messages on this topic, building on the small group presentation. Write key messages on flip chart or present them on slides. Refer participants to the counselling cue card in *Appendix 7C* and remind them how they can use the cue cards in their work.

Step 4: Allow time for discussion and for participants to ask questions about the key messages. Be sure to discuss changes to the national PMTCT guidelines, including the promotion of safe breastfeeding (with ARVs) and ARVs for the mom or baby for the duration of breastfeeding.

Step 5: Break participants into groups of 3. Assign each small group one of the case studies below and ask one person to play the role of the lay counsellor, another to play the role of the client, and the third to play the role of observer. Remind participants that they should be creative and expand upon the information given in the case study.

Hand out extra copies of the cue cards to each participant. Encourage participants to use the counselling cue cards to help guide the session and their key messages when they are playing the role of the lay counsellor. When they are playing the role of observer, they should use the cue card as a checklist. Remind participants of the key counselling messages for antenatal care discussed in Module 6 and encourage them to weave these messages into the role plays, as appropriate.

After about 10 minutes, stop the role plays and ask the observers to give feedback. Then, ask the small groups to switch roles and to conduct another role play.

Do this until everyone has had a chance to play each role. The trainers should circulate and provide assistance as needed.

Step 6: Once everyone has had a chance to play the role of the lay counsellor, bring participants back to the large group and, as time allows, ask some of the small groups to present their role play to the large group. Allow all participants time to give feedback and debrief the activity, using these questions:

- *What did the lay counsellor do well?*
- *What other points do you think the lay counsellor could have discussed with the client or caregiver about safely feeding the infant?*
- *How did you use the counselling cue card during the role play?*
- *What was easy? What was challenging?*
- ***How do you think you can use this counselling cue card in your work?***

KEY INFORMATION

See Appendix 7C: Key Counselling Messages on:

- ***Exclusively Breastfeeding Your Baby***
- ***Exclusively Replacement/Formula Feeding Your Baby***
- ***Introducing Complementary Foods to Your Child at 6 Months***

CASE STUDIES

CASE STUDY 1:

Puleng is living with HIV and gave birth to a baby girl last week. Puleng took the PMTCT regimen during her pregnancy. She has only been feeding her baby breast milk so far, but does not fully understand the importance of breastfeeding exclusively and says the baby does not want to drink very often. Talk with her about the key things she needs to know about exclusively breastfeeding her baby and lowering the chances that the baby will become HIV infected.

(see Taking Care of Yourself After Your Baby is Born, Caring for Your HIV Exposed Baby and Adhering to Care and Medicines, and Exclusively Breastfeeding Your Baby cue cards)

CASE STUDY 2:

Rethabile is living with HIV and gave birth to a baby boy 2 days ago. She has decided that instead of breastfeeding her baby, she wants to feed the baby using formula. Talk with her about the key things she needs to know about exclusively replacement feeding her baby. (see *Taking Care of Yourself After Your Baby is Born, Caring for Your HIV Exposed Baby and Adhering to Care and Medicines, and Exclusively Replacement/Formula Feeding Your Baby cue cards*)

CASE STUDY 3:

Itumeleng is HIV positive and has a 6-month old baby that she is breastfeeding. The nurse refers Itumeleng to you and asks that you counsel her on introducing complementary foods to her child and lowering the chances that the baby will become HIV infected. (see *Caring for Your HIV Exposed Baby and Adhering to Care and Medicines and Introducing Complementary Foods to Your Child at 6 Months cue cards*)



*Hope is but the dream
of those who wake*

Matthew Prior

SESSION 7.5

TESTING THE BABY OR CHILD FOR HIV (50 MINUTES)



TRAINER INSTRUCTIONS

Methodologies: Interactive Trainer Presentation, Small Group Work, Large Group Discussion, Case Studies, Role Play

- Step 1:** Introduce the session by stating that, now, we will focus on the key counselling messages to help clients and caregivers understand what they need to know about testing their baby or child for HIV.
- Step 2:** Ask the small group assigned to this topic (in *Session 7.1*) to present the main points of their discussion back to the large group, focusing on common challenges women or caregivers face getting their baby or child tested for HIV and key counselling messages on testing a child for HIV. Give the group about 10 minutes to present and then open up the discussion to the large group.
- Step 3:** Using the content in the counselling cue card called **TESTING YOUR BABY OR CHILD FOR HIV** in *Appendix 7D*, review the key counselling messages on this topic, building on the small group presentation. Write key messages on flip chart or present them on slides. Refer participants to the counselling cue card in *Appendix 7D* and remind them how they can use the cue card in their work.
- Step 4:** Allow time for discussion and for participants to ask questions about the key messages.
- Step 5:** Break participants into groups of 3. Assign each small group one of the case studies below and ask one person to play the role of the lay counsellor, another to play the role of the client, and the third to play the role of observer. Remind participants that they should be creative and expand upon the information given in the case study.

Hand out extra copies of the cue cards to each participant. Encourage participants to use the counselling cue card to help guide the session and the key messages when they are playing the role of the lay counsellor. When they are playing the role of observer, they should use the cue card as a checklist.

After about 10 minutes, stop the role plays and ask the observers to give feedback. Then, ask the small groups to switch roles and to conduct another role play. Do this until everyone has had a chance to play each role. The trainers should circulate and provide assistance as needed.

Step 6: Once everyone has had a chance to play the role of the lay counsellor, bring participants back to the large group and, as time allows, ask some of the small groups to present their role play to the large group.

Allow participants time to give feedback and debrief the activity using these questions:

- *What did the lay counsellor do well?*
- *What other points do you think the lay counsellor could have discussed with the client or caregiver about testing the child for HIV?*
- *How did you use the counselling cue card during the role play? What was easy? What was challenging?*
- ***How do you think you can use this counselling cue card in your work?***

KEY INFORMATION

See Appendix 7D: Testing Your Baby or Child for HIV

CASE STUDIES

CASE STUDY 1:

Teresa is on lifelong ART and is exclusively breastfeeding her 6-week old child. She says she does not know if she can face finding out whether or not the baby is HIV infected. Counsel her on testing her baby for HIV.

(see Testing Your Baby or Child for HIV cue card)

CASE STUDY 2:

Limpho has brought her 1-year old nephew she has been caring for to the clinic. The child's mother died of AIDS and the child has not yet been tested. Counsel Limpho on testing the child for HIV.

(see Testing Your Baby or Child for HIV cue card)

SESSION 7.6

CARING FOR THE HIV INFECTED CHILD (60 MINUTES)



TRAINER INSTRUCTIONS

Methodologies: Interactive Trainer Presentation, Small Group Work, Large Group Discussion, Case Studies, Role Play

- Step 1:** Introduce the session by stating that, now, we will focus on the key counselling messages to help clients and caregivers care for their HIV infected child.
- Step 2:** Ask the small group assigned to this topic (in *Session 7.1*) to present the main points of their discussion back to the large group, focusing on common challenges women or caregivers face caring for an HIV infected child and key counselling messages on this topic. Give the group about 10 minutes to present and then open up the discussion to the large group.
- Step 3:** Using the content in the counselling cue card called **CARING FOR YOUR HIV INFECTED BABY OR CHILD AND ADHERING TO CARE AND MEDICINES** in *Appendix 7E*, review the key counselling messages on this topic, building on the small group presentation. Write key messages on flip chart or present them on slides. Refer participants to the counselling cue card in *Appendix 7E* and remind them how they can use the cue card in their work.
- Step 4:** Allow time for discussion and for participants to ask questions about the key messages. Be sure to discuss changes to the national PMTCT guidelines, including that all children under 1 year who are HIV infected should start ART.
- Step 5:** Break participants into groups of 3. Assign each small group one of the case studies below and ask one person to play the role of the lay counsellor, another to play the role of the client, and the third to play the role of observer. Remind participants that they should be creative and expand upon the information given in the case study.

Hand out extra copies of the cue cards to each participant. Encourage participants to use the counselling cue card to help guide the session and the key messages when they are playing the role of the lay counsellor. When they are playing the role of observer, they should use the cue card as a checklist.

After about 10 minutes, stop the role plays and ask the observers to give feedback. Then, ask the pairs to switch roles and to conduct another role play. Do this until everyone has had a chance to play each role. The trainers should circulate and provide assistance as needed.

Step 6: Once everyone has had a chance to play the role of the lay counsellor, bring participants back to the large group and, as time allows, ask some of the small groups to present their role play to the large group.

Allow participants time to give feedback and debrief the activity using these questions:

- *What did the lay counsellor do well?*
- *What other points do you think the lay counsellor could have discussed with the client or caregiver about caring for the child?*
- *How did you use the counselling cue card during the role play? What was easy? What was challenging?*
- ***How do you think you can use this counselling cue card in your work?***

KEY INFORMATION

See Appendix 7E: Caring for an HIV Infected Child

CASE STUDIES

CASE STUDY 1:

Mohlakore is on lifelong ART, and has just found out that her 3-month old child is HIV infected. She is very upset, and afraid that her son will soon die.

Counsel her on caring for her child and on adhering to care and medicines.

(see Caring for an HIV Infected Child cue card)

CASE STUDY 2:

Madiako has brought her 1-year old granddaughter in for testing, and the test results are positive. The child's mother died recently. Counsel Madiako on caring for her grandchild and on adhering to care and medicines.

(see Caring for an HIV Infected Child cue card)

SESSION 7.7

CLASSROOM PRACTICUM (60 MINUTES)



TRAINER INSTRUCTIONS

Methodologies: Small Group Work, Case Studies, Role Play, Large Group Discussion

Step 1: Break participants into small groups of 4. Refer to the case studies written in the Participant Folder. Ask the groups to assign one person to play the role of a lay counsellor, one the role of the client, and two the role of observer. Explain that each small group will go through each of the 4 case studies, with group members shifting roles so that each person has the chance to play the role of the lay counsellor.

Encourage participants to use the extra copies of the counselling cue cards to help guide the session and their key messages when they are playing the role of the lay counsellor. Also remind participants to think about the key counselling messages they learned in Modules 5 (psychosocial assessment) and 6 (counselling during pregnancy) and to weave these into their role plays, as appropriate. One of the observers should use the extra copies of the counselling cue cards as a checklist to ensure that all key messages are covered. The other observer should use the Counselling and Communication Checklist in *Appendix 7F* to ensure that the person playing the lay counsellor is using the key skills covered in Module 3.

Step 2: Ask the small groups to role play the first case study. After about 10 minutes, ask the observers to give feedback (on the content and key messages covered as well as on counselling and communication skills used in the role play). Ask the groups to change roles and to move onto the second case study. Continue until all of the small groups have worked through each case study.

Step 3: If time allows, some groups can also do a short role play of their case study for the large group. Go over the key points and considerations of each case study as a large group and be sure to answer any questions. Debrief the activity by reminding participants that lay counsellors should be comfortable discussing key counselling messages and providing necessary information during sessions with postpartum women living with HIV or with caregivers. The counselling cue cards can serve as a useful reminder of these key messages, and it is a good idea for lay counsellors to continue practice using them.

KEY INFORMATION

CASE STUDIES

CASE STUDY 1:

Maki found out that she is HIV positive 7 months ago, while she was pregnant. She just gave birth to a baby girl and doesn't think it's safe for her to breastfeed the baby. She is willing to do anything to make sure her daughter remains HIV negative. However, she also has to return to work soon because she is a single mother and has 2 other children to support. Counsel Maki on taking care of herself and caring for her HIV exposed daughter.

(see Taking Care of Yourself After Your Baby is Born; Caring for Your HIV Exposed Baby and Adhering to Care and Medicines; Exclusively Breastfeeding Your Baby; and Testing Your Baby or Child for HIV cue cards)

CASE STUDY 2:

Mary is a client in the PMTCT programme. She gave birth to her son about 2 months ago. She missed the baby's 6-week follow-up appointment, but returns to the clinic 2 weeks later. Mary is breastfeeding her son, but complains that her nipples are very sore. Mary's family does not know she is HIV positive and she is having trouble remembering to give her baby nevirapine. Counsel Mary on adherence to care and medicines for her HIV exposed baby, HIV testing for the baby, and also on safely feeding her baby.

(see Caring for Your HIV Exposed Baby and Adhering to Care and Medicines; Exclusively Breastfeeding Your Baby; and Testing Your Baby or Child for HIV cue cards)

CASE STUDY 3:

Nokuphiwa returns for her 8-week old baby's HIV test results. The results show that the baby is HIV negative. Nokuphiwa is exclusively breastfeeding her baby and taking lifelong ART. Nokuphiwa is very happy about the results and says she thinks she should stop breastfeeding immediately since her baby is negative. Counsel Nokuphiwa on caring for her HIV exposed baby and give her information on safe breastfeeding and when to retest the baby.

(see Caring for Your HIV Exposed Baby and Adhering to Care and Medicines; Exclusively Breastfeeding Your Baby; and Testing Your Baby or Child for HIV cue cards)

CASE STUDY 4:

Thandi is the primary caregiver of her 8-month old nephew, who has been sick a lot and is not gaining weight. She is shocked to learn that the baby is HIV infected and had no idea that her sister was HIV positive. She feels frustrated because she is already caring for her own children and doesn't have much money or time to keep bringing her nephew to the clinic. Counsel Thandi on caring for her HIV infected nephew, including on adherence to care and medicines.

(see Caring for Your HIV infected Child and Adhering to Care and Medicines cue card)

*Childhood is the most
beautiful of life's seasons*

Author Unknown



SESSION 7.8

MODULE SUMMARY AND EVALUATION (15 MINUTES)



TRAINER INSTRUCTIONS

Methodologies: Large Group Discussion, Interactive Trainer Presentation

- Step 1:** Ask participants what they think are the key points of this Module. What information will they take away from the Module?
- Step 2:** Summarize the key points of the Module using participant feedback and the content below. Review the learning objectives with participants and make sure all are confident with their skills and knowledge in these areas.
- Step 3:** Ask if there are any questions or clarifications.
- Step 4:** Ask each participant to share with the group one thing he or she will do differently in his or her work as a lay counsellor or social worker, based on the information and skills learned in this Module.
- Step 5:** Hand out a Module evaluation form to each participant (see *Appendix 7A*) and ask that they take about 5 minutes to fill it out and to return it to the trainers. Remind participants that they do not need to put their name on the form.



THE KEY POINTS OF THIS MODULE INCLUDE:

- Lay counsellors should be up-to-date and knowledgeable about the revised national PMTCT guidelines.
- Postpartum women and caregivers of HIV exposed and HIV infected babies and children often have a number of psychosocial and adherence support needs.

Their needs will depend on their specific situation and may also change over time.

- Lay counsellors can use cue cards to help remember key counselling messages for postpartum women living with HIV and their families, as well as other caregivers.
- When counselling, it is always important to use the 7 key counselling and communication skills from Module 3.
- Communicating key counselling messages to postpartum women who are living with HIV is a critical part of assisting and supporting them to take care of themselves and their HIV exposed infants.
- Clients need to understand the importance of managing their postpartum care and need encouragement and support to adhere to their care and treatment during all stages of the PMTCT Care Spectrum, especially after delivery and if breastfeeding.
- Clients might have concerns about caring for their baby and therefore require information and support, especially to help them adhere to the baby's care plan and medications.
- All babies born to mothers living with HIV need to take ARVs.
- Lay counsellors can help clients understand how they can stay healthy after delivery, including getting enough rest and food, finding emotional support, bonding with their baby, continuing to take ART, coming back within 3 days for a postpartum visit and then at 6 weeks post delivery, practicing safer sex, and planning future pregnancies (spacing, preventing, etc.).
- Lay counsellors can help clients understand how to care for their HIV exposed baby, including understanding that all HIV exposed babies need to take ARVs and need to be seen regularly at the clinic, and knowing how to safely feed the baby – including ARVs for the mother or baby for the duration of breastfeeding.
Lay counsellors should also offer practical support on how to adhere to the baby's care and medicines and on early infant diagnosis at 6 weeks.
- Lay counsellors can also help clients make an adherence plan – for themselves and their baby - that fits with their lives.
- Remember: It is important that lay counsellors follow-up with clients about their own and the baby's adherence at EVERY clinic visit.
- Lay counsellors can help clients decide the safest way to feed their baby, noting that the Department of Health in South Africa recommends exclusive breastfeeding for 6 months.
- While breastfeeding is the most encouraged feeding option, clients need information and guidance on both safer infant feeding options and the advantages and disadvantages of each to make an informed decision.

- It is critical to assess the client's circumstances and support when assisting her in making her infant feeding decision. Remember that it is the client's decision.
- Lay counsellors can support clients to safely breastfeed or safely formula feed, and to introduce complementary foods to the baby's diet at 6 months.
- Lay counsellors can encourage mothers and caregivers to get their baby tested for HIV at 6 weeks of age and give information and support on testing the baby, testing all children of all ages in the home, and retesting, if needed. They can also help clients understand their baby's test result and next steps.
- Lay counsellors can provide information and counselling to mothers, parents, and other caregivers of HIV infected babies and children, including offering practical support on giving the child medicines and adhering to the care and treatment plan.



APPENDIX 7A

KEY COUNSELLING MESSAGES - POSTPARTUM CARE FOR THE MOTHER



TAKING CARE OF YOURSELF AFTER YOUR BABY IS BORN

Open the session and gather information

- *Delivering a baby is hard but rewarding work. Like their babies, mothers also need care after giving birth. Taking care of yourself after delivery and ongoing is important for you to feel strong and healthy, and will help you have the energy you need to care for your baby*
 - *What do you think you can do to take care of your own health after your baby is born?*
-

Take care of yourself after the delivery

- Spend as much time as you can with the baby skin-to-skin on your chest or resting together. Cuddle, sing, and talk to the baby.
 - Try to get help and emotional support from friends or family.
 - Try not to do too much physical labour.
 - If you have heavy bleeding, problems breathing, fever, pain in the belly, or bad-smelling discharge, come to the clinic right away.
 - Try to eat at least one extra meal each day.
 - You should wash often and try to keep your genitals very clean – but only use clean water with no soap.
 - Wait a couple of weeks before you sit in water.
-

Keep taking your ART or ARVs

- If you are on lifelong ART, keep taking your medicines at the same time every day during and after you deliver the baby and for your whole life.
 - If you took the PMTCT regimen during pregnancy, the nurse or doctor will give you other ARVs to take right away after you deliver the baby.
-

Come back to the clinic within 3 days of delivery and again 6 weeks after you deliver

- You will need a postnatal check-up within 3 days after you deliver.
 - You will need a second check-up within 6 weeks after the baby is born to make sure you are still healing properly. We will also check your baby and give him or her an HIV test.
 - You need to continue your own HIV care and treatment for your whole life.
 - You will need to get another CD4 test done 6-9 months after you deliver your baby.
 - If you feel unwell, or have questions about your own or your baby's health, remember that you can always come to the clinic.
-

Practice safer sex with your partner(s)

- In order to prevent infection, wait at least 6 weeks after you deliver to have sex again.
- Talk with your partner about using condoms while you are breastfeeding and afterwards.
- Using water-based lubricants can make sex less painful and more pleasurable.
- Although it may be difficult, talk to your partner about being faithful or always using condoms with other partners.
- Encourage your partner(s) to come for an HIV test. We can also talk to your partner if he or she comes to the clinic with you.
- If you or your partner has itching, a rash, strange discharge, or sores around the genitals, come to the clinic right away.

Gather information

- *Would you like to have more children?*
 - *If yes, would you like to have another child soon, or would you like to wait some time before having another child?*
 - *Have you talked to your partner about family planning?*
 - *Are you using a family planning method now?*
 - *Would you like to use one in the future?*
-

All women and couples, including people living with HIV, have a right to make informed decisions about their reproductive lives and the number and spacing of their children.

If you and your partner wish to have more children, there are times when it is safest to get pregnant and have a baby

- It is healthiest for you and your children if you wait at least 2 years between pregnancies.
 - If you want to have another baby, the safest time to get pregnant is when:
 - Your CD4 count is over 350.
 - You do not have any opportunistic infections (including TB) or advanced AIDS.
 - You are taking and adhering to ART.
 - If you decide you want to have another baby in the future, come to the clinic with your partner and we can help you decide the safest times and ways to get pregnant.
-

There are many safe family planning options for you and your partner if you want to prevent pregnancy or if you want to wait some time before becoming pregnant again (give referrals to family planning, if needed).

Check understanding and plan next steps

- *Can you tell me some of the ways you will take care of yourself after you have your baby?*
- *How do you think you will talk with your partner about safer sex?*
- *What are your plans for having more children or preventing future pregnancies?*
- *Would you like to talk more about starting on a family planning method today? (give referrals as needed)*

APPENDIX 7B

KEY COUNSELLING MESSAGES -
CARING FOR YOUR HIV EXPOSED BABY AND ADHERING
TO CARE AND MEDICINES

CARING FOR YOUR HIV EXPOSED BABY AND ADHERING TO CARE AND MEDICINES

Open the session and gather information

- *Caring for yourself and your baby after birth is very important. Your baby will need a lot of attention in the first few months of life.*
- *Who can help you care for your baby?*
- *What have you heard about caring for babies born to mothers living with HIV?*

Your baby needs ARVs and should come back to the clinic every month

- The medicines that you and your baby take during this period can lower the chance that your baby will become HIV infected.
- The medicines work by protecting your baby from HIV during delivery and breastfeeding.
- Your baby needs to take **nevirapine** syrup as soon as possible after birth – **within 3 days of delivery**.
- **All HIV exposed babies also need to take nevirapine syrup for at least 6 weeks after birth.**
 - **For breastfeeding mothers on the PMTCT regimen:** Your baby will continue to take nevirapine syrup once every day, until one week after you stop breastfeeding.
 - **For breastfeeding mothers on lifelong ART:** Your baby will continue to take nevirapine syrup once every day until he or she is 6 weeks old.
 - **For mothers who are NOT breastfeeding:** Your baby will take nevirapine syrup once every day from birth until he or she is 6 weeks old.
- When your baby is 6 weeks old, he or she will also need to start taking a medicine called cotrimoxazole to prevent infections.
- It is important that you and your baby come back to the clinic every month so we can make sure everything is going well with your and your baby's health.

Gather information

- *Breast milk is the healthiest food for all babies. There is HIV in breast milk, but mothers living with HIV can safely breastfeed when they or their baby take ARVs.*
- *Can you tell me how you plan to feed your baby?*

It is important to feed your baby safely

- **Exclusive breastfeeding for the first 6 months of life (with ARVs)** is the safest way to breastfeed and lowers the chance that your baby will be HIV infected.
- Exclusive breastfeeding means giving your baby **ONLY** breast milk and no other liquids or foods.
- **Exclusive formula feeding** for the first 6 months of life is an option for some women.
- Exclusive formula feeding means giving your baby **ONLY** formula and no other liquids or foods.
- After 6 months, the baby will need other foods in addition to breast milk/formula.

Gather information

- *It is important that your baby gets his or her medicines the right way, every day, and that you bring the baby back to the clinic often, including for an HIV test at 6 weeks.*
- *What will help you do these things for yourself and your baby?*

Adherence means how faithfully you stick to and participate in your own and your baby's care and treatment plan

- Bringing your baby for all appointments at the clinic.
- Giving your baby his or her ARVs the right way, every day, for as long as the doctor says.
- This includes giving your baby nevirapine syrup for the first 6 weeks (and longer if you are breastfeeding and not taking ART).
- Giving your baby cotrimoxazole every day starting at 6 weeks.
- Giving the right dose of medicines to your baby.
- Making sure the baby gets an HIV test at 6 weeks and picking up the results.
- Taking your own ART the right way, every day, so you will feel better and lower the chances that your baby will become HIV infected.

It is important to make an adherence plan for you baby.

Here are some tips.

- If you are taking medicines, give your child medicines at the same time you take yours.
- Try to schedule your own and your baby's appointments on the same day.
- Get support from someone you trust.

Here are some tips on giving your baby syrups

- Sometimes the nurse or pharmacist will put colored tape on the syringe to help you measure the right dose.
- You can reuse syringes until the markings begin to wear off or the plunger is hard to use.
- Wash the syringes with warm, soapy water, rinse, and let them air dry.
- If the medicine is too sticky, add a little breast milk or formula to the syringe.
- DO NOT add medicines to a baby bottle or cup of milk.

If your baby does not want to take his or her medicine, here are some tips

- Wrap your baby in a blanket and hold him or her in the bend of your arm.
- Place the dropper in the corner of the baby's mouth and slowly give the medicine.
- Aim for the inside of the baby's cheek, instead of the back of the tongue.
- Blow gently into your baby's face.
- Do not give medicine when your baby is crying or by pinching his or her mouth open.
- If your baby vomits medicine within 30 minutes of giving it, give the dose again.

You should bring your baby for an HIV test when he or she is 6 weeks old

- It is important that all of your children get an HIV test.
- The nurse will take a small amount of blood from your baby's foot and put it on a piece of paper that will be sent to the lab.
- It is very important to come back to the clinic to get your baby's test results (it usually takes 2-3 weeks to get the results).
- If your baby tests HIV negative and you are breastfeeding, he or she will need to get another HIV test when you stop breastfeeding.

Check understanding and plan next steps

- *Can you tell me the most important things about caring for your baby?*
- *Why is adherence to your baby's care and medicines important?*
- *What questions do you have about caring for your baby?*

APPENDIX 7C

KEY COUNSELLING MESSAGES - SUPPORTING SAFE INFANT FEEDING



EXCLUSIVELY BREASTFEEDING YOUR BABY

Open the session and gather information

- *Now that your baby is here, I would like to talk with you about some of the challenges women face with exclusive breastfeeding and how you can overcome them.*
- *Remember: it is very important to give your baby ONLY breast milk (and any medicines given by the health care worker) for as long as possible, up to 6 months.*
- *Exclusive breastfeeding, taking your ARVs, or if you are not continuing ARVs, giving your baby ARVs, and coming to all clinic appointments can lower the chance that your baby will be HIV infected, and will help keep your baby healthy.*
- *What questions or concerns do you have about exclusively breastfeeding your baby?*

It is important that you or your baby are taking ARVs the right way, every day, the whole time you are breastfeeding

- These medicines will make breastfeeding safer for your baby and lower the chance that the baby will become HIV infected.

How do you know your baby is getting enough to eat?

- Remember, the only food your baby needs before 6 months is breast milk. This means no water, porridge, baby food, or any other food or liquid – except for medicines you get from the nurse or doctor.
- During the first 1-2 days after your baby is born, you will make a small amount of milk. This is very rich and good for your baby.
- About 3-5 days after your baby is born, your full milk will “come in” and you will start making more milk.
- It is important to breastfeed your baby often during the first few days – this will help your milk come in and give the baby important nutrients.
- You should feed your baby between 8 and 12 times each day, with each feeding lasting about 30 minutes total.
- You should alternate which breast you feed from at each feeding.
- Your baby should have around 3 bowel movements per day.
- Most of the time, your baby will let you know when he or she is hungry.
- Common signs that a baby is hungry include sucking hands, smacking lips, and acting fussy.

Some women face challenges with exclusive breastfeeding.

If you have sore nipples, here are some tips.

- You may have some discomfort during the first week of breastfeeding.
- Usually this goes away over time, but if you keep having a lot of pain, you should come to the clinic.
- **One cause could be poor positioning:** The baby should take your whole nipple in his or her mouth each time.
- **Another cause could be cracked nipples:** Expose your nipples to air and sunlight as much as possible and put a bit of breast milk on them between feedings.
- Do not use soap on your nipples.
- **Another cause could be thrush:** If you have a burning feeling on your nipples or pain for many days, and see white spots or redness on your nipples and in your baby’s mouth, you and the baby may have thrush. Come to the clinic right away for medicines.

If your baby will not latch, here are some tips (demonstrate proper positioning and latch)

- **Your baby may be sleepy:** If your baby falls asleep while breastfeeding, keep offering your breast and try to feed whenever the baby wakes up.
 - You can wake the baby up by tickling its feet, wiping its face with a cool cloth, or undressing the baby.
 - **Your baby may be fussy:** Try to calm your baby by putting him or her on your skin naked, rocking the baby, offering a finger to suck on before switching to the breast, or squeezing your nipple and putting some milk on your baby's lips.
-

What are engorged breasts?

- If your breasts feel hard and firm for a few days; if you feel swelling, tenderness, warmth, and throbbing; or if your nipples are flat, you may have engorged breasts/nipples.
 - You may have engorged breasts because:
 - Your milk just came in.
 - Your baby is not feeding enough or you waited some time to breastfeed.
 - Your baby is not positioned the right way or is not latching well.
-

If you have engorged breasts, here are some tips

- Use your hand to express as much milk from the breast as possible.
 - Put both of your breasts into a sink or dishpan filled with warm water.
 - Put the baby to your breast often. After the feeding apply fresh cabbage leaves or cool wet cloths to your breasts.
-

If your family wants to feed your baby foods or liquids other than breast milk, here are some tips

- Family members and friends might want to give your baby food other than breast milk.
 - Some things you could say to your family and friends:
 - *"Breast milk is the only food my baby needs for the first 6 months of life."*
 - *"I do not want my baby to get diarrhoea from the water/tea/food."*
 - *"I am trying to keep my baby healthy and prevent HIV so I am exclusively breastfeeding."*
 - If you think it would be helpful, someone from the clinic can talk to your family about the importance of exclusive breastfeeding.
-

You need to eat enough foods and drink enough liquids while you are breastfeeding

- You should eat nutritious foods while breastfeeding, including foods with proteins and fats, and many fruits and vegetables.
 - If possible eat one extra full meal per day.
 - Drink plenty of fluids like clean water, milk, or tea.
 - No matter how much or how little a woman eats, her body will make good breast milk.
-

Breastfeeding if you are sick or unwell

- Even if you are not feeling well, it is still good to continue breastfeeding your baby.
 - Drink plenty of fluids and breastfeed often.
 - Always take your medicines the right way, every day, including ARVs.
-

Check understanding and plan next steps

- ***What questions or concerns do you have about exclusively breastfeeding your baby for as long as possible, up to 6 months?***

EXCLUSIVELY REPLACEMENT/FORMULA FEEDING YOUR BABY

Open the session and gather information

- *Now that your baby is here and you will be using formula, I would like to talk with you about how to safely prepare formula and some of the challenges women face with exclusive formula feeding. Remember: it is very important to give your baby ONLY formula for the first 6 months.*
 - *Exclusive formula feeding, taking your ARVs, giving your baby ARVs, and coming to all clinic appointments can lower the chance that your baby will become HIV infected.*
 - *What questions or concerns do you have about giving your baby formula?*
-

It is important to prepare formula safely every time so your baby does not get sick (demonstrate and ask for return demonstration)

- Wash your hands with soap and dry them on a clean cloth before making formula.
 - Be sure to have clean utensils to make the formula each time.
 - Prepare the formula on a clean table or mat.
 - Rinse utensils with cold water right away after each use to remove milk before it dries on them, and then wash with hot water and soap.
 - Make sure the utensils are covered to keep off insects and dust.
 - Use a clean cup and spoon to give formula to your baby.
 - Use safe water to make your baby's formula.
 - Boil water for at least 5 minutes before using it to make formula.
 - Always keep water in a clean, covered container.
-

Store the formula safely

- Keep the formula powder in a tightly covered tin.
 - Use a clean scoop to get the powder out of the tin.
 - Use prepared formula within **one hour** of making it.
 - If a baby does not finish the feed, you can give it to an older child or use it for cooking. Do not give it to your baby for the next feed.
 - If you have a refrigerator, all the formula for one day can be made at once and stored in the refrigerator in a sterilized container with a tight lid.
 - If you do not have a refrigerator, you will have to make feeds freshly each time the baby needs to be fed.
-

Make sure you are giving your baby enough formula

- Babies do not need any foods or drinks other than formula until about 6 months of age.
- Your baby will need to drink small amounts of formula often – at least 8 times each day at first (about every 3 hours).
- You will need to give your baby more formula more often as he or she grows.
- The amount of formula you give depends on your baby's age and weight.
- Your baby may eat a bit more or less formula at each feed.
- When your baby is feeding by cup, offer a little extra but let the baby decide when to stop.

Make sure you are giving your baby enough formula

- If your baby takes a very small feed, offer extra at the next feed, or give the next feed earlier – especially if he or she seems hungry.
 - If your baby is not gaining enough weight, he or she may need to be fed more often or be given larger amounts at each feed.
 - Always bring your baby to the clinic if he or she is not gaining weight or is sick.
-

Feed your baby from a cup and make sure you have skin-to-skin contact during the feedings (demonstrate feeding with clean cup and spoon)

- Cup feeding is safer and healthier than bottle feeding.
 - Cups are easier to clean than a bottle.
 - Cup feeding can help you and your baby bond more than bottle feeding.
-

Gather information

- *There are some common challenges that many women face when exclusively formula feeding their babies.*
 - *What challenges do you think you might face?*
-

Let's plan ahead for some of the challenges you may face with exclusive formula feeding

- Some people in your family or community may wonder why you are giving the baby formula.
 - It is important to plan what you will say.
 - It is important to plan ahead if you and the baby are going to be away from home during feeding times.
 - It is important to plan ahead if you are going to leave the baby with someone else during feeding times.
 - If you see you are running low on formula, be sure to get more before you run out.
 - What would you do if there was no formula available at the clinic?
 - Many women want to put the baby on the breast when he or she is crying. You will need to think of other ways to comfort your baby during these times.
 - Feeding your baby at night can be difficult if you are tired and have to make formula often and in the dark.
 - It is important to make these night feeds safely.
-

Check understanding and plan next steps

- *Can you tell me how you will prepare your baby's formula?*
- *How often?*
- *How much?*
- *What will you say to people if they ask you about the formula?*
- *What questions or concerns do you have about exclusively formula feeding your baby for the first 6 months?*

INTRODUCING COMPLEMENTARY FOODS TO YOUR CHILD AT 6 MONTHS

Open the session and gather information

- *Now that your baby is getting close to 6 months old, he or she will need foods other than breast milk/formula (Note: Adjust according to woman's feeding choice).*
 - *What have you heard about starting to give your baby other foods?*
 - *Why do you think it is important to start giving other foods to your baby at 6 months?*
-

Your baby needs to start eating foods other than breast milk/formula at 6 months of age

- Complementary foods are foods you feed your baby in addition to breast milk/formula.
 - Breast milk/formula alone is not enough to meet your growing baby's nutritional needs after 6 months.
 - It is important that you or your baby take ARVs the whole time you are breastfeeding to lower the chances that your baby will be HIV infected.
-

Gather information

- *What kinds of food do you think will be good to give your baby?*
 - *What kinds of food do you have at home that you can give your baby?*
-

You should start giving your baby different kinds of foods starting at 6 months

- Continue to breastfeed/formula feed as frequently as the baby wants, about 8 times throughout the day and night. Give the breast or some formula first, then offer some food.
 - Start by giving a teaspoonful of food. Increase this amount over time.
 - Your baby's first foods other than breast milk/formula should be soft and mild, such as maize meal or oats porridge.
 - Baby cereals and foods from the store are fine, but they are a lot more expensive than making your own.
 - Introduce different foods one at a time so your baby can get used to them.
 - All foods should be mashed or pureed for children between 6-12 months.
 - Good foods to start with are mashed pumpkin, carrots, potato, butternut, banana, and grated apple.
 - Start giving vegetables before you give fruit.
 - You can later add some protein to your baby's food, such as ground meats, chicken, or well-cooked, mashed beans.
 - You can also add colorful foods to porridge, such as orange and green vegetables or fruits. Be sure to mash them well.
 - You can add some butter, oil, or milk to porridge to provide some fat.
 - If you are giving the baby animal milk, you should always boil it first.
 - Always use a clean cup or bowl and a clean spoon to feed your baby.
-

Foods to avoid

- Before 12 months, do not give cow's milk (full cream, low-fat, 2%, or fat free).
- Do not give tea.

Foods to avoid

- It is best to wait until after 1 year to give cow's milk, fish, peanut butter, and eggs because they may cause allergies.
- Do not give sweets, fizzy drinks, biscuits, crisps, cheese curds, or chocolates.

How often to feed your baby

- You will need to give the baby complementary feeds more often over time, while also continuing to breastfeed/formula feed.
- When your baby is 6-9 months old, you should give him or her about half a cup (1-2 large palmfuls) of other foods 2-3 times a day.
- Then, when the baby is 9-12 months old, you can increase the number of complementary feeds to 3-4 times a day.
- After that, you can give your baby 4-5 complementary feeds every day until he or she is 2 years old – or until you have completely stopped breastfeeding/formula feeding.

If your baby is sick, he or she may not be hungry

- If your baby is sick, bring the baby to the clinic right away.
- When your baby is sick, try to breastfeed or formula feed him or her more often.
- If your baby has diarrhoea, he or she will need more liquids.
- Be patient and encourage your baby to eat while he or she is sick.
- If your baby is more than 6 months old and gets sick, give him or her an extra meal of enriched porridge every day for 2 weeks afterwards.
- It is important to always give your baby any medicines prescribed by the doctor, even when he or she is sick.

Gather information

- *If you are breastfeeding, when do you think you will stop breastfeeding?*
- *What questions do you have about weaning your baby off of breast milk?*

When you do decide to stop breastfeeding, it is important to do it in a safe way

- Do not try to stop breastfeeding quickly.
- Instead, stop breastfeeding over one month, slowly decreasing the number of times you breastfeed per day, and increasing the amount and number of times you give your baby other foods.
- If you have questions about how to stop breastfeeding safely and comfortably, you can always talk with us here at the clinic.

Breastfeeding and your baby's HIV test results

- If your baby has a negative HIV test, you should start thinking about weaning when he or she is 1 year old.
- In most cases, it is not safe to wean the baby earlier than that.
- If your child is HIV infected, it is recommended that you continue breastfeeding while also feeding your baby other foods until your baby is 2 years old (or even older).
- You should only stop breastfeeding if you have enough healthy foods and clean water to feed your baby.

Check understanding and plan next steps

- *Why do you need to start giving your baby food other than breast milk/formula when he or she is 6 months old?*
- *What kinds of foods do you have at home that you can give your baby?*
- *Will you need to buy other kinds of foods?*
- *How often do you need to feed your baby other foods?*
- *If you are breastfeeding, when and how will you stop?*
- *What questions do you have about feeding your baby?*

TESTING YOUR BABY FOR HIV

Open the session and gather information

- *Not all children born to women living with HIV are HIV infected, but some babies will become infected. In order to know if your child is HIV infected or not, we need to do an HIV test.*
 - *Babies should be tested for HIV at 6 weeks of age, or as soon as possible after that, since HIV can make infants very sick very quickly.*
 - *What have you heard about HIV testing in children?*
 - *What plans do you have to test your child/children for HIV?*
-

There is a chance that babies born to mothers living with HIV will also be HIV infected

- Babies can get HIV during pregnancy, during labour and delivery, or during breastfeeding.
 - The medicines that you and your baby took or are taking help lower the chance that your baby will be HIV infected, but you will only know for sure if the child is tested and you receive the results.
-

It is important for your baby and all of your children to get tested for HIV

- Even though you are living with HIV, this does not mean that your children are also HIV infected.
 - We need to do an HIV test to find out for sure.
 - Even if your children do not seem sick, they still might be HIV infected.
 - It is very important that we identify HIV infection in children as early as possible so that the child can be protected and treated.
 - HIV testing is strongly recommended because it allows children with HIV to access life-saving treatment as early as possible.
 - Children living with HIV need care and treatment, which is available for free.
 - HIV care and treatment, including ARVs, can help save your child's life and help him or her grow and become a healthy adult.
 - You have the right to say no to testing.
 - The result of your child's HIV test is confidential; it is only shared with you (or the primary caregiver) and those health care workers who need this information in order to care for your child.
 - Knowing your child's HIV status for sure can help you and your family plan for the child's care and make sure the child gets the care and treatment he or she needs as early as possible.
-

If your child is 6 weeks – 18 months old

- Children born to mothers who know they are living with HIV should be enrolled in follow-up care.
- All babies who are born to mothers living with HIV should have an HIV test when they are 6 weeks old.
- For HIV tests in babies and children 6 weeks to 18 months of age, we will do a Dried Blood Spot Sample, also called a DBS.
 - To get a DBS sample, we will prick your child's heel, toe, or finger (depending on his or her age) with a small needle and put some drops of blood on a piece of paper.
 - The paper will then be sent to a lab, and we will get the results back in about 2-3 weeks.

It is very important to come back for your child's test results.

What do the results mean?

- If the results are negative and you are breastfeeding now or have breastfed in the last 6 weeks, the virus can't be detected in your child's blood right now, but it is still possible for your child to become HIV infected.
- It is important to repeat the HIV test 6 weeks after you stop breastfeeding completely.
- If the results are negative and you are NOT breastfeeding now and have not breastfed in the last 6 weeks, your child is not HIV infected.
- We will do a confirmation test when the baby is 18 months old to be sure.
- **If the results are positive**, this means your baby is HIV infected and should start care and treatment right away.
- HIV infected children 12 months of age or younger will start taking medicines called ART right away to keep them healthy.
- We will help you learn about HIV treatment and ways to care for yourself and your child at home.
- We will help you with a follow-up plan and give ongoing support to you, your family, and your child.

If your child is over 18 months old

- We can use a rapid HIV test and you will get the result the same day.
- For this test, the nurse will take a small blood sample from your child's toe or finger.
- You will get the results of the test within 30 minutes.

What do the results mean?

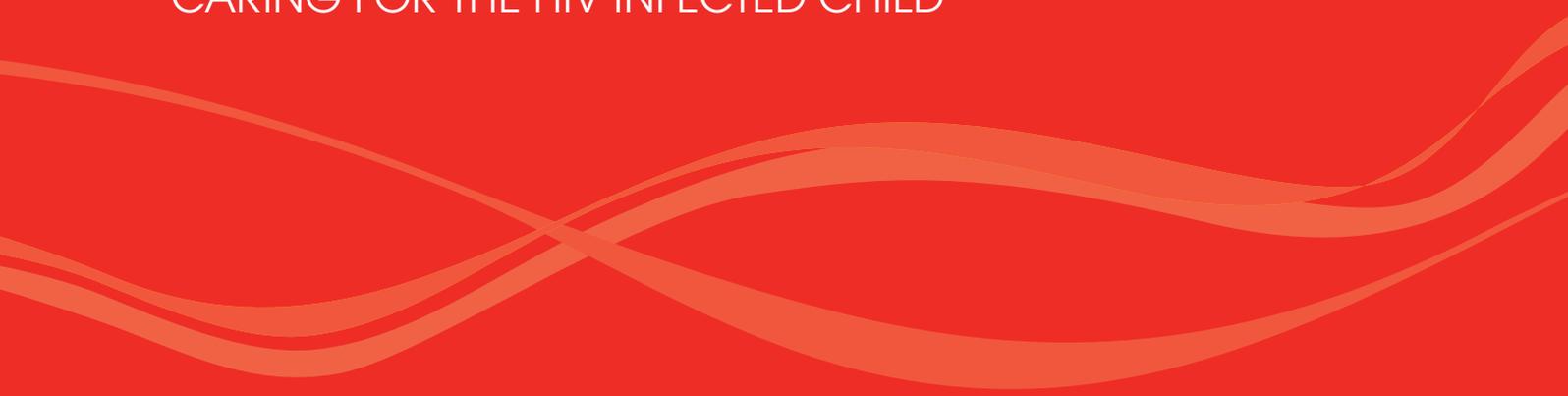
- **If the results are negative** and you are breastfeeding now or have breastfed in the last 6 weeks, the virus can't be detected in your child's blood right now, but it is still possible for your child to become HIV infected.
- It is important to repeat the HIV test 6 weeks after you stop breastfeeding completely.
- If the results are negative and you are NOT breastfeeding now and have not breastfed in the last 6 weeks, your child is not HIV infected.
- **If the results are positive**, this means your child is HIV infected and should start care and be evaluated for treatment right away.
- We will help you learn about HIV treatment and ways to care for yourself and your child at home.
- We will help you with a follow-up plan and give ongoing support to you, your family, and your child.

Check understanding and plan next steps

- *What questions do you have about testing your children for HIV?*
- *(If the client is with her child and the child is more than 6 weeks old): would you like us to test your child for HIV now?*
- *Would you like to make an appointment to bring your baby or the other children that live with you to the clinic for an HIV test?*

APPENDIX 7E

KEY COUNSELLING MESSAGES - CARING FOR THE HIV INFECTED CHILD



CARING FOR YOUR HIV INFECTED BABY OR CHILD AND ADHERING TO CARE AND MEDICINES

Open the session and gather information

- *I would like to talk with you about the important care and medicines your child will need to be well and to become a healthy adult.*
 - *What have you heard about caring for an HIV infected baby or child?*
 - *What concerns do you have now that you know your child is HIV infected.*
-

Important things to remember if your child is HIV infected

- There is a lot we can do to keep your child healthy.
 - Children living with HIV need the same things that all children need.
 - HIV develops much faster in children than it does in adults.
 - All children living with HIV need care and treatment, which is available for free.
 - Without treatment, many children living with HIV will become sick and die.
 - HIV care and treatment, including ARVs, can help save your child's life and help him or her grow to become a healthy adult.
-

Feeding your child

- If you are exclusively breastfeeding your child, continue until your baby is 6 months old.
 - Your baby needs other foods after he or she is 6 months old, but continue breastfeeding up to or beyond 2 years of age. This helps protect your baby from diarrhoea and other diseases.
 - HIV infected children need more food each day to stay healthy.
 - Try and give your child at least 3-5 meals every day so he or she gets enough nutrition and gains weight.
-

Bring your child for regular care at the clinic

- Your child needs to come to the clinic often and for all appointments.
 - When your child starts ART, it is important to come back to the clinic every 2 weeks.
 - After your child has adjusted to the medicines, bring him or her to the clinic every month for a check-up and lab tests.
 - If your child is not taking ART, it is important to bring him or her to the clinic every month for a check-up and lab tests.
 - Children with HIV can get sick very quickly, so it is important to bring your child for all clinic appointments and whenever he or she seems sick or has a fever.
-

Giving your child medicines

(show the mom or caregiver the syrups and/or tablets the child will take, the dosing, and how to give them to the child. Allow time for practice and questions)

- Antiretrovirals, or ARVs, are medicines that help lower the amount of HIV in the body.
- When a child takes different ARVs at the same time, we call this antiretroviral therapy, or ART.
- ART does not cure HIV.
- All HIV infected children **under age 1 year** need to start taking ART.
- The doctor will do a check-up and tests to see when older children need to start taking ART.
- Usually babies and young children take ARV syrups.
- Once your child starts ART, he or she will need to take it every day, at the same times, for his or her whole life.
- Your child will also need to take a medicine called cotrimoxazole to prevent infections.

Gather information

- *It is very important that your baby gets his or her medicines the right way, every day, and that you bring the baby back to the clinic often.*
 - *What things do you think will help you and your child stick to the care and treatment plan.*
-

Adherence means how faithfully you stick to and participate in your own and your baby's care and treatment plan

- Bringing the baby for all appointments at the clinic for check-ups, growth and developmental monitoring visits, lab tests, pharmacy refills, immunizations, if the baby gets sick, and for other care.
 - Giving your baby his or her ARVs the right way, every day, for his or her whole life.
 - Giving your baby cotrimoxazole every day once the baby is 6 weeks old.
 - Giving the right dose of medicines to your baby.
 - The amount of medicine will change when he or she gains weight.
-

It is important to make an adherence plan that fits with your life.

- If you are taking medicines, give your child medicines at the same time you take yours.
 - Try to schedule your own and your baby's appointments on the same day.
 - Taking care of a child living with HIV can be hard work. You need emotional support.
-

Here are some tips

Here are some tips on giving your baby syrups

- The nurse or pharmacist may put colored tape on the syringe to help you give the right dose.
 - You can reuse syringes until the markings begin to wear off or the plunger is hard to use.
 - Wash the syringes with warm, soapy water, rinse, and let them air dry.
 - If the medicine is too sticky, add a little breast milk or formula to the syringe.
 - DO NOT add medicines to a baby bottle or feeding cup.
 - If syrups are not available or if your child prefers it, you can crush pills and mix them with some expressed milk or formula.
-

If your child does not want to take his or her medicine, here are some tips

- Talk or sing to the child to help him or her stay calm.
 - Wrap your child in a blanket and hold him or her in the bend of your arm.
 - Place the dropper in the corner of the baby's mouth and slowly give the medicine.
 - Aim for the inside of the baby's cheek instead of the back of the tongue.
 - Blow gently into your baby's face.
 - Do not give medicine when your baby is crying or by pinching his or her mouth open.
 - If your baby vomits medicine within 30 minutes of taking it, give the dose again.
 - If the problem doesn't get better, you should talk to your doctor.
-

Check understanding and plan next steps

- *Can you tell me the most important things about caring for your child?*
- *Can you tell me why adherence to your child's care and treatment plan is important?*
- *What do you think can help you adhere to your own and your child's care and treatment plan?*
- *What questions do you have about caring for your child?*

APPENDIX 7F

COUNSELLING AND COMMUNICATION CHECKLIST

APPENDIX 7F

COUNSELLING AND COMMUNICATION CHECKLIST

SKILL	SPECIFIC STRATEGIES, STATEMENTS, BEHAVIOURS	TICK
Establish a relationship with the client	• Ensure privacy (make sure others cannot see or hear).	
	• Introduce yourself (name and role).	
	• Ask the client to introduce herself (or himself) to you.	
	• Ensure client about confidentiality / explain shared confidentiality	
	• Start the session with an open-ended question (“Where would you like to start?” or “Tell me more about why you came today.”)	
SKILL 1: Use helpful non-verbal communication	• Make eye contact.	
	• Face the person (sit next to her or him) and be relaxed and open with posture.	
	• Use good body language (nod, lean forward, etc.).	
	• Smile.	
	• Do not look at your watch, the clock or anything other than the client.	
	• Do not write during the session.	
	• Other (specify)	
SKILL 2: Actively listen and show interest in your client	• Nod and smile. Use encouraging responses (such as “yes,” “okay” and “mm-hmm”).	
	• Use a calm tone of voice that is not directive.	
	• Allow the client to express emotions.	
	• Do not interrupt.	
	• Other (specify)	
SKILL 3: Ask open-ended questions	• Use open-ended questions to get more information.	
	• Ask questions that show interest, care and concern.	
	• Other (specify)	
SKILL 4: Reflect back what your client is saying	• Reflect emotional responses back to the client.	
	• Other (specify)	
SKILL 5: Show empathy, not sympathy	• Demonstrate empathy: show an understanding of how the client feels.	
	• Avoid sympathy.	
	• Other (specify)	
SKILL 6: Avoid judging words	• Avoid judging words such as “bad,” “proper,” “right,” “wrong,” etc.	
	• Use words that build confidence and give support (e.g., recognize and praise what a client is doing right).	
	• Other (specify)	
SKILL 7: Help your client set goals and summarize each counselling session	• Work with the client to come up with realistic “next steps.”	
	• Summarize the main points of the counselling session.	
	• Make a next appointment date with the client and reassure her or him that you, or someone else at the clinic, are always available.	

APPENDIX 7G

MODULE 7 EVALUATION FORM

APPENDIX 7G

MODULE 7 EVALUATION FORM

Name (optional): _____ Health Facility: _____ Position: _____

Please note the following statements on a scale of 1 to 5:

	 Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	 Strongly Agree
1. The module objectives were clear	1	2	3	4	5
2. This module met my expectations	1	2	3	4	5
3. The technical level of this module was appropriate	1	2	3	4	5
4. The pace of speed of this module was appropriate	1	2	3	4	5
5. The facilitators were engaging and informative	1	2	3	4	5
6. The information I learned in this module will be useful to my work	1	2	3	4	5

How helpful were each of the workshop sessions to you and your work?

You can write extra comments on the back.

	 Not Helpful				 Very Helpful
The Counselling and Support Needs of Postpartum Women and Caregivers	1	2	3	4	5
Postpartum Care for the Mother	1	2	3	4	5
Caring for an HIV Exposed baby and Adhering to Care and Medicines	1	2	3	4	5
Supporting Safe Infant Feeding	1	2	3	4	5
Testing the Baby or Child for HIV	1	2	3	4	5
Caring for an HIV Infected Child	1	2	3	4	5
Classroom Practicum	1	2	3	4	5

What was the BEST THING about this Module?

What was NOT USEFUL about this Module?

Do you have other comments (use the back of the page if needed)?

MODULE 8

Providing Disclosure Counselling



MODULE 8

Providing Disclosure Counselling



CONTENT

- Session 8.1:** Examining Our Own Attitudes and Values Around Disclosure
- Session 8.2:** The Disclosure Process
- Session 8.3:** Providing Disclosure Preparation and Ongoing Counselling to Adults
- Session 8.4:** Providing Pediatric Disclosure Preparation and Ongoing Counselling
- Session 8.5:** Legal Issues Related to Disclosure and Delivery of Health Services to Children
- Session 8.6:** Classroom Practicum
- Session 8.7:** Module Summary and Evaluation



DURATION

375 minutes (6 hours, 15 minutes)



LEARNING OBJECTIVES

By the end of this Module, participants will be able to:

- Identify their own values and opinions related to talking about disclosure with adults, children, and caregivers
- Define key terms related to disclosure
- Understand how and why disclosure is a process
- Support clients to understand the advantages and disadvantages of disclosure in their lives
- Provide supportive counseling to clients to decide about and prepare for disclosure
- Discuss why it is important for children to know their HIV - status and help families prepare to disclose to children
- Understand the definitions and importance of partial and full disclosure to children
- Provide follow-up counselling to clients and family members after disclosure
- Understand the legal implications in the disclosure process and in delivering health services to children



PREVIOUS TRAINING/KNOWLEDGE REQUIRED FOR THIS MODULE

- Basic knowledge about PMTCT protocols and guidelines
- Experience in HIV counselling and testing (e.g., VCT and PICT), PMTCT, and ARV/ART education/counselling
- Completion of Modules 1-3 (or more) of this lay counsellor training curriculum



METHODOLOGIES:

- Large Group Discussion
- Large Group Activity
- Interactive Trainer Presentation
- Brainstorming
- Small Group Work
- Case Studies
- Role Play



MATERIALS NEEDED

- Flip chart and stand
- Markers/Khoki's
- Tape or Bostik
- Participant Handouts for Module 8 (to be inserted into the Participant Folder)



WORK FOR THE TRAINER TO DO IN ADVANCE

- Read through the entire Module and make sure you are familiar with the training methodologies and content.
- Write the Module learning objectives on flip chart or list them on a PowerPoint slide.
- Carefully review the case studies in Sessions 8.3, 8.4, and 8.6.

Sadness flies away on the wings of time

Jean de la Fontaine



SESSION 8.1

EXAMINING OUR OWN ATTITUDES AND VALUES AROUND DISCLOSURE (30 MINUTES)



TRAINER INSTRUCTIONS

Methodologies: Large Group Activity and Discussion, Interactive Trainer Presentation

- Step 1:** Post the pre-prepared flip chart papers that say AGREE and DISAGREE on opposite sides of the training room.
- Step 2:** Ask participants to stand up and move to the open space in the room where the AGREE and DISAGREE signs are posted. Tell participants that you will read some statements out loud and that, after each statement, they should move to the AGREE or the DISAGREE sign, based on their opinion. If participants are not sure whether they agree or disagree with the statement, they can stand somewhere between the two signs.
- Step 3:** Read each of the sentences listed below out loud. Allow participants a few seconds to move to the side of the room that reflects their opinion. Ask a few participants to tell the group why they AGREE or DISAGREE with the statement.
- Step 4:** Once you have read all of the statements below, or 20 minutes have passed, ask participants to return to their seats. Debrief the activity reminding participants that it's important for us to be aware of our own values and attitudes related to disclosure so that we can make sure they do not affect the quality of counselling we provide to clients.

KEY INFORMATION

Statements for Values Clarification Exercise:

1. It is wrong for people who are HIV positive not to tell their partners their HIV status.
2. Young children do not need to know they are HIV positive, so it is better to wait until they are older to tell them.
3. Each person should get to decide when and how to tell others his or her HIV status.
4. It may not be safe for a woman to tell her partner that she is HIV positive.
5. Parents of an HIV infected child should be open with the child about HIV as early as possible.

6. As a lay counsellor, it is a good idea to encourage clients to be open with their HIV status.
7. Some clients might choose not to tell anyone that they are HIV positive, and that is okay.
8. If parents or caregivers refuse to tell their child that he or she is HIV infected, it becomes the job of health care workers to tell the child.
9. A child does not really need to know how he or she got HIV.
10. A lay counsellor is the best person to tell a child about his or her HIV status.



SESSION 8.2

THE DISCLOSURE PROCESS (50 MINUTES)



TRAINER INSTRUCTIONS

Methodologies: Brainstorming, Interactive Trainer Presentation, Large Group Discussion

- Step 1:** Ask participants what is meant by the term “disclosure.” How does this translate into the local language? Record responses on flip chart.
- Step 2:** Ask participants what they think is meant by the phrase, “Disclosure is an ongoing process.” Discuss that disclosure is not a one-time event, and give the example of a client who spends time talking with the lay counsellor about disclosure, then first discloses her status to her partner, then later to certain members of her family, and maybe years later, to her neighbours/others in the community.
- Step 3:** Ask participants what have been the advantages and disadvantages of disclosure in their own lives or the lives of people living with HIV that they know. Record responses on flip chart and fill in, as needed, using the content below.
- Step 4:** Prepare a flip chart or slide with the circles of disclosure diagram below. Discuss how lay counsellors and social workers can help clients think about the circles of disclosure in their lives, using the content below. Ask for a participant to volunteer his/her own circles of disclosure, if he or she feels comfortable.
- Step 5:** Break participants into pairs. Ask that one person role play the part of the lay counsellor and the second person play the part of the client. The lay counsellor should work with the client to draw his or her disclosure circle. Ask those role playing the client to think about who they would disclose to, and in what order, in real life (based upon their own experience with disclosure and/or the experiences of their clients). After 10 minutes, ask the pairs to switch roles and to perform the role play again. As time allows, ask some of the small groups to share their disclosure circles and discuss.
- Step 6:** Close the session by reminding participants that taking the time to work through a client’s disclosure circle will not only help the client visualize and plan the disclosure process, but will make her feel supported to take the next step in this sometimes difficult process. Also remind participants that lay counsellors play an important role in helping clients to think about and prepare to disclose to people they trust, and in providing follow-up counselling and support.

KEY INFORMATION

What is disclosure?

- Disclosure is when a person tells one or more people about his or her 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 clients need ongoing support during the whole process, including to prepare to disclose to another person and follow-up support after they have disclosed.

Advantages of disclosure may include:

- Client will not have to keep her HIV status a secret anymore
- Client will not have to worry about that person finding out her HIV status accidentally
- Client will have more access to emotional and practical support to adhere to her own and her baby's care and treatment plan
- Client will be able to talk more openly about her symptoms and concerns
- Client will have easier access to health care
- Client will be able to ask that friend or relative to be a treatment buddy
- Client will have access to patient support groups and community organizations
- Client will serve as a role model for other people on disclosure
- If client discloses to her partner, she will have greater ability to discuss safer sex and family planning choices with him or her
- If client discloses to her partner, she will be able to refer her partner and children for HIV counselling and testing, and to care and treatment, if needed

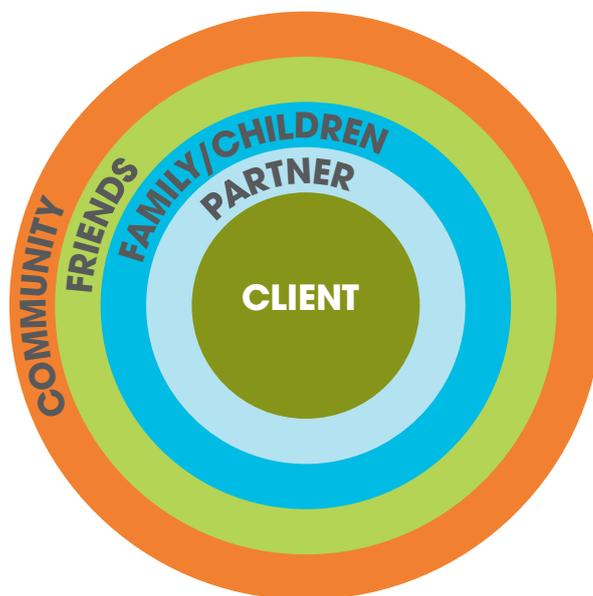
Disadvantages of disclosure may include:

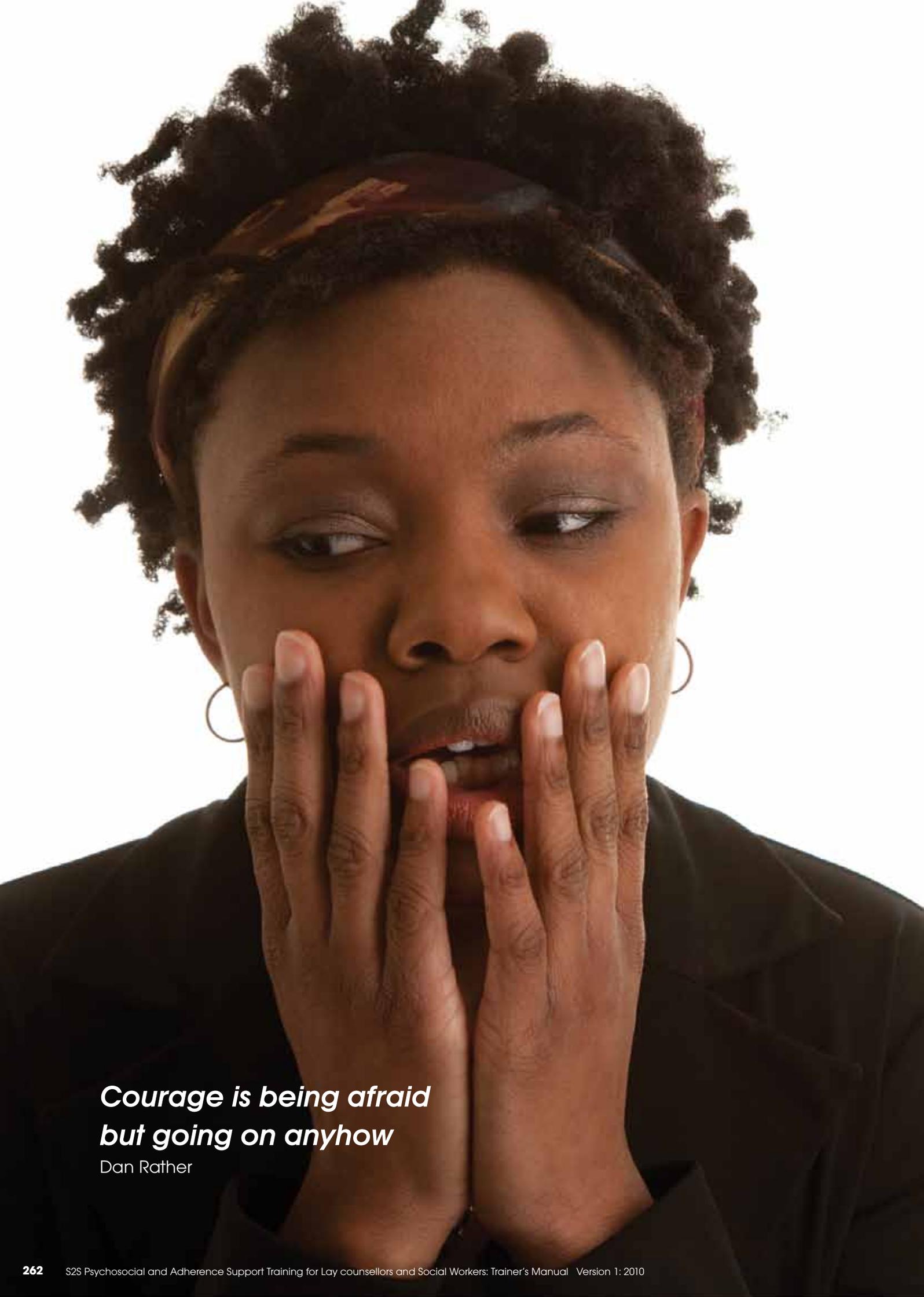
- Client may be blamed by partner or family for bringing HIV into the household
- Client's partner, family, or friends may reject, abandon, or distance themselves from the her
- Client may lose the financial support of a working partner
- Client may face discrimination in the community
- Client may face discrimination at work, including possibly losing her job
- Others may make assumptions about the client's sexuality, promiscuity, or lifestyle choices
- Client's children may face rejection at school or in the community
- Client may face physical violence

Deciding about disclosure:

- A good way to understand disclosure and to help people decide who they will disclose to is by creating a disclosure circle with clients.
- The centre of the circle is the client herself.
- The next circle out is a person or people the person is very close to, such as a mother, sibling, or partner.
- The next circle includes larger groups of people that the person is not as close to, such as people at work or others in the community.
- There can be many layers to a client's disclosure circle.
- Each layer of disclosure represents a process in itself – preparing for disclosure, the disclosure process, and ongoing conversations after disclosure. Remember that the conversation does not end after disclosure. There will probably be ongoing discussions over time between the client and the person she or he has disclosed to.
- The goal is NOT that all people will eventually disclose to all of the people in their disclosure circle. Instead, the disclosure circle gives lay counsellors a way to discuss with clients the disclosure process and the risks and benefits of disclosing to different people.

Here is an example of a disclosure circle:





***Courage is being afraid
but going on anyhow***

Dan Rather

SESSION 8.3

PROVIDING DISCLOSURE PREPARATION AND ONGOING COUNSELLING TO ADULTS (60 MINUTES)



TRAINER INSTRUCTIONS

Methodologies: Interactive Trainer Presentation, Brainstorming, Small Group Work, Large Group Discussion, Case Studies, Role Play

Step 1: Introduce the session by stating that, now, we will talk about ways to support clients and caregivers during the disclosure process.

Step 2: Ask participants to brainstorm what they think characterizes a helpful approach to disclosure counselling with pregnant and postpartum women. Record on flip chart, filling in using the content below.

Step 3: Using the content in the counselling cue card called **DISCLOSING YOUR HIV STATUS** in *Appendix 8A*, review the key counselling messages on this topic. Write key messages on flip chart or present them on slides. Refer participants to the counselling cue card in *Appendix 8A*.

Step 4: Allow time for discussion and for participants to ask questions about the key messages.

Step 5: Break participants into groups of 3, and review the case studies below. Assign each small group one of the case studies below and ask one person to play the role of the lay counsellor, another to play the role of the client, and the third to play the role of observer. Encourage participants to use the counselling cue card to help guide the session and their key messages. After about 10 minutes, ask the small groups to switch roles and to conduct another role play. After 10 more minutes, ask the groups to switch again so that each person gets to play each of the 3 roles. The trainers should circulate and provide assistance as needed.

Step 6: Once everyone has had a chance to play the role of the lay counsellor, bring participants back to the large group and, as time allows, ask some of the groups to present their role play to the large group. Allow participants time to give feedback and debrief the activity using these questions:

- *What did the lay counsellor do well?*
- *What other points do you think the lay counsellor could have discussed with the client about disclosing her HIV status?*
- *How did you use the counselling cue card during the role play? What was easy? What was challenging?*
- ***How do you think you can use this counselling cue card in your work?***

Step 7: Now that participants have seen some examples, ask them to brainstorm other ways a person could start a disclosure conversation with a person they want to share their status with. Remind participants that helping clients prepare for disclosure, including how, when, and where to start the conversation, is an important part of disclosure counselling.

Step 8: Close the session by reminding participants that because disclosure is a process, it is important that they continue to check in with clients about the progress they are making and/or the challenges they are encountering disclosing their HIV status to others. This should NOT include putting pressure on clients to disclose, but should rather focus on supporting clients to work through issues related to disclosure, allowing them to voice their concerns, and helping them make a plan if they have decided they want to disclose their status to others.

KEY INFORMATION

See Appendix 8A: Key Counselling Messages on Disclosure Preparation and Counselling

General helpful approach to disclosure counselling:

- Use good communication and counselling skills.
- Discuss the advantages and disadvantages of disclosure specific to the client's life.
- Help the person to identify barriers and fears about disclosure.
- Explore possible options to overcome specific barriers.
- Encourage the client to take the time needed to think things through.
- Talk about sexual partners who need protection from HIV infection.
- Identify sources of support.
- Support clients to make their own decisions about disclosure.
- Do not pressure clients to disclose.

CASE STUDIES:

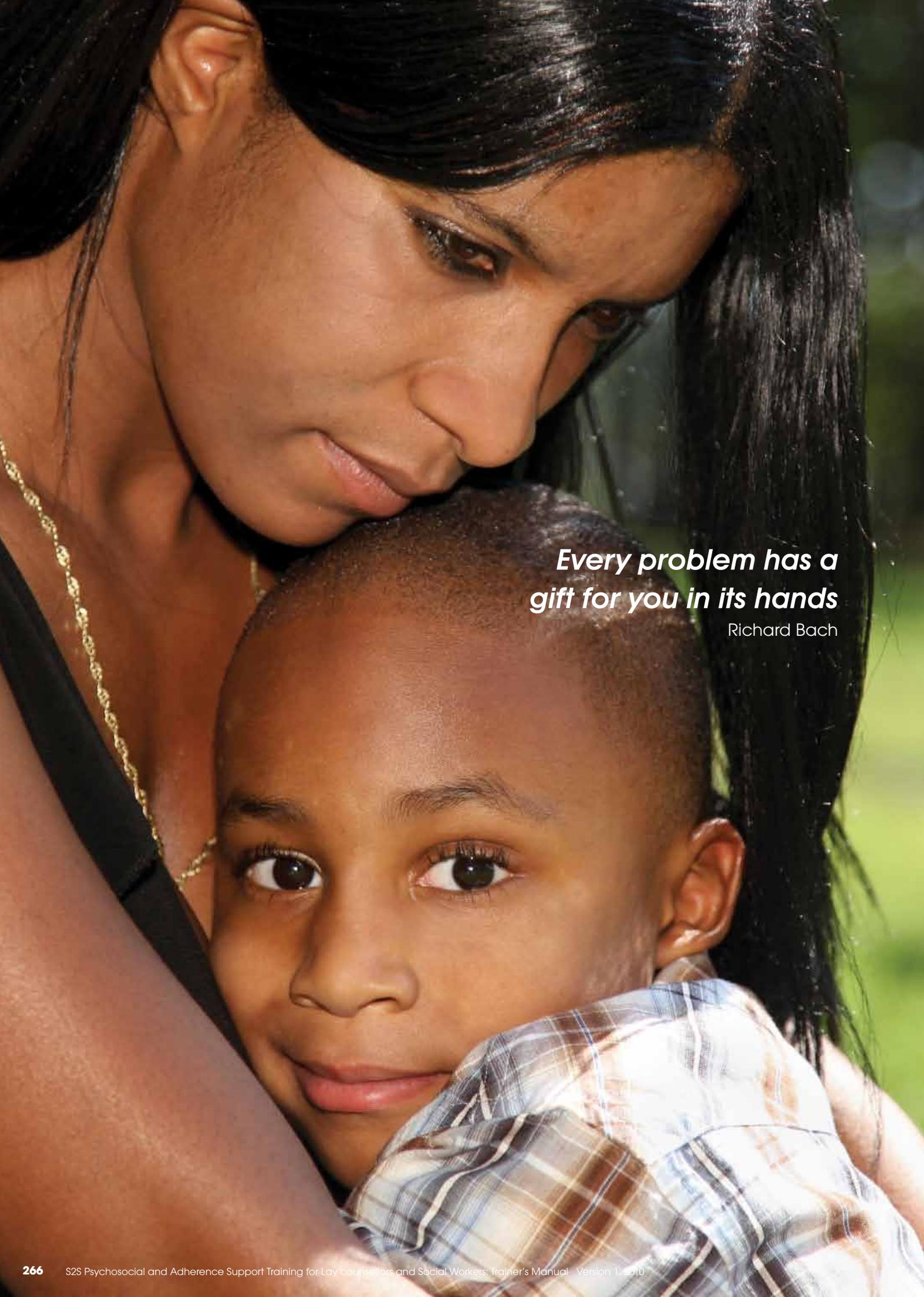
CASE STUDY 1:

Julia found out that she is HIV positive at her first ANC visit one month ago. She is here for her second visit, and says that she has not yet told anyone about her HIV status because she is too ashamed and scared. Help Julia explore and prepare to begin her disclosure process.

CASE STUDY 2:

Limphe has come into the clinic for her first ANC visit - she is 4 months pregnant. She has tested positive for HIV, and has received post-test counselling. The nurse asks you to speak with her more about disclosure, as this was a big concern expressed during her post-test counselling session.





*Every problem has a
gift for you in its hands*

Richard Bach

SESSION 8.4

PROVIDING PAEDIATRIC DISCLOSURE PREPARATION AND ONGOING COUNSELLING (120 MINUTES)



TRAINER INSTRUCTIONS

Methodologies: Small Group Work, Interactive Trainer Presentation, Large Group Discussion

Step 1: Ask participants, How is telling a child he/she has HIV different from an adult disclosing his/her own HIV status? Fill in using the content below.

Step 2: Next, ask participants, What are some reasons so many adults, including health care workers, do not want to tell children about their HIV status? Discuss and fill in using the content below.

Step 3: Next, ask participants, Do you believe that children should be told about their HIV status? Why or why not? Present the reasons why children should know their HIV status, using the content below, and discuss.

Step 4: Ask participants what they think the difference is between “partial disclosure” and “full disclosure.” Fill in, as needed, using the content below. Remind participants that they should encourage parents and caregivers to start the partial disclosure process early – and definitely by the time the child is 5 years old. This will help the disclosure process continue over time. As the child develops, lay counsellors should support caregivers to move towards full disclosure – where the child knows specifically that he or she is HIV infected. While there is not one size fits all approach, most children should be fully disclosed to between the ages of 8-11.

Step 5: Present the key steps/strategies to help families with disclosure to children (Preparation, Education, Planning, and Follow-up) on flip chart or slides, using the content below. Discuss the key things lay counsellors can do during each step.

Step 6: Ask participants to share their experiences talking with and/or counselling children. What strategies did they use to build trust and encourage communication for different aged children? Present and discuss the Tips on Talking with Children, from the box below.

Step 7: Ask participants to discuss the following questions. Fill in, as needed, using the content below. Refer participants to the summary table on disclosing to children in the Participant Handouts.

- *Why do we need different strategies and language for disclosure based on the child's age and developmental status?*

- *What are the key characteristics of pre-school children? What are some ways that caregivers and lay counsellors can talk to children this age about their HIV status?*
- *What are some of the characteristics of primary school-aged children? What are some ways that caregivers and lay counsellors can talk to children this age about their HIV status?*
- *What are some of the characteristics of adolescents? What concerns do adolescents have? What are some ways caregivers and lay counsellors can talk to adolescents about their HIV status?*

Remind participants that it is a child's right to know about his or her own health and that, as lay counsellors, we must work with caregivers to encourage disclosure - starting with partial disclosure to younger children and moving towards full disclosure when the child reaches 8-11 years old.

Step 8: Divide participants into groups of 4. Assign each group one of the 2 case studies below and in the Participant Handouts. Explain that each group should select a facilitator and a notetaker. Groups should read through their assigned case study, and the notetaker should fill in the groups' suggestions under each question. Give the groups about 20 minutes to complete their case study and to develop a role play about it.

Step 9: Bring participants back to the large group and, as time allows, ask some of the small groups to present their case study and role play to the large group. Also allow participants time to give feedback and discuss the main issues of the case study, what the lay counsellor did well, and what other points the lay counsellor could have discussed with the client.

KEY INFORMATION

How is telling a child that he or she is living with HIV different from an adult disclosing his or her own HIV status?

PRE-DISCLOSURE ASSESSMENT

Before disclosing to children, we must consider:

- The needs, feelings, and beliefs of the child
- The needs, feelings, and beliefs of the parents or caregivers
- The age and developmental stage of the child
- The specific family situation of the child
- How the parents or caregivers communicate with the child
- The level of peer support the child has

- The child's level of functioning in school
- The child's interests and activities

What are some of the reasons adults (including health care workers) do not want to tell children about their HIV status?

- Sometimes they do not know where to start.
- If there are other children who are not HIV infected in the home, there may be concerns about how the other children will react or how the HIV infected child will feel.
- They fear that disclosing will cause psychological harm to the child.
 - They fear that disclosing will reduce the child's will to live.
 - They fear that disclosing will make the child think he or she is not normal.
 - They have the belief that children are supposed to be happy, and that knowing they have HIV will make them no longer enjoy their childhood.
- They are afraid that the child's or family members' HIV status will be revealed by accident.
 - Children are not always good at keeping secrets.
 - Children may not understand the stigma attached to HIV.
- They want to protect the child from social stigma, discrimination, and rejection. They feel guilty that the child is HIV infected.
- They are not comfortable talking about taboo subjects, such as sex, with children.
- They have difficulty coping with their own illness, or that of loved ones.
- As a result of traditional family coping strategies, such as:
 - Silence around death and illness
 - Limited open communication
 - Denial as a coping strategy
- They believe that children are too young to understand complicated health issues.

What are the reasons to disclose a child's HIV status?

- Children have a right to know about their own health care.
- Children who have not been disclosed to may:
 - Have frightening or incorrect ideas about their illness
 - Feel isolated and alone
 - Learn their HIV status by mistake
 - Have poor adherence
- Children often want and ask to know what is wrong. Children are observant, smart, and curious. They often know much more than we adults think.
 - Children may already suspect their HIV status but are keeping it a secret or waiting for an adult to talk to them about it.
 - Children may have fears about their HIV status, especially if one or both of their parents has died.
- The later a child is told about his or her status the more difficult it will be for the child to accept.
- When children learn about their status directly from their caregivers, it can provide comfort

and reassurance. Too often, children overhear health care workers and caregivers talking about their health as if they are not in the room.

- Children who know their HIV status can take an active role in their care and treatment plan and, when old enough, take steps to live positively and prevent new infections.
- Orphaned or other vulnerable children may wonder why they have lost a parent or been rejected by the family. They need to know the truth – this will also help children seek the services they need, especially those who do not have regular caregivers.

PARTIAL AND FULL DISCLOSURE

PARTIAL DISCLOSURE

- Giving a child information about his or her illness without using the actual words HIV or AIDS
- Should start at an early age (and definitely by age 5)
- Helps move the disclosure process forward and prepares the child for full disclosure later on
- Is an effective strategy to help caregivers who do not yet feel ready to use the terms “HIV” and “AIDS” or for caregivers of young children who are not ready for full disclosure
- Is part of a process in which caregivers gradually move toward full disclosure
- Is useful for building a context in which full disclosure can be more meaningful for the child

FULL DISCLOSURE

- Telling a child specifically that he or she is HIV infected and giving him or her information about what this means, including that the child will need lifelong HIV care and treatment.
- Is easier for the child if they have been partially disclosed to over time, understand some basics about their health and their care and medicines, and have received ongoing support throughout the disclosure process.

ASSISTING FAMILIES WITH DISCLOSURE:

1. PREPARING FAMILIES

Remember: If the parents or caregiver are not ready to disclose, we cannot force the process. Asking and discussing the following questions can help determine what kind of support the caregivers need:

- *What do they think is important to communicate to the child?*
- *What do they think will be the hardest part of the disclosure process?*
- *What do they think will be the hardest questions to answer?*

2. EDUCATING FAMILIES

- Acknowledge that disclosure is very difficult.
- Affirm the parents' or caregiver's commitment to disclosing to the child.
- Answer any questions about paediatric HIV the family may have.
- Help families think about what questions the child might ask.
- Help plan how the child will receive support after disclosure.

3. PLANNING FOR DISCLOSURE

- When and where will disclosure start?
 - Ideally when the child is in a comfortable place, such as at home.
 - Start by playing with the child, or talking about the child's day.
 - Disclosure should not happen immediately after the family has learned about the child's status. There needs to be some time for the family to get used to the idea and to come to terms with the child's status.
 - Disclosure should not happen at the same time as another important event, such as a birthday, graduation, etc.
- Who will lead the conversation and what is the person's relationship to the child?
 - The best person to tell a child about his or her HIV status is usually a parent or caregiver.
- Will there be other people involved, for example, if the child becomes angry and withdrawn or has questions that the caregiver may have trouble answering?
- How will the conversation be started?
- At this time, is the goal partial or full disclosure?
- How will the caregivers provide support to the child after disclosure?
- How will they continue the disclosure process (for example if they are partially disclosing)?
- What anxieties does the family have and what can help reduce this anxiety?
- What support does the family need?
- Make sure to ask about all of the child's caregivers to make sure everyone has the same messages and knows how and when the child will be disclosed to.
- Encourage disclosure to brothers and sisters of the child living with HIV; they can be a very important source of support for the child.

4. PLANNING FOLLOW-UP SUPPORT

- It is important to talk with the parents or caregiver at follow-up appointments to see how the child is handling knowing his or her status.
- Make sure the child knows who to ask when he or she has questions.
- Offer support to the child to cope with his or her emotions and feelings after disclosure. Refer to a children's support group if possible.
- Make sure the child is given a chance to express his or her feelings – through talking, role play, drawing, etc.
- Plan for a follow-up counselling session with the child and caregiver at the clinic.
- Focus on steps the child can take to live a long, healthy life.
- Plan for disclosure to others (other family members, teachers, peers, etc.).
- Tell the caregiver about any support services in the area, for example, a support group for mothers or children who are living with HIV.
- Tell the parents or caregiver that it is a good idea to:
 - Ask the child what he or she has been feeling since finding out about his or her HIV status.
 - Talk to the child about bad or frightening feelings being normal, but that if they get to be too much, he or she should talk with someone he or she trusts.
 - Tell the child that others also have the same feelings and that these feelings are very normal.
 - Ask the child regularly how he or she is doing with school, friends, and other parts of life.
 - Talk to the child about with whom it is ok to talk about HIV.
 - Explain to the child that it is important that he or she talk to someone older when feeling bad, for example, an older sister or brother, aunt, or grandmother.
 - Ask the child if they have told anyone about having HIV (and who he or she told, what their reaction was, etc.).
 - Tell the child that, for those with sad/angry reactions, sometimes people do not understand HIV.

REMEMBER:

- Disclosure is more than telling a child his or her HIV status.
- Disclosure is an ongoing process.
- Caregivers should talk about health issues with children at an early age, including giving simple explanations about illness to young children. This is called partial disclosure.
- Younger children, particularly if they are sick, are more interested in what will happen to them in the near future – they need comfort and assurance.
- When to say “HIV” varies with the child and the family, but most children should know they have HIV as soon as they have developed the emotional maturity to understand what this means. Ideally, children will be fully disclosed to between the ages of 8-11 years.

SOME TIPS ON TALKING WITH CHILDREN

- Many of the listening and learning skills discussed in Module 3 apply to children as well as adults.
- When talking with children, adults should be at the same level (such as sitting on the floor together).
- Make sure there is privacy.
- Listen to the child, and show that you are listening.
- See what concerns the child has before giving information.
- Allow the child time to talk without being interrupted.
- Use play and drawing to help learn how the child is feeling.
- Let the child be the guide – children will naturally ask questions.
 - Find ways to help caregivers stimulate the discussion, as some children may not ask questions – depending on their relationship with the caregiver.
 - Caregivers can stimulate the discussion by asking questions to see if the child is curious – for example, about why they go to the clinic often or why the nurse takes his or her blood.
- Individualize the approach according to the child's age, developmental stage, maturity, coping skills, and family situation.
- Use language and words that the child will easily understand.
- Always give the child correct information. Never lie to the child.
- It is important to emphasise over and over again that the sickness/HIV is not his or her fault.
- Try to make HIV seem as normal as possible, like any other long-term illness.
- A child does not always need to know how he or she got HIV.
- Help the child understand his or her choices and empower him or her to make decisions.
- Remind the child that he or she can come to you any time to talk or ask questions.

- In many cases, children may feel very shy or embarrassed about asking questions of an adult, therefore the caregiver's job is to let the child know that he or she is allowed to ask questions.
- If a child asks a question and the caregiver thinks that the child is not yet mature enough to hear the answer, the caregiver should not make the child feel bad because he or she asked this question. Encourage the caregiver to answer as much of the question as he or she can in a way that is appropriate for the child's level of development.



HIV DISCLOSURE STRATEGIES FOR CHILDREN OF DIFFERENT AGES AND DEVELOPMENTAL STAGES

AT ALL AGES:

- Create an environment in which the child will feel free to ask questions.
- Anticipate and plan how to respond to possible responses (verbal and non-verbal) of the child.
- Anticipate and plan for the impact of disclosure on family members, friends, school, and community members.
- Be led by the child (their questions, reactions) about the amount and type of information given.
- Use language appropriate to the child's developmental stage and emotional readiness.
- Keep what is said simple, clear, and most of all, honest.
- Children may need reassurance that they have not done anything wrong.
- Offer ongoing post-disclosure counselling and support to the child and caregivers.

GENERAL QUESTIONS TO ASK CAREGIVERS IN ORDER TO GATHER INFORMATION:

- *Has your child been asking any questions yet about his or her sickness?*
- *If yes: What kinds of questions has he or she been asking?*
- *How have you been answering the questions?*
- *Have you tried to talk to your child about HIV before?*
- *What kinds of things have you talked about with your child?*

AGE GROUPS AND IMPLICATIONS OF DEVELOPMENTAL STAGE FOR DISCLOSURE

SUGGESTIONS OF WHAT TO SAY TO THE CHILD

PRE-SCHOOL CHILDREN (AGE 2-5 YEARS)

- Understanding is closely tied to the child's own experiences (me, here, and now), language is mainly used to communicate wants.
- Emphasize the child's health and illness, and delay disclosure specifically of HIV status.
- Give information in response to the child's questions ("Why does the doctor take my blood?") or reactions (e.g. refusing to take medication).
- Use play activities (e.g. playing "doctor") to help the child express feelings and concerns.
- The child may normally start asking questions about his or her sickness. If the child has not started asking questions by about age 5 or 6, it may be helpful for you to give explanations to the child about why he or she has to go to the clinic and take medicines.

- *You have to see the nurse so she can check your blood.*
- *The nurse takes your blood to make sure you stay well.*
- *You need to take medicine because there's a germ in your blood that can make you sick.*

PRIMARY SCHOOL CHILDREN (AGE 6-10 YEARS)

- It is important to start the disclosure process at this stage, if not before. Healthcare workers/ caregivers will know it is time to start thinking about disclosing the child's status when he or she starts asking more specific questions — such as, why they are taking medicines, why they have to go to the clinic so often — and the normal responses no longer seem to be enough for the child.
- Give more detailed information, with concrete examples.
- If a child asks for more information (e.g. "What's the germ called?", "How did the germ get in my body?"), give short, clear answers.
- Help the child deal with possible stigma.
- Reassure the child that he or she can ask further questions or share any concerns now or later.

- *Going to the doctor will help you stay well.*
- *You have a virus in your blood called HIV. It attacks the germ fighters in your body. This is why you get sick sometimes.*
- *You and I both have HIV in our bodies.*
- *You have to take medicine so the germ fighters can work and you won't get sick so much.*
- *You (and I) take medicine to keep us strong.*
- *You cannot give the sickness to anyone else by playing with them, touching or hugging them, eating from the same plate, or using the same toilets.*
- *HIV is nothing to be ashamed of, but it is something private. You don't have to tell other people if you don't want to.*
- *Maybe we should keep this in the family for now?*

AGE GROUPS AND IMPLICATIONS OF DEVELOPMENTAL STAGE FOR DISCLOSURE	SUGGESTIONS OF WHAT TO SAY TO THE CHILD
<p>ADOLESCENTS (AGE 11 YEARS AND OVER)</p> <ul style="list-style-type: none"> • Accurate and more detailed information can be given in response to questions. • Realistic information about health status should be given, and all questions should be answered. • Be sure to ask about and discuss the adolescent's feelings and fears about HIV. • Ways to live meaningfully with HIV, including having relationships, are a common concern. • It is very important to assure them that their status and what they say is confidential. • Normal adolescent striving for independence may complicate the response to disclosure (e.g. result in a decline in adherence). • Issues of disclosure to others should be discussed, but the adolescent should make his or her own decisions on this matter. • Assurance of support and willingness to help should be given without seeming intrusive. 	<ul style="list-style-type: none"> • <i>You have the HIV virus. A virus is something that gets into your blood and can make you sick. Having HIV does not mean that you are sick all the time.</i> • <i>You can control the virus by taking your medication every day. But, there is no way you can get rid of HIV completely.</i> • <i>Knowing that you have HIV gives you a special responsibility to take extra good care of yourself and not to pass HIV to other people.</i> • <i>Having HIV does not mean that you can't live a long life, have relationships, or get married.</i> • <i>If you have sex, it is important for you and your partner that you use condoms.</i> • <i>You can have a baby in the future, but there are risks of passing HIV to your partner or to the baby. There are many things you could do to lower the chances that your baby will get HIV. We can talk more about this whenever you like.</i>

Note: The content of this session was adapted in part from: Adherence Networking Group. (2006). *Kids Count: Children's ART adherence resource pack*. Centre for the Study of AIDS, University of Pretoria and the Perinatal HIV Research Unit, South Africa.

PAEDIATRIC DISCLOSURE CASE STUDIES

CASE STUDY 1:

Itumeleng is a 12-year-old female orphan who lives with her maternal aunt and uncle. Her aunt, Matshepo, monitors her ARV medication and reports very good adherence. When asked to consider disclosure of HIV status, Matshepo was tearful. She stated that she knew this day would come and would like to discuss the options with her husband before making final decisions.

She is not sure how to explain the diagnosis to Itumeleng in a way that she will understand. Matshepo is also concerned that Itumeleng “will feel different from other kids.” At school, Itumeleng has already learned about HIV. No one has told her anything about why her parents died, but she is worried that her parents had HIV and that she will die soon too. She has only been told that the medication she takes is to “keep her strong.”

QUESTIONS:

- 1. What would you discuss with Mathsepo?***
- 2. How would you support Matshepo when she and her husband decide to tell Itumeleng about her HIV status?***

CASE STUDY 2:

Lerato is a 6-year-old girl living with HIV and taking ART. She lives with her mother Mpho, maternal uncle, and 5 older half-siblings and cousins. Each time Lerato comes to the clinic she gets very agitated when she gets blood drawn, and recently has been asking “why do I need to take medicines” and “why am I always sick”?

Today, Lerato seems very upset that she has to come to the doctor instead of playing with her cousins. When you ask, Mpho hasn't told Lerato anything about her HIV status or the reasons she has to come to the clinic so much.

QUESTIONS:

- 1. What would you say to Mpho? What other information would you want to know?***
- 2. What do you think Mpho should say to Lerato?***
- 3. What type of follow-up would you plan with Mpho and Lerato?***

SESSION 8.5

LEGAL ISSUES RELATED TO DELIVERY OF HEALTH SERVICES AND DISCLOSURE TO CHILDREN (30 MINUTES)



TRAINER INSTRUCTIONS

Methodologies: Large Group Discussion, Interactive Trainer Presentation

- Step 1:** Ask participants what they have heard about the Children’s Act, which was fully enacted across South Africa in April, 2010. Review the main objectives of the Children’s Act, using the content below.
- Step 2:** Next ask participants to discuss implications of the Children’s Act related to HIV- testing, HIV disclosure, and HIV services. Fill in, as needed, using the content below.
- Step 3:** Discuss that the role of lay counsellors and social workers is not necessarily to do the actual partial or full disclosure to children, but instead to encourage parents and caregivers to start the disclosure process early with children and to provide supportive counselling – to parents, caregivers, and children - throughout the disclosure process. Point out that lay counsellors and social workers should always consult with other members of the multidisciplinary care team for difficult cases, such as those involving child abuse and neglect, adoption, etc. and should provide referrals when needed.
- Step 4:** Close the session by reminding participants that they need to follow the guidelines in the Children’s Act when delivering HIV and other health-related information and services to children at their clinics.

KEY INFORMATION

The main objective of the Children’s Act is to give effect to children’s constitutional rights to:

- Family care, parental care, or appropriate alternative care when removed from the family environment
- Social services
- Protection from maltreatment, neglect, abuse, or degradation
- Have their best interests considered of paramount importance in every matter concerning the child

The Act gives effect to these and other constitutional rights mainly through the provision of a range of social services for children and families. These include:

- Crèches and early childhood development programmes
- Prevention and early intervention programmes (including home-based care for families affected by chronic illnesses such as HIV/AIDS, parenting programmes, and child and family counselling)
- Drop-in centres
- Protection services (identifying, reporting and supporting abused and vulnerable children)
- Foster care and cluster foster care
- Adoption
- Child and youth care centres

Implications of the Children’s Act on HIV Disclosure to Children

- The Act says that every child has the right to confidentiality regarding his or her HIV status.
- The Act says that every child has the right to participate in decisions about his or her health, access a range of information about his or her health, and access a range of health services.
- The HIV status of a child may be disclosed with the consent of the child, if the child is:
 - 12 years of age or older; or
 - Under the age of 12 years and of sufficient maturity to understand the benefits, risks, and social implications of such a disclosure
- The HIV status of a child under the age of 12 years who is not of sufficient maturity to understand the benefits, risks, and social implications of disclosure may be disclosed with the consent of:
 - The parent or caregiver (regardless of whether the parents are alive or dead)
 - A designated child protection organization arranging the placement of the child, such as Child Welfare or the Department of Social Development
 - The superintendent or person in charge of a hospital, if the child has no parent or caregiver and if there is no designated child protection organization arranging the placement of the child
 - A children’s court, if consent is unreasonably withheld; if disclosure is in the best interests of the child; or if the child or the parent or caregiver of the child is incapable of consenting to such disclosure
- The HIV status of a child may be disclosed without consent in the following circumstances:
 - If the disclosure is within the scope of that person’s powers and duties in terms of the law and if it is in the best interest of the child
 - If it is necessary to carry out an obligation in the Children’s Act
 - During legal proceedings in which disclosure is necessary for those proceedings; or in terms of a court order

Note: Citation and for further information: Mahery, P, Proudlock, P & Jamieson, L. (2010). *A guide to the children’s act for health professionals*, 4th edition. 1 June 2010. Children’s Institute. University of Cape Town.

SESSION 8.6

CLASSROOM PRACTICUM (70 MINUTES)



TRAINER INSTRUCTIONS

Methodologies: Small Group Work, Case Studies and Role Play, Large Group Discussion

Step 1: Break participants into small groups of 4. Refer to the case studies written below and in the Participant Handouts. Ask the groups to assign one person to play the role of a lay counsellor, one the role of the client, and two the role of observers. Explain that each small group will go through each of the 4 case studies, with group members shifting roles so that each person has the chance to play the role of the lay counsellor.

During each role play, one observer should use the listening and learning skills checklist in *Appendix 8B* to record the different skills used by the lay counsellor, and the second observer should use the counselling cue card and information on paediatric disclosure in the Participant Handouts to record key counselling messages covered during the role play.

Step 2: Ask the small groups to role play the first case study. After about 10 minutes, ask the observers to give feedback. Ask the groups to change roles and move on to the second case study. Continue until all of the small groups have worked through each case study. Trainers should participate in the small groups and provide guidance.

Step 3: If time allows, ask some groups to do a short role play of the case studies for the large group. Discuss the key points and considerations of each case study as a large group and be sure to answer any questions. Debrief the activity by reminding participants that lay counsellors should be comfortable discussing key messages and providing necessary information, preparation, support, and follow-up on disclosure – both to pregnant and postpartum women, as well as parents and caregivers of HIV infected children.

KEY INFORMATION

CASE STUDIES:

CASE STUDY 1:

Mampho is 32 weeks pregnant and is taking PMTCT prophylaxis. She stays with her boyfriend, who has an alcohol problem and is emotionally abusive. Mampho's boyfriend is also suspicious about the medication that Mampho has been taking.

CASE STUDY 2:

Thato's daughter is 6 weeks old and is on AZT. Thato, who stays with her mother-in-law, is exclusively breastfeeding her daughter. Thato's mother-in-law is curious about the medication that the baby is getting every day. However, Thato is anxious and scared about disclosing her HIV status to her mother-in-law.

CASE STUDY 3:

Refilwe is HIV infected and gave birth to a baby boy 5 months ago. He tested HIV negative, and is being exclusively formula fed. Refilwe is supposed to start ARVs because her CD4 count has dropped to 200. During her preparation to initiate ARVs, she says that she is not ready to disclose her HIV status to her partner.

CASE STUDY 4:

Katleho is 4 years old and has been on ARVs since the age of 2 years. His mother died due to HIV related illnesses, and Katleho's grandmother is now his caregiver. Katleho has been asking his grandmother a lot of questions lately about why he always has to go to the clinic for checkups even though he is feeling fine.

SESSION 8.7

MODULE SUMMARY AND EVALUATION (15 MINUTES)



TRAINER INSTRUCTIONS

Methodologies: Large Group Discussion, Interactive Trainer Presentation

- Step 1:** Ask participants what they think are the key points of this Module. What information will they take away from the Module?
- Step 2:** Summarize the key points of the Module using participant feedback and the content below. Review the learning objectives with participants and make sure all are confident with their skills and knowledge in these areas.
- Step 3:** Ask if there are any questions or clarifications.
- Step 4:** Ask each participant to share with the group one thing he or she will do differently in his or her work as a lay counsellor or social worker, based on the information and skills learned in this Module.
- Step 5:** Hand out a Module evaluation form to each participant (see *Appendix 8C*), and ask that they take about 5 minutes to fill it out and to return it to the trainers. Remind participants that they do not need to put their name on the form.



THE KEY POINTS OF THIS MODULE INCLUDE:

- Lay counsellors should try to be aware of their own values and attitudes related to disclosure so the quality of counselling they provide to clients is not affected.
- Disclosure is an on-going process that takes place over time, and after careful preparation. Ongoing support and follow-up counselling is also part of the disclosure process.
- Drawing a “disclosure circle” with clients gives lay counsellors a way to discuss the disclosure process and the risks and benefits of disclosing to different people.
- The counselling cue card called **DISCLOSING YOUR HIV STATUS** can be a useful tool for lay counsellors to remember the key counselling messages when counselling a PMTCT patient on disclosure preparation.
- Because disclosure is a process, it is important that lay counsellors continue to check in with clients about the progress they are making and/or the challenges they are encountering disclosing their HIV status to others.
- Disclosure for children requires attention to the child’s age, developmental stage, coping skills, as well as beliefs of the caregivers and the family situation.

- Disclosure should be part of an on-going conversation about the child's health.
- Disclosure to children has many benefits, even though many adults are hesitant to talk to children about HIV.
- Lay counsellors and social workers can help prepare, guide, and follow-up with families in the disclosure process over time, but usually, it is best for parents and caregivers to actually talk with children directly about their HIV status.
- Caregivers should start partial disclosure to children at a young age – around 5 years old or before. By age 7 or 8, the disclosure process should be well underway with children, with the goal of full disclosure between the ages of 8 and 11 years.
- Postponing the disclosure process will only create problems later on, so lay counsellors should encourage parents and caregivers to start talking with their children at a young age. Lay counsellors can give specific guidance on how to talk to children of different ages about their health and HIV status.
- Children should be offered post-disclosure support from people they trust at home and at the clinic.
- Lay counsellors and social workers should follow the South Africa Children's Act, which gives specific guidance on delivery of HIV and other health-related information and services, to children.

APPENDIX 8A

KEY COUNSELLING MESSAGES - DISCLOSURE PREPARATION
(FOR PREGNANT AND POSTPARTUM WOMEN)

DISCLOSING YOUR HIV STATUS

Open the session and gather information

- *Who have you told about your HIV status, if anyone?*
 - *Can you tell me more about your concerns and your experiences talking with others about your HIV status?*
-

If the client has not yet disclosed to her partner

- *How do you think your partner would react if you told him or her your HIV status?*
 - We recommend that you talk to your partner about your HIV status if you feel safe doing so.
 - You could say that HIV testing is a routine part of care for all pregnant women, and that this is why you were tested.
 - It is possible that your partner will be supportive of you, help you protect your baby from HIV, and help you stay healthy.
 - It may be hard for you to adhere to your and your baby's care and medicines if your partner does not know your HIV status.
 - Your partner should also have an HIV test and, if positive, enroll in care and treatment.
 - We can provide information, services, and support to your whole family so you can all get the care you need.
 - If you want, we can help you talk to your partner about your HIV status.
-

Gather information

- *What good things do you think could result from telling someone your HIV status?*
- *What bad things do you think could result from telling someone your HIV status?*

Possible benefits of telling someone you trust about your HIV status

- You will not have to keep your HIV status a secret anymore.
- You will not have to worry about the person finding out your HIV status accidentally.
- You might be able to talk to the person about your concerns and get his or her support.
- The person might be able to help you with your own and your baby's care and treatment.

Gather information

- ***Who do you think you could tell about your HIV status?***
- ***When do you think would be a good time and place to tell this person?***
- ***How will you tell him or her?***
- ***How do you think the person will react?***

Disclosing your HIV status is a process

- Many people prefer to disclose to one person they trust at a time, instead of disclosing to many people at once.
- Let's talk about your "circles of disclosure."
- Here are some ways that you could start the conversation:
 - *"I wanted to talk to you about something because I know you can help and support me."*
 - *"I went to the clinic today for a check-up and they talked to me about how it is important for everyone to get an HIV test because you can't tell if someone is positive just by looking at them."*
 - *"I need to talk to you about something difficult. It is important for our family that I be able to tell you even the hard things. We need to support each other."*

Summarize and plan next steps

- ***We are here to support you during your disclosure process.***
- ***Would you like to set up another appointment to continue talking about this – either alone or with your partner, a friend, or a family member?***

APPENDIX 8B

COUNSELLING AND COMMUNICATION CHECKLIST



APPENDIX 8B

COUNSELLING AND COMMUNICATION CHECKLIST

SKILL	SPECIFIC STRATEGIES, STATEMENTS, BEHAVIOURS	TICK
Establish a relationship with the client	• Ensure privacy (make sure others cannot see or hear).	
	• Introduce yourself (name and role).	
	• Ask the client to introduce herself (or himself) to you.	
	• Ensure client about confidentiality / explain shared confidentiality	
	• Start the session with an open-ended question (" <i>Where would you like to start?</i> " or " <i>Tell me more about why you came today.</i> ")	
SKILL 1: Use helpful non-verbal communication	• Make eye contact.	
	• Face the person (sit next to her or him) and be relaxed and open with posture.	
	• Use good body language (nod, lean forward, etc.).	
	• Smile.	
	• Do not look at your watch, the clock or anything other than the client.	
	• Do not write during the session.	
	• Other (specify)	
SKILL 2: Actively listen and show interest in your client	• Nod and smile. Use encouraging responses (such as " <i>yes,</i> " " <i>okay</i> " and " <i>mm-hmm</i> ").	
	• Use a calm tone of voice that is not directive.	
	• Allow the client to express emotions.	
	• Do not interrupt.	
	• Other (specify)	
SKILL 3: Ask open-ended questions	• Use open-ended questions to get more information.	
	• Ask questions that show interest, care and concern.	
	• Other (specify)	
SKILL 4: Reflect back what your client is saying	• Reflect emotional responses back to the client.	
	• Other (specify)	
SKILL 5: Show empathy, not sympathy	• Demonstrate empathy: show an understanding of how the client feels.	
	• Avoid sympathy.	
	• Other (specify)	
SKILL 6: Avoid judging words	• Avoid judging words such as " <i>bad,</i> " " <i>proper,</i> " " <i>right,</i> " " <i>wrong,</i> " etc.	
	• Use words that build confidence and give support (e.g., recognize and praise what a client is doing right).	
	• Other (specify)	
SKILL 7: Help your client set goals and summarize each counselling session	• Work with the client to come up with realistic "next steps."	
	• Summarize the main points of the counselling session.	
	• Make a next appointment date with the client and reassure her or him that you, or someone else at the clinic, are always available.	

APPENDIX 8C

MODULE 8 EVALUATION FORM



APPENDIX 8C

MODULE 8 EVALUATION FORM

Name (optional): _____ Health Facility: _____ Position: _____

Please note the following statements on a scale of 1 to 5:

	 Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	 Strongly Agree
1. The module objectives were clear	1	2	3	4	5
2. This module met my expectations	1	2	3	4	5
3. The technical level of this module was appropriate	1	2	3	4	5
4. The pace of speed of this module was appropriate	1	2	3	4	5
5. The facilitators were engaging and informative	1	2	3	4	5
6. The information I learned in this module will be useful to my work	1	2	3	4	5

How helpful were each of the workshop sessions to you and your work?

You can write extra comments on the back.

	 Not Helpful				 Very Helpful
Examining Our Own Attitudes and Values around Disclosure	1	2	3	4	5
The Disclosure Process	1	2	3	4	5
Providing Disclosure Preparation and Ongoing Counselling to Adults	1	2	3	4	5
Providing Paediatric Disclosure Preparation and Ongoing Counselling	1	2	3	4	5
Legal Issues Related to Disclosure and Delivery of Health Services to Children	1	2	3	4	5
Classroom Practicum	1	2	3	4	5

What was the BEST THING about this Module?

What was NOT USEFUL about this Module?

Do you have other comments (use the back of the page if needed)?

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