National Training Package on Adolescents Living with HIV and AIDS

Participants' Manual

August 2017

THE UNITED REPUBLIC OF TANZANIA
Ministry of Health, Community Development, Gender, Elderly and Children

unicef

The United Republic of Tanzania

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National AIDS Control Programme (NACP)

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Acronyms

ADHD	attention deficit hyperactivity disorder
AGPAHI	Ariel Glaser Pediatric AIDS Healthcare Initiative
AIDS	acquired immunodeficiency syndrome
ALHIV	adolescents living with HIV
ANC	antenatal care
APE	adolescent peer educator
ART	antiretroviral therapy
ARV	antiretroviral
AZT	zidovudine (*earlier known as azidothymidine*)
BATHE	background, affect, trouble, handle and empathy
BD	twice a day
BIPAI	Baylor International Paediatric AIDS Initiative
BMC	Bugando Medical Centre
BMI	body mass index
CAGE	cut down, annoyed, guilty, eye-opener
CBHC	community-based health care
CBHS	community-based health service
CDC	U.S. Centers for Disease Control and Prevention
CECAP	cervical cancer prevention
CHACC	council HIV AIDS control coordinator
CTC	Care and Treatment Center
CTX	cotrimoxazole
DAST	drug abuse screening test
EAC	enhanced adherence counselling
EFV	efavirenz

EGPAF	Elizabeth Glaser Pediatric AIDS Foundation
FP	family planning
FTC	emtricitabin
GBV	gender-based violence
HCP	health care provider
HIV	human immunodeficiency virus
HJFMRI-WRP	Henry Jackson Foundation Medical Research International – Walter Reed Program
HPV	human papilloma virus vaccine
HVL	HIV viral load
IAS	International AIDS Society
ICAP	International Centre for AIDS Care and Treatment Program
ICF	intra cellular fluid
IGA	income-generating activities
IMAI	integrated management of adult and adolescent illness
INH	isoniazid
IPT	isoniazid preventive therapy
IRIS	immune reconstitution inflammatory syndrome
I-TECH	International Training and Education Center for Health
M&E	monitoring and evaluation
MDH	Management and Development for Health
MDR	multidrug-resistant
MNH	Muhimbili National Hospital
MoHCDGEC	Ministry of Health Community Development, Gender, Elderly and Children
MSM	men who have sex with men
MSW	male sex worker
MUAC	mid-upper arm circumference
MUHAS	Muhimbili University of Health and Allied Sciences
MZRH	Mbeya Zonal Referral Hospital
NACP	National AIDS Control Programme
NNRTI	non-nucleoside reverse transcriptase inhibitor
NVP	nevirapine

OD	once daily
OI	other co-infections
ORS	oral rehydration solution
PASADA	Pastoral Activities and Services for people with AIDS Dar es Salaam Archdiocese
PE	peer educator
PI	protease inhibitor
PLHIV	people living with HIV
PMTCT	prevention of mother-to-child transmission
PWID	people who inject drugs
QA	quality assurance
QI	quality improvement
R/CHMT	regional and council health management team
RCHS	reproductive and child health services
SBCC	socio-behavioural change communication
SOSPA	Sexual Offences Special Provisions Act
SRH	sexual and reproductive health
SRHR	sexual and reproductive health rights
STD	sexually transmitted disease
STI	sexually transmitted infections
TACAIDS	Tanzania Commission for AIDS
TB	tuberculosis
TDF	tenofovir disoproxil
TFC	treatment foster care
THPS	Tanzania Health Promotion Services
UNICEF	United Nations Children's Fund
USAID	United States Agency for International Development
VAC	violence against children
VL	viral load
WHO	World Health Organization
XDR	extensively drug-resistant

Time table for National Training on Adolescents Living with HIV and AIDS

Day 1

Time	Topic/Content	Facilitator(s)
0800–0830	Registration and welcome remarks	
0830–1000	**Session 1.1** Introduction and purpose of the training *Pre- training questionnaire (30 minutes)*	
1000–1030	**Tea**	
1030–1100	**Session 1.2** Background information on adolescents living with HIV	
1100–1115	Energizer	
1115–1205	**Session 2.1** Stages and changes during adolescence	
1205–1235	**Session 2.2** Adolescent vulnerabilities, risk-taking behaviours, and their consequences	
1235–1335	**Lunch**	
1335–1405	**Session 2.3** Adolescent-friendly services	
1405–1435	**Session 2.4** ALHIV legal issues and bioethical considerations	
1435–1450	Energizer	
1450–1550	**Session 3.1** HIV prevention services for adolescents	
1550–1635	**Session 4.1** Developing effective communication skills	
1635–1650	Daily evaluation	
1650–1705	**Tea**	
1705–1720	Facilitators' meeting	

Day 2

0800–0830	**Recap of day 1** Responding to issues/questions from daily evaluation and secretariat report of day 1	
0830–0915	**Session 4.2** Establishing trust and rapport with adolescent clients	
0915–1000	**Session 4.3** Effective techniques for counselling adolescents	

1000–1030	**Tea**	
1030–1110	**Session 5.1** Overview of the disclosure process among adolescents	
1110–1245	**Session 5.2** Health workers' role in disclosure	
1245–1315	**Session 6.1** HIV acquisition – modes and implications for care and treatment	
1315–1415	**Lunch**	
1415–1500	**Session 6.2** SDMs for differentiated care for adolescents	
1500–1700	**Session 6.3** Comprehensive care for ALHIV	
1700–1715	Daily evaluation	
1715–1730	**Tea**	
1730–1745	Facilitators' meeting	
Day 3		
0800–0900	**Recap of day 2** Responding to issues/questions from daily evaluation, secretariat report of day 2, and cabbage ball review	
0900–1015	**Session 7.1** Psychosocial needs of adolescent clients	
1015–1045	**Tea**	
1045–1115	**Session 7.2** Peer support in psychosocial services for adolescents	
1115–1200	**Session 7.3** ALHIV and clubs	
1200–1230	**Session 7.4** Life skills for ALHIV	
1230–1315	**Session 8.1** Introduction to adherence and retention	
1315–1415	**Lunch**	
1415–1515	**Session 8.2** Adherence preparation support to ALHIV and caregivers	
1515–1600	**Session 8.3** Assessing adherence and providing ongoing adherence support	
1600–1615	Energizer	
1615–1700	**Session 8.4** Follow-up with ALHIV who have missed visits	
1700–1715	Daily evaluation	
1715–1730	**Tea**	
1730–1745	Facilitators' meeting	

Day 4		
0800–0830	**Recap of day 3** Responding to issues/questions from daily evaluation and secretariat report of day 3	
0830–0915	**Session 9.1** Importance of facility–community linkages	
0915–1015	**Session 9.2** Creating a community resource directory	
1015–1045	**Tea**	
1145–1215	**Session 9.3** Adolescent participation and peer education programmes	
1215–1300	**Session 10.1** Overview of mental health and mental illness in ALHIV	
1300–1400	**Lunch**	
1400–1545	**Session 10.2** Management of common mental illnesses among ALHIV	
1545–1715	**Session 11.1** Nutritional care and support among ALHIV	
1715–1800	**Session 12.1** Attitudes, values, and beliefs about adolescent sexuality and HIV	
1800–1815	Daily evaluation	
1815–1830	**Tea**	
1830–1900	Facilitators' meeting	

Day 5		
0800–0830	**Recap of day 4** Respond to issues/questions from daily evaluation and secretariat report of day 4	
0830–0900	**Session 12.2** Adolescents' reproductive health services	
0900–0945	**Session 12.3** Support adolescent clients in practising safe sex	
0945–1030	**Session 12.4** Contraception, pregnancy, STI and CECAP in ALHIV	
1030–1100	**Tea**	
1100–1130	**Session 13.1** Key considerations when transitioning ALHIV from adolescent care to adult care	
1130–1200	**Session 13.2** Preparing and empowering adolescents to transition into adult care	
1200–1215	Energizer	

1215–1400	**Session 14.1** Monitoring and evaluation (M&E)	
1400–1445	**Lunch**	
1445–1530	**Session 14.2** Quality improvement and supportive supervision	
1530–1600	**Session 15.1** Site-specific adolescent HIV care and treatment implementation and action planning	
1600–1630	**Session 15.2** Reflection on training objectives and concerns, expectations, and strengths	
1630–1715	**Session 15.3** Post-test, training evaluation, and closing	
1715–1730	**Tea**	
1730–1800	Facilitators' meeting	

Foreword

In Tanzania and globally, there have been improvements in AIDS-related morbidity and mortality due to scale-up of HIV prevention and treatment services, advanced treatment options, advances in treatment access and the establishment of effective prevention strategies. These improvements have also been seen among infants and children, resulting in an increase in the number of adolescents and young adults needing chronic disease management.

Worldwide, adolescents (10–19 years) represent a growing share of people living with HIV. Despite the presence of various interventions, there has been an increase in infection patterns among adolescents. In 2016 alone, 610,000 young people in the 15–24 years age group were newly infected with HIV, of whom 260,000 were adolescents aged 15 to 19 years. To compound this issue, recent data from sub-Saharan Africa – the region most affected by HIV – indicates that only 13 per cent of adolescent girls and 9 per cent of adolescent boys aged 15 to 19 years have been tested for HIV in the past 12 months and received the result of their last test (UNICEF 2016). With the new global strategy to end the HIV epidemic by 2030 in place, there is a need to accelerate efforts to address the epidemic among adolescents.

This training package was developed to support health workers to acquire appropriate knowledge and skills in providing quality HIV care, treatment and support to adolescents living with HIV. The materials cover a broad range of subjects, including stages of adolescent development; adolescent vulnerabilities; risk-taking behaviours and their consequences; characteristics of adolescent-friendly HIV care and treatment services; adolescents living with HIV(ALHIV) legal issues and ethical considerations; combination HIV prevention for adolescents; management of gender-based violence (GBV) among ALHIV; behaviour risk assessment among ALHIV; effective communication skills in counselling ALHIV; disclosure process for ALHIV; service delivery models (SDMs) for differentiated care for adolescents; common psychosocial needs of adolescents and ALHIV; psychosocial support services for adolescents and caregivers; importance of peer support groups for ALHIV; adherence and retention to HIV care and treatment; importance of facility–community linkages for ALHIV; involvement of adolescents in service delivery; mental health for ALHIV; common nutritional issues among ALHIV; measures for preventing drugs and alcohol use among ALHIV; empowering adolescent clients to practise safer sex; contraceptive; pregnancy; STI and CECAP services among ALHIV; transitioning ALHIV from adolescent care to adult care; and monitoring and evaluation (M&E) and quality improvement (QI) of adolescent HIV services.

Commitment among implementers and health workers is the key to scaling up HIV services among ALHIV in Tanzania. This training package should be used to improve the knowledge and skills of health workers so that they are equipped to address the specific needs of ALHIV.

The Ministry of Health, Community Development, Gender, Elderly and Children (MoHCDGEC) will ensure the provision of adolescent-friendly HIV services and information at all levels of health care. We call upon regional and district authorities to ensure that this training package is used and adhered to in order to provide high-quality and friendly adolescent HIV services in the health facilities offering HIV care services. We hope that all stakeholders involved in the provision of adolescent HIV services will be committed to training health workers in accordance with this training package.

Dr. Mpoki M. Ulisubisya
Permanent Secretary

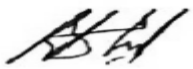
Acknowledgment

This training package on adolescents living with HIV (ALHIV) and AIDS was designed to train and equip health providers with appropriate knowledge and skills in providing quality HIV care, treatment and support to adolescents living with HIV in Tanzania. These materials were developed by the Ministry of Health Community Development, Gender, Elderly and Children (MoHCDGEC) through the National AIDS Control Programme (NACP) with technical and financial assistance by the United Nations Children's Fund (UNICEF). Several modules of this training package were adopted from different resources, including the generic curriculum for health workers on adolescent HIV care and treatment of the ICAP (2012); National Management of HIV and AIDS guidelines (sixth edition); Making Health Services Adolescent-Friendly (WHO 2012); and Standards For Adolescent-Friendly Reproductive Health Services (Ministry of Health, Tanzania 2005).

The MoHCDGEC would like to express sincere gratitude to UNICEF for their technical and financial support in the development of this training package. Special thanks to Ms Ulrike Gildert-Nandra and Dr Sajida Kimambo of UNICEF Tanzania, and Dr Sode Matiku, the MoHCDGEC consultant. Acknowledgement is also extended to the U.S. Centers for Disease Control and Prevention (CDC) and U.S. Agency for International Development (USAID); World Health Organization (WHO); and HIV implementing partners – EGPAF; AGPAHI; HJFMRI-WRP; ICAP; MDH; PASADA; Baylor International Paediatric AIDS Initiative (BIPAI); THPS; I-TECH; TACAIDS; R/CHMTs; Bugando Medical Centre (BMC); Mbeya Zonal Referral Hospital (MZRH); MUHAS; Muhimbili National Hospital (MNH); and regional administrative secretaries and municipal/council directors – for their technical support.

The MoHCDGEC appreciates and acknowledges the valuable technical assistance from various stakeholders during the process of developing this training package. While it is difficult to mention all who played key roles in the development process, I would like to thank the entire staff of the National AIDS Control Programme, in particular, Dr Angela Ramadhani, the Programme Manager; Dr. Anath Rwebembera, Head of Care, Treatment and Support Unit; and the Adolescent HIV focal person Dr. Mastidia Rutaihwa for the coordination during the process of developing this guide. I extend my gratitude to the RCHS and PMTCT programmes for their technical support during the process.

Finally, the MoHCDGEC is very grateful to all the individuals and institutions who contributed to the development of the guide for HIV services for adolescents living with HIV (ALHIV) for their dedication and commitment throughout the process.



Prof. Muhammad Bakari Kambi
Chief Medical Officer

MODULE 1:

INTRODUCTION AND TRAINING OVERVIEW

Total module time: 2 hours

Module 1 objectives

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

- Get to know the other participants
- Describe the training objectives and ground rules
- Explain the epidemiological statistics of HIV infection in adolescents

Session: 1.1

Total time taken:
1 hour 30 minutes

Introduction and purpose of the training

Learning objectives

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

- Get to know the facilitators and their fellow participants
- Understand the goal of the training
- Mention the modules of the training
- Understand the training methodology that will be used

1.1 Goal, training overview and modules

1.1.1 Goal

The goal of the training is to equip health-care workers with the knowledge, skills and attitudes to provide quality HIV care, treatment and support to adolescents living with HIV (ALHIV).

Objectives

- Describe the stages and characteristics of adolescence as well as the unique needs and challenges of adolescent clients
- Implement strategies to make HIV-related services youth-friendly
- Define and implement the package of HIV-related care and treatment services for adolescents
- Demonstrate effective communication and counselling skills with adolescent clients
- Conduct psychosocial assessments of adolescent clients and provide them ongoing psychosocial support services
- Describe the importance of mental health services for adolescent clients, recognize when a mental health problem may exist, and provide appropriate referrals and support
- Provide developmentally appropriate disclosure counselling and support to adolescents and, where required, to their caregivers
- Describe developmentally appropriate adherence preparation to adolescent clients and caregivers and deliver ongoing adherence support
- Conduct sexual risk screening and provide non-judgmental, comprehensive counselling on sexual and reproductive health (SRH) to adolescent clients

- Describe nutritional requirements, care and support among ALHIV
- Describe basic, non-judgmental contraceptive counselling and services for adolescent clients
- Describe key components of SRH services for adolescents and provide referrals and support along the continuum of care
- Describe ways to link adolescents with needed facilities and community-based support services
- Describe and implement activities to meaningfully involve adolescent clients in clinical services, such as through adolescent peer education programmes
- Prepare and support adolescent clients throughout their transition to adult care
- Describe how monitoring and evaluation can be used to support adolescent HIV programme improvements
- Demonstrate core competencies in adolescent HIV care and treatment services in a clinical setting
- Develop a site-specific action plan for implementing adolescent HIV care and treatment services

1.1.2 Training overview 

Target participants

This course is designed for health workers who have preferably attended basic adult antiretroviral therapy (ART) training and is appropriate for clinicians, nurses, social workers, counsellors and pharmacists.

Course duration

The duration of the training is five days.

1.1.3 Training modules 

There are 15 training modules:

Module 1: Introduction and training overview

Module 2: Nature of adolescence

Module 3: HIV prevention services for adolescents

Module 4: Communicating with, and counselling, adolescents

Module 5: Disclosure counselling and support

Module 6: Clinical care for ALHIV

Module 7: Psychosocial support services for adolescents

Module 8: Supporting retention of adolescents

Module 9: Community linkages and adolescent involvement

Module 10: Adolescents, HIV and mental illness

Module 11: Nutritional care and support among ALHIV

Module 12: Adolescent sexual and reproductive health (SRH) services

Module 13: Supporting the transition to adult care

Module 14: Monitoring, evaluation and quality improvement

Module 15: Action planning, course evaluation and closure

1.2 Methodology, expectations and key points

1.2.1 Teaching methodology

The methodology used for this training is designed to be interactive in order to appeal to a variety of learning styles. The many activities included in the training programme help build skills in the care and treatment of people living with HIV. The activities include:

- Lectures/discussions
- Group discussions and small group activities
- Case studies
- Role plays
- Demonstrations
- Assignments

1.2.2 Expectations

Exercise 1: Individual reflection

Strengths: What is the one personal strength that helps you – or will help you – work effectively with adolescent clients?

Concerns: What concerns or worries do you have about providing care to adolescents living with HIV?

Expectations: What do you hope to learn during this training course?

Exercise 2: Large group discussion

Strengths (experience or sense of humour)
Concerns (worries or fears)
Expectations (hopes and personal goals)

1.2.3 Key points

Your experience, input and commitment is crucial in achieving the overall goal of the training. Facilitators and organizers are available to assist and respond to your questions at every step of the training process.

1.3 Pre-test knowledge assessment

During the workshop, a pre-test assessment will be used to assess your knowledge. Similarly, after the workshop, there will be a post-test assessment.

Session: 1.2

Total time taken: 30 minutes

Background information on adolescents living with HIV

Learning objectives

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

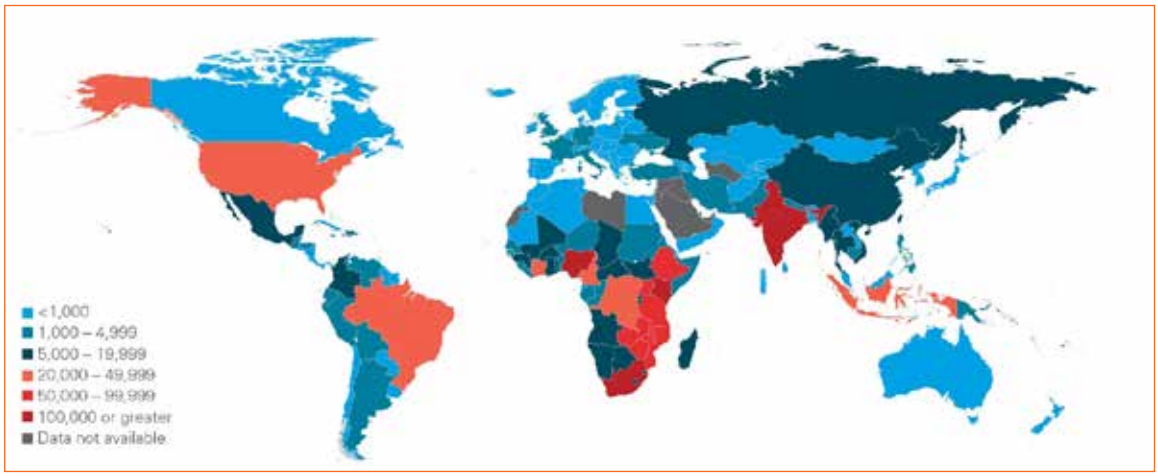
- Explain the epidemiological statistics of HIV infection in adolescents
- Explain the reasons for training on HIV care for adolescents among health workers

1.2 Epidemiological statistics of HIV infection in adolescents

Global epidemiology

Worldwide, in 2015, about 1.8 million adolescents (10–19 years) were living with HIV; 1.4 million (80 per cent) were in sub-Saharan Africa. Adolescents account for about 5 per cent of all people living with HIV and 12 per cent of new adult HIV infections (see Figure 1.1).

Figure 1.1: Estimated number of adolescents living with HIV in 2015

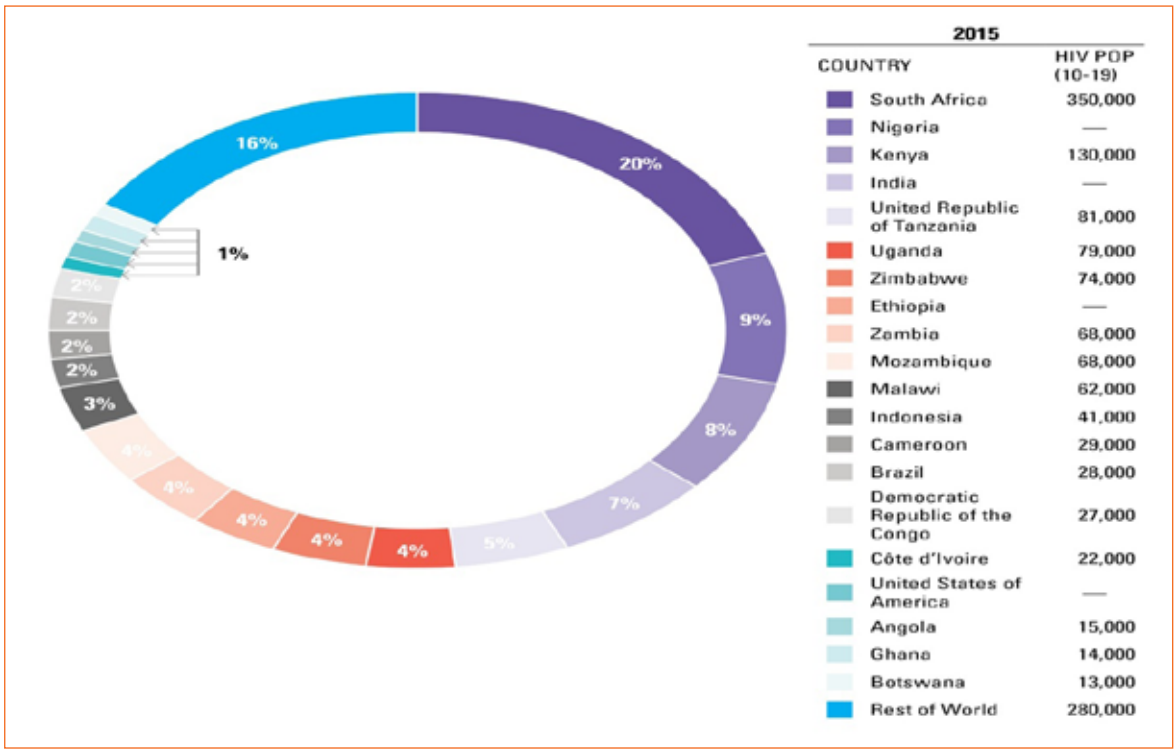


Note: *The boundaries and the names show and the designations used on this map do not imply official endorsement or acceptance by the United Nations.*

Source: *UNAIDS 2016 estimates.*

Nearly 75 per cent of all adolescents living with HIV are from 12 countries (see Figure 1.2).

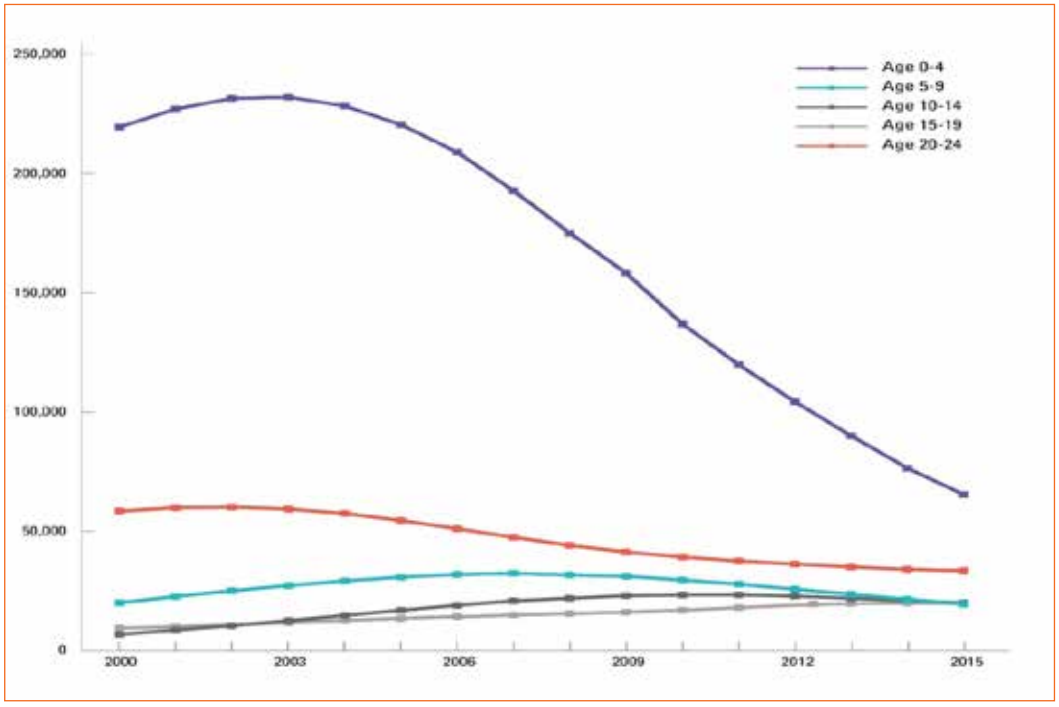
Figure 1.2: Distribution (%) of ALHIV by country (2015)



There has been a decline in AIDS-related deaths among younger children and adults, but such deaths have increased among adolescents (see Figure 1.3).

Figure 1.3 indicates the trend of AIDS-related deaths among different age groups.

Figure 1.3: AIDS-related deaths by age group



Tanzania:

In 2016, the number of ALHIV was estimated at 98,000 (54,000 girls and 44,000 boys). Instances of new infections were estimated at 5,500 and of death among ALHIV at 3,200 (UNAIDS 2017).

1.3 Reasons for HIV adolescent training

Adolescents are at the centre of the HIV epidemic. They are particularly vulnerable to HIV infection due to various social, political, cultural, biological and economic factors. It is essential to train health-care workers in providing care to ALHIV to:

- Build their capacity to address the needs of ALHIV
- Equip them to face the unique health, adherence and psychosocial issues and challenges pertaining to ALHIV care
- Provide support to the growing number of ALHIV who have reached adolescence and adulthood after being perinatally infected as a result of the successes in prevention of mother-to-child transmission (PMTCT)
- Ensure health-care services to the significant number of adolescents who have enrolled as a result of raised awareness of HIV, reduced stigma, greater access and acceptance of testing
- Make programmes and clinical services adolescent-friendly to attract and retain adolescent clients
- Equip health workers with the knowledge and skills necessary to meet the specific needs of adolescent clients

1.4 Key points

Young people engaging in risky sexual behaviour (such as not using condoms), having multiple sexual partners and having sex before the age of 15 remain significant challenges for the country's HIV response. You need to understand HIV trends among adolescents to be able to deal with the specific needs of ALHIV clients.

MODULE 2:

ADOLESCENCE AND ADOLESCENT-FRIENDLY SERVICES

Total module time: 2 hours 20 minutes

Module 2: Objectives

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

- Describe the stages of adolescent development
- Describe adolescent vulnerabilities, risk-taking behaviours and their consequences
- Explain the characteristics of adolescent-friendly HIV care and treatment services
- Describe ALHIV legal issues and ethical considerations

Session 2.1

Total time taken: 50 minutes

Stages and changes during adolescence

Learning objectives

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

- Define adolescence
- Explain changes that occur during adolescence
- Describe special considerations for ALHIV when providing HIV care

2.1.1 Overview

2.1.1.1 Definition of adolescence

Adolescence is the process whereby an individual makes the gradual transition from childhood to adulthood (WHO 1987). Adolescents are people between 10 and 19 years of age. Adolescence is a phase of life that is defined differently across cultures. Other commonly used terms for adolescents are 'youth' and 'young people'. These terms have slightly different definitions but are often used interchangeably with the term 'adolescents'.

- Adolescent: 10–19 years
- Youth: 15–24 years
- Young people: 10–24 years

2.1.1.2 Key physical and sexual changes occurring during adolescence

Several physical and sexual changes occur during adolescence (see Table 2.1).

Table 2.1: Key physical and sexual changes occurring during adolescence.

Females	Males
Development of breasts	Growth of penis, scrotum and testicles
Appearance of pubic and underarm hair	Appearance of pubic, underarm, chest and leg hair
Widening of hips	Wet dreams (nocturnal emission)
Menarche	Morning erection
Development of the vulva and pelvis	Development of back muscles

Several changes occur in both boys and girls:

- Accelerated growth
- Increased sweating
- Pimples/acne
- Facial characteristics of a young adult
- Changes in tone of voice
- Feelings of sexual desire
- Initiation of sexual activities

2.1.1.3 Key psychological and emotional changes during adolescence

Adolescence also marks key psychological and emotional changes in a person, including but not limited to:

- Mood swings
- Self-centredness
- Feelings of being misunderstood and/or rejected
- Need to feel autonomous and independent
- Concern about body image
- Insecurities, fears and doubts
- Behavioural expressions of emotion such as withdrawal, hostility, impulsiveness and non-cooperation
- Concern about sexual identity, decision-making and reputation
- Fluctuating self-esteem
- Interest in physical activities

Table 2.2: Stages of adolescence

Category of change	Early (10–15 years)	Middle (14–17 years)	Late (16–19 years)
Growth of body	Secondary sexual characteristics appear Rapid growth reaches a peak	Advanced secondary sexual characteristics appear Growth slows down, reaches approximately 95% of adult size	Physically mature
Cognition (ability to get knowledge through different ways of thinking)	Thinks in concrete terms (i.e., the 'here and now') Does not understand how actions affect future	Thinking can be abstract (theoretical) but reverts to concrete thinking under stress Begins to understand long-term results of own actions	Abstract thinking now established Plans for the future Understands how current choices and decisions have an impact on the future
Psychological and social	Worries about rapid physical growth and body image Has frequent mood changes	Has established body image Thinks about fantasies or impossible dreams Feels very powerful May experiment with sex, drugs, friends, risks, etc.	Plans and follows long-term goals Has established a sense of identity (who he or she is)
Family	Still defines comfort with independence/ dependence	Has conflicts with authority figures	Is moving from a child-parent/guardian relationship to adult-adult relationships

Category of change	Early (10–15 years)	Middle (14–17 years)	Late (16–19 years)
Peers	Peers considered very important for development Has intense friendships with the same sex Has interactions with the opposite sex in groups	Has strong peer friendships that help affirm self-image Peer groups define right and wrong	Decisions/values less influenced by peers and more influenced by individual friendships Selection of partner based on individual choice rather than on what others think
Sexuality	Focuses on self-exploration and evaluation	Is preoccupied with romantic fantasies Tests how he/she can attract others Sexual drive is emerging	Forms stable relationships Has mutual and balanced sexual relations Is able to manage close and long-term sexual relationships Plans for the future

Sources: *World Health Organization, Orientation Programme on Adolescent Health for Health Care Providers, WHO, Geneva, 2003.*
World Health Organization, IMAI One-Day Orientation on Adolescents Living with HIV, WHO, Geneva, 2010.

Adolescents undergo rapid growth and development, and they experience changes in body and thinking, social skills, problem-solving and relationships. These changes influence how adolescents interact, behave and process information.

Questions for discussion

- Do these changes and characteristics sound familiar based on your experiences?
- Which of these characteristics are most noticeable in the adolescents of the age group that you work with?

2.1.1.4 Stages of adolescence

Adolescence can be categorized into three overlapping developmental stages: early, middle and late. The ages that correspond with these stages are approximate; maturation is more important than specific ages. Maturation occurs in fits and starts, and growth in each category of change can occur at different rates for different people.

2.1.1.5 Effects of HIV infection on growth of adolescents

Adolescents who acquire HIV perinatally may experience delays in physical development and appear younger or smaller. Their small stature, and how people view them , may lead to a

negative self-image. Adolescents living with HIV may experience drug-related side effects, including those that change physical appearance. While HIV affects growth in perinatally infected adolescents, it does not affect adolescents in the same way, as ALHIV have typically already reached their adult height by the time they are diagnosed. Even in perinatally infected children, the physical effects of HIV may be minimized with effective ART.

2.1.1.6 Effects of HIV infection on adolescent cognition

Adolescents who acquire HIV perinatally may experience the neurological consequences of long-standing infection, resulting in developmental delays and learning problems.

2.1.1.7 Psychosocial effects of HIV infection on adolescents

- Adolescents living with HIV are likely to experience emotional difficulties, not necessarily due to health status, but rather due to the pressures of life and a history of loss (including the loss of parents and home).
- Due to their illness, ALHIV may miss out on activities that help define adolescents' identities.
- HIV can bring with it concerns that may affect ALHIV's mental health and their sense of fitting in with peers.
- Many ALHIV live with one birth parent or neither. Absence of either parent may cause ALHIV to feel like they are not a part of their adoptive home, which can lead to a sense of isolation. ALHIV may experience problems fitting in with peers, which can be exacerbated by the stigma associated with HIV.
- ALHIV may have to regularly miss school to attend clinic appointments, which may have an impact on the ALHIV's educational attainment and their sense of belonging in school. It also suggests that the school's environment is not supportive of the ALHIV's needs.
- If adolescents feel different from their peers, they have a harder time bonding with both peers and caregivers.

2.1.1.9 Distinguishing characteristics of adolescents from children and adults

Several characteristics distinguish adolescents from children and adults, but these do not apply to every adolescent client since these are generalizations, or even stereotypes. Adolescents are understood in general to be:

- Energetic, open, spontaneous, inquisitive
- Unreliable and/or irresponsible
- Moody
- Desire independence
- Easily influenced by friends
- Less influenced by family
- Look for role models (often outside the family)
- Embarrassed to talk to adults about personal issues
- Desire to be different from parents and the previous generation in general

2.1.2 How adolescents differ from each other

Adolescents are a heterogeneous group, and they may differ from each other in many ways:

- Stage of development
- Gender
- Sexual orientation
- Home or family situation
- Educational level
- Financial situation
- Geographical location
- Relationship or marital status
- Experience with stigma and discrimination
- Culture
- Religion

The personality and expectations of a 10-year-old are very different from that of a 19-year-old, even though both are technically adolescents. Remember that counselling and education should meet the unique needs of each adolescent. Assess carefully every adolescent client's care, treatment and support needs and tailor the care and treatment plan to meet these unique needs. In particular, counselling and education need to 'meet the adolescent where he or she is'.

***Note**: Sexual orientation is discussed further in Module 12.*

2.1.3 Key points

- Care, treatment and support provided to an adolescent client needs to be tailored to that adolescent's maturity level, social situation and level of understanding.
- ALHIV differ from both children and adults living with HIV because of the rapid changes that occur during adolescence.
- Adolescents are a heterogeneous group – not only do they differ from each other, but each individual adolescent also changes as he or she matures.

You need to understand and consider these differences when providing care to ALHIV.

Session 2.2

Total time taken: 30 minutes

Adolescent vulnerabilities, risk-taking behaviours and consequences

Learning objectives

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

- Discuss risk-taking as a normal part of adolescence, as well as the consequences of negative risk-taking
- Discuss vulnerabilities faced by adolescents

2.2.1 Risk-taking and consequences of unhealthy risk-taking behaviour

2.2.1.1 Risk–taking

Adolescents take risks as a normal part of growing up. Risk-taking is the tool adolescents use to define and develop their identity. Healthy risk-taking is a valuable experience, but risk-taking can be caused by a lack of knowledge. The sense of control, feelings of invulnerability and impulsiveness that usually characterize risky behaviour can lead to a lack of future planning. In some cultures, young men are encouraged to take risks as a way of proving their masculinity.

Healthy risk-taking includes participating in sports, developing artistic and creative abilities, travelling, making new friends and contributing constructively to one's family or community.

Unhealthy/ negative risk-taking includes stealing, reckless driving, unsafe sex, etc. and results from curiosity, sexual maturity, a natural inclination towards experimentation and peer pressure.

2.2.1.2 Consequences of unhealthy risk-taking behaviour

Unhealthy risk-taking can result in:

- Poor adherence to ARVs or HIV care and treatment
- Unprotected sex
- Experimentation with alcohol and drug abuse, which may lead to interference with judgment and adherence, suppression of the immune system, and interaction with HIV medication

'Most-at-risk' adolescents

Vulnerability refers to the circumstances and conditions that can put ALHIV at risk. Most-at-risk ALHIV include adolescents who are both HIV-positive and particularly vulnerable or at risk, such as those who are homeless, homosexual or bisexual, transgender, disabled, imprisoned, caregivers, orphans, migrants, refugees, gang members, sex workers or injecting drug users.

Most-at-risk ALHIV are among society's most marginalized groups. They generally have few connections with social institutions like schools and organized religion, where many support services are traditionally provided. Most-at-risk adolescents often have greater, more complex psychosocial and mental health needs and are more vulnerable to risky sexual behaviours and mental health problems – including substance abuse. They may face extreme challenges, like lack of education and access to health care, among others.

Challenges experienced by most-at-risk ALHIV include:

- Displacement
- Severe social exclusion, isolation, stigma and discrimination
- Extreme poverty
- Substance abuse
- Physical or sexual abuse/violence
- Exploitation
- Migration
- Fear of arrest or violence due to sexual orientation
- Chronic mental health issues, psychiatric and learning disorders
- Disabilities

2.2.1.3 Risk-taking role of health workers

You can help adolescents avoid unhealthy risk-taking by:

- Encouraging and helping adolescents to find healthy risks
- Helping adolescents evaluate risks, anticipate consequences and develop strategies for diverting their energy into healthier activities when necessary
- Sharing lessons learned from their own histories of risk-taking and experimenting
- Advising adolescents to seek additional help if they experience psychological problems or problems at school or end up engaging in illegal activities

2.2.2 Vulnerabilities of adolescents

The vulnerabilities of adolescents may be physical, social, psychological, emotional and socioeconomic.

2.2.2.1 Physical vulnerabilities

- Young people, particularly adolescent women, are more vulnerable to sexually transmitted infections (STIs) than adults.
- ALHIV, like all people living with HIV (PLHIV), are particularly vulnerable to nutritional and caloric deficiencies due to the increased energy demands HIV imposes on their body.
- HIV can contribute to compromised physical and psychological development, including stunting and a slower-than-normal growth rate. The cells lining the inside of the normal adolescent cervical canal are more vulnerable to infections than the cells that line the mature cervical canal of adults.

2.2.2.2 Psychosocial and emotional vulnerabilities

- Adolescents experience a general sense of invulnerability; the desire to try new things; and willingness to take risks.
- Adolescents' family situations may offer little social and material/financial support.
- Mental health problems can increase during adolescence.
- Lack of maturity, assertiveness and good communication skills among adolescents can result in difficulty making decisions, articulating needs and withstanding peer pressure.
- Unequal power dynamics between adolescents and adults make adolescents more vulnerable to abuse.

2.2.2.3 Socioeconomic vulnerabilities

- The need for money often increases during adolescence.
- Disadvantaged adolescents are at greater risk of substance abuse.
- Adolescent girls are particularly more vulnerable than boys as they face gender discrimination and gender-based violence (GBV).
- Adolescents who are involved in politics and social marketing have high vulnerability risk

Lack of access to money or employment can lead adolescents to steal or work in hazardous situations. Economic hardship can also increase health risks. Adolescent girls often face gender discrimination affecting food allocation, access to health care, adherence to care, the ability to negotiate safer sex and opportunities for social and economic well-being. Some girls have to resort to marrying young to escape poverty.

2.2.3 Key points

- ALHIV are physically, socially, economically, psychologically and emotionally more vulnerable and this affects their adherence to care and ART.
- Adolescents take risks as a healthy part of growing up but unhealthy risk-taking can have lifelong consequences.

Session 2.3

Total time taken: 30 minutes

Adolescent-friendly services

Learning objectives

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

- Describe the characteristics of adolescent-friendly HIV care and treatment services

2.3.1 Adolescent-friendly services and their characteristics in HIV care and treatment services

2.3.1.1 Adolescent-friendly services

HIV care services can be called adolescent-friendly if they are:

- Equitable – all ALHIV are able to obtain the health services they need
- Accessible – services provided are within the reach of ALHIV
- Acceptable – meet the expectations of ALHIV
- Appropriate – meet the unique needs of ALHIV
- Effective – are able to successfully provide care to ALHIV

2.3.1.2 Characteristics of adolescent-friendly services

Health worker characteristics

Health workers offering adolescent-friendly services should be:

- Specially trained/oriented
- Display respect for the adolescent client
- Maintain privacy and confidentiality
- Display a positive attitude towards adolescent clients
- Give enough time for health worker–client interaction

ALHIV need many services: HIV prevention, care, treatment, support and related health services. To serve them, clinics and programmes must be able to attract them, meet their needs and retain these clients.

Health facility characteristics

Health facilities that offer adolescent-friendly services should provide adolescents:

- A separate space and a special time to receive services
- Convenient hours
- Convenient locations
- Adequate space and privacy
- Comfortable and friendly surroundings
- Peer educators

Considerations while designing adolescent care programmes

Adolescent-friendly programmes should:

- Involve adolescents in programme design and monitoring
- Welcome drop-in clients
- Use an appointment and tracking system and keep waiting times short
- Provide chronic disease management
- Provide affordable or free services
- Be available at a one-stop centre
- Offer referrals to clinical and community-based services
- Make adolescent-friendly educational and publicity material that inform and reassure available to take away
- Have adolescent support groups and peer educators
- Be friendly to both male and female clients

2.3.1.3 Organizing adolescent-friendly services

Follow ADIPI, a step-by-step guide to make services more adolescent-friendly:

A – Assess clinic needs and work out what needs to be done to make services more adolescent-friendly

D – Design an action plan that will respond to the needs identified in assessment

I – Identify the needed human and material resources

P – Present the action plan to stakeholders

I – Implement, monitor and evaluate the planned activities

Table 2.3: Making services more youth-friendly

Step	How
Assess clinic needs: Figure out what needs to be done to make services more youth-friendly.	■ Conduct an assessment using tools included in *Appendix 2A: Checklist and assessment tool for youth-friendly HIV care and treatment services*. • Ask clients what they like about the clinic and what needs improvement. • Interview clients who have dropped out of care – ask them why they decided not to come back and what could be done to make the clinic more youth-friendly. ■ Ask parents what could make services more welcoming for their children. ■ Ask colleagues what needs to change in order to ensure that services are accessible and meet the needs of young people. ■ Review national or local reports on the topic or review manuals or programmes from other clinics to find out what others have done to attract and retain young people. ■ Visit a neighboring clinic that has been successful in welcoming the youth.
Design an action plan that will respond to the needs identified in the assessment. This plan should first list the most important activities. For each activity, the plan should include a timeline and list the person responsible for that activity.	■ Based on interviews and research done during the assessment phase, list the areas that need improvement and how they can be improved. ■ For example, if several clients mentioned that they are scared of the receptionist because she is rude, one of the areas for improvement can be: 'Ensure that the receptionist makes clients feel welcome.' Then suggest ways to address this need, for example, by providing one-to-one training and support for the current receptionist, by relieving the receptionist of other duties so that he/she can focus solely on welcoming clients, by recruiting a new receptionist, etc. Be sure to include the date by which this activity should be completed and the person who is going to make it happen (see Module 16 for a template).
Identify the needed human and material resources.	■ If an activity requires funds, identify where these funds could come from. Remember that making services youth-friendly does not need to be expensive.
Present the action plan to stakeholders.	■ To gain general agreement and support for the action plan, present it first to the manager/supervisor. ■ Work with others in the management to ensure that the needed support exists to implement the recommended changes. ■ The action plan may need to be revised several times to incorporate the suggestions of those in the management and ensure their support. ■ Once the management has approved the plan, present it to the health workers and youth that will be involved in the programme.

In conducting assessment you can use tools like *Appendix 2A: Checklist and assessment tool for youth-friendly HIV care and treatment services*.

In designing adolescent-friendly services, the adolescent client's opinions are the most valuable and can be captured by conducting client satisfaction surveys.

Review *Appendix 2C: Sample of client satisfaction survey for youth*.

2.3.2 Key points

- To provide HIV-related health services to adolescent clients, clinics and programmes must be able to attract these clients and meet their needs to retain them as clients.
- When working to make services friendlier to ALHIV, first assess where you currently are so that we can identify the improvements needed.

Session 2.4

Total time taken: 30 minutes

ALHIV legal issues and bioethical considerations

Learning objectives

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

- Describe the rights and obligations of ALHIV
- Describe bio-ethical considerations for ALHIV services

2.4.1 Rights and obligations of ALHIV

The rights of adolescents align with general 'basic rights and duties' stipulated in the National Constitution from Articles 12–29 as well as HIV (Prevention and Control) Act 2008.

Right

- Right to equality
  - ALHIV should be treated with recognition and respect for their dignity
- Right to avoid discrimination
- Right to live and to the protection of life
  - Right to highest attainable standard of physical and mental health
  - Right to treatment of OIs
- Right to live as a free person
  - Voluntary HIV testing and disclosure
- Right to respect and protection of their privacy, privacy of their family and matrimonial life
  - Confidentiality of HIV test results

Obligations of ALHIV

- ALHIV shall immediately:
  - Inform spouse/sexual partner about HIV infection
  - Take measures and precautions to prevent transmission to others

Health care workers should assist ALHIV in disclosing their HIV status to their sexual partners and taking preventive measures.

2.4.2 Bioethical considerations for ALHIV services

Consider the adolescent's competence; informed consent; and confidentiality.

2.4.2.1 Assessment of adolescent's competence

- Each adolescent is autonomous when it comes to his or her decision-making capacity.
- All adolescents who have attained the age of 18 years are considered competent, unless they suffer from mental illness.

You should assess each adolescent's cognitive development individually and decide on appropriate HIV interventions.

Competence requires advanced cognitive thinking and understanding long-term consequences of HIV infection. A young person might not understand long-term consequences in general but have a very good knowledge of the conditions of his or her particular disease. You should check their maturity level and reflective thinking by probing deeper and asking questions like:

- What will you do next?
- If this happens, what do you do?
- What responsibilities do you have in your daily life?
- How do you manage them?
- What is your experience of the condition in question?
- From where do you get your information?

Negotiating a decision

Depending on the assessment results of an adolescent's competence, you negotiate a final decision.

- If he/she is judged competent, then the decision depends on him/her (with the support of the health worker).
- If he/she is judged non-competent, then the decision depends on the health worker and the parents/caregiver.

In most cases, the decision is negotiated.

Be reminded that there is no right or wrong decision after a competence assessment, as it does not tell the client what to do. It helps you and the adolescent client analyse their thinking and see clearly where the best interests of the adolescent lie, depending on the circumstances.

2.4.2.2 Informed consent

ALHIV who are considered competent have the right to make their own decisions in regards to HIV testing, ARV prescription, etc. ALHIV who are not considered competent still have the right to be informed under the guidance of their parents/caregiver. Information given to them should be adapted to their level of understanding. However, they cannot refuse intervention if it is considered to be in their best interests.

2.4.2.3 Confidentiality

Competent ALHIV have the right to demand that the health worker does not disclose their information to any other person. Health workers should disclose only that information which is necessary to achieve the purpose of disclosure and only to people qualified to have that information. All confidential client information must be securely stored, including hard and electronic copies, and be made accessible to the counsellor.

Bioethical care to survivors of GBV

Safety and confidentiality

- Many acts of violence against adolescents are socially acceptable; survivors have to rely on the family and/or health workers for help.
- Survivors are exposed to different risks after violence and it is imperative to:
  - Conduct conversations and assessments in a safe setting
  - Assess the safety of the survivor
- You may share a survivor's information only when there is clear understanding and consent.

Rights and dignity of the survivor

- A survivor has the right to make the choice she or he wants.
- The best interests of the adolescent should be the primary consideration by
  - Allowing the adolescent to participate in decisions related to their lives
  - Taking into account the adolescent's age and capacity for indicating consent

2.4.3 Key points

- Rights of ALHIV should always be considered when providing HIV care and treatment services
- ALHIV should be aware of their obligations as members of the community
- You need to consider social, legal and bioethical issues when providing GBV survivors HIV care

Appendix 2A: Checklist and assessment tool for youth-friendly HIV care and treatment services

Facility name: Type of facility/clinic: Questions to assess youth-friendliness	Answer	Comments/ recommendations
Location		
How far is the facility from public transportation?		
How far is the facility from places where adolescents spend their time?		
How far is the facility from local schools?		
Facility hours		
During what hours is the clinic open?		
Does the clinic have separate hours/days for adolescents?		
Does the clinic have a sign listing services and working hours?		
What times are convenient for adolescents to seek services?		
Facility environment		
Does the facility provide a comfortable setting for young clients?		
Does the facility have a separate space to provide services to adolescent clients?		
Does the facility have a separate waiting area for adolescent clients?		
Is there a counselling area that offers both visual and auditory privacy?		
Is there an examination room that provides both visual and auditory privacy?		
Are both young men and women welcomed and served at the clinic?		
Staffing		
Are all health workers trained in paediatric HIV care and treatment?		
Are all health workers trained in adolescent HIV care and treatment?		
Have all staff members (including data clerks, pharmacists, receptionists, etc.) received an orientation on adolescent services?		

Facility name: Type of facility/clinic: Questions to assess youth-friendliness	Answer	Comments/ recommendations
Do health workers show respect to adolescent clients during counselling sessions and group sessions?		
Are there job aides available to help health workers in their daily work with adolescents?		
Services provided		
Is one-stop shopping provided to adolescent clients? Describe.		
Are the following services provided to adolescent clients directly (note if services are provided through referral):		
■ HIV testing and counselling		
■ Comprehensive care, including the prevention and treatment of OIs		
■ Malaria prophylaxis and treatment		
■ ARVs/ART		
■ Adherence preparation		
■ Ongoing adherence assessment and counselling (at each visit)		
■ Pregnancy testing, antenatal care and PMTCT		
■ Sexual and reproductive health counselling		
■ Condoms and water-based lubricants		
■ Methods of contraception		
■ STI screening and treatment		
■ Positive prevention counselling		
■ Psychosocial counselling and support		
■ Nutrition counselling		
■ Laboratory tests (CD4, other HIV tests)		
■ Post-exposure prophylaxis (PEP), as per national guidelines		
Are there outreach services, especially targeting most-at-risk adolescents? Explain.		
Do adolescents request services other than the ones offered? Which ones?		
Is there a formal referral system for services not provided at the clinic?		

Facility name: Type of facility/clinic: Questions to assess youth-friendliness	Answer	Comments/ recommendations
Is there a formal referral system for services required by most-at-risk adolescents (sexual abuse counselling and treatment, drug/alcohol rehabilitation, support for youth-heads of household, etc.)? Which ones?		
Is there a tracking and follow-up plan in place for clients who do not return?		
Peer education and counselling		
Is a peer education program available?		
How many peer educators are working at the facility?		
How many hours/days per week do peer educators work at the facility?		
What are the roles and responsibilities of peer educators?		
How are the peer educators trained?		
Is there a system for supervising and monitoring peer educators?		
Educational activities		
Are educational/information materials available? Which ones?		
Are educational posters displayed?		
Are there posters or brochures that describe clients' rights?		
Are there materials for adolescent clients to take home?		
In what languages are the materials available?		
Are group education sessions held with younger adolescents? Describe.		
Are group education sessions held with older adolescents? Describe.		
Are group education sessions held with parents/caregivers? Describe.		
Are adolescent support groups held (with younger adolescents)? Describe.		
Are adolescent support groups held (with older adolescents)? Describe.		
Are there ways for adolescent clients to access information or counselling off-site (via a hotline, etc.)?		

Facility name: Type of facility/clinic: Questions to assess youth-friendliness	Answer	Comments/ recommendations
Youth involvement		
Are adolescents involved in decision-making about how programs and services are delivered?		
What ways are there for adolescents to give feedback to the clinic staff?		
How could adolescents be more involved in decision-making at the facility?		
What other roles could adolescents play in clinic planning, operations and evaluation?		
Supportive policies		
Do clear, written guidelines or standard operating procedures (SOPs) exist for adolescent services?		
Do written procedures exist for protecting client confidentiality?		
Are records stored so that confidentiality is ensured?		
Is parental/guardian/spousal consent ever required? In what cases?		
Is there a minimum age for adolescents to receive HIV testing?		
Is there a minimum age for adolescents to receive contraceptives?		
Are there policies or procedures that pose barriers to youth-friendly services?		
Administrative procedures		
Is the registration process private so that others cannot see or hear?		
Can adolescent clients be seen without an appointment?		
How long do adolescent clients normally have to wait?		
What is the average time allotted for client–health worker interaction?		
Publicity/recruitment		
Does the clinic publicize the services available to adolescents, with a stress on confidentiality?		
Are there staff or volunteers who conduct outreach activities? Describe.		

Facility name: Type of facility/clinic: Questions to assess youth-friendliness	Answer	Comments/ recommendations
Fees		
Are adolescents charged for any services? If so, which ones and how much?		
If there are fees, are they affordable to adolescent clients?		
OTHER		

Adapted from Senderowitz, J., C. Solter, and G. Hainsworth, Clinic Assessment of Youth Friendly Services: A tool for assessing and improving reproductive health services for youth, Pathfinder International, Watertown, MA, 2002.

Appendix 2B: Sample of client satisfaction survey for youth

Clinic/facility _____

Lead physician or nurse (if applicable) _____

Your name (optional) _____ Date _____

Please help us improve our services by answering some questions about the services you received.

We are interested in your honest opinion – whether positive or negative. Your answers will be kept confidential.

1. The staff at the clinic communicated clear information to me.

1	2	3	4	5
Strongly disagree	Disagree	Somewhat agree	Agree	Strongly agree

2. People at the clinic considered my opinions when making decisions.

1	2	3	4	5
Strongly disagree	Disagree	Somewhat agree	Agree	Strongly agree

3. The staff at the clinic listened to me.

1	2	3	4	5
Strongly disagree	Disagree	Somewhat agree	Agree	Strongly agree

4. The staff at the clinic involved my family/caregivers in my care.

1	2	3	4
More than I wanted	About the right amount	Less than I wanted	No involvement, which is what I wanted

5. I am satisfied with the progress I have made towards my treatment goals (taking medication/ adherence, participating in psychosocial support activities, etc.)

1	2	3	4	5
Strongly disagree	Disagree	Somewhat agree	Agree	Strongly agree

6. The staff at the clinic worked well together.

1	2	3	4	5
Strongly disagree	Disagree	Somewhat agree	Agree	Strongly agree

7. The staff at the clinic spent enough time with me.

1	2	3	4	5
Strongly disagree	Disagree	Somewhat agree	Agree	Strongly agree

8. The staff at the clinic treated me with respect.

1	2	3	4	5
Strongly disagree	Disagree	Somewhat agree	Agree	Strongly agree

9. The staff at the clinic gave me support.

1	2	3	4	5
Strongly disagree	Disagree	Somewhat agree	Agree	Strongly agree

10. I would recommend this clinic/programme to a friend who needed similar help.

1	2	3	4	5
Strongly disagree	Disagree	Don't know	Agree	Strongly agree

11. On a scale of 1–10, how would you rate the care you received?

1	2	3	4	5	6	7	8	9	10
WORST									BEST

12. Is there a staff member who worked especially well with you? If yes, can you explain why?

_____

_____

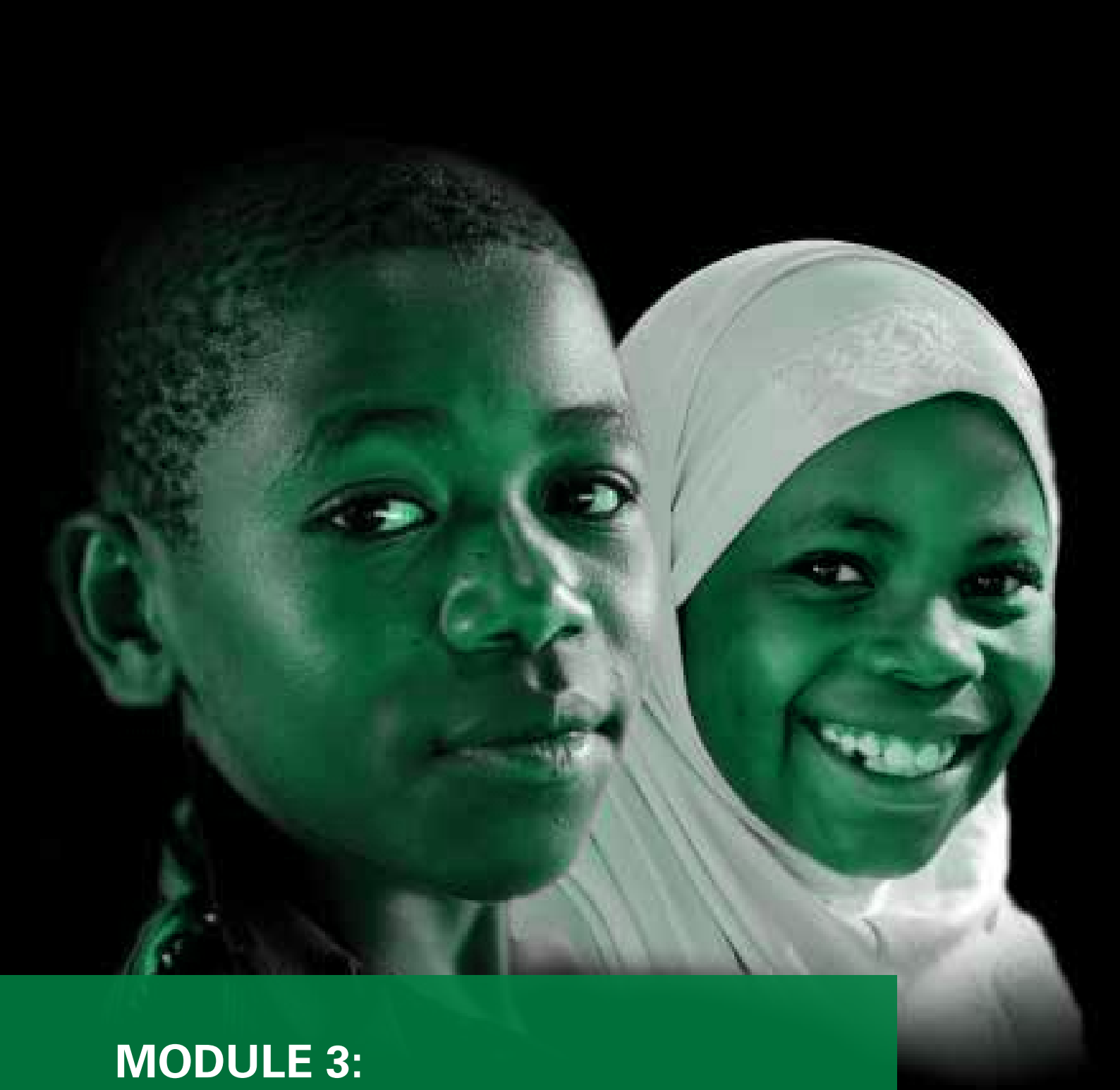
13. Comments (Please use the back of this page if necessary).

_____

_____

Thank you for helping us improve the quality of our services. Your opinion is important to us!

***Adapted from**: Foster Family-based Treatment Association, Sample TFC Youth Satisfaction Survey, 2008. Foster Family-based Treatment Association, Customer satisfaction survey, Child version 2007.*



MODULE 3:

HIV PREVENTION SERVICES FOR ADOLESCENTS

Total module time: 1 hour

Module 3: Objectives

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

- Describe combination HIV prevention for adolescents
- Describe management of GBV among ALHIV
- Describe behavioural risk assessment among ALHIV

Session 3.1

Total time taken:
1 hour

HIV prevention services for adolescents

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

- Describe combination HIV prevention for adolescents
- Describe management of GBV among ALHIV
- Describe behavioural risk assessment among ALHIV

3.1.1 Combination HIV prevention for adolescents

Combination prevention refers to rights-based, evidence-informed and community-owned programmes that use a mix of biomedical, behavioural and structural interventions prioritized to meet the current HIV prevention needs of particular individuals and communities "so as to have the greatest sustained impact on reducing new infections" (UNAIDS 2010). It is a combination of three types of interventions into a single, integrated approach. Combination HIV interventions need to be tailored to the local context so that they can work beyond the individual at the level of the family, community and society.

Tanzania adopted a combination HIV prevention approach using a mix of behavioural, biomedical and structural interventions. This mix of interventions helps to meet the HIV prevention needs of the population so as to have the greatest possible impact on reducing new infections.

People rarely use basic HIV screening services because of the stigma related to HIV; also, access to health services is poor. Different population groups require different HIV prevention approaches; by providing services at the community level, combination HIV interventions make it easy for different population groups to tackle multiple health issues. In comparison to one prevention approach at a time, combination HIV prevention is cost-effective.

Everyone at increased risk of HIV infection has the right to access appropriate prevention services. We need to focus on the people, places and programmes where we can have maximum impact with the available resources.

3.1.1.2 Behavioural interventions

Interventions that encourage safe behaviour include:

- Risk reduction counselling
- Community mobilization
- Advocacy
- Comprehensive sexuality education
- Peer education programmes
- Social marketing campaigns that promote condom use

The priority of behavioural interventions is to:

- Delay adolescents' sexual debut
- Encourage them to avoid unsafe sex
- Encourage adolescents to avoid multiple sex partners, especially concurrent sexual partnerships
- Discourage cross-generational and transactional sex

3.1.1.3 Biomedical interventions

Interventions that use clinical and medical methods include:

- Condom promotion and distribution
- Antiretroviral treatment as prevention
- PEP
- PMTCT services
- FP services
- Voluntary medical male circumcision
- Tuberculosis (TB) treatment and diagnosis
- STI/RTI diagnosis and treatment
- HIV testing services

3.1.1.4 Structural interventions

A 'structural approach' to HIV prevention is the process of selecting a set of interventions that use structural factors to reduce HIV risk at individual and/or group level. Structural factors are elements outside individual knowledge or awareness that have the potential to influence people's vulnerability to HIV infection.

Interventions that promote an environment for preventing/reducing HIV infections include:

- Social – Interventions that reduce stigma, discrimination, gender inequality and GBV
- Legal-political – Laws, regulations and supportive policies
- Cultural – Religious and cultural beliefs
- Economic – Income generating activities and other livelihood opportunities

- Advocacy
- Health service integration

3.1.2 Management of GBV among ALHIV

3.1.2.1 GBV

Any act or conduct that is perpetuated against a person's will and that is based on socially ascribed differences (gender) between men and women – including but not limited to sexual violence, physical violence, harmful traditional practices and economic and social violence – is referred to as gender-based violence (GBV). The term 'gender-based violence' targets violence towards individuals or groups on the basis of their being men or women.

Gender-based violence is rooted in the structurally unequal power relations between men and women in society. These unequal power relations are at the centre of subordination between genders. Some institutions that reinforce the cycle of violence are state policies and laws, an inequitable justice system, educational institutions, the media, family, the new economic global order, culture, religion and patriarchy.

3.1.2.2 Forms of GBV

Gender-based violence can be physical or sexual, or it may be psychological abuse.

Physical violence includes domestic violence, spousal beating, abortion , abduction, murder, forced marriage, female genital mutilation and human trafficking.

Sexual violence includes rape, defilement, incest, widow cleansing and forced prostitution.

Psychological abuse includes quarrels, abusive language, insults, threats, dowry-related violence, embarrassment and intimidation.

3.1.2.3 GBV among adolescents

The marriage law in Tanzania allows girls to be married at fifteen. Four out of every ten girls are married before their eighteenth birthday (National Bureau of Statistics Tanzania and ICF Macro 2011). Before they turn eighteen, three out of ten girls and one out of seven boys experience sexual violence (Violence against Children (VAC) Survey 2009) and three-fourths of the total population experience physical violence (UNICEF et al. 2011).

3.1.2.4 Prevention and management of GBV among ALHIV

- Adolescents should be assessed for GBV at least once every six months as part of the HIV programme.
- Gender-based violence, like rape, has the potential to increase the risk of acquiring new HIV infections.
- GBV can negatively affect retention and ART adherence of adolescents, leading to poor treatment outcomes.

It is imperative to teach life skills to ALHIV to empower them in the face of GBV.

You should be kind and observant when attending to ALHIV to be able to notice signs of GBV. National guidelines and tools should be used for screening and managing clients affected with GBV in clinical settings. More information on life skills is discussed in Module 4.

3.1.2.5 GBV and human rights

- Human rights refer to the basic rights that all people are entitled to regardless of nationality, sex, national or ethnic origin, race, religion, language or any other status.
- GBV and human rights abuse Domestic violence has direct health consequences – where sexual molestation occurs, physical injuries increase the chance of HIV transmission.

The Law of Marriage Act (revised 2002) prohibits a spouse from inflicting corporal punishment on his/her spouse.

3.1.2.6 Challenges in eliminating GBV

The Law of Marriage Act (revised 2002) has not changed the age of marriage for girls (15 years), although one is still a school-going child at that age.

The Sexual Offences Special Provisions Acts 1998 (SOSPA) does not consider marital rape. The provision for rape applies to "… non-consensual sexual intercourse between a man and a girl or woman, where the girl or woman is not the man's spouse or the man is a separate spouse". This completely ignores instances wherein women are forced by their husbands to have sexual intercourse without their consent.

On female genital mutilation, the SOSPA states that "Any person who, having the custody, charge or care of any child less than 18 years of age … causes female genital mutilation or carries or causes to be carried out female genital mutilation … commits the offence of cruelty to children."

This provision, however, only protects children under the age of 18 years, giving room for the practice to be performed on older girls and women.

3.1.2.7 Services to victims of GBV

- Clear guidelines and protocol on how to handle cases of GBV should exist in written form.
- All staff members should be familiar with GBV guidelines, protocol and procedures for implementing them in their everyday work.
- Access to family planning, contraception and legal and safe abortions should be available to all adolescents.
- Care providers need to ensure privacy during any conversation with the survivor so that no one in the waiting room or adjoining areas can overhear them.
- Identify, refer and link adolescents to non-clinical services including:
  - Long-term psychosocial support
  - Police (investigations, restraining orders)
  - Economic empowerment
- Emergency shelters
- Peer support groups

Health and social welfare services should that ensure health workers are equipped with relevant information regarding GBV issues. Health workers should be able to identify adolescents' needs and refer and link them to the relevant services.

3.1.2.8 Post-rape care for adolescents

- If an adolescent's HIV status is unknown, test for HIV and manage them according to the national guidelines
- For ALHIV, review ART history and ascertain adherence to medication
- Screen for STI and offer corresponding treatment
- Facilitate forensic interviews and examinations
- Give/refer for emergency contraception according to national guidelines if the person is attended to within the first 72 hours
- Counsel the adolescent and assess his/her mental health

3.1.3 Behavioural risk assessment among ALHIV

3.1.3.1 Benefits of identifying risk behaviour among ALHIV

Identifying risk behaviours in ALHIV can help in:

- Preventing and treating STDs, HIV and hepatitis, and helping reduce disease and death among patients
- Identifying and treating sexual problems and low sexual satisfaction, leading to improvements in patients' mental health and well-being

When we show our clients that we are interested in and compassionate about their sexual problems, behaviours and identities, an improvement in our relationship with patients will be seen.

From the clinician's perspective, behavioural risk assessment helps to:

- Direct exams
- Determine screening tests
- Guide risk reduction interventions
- Improve patient's overall health

From the patient's perspective, behavioural risk assessment helps to:

- Provide opportunities to ask questions
- Increase self-motivation for behavioural change

Patients who want to have these discussions often will not initiate one on their own.

3.1.3.2 Risk assessment techniques

- Initiate conversation
- Lead with open-ended questions
- Use closed-ended questions to fill in details

Direct, open-ended questions are indispensable when it comes to getting adolescents to talk, which is our primary goal. Asking 'who, what, when, where, how' questions helps to gain insight into the behaviours of ALHIV without the conversation turning invasive. For example, asking "What brings you in today?" or "What can I do for you?" helps adolescents loosen up without the pressure on them to direct the interview.

Things to say

Almost any 'Yes/No' question can be easily turned into an open-ended one by beginning it with "Tell me about…" For instance:

- "Do you have discharge?" can become "Tell me about any symptoms you have."
- "Have you ever had an STD?" can become "Tell me about any STDs you've had in the past."
- A 'yes/no' question can be followed by "Tell me about that" or "How did that go?"

Permission-giving statements let adolescents know that they are allowed to comfortably have these discussions with their provider. An opening statement can begin with: "Tell me more…" or "I'd like to hear about…"

3.1.3.3 How to conduct a risk assessment

Steps to follow while conducting a risk assessment include:

- Knowing what questions should be asked
  - Who – Ask about sexual partners
  - What – Ask about the types of sexual activity they've engaged in
- How – Ask about prevention methods being used
- What to ask about sexual partners
  - Partners – "Tell me about your partner/s"
  - Gender – "Have you had sex with men, women or both?"
  - Number – "How many partners have you had (in last 3 months, in the past year, since I saw you last)?"
  - New partners – "How many of these partners are new?"

Partners with other partners – "Have any of your partners had sex with others while they were in a relationship with you?"

These are the various ways you could gather information about the sexual behaviour of an adolescent.

- What to ask about sexual practices
  - "Tell me about how you have sex"
  - "What type of sex have you been having…..vaginal? anal? oral?"

Sometimes you might need to be very specific, i.e., "When was the last time you put your penis into a person's mouth or vagina". This specificity can open the door to more honest communication and give the adolescents permission to discuss risk behaviours. When asking about where the adolescent meets her/his partners, don't forget to ask about some of the more unusual venues, like the Internet. Getting an idea of the places the adolescents meets her/his partners may also give you an insight into other risk behaviours.

What to ask about safe sex practices

- Ask about HIV status of sex and/or injection partner
  - "Talk to me about the HIV status of your partner/s"
  - "How do you protect your partner/s and yourself during sex?"
- Ask about condoms
  - "What has your experience been with condom use?"
- Ask about drug-injection equipment
  - "How do you make sure your works are clean?"

It is important to ask open-ended questions about protective behaviours the adolescent may be employing. Emphasize both protecting partners from HIV and protecting themselves from STIs and unplanned pregnancy. Also ask all women and men who have sex with only women (MSW) about their pregnancy plans and contraception use.

Be reminded that reports of condom use do not always predict the absence of STIs. Screening for STIs is still important and for men who have sex with men (MSM), specimens are obtained from all exposed anatomic sites.

3.1.3.4 Behavioural change and risk reduction among ALHIV

- Discuss delay of onset of sexual debut in adolescents (abstinence)
- Discuss correct and consistent condom use and where appropriate, offer condoms for adolescents who are sexually active
- Discourage multiple, concurrent sexual partnerships in favour of faithfulness with a partner of known status for adolescents who are sexually active
- Discourage cross-generational and transactional sex for adolescents who are sexually active
- Assess for physical, emotional or sexual violence; if an adolescent discloses sexual violence, assess if the adolescent was raped and act immediately
- Provide socio-behavioural change communication (SBCC) and link to services as appropriate

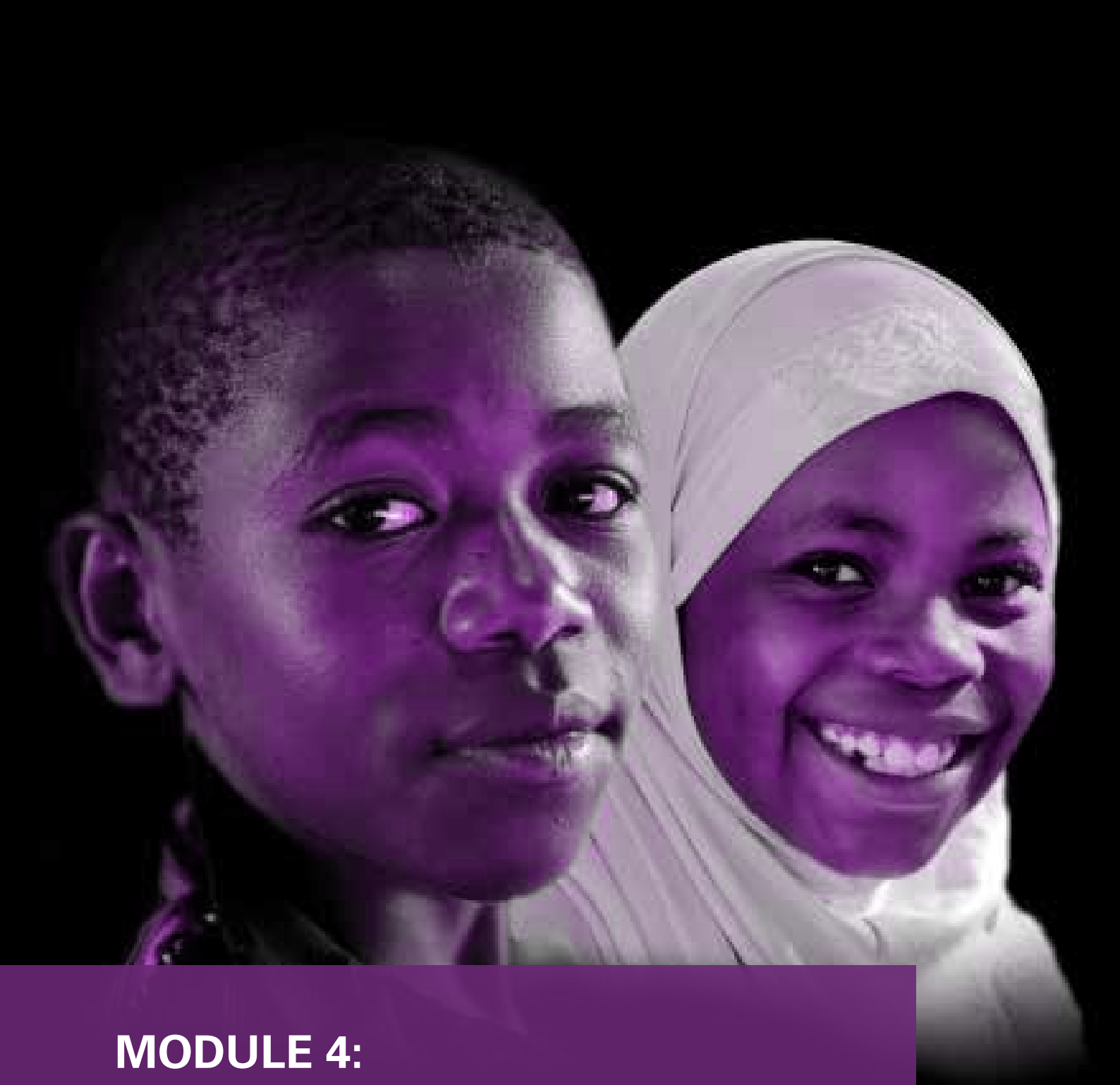
Condom promotion and provision

- With sexually active adolescents, discuss condom use as an option for risk reduction
- Discuss barriers to condom use
- Clarify questions about condoms and dispel myths
- To those unaware, demonstrate how to use condoms
- Allow sexually active adolescents to role-play
- Practise how to introduce condoms in a relationship
- Provide condoms to sexually active adolescents

3.1.4 Key points

- Combination HIV interventions need to be tailored to the local context so that they can work beyond the individual level and at the level of the family, community and society
- Among ALHIV, GBV has the potential to increase the risk of acquiring new HIV infections

You should be able to identify adolescents' needs and refer or link them to the relevant services.



MODULE 4:

COMMUNICATING WITH AND COUNSELLING ADOLESCENTS

Total module time: 2 hours 15 minutes

Module 4: Objectives

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

- Discuss ways of establishing trust and rapport with adolescent clients
- Describe effective communication skills among ALHIV
- Describe effective skills in counselling ALHIV

Session 4.1

Total time taken: 45 minutes

Developing effective communication skills

Learning objectives

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

- Describe tips for communicating with adolescents
- Explain issues to be considered when communicating with younger and older adolescents
- Demonstrate effective learning and listening skills with adolescents

4.1.1 Tips for communicating with adolescents

4.1.1.1. Basic communication skills

Communication is the process by which information, meaning and feelings are shared by people through the exchange of verbal or non-verbal messages, with feedback from both sides.

- Basic communication skills include:
  - Active listening
  - Checking understanding
  - Asking questions
  - Answering questions

4.1.1.2 Tips for communicating with adolescents

When communicating with adolescents:

- Create a safe, adolescent-friendly environment
- Establish rapport
- Get to know your client and help them feel comfortable
- Discuss reasons for their referral
- Explore related issues
- Assess risks, including emergent psychological concerns
- Provide them with relevant information

- Discuss next course of action
- Repeat information back to clients in the form of a question so as to encourage them to re-think what they have just said; for example, if an adolescent says "I do not care that my cousin stopped talking to me when I told him I had HIV", ask "So it doesn't bother you that your family is giving you a hard time?"

Encourage peer support

When initiating conversation with adolescent clients, begin by establishing rapport with them (see Session 4.2). Ask questions about their home, family, school and hobbies before moving on to more sensitive topics like adherence to medication, disclosure, sexual and reproductive health issues. In common areas, put up posters that communicate important messages.

Some effective ways of communicating with adolescents include: giving real life examples through storytelling, reducing stigma around a sensitive issue by normalizing it, asking indirect questions, talking about non-threatening topics before bringing up sensitive ones, encouraging, and offering opportunities for peer support.

You should encourage ALHIV to discuss issues with peers – either one-to-one or during group discussions. Peer support helps adolescents recognize that they are not alone in dealing with the types of problems they have. ALHIV may not respond to adults who tell them to take their medication every day, but they might listen to a peer who tells them the same thing. Interacting with other adolescents who have struggled with the same problems related to care and treatment, like adherence challenges or disclosure, can be an extremely effective motivator for adolescent clients (see Session 5.3 for more information on peer support).

4.1.1.3 Communicating with ALHIV – role of parent/caregiver

A caregiver is an individual who is responsible for the care of a child or an adolescent mainly a parent, guardian or an important other. Communication with parents or caregivers should encourage appropriate support for the child and also take into account the perceptions, feelings and needs of the parent or caregiver. A good caregiver–adolescent relationship is important because:

- Parents/caregivers provide consent for adolescents
- Parents/caregivers are expected to give continued support to adolescents
- Adolescents are still dependent on their parents/caregivers
- It is part of the standard care procedure to involve parents/caregivers
- Parents/caregivers spend more time with adolescents than health workers

While interacting with caregivers, health-care providers should:

- Show respect for the caregiver's views
- Display a non-judgmental attitude
- Build confidence in the caregiver to communicate with the adolescent
- Appreciate the caregiver's contributions and reinforce their strengths
- Support them in addressing communication gaps with the adolescent
- Discuss with the caregiver the importance of good communication with the adolescent
- Support the caregiver in appreciating the communication needs of adolescents
- Support the caregiver in using age-appropriate language while communicating with the adolescent

4.1.2 Considerations for younger and older adolescents

4.1.2.1 Considerations for adolescents aged 10–14 years

Younger adolescents need time to feel safe and trust someone. Try starting the session by doing something casual together, like playing a game. Explain things in simple terms. Make them understand things with the help of concrete concepts that they can touch and see, like drawings, demonstrations and visual aids.

Remember:

- Younger adolescents may feel scared of being judged
- They may feel too anxious or embarrassed to ask for help
- They may hesitate while responding to questions
- Instead of forcing them to share, positively reinforce their efforts to express themselves
- If an adolescent is rude or aggressive, remember that this behaviour may not be directed at you. Be patient and don't take it personally

4.1.2.2 Considerations for adolescents aged 15–19 years

When advising adolescents, remember that they have not yet had the opportunity to learn what you are explaining to them. Avoid criticizing them. Make use of listening and learning skills to ensure effective communication with adolescents.

It might be helpful to:

- Ask adolescents about things that are important to them
- Try to understand things from their perspective
- Avoid assuming that they are not yet sexually active and vice versa Avoid assuming that an adolescent has the same interests or issues as any other adolescent under your care

Adolescents may feel good and confident by being different. When communicating with adolescents, never make assumptions. Ask them open-ended questions and always remain non-judgmental.

Table 4.1: Activities to do with adolescents to promote expression

Appropriate for		Activity
Younger adolescents	Older adolescents	
Yes	Probably not	**Storytelling or reading together:** You could read or tell a story during group or individual counselling sessions. After finishing the story, you could ask key questions to encourage thought and discussion.
Yes	Yes	**Journaling:** Encourage adolescent clients to keep a journal or diary. A journal is a place adolescents can write about what is happening in their lives and how they feel about it (for example, they could answer the question 'How would I describe myself?' or fill in the sentence 'Last week I felt….. because….'). Younger adolescents may prefer to draw in their journals.
Yes	Probably not	**Drawing:** Encourage clients to draw a picture of their families or their homes. You should then ask the following kinds of questions about the drawing to show interest and encourage expression: ☐ "Tell me about your drawing." ☐ "What happened here?" ☐ "How did you feel then?"
Yes	Yes	**Letter writing:** Encourage adolescent clients to write letters to friends or family members about what is happening with them or how they are feeling.
Yes	Yes	**Doing something fun:** Do something fun while you are talking. This could include playing games, playing cards, taking walks, pursuing a hobby (making toys, knitting, hand sewing, etc.) or playing sports. Young people often feel more comfortable talking when discussion is secondary to something else they are doing.

4.1.3 Developing effective learning and listening skills with adolescents

4.1.3.1 Listening and learning skills

Clear and effective communication is the key to good counselling. As health workers, we need good communication skills to engage and help our clients. There are seven basic listening and learning skills health workers should use for counselling and effective communication with clients:

Skill 1 Using helpful non-verbal communication

Skill 2 Actively listening to and showing interest in the client

Skill 3 Asking open-ended questions

Skill 4 Reflecting back what the client is saying

Skill 5 Empathizing – showing that you understand how the client feels

Skill 6 Avoiding words that sound judgmental

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

Refer to *Appendix 4A: General tips on how to talk to adolescents*, *Appendix 4B: Basic counselling guidance for ALHIV*, and *Appendix 4D: Listening and learning skills checklist* for additional information.

4.1.4 Key points

- When communicating with adolescent clients, be respectful, ensure privacy, maintain confidentiality, be honest and use language they can understand.
- You need to adjust your communication style to suit the adolescent you are counselling keeping in mind his or her age and developmental stage.

Session 4.2

Total time taken:
45 minutes

Establishing trust and rapport with adolescent clients

Learning objectives

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

- Explain the importance of establishing trust and rapport to facilitate communication with ALHIV
- Describe tips for building trust and rapport with adolescent clients

4.2.1 Importance of establishing trust and rapport to communicate with ALHIV

4.2.1.1 Establishing trust and rapport

Trust is the starting point which paves the way for effective communication and counselling with ALHIV. The clients may have concerns related to their diagnosis, disclosure of their HIV status, feeling isolated among peers and coping with a chronic condition. You should display the desirable attributes of an effective care provider for the adolescent client to open up and trust you.

Building trust and rapport with adolescents starts with understanding their feelings and mindset. Being able to understand the perspective of an adolescent will enable you to respond appropriately and create a positive and effective service experience for the adolescent. Adolescents may have feelings of discomfort, embarrassment, shyness and uncertainty when communicating with you about personal issues like sexuality, wanting to have sex, wanting to have a baby, etc.

4.2.1.2 Desirable attributes of an effective care provider

Being empathetic conveys that you hear the adolescent's words, understand their thoughts and sense their feelings. Cultivate traits like:

- Empathy
- Genuineness
- Warmth

- Promoting open dialogue
- Being non-judgmental
- Unconditional Positive Regard (UPR)

Maintaining confidentiality

Health workers should:

- Reassure adolescents that anything they say will be kept confidential. Members of the multidisciplinary care team will not tell other people any information about the clients, including what they say or their HIV status.
- Never threaten to break adolescents' confidentiality, even 'for their own good'.
- Stress that the information entrusted to them will not be shared – even with caregivers – unless the client gives his or her permission (adolescents may be reluctant to disclose personal information if their parents or caregivers are present).
- Facilitate 'shared confidentiality' in settings where health workers need to bring in other health workers or those in management.

4.2.1.3 Feelings of adolescents

Adolescents may have feelings of discomfort when communicating with you about personal issues like sexuality, wanting to have sex, wanting to have a baby, etc. Adolescents are more likely to improve when treatment is integrated with warmth, genuineness and empathy. Feelings of discomfort that adolescents may display include shyness, embarrassment and intimidation; worry, anxiety, fear and feelings of inadequacy; uncertainty, defensiveness and resistance. Adolescents may be fearful, embarrassed or uncomfortable around health workers; have concerns about confidentiality; and fear being scolded or mocked, especially if a caregiver is present.

4.2.1.4 Effects of adolescents' feelings on establishing relationships with health workers

Adolescence is a unique phase of life charged with dramatic biological and emotional changes. Seeking health care may seem challenging to adolescents because the normal changes of adolescence affect their self-confidence, relationships, social skills and general thinking. Remember that building trust and rapport with adolescent clients starts with understanding their feelings and mindset.

4.2.2 Exercise 1: Role play

The purpose of the exercise is to practise establishing rapport and building trust with adolescent clients. Remember that adolescents may feel anxious, uncomfortable or uncertain when speaking to you, especially when disclosing personal information. Therefore, as health workers, you must be aware of your own behaviour. You should be able to identify what you should do and what you should avoid to facilitate the establishment of trust with adolescent clients. This exercise will give you an opportunity to apply some trust-building strategies and to discuss how to respond to adolescent clients.

Please follow the instructions provided by facilitators for the role play.

Exercise 1: Scenario 1

Mandle is 18 years old and recently found out that she is HIV-infected. She disclosed her HIV status to her boyfriend who, much to her surprise, broke up with her immediately. Now Mandle is not only heartbroken but also worried that her ex-boyfriend will, out of anger, disclose her HIV status to others.

How do you proceed with Mandle?

Exercise 1: Scenario 2

Emby is 15 years old and has been living with HIV since she was an infant. Her mother passed away a few years ago and she lives with her father now. She is responsible for caring for her three younger siblings. Today, she comes to the clinic claiming that she has stomach pains. You suspect that the real reason she has come is because she wants to talk about something.

How do you proceed with Emby?

4.2.3 Key points

- Building trust and rapport with adolescent clients starts with understanding their feelings and mindset.
- Establishing trust and rapport with adolescents can be challenging, but it is crucial to communication and to ensuring that their needs are addressed.

Session 4.3

Total time taken:
45 minutes

Effective techniques for counselling adolescents

Learning objectives

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

- Describe effective counselling skills

4.3.1 Overview of counselling

Counselling is a way of working with people to understand how they feel and to help them decide what they think is best to do in their specific situation.

The role of health workers is to support and assist a client's decision-making process. You are not responsible for solving the client's problems. Ultimately, it is the client's responsibility to make his or her own decisions and to carry them out.

4.3.1.1 Reasons for counselling adolescents

Counselling helps adolescents to:

- Talk, explore and understand their thoughts and feelings
- Work out for themselves what they want to do and how they want to do it
- Make an informed personal decision and cope with stress

In the context of ALHIV, counselling helps in:

- Prevention – HIV counselling helps to prevent and mitigate the continued spread of HIV
- Support – HIV counselling helps provide emotional, psychological and social support to adolescents affected by HIV
- Referral – HIV counselling helps to identify and facilitate referrals for other HIV care, treatment and support services

4.3.1.2 Components of counselling

- Establishing supportive relationships
- Having conversations with a purpose (not just chatting)

- Listening carefully
- Helping people talk without fear of stigma or judgment
- Giving correct and appropriate information
- Helping people make informed decisions
- Exploring options and alternatives
- Helping people recognize and build on their strengths
- Helping people develop a positive attitude and become more confident
- Respecting everyone's needs, values, culture, religion and lifestyle
- Being willing to trust clients' feelings and decisions

Remember Counselling requires that you as health workers recognize your own values and ensure that they are not imposed on your clients.

Refer to *Appendix 4B: Basic counselling guidance for ALHIV.*

4.3.2 Tips for counselling adolescents

Counselling and communication approaches are usually different for each client, and markedly different for older adolescents than for younger adolescents. Some younger adolescents may want to express their thoughts and feelings but have difficulty verbalizing them (see Session 4.2 for considerations).

General tips for counselling adolescents are:

- Involve them in their own care
- Assess their emotional and developmental levels
- Be aware of the client's changing capacities and adapt accordingly
- Be guided by the client's questions
- Listen to ALHIV, reflect back feelings, offer empathy and show that you care about what they are going through
- Encourage them to ask questions to check their understanding
- Be aware of the client's attention span
- Watch the client's body language; if they are inattentive, try again at a later time
- Have adolescents see the health worker with whom they best get along/relate
- To meet clients' needs, use the skills, strengths and approaches of the health workers on the multidisciplinary team
- Teach adolescents life skills

See *Appendix 4C: Common counselling scenarios.*

4.3.2.2 Common counselling mistakes

During a counselling session, a counsellor should not:

- Provide solutions/answers to clients' problems
- Tell clients what to do
- Make decisions for clients
- Blame anyone
- Interrogate or question another person
- Sympathize with the person
- Judge another person
- Preach to or lecture another person
- Make promises that cannot be kept
- Impose one's own beliefs on another person
- Provide inaccurate information

4.3.4 Key points

- Counselling is a way of working with people to understand how they feel and to helping them decide what they think is best to do in their specific situation.
- Your role as health worker is to support and assist the client's decision-making process.
- Ultimately, the client is responsible for making his or her own decisions and carrying them out.

Personal and social skills are required for young people to function confidently and competently with themselves, with other people and the wider community.

Appendix 4A: General tips on how to talk to adolescents

This section presents general guidelines on interacting with adolescents when providing testing services or ongoing care and treatment. Establishing a comfortable and open relationship (using the listening and learning skills discussed in Session 4.2) is the foundation for good communication. It also increases the chances that a client (and his or her caregivers) will return to the clinic. The age and developmental stage of the adolescent is critical to the way you should communicate with him or her. When working with adolescents:

- Before moving on to specific issues, make the adolescent feel comfortable by encouraging him or her to talk about things of interest ("Did you hear about the football match last night?", "How is school going?", "I like the blouse you're wearing, where did you buy it?")
- Engage with and take an interest in the adolescent as a person, and not just in his or her physical condition
- Present concrete information
- Maintain eye contact
- Do not ask too many questions
- Listen attentively
- Use direct, clear and age-appropriate language; avoid language that is technical or complex
- Do not make false promises
- Do not impose your personal beliefs on any situation
- Involve caregivers and other family members in the counselling process as younger adolescents need the presence of a trusted adult to feel secure
- Explain confidentiality to clients; inform them that it may be necessary to breach confidentiality in some situations
- Act appropriately and authoritatively; do not be authoritarian
- Use an interactive, participatory communication style
- Give the adolescent time to explain his or her ideas and decisions

Appendix 4B: Basic counselling guidance for ALHIV

Appendix 4B provides suggested conversational cues or prompts for introducing some core topics related to HIV care and treatment. This is a simplified framework, which outlines the main discussion points around care and treatment, rather than a comprehensive counselling script.

Counselling ALHIV, Ages 10–12	
Guidance ■ Remember to incorporate the seven listening and learning skills described in this module. ■ Determine disclosure status for younger adolescents and tailor the discussion accordingly. Use the term 'HIV' only if the adolescent knows of his or her diagnosis; otherwise, substitute a word such as 'a germ' or 'your health' for HIV and continue working with caregivers on the disclosure process (see Module 7). ■ Give the client realistic information about his or her health status. ■ Consider the client's age and developmental level to determine if it may be appropriate to begin discussions about HIV. ■ Emphasize that PLHIV can live meaningful lives and have normal relationships. ■ Help the client deal with possible stigma.	
Objectives	**Script**
Tell the client that you are here to address his or her specific questions and concerns.	*I want to talk to you about any questions you may have about your HIV result.* or *I want to talk to you about any questions or concerns you may have about your health and about your care at the clinic.*
Talk about HIV in age-appropriate terms.	*What is HIV?* (Tailor explanation to the client's response and level of understanding. Key points you may want to include in your explanation follow.) *HIV is a germ that lives in your blood and that makes it easier for you to get other germs. That means you could get sick if you don't take your medicines or if you don't take them correctly. You should know that you can still grow up to live a good life even though you have HIV.*
Ask about HIV-related discrimination.	*Some people have heard wrong information about HIV. If they think you have HIV, they might treat you differently just because they don't know any better. Has this happened to you?* (Tailor explanation to the client's response and level of understanding. Key points you may want to include in your explanation follow). *Some of the things you can do are: talk to someone you trust, who can help you manage the bad feelings, know that you have friends and family who love and care for you and understand that HIV is just a germ.*
Emphasize that ALHIV are normal.	*Having HIV does not make you a bad or different person; it just means you have to take care of your health. If you take care of your health, you will be able to live a healthy life just like other people.*

Objectives	Script
Discuss ART and adherence.	*How many times have you taken your ARVs in the last 3 days? What problems have you had taking your ARVs lately? How many doses did you miss? What can you do to make it easier to remember the doses you tend to miss?* (Tailor explanation to the client's response and level of understanding. Key points you may want to include in your explanation follow). *It is important for you to take your medicines every day and to not skip any doses, even if you don't feel like taking them. These medicines will help you to stay healthy. Are you having any problems taking your medicines or problems remembering to take them?*
Talk about ways to stay healthy.	*How do you stay healthy?* (Tailor explanation to the client's response and level of understanding. Key points you may want to include in your explanation follow.) *Knowing that you have HIV will let you take control of your health. To stay healthy, you should always take your medicines. You can also stay healthy by eating healthy foods, exercising and getting enough sleep.*
Discuss confidentiality. **Encourage the client to decide with his or her caregivers which people are okay to talk to about HIV.**	*While knowing your HIV status is necessary for taking good care of yourself, it is not something you have to share with everyone. Your test results are confidential. That means that they are only shared with doctors and nurses who help take care of you. You and your caregivers can decide together who else you feel comfortable talking to about your HIV status.*
Provide referrals.	*There are doctors who are experts in taking care of people just like you. There are also support groups and services available to you in the community, such as _____, _____ and _____. Our referral team can help you get in touch with these services.*
Comfort the adolescent. **Address any questions and concerns.**	*There are a lot of ways you can stay healthy and we are here to help you.* *What questions do you have? If you think of any questions later on, I will be available to answer them. Let's talk about how you can contact me if you have any more questions.*

Counselling ALHIV, Ages 13–19	
Guidance ■ Remember to incorporate the seven listening and learning skills described in this module. ■ Give realistic information about the client's health status and answer all questions. ■ The client should know his or her HIV status by this age. The later they learn their status he harder it is to accept their status. ■ Emphasize that ALHIV can live meaningful lives and have normal relationships. ■ Help the client deal with possible stigma and with determining how and when to disclose to others. ■ Include prevention information in pre- and post-test counselling.	
Objectives	**Script**
Tell the client that you are here to address his or her specific questions and concerns.	*I want to talk with you about any questions or concerns you may have about your health, about your care here at the clinic, or about HIV.*
Talk about HIV in age-appropriate terms.	*What is HIV?* (Tailor explanation to the client's response and level of understanding. Key points you may want to include in your explanation follow.) *HIV is a virus that lives in your blood and makes it easier for you to get other illnesses. That means you will get sick very often if you don't take your daily medicines or if you don't take them correctly. You should know that you can still have a good life even though you have HIV – you can even get married if you want to.*
Ask about HIV-related discrimination.	*Some people have incorrect information about HIV. If they think you have HIV, they might treat you differently just because they don't know any better. Has this happened to you? (Tailor explanation to the client's response and level of understanding. Key points you may want to include in your explanation follow.)* *If you feel you've been discriminated against because you have HIV, talk to someone you trust. Take reassurance in the fact that you have friends and family who love and care for you and who understand that HIV is just a virus.* *If you have been discriminated against by someone who you feel you can talk to, and if you feel comfortable doing so, go ahead and address this person's misconceptions. You don't have to disclose to this person, simply address their misinformation with correct, factual information.*
Emphasize that ALHIV are normal.	*Having HIV does not make you a bad or different person; it just means you have to take care of your health. If you take care of your health, including taking your medicines, coming to the clinic and living positively, you will be able to live a healthy life just like other people.*

Discuss ART and adherence.	*How many times have you taken your ARVs in the last 3 days?* (Tailor explanation to the client's response and level of understanding. Key points you may want to include in your explanation follow). *It is important for you to take your medicines every day and to not skip any doses even if you don't feel like taking them. These medicines will help you to stay healthy. What problems have you had taking your ARVs lately? Which doses did you miss? What are you doing now to remember to take your medicines every day?* If appropriate: *Tell me a bit more about why you missed some doses of your medicine? What ideas do you have to improve your adherence (in other words, to remember to take your medicines every day at the right time)?*
Talk about ways to stay healthy.	*How do you stay healthy?* (Tailor explanation to the client's response and level of understanding. Key points you may want to include in your explanation follow). *Knowing that you have HIV will let you take control of your health. To stay healthy, you should take your medicines every day, twice a day, exactly as the health worker described. You can also stay healthy by eating healthy foods, exercising and getting enough sleep.*
Discuss confidentiality. **Encourage the adolescent to decide with his or her caregivers which people are okay to talk to about HIV.**	*While knowing your HIV status is necessary for taking good care of yourself, it is not something you have to share with everyone. Your test results are confidential. That means that they are only shared with doctors and nurses who help take care of you. You and your caregiver can decide together who else you feel comfortable talking to about your HIV status.*
Provide referrals.	*There are doctors who are experts in taking care of young people with HIV. There are also support groups and services available to you in the community, such as _____, _____ and _____. Our referral team can help you get in touch with these services.*

Talk about the responsibility to protect others. **When age-appropriate, talk about safer sex.**	*Many adolescents have sex with their partners. Are you having sex? If so, how do you and your partner protect yourselves?* (If client is sexually active and did not use condoms the last time, ask: *When was the last time you used a condom?* Tailor discussion to the client's response and level of understanding. Key points you may want to include in your explanation follow). *Now that you know your HIV status, you have the power to stay healthy. It is also your responsibility to prevent the spread of HIV.* *If you are not yet having sex, it is important that you stay abstinent until you are at an age when you are ready to handle any possible consequences of sex, like getting pregnant or getting a sexually transmitted infection.* *You can pass on HIV to your partner if you have sex without a condom. In fact, having sex without a condom is the most common way that HIV is spread. This means that you should always use a condom when you have sex. This will also help prevent unwanted pregnancies (and we recommend using condoms PLUS another method of contraception to be safe). If you are having sex, it is important that you stay with only one partner and that you talk to your partner about having sex only with you.*
Comfort the adolescent. **Address any questions and concerns.**	*There are a lot of ways you can stay healthy and we are here to help you.* *What questions do you have? If you think of any questions later on, I will be available to answer them. Let's talk about how you can contact me if you have any more questions.*

Appendix 4C: Common counselling scenarios

Scenario	What the health worker can do
Silence	Remember that silence can be a sign of shyness, embarrassment, anger or anxiety. If an adolescent client is silent in the beginning of a session, you can say, *"I realize it's hard for you to talk. Talking to someone you don't know can be scary. Many people are scared (or embarrassed, angry, anxious) to share their feelings."*
Anger	Say, *"You seem angry. It's OK to be angry, but would you like to talk about it?"* Or, if you think you know why the client is angry, you can say something like: *"Sometimes when someone comes to see me against his or her will and doesn't want to be here, it is difficult for him or her speak. Is that what is going on?"*
Shyness	Legitimize their feelings by saying, *"I would feel the same way in your place. I understand that it's not easy to talk to a person you have just met."* Use books, brochures or posters to encourage discussion or refer to a story or anecdote so the adolescent can talk about things other than himself or herself *(see 'Activities to promote expression with younger adolescents' on pages 4–15).* Some adolescents simply need time to feel comfortable with someone new. If the adolescent cannot or will not talk, you should propose another meeting.
Crying	Try to evaluate what provoked the tears and assess if it makes sense in the given situation. If the client is crying to relieve tension, you can give the adolescent permission to express his or her feelings by saying, *"It is okay to cry…it's the normal thing to do when you're sad."* If the client is using crying as manipulation, you can say, *"Although I'm sorry you feel sad, it's good to express your feelings."* You should allow the client to freely express emotions and should not try to stop their feelings or belittle their importance.
Threat of suicide	Take all suicide threats very seriously. Refer the adolescent to a qualified counsellor, psychiatrist or psychologist and accompany him or her to the appointment. Work together with relevant members of the multidisciplinary care team to form an appropriate plan of action.
Refusal of help	Discreetly try to find out why the adolescent is refusing help. If the underlying feeling is anger, refer to some of the suggestions under 'Anger' listed above). If the client has been sent against his or her will, you can say, *"I understand how you feel. I'm not sure I can help you but maybe we could talk for a minute and see what happens."*

Scenario	What the health worker can do
Difficulty dealing with short stature (Many adolescents with perinatally-acquired HIV feel self-conscious about being 'different'. These physical differences can interfere with their self-esteem).	■ Reassure the ALHIV that most adolescents go through a period of feeling unhappy about themselves. One study from the U.S. suggests that almost 54% of American girls aged 12 to 23 years are unhappy with their bodies;[1] while another study suggests that 9 out of 10 British girls are unhappy with their bodies.[2] Although only a few of these young people had HIV, these statistics illustrate that adolescents, regardless of HIV status, often feel self-conscious and even dissatisfied with their looks. ■ Encourage ALHIV to reframe their differences by seeing them not as 'different', but rather defining them as individuals. A young man who is shorter than the average might feel better about himself if he focuses on the skills and qualities that he sees as positive, e.g., being artistic, creative or naturally outgoing. ■ It is difficult for young people to reframe their differences as positive. Give them time and encourage them to talk about their differences with friends and within support groups. Support groups can also give adolescents tips on dealing with teasing. ■ Encourage caregivers of ALHIV to encourage their children to feel good about themselves. A care giver's unconditional love and support is the core of self-esteem. Self-esteem is the armor adolescents need to ignore peer teasing.
Need to talk	■ It can be a counselling challenge when a client is very vocal and wants an outlet to express concerns that you do not perceive to be directly related to the client's immediate counselling needs. In this situation, you should give the client an opportunity to express his or her needs and concerns. You should then summarize the discussion so far and identify the key issues that need to be discussed that day. This sets the agenda for the rest of the meeting and gives the health worker permission to pull the session back on track if the client starts discussing tangential issues. ■ Sometimes you, as the health worker, simply do not have enough time to devote to a particularly needy or talkative client. In this case, you should get about halfway through the session and should then summarize the session so far, identifying key points that require further discussion. Assuming that the client agrees the summary is accurate, you should then try to prioritize the client's issues. You should suggest that the client and you talk about the first 2 or 3 issues in the time remaining during that day's session and that they tackle the other issues at the next session. Assuming the client agrees with this listing of priorities, you should then make a note of the agenda of items to be covered during the next session so they are not forgotten. ■ Refer client to a peer support group; talkative clients tend to benefit greatly from opportunities to interact with their peers.

[1] *Janie Lacy. Did You Know That…? Available at: http://janielacy.com/orlando-counseling-services/teens/body-image/*

[2] *Mail online. (July 26, 2011.) 90% of teens unhappy with body shape. Available at: http://www.dailymail.co.uk/news/article-205285/90-teens-unhappy-body-shape.html*

Appendix 4D: Listening and learning skills checklist

Skill	Specific strategies, statements and behaviours	(√)
Skill 1: Use helpful non-verbal communication.	■ Make eye contact.	
	■ Face the person (sit next to him or her), be relaxed and open with your posture.	
	■ Use good body language (nod, lean forward, etc.).	
	■ Smile.	
	■ Avoid looking at your watch, the clock or anything other than the client.	
	■ Do not write during the session. (Or, if you need to take notes to remember key points, explain this to the client and reassure them that the notes will be kept confidential in his/her medical file).	
	■ Other (specify).	
Skill 2: Actively listen and show interest in the client.	■ Use gestures that show interest (nodding, smiling) and use encouraging responses (such as "yes","okay", and "mm-hmm").	
	■ Clarify everything to prevent misunderstandings.	
	■ Summarize to review key points at any time during the session.	
	■ Other (specify).	
Skill 3: Ask open-ended questions.	■ Use open-ended questions to get more information.	
	■ Other (specify)	
Skill 4: Reflect back what the client is saying.	■ Reflect back or paraphrase.	
	■ Encourage the client to discuss further ("Let's talk about that some more").	
	■ Other (specify).	
Skill 5: Empathize – show that you understand how the client feels.	■ Demonstrate empathy: show an understanding of how the client feels by naming the emotion he or she has expressed.	
	■ Avoid sympathy.	
	■ Other (specify).	
Skill 6: Avoid words that sound judgmental.	■ Avoid judgmental words such as bad,proper,right,wrong, etc.	
	■ Use words that build confidence and give support (for example, 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.	
	■ Set a next appointment date and discuss availability of clinical services outside of clinic visits.	

Appendix 4E: Common counselling mistakes

The 'listening and learning skills' are easy to learn but difficult to apply. Some common mistakes while applying them include:

- Not allowing enough time for counselling, which can make it hard for the client to take in all the information and react to it
- Conducting counselling in a non-private space, like in a corridor or waiting area, or allowing interruptions during the session
- Controlling the discussion instead of allowing the client to control it and giving him or her time to ask questions and express his or her feelings and needs
- Judging the client – making statements that show the client does not meet your standards
- Preaching to the client – telling him or her how to behave or lead his or her life, for example, by saying "You never should have trusted that guy, now you have created a big problem for yourself."
- Labelling the client instead of finding out his or her individual motivations, fears or anxieties
- Reassuring the client without even knowing his or her health status – for example, telling the client that "you have nothing to worry about."
- Not accepting the client's feelings – for example, by saying "you shouldn't be upset about that."
- Advising the client before he or she has enough information or before he or she has had enough time to arrive at his or her own solution.
- Interrogating or asking accusatory questions to the client; questions that start with "why…?" can sound accusatory, although the tone makes a difference ("why" questions can also be a way of asking an open-ended question)
- Encouraging dependence – increasing a client's need for your guidance
- Persuading or coaxing – trying to get the client to accept new behaviour by flattery or fakery: "I know you are a good girl and will take your ARVs like I have told you."

MODULE 5:

DISCLOSURE COUNSELLING AND SUPPORT

Total module time: 2 hours 15 minutes

Module 5: Objectives

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

- Describe the disclosure process among ALHIV
- Explain the roles of health workers in the disclosure process

Session 5.1

Total time taken: 40 minutes

Overview of the disclosure process among adolescents

Learning objectives

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

- Describe the meaning and different types of disclosure
- Explain the reasons for disclosure
- Mention the advantages and disadvantages of disclosure
- Describe the barriers to disclosure and their solutions

5.1.1 Meaning, types and reasons of disclosure

5.1.1.1 Definition of disclosure

Refer to the action of making secret or new information known. Disclosure among ALHIV is an ongoing process that involves:

- Telling an adolescent that he or she has HIV
- Helping him or her understand HIV infection
- Helping him or her disclose their HIV status to their significant others

It is a two-way conversation that involves speaking truthfully with the adolescent, over time, about his/her health. Disclosure processes help and prepare adolescents disclose to others.

Through the process, the adolescent should come to understand:

- Their diagnosis, infection, disease process and health changes that could occur
- Strategies to lead a healthy life (e.g., adherence) and his or her responsibilities now and in the future
- How to cope with the possible negative (and positive) reactions of others

Remember The disclosure process should begin early by addressing the adolescent's health status and his or her need for care and treatment. In the early stages, very simple terms should be used. Ideally, adolescent clients will already know their HIV status and that of their caregivers, and will be well into the disclosure process. Some adolescent clients, especially those on the younger end of the adolescent spectrum, may not be fully disclosed to yet.

Levels of disclosure

- Disclosure of HIV status to the adolescent
- Disclosure of parent HIV status to the adolescent
- Disclosure of paediatric/adolescent HIV status to close relative, school or community with specific reasons

5.1.1.1.1 Disclosure approaches

Developmental approach to disclosure:

- Decision to initiate disclosure should be based on the readiness of the caregiver and the developmental stage of the adolescent
- Understanding an adolescent's developmental stage and needs is vital to disclosure and will help ensure that information is presented when the adolescent is able to cope with it
- Understanding an adolescent's developmental stage and needs is vital to disclosure. An adolescent's understanding of his or her HIV diagnosis will evolve as his or her brain becomes more equipped to absorb complex information and their level of emotional maturity increases. Understanding adolescent development will help health workers and caregivers better guide the disclosure process, ensuring that appropriate information is presented at a time when the young person is able to cope with it.

Developmental stages are associated with approximate ages; however, just because a young person is a certain age does not necessarily mean that his or her development is the same as that of others in his or her age group. Therefore, it is essential that you ask questions to assess each young person's understanding.

See *Appendix 5A: Guide for developmentally appropriate disclosure* for additional information.

5.1.1.1.2 Partial disclosure

Partial disclosure refers to giving information about their health to a client without using the words 'HIV' or 'AIDS'. This helps move the disclosure process forward and prepares the client and caregivers for full disclosure later on. It is an effective strategy in helping caregivers who do not feel ready for full disclosure, and it is useful for creating a context in which full disclosure can be more meaningful for the adolescent. Partial disclosure may be considered for younger adolescents who may not be aware of their illness.

The disclosure process with perinatally infected adolescents should begin early. It should start (partial disclosure) by the time a child is six years old, and more information and details should be given as the child grows and develops, until the age of 12 years when all details should (ideally) have been fully disclosed.

5.1.1.1.3 Full disclosure

An adolescent needs to be told that he or she is HIV-infected and given further HIV-related details. Caregivers are ideally the ones who should decide when it is time for full disclosure with the assistance of the health workers.

Full disclosure should happen by the time a client is 10–12 years old. Full disclosure should be considered when the adolescent starts asking specific questions about his or her illness. It is easiest if the adolescent has been partially disclosed to over time and has been supported throughout the disclosure process.

5.1.1.2 Reasons for disclosure

- Results in health and psychological benefits for the adolescent
- Adolescents have a right to know their health status
- Improves social functioning and school performance
- Allows caregivers to offer comfort and reassurance
- Allows adolescents to take an active role in their care and live positively
- Minimizes anxiety, depression and low self-esteem among adolescents

Orphans and other vulnerable adolescents may wonder why they've lost a parent or been rejected by family. Adolescents often ask and want to know what is wrong with them. Parents who have disclosed their HIV status to children also experience better post-disclosure mental health outcomes.

Non-disclosure may lead to incorrect ideas, feelings of being alone, learning one's status by mistake and poor adherence, On the other hand, disclosure may improve adherence and prevent sexually active adolescents from unknowingly exposing others to HIV.

5.1.1.3 Reasons for delaying disclosure

Reasons that may necessitate delay of initiating disclosure process include:

- When the adolescent has severe cognitive and developmental delays
- When the adolescent is grappling with serious health or mental health conditions
- When one or both parents/caregiver has an acute health problem or mental health crisis

How to initiate the disclosure process step-by-step:

- Age 5–7: Start with partial disclosure; avoid using the words 'HIV' and 'AIDS'. The HCP can use 'mdudu'.
- Age 8–11: Partial disclosure; use the word 'HIV', but avoid details
- Age 12–14: Full disclosure of information about HIV and AIDS and transmission of HIV

5.1.2 Advantages and disadvantages of disclosure

5.1.2.1 Advantages of disclosure

- Avoiding the burden of secrecy
- Avoiding anxiety about accidental disclosure
- Gaining access to emotional and practical support
- Easier access to health care
- Better adherence
- Easier to discuss safer sex and family planning with partners
- Easier to talk about testing with partners
- Gaining the freedom to find a treatment buddy
- Gaining access to peer support groups and community organizations
- Serving as a disclosure role model for others

5.1.2.2 Disadvantages of disclosure

- Blame from partner or family
- Distancing, fear, rejection or abandonment from family, partners or friends
- Discrimination or rejection at school, in the community or at work
- Assumptions made by others about one's sexuality, promiscuity or lifestyle choices
- Partner reluctance to enter into intimate relationships or have children
- Physical violence
- Self-stigma

Loss of economic/ subsistence support from family members or partners

You can help adolescents understand that one of the advantages of disclosure is that they will have friends who know their diagnosis and who can support them. Adolescents should always make their own decisions about disclosure. You can support ALHIV in deciding who to disclose to, when and where to disclose, to weigh the advantages and disadvantages of disclosure and to anticipate likely responses.

5.1.4 Key points

- Disclosure is an ongoing process, not a one-time event.
- Understanding an adolescent's developmental stage and needs is vital to disclosure and will help ensure that information is presented when an adolescent is able to cope with it.

Knowing the backgrounds, limitations and resources of care givers will help to improve health care workers' sense of mastery and comfort in assisting and supporting the disclosure process.

Session 5.2

Total time taken:
1 hour 35 minutes

Health worker's role in disclosure

Learning objectives

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

- Explain the roles of health workers during the disclosure process
- Describe ongoing disclosure support needs for adolescents and caregivers

5.2.1 Role of health workers during disclosure process

5.2.1.1 Health workers' role in the disclosure process

During the disclosure process, you should:

- Encourage open dialogue and disclosure
- Offer practical and development ally appropriate strategies for disclosure
- Assess the adolescent's readiness for partial/full disclosure
- Prepare the adolescent for disclosure
- Facilitate disclosure discussion
- Work with the caregiver/family to develop and follow a disclosure plan
- Advocate for the needs of the adolescent
- Encourage other health workers to work as a team and consult each other for suggestions on how best to support children, adolescents, caregivers and families through the disclosure process

5.2.1.2 Health workers' role in supporting caregivers during the disclosure process

In supporting caregivers during the disclosure process, you should:

- Build trust by getting to know them and finding out what HIV means to them
- Assess their psychosocial situation and ability to cope, answer their questions and identify their sources of support

- Discuss the implications of disclosure and possible reactions
- Assess the client's readiness for disclosure and share impressions with the caregiver
- Help caregivers develop a plan for disclosure
- Arrange follow-up visits
- If there is disagreement between family members, assess concerns and discuss benefits and risks
- Respect and try to understand their reasons for fearing or resisting disclosure

Remember If the caregiver is not ready to disclose, the process cannot be forced; however, you should always advocate for the adolescent's best interests.

5.2.1.3 Helping the caregiver with disclosure

Allow the caregivers to go through the phases of disclosure:

- The secret phase, where most caregivers want to keep it a secret after diagnosis
- The exploratory phase, where caregivers may disclose to one person close to them to test their reaction (sometimes inventing a story to test reactions)
- The preparatory phase, where the caregiver is prepared to disclose, share with others and learn from experience
- The disclosure phase, where they are fully ready to disclose
- Always keep in mind the adolescent client's needs
- Create a climate of freedom for the child to ask questions comfortably
- Anticipate and plan how to respond to possible responses
- Anticipate and plan for the impact on family members, friends school and community

What is said will vary according to the need and circumstances of the client's situation. Caregivers also undergo different phases of disclosure before being ready to disclose to their children.

Therefore, it is important for health-care workers to facilitate caregivers in going through these phases until they are ready.

5.1.3 Barriers to disclosure and solutions

5.1.3.1 Barriers to disclosure

Barriers to disclosure among health care workers include:

- Not knowing where to start or being concerned about harming the adolescent
- Being unsure about your role or thinking that the process of disclosure is not your responsibility
- Having different opinions between yourself and caregivers
- Having different opinions among other health workers in the facility – generally or related to a specific client

Caregivers may:

- Fear that disclosure will cause psychological harm
- Think that the topic is too complicated for the adolescent to understand
- Not know where to start or how to respond to questions
- Lack knowledge or not be comfortable with the topic
- Fear stigma and discrimination against the adolescent and other family members
- Experience parent guilt regarding transmission

See Table 5.1 Addressing caregiver barriers to disclosure.

5.1.3.2 Solutions to disclosure barriers

All members of the multidisciplinary team can support the process of disclosure in various ways. Discussing and defining health-care workers' roles in the process of disclosure can promote effective coordination among the team members involved. Careful assessment of barriers to disclosure and working with the caregiver is often required to agree on what, when and how to disclose to the adolescent.

It can be challenging when you think that the adolescent needs to understand their HIV diagnosis but the caregiver is not ready to start or move ahead with the disclosure process. When conflicts about disclosure arise, it is helpful to remember that disclosure is a process that takes time.

Training is essential to equip health-care workers to support caregivers and adolescents throughout the disclosure process. Asking the advice of other health-care workers who have been through this process with caregivers and observation of more experienced health care workers is beneficial.

Knowing the backgrounds, limitations and resources of caregivers will help to improve your sense of mastery and comfort in assisting and supporting the disclosure process. It is always important to remember that the decision of the caregiver should be respected.

Table 5.1: Addressing caregiver barriers to disclosure

Caregiver barrier	Suggested health-care worker response
Fear that disclosure will cause psychological harm.	Those who fear that disclosure will cause psychological harm, may assume that disclosure could: ■ Reduce the adolescent's will to live ■ Make the adolescent think that they are not normal ■ Strip adolescents of their happiness – an unconscionable gamble for care givers who believe that children/adolescents are supposed to be happy You can: ■ Reassure care givers that contrary to common assumptions, studies have shown that there are positive psychological benefits to being appropriately aware of one's own illness. Studies suggest that young people who know their HIV status have higher self-esteem than young people who are unaware of their status. Parents who have disclosed the status to their children also experience better mental health outcomes (for example, less depression compared to those who do not) ■ Connect care givers to others who have gone through the process of disclosure (peer support) and are willing to share their experiences
Concern that the topic is too complicated for the adolescent to understand.	Reassure care givers that you will work with them to ensure that all disclosure-related conversations are appropriate for the adolescent's age and developmental status (for example, understanding, emotional maturity, etc.). The aim of these conversations, that will take place over many years, is to help the adolescent become 'appropriately aware of his or her illness', not to explain everything all at once.
Unsure of where to start or how to respond to questions.	You can begin talking to the care giver very early about the disclosure process – long before anything is said to the adolescent. This will help the care giver make a plan for where, when and how to begin the process of disclosure.
Lack of knowledge/comfort with topic.	You should: ■ Provide care givers with the background information they need to discuss HIV with their children. Ensure that the care giver's questions are answered throughout the disclosure process ■ Provide the care giver with possible answers to the adolescent's anticipated questions ■ Role-play various disclosure scenarios to give the care giver practice sessions ■ Decide with the care giver what is appropriate/necessary to tell the adolescent at each stage of development, given the adolescent's level of understanding

Caregiver barrier	Suggested health-care worker response
Fear of stigma and discrimination against the adolescent and other family members.	Disclosure of HIV status is complicated by the fact that HIV infection brings with it stigma and discrimination that is rarely associated with other diseases. You can help reduce this stigma and discrimination within family systems by: ■ Supporting care givers in providing guidance to adolescents about disclosure, and with whom they may safely speak about their illness (confidentiality within the home and community) ■ Suggesting to care givers that they identify one or more trustworthy people with whom the adolescent is regularly in contact (other than the healthcare worker) to be a 'safe' person – one with whom the child can discuss his or her HIV status, concerns and treatment. If adolescents have one 'safe' person, they will be less likely to disclose inappropriately ■ Involving care givers and other family members early in the disclosure process to ensure misinformation about HIV is corrected early on ■ Referring the adolescent and care givers to support groups where others can provide advice on dealing with stigma ■ Maintaining a continuous open line of communication with the adolescent to help him or her deal with their changing feelings about HIV and negative reactions from society
Parent guilt regarding transmission.	You should remember that disclosure of HIV status to adolescents is often a family issue as it is related to one or both of the parents' infection status. You can help parents deal with the shame or guilt of passing on HIV to their children by encouraging them to: ■ Understand that they should not blame themselves for getting HIV ■ Take care of themselves, by going to the clinic regularly and taking their medication. Taking specific actions to improve their health will reduce the sense of powerlessness that may accompany feelings of guilt ■ Model positive living for their children. Healthy behaviours reflect a positive attitude towards life, thereby encouraging children to also see life with optimism

Adapted from: *The South to South Partnership for Comprehensive Family HIV Care and Treatment Program; International Center for AIDS Care and Treatment Programs; François-Xavier Bagnoud Center, University of Medicine and Dentistry of New Jersey. 2010. "HIV Care & Treatment Training Series", Module 6: Disclosure Process for Children Ages 3 to 18 Living with HIV.*

5.2.2 Disclosure support needs for adolescents and caregivers

5.2.2.1 Providing ongoing disclosure support to caregivers

At each visit, ask the caregiver follow-up questions, such as:

- Have you noticed any changes in the adolescent's behaviour since he or she learned about his or her HIV status?
- Who else at home knows about the adolescent's HIV status?
- What kind of help, support or information do you still need?
- What feelings or concerns do you have about the disclosure process with your adolescent?
- Who does your adolescent talk to if he or she has questions?
- What questions do you have?
- When will we meet again?

Remember Caregivers will also need ongoing support from health workers, family members and peers as the disclosure process proceeds over time.

5.2.2.2 Ways to assist ALHIV during the disclosure process

- Use good communication and counselling skills to interact with them
- Talk about their feelings and fears regarding disclosure
- Discuss advantages and disadvantages of disclosure
- Support them in making their own decisions
- Help them decide who to disclose to, when and where
- Help them identify barriers and possible solutions to them
- Provide accurate information in response to questions
- Help them anticipate likely responses to disclosure
- Talk about sexual partners
- Offer reassurance and emotional support
- Encourage them to take time to think things through
- Practise disclosure through role plays
- Provide ongoing follow-up and support
- Identify sources of support and refer adolescents to peer support groups

5.2.2.3 Peer support and disclosure

Peer support can be an excellent resource for adolescents making decisions about disclosure.

Peer educators and peer support groups Adolescents may find it is helpful to meet each other for mutual support.

Groups for caregivers of ALHIV Family members of ALHIV may benefit from talking with other families or with a health worker in a support group setting.

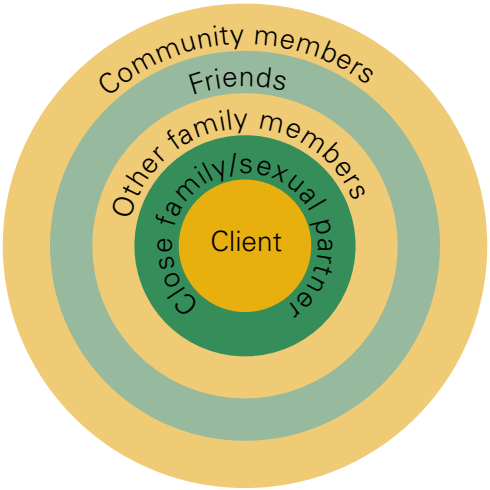
You can prepare the adolescent for disclosure through youth-friendly counselling and information sessions (see Module 4 for tips on communicating with adolescents) and by linking clients with peer support groups and adolescent peer educators. You can actively assess the child/young adolescent's readiness for partial or full disclosure by asking questions about his or her understanding of why he or she takes medicines and comes to the clinic. They can share impressions of the client's readiness for disclosure with caregivers and other members of the care team and work with them to make and implement an appropriate disclosure plan.

5.2.2.5 Deciding details about disclosure

Creating disclosure circles can help adolescents decide who to disclose to; each level represents a process in itself.

Figure 5.1 Disclosure circles

People adolescent is closest to:



The disclosure cycle has four circles, each representing different people:

- The adolescent is at the centre of the circle.
- The next circle is a person or people the adolescent is very close to, such as his or her mother, siblings or partner. (Give the adolescent a piece of paper so that he or she can write the names of the people on this and the following layers of his or her own disclosure circles.)
- 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.

Each level of disclosure represents a process in itself – preparing for disclosure, the actual disclosure process and ongoing conversations after disclosure. Remember that the conversation does not end after disclosure – there will likely be ongoing discussions over time between the client and the person to whom he or she disclosed to.

The circles provide a way of discussing the disclosure process and considering the risks and benefits of disclosing to different people, while also assisting in prioritizing disclosure activities and who NOT to disclose to.

5.2.2.6 Post disclosure support

After disclosure, adolescents and their caregiver may need to be linked with community services, psychiatric services, group therapy, social workers, spiritual intervention and other support services (e.g., food and clothing).

During post-disclosure support, you should consider the following:

- Discuss the pain and distress after disclosure (otherwise pain will become internalized)
- Assess emergent psychological symptoms regularly, particularly during the disclosure process and afterwards
- Offer continued support and availability and discuss the importance of having continued counselling sessions on a regular basis
- Address the adolescent's self-perception/esteem and their outlook on life
- Encourage the adolescent to draw on inner-strength and support from his/her caregivers/ community/ friends to help bring about change in their self-perception and outlook on life
- Give the adolescent current information on HIV treatment in a manner which he/she can understand and use

5.2.2.7 Ongoing disclosure support for adolescents

Disclosure does not begin or end with a single conversation. As adolescents grow and develop, they need to be able to continue to ask questions and discuss their feelings. Disclosure is an ongoing process – follow-up and additional support for adolescents and caregivers is essential. Practise supportive conversations, such as:

- "Who else knows about your HIV status? What do you think about disclosing your status to (other) people you are close to?"
- "What are some of the ways you are taking care of yourself? How do you think you can live positively with HIV?"
- "How are you doing with your medications?"
- "What other questions do you have about your illness?"
- "When should we meet again to talk more?"

5.2.2.8 Special cases

When working with adolescents who do not have caregivers or do not have caregivers who are actively involved, you may have to take a more active or 'parental' role in the disclosure process.

When working with adolescents in institutional care, you should identify the person who is legally responsible for the adolescent and, if possible, invite that person to the clinic for a session related to disclosure.

Sometimes adolescents do not have caregivers or do not have caregivers who play an active or consistent role in their care. They may be heads of households, living with a sexual partner or they may be homeless. In such situations, particularly if the client is coming to the clinic alone, you (and if possible, more than one member of the multidisciplinary team) may have to take a more active or 'parental' role in the disclosure process. This includes deciding when and how to begin and move forward with the disclosure process according to the client's unique situation and developmental stage.

For adolescents living in institutions like orphanages, foster homes and education- or employment-related housing programmes, you should identify the person who is legally responsible for the child or adolescent and, if possible, invite that person (with the consent of the adolescent client) to the clinic for an educational and counselling session related to the disclosure process.

5.2.3 Exercise 1: Role plays

The purpose of the exercise is to give you an opportunity to develop the knowledge, skills and confidence to support caregivers and clients during the disclosure process.

Please follow instructions provided by facilitators for the role play.

Although the primary caregiver should preferably be the one who discloses to the child, caregivers may sometimes ask for help with the process. You can assist – first by preparing the caregiver and then, if asked, by being present when the caregiver makes the disclosure. Your role is to support the caregiver and to facilitate his or her conversation with the adolescent.

5.2.3.1 Exercise 1: Role play 1

A mother named Emae has been caring for her HIV-infected 10-year-old son, Tyson. Tyson keeps asking you why he has to take these pills and says he wants to know when he will be done with them. When you ask the mother what Tyson knows about his health, she becomes quiet.

How would you proceed?

Exercise 1: Case study of discussion questions

- What types of questions is Tyson likely to ask about his illness? What are some possible responses?
- What can you do to help the caregiver prepare for the disclosure process?
- How can you assess the caregiver's readiness for or knowledge about disclosure?
- What age-specific activities, if any, can you introduce during the session?

5.2.3.2 Exercise 1: Role play 2

Amalia is 11 years old. She has lived with her grandmother since her mother died three years ago. Amalia and her grandmother have been coming to the clinic since Amalia started to become symptomatic and the doctor wants her to start ART soon. The grandmother is having problems giving Amalia her CTX . You believe that Amalia would cooperate better if she understood more about the medication and why she needs it, especially since ART is now about to become a part of their everyday lives. The grandmother thinks Amalia is too young to know her status and insists she does not need to know yet.

How would you proceed?

Exercise 1: Case study of discussion questions

- What types of questions is Amalia likely to ask about her illness? What are some possible responses? (See Appendix 5A)
- What can you do to help the caregiver prepare for the disclosure process?
- How can you assess the caregiver's readiness for or knowledge about disclosure?
- What age-specific activities, if any, can you introduce during the session?

Ways not to disclose to an adolescent:

- Accidentally (child overhears, or reads something left lying about)
- Carelessly (without thinking how)
- In anger (in reaction to something child has done or said)
- Unplanned response to child confronting adult care giver or health worker
- After child has already worked things out for him/herself
- When the child is dying

5.2.4 Key points

- Everyone needs a unique disclosure plan. An adolescent's disclosure plan should consider age, developmental status, personal and family experience of stigma and discrimination.
- One way for health workers to help ALHIV understand disclosure and to help them decide who they will disclose to is by creating disclosure circles.

The role of the health worker is to support the disclosure process; the adolescent will make the final decision about who to disclose to and when and how.

Appendix 5A: Guidance for developmentally appropriate disclosure

Age group characteristics	Disclosure considerations and guidance	Possible questions the adolescent might have	Possible responses to questions or ways of explaining things to the adolescent
Younger adolescents (approx. 10–13 years old)			
■ Beginning to understand cause and effect, but still struggle with abstract concepts ■ Growing vocabulary, but struggles to express ideas and feelings in words ■ Enjoys activities that give a chance to control, organize and order things ■ May regress and want help from adults if feeling insecure or unsure	■ Be truthful ■ Ideally, the disclosure process will have already started by this age ■ Give more detailed information with concrete examples. ■ If a child asks for more information (for example, "What's the germ called?" or "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	■ Why do I have to go to the clinic? ■ Why am I sick? ■ Why do I have to go to the clinic so much? ■ Why do I have to take medicine? ■ Am I going to die? ■ How did I get HIV? ■ Who knows that I have HIV? ■ Do I have to tell people I have HIV? ■ What will happen if people know I have HIV?	■ Going to the clinic 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 (if mother or care giver is also HIV infected) both have HIV in our bodies ■ You have to take medicine so that the germ fighters can work and you won't get sick so much ■ You (and I, if appropriate) take medicine to keep us strong ■ The medicines that we have to treat this virus are very good. If you take your medicine the right way, every day and never miss a dose, you can stay healthy for a very long time ■ 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 ■ You can always talk to me about it at any time ■ Maybe we should keep this in the family for now?
Older adolescents (approx. 14–19 years)			
■ Early adolescents are just beginning to think in more abstract terms ■ Want solid, well thought-out explanations	■ Ideally, the adolescent will have been fully disclosed to by this age ■ Accurate and more detailed information can be given in response to questions	■ What is HIV? ■ Why do I have it?	■ 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 ■ Healthcare workers look at your blood to see how many healthy cells, called CD4 cells, are in it. The higher your CD4 count, the better

■ Body changes can create feelings of insecurity ■ Forming a sense of identity – peer approval and social acceptance is very important	■ 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 ■ Ask questions about their understanding and address mis-perceptions, for example, "What have you heard about HIV?" ■ Discuss ways to live meaningfully with HIV, including having relationships, are a common concern. Issues like risk reduction and living positively with HIV should be discussed ■ Assurance that their status and what they say is confidential is very important ■ Normal adolescent striving for independence may complicate the response to disclosure (for example, 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	■ Can I give HIV to my (girl/boy) friends? How? ■ Why do I have to go to the clinic so often? ■ What are the healthcare workers looking at in my blood? ■ What if I want to get married and have children? Is that possible for people living with HIV? ■ Who should I tell that I have HIV? ■ Why are others mean to people with HIV?	■ You can control the virus by taking your medication every day, at the same time and never missing a dose. But there is no way you can get rid of HIV completely ■ If you stop taking your medicine, the virus will get stronger and damage all of your healthy CD4 cells. If that happens you can get sick ■ Knowing that you have HIV gives you a special responsibility to take extra good care of yourself and not pass HIV to other people ■ People with HIV can and do live long lives, have relationships and get married ■ If you have sex, it is important for you and your partner that you use condoms. Taking your ARVs the right way, which is every day, also lowers the amount of virus in your body and makes it less likely that you will pass HIV to your partner during sex ■ 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 of your baby getting HIV. Taking your ARVs the right way, every day will help lower the chance of passing HIV. We can talk more about this whenever you like

Adapted from *The South to South Partnership for Comprehensive Family HIV Care and Treatment Program; International Center for AIDS Care and Treatment Programs; François-Xavier Bagnoud Center, University of Medicine and Dentistry of New Jersey. 2010. "HIV Care & Treatment Training Series", Module 6: Disclosure Process for Children Ages 3 to 18 Living with HIV.*

MODULE 6:

CLINICAL CARE FOR ADOLESCENTS LIVING WITH HIV

Total module time: 3 hours 15 minutes

Module 6: Objectives

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

- Describe the characteristics of adolescents who acquired HIV perinatally and those who acquired HIV during childhood or adolescence
- Describe the service delivery models (SDMs) for differentiated care for adolescents
- Describe the characteristics of comprehensive care for ALHIV

Session 6.1

Total time taken: 30 minutes

HIV acquisition – modes and implications for care and treatment

Learning objectives

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

- Identify groups of HIV acquisition among adolescents
- Differentiate characteristics of adolescents who acquired HIV perinatally versus those who acquired HIV during childhood or adolescence
- Explain the common challenges faced by adolescents with different modes of HIV acquisition

6.1.1 Groups,characteristics and challenges of adolescents with HIV Infections

6.1.1.1 Groups of ALHIV

ALHIV may be grouped by mode of acquisition into adolescents who acquired HIV perinatally (from the mother during pregnancy, delivery or breastfeeding) and adolescents who acquired HIV during childhood or adolescence.

6.1.1.2 Characteristics of adolescents who acquire HIV infection perinatally

Characteristics of adolescents with HIV acquired during perinatal period include:

- Being enrolled in HIV care since infancy, or identified later in life during an acute illness or through routine testing
- Starting ART in infancy and having taken various ART regimens by the time they reach adolescence
- Others may still be taking the initial regimen they started during early childhood
- Many have been 'missed' by the health care system, despite being symptomatic
- /May or may not have been fully disclosed to (depending on their age and caregivers)

Adolescents who acquire HIV perinatally:

- Probably acquired HIV via MTCT
- Are now surviving into adolescence and adulthood because of the availability of HIV treatment programmes

6.1.1.3 Challenges facing adolescents who acquired HIV perinatally

Challenges facing adolescents who acquired HIV perinatally are:

- Developmental delays and physical disabilities
- Disclosure of HIV status to the adolescent
- Self-acceptance of HIV status
- Parents' acceptance of their HIV status
- Demands of caring for adolescent with chronic HIV infection in the family
- Complexity of living in a home affected by HIV, particularly if caregivers are unemployed, unwell or have died

6.1.1.4 Characteristics of adolescents who acquire HIV during childhood or adolescence

Adolescents who acquire HIV during childhood or adolescence do so probably through sexual intercourse; sexual abuse, including rape; and, less frequently, through blood transfusion, sharing cutting/piercing instruments or injecting drug use. They may have recently learned their HIV status and generally not had extended contact with the health system. They are often identified via HIV testing programmes. Some adolescent girls are identified when they seek ANC and receive routine testing as part of PMTCT services.

6.1.1.5 Challenges facing adolescents who acquire HIV in adolescence

Adolescents who acquire HIV in childhood or during adolescence may face the following challenges:

- Denial in accepting HIV status
- Delay in disclosure to family, partner and peers
- If raped or abused, dealing with the emotional and physical repercussions of the experience
- Fear of seeking health-care services

6.1.1.6 Common challenges that ALHIV face

Adolescents who acquired HIV perinatally and those who acquired it during childhood or adolescence may both have issues related to adherence to ART: retention in care; positive living and positive prevention; and stigma and discrimination. Both groups likely worry about their future and about finding a partner/starting a family.

There are health systems challenges, such as shortages of trained personnel offering adolescent-friendly services and inadequate infrastructure for offering adolescent-friendly services.

Table 6.1: Differences and similarities between ALHIV based on transmission period

Differences (and similarities) related to:	Period when HIV was acquired	
	Perinatal (dependent on current age and stage of development)	**Adolescence**
Age at Presentation in Adolescent Care	■ May be present at an earlier age, but tend to be younger: 10–19 years	■ Tend to be older: 15–19 years
Physical Development	■ May be delayed: short stature and late puberty	■ Normal physical development and puberty
Sexual and Reproductive Health	■ Not yet sexually active (or, if older, may be thinking about sex or have already had sexual debut)	■ Probably sexually active ■ May have been sexually abused
	Similarities: ■ May need SRH services, including safe sex education and support ■ May want children	
Relationships/ Marriage	■ May or may not be in a relationship (depending on age and development) ■ May want intimate relationship ■ May want marriage	■ Probably in a sexual relationship ■ May want marriage
Disclosure	■ Primary caregiver knows adolescent's HIV status ■ Caregiver needs to disclose to adolescent if he or she does not already know status	■ Coping with new diagnosis ■ Coping with disclosure to primary caregiver ■ Coping with disclosing to partner
	Similarities: ■ Coping with the process of disclosing to family and peers	
Family Support	■ Living with parents or caregivers, who typically know adolescent's HIV status so that they can offer support	■ Support system for HIV depends on disclosure
Economic Support	■ May be unstable if adolescent has been orphaned	■ May have few resources (money, information, experience) if adolescent has left home
ART	■ Often on ART for many years	■ May not need ART yet
	Similarities: ■ Adherence challenges in childhood and adolescence	
STIGMA/ "BLAME"	■ Less likely to be blamed ■ Considered 'innocent'	■ More likely to be blamed because of 'irresponsible' behaviour
	Similarities: ■ Face stigma	

Adapted from: *WHO.(2010). IMAI one-day orientation on adolescents living with HIV, Facilitator guide. Geneva: WHO*

6.1.2 Key points

- Adolescents may have acquired HIV perinatally, during childhood or in adolescence.
- Both groups are likely to worry about their futures and about finding a partner/starting a family.
- Both groups need ongoing care, support and monitoring for ART.

Session 6.2

Total time taken: 45 minutes

SDMs for differentiated care for adolescents

Learning objectives

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

- Explain SDMs
- Describe differentiated ART initiation for adolescents with early and advanced disease
- Describe differentiated ART delivery for stable and unstable adolescents on ART

6.2.1 Overview of SDMs

6.2.1.1 SDMs for differentiated care

'Service delivery models for differentiated care' refers to a client-centred approach that simplifies and adapts HIV services across the treatment cascade in order to reflect the preferences and expectations of various groups of PLHIV. Treatment cascade entails steps from initial HIV diagnosis, linked to care, receiving ART, retained into care to achieving viral suppression.

6.2.1.2 Types of SDMs for differentiated care

HIV services usually face an increasing number of clients on ART. Among these clients, four groups with specific needs can be categorized through the differentiated SDMs as follows:

- **Clients with early disease:** These are the clients who are present with WHO Stage 1 or 2, and CD4 count ≥350 cell/ mm^3 (or ≥35 per cent for children ≤5 years old)
- Clients with advanced disease: These are clients who are present with low CD4 count ≤200 cells/mm^3 for adults and ≤25 per cent for paediatrics or WHO stage 3 and 4.
- Stable clients on ART

Unstable clients on ART

SDMs for differentiated care also reduce unnecessary burdens on the health system and enable it to refocus resources to the clients who need them the most.

Stable clients on ART include clients:

- Aged above five years
- Have received ART for at least six months
- Have no adverse drug reactions that require regular monitoring
- No current illnesses (OIs and comorbidities)
- Have good understanding of lifelong adherence of 95 per cent and have kept clinic visit appointments for the past six months
- On first-line ARVs, with undetectable viral load (VL) below 50 copies/ml
- In the absence of VL monitoring, rising CD4 counts are ≥350 cells/mm^3

This group represents the majority of people on ART. The clients in this group should be offered less frequent clinical visits and extended drug refills.

Unstable Clients on ART: Includes clients

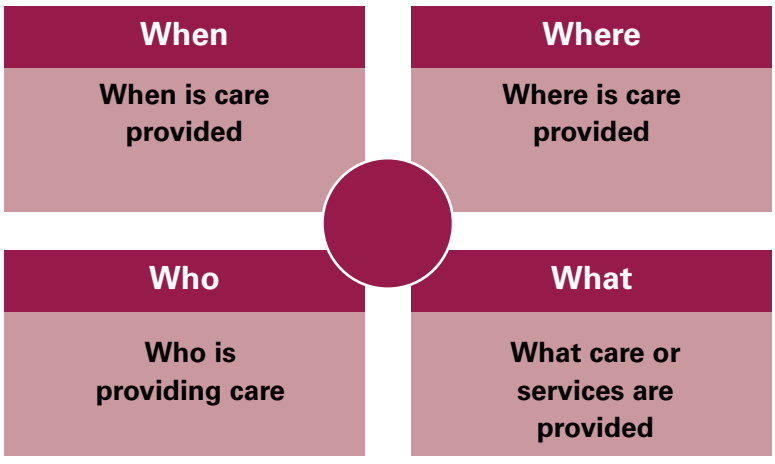
- Aged under five years
- Have received ART for less than six months
- Presence of an active OIs (including TB) in the past six months
- Poor or questionable adherence to scheduled clinic visits in the past 6 months
- Recent detectable VL above 50 copies/ml
- In absence of VL monitoring decreasing CD4 cell count or CD4 ≤ 200 cell/mm^3
- People who inject drugs (PWID)
- Pregnant women

Clients on second-line regimen

These clients require additional clinical care, adherence support and timely switch to second-line ART regimens in the case of treatment failure.

6.2.1.3 Building blocks of SDMs

Figure 6.1 Building blocks of SDMs



Adapted from *International AIDS Society (IAS). Differentiated Care for HIV: A decision framework for antiretroviral therapy delivery, July 2016.*

Delivery models are designed using the building blocks approach with four delivery components:

- The types of services delivered: What care or services are provided?
- The location of service delivery: Where is care provided?
- The provider of services: Who is providing care?
- The frequency of services: When is care provided?

6.2.1.4 Differentiated ART initiation for clients with early disease

WHEN:

- Initiation should take place preferably within two weeks of a positive HIV test, unless there is a medical or psychosocial contraindication.
- Follow-up should be weekly until ART initiation, then after two weeks, then monthly until the patient is stable.
- Additional visits may be needed to address any medical or psychosocial concerns.

WHERE:

- At all health facility levels; management of clients is done at any ART service delivery point.
- Starting ART will decrease risk of developing wasting and other infections. All adolescents and caregivers should be assessed for the option of rapid initiation. This must include an assessment of both clinical and psychosocial readiness.

WHO:

- Initiation may be performed by a trained health-care worker (clinician and trained nurses).

WHAT:

- An assessment of both clinical (OI screening) and psychosocial readiness must be carried out before ART initiation.
- Counselling should include basic HIV and ART education and assessment for readiness to start ART.

See National guidelines for management of HIV and AIDS (2017) for detailed information on differentiated ART delivery for clients with early disease.

6.2.1.5 Differentiated ART Delivery for clients with advanced disease

WHEN:

- Initiation should take place preferably within two weeks of a positive HIV test, unless there is a medical contraindication or psychosocial contraindication.
- Weekly follow-up until ART initiation, and then at weeks two and four after ART initiation, and then monthly until the patient is stable.
- More frequent visits or hospitalization may be required to stabilize acute medical conditions and address psychosocial and other concerns.

WHERE:

- At all health facility levels.
- Management of adolescents is done at any ART service delivery point.
- Referral to a higher-level facility when feasible, if consultation is not adequate to stabilize the adolescents with advanced disease.

ART is required to prevent further damage to the immune system. Starting ART soon will decrease risk of disease progression, including wasting and OIs.

WHO:

- Initiation may be performed by a trained health care worker

WHAT:

- An assessment of both clinical and psychosocial readiness must be carried out before ART initiation
- Assessment for cryptococcal disease if CD4 < 100 cell/mm^3)
- Counselling should include basic HIV and ART education and assessment of readiness to start ART

Refer to national guidelines for management of HIV and AIDS (2017) for detailed information on differentiated ART delivery for clients with early disease.

6.2.2 Differentiated ART delivery for stable and unstable adolescents on ART

6.2.2.1 Differentiated ART Delivery for stable clients

WHEN:

- Clients should have a clinical review twice a year
- ART refills for stable clients should be provided for two months depending on supply
- Clients should choose a 'blocked appointment time (a.m./p.m.)' as well as an appointment date
- Clinics should provide extended opening hours for specific subpopulations (e.g., adolescents and youth)
- Frequency of extended hours should be determined based on local demand

WHERE:

- ART refill should be provided to all existing facilities
- Clients should receive ART at the health facility of their choice
- In hard to reach areas, ART refills should happen through a mobile outreach strategy by health care workers

WHO:

- Follow-up on ART may be performed by a trained health care worker (clinicians and nurses)

WHAT:

- Full clinical review should be done during clinical consultations
- ART refills should be provided to clients according to service delivery model in use

Refer to national guidelines for management of HIV and AIDS (2017) for detailed information on differentiated ART delivery for clients with early disease.

6.2.2.1.1 Differentiated ART delivery for stable clients: special considerations for adolescents

Special considerations to observe when offering differentiated ART delivery for stable adolescents include:

- Adolescents should receive two month refills
- All sites providing ART services must have health workers trained in adolescent HIV care services
- ART delivery should be provided outside school hours, during weekends or holidays
- Adolescents and their guardians should be offered a group refill approach and be booked on the same day
- Group activities in adolescent clubs should be coordinated by the health care workers to facilitate disclosure, peer support and adherence
- Adolescents should be offered a group refill approach and peer support. They should be grouped according to age and consideration of disclosure status
- Adolescents attending boarding schools should be offered additional support while at school and follow-up appointments during their school holidays

6.2.2.1.2 Possible additional support for adolescents at boarding schools and follow-ups

- Encourage adolescents and caretakers to disclose the adolescent's HIV status to teachers, matron patron, etc.
- Health workers, in collaboration with DACCs, CHACCs , school health coordinators should provide education on how to care and support for ALHIV
- Stable ALHIV should be offered two months ARV refill
- Treatment supporters should be encouraged to collect refills for stable ALHIV and encourage them to attend nearby clinics in case of any problem and return to host CTC during holidays
- Some ALHIV should be given referrals to attend nearby CTC

6.2.2.2 Differentiated ART delivery for unstable clients

WHEN:

- Every month
- Additional visits as required to address any medical or psychosocial concerns
- The decision to switch to second-line should preferably take no longer than two weeks from the receipt of the second high VL >1000 copies/ml

WHERE:

- At all health facility levels
- Management of client is done at any ART service delivery point
- Second-line initiation should be decentralized to all sites that have a qualified health care worker

WHO:

- All levels of health care workers who have received training should be able to prepare a VL sample
- All health-care workers who have been trained and assessed as competent to assess clients with treatment failure should be able to switch adolescents to second-line

WHAT:

Case management to address reason/s for not meeting stable eligibility criteria include:

- Enhanced adherence counselling, should be available both at facility and community level
- VL monitoring according to the national algorithm
- Appropriate switch to second line ART

Unstable clients/adolescents on ART include:

- Current ART for less than six months
- Presence of an active OIs (including TB) in the past six months
- Poor or questionable adherence to scheduled clinic visits in the past 6 months
- Recent detectable VL above 50 copies/ml
- In absence of VL monitoring, decreasing CD4 cell count or CD4 ≤ 200 cell/mm^3
- Adolescents who inject drugs (AWID)
- Pregnant adolescent girls
- Adolescents on second-line regimen

Refer to a higher-level facility when feasible or if consultation is not adequate to stabilize an unstable adolescent on ART.

See National guidelines for management of HIV and AIDS (2017) for detailed information on differentiated ART delivery for clients with early disease.

6.2.3 Key points

- SDMs for differentiated care for adolescents is an adolescent-centred approach that simplifies and adapts HIV services across the treatment cascade.
- Delivery models are designed using the building blocks approach with four delivery components: WHO, WHERE, WHEN and WHAT.
- Four groups of clients with different specific needs can be categorized through the differentiated SDMs as follows: clients with early disease; clients with advanced disease; stable clients on ART; and unstable clients on ART.

Session 6.3

Total time taken: 2 hours

Comprehensive care for ALHIV

Learning objectives

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

- Define comprehensive care for ALHIV
- Describe the goal of comprehensive care for ALHIV
- Describe the components of comprehensive care for ALHIV

6.3.1 Definition and goal of comprehensive care for ALHIV (SDMs)

6.3.1.1 Comprehensive care for ALHIV

The goal of comprehensive care for ALHIV is to provide adolescents with detailed care and treatment for HIV and AIDS. Comprehensive care for ALHIV refers to all approaches that hold the potential to enhance the health and well-being of adolescents with or affected by HIV and AIDS.

Comprehensive HIV care aims to:

- Prevent further spread of HIV
- Improve the lives of families and communities affected by HIV
- Reduce HIV-related illnesses and deaths
- Improve quality of life

ALHIV services should:

- Be integrated
- Be age and developmentally appropriate
- Be responsive to the needs of perinatally and behaviourally infected adolescents
- Be empowering by encouraging adolescents to take responsibility for their own health
- Emphasize care, treatment, adherence and retention into care

6.3.2 Components of comprehensive care for ALHIV

6.3.2.1 Components of care

- Enrolment visit
- Follow-up visits
- Laboratory monitoring
- ART initiation
- Prophylaxis (Cotrimoxazole, IPT and Fluconazole)
- Treatment failure and second-, third-line ART initiation

6.3.2.1.1 Enrolment visits

There are different steps to follow during enrollment visits for adolescent care, including the There are different steps to follow during enrolment visits for adolescent care, including the national guidelines for management of HIV and AIDS. You should follow steps to be conducted at the initial or enrolment visit (for entry into the adolescent care).

Adolescents with perinatally acquired HIV have been in care for years and will have undergone an enrolment assessment as infants or children. It may take several visits to complete all of the steps.

Table 6.2: Key steps – enrolment visit

✓	Steps
	1. Take history
	■ Take a complete medical and social history, including prenatal, birth and family history
	■ Confirm HIV infection status
	■ Identify concomitant medical conditions (e.g., TB disease, hepatitis B or C infection, other co-infections or OIs, pregnancy in adolescent girls)
	■ Enquire about disclosure to the adolescent (if perinatally infected, take time alone with caregiver to discuss) or disclosure to others
	■ Enquire about HIV and treatment status of family and household members
	■ Enquire about concomitant medication (e.g., CTX, oral contraceptives, traditional therapies)
	■ Review immunization status
	■ If clinically indicated, undertake a nutritional status assessment
	■ Ask about sexual activity, condom and other contraceptive use (alone with adolescent)
	■ Conduct psychosocial assessment and provide counselling, referrals and support (see Module 5 and *Appendix 5B: HE ADSS Interview Questions*)
	■ Assess any other practical needs, such as legal support, housing, school/career and finance
	2. Conduct physical exam
	■ Assess growth and nutrition (weight, height and body mass index or BMI), as appropriate for age

	■ Assess development and neurodevelopment, as appropriate for age
	■ Conduct physical examination, including tanner staging
	■ Conduct skin exam (tattoos, bruises, acne) and scoliosis evaluation
	■ Screen for STIs in adolescents who are sexually active
	■ Screen for pregnancy in sexually active adolescent women
	■ Screen for TB; screen for OIs and other concomitant conditions, diarrhoea, malaria
	■ Discuss findings from physical examination with ALHIV and his or her caregivers
	3. Make laboratory assessment plan
	■ Conduct baseline tests according to local resources and guidelines: ■ CD4: recommended; HBsAg: desirable; other tests, if clinically indicated
	4. Make assessments
	■ Review findings from history, physical assessment and laboratory work and make diagnosis
	■ Assess WHO clinical stage. If on ART, determine if there are any new stage 3 or 4 events
	■ If not on ART, determine if ALHIV meets the criteria for ART initiation
	■ Decide if CTX or isoniazid preventive therapy (IPT) is indicated
	5. Make decisions
	■ Discuss prevention of illnesses (OIs, including TB, STIs, diarrhoea, malaria, and other illnesses) and initiation or continuation of CTX, IPT and any other medications
	■ If applicable, discuss prevention of STIs, positive prevention and prevention of unintended pregnancy, provide condoms and contraceptive counselling methods
	■ For those eligible for ART, initiate adherence preparation
	■ Discuss treatment of current illnesses identified in physical examination
	■ If eligible, initiate CTX or IPT; discuss adherence and side effects
	■ If applicable, provide nutrition counselling and support
	■ Provide counselling, support and referrals based on psychosocial assessment and needs
	6. Agree on an action plan
	■ Agree on key action steps from history and physical examination
	■ Discuss when to seek medical care; for example, with unexpected illness or side effects
	■ Reiterate agreed upon plan to support adherence to medications
	■ Discuss steps to live positively and prevent further HIV infections
	■ Agree on key action steps based on psychosocial assessment (e.g., reduce alcohol intake, discuss HIV status with friend, join support group)
	■ Provide referrals, including name of person/agency, address and contact information of referral point. If possible, contact referral and make appointment on behalf of ALHIV
	■ Schedule next visit as per national guidelines.

Key differences between enrolment and follow-up visits are:

- During follow-up visits, we focus on interim history (therefore, it is quicker)
- During follow-up visits, we have access to history and laboratory tests, so there is more information for assessment and decision-making
- Focus is on adherence assessment, counselling, support and retention

Review these steps for follow-up visits in *Table 6.3: Key steps – follow-up visit, clients on ART.*

Table 6.3: Key steps – follow-up visit, clients on ART

✓	Steps
	1. Take history
	■ Review interim medical history
	■ Review concomitant medication (e.g., CTX, oral contraceptives, traditional therapies)
	■ Conduct psychosocial assessment and provide counselling, referrals and support
	■ Re-assess other practical needs, such as legal support, housing, school/career and finance
	2. Conduct physical exam
	■ Assess growth and nutrition (weight, height and BMI), as appropriate for age
	■ Assess development and neurodevelopment, as appropriate for age
	■ Conduct physical examination, including tanner staging
	■ Conduct skin exam (tattoos, bruises, acne) and scoliosis evaluation
	■ Screen for STIs in adolescents who are sexually active
	■ Screen for pregnancy in sexually active adolescent females
	■ Screen for TB; screen for other OIs and other concomitant conditions, diarrhoea, malaria
	■ Discuss findings from physical examination with ALHIV and his or her caregivers
	3. Make laboratory assessment plan
	■ Conduct laboratory tests according to local resources and guidelines
	4. Make assessments
	■ Review clinical findings at this visit and laboratory findings (including CD4 cell count) from recent visits
	■ Assess WHO clinical stage; determine if there are any new stage three or four events; assess CD4 cell count to check response to treatment; determine if treatment failure has occurred
	■ Provide ART refills; monitor and discuss adherence and side effects
	■ If on CTX, provide refill; monitor and discuss adherence. Consider discontinuation
	■ If on IPT, provide refill; monitor and discuss adherence. If not on IPT, re-assess eligibility

	5. Make decisions
	■ If applicable, discuss prevention of STIs, positive prevention and prevention of unintended pregnancy; provide condoms and contraceptive counselling methods
	■ Discuss treatment of current illnesses identified in physical examination
	■ If applicable, provide nutrition counselling and support
	■ Discuss disclosure to the adolescent (if perinatally infected) or disclosure to others
	■ Discuss positive living and positive prevention
	■ Provide counselling, support and referrals based on psychosocial assessment and needs
	■ Provide education, care and support for family members and/or partner
	■ Provide support for clients who are switching providers or transitioning into adult care
	6. Agree on an action plan
	■ Agree on key action steps from history and physical examination
	■ Discuss when to seek medical care, for example, with unexpected illness or side effects
	■ Reiterate agreed upon plan to support adherence to medications
	■ Agree on key action steps based on psychosocial assessment
	■ Provide referrals and, if possible, contact referral to make appointment on client's behalf
	■ Schedule next visit as per national guidelines

6.3.2.1.3 Laboratory monitoring

Laboratory results can support findings from history and examination. Conduct laboratory tests at enrolment, before, during and after initiating ART.

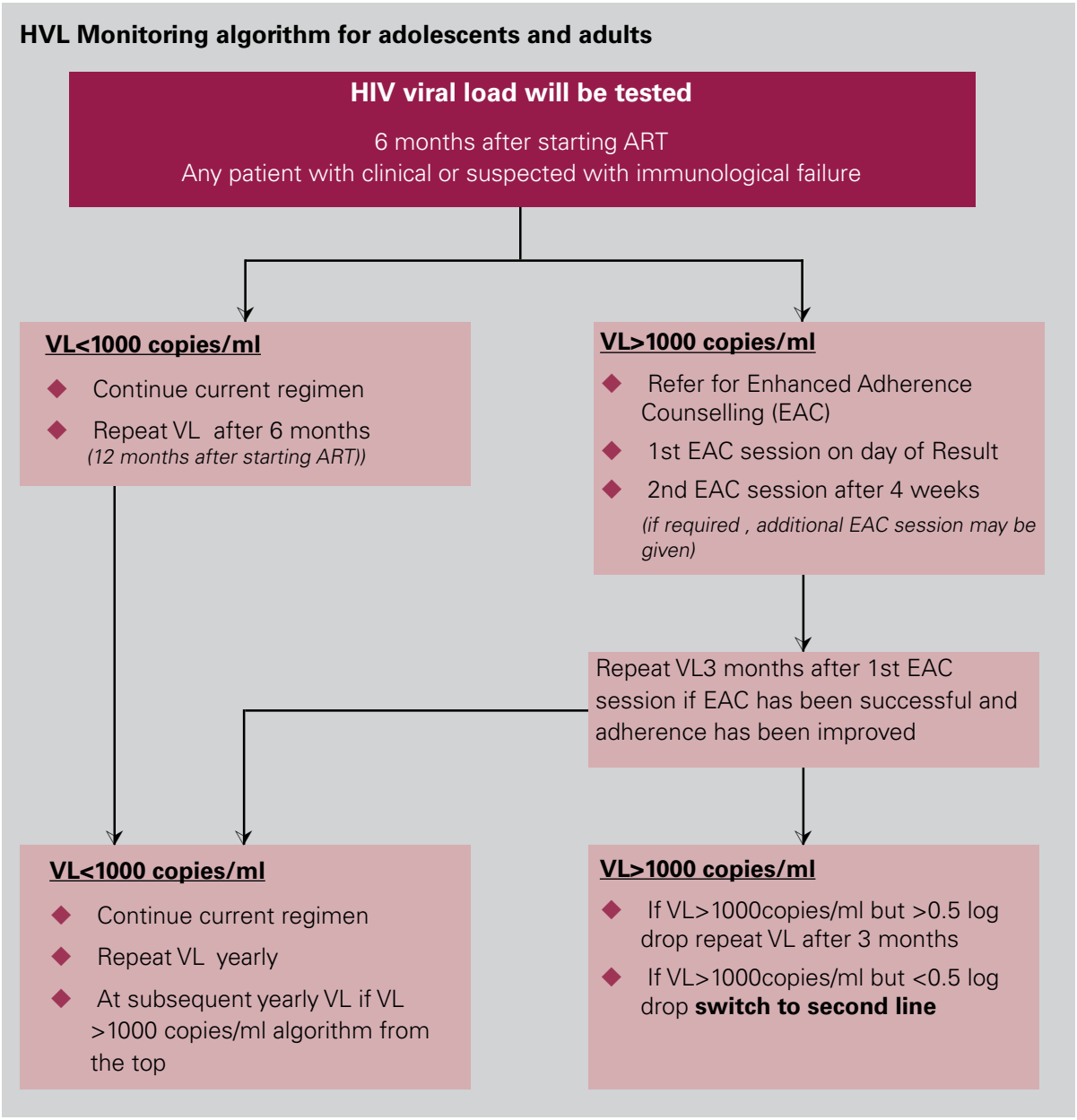
Guiding principles

1. Laboratory monitoring should be done, but it is not a prerequisite for ART initiation
2. Although CD4 is not required for initiating ART, is recommended for monitoring
3. Haemoglobin desirable test at initiation of ART if AZT-containing regimen will be used
   - VL testing can be used to monitor ART and to diagnose treatment failure
   - Measure every 6 months with the objective of detecting failure earlier
   - If resources are not available, use immunological and/or clinical criteria alone to define failure or prioritize the use of VL testing to confirm suspected treatment failure
4. Symptom-directed laboratory monitoring for safety and toxicity is recommended for those on ART

CD4 should be measured at the time of diagnosis.

- For adolescents on ART, measure CD4 as baseline investigation
- Measure CD4 if a new clinical staging event develops, including growth faltering and neuro-developmental delays

Figure 6.1 HIV viral load testing regimen



The first HVL test should be performed at six months after initiation of ART. Repeat HVL test six months later if the initial HVL test result was less than 1000 copies/ml. Then, HVL test will be performed annually if two preceding HVL test results were less than 1000 copies/ml.

If the preceding HVL test result was more than 1000 copies/ml, perform HVL test after three months of enhanced adherence counselling.

For clients who have been on ART and immunological monitoring for more than six months without being tested, HVL test to be performed at any time at any first encounter.

During subsequent HVL tests, if the results are more than 1000 copies/ml, the client should be subjected to enhanced adherence counselling (EAC) and repeat the HVL test after three months. Where HVL monitoring is unavailable, CD4 cell count and clinical monitoring are recommended.

6.3.2.1.3 Cotrimoxazole (CTX) Prophylaxis in adolescents

Criteria for initiating, discontinuation and contraindication of CTX prophylaxis is not different from adult clients.

WHO criteria for initiating CTX

- **Clinical criteria** Start CTX when adolescent is symptomatic (WHO clinical stage 2, 3 or 4)
- **Immunologic criteria** When CD4 testing is available, start CTX when CD4 count is <350, regardless of clinical stage

Discontinuing CTX

- CTX can be discontinued if there is evidence of sustained immune recovery of CD4 >350 after at least 6 months of treatment
- If there is no CD4 machine, CTX can be discontinued if there is evidence of good clinical response to ART (absence of clinical symptoms after at least a year of therapy), good adherence and access to ART

Note: *Restart if CD4 falls below 350 or if there is a new or recurrent WHO clinical stage 2, 3 or 4 condition.*

Contraindications to CTX

For adolescents with a history of severe and life-threatening adverse reactions – grade 3 and 4 to CTX or other sulfa drugs, give Dapsone 100 mg/day instead, for severe liver insufficiency and severe renal insufficiency.

6.3.2.1.4 Key points

You should help ALHIV, caregivers and families:

- To understand that they are starting lifelong therapy
- To be prepared to adhere to their HIV care plan and ART regimen
- To ensure adequate ART literacy on the importance of optimal adherence, consequences of non-adherence, self-assessment of clinical red flags for seeking unscheduled clinic visits
- To be linked to a peer support group according to age and disclosure status
- To receive adolescent-friendly services

Be reminded that before the adolescent is initiated on ART, the following psychosocial conditions should preferably be met:

- The adolescent has to disclose his/her HIV status to a treatment supporter or to a self-chosen family member
- The adolescent is willing and ready to adhere to lifelong ART
- The adolescent commits himself/herself to attend clinics as per schedule
- The adolescent does not abuse alcohol and if he/she does, is willing to stop it
- HIV-infected PWID adolescent should be willing to attend medically assisted therapy e.g., methadone replacement therapy

When to start ART in ALHIV

All HIV-infected individuals regardless of age, WHO clinical stage, CD4 count HIV risk group, pregnancy status, associated comorbidities and degree of immunosuppression are eligible for ART.

The importance of early-initiation of ART is as follows:

- Helps preserve and enhance the immune systems of ALHIV
- Reduces the risk of OIs
- Restores growth
- Improves mental functioning and overall quality of life

Table 6.4: First line ARV regimen for adolescents under 15 years

Patient Group	Preferred 1 L Regimen	Alternatives
Children 3 to 15 years	ABC+3TC+LPV/r	AZT+3TC+EFV ABC+3TC+EFV TDF+3TC+EFV AZT+3TC+LPV/r AZT+3TC+NVP
For TB co-infected children aged 3–15 years already on LPV/r based regimen	ABC+3TC+LPV/r	
For newly initiated TB co-infected children aged 3–15 years	ABC+3TC+EFV	ABC+3TC+LPV/r but the dose of LPV/r should be doubled due to the interaction between ritonavir and rifampicin

TDF may only be given to children > 12 years and above 35 kg in weight. ATV/r can be used as an alternative to LPV/r in children older than 6 years if paediatric formulation is available but adolescents >40 kg can take adult formulation.

Recommended first line ARV regimens for adolescents above 15 years

Patient group	Preferred (Default) Regimen	Alternatives
Adults and adolescents over15 years, pregnant/lactating mothers	TDF/3TC/EFV600mg	TDF/FTC/EFV 600mg TDF/ (3TC or FTC) +DTG ABC/3TC+EFV 600 or DTG AZT/3TC+EFV 600 or DTG AZT/3TC/NVP
TB co-infections	TDF/ (3TC or FTC) / EFV600mg	TDF/FTC/EFV 600mg TDF/ (3TC or FTC) +DTG AZT/3TC+EFV 600 or DTG ABC/3TC+EFV 600 or DTG
People Who Inject Drugs (PWID)	TDF/(FTC or 3TC) +DTG	TDF/ (FTC or 3TC) +ATV/r

Table 6.5: Recommended second line ARV regimens for adults and adolescents

Patient group	Preferred (default) regimen	Alternatives
Adults, adolescents over15 years and pregnant women/ lactating mothers	AZT/3TC+ATV/r: if TDF was used in first line TDF/FTC+ATV/r: if AZT was used in first line	AZT/3TC+LPV/r in Case of TB ABC/3TC+ATV/r ABC/3TC+LPV/r TDF/FTC+LPV/r
HIV and TB co-infections	AZT/3TC+LPV/r ABC/3TC+LPV/r TDF/FTC+LPV/r	***Note**: double dosage of LPV/r to 800/200mg for Rifampicin-based TB treatment*
People Who Inject Drugs (PWID)	ABC/3TC + ATV/r	DTG+(ABC/3TC)+ATV/r

Table 6.6: Recommended third-line regimens for adults and adolescents

Patient group	Preferred (default) regimen	Alternatives
Adults, adolescents over 15 years	DTG+DRV/r+ ETV	DTG+ATV/r+ ETV
Pregnant women/lactating mothers	(DTG or RAL)+DRV/r+ ETV	DTG+ATV/r+ ETV
HIV and TB co-infections	DTG+ ETV+ (3TC or FTC)	
People Who Inject Drugs (PWID)	DTG+DRV/r+ ETV	DTG+ATV/r+ ETV

***Note:** For second and third line regimens which are non TDF-based, in case of new Hepatitis B co-infection TDF with FTC should be added to the new regimen as treatment of Hepatitis B.*

Key signs of an adolescent responding to ART include:

- Improvement in growth or weight gain in adolescents who have been failing to grow
- Decreased frequency of infections (bacterial infections, oral thrush and/or other OIs)

The first six months on ART are critical because:

- Most adolescents respond well to ART initiation, but with increases in CD4 cell count, some fail to respond as expected
- Complications in the first few weeks following ART initiation are most common in those with severe immunodeficiency (immune reconstitution inflammatory syndrome or IRIS)
- Failure to improve does not necessarily reflect a poor response to ART as ART takes time to control viral replication; It may, however, reflect inadequate adherence

Immune reconstitution inflammatory syndrome (IRIS) often occurs in the first weeks to months after ART initiation. It is a complication caused by reactivation of the immune system. It can present as a flare-up of symptoms when the recovering immune system begins to respond to an existing infection (e.g., TB). It is not due to failure of ART, but rather its success (and the resulting immune reconstitution).

ARVs toxicities

Toxicity can be monitored clinically, based on client report and physical examination, and assessed by a limited number of laboratory tests.

There are three categories of drug toxicity. Mild toxicities do not require discontinuation of ART or drug substitution; symptomatic treatment can be given. Moderate or severe toxicities may require drug substitution, but do not require discontinuation of all ART. Severe life-threatening toxicities require discontinuation of all ARVs and initiation of supportive therapy until the patient is stabilized and the toxicity is resolved.

6.3.2.1.6 Treatment failure

Treatment failure is when ARV regimen is unable to control HIV infection. Failure can be clinical, immunologic or virological or any combination of the three.

Factors that can contribute to treatment failure include drug resistance, drug toxicity or poor treatment adherence. It needs to be confirmed in a timely manner, because:

- If diagnosed prematurely, clients are often switched to second-line or third line ART regimens unnecessarily
- If diagnosed late, the result could be disease progression or even death

You should be reminded that virological failure is the most accurate method to determine ART failure. If not available, use immunological criteria (i.e. CD4 cell count). Once treatment failure has been detected, select a new regimen using national guidelines.

Table 6.7: WHO definitions of treatment failure in chronological order of occurrence: virological, immunological and clinical failure for the decision to switch ART regimens

Failure	Definition	Comments
Virological	Plasma viral load above 1000 copies/ml based on two consecutive viral load measurements after 3 months, with adherence support	An individual must be taking ART for at least 6 months before it can be determined that a regimen has failed.
Immunological	CD4 cell count falls to the baseline (or below) or Persistent CD4 levels below 100 cells/mm^3	Without concomitant or recent infection or steroid use to cause a transient decline in the CD4 cell count, immunological and clinical characteristics of treatment failure develop much later after virological failure. Immunological and clinical criteria of treatment failure may also misclassify treatment failure and lead to unnecessary ARV switch to subsequent (line of treatment) regimen
Clinical	New or recurrent clinical event indicating severe immunodeficiency (WHO clinical stage 4 conditions) after six months of effective treatment.	The condition must be differentiated from IRIS

Confirmation of treatment failure

Things that should be reviewed to confirm treatment failure include:

- The adolescent should have been on ART for at least 24 weeks (six months).
- The adolescent should have been adherent. If not, keep ALHIV on same regimen and provide EAC and support.
- Any inter-current infection or major clinical event should have been treated and resolved.
- IRIS should have been excluded.
- The adolescent should have received adequate nutrition (if not, consider a change in treatment because of growth failure).

Switching to a new regimen

Whenever an adolescent client is switched to a new regimen:

- Counsel him or her on reasons for the change in regimen, differences in drug types, dosages and timing of administration
- Review possible side effects of the new regimen
- Re-assess for social issues that could negatively influence adherence and review the importance of adherence
- Provide ongoing adherence counselling and support

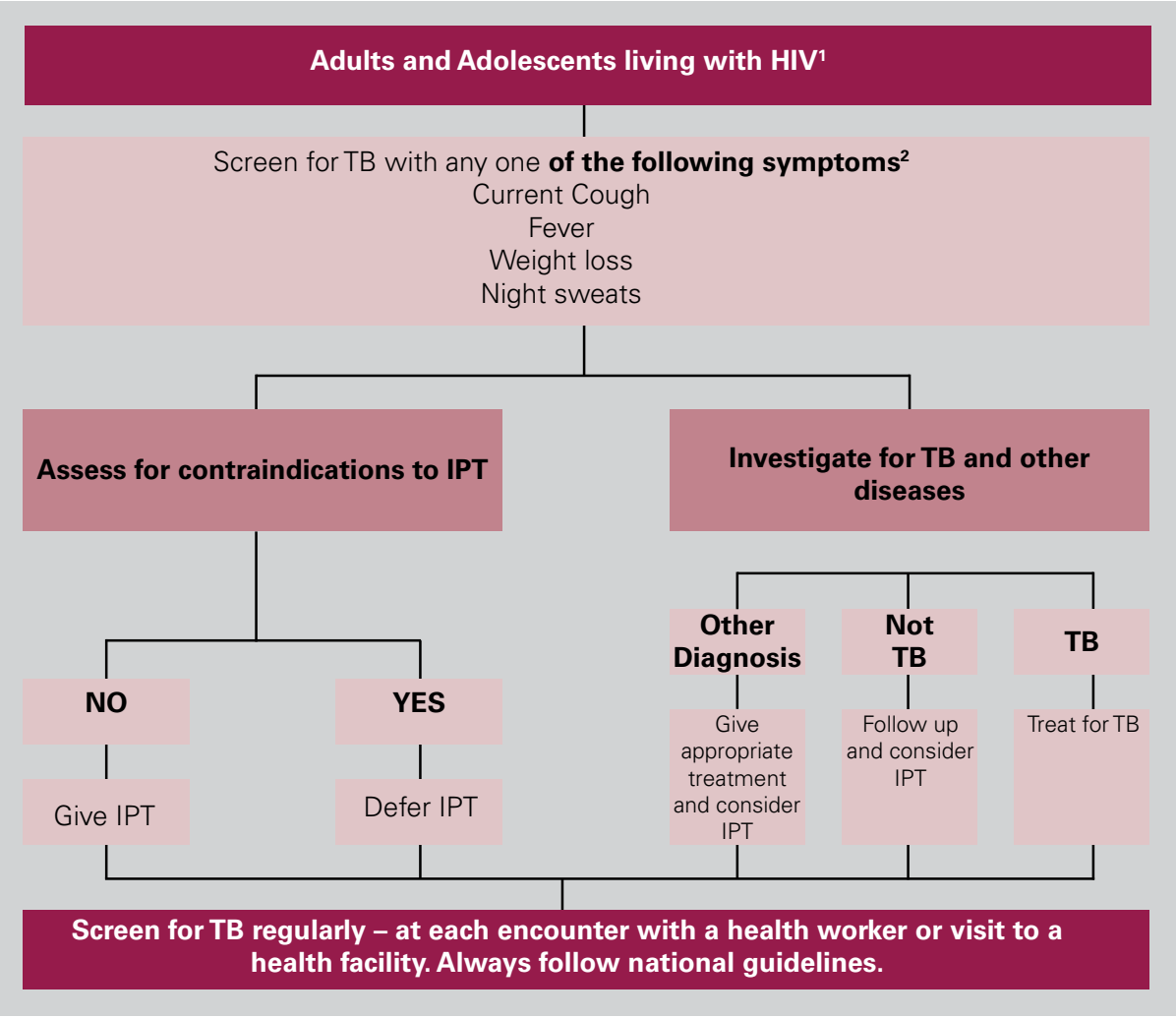
Note: *Switch client to a new regimen within a month of confirming treatment failure.*

Tuberculosis in ALHIV

All ALHIV should be screened for active TB at each visit:

- If found to be co-infected, they should be started on anti-TB medicines immediately
- All ALHIV who do not have signs of active TB should be offered IPT for at least six months
- ALHIV who have had a significant TB contact should be screened for TB. If there is no active TB, give IPT for six months
- ALHIV who have been treated for TB can benefit from IPT and should be offered secondary pro

Figure 6.2 Algorithms for tuberculosis screening



Prevention of tuberculosis with IPT

The three Is strategy of the WHO to improve TB case-finding and prevent TB includes IPT. The three Is stand for intensified case-finding for active TB, IPT and infection control.

The following should receive IPT:

- All ALHIV with no evidence of active TB disease and no contraindications to IPT
- ALHIV who do not have any TB symptoms (should be offered IPT for at least six months)
- ALHIV who have been successfully treated for TB disease (should be offered IPT for six months, unless MDR or XDR TB)
- ALHIV who have had contact with a TB case and do not have active TB disease (should be offered IPT for six months)

IPT dosage

- The recommended dose of isoniazid (INH) for preventive therapy in ALHIV is one adult tablet (300 mg) or three (100 mg) tablets daily (if pill size or formulation is limited)
- It is also necessary to give 25 mg daily of vitamin B6

Table 6.8: Simplified dosing schedule for INH

Weight range (kg)	Number of 100 mg tablets of INH to be administered per dose (total dose 10 mg/kg/day)	Dose given (mg)
10–13.9	1 ½ 100mg tablets	150
14–19.9	2 100mg tablets	200
20–24.9	2 ½ 100mg tablets	250
> 25 (most adolescents)	3 100mg tablets or 1 adult 300mg tablet	300
Give vitamin B6 with INH at a dose of 25 mg daily.		

Source: *WHO, Department of HIV/AIDS and Stop TB Department (2011). Guidelines for intensified tuberculosis case-finding and IPT for people living with HIV in resource-constrained settings.*

Treatment considerations in adolescents with TB and HIV co-infection

ALHIV with active TB disease should begin TB treatment immediately and should start ART as soon as possible – within two to eight weeks. Co-management of TB and HIV is complicated by drug interactions, particularly between rifampicin and the PI classes of ARVs such as EFV, which is the preferred NNRTI in patients starting ART while on TB treatment.

Remember to offer ALHIV and caregivers adherence counselling and monitoring at every clinic visit, while adherence support for IPT or anti-TB therapy can be included in the ART adherence discussion.

ART switching for ALHIV who develop TB while on first line ART

ART should continue in ALHIV already on first line regimen who are subsequently diagnosed with TB. The ART regimen should be reviewed and may need adjustment to ensure optimal treatment of both TB and HIV, and also to decrease the potential for toxicities and drug-drug interactions.

In ALHIV on a standard NNRTI-based first line regimen who develop TB, make these adjustments: for instance, if on a regimen of 2 NRTI + NVP , switch NVP with EFV. If on a PI regimen, consult an expert for guidance.

Where TB is being considered as a sign of treatment failure of the first line regimen, consider switching to second-line regimen if the adolescent has taken ART for more than 24 weeks or six months, has initially responded to it, and has not responded to anti-TB treatment.

Exercise 1: Case study 3

Todd is 17 years old and was diagnosed with HIV a year ago. Todd is quite healthy: during her last visit, her CD4 cell count was 500 and she was a clinical stage 1. The only reason she was tested the previous year was because she had heard through a friend that her old boyfriend was rumoured to have HIV. Today, however, Todd looks thin and tired, much different from the way she looked the last time you saw her just six months ago. When she comes into the exam room, you realize that she has also been coughing.

- How do you proceed with Todd?

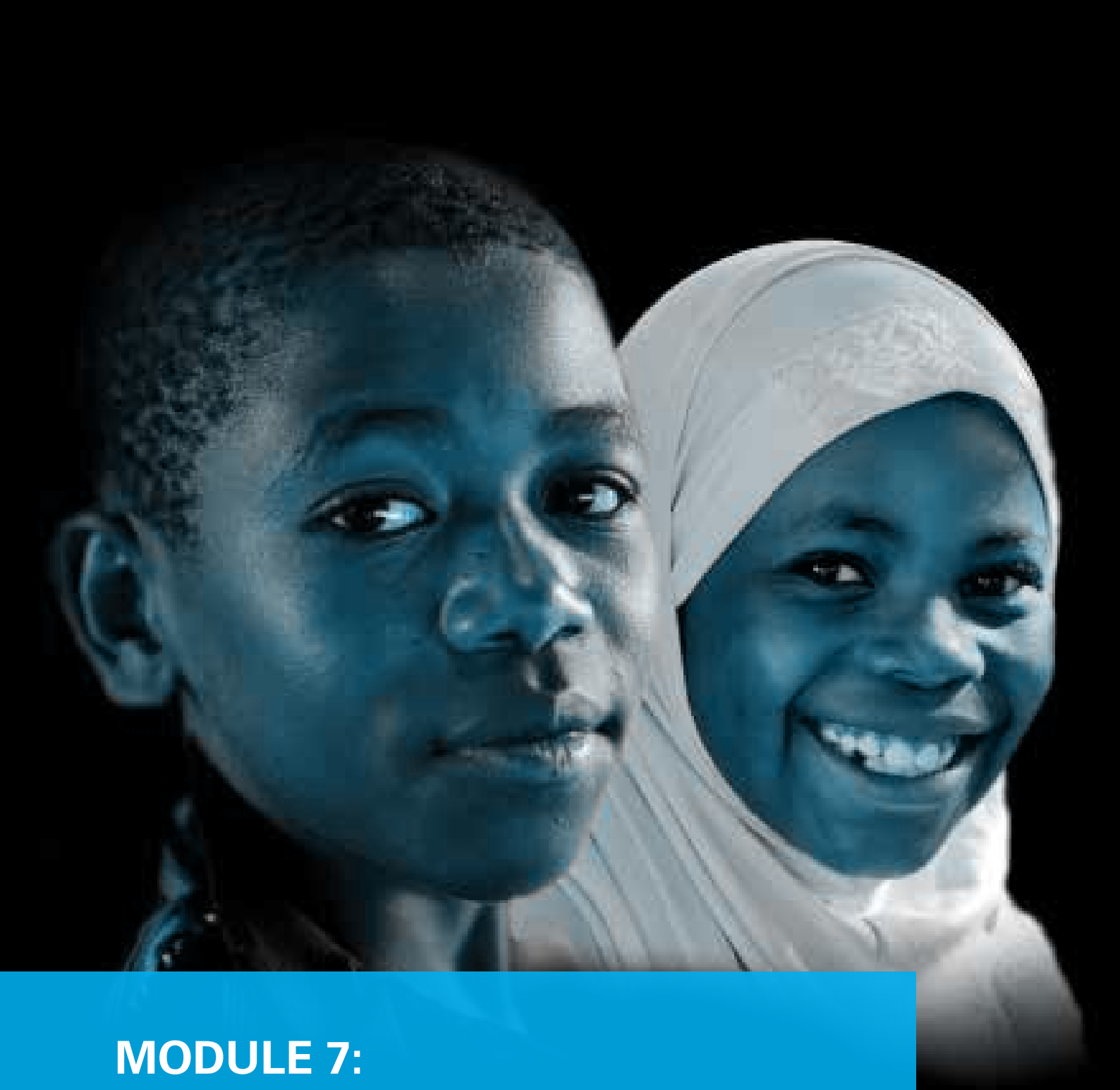
Exercise 1: Case study 4

Antonio is 13 years old and acquired HIV perinatally. He is at the clinic today for his routine appointment. Antonio has been on AZT + 3TC + EFV since he was 5 years old. He remains on this same regimen and was just discharged from the inpatient unit with bacterial pneumonia. When you examine Antonio today, you realize that he has lost 4 kg since his last visit. His CD4 cell count is currently 350, when previously it was over 500.

- How do you proceed with Antonio?

6.3.3 Key points

- Conduct thorough clinical assessment focusing on clinical, laboratory, social, developmental, growth and emotional factors each time an ALHIV visits the clinic.
- HIV-related care must be family centred.
- Ensure that the care provided to a client is multidisciplinary.
- You should be aware of and look out for possible events after ART initiation. It is important to allow at least six months before judging a regimen's effectiveness.



MODULE 7:

PSYCHOSOCIAL SUPPORT SERVICES FOR ADOLESCENTS

Total module time: 3 hours

Module 7: Objectives

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

- Explain common psychosocial needs of adolescents and ALHIV
- Describe psychosocial support services for adolescents and caregivers
- Explain the importance of peer support groups for ALHIV

Session 7.1

Total time taken:
1 hour 15 minutes

Psychosocial needs of adolescent clients

Learning objectives

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

- Explain the meaning of psychosocial wellbeing and psychosocial support
- List common psychosocial needs of both adolescents in general and ALHIV
- Explain strategies to support adolescent clients and caregivers in dealing with stigma and discrimination
- Describe psychosocial challenges among most-at-risk ALHIV and provide support and referrals

7.1.1 Definitions

7.1.1.1 Definition of psychosocial

'Psycho' refers to the mind and soul of a person (unique feelings, emotions, thoughts, understanding, attitudes and beliefs that an individual has.)

Psycho – what an adolescent feels and thinks about himself or herself and about life.

'Social' refers to interpersonal relationships and what goes on in the surrounding environment, and the connections between the adolescent, family community and society.

7.1.1.2 Psychosocial well-being

Psychosocial well-being is the state where a person's internal and external needs are being met and he or she is physically, mentally and socially healthy. The psychological aspect includes emotional, cognitive, mental health and spiritual issues, while the social aspect refers to relationships with others, the environment and society.

These aspects of well-being also influence physical health, and how a patient engages in his/her own treatment, adherence and disclosure.

7.1.1.3 Psychosocial support services (PSS)

These services address the ongoing concerns of ALHIV to meet their age-appropriate emotional, spiritual, cognitive, social and physical needs through interacting with their surroundings and the people who care for them. Psychosocial support helps build resiliency. It is an ongoing process within the family circle and the community. It is about day-to-day consistent care and support through family and community interaction.

7.1.2 Psychosocial support needs of ALHIV

7.1.2.1 Psychosocial support needs

An adolescent's psychosocial needs change over time and should be discussed and given consideration at every clinic visit. Key areas of consideration include:

- Understanding and coming to terms with own and family members' HIV status
- Grieving the illness or loss of family members and coping with added responsibilities
- Coping with cycles of wellness and poor health
- Long-term adherence
- Disclosure
- SRH
- Anxiety over physical appearance and body image
- Developing self-esteem, confidence and a sense of belonging
- Dealing with stigma, discrimination and social isolation
- Accessing education, training and work opportunities
- Managing mental health issues

Figure 6.3 The support needs of ALHIV

Data have shown that unsupervised adolescents are more likely to engage in risky behaviour such as drug abuse, unsafe sex and poor adherence. Adolescents should be protected against violence, ab use, exploitation and neglect. Adolescent HIV services should be linked with economic support services to improve adolescents' overall well-being.

7.1.3 Psychosocial support needed by ALHIV

7.1.3.1 Coping strategies

Coping strategies that you could suggest to your clients include:

- Talking about problems with someone trustworthy
- Seeking help from clinic staff, especially if sad, depressed or anxious
- Joining a support group
- Creating an 'escape' by taking a walk or listening to music
- Seeking spiritual support
- Participating in recreational activities or cultural events
- Returning to a daily routine
- Doing something to feel useful

7.1.3.2 Ways to strength relationship between caregiver and adolescent

You can suggest different ways to caregivers to strengthen their relationship with adolescents, some of which include:

- Spending time with and listening to adolescent
- Letting them know their feelings are normal
- Communicating unconditional love
- Helping the adolescent plan activities
- Involving them in family activities
- Helping them get enough rest and eat well
- Getting them help from a counsellor or social worker
- Being aware of changes in their behaviour or mood
- Talking to someone if they need help
- Getting help from a community-based support organization
- Continuing their regular religious or spiritual practices

7.1.3.3 Challenges/barriers in providing psychosocial support to ALHIV

In providing psychosocial support to ALHIV, health-care systems face challenges such as:

- Inadequate skilled human resource to meet the high demand

- Low comprehensive knowledge of psychosocial support among health providers
- Limited infrastructure including counselling rooms at facility level
- Low community participation and involvement
- Stigma and discrimination

7.1.4 Strategies to support adolescent clients and caregivers in dealing with stigma and discrimination

7.1.4.1 Definitions

Stigma Having a negative attitude towards people we think are not 'normal' or 'right'. For example, stigma can mean not valuing PLHIV or people associated with PLHIV.

To stigmatize someone Seeing a person as inferior (less than or below others) because of something about him or her.

Discrimination Treating someone unfairly or worse than others because he or she is different (for example, because a person has HIV). Discrimination is an action that is typically fuelled by stigma.

Stigma and discrimination hinder access to HIV prevention, care and treatment services for adolescents.

7.1.4.2 Different types of stigma and discrimination

Stigma

- **Stigma towards others** Having a negative attitude about others because they are different or assumed to be different.
- **Self-stigma** Taking on or feeling affected by the cruel and hurtful views of others, which can lead to isolating oneself from family and community.

Secondary stigma: When people are stigmatized because of their association with PLHIV.

Discrimination

- Facing violence at home or in the community
- Not being able to attend school
- Being expelled from school
- Not being able to get a job
- Being isolated from or ignored by the family or community
- Not having access to quality health or other services
- Being rejected from church, mosque or temple
- Police harassment
- Verbal discrimination gossiping, taunting or scolding
- Physical discrimination insisting a person use separate eating utensils or stay in a separate living space

Stigma and discrimination have short- and long-term effects on clients' and caregivers' psychosocial well-being. They deter access to HIV prevention, care and treatment services for many people and can prevent ALHIV and their families from living healthy and productive lives.

7.1.4.3 Effects of stigma and discrimination on ALHIV

Stigma and discrimination affect ALHIV by:

- Hindering them from accessing health care services
- Causing anxiety, stress and/or depression
- Making them feel isolated and as if they do not fit in
- Making it difficult to succeed in school
- Resulting in poor adherence to medications
- Making disclosure difficult
- Making it difficult to willingly discuss safer sex with partners
- Discouraging pregnant women from accessing PMTCT services
- Preventing people from caring for PLHIV
- Impacting some ALHIV more than others

Stigma and discrimination increase adolescents' resistance to receiving help and contribute to their discomfort and fear around accessing health services. Health workers should discuss with ALHIV the various strategies they can employ in dealing with stigma.

7.1.4.4 Strategies for dealing with stigma

There are various individual and health facility strategies that can be used in dealing with stigma.

7.1.4.4.1 Individual strategies

- Stand up for yourself
- Educate others
- Be strong and prove yourself
- Talk to people you feel comfortable with
- Join a support group
- Try to explain the facts surrounding HIV
- Ignore people who stigmatize you
- Avoid people who you know will stigmatize you
- Take ART openly

7.1.4.4.2 Strategies for health care settings

We, as health workers too are responsible for challenging stigma and discrimination and should play a role in educating others as well as in advocating for new attitudes and practices. Various strategies for dealing with stigma within health facility settings include:

- Making sure PLHIV and ALHIV are part of the care team
- Making sure adolescents are given opportunities to evaluate clinical services and that feedback is formally reviewed

- Supporting linkages to community-based groups for ALHIV
- Encouraging discussions on feelings, fear and behaviours (to avoid burnout)
- Taking appropriate measures/initiatives for any discrimination in the health care setting
- Listening to clients' concerns about stigma and discrimination
- Working with the entire multidisciplinary team to identify and reduce stigma and discrimination in the clinic

7.1.5 Defining and conducting psychosocial assessment for ALHIV

7.1.5.1 Definition of psychosocial assessment

Psychosocial assessment is an in-depth evaluation of the psychosocial dynamics (mental status, social status and functional status) that affect clients and their environment.

It takes account of the client's perception of self and his/her ability to function in the community. It is helpful to use a standardized tool/questionnaire to carry out psychosocial assessment.

7.1.5.2 Psychosocial assessment tool

Psychosocial assessment tool can help to determine what services and referrals are needed for psychosocial assessment. Regular psychosocial 'check-ins' should be done for adolescents using various tools like the 5 A's (see Module 3) and be stored in the client's file.

Psychosocial assessment should be conducted at enrolment, annually and whenever needed. Following findings of psychosocial assessment, you should help the ALHIV with developing coping strategies. Health workers play a critical role in assessing and meeting a client's psychosocial needs.

7.1.5.3 Conducting a psychosocial assessment

- Pair work – practise how to conduct psychosocial assessment
- What do you think of this psychosocial assessment tool?
- How did you feel using the tool? What was challenging?
- How could you use this tool with adolescents in your clinical setting?

During emergencies, instead of working through the 5 A's, you should focus on the client's immediate safety. You may need to break confidentiality and take actions to ensure the client's immediate safety.

In absence of emergency issues threatening the client's immediate safety and well-being, you can suggest coping strategies to the client and his or her caregivers to help them reduce stress, deal more effectively with challenges and promote their psychosocial well-being.

Table 7.1: Using the 5 A's during clinical visits with adolescents, including psychosocial and counselling sessions (the 5 A's were also covered in Module 3)

The 5 As	More information	What the health worker might say
ASSESS	■ Assess the client's goals for the visit ■ Assess the client's clinical status, classify/identify relevant treatments, and/or advise and counsel ■ Assess risk factors ■ Assess the client/caregiver's knowledge, beliefs, concerns and behaviours ■ Assess the client's understanding of the care and treatment plan ■ Assess adherence to care and treatment (see module 8) ■ Acknowledge and praise the client's efforts	■ What would you like to address today? ■ What can you tell me about _____? ■ Tell me about a typical day and how you deal with _____? ■ Have you ever tried to _____? What was that like for you? ■ To make sure we have the same understanding, can you tell me about your care and treatment plan, in your own words? ■ Many people have challenges taking their medicines regularly. How has this been for you?
ADVISE	■ Use neutral and non-judgmental language ■ Correct any inaccurate knowledge and gaps in the client's understanding ■ Counsel on risk reduction ■ Repeat any key information that is needed ■ Reinforce what the client needs to know to manage his or her care and treatment (for example, recognizing side effects, adherence tips, problem-solving skills, when to come to the clinic, how to monitor one's own care, where to get support in the community, etc.)	■ I have some information about ____ that I'd like to share with you. ■ Let's talk about your risk related to ____. What do you think about reducing this risk by _____. ■ What can I explain better? ■ What questions do you have about _____?
AGREE	■ Negotiate WITH the client about the care and treatment plan, including any changes ■ Plan when the client will return	■ We have talked about a lot today, but I think we've agreed that _____. Is this correct? ■ Let's talk about when you will return to the clinic for ____.

The 5 As	More information	What the health worker might say
ASSIST	■ Provide take-away information on the plan, including any changes ■ Provide psychosocial support as needed ■ Provide referrals, as needed (to support groups, peer education, etc.) ■ Address obstacles ■ Help the client come up with solutions and strategies that work for him or her	■ Can you tell me more about any obstacles you've faced with _____ (for example, taking your medicines regularly, seeking support, practicing safer sex)? ■ How do you think you can overcome this obstacle? ■ What questions can I answer about _____? ■ I want to make sure I explained things well – can you tell me in your own words about _____?
ARRANGE	■ Arrange a follow-up appointment ■ Arrange for the client to participate in a support group or group education sessions, etc. ■ Record what happened during the visit	■ I would like to see you again in ____ for _____. It is important that you come for this visit or let us know if you need to reschedule. ■ What day/time would work for you?

Sources: *WHO 2004. General principles of good chronic care: IMAI. Guidelines for first-level facility health workers.*

Exercise 1: Case study 1

A 17-year-old woman named Tasha tested positive for HIV 6 months ago. She is currently caring for her 3 younger sisters with the help of her grandmother. She is so busy that she has missed a couple of appointments at the ART clinic, including refill appointments for ARVs. Her partner is the only one who knows she is HIV-positive, but he himself has not been tested.

- How do you proceed with Tasha today?

Exercise 1: Case study 2

A 12-year-old boy named Manga has come to the clinic today with his mother. He looks like he is feeling down. You sense that he wants to talk to someone, but he seems very quiet and won't make eye contact with anyone.

- How do you proceed with Manga?

Exercise 1: Case study 3

Kayel is a 17 year old young woman living with HIV. Her mother died when she was 5 years old and she doesn't know her father. For the past year, Kayel has been living with her 28-year-old boyfriend. She has come to the clinic today because she thinks she is pregnant.

- How would you proceed with Kayel?

7.1.6 Key points

- Psychosocial support addresses the ongoing emotional, social and spiritual concerns and needs of ALHIV, their partners and their family.
- Stigma and discrimination hinder access to HIV prevention, care and treatment services for adolescents.
- Health services for young people need to be adapted to identify and meet the needs of most-at-risk adolescents.
- A client's psychosocial needs change over time and should be informally assessed and considered at every visit.
- Health workers play a key role in assessing clients' and caregivers' psychosocial needs.
- The five As – assess, advise, agree, assist and arrange – can help structure assessment sessions so that none of the key steps are forgotten.

Session 7.2

Total time taken: 30 minutes

Peer support in psychosocial services for adolescents

Learning objectives

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

- Define peer support group
- Describe the importance of peer support in meeting psychosocial support needs for ALHIV

7.2.1 Definition and importance of peer support

7.2.1.1 Definition

Peers are people/persons who are equal with the ALHIV in aspects such as age, education, social class or life experience. Peer support refers to a system of giving and receiving help founded on key principles of respect, shared responsibility and mutual agreement of what is helpful. Peer support groups are groups of people who come together because they share a common situation.

Adolescents generally depend on peers for information, approval and connection. In addition to the other psychosocial support strategies described in this module, peer support can help ALHIV counter stigma and discrimination, cope with fear and hopelessness after diagnosis, improve adherence to care and treatment services and deal with issues like disclosure to partners, friends and family.

When people find affiliation with others who they feel are 'like' them, they feel a sense of connection.

7.2.1.2 Types of peer support groups

Although there are different types of support groups, their purpose is the same: to reduce isolation and provide psychosocial and emotional support to members. Types of support groups include:

- Adolescent support groups
- Playgroups for younger adolescents

- Young mothers support groups
- Couples support groups
- Post-test clubs
- Groups for other specific populations

7.2.1.3 Importance of support groups

Psychosocial support groups:

- Help members solve their own problems
- Provide emotional support
- Promote learning, sharing and skill building around disclosure, adherence and dealing with stigma and discrimination
- Maintain members' motivation and commitment to HIV care and treatment
- Effectively engage most-at-risk adolescents
- Encourages members to live positively
- Link members to community-based services
- May provide income generating or educational assistance

A support group:

- Helps members feel accepted and valuable, reducing their sense of isolation
- Is a safe place to talk about personal issues
- Helps members manage their situations better, share challenges and discuss various topics and solutions. Members support each other in implementing decisions taken to meet their psychological, social, physical and medical needs
- Health workers have a role in initiating and facilitating peer support groups and in linking ALHIV with existing support groups.

7.2.1.4 Topics that can be discussed in support groups

- Positive living
- Adherence
- Disclosure
- SRH
- Relationships and sexuality
- Positive prevention
- Preventing OIs
- Coping with school
- Life skills
- Drug and substance abuse
- Finding work (income generating activities)
- Strategies to reduce GBV

- Dealing with stigma
- Nutrition
- Getting help for mental health problems
- Dealing with dying and the death of a friend or family member
- Managing disabilities.

2.2 Key points

- Peer support is an important source of psychosocial support for ALHIV.
- Support groups help people meet others living with HIV, which can reduce isolation and provide people with encouragement to live more fully and positively.
- Adolescents benefit from support groups because they trust information that they get from peers.
- Health workers have a role in initiating and facilitating peer support groups and in linking ALHIV with existing support groups.

Session 7.3

Total time taken: 45 minutes

ALHIV and clubs

Learning objectives

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

- Define ALHIV clubs
- Explain how to formulate ALHIV clubs
- Describe how to run ALHIV clubs

7.3.1 ALHIV and clubs

Adolescent clubs are facility-based clubs for adolescents who understand their HIV status and are enrolled in HIV care and treatment. These clubs run monthly on a Saturday or Sunday outside of normal clinic hours and are only for adolescents. They can range in size from 15 to 200 clients. They are facilitated by a club mentor/s (trained health care provider). Adolescents attend their club for adherence and psychosocial support, as well as for peer group building activities.

Note: *In larger clubs, younger and older adolescents are split for purposes of psychosocial support with older teens also receiving sexual and reproductive health literacy.*

During club activities, a nurse sees each adolescent individually for their ART refill and clinical review.

7.3.1.1 Eligibility for adolescent clubs

- Fully disclosed adolescent living with HIV
- Aged 10–19 years
- No restrictions on stability (viral suppression, treatment failure, psychosocial issues, etc.)
- Must agree to confidentiality – disclosing status of a peer results in immediate dismissal from the adolescent club and this applies to both adolescents and staff.

7.3.1.2 Services offered in adolescent clubs

- Clinical care – ART refills, ART monitoring, nutrition screening/treatment, anaemia screening, TB screening/treatment and referrals for specialized care.
- Psychosocial support, adherence counselling , peer support, mental health screening, coping with stigma/discrimination, life skills and future planning.
- SRH services education and contraception administration.
- Others laboratory collection (VL)

7.3.1.3 Topics discussed during adolescent club sessions

Topics to be discussed include but are not limited to nutrition, World AIDS Day, money and budgeting/financial literacy, communication, peer pressure and bullying, human rights, career day, reproductive health, sports and games, HIV basics, leadership, anger and depression, relationships and self-expression.

7.3.1.4 Formulating adolescent clubs

The following should be prepared when formulating an adolescent club:

- A consent form must be signed by both parents/caregivers and adolescents
- Care and treatment (CTC) recording forms (CTC 1, CTC 2 and registers) must be available
- Meeting dates must be communicated to the adolescents through SMS
- A health care provider who will lead the group must be identified
- Issues/topics for discussion must be identified by club members

7.3.1.5 Running adolescent clubs

7.3.1.5.1 Planning a schedule

- Two or three weeks before holding adolescent club, hold planning meeting with club leaders to discuss ideas for activities surrounding predetermined topics.
- Before the second club leaders meeting, discuss the leaders' ideas with other staff as a group to identify any problems or suggestions.
- A week before teen club, hold a second planning meeting with leaders to create final schedule and plan logistics for materials, assignments of roles, etc.

7.3.1.5.2: Day of adolescent club

8:30 a.m. – 9:00 a.m.

Registration check-in at table outside the clinic and sorting files – done by teen leaders and adolescent PEs. While registration is occurring, have music playing and games available for teens to stay busy until the event begins.

7.3.1.5.3: Adherence

9:00 a.m. – 9:40 a.m.

Welcome new members. Carry out adherence activity related to theme (*Kauli mbiu*) of the day. Adherence prize. Two criteria to be put into the lottery: good attendance and good ARV adherence. We usually put about ten names in the bag and pull out five.

7.3.1.5.4: Topics

9:40 a.m. – 11:00 a.m.

Icebreaker/energizer (something to get the teens up and moving/laughing). Have the main activities – topics (unaweza kualika mgeni). Aim to make these activities educational but also interactive. Teens do not respond well to long lectures, so be creative in the ways that you incorporate a topic. We aim to have the teen leaders and PE facilitating as many of the activities as possible. Staff is there for support. At the end of the activities, we conclude the topic and make an announcement regarding the date of next club.

7.3.1.5.5: Clinical care

11:00 a.m.

Clinical care begins. Have a 10-minute meeting with teen leaders and PE to plan for next club day.

7.3.2 Key points

- Adolescent clubs are facility-based clubs for adolescents who understand their HIV status and are enrolled in HIV care and treatment.
- Consent forms and CTC recording tools are important tools during preparation of adolescent clubs.
- Running adolescent club requires prior planning to discuss ideas for activities surrounding predetermined topics, problems or suggestions to be discussed during the group meetings.

Session 7.4

Total time taken: 30 minutes

Life skills for ALHIV

Learning objectives

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

- Describe life skills for ALHIV.

7.4.1 Life skills

Life skills are skills needed by an individual to operate effectively in society in an active and constructive way. Personal and social skills are required for young people to function confidently and competently by themselves, with other people and the wider community. Life skills facilitate development of adaptive and positive behaviours and enables adolescents to effectively deal with the demands and challenges of life.

7.4.1.1 Categories of life skills

Learning life skills is a process; life skills cannot be imparted in one day. It is important to continually help adolescents to build life skills at every opportunity. Acquiring skills, behavioural changes and teaching adolescents is a continual process that requires a lot of patience and understanding.

The skills of knowing and living with oneself are self-awareness, self-esteem, assertiveness, coping with emotions and coping with stress.

The skills of knowing and living with others are interpersonal relationships, friendship formation, empathy, peer pressure/resistance, negotiation, non-violent conflict resolution and effective communication.

The skills of making effective decisions are decision-making, critical thinking, creative thinking and problem-solving.

7.4.1.2 Examples of adolescent life skills

Communication and interpersonal skills

- Interpersonal communication skills
- Negotiation/ refusal skills
- Empathy

- Cooperation and teamwork
- Advocacy skills
- Decision-making and critical thinking skills
- Decision-making and problem-solving skills
- Critical thinking skills

Coping and self-management skills

- Skills for increasing internal locus of control
- Skills for managing feelings
- Skills for managing stress.

7.4.1.3 Life skills education helps adolescents

- Be confident, knowledgeable and capable of taking responsibility for their own lives
- Develop into stronger, more aware and more caring human beings
- Better cope with the demands and pressures of everyday life and living with HIV
- Assess risks and make decisions that will lead to positive outcomes and a better, healthier life

7.4.2 Key points

- Life skills are needed by an individual to operate effectively in society in an active and constructive way.
- Life skills enable adolescents to effectively deal with the demands and challenges of life.
- Key categories of life skills include skills of knowing and living with self, skills of knowing and living with others and skills of making effective decisions.

Appendix 7A: Psychosocial assessment tool

How to use this tool

This psychosocial assessment tool was developed to support trained health workers who work with ALHIV and their families. Conducting a psychosocial assessment with each client (and caregiver, if applicable) helps providers learn more about the client's specific situation, helps to prioritize needs and give direction to ongoing counselling and psychosocial support. This includes referrals for needed community- and home-based services.

A psychosocial assessment should be conducted with each adolescent client both after enrolment in HIV care and treatment services and annually after that. You may want to conduct another psychosocial assessment or revisit specific psychosocial issues when a client's situation changes in a significant way, such as when a client reaches a new developmental stage or starts to show signs that he or she is facing new challenges or problems. Always respect client confidentiality and conduct sessions in a space that offers visual and auditory privacy. Key information from the psychosocial assessment should be recorded on the form and the form should be kept in the client's file for reference during follow-up visits.

Basic information

Write down the client's name and file number. Be sure to sign and date the form at the end of each session.

Questions to ask the client/caregiver

These questions allow you to discuss and assess the client's psychosocial issues and needs. 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. Write down any important information from the client's responses in the right-hand column, as this will help you decide on effective next steps, important areas for follow-up and in supporting the client's psychosocial well-being over the long term. Also make sure that the client has time to ask questions and that you have time to summarize the session and agreed upon next steps. Record key next steps in the space provided.

Additional notes

Write any additional notes about the session or the client's psychosocial needs in the space provided.

Referrals made

Linkages and referrals to psychosocial support services are an important element of HIV care, treatment programmes and the ongoing support to adolescent clients and their families. Each clinic should have an up-to-date list of community support services (such as adolescent PE, adherence supporters, ALHIV associations, food support, education and job training programmes, gender-based violence services, legal support, etc.) and formal two-way referral systems to these organizations and services. Clients with severe psychosocial and psychological issues (such as depression, alcohol or other substance use disorders, suicidal feelings) will require careful follow-up and immediate referrals to ongoing professional counselling and other services. Record any referrals made to the client in the space provided. At the next session, follow up to determine if the client accessed these services.

Date of next counselling session/clinic appointment

Schedule a follow-up counselling appointment with the client and record this date, as well as any other clinic appointments, in the space provided.

REMEMBER

- Do not talk down to an adolescent.
- Allow the adolescent to speak for him or herself. Respect his or her opinions.
- Be patient! Allow the adolescent to express his or her views and to describe his or her experiences.

ALHIV psychosocial assessment guide and recording form

Client Name: _____ Client File#: _____

Date: _____

1. Smile, introduce yourself and give a short explanation of your role. Explain that this discussion will be confidential.	
2. Can you tell me how things have been going since you learned your HIV status (or since we last met)? How are you coping? **Explore and discuss client's coping strategies**	
3. Tell me about your mood now. Do you feel sad or stressed? What changes have you noticed in your mood? What about in your eating and sleeping habits? **Assess risk of depression and need for referral**	
4. How often in the last week have you used cigarettes, alcohol or other drugs? **Assess for harmful coping strategies, such as drug/alcohol use, provide counselling and referrals**	
5. To whom have you disclosed your HIV status? What was their reaction? Do you want to disclose to anyone else? What concerns do you have about disclosure? **Counsel on disclosure**	
6. Who do you feel close to? Who can you go to for emotional support? **Counsel on importance of social support**	
7. Do you belong to a community/religious organization or support group? Would you be willing to join a support group to meet other ALHIV? **Make referrals as needed**	

8. Tell me about any negative attitudes or treatment you've experienced. Has anyone caused you harm (e.g., been violent, made unwanted sexual advances)? **Counsel and discuss support services; consider gender-based violence services, if appropriate**	
9. Some adolescents have sex with their partners. It's important for you and your partner to do this safely. Are you having sex? If so, what are you doing to prevent pregnancy and the spread of STIs and HIV? **Screen for sexual risk-taking and counsel on safer sex, dual protection, etc.; give condoms**	
10. Let's talk about your living situation. Who are you living with? How long have you lived with them? How well do you get along? **Assess living situation** *If not living with parents, ask*: Where are your parents? When did this happen? How did this affect you?	
11. Tell me what you do most days. Do you, for example, go to school or work outside the home? Where do you go to school/work? How is this going for you? **Assess school/work situation**	
12. Do you have financial support from your family or partner, a regular source of income, or do you receive help, such as social grants or food? **Refer to social worker and community-level support**	
13. Other than coming to this clinic, where else do you go for health services (for example, other clinics, traditional healers, etc.)?	
14. How do you/will you remember to come to this clinic for your appointments and refills? How do you/will you manage it with your school or work? Who can help you? **Counsel on adherence to care**	

15. How do you/will you remember to take your medications every day? How do you/will you remember when to come back to the clinic? Who can help you? **Counsel on adherence and briefly discuss:** ■ WHO will give or manage your medicines? ■ WHEN will you take them? ■ WHERE will you store them? ■ HOW will you remember to take them (review use of reminders, like calendars, pill boxes, etc.)	
16. What other questions or concerns do you want to discuss today? Would you like to bring someone else into our conversation – today or at another visit (e.g., family member, partner)?	
17. Summarize the session and review immediate plans and next steps, including the next clinic visit date.	

Notes:

Referrals made:

Appendix 7B: Starting/planning a peer support group

Key steps to think about when starting/planning a support group

- First, find out what HIV-related support groups already exist in the area. Then, try to understand what support groups are needed
- Work in partnership with clients, counsellors, social workers and/or PE to determine what types of support groups are needed
- Ask adolescents who attend the clinic when they could come to a meeting, where they would like the meeting to be held and what they would like to talk about (for example, adherence strategies, stigma, disclosure, etc.)

Decide WHO the support group is for

- Who will be invited to attend? Generally, it is best to have different support groups for younger and older adolescents
- What is the ideal number and type of participants? It is recommended that support groups not have more than 10–15 people in the same meeting so that everyone can participate

Define the overall goals of the support group

- What is the purpose of the support group?
- What will members gain from the support group?
- Is the support group meant to go on indefinitely? Or will it cover a certain number of topics and then end?

Recruit support group members

- How will you let people know about the support group?
- Will members of the multidisciplinary team refer people to the support group? How will it be advertised?

Decide on the location of support group meetings

- Can it be held at the health facility? Is this convenient for adolescents or should it be located in the community?
- If support group meetings are held at a health facility, will members be able to get HIV services before/after the meeting?

Decide how often the group will meet

- What time and how often will the groups be held? Do most participants go to school during the day or do they have household chores at certain times of the day? Is one hour enough or is two hours better?
- Will the group meet once each month? More often? Less often?

Develop the meeting agenda

- Who will run the support group?
- Who will be invited to speak? What will the topic(s) be?
- Will there be guest speakers?

Think about venue, food and other logistics

- Is there privacy at the meeting space?
- Are there enough places for people to sit?
- Can the room be arranged so participants are in a semicircle (instead of in rows)?
- Will you arrange for tea or snacks for the meeting? Who will get them? How will they be paid for? Who will keep attendance and other records of the support group?

Suggested agenda items for support group meetings:

- ☐ Registration/sign-in
- ☐ Refreshments (tea, coffee, snacks, etc.)
- ☐ Welcome/opening (song, prayer, dance, etc.)
- ☐ Introductions
- ☐ Overview of the agenda
- ☐ Reminder about confidentiality and other ground rules
- ☐ Main group learning activity (game, health talk, etc.)
- ☐ Questions and answer session (make use of an anonymous question box)
- ☐ Plan for the next meeting
- ☐ Closing (song, prayer, dance, etc.)

Most support group meetings last between 1–2 hours.

Suggest and plan new learning opportunities and fun activities for support group members.

- Keep everyone busy and having fun! Use games and participatory activities (refer to suggestions in *Appendix 5D: Ideas for peer support group activities*).
- Consider including a health talk as a part of each support group meeting. The health talk can be focused on a different topic area at each of the meetings. Health talks should be kept short and simple (about 15–20 minutes) so that support group members have time to discuss their feelings, questions and concerns.
- Plan an activity or ongoing project for each group meeting that relates to the overall theme of the group.
- Get feedback from support group members on topics they would like to discuss during the meetings and incorporate them into the agenda. This can be done through an anonymous questions box.

Appendix 7C: Facilitating a peer support group[3]

Be sure to plan the group session ahead of time and practice what you are going to say.

Set up the room so that everyone can participate.

- Encourage participants to sit in a semicircle to make it feel less like a classroom and more comfortable to talk.
- The person leading the meeting should be part of the semicircle rather than standing behind a desk or other furniture.
- If possible, provide tea or a light snack for members, facilitators and invited guests.

Remind participants about confidentiality

Support group members will only feel open to discussing their experiences and feelings if they know others will ensure that the discussion is kept confidential. It is always a good idea to remind support group members at the start of each meeting that what is said during the meeting will not be repeated in the community or elsewhere.

Ask participants to establish ground rules

During the first group meeting, ask the participants to brainstorm ground rules for the group. Ground rules might include any of the following: respecting others' opinions, not interrupting, allowing everyone a chance to speak, not tolerate homophobic comments, etc.

Offer participants ongoing support and referrals

- Encourage participants to speak with you or another facilitator in private afterwards if they have concerns they do not want to share with the group
- Know what support and services are available in the community and at nearby health facilities so you can provide referrals.
- If the meeting takes place at a health facility, try to time it so members can seek services before or after the meeting.
- Seek input from multidisciplinary team members and other experts on topics beyond your area of expertise.
- Create a plan for situations where support group members need assistance right away (for example, if they are mentally distressed, suicidal, violent or victim of violence).

Keep records of the meeting

- Always keep an attendance record. Remember, this information is confidential
- Ask someone to take simple notes during the meeting. Note what topics were discussed, key concerns of members and any next steps. Also note the date, time and location of the next meeting
- All meeting records must be stored in a locked cabinet to ensure confidentiality

Be a good facilitator or co-facilitator

- Partner with a peer educator, social worker or counsellor as a co-facilitator. Decide what role the co-facilitator will play during the meeting

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[3] ***Schley,*** *A., Colton, T., Schoeneborn, A., and Abrams, E. (2011). Positive voices, positive choices: A comprehensive training curriculum for adolescent peer educators, Version 1.0. ICAP.*

- Create a safe and welcoming environment for support group members. Support groups should not feel like health education sessions or lectures. Instead, members should feel that it is 'their' meeting
- Lead an introductory activity (have people introduce themselves or say something about their family) so participants feel more comfortable with one another
- Review the agenda with support group members and ask if there are questions. Always ask for suggestions for the next meeting's agenda
- Stick to the agenda and keep time
- Interact with participants and get them involved by moving around the room, by asking questions and by asking people to share personal stories/concerns, etc.
- Pay attention to participants who seem shy or quiet and emphasize that everyone's personal experiences, questions and concerns are important
- Use visual aids and avoid lecturing
- At the end of the meeting, ask participants to summarize what they have learned and the actions they plan to take
- Always leave time for questions and re-explain anything that participants did not understand fully

Use the seven listening and learning skills when leading a support group meeting:

Seven listening and learning skills

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 judgmental.

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

Note: If a participant is being disruptive:

- Try to understand why he or she is acting this way
- Do not ignore or argue with him or her
- During a break, talk to the participant one-on-one and ask what is bothering him or her

Appendix 7D: Ideas for peer support group activities

Charades

Players try to act out terms or concepts without speaking.

Materials Watch or timing device, pieces of paper (cut a sheet of A4 paper into eight pieces – papers can be blank or can already have health terms written on them), two baskets, hats, or other containers for the paper, score keeping method

Play Divide the participants into two teams and give each team half of the slips of paper. If the pieces of paper are blank, give the teams time to privately consult and write one term, phrase or concept related to material they are learning on each piece of paper. Choose a neutral timekeeper/scorekeeper or have the teams take turns keeping score. Review the gestures and hand signals that will be used during the game and invent any others, as needed.

To play, teams take turns having a player choose a piece of paper from the other team's basket. Without speaking, the player has three minutes to use gestures and actions to help his or her team members guess what is written on the piece of paper.

Normally, the game continues until every player has had a chance to act out a phrase. Scoring may be based on one point for every paper correctly guessed. Another scoring option is based on the total time that each team needed for all of the rounds – with this system, the team with the lowest score wins the game.

Sculpturing

Participants put themselves into certain poses using their whole body (including gestures and facial expression) to communicate an image of an issue or relationship. The 'sculpture' is then discussed.

Example Ask participants to get in pairs and then ask each pair to make a sculpture showing how people treat orphans. Ask them to decide on roles – one person will be the orphan and the other a community member. After all pairs have come up with their sculptures, ask some to show their sculptures in the centre of the circle. After each demonstration, ask:

- What do you think this person is saying?
- How do you think these people are feeling?

Ask the people in the sculpture:

- What are you thinking?
- Why are you doing that?
- How are you feeling?

Journaling

Ask participants to create 'All About Me' journals using magazines, markers and any other materials that could be used to decorate the journal. Ask participants to think about the special characteristics (hobbies, traits, talents, strengths, etc.) that make up their identity. Also ask them to think about their future goals and dreams. A counsellor or peer educator at the clinic may want to write back/respond to clients' journal entries in writing.

Question box

Create a box at the health facility for anonymous questions. Tell clients that they can drop-in questions any time. These questions can then be picked out of the box at random during one portion of the support group meeting and discussed by everyone.

Songs

Ask participants to work in small groups to create a song about a health topic, about positive living or about reducing stigma.

Plays/drama

Ask participants to work in small groups to create a play about a specific issue, such as combating stigma in schools or in the community.

Arts and crafts games

These games help adolescents think about themes in their lives in new ways and can be quite useful for appealing to younger adolescents who enjoy doing activities that are hands-on, participatory and creative. One technique for slowing down youth who rush through art projects is to tell them that within the time frame, the LAST artists to finish are the winners.

Example Create a painting or drawing of a scene where participants were discriminated against and ask participants to discuss their feelings/reactions.

_____

_____

_____

Date of next counselling session/clinic appointment _____

Health worker signature _____Date _____

Adapted from *ICAP (2010). Improving retention, adherence, and psychosocial support within PMTCT services: A toolkit for health workers. New York, NY: Columbia University/ICAP.*

MODULE 8:

ADHERENCE, RETENTION AND FOLLOW-UP OF ADOLESCENTS IN HIV CARE

Total module time: 3 hours 15 minutes

Module 8: Objectives

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

- Describe adherence and retention in HIV care and treatment
- Explain different factors affecting adherence
- Identify common barriers to adherence and retention in care for treatment of adolescent clients
- Discuss ways that health workers and health facilities can support ALHIV's adherence in, and retention to, care
- Conduct adherence preparation sessions with ALHIV and their caregivers
- Identify strategies of retaining ALHIV into HIV care

Session 8.1

Total time taken: 45 minutes

Introduction to adherence and retention

Learning objectives

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

- Define adherence and retention in HIV care and treatment
- Explain the importance of good adherence
- Describe factors affecting adherence and retention in HIV care
- Describe factors that can support ALHIV to improve adherence and retention in HIV care

8.1.1 Adherence and retention in HIV care and treatment

8.1.1.1 Overview of adherence and retention

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

- Includes active participation of the client (and caregiver)
- Includes adherence to both medications and care
- Depends on a shared decision-making process
- Determines the success of HIV programmes
- Changes over time

Retention implies remaining connected to medical care once entered into treatment plan.

- A goal of all HIV care and treatment programmes is to retain clients in care and treatment.
- For ALHIV, supporting retention also means supporting their transition to adult care and treatment.

Retaining ALHIV in care and supporting their adherence to both HIV care and treatment is one of the most important, yet challenging tasks we as health workers face.

8.1.2 Importance of good adherence and factors affecting adherence and retention in HIV care

8.1.2.1 Importance of good adherence

Excellent adherence to treatment is important due to the following reasons:

- Ensures that medicines function optimally so as to increase CD4 count, viral suppression and prevent OIs
- Reduces risk of spreading the virus to others (altruistic adherence)
- Helps ALHIV grow and develop into healthy adults
- Minimizes drug resistance

Excellent adherence to medications also helps to keep adolescents looking and feeling good and getting them back to 'normal' life.

- Adherence and retention are closely related.
- Health workers and health systems play an important role in retaining clients in care.
- Adherence support should be an ongoing and not a one-time event, and the entire multidisciplinary team is responsible for providing these services.
- **No one is perfect.** It is important not to judge adolescent clients (or caregivers) if they are non-adherent.
- Instead, we should try to understand why they do not adhere and help figure out ways to resume good adherence as soon as possible.

Indicators of poor adherence:

- Missing one or many appointments
- Not following the care plan
- Missing a dose or several doses of medicine
- Sharing medicines with other people
- Stopping medicine for a day or many days
- Taking medicines at the wrong times
- Taking medicines without following instructions about timing or food intake

8.1.2.2 Factors affecting adherence and retention in both early and late adolescents

The most common factors affecting adherence and retention in both early and late adolescents can be categorized into health services, individual, community,cultural or medication-related factors.

8.1.2.2.1 Health service-related factors affecting adherence

- Adolescent-friendliness of services
- Level of confidentiality
- Provider attitudes
- Drug stock-outs
- Distance/transportation costs
- Convenience of clinic hours/long waiting hours
- Patient record and tracking systems
- Communication skills
- Length of waiting times
- Space for private counselling and edutainment activities(edutainment means education and entertainment, for example, playing, singing, drama activities)
- Shortage of skilled staff
- Linkages between services
- Referral systems
- Level of ALHIV involvement
- Cost of health services or medicines
- Language barrier
- Lack of peer support groups

8.1.2.2.2 Individual factors affecting adherence

- Desire to fit in with peers
- Forgetting to take medicine
- Medicinal side effects
- Having difficulty accepting one's HIV status
- Stigma and discrimination
- Disclosure
- Refusal
- Denial
- Lack of HIV knowledge/information
- Fear
- Emotional and behavioural issues
- Familial or social support
- Presence of mental illness
- Self-awareness
- How sick or well a person feels
- Migration or relocation affecting continuity of care

8.1.2.2.3 Community and cultural factors affecting adherence

- Familial and social support
- Poverty and lack of food
- Stigma and discrimination
- Societal discomfort with adolescents and related issues, such as sexuality
- Extent of disclosure
- Violence
- Religion
- Cultural belief
- Inability to take time off from school or work for clinic visits
- Distrust of the clinic/ hospital
- Use of traditional medicine
- Political instability or war
- Physical environment

8.1.2.2.4 Medication-related factors affecting adherence

- Side effects
- Changing paediatric doses
- Changing regimens
- Number of pills in regimen
- Dose timing
- Availability of reminder cues such as calendars, alarms, etc.
- Taste
- Changes in drug supplier – labelling, pill size, colour, formulation, etc.
- Packaging and storage

8.1.2.3 Improving adherence and retention in care

Steps health facilities can take to enhance adherence and retention in care are:

- Ensure that services are adolescent-friendly and convenient
- Use a developmental approach in counselling and education
- Ensure 5 R's – Right (drugs, time, dose, frequency and way)
- Establish relationships of trust and respect with adolescents
- Make time for private counselling and ensure confidentiality
- Ensure that appointment systems are in place, and that adolescents receive reminders via phone, SMS or home visit
- Rescheduling procedures in place for adolescents who miss appointments or pharmacy refills

- Check in with clients often after they start or change medicines
- Review each client's drug regimen to assess whether changes can be made to facilitate adherence
- Use fixed dose combinations of ARVs to reduce clients' pill burden

Proper documentation of client information

During enrollment, and at least once a year, make sure personal client information like addresses and phone number are updated

- Ensure linkages to adolescent peer educators and support groups
- Provide transportation stipends to clients who are unable to pay (if possible)
- Obtain client feedback

Be reminded to ensure that each adolescent has a laboratory monitoring test schedule that is adhered to (follow-ups viral load, CD4).

8.1.3 Key points

- Adolescent-friendly services are important for good adherence and improving retention in care for ALHIV.
- Retention means that clients continue accessing lifelong HIV care and treatment services.

Session 8.2

Total time taken:
1 hour

Adherence preparation support to ALHIV and caregivers

Learning objectives

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

- Describe the assessment process of adolescents' and caregivers' readiness for ART
- Support adolescents and caregivers in making a personal adherence plan
- Describe an adolescent-friendly ART adherence plan

8.2.1 Overview of adolescent-friendly ART adherence preparation

8.2.1.1 Overview of adolescent-friendly ART adherence preparation

Adherence preparation may include 1 to4 group or individual sessions. Ongoing adherence assessment and support is necessary for ALHIV and caregivers. Group sessions are useful for giving information to many people at once,while individual sessions can be used to:

- Find out what the client learned from previously attended group sessions
- Identify support needs and develop an individual adherence plan

After a group session, all ALHIV should be given time to speak to a counsellor, health worker and/or adolescent peer educator in private to discuss potential adherence challenges and make an individual adherence plan.

Ideally, adherence preparation counselling should begin early in HIV care. While providing as much support as possible, you should be flexible when addressing ART readiness. The preparation process should always facilitate ART initiation and never act as a barrier.

8.2.1.2 Treatment supporter

A treatment supporter is someone chosen by a client to provide him or her with ongoing support for adherence to care and treatment. This is usually a client's caregiver, friend, family member or another ALHIV who is also enrolled in care and is a trusted person to whom the client can disclose his or her status. You should explain the importance of having a treatment supporter to

ALHIV and should make sure treatment buddies have the needed information and skills.

Remember that not having a treatment buddy should not act as a barrier to any client initiating ART. You should encourage treatment buddies to accompany ALHIV on clinic visits.

8.2.2 ALHIV personal and friendly ART adherence plan

8.2.2.1 ALHIV personal adherence plan

This plan should address the following questions:

- **Are you ready to take your medicines?** If the response is no, consider delaying ART initiation
- **Who** will help you remember to take your medicines every day at the same time and to come to the clinic for appointments?
- **What** medicines are you taking? What is the dose of each and how often will you take them? What will you do when you are about to run out of your medicines? What will you do if you miss a dose of your medicine?
- **When** will you take your medicines? (Establish a routine.)
- **Where** will you take your ART (e.g., at school, at home, at work, etc.)? Where will you store your ART?
- **How** will you remember to take your medicines at the same time, every day? How will you know that you have taken your doses so that you don't miss any or take them twice?

When helping clients and caregivers prepare for ART, health workers should always address the **'ARE YOU COMMITTED'** question.

8.2.2.2 The adherence support tree

This is a tool you can use to help clients and caregivers prepare for adherence to ART. It can also be used to ask about adherence at follow-up visits. Practise using the adherence support tree with fellow participants.

8.2.2.3 Assessing ALHIV and caregivers' readiness for ART

Standardized readiness assessment tools can:

- Help you assess a client's and caregiver's readiness
- Help clients understand the importance of lifelong adherence
- Ensure a shared understanding of the client's care and medication plan
- Identify potential adherence challenges and help to brainstorm practical solutions

You can use the plan agreed upon during the WHO, WHAT, WHEN, WHERE and HOW discussions when completing these guides with clients and caregivers.

REMEMBER It may take one, two or even more individual counselling sessions before a client is ready to start ART. Assessment questions should be used to identify areas where the client may need additional support. It should not be used as a 'test' that the client needs to pass before starting ART.

Exercise 1: Developing an adherence plan

Follow instructions provided by facilitators.

Exercise 1: Case study 1

Becky is 11 years old and is supposed to start taking ART today. Becky and her auntie have already gone through the group education sessions and today is Becky's adherence preparation visit. Becky's auntie is her primary caregiver and will be responsible for giving Becky her medicines every day. Becky understands that she has HIV and that she needs to take medicines every day, but her auntie is still worried about how she will manage.

- How would you help Becky and her auntie prepare today for adherence?
- What questions would you ask to assess their understanding of adherence and Becky's readiness to start ART?

Exercise 1: Case study 2

Salama is 17 years old and lives by himself. He needs to start taking ART, and now that he has attended the group adherence preparation sessions, the doctor asks you to counsel him individually to further prepare him for ART adherence. Salama works during the day as a taxi assistant and you sense that it might be challenging for him to take his medicines the right way since he has not disclosed to anyone and works long hours.

- How do you help Salama prepare to start taking ART?
- What questions would you ask to assess Salama's readiness for ART?

Exercise 1: Case study 3

Leila is 17 years old and lives with her mother and father. She is going to start taking ART, and now that she has attended the group adherence preparation sessions, you have been asked to help prepare her and make an adherence plan. Leila is at the clinic with her older cousin and says that she does not talk much with her mother and father about HIV. Instead, her cousin has agreed to be her treatment supporter.

- How would you prepare Leila and her cousin for good adherence?
- What questions would you ask to assess their readiness and understanding?

Exercise 1: Small group work –Case study 4

Julia is 14 years old. She has come to the clinic today with her father for adherence preparation and ART initiation (she has already attended group preparation sessions). Her mother passed away recently, so her father will be her main treatment supporter. While conducting adherence preparation counselling with Julia and her father, her father expresses some concern that ART might be bad for children. He goes onto say that his daughter feels fine without medicine, adding that he works long hours so Julia spends a lot of time at home with her older brother.

- How would you proceed in preparing Julia and her father?

Exercise 1: Small group work –Case study 5

Nathan is 16 years old and lives with his mother and four younger siblings. Nathan is still in school, but only because his mother makes him go. Nathan would prefer to spend his time with his friends, which he does as soon as school ends. He is rarely home before nightfall and is failing nearly half of his classes. He has not told his mother or siblings about his HIV status, but he has told his best friend and partner, Alia. Alia is 17 and also has HIV.

- How do you help Nathan prepare to start taking ART? (Assume that he has already attended group adherence preparation sessions.)
- What questions would you ask to assess his readiness for ART?

Exercise 1: Large group discussion questions

- How did you decide on an adherence plan with the client or caregiver?
  - What tools did you use?
  - How would you measure the plan's success or outcome?
- Did you have any concerns about the client initiating ART?
  - How would you address these concerns with the client and/or caregiver?
- What advice did you give to the client and their caregiver about adherence to care and medicines?

8.2.3 Key points

- Health workers can help ALHIV develop a personal adherence plan by using the adherence support tree.
- Preparation support guides and adherence support services should be ongoing and the entire team of the health facility is responsible for providing these services.
- It is often helpful to ask ALHIV and caregivers about adherence separately.

Session 8.3

Total time taken: 45 minutes

Assessing adherence and providing ongoing adherence support

Learning objectives

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

- Assess ALHIV and caregiver adherence to ART
- Describe age-appropriate support to improve ALHIV adherence to ART

8.3.1 Assessing adherence

8.3.1.1 Assessing adherence

The following are the procedures to assess adherence:

- Assess adherence at every visit
- Conduct separate sessions with ALHIV and their caregivers
- Discuss differing answers with the client and caregiver together
- Use tools to help assess and improve adherence, such as:
  - Pill count tables (BD and OD)
  - Review of clinical findings and lab tests
  - Review the 'seven days recall' and follow-up adherence form

For ALHIV, missing pharmacy refills or clinic appointments is a RED FLAG indicating poor adherence that should be addressed immediately. Always follow national guidelines and use national tools to assess adherence. Do not be judgmental.

8.3.1.2 Ongoing adherence support

When providing adherence support, build on previously established trust and rapport, maintain a safe space to discuss any problems and give ongoing encouragement.

If the client seems to be adhering well:

- Praise the client (and the caregiver, if present) for good adherence
- Remind the client to come back if there are any problems

- Talk about how important it is to be open with health workers and solve challenges together

If the client seems to be experiencing challenges with adherence, provide individual counselling and:

- Praise the client for sharing his or her challenges
- Identify the client's specific challenges
- Help client resolve each challenge
- Discuss importance of adherence
- Refer client to an adolescent peer educator (APE), adolescent support group, etc.
- Refer difficult cases to other support services according to need
- Plan for next step

Once you have planned for the next steps for an adolescent who experiences challenges with adherence,you should not forget to:

- Record the session on the patient record
- Follow up at the next visit
- Share observations with the health facility team

Refer *to review ongoing adherence support in national guideline for management of HIV and AIDS (2017)– Barriers to treatment adherence and how to alleviate them for more details.*

8.3.2 Appropriate support to improve ALHIV adherence to ART

Exercise 2: Assessing adherence and providing support

Follow instructions provided by facilitators.

Exercise 2: Case study 1

- **Jason's uncle says** Jason is often out all night and comes home drunk. The family is upset with his behaviour and is afraid for him. Jason used to be a good student and did well in school. Recently, he has not been taking his ART regularly, and it is possible that he is not taking it at all. I found medicines thrown away in the outhouse – I am angry with my nephew. I need the clinic staff to scare Jason into taking his medicines. I also have HIV, but Jason does not know.
- **Jason says** I think I have taken about half of my ART doses over the past week, mostly because I've been too busy.

Discussion question for this case study – Ask the small group

What did the health worker do to address differences between the two stories (Jason's and his uncle's)?

Exercise 2: Case study 2

- **The client (Naton) introduces himself to the health worker** I am Naton, I am 12 years old and have been coming to the clinic for a long time. My mother is here with me today.

- **Background**
  - **Naton's mother says** Naton always used to cooperate and take his medicines with no problems. But these days he fights with me during every dose – he runs away and spits out his ART. I am planning to tell Naton his diagnosis, but he is still too young to know. I haven't used the word 'HIV' with him yet.
  - **Naton says** My mother forces me to take my medicine every morning and every evening. But I don't want to take it anymore – I just want to be normal and not take medicine. My friends don't take medicine, so why do I have to?

Discussion question for this case study – Ask the small group:

Did the issue of disclosure come up during your counselling session with either Naton or his mother?

Exercise 2: Case study 3

- **The client (Pili) introduces herself to the health worker** I am Pili and I'm 14 years old. I am feeling bad and want to stop taking ART. My best friend is with me today.
- **Background:**
- **Pili says** I've missed about three doses of my ART this month, but I think that taking my doses most of the time is good enough. I think the pills are making me look fat. There is a boy in my class that I really like, but I'm sure he thinks I'm ugly. I get teased when I go to school and I only have one friend. She is with me today – in the waiting room.

Discussion question for this case study – Ask the small group:

Did you include Pili's friend in any way? How could she be helpful?

Exercise 2: Case study 4

- **The client (Mumu) introduces herself to the health worker** I am Mumu, I am 16 years old, and I have come in today for my 3-month check-up. As always, my mother is here with me. The doctor told me to give this to you (Mumu should hand over her pretend medical record with the results of her last 2 CD4 tests, which show a decrease in her CD4 count).
- **Background:**
- **Mumu's mother says** Mumu has taken 100 per cent of her medicines on time this month.
- **Mumu says** I've taken 100 per cent of my medicines on time this month.

Discussion question for this case study – Ask the small group:

Do you think Mumu was really taking 100 per cent of her medicines?

Exercise 2: Large group discussion questions

- What do you think will be the most challenging aspects of conducting adherence assessments with ALHIV and their caregivers at your clinic?
- What approaches should you take to make clients and caregivers feel comfortable giving honest answers about adherence?

8.3.3 Key points

- Adherence is challenging and requires ongoing, individual adherence assessment and counselling.
- Ongoing adherence support is especially important for adolescents because their adherence to care and medications will change over time.
- Refer difficult cases to other support services according to need.

Session 8.4

Total time taken: 45 minutes

Follow-up with ALHIV who have missed visits

Learning objectives

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

- Outline the reasons for missed or lost appointments to follow-up
- Describe strategies to follow-up with adolescents who have missed their appointments

8.4.1 Reasons for missing clinic visits

8.4.1.1 Common reasons for missing clinic visits

- Provider's attitude and language
- Peer influence
- Clinic hours are not convenient
- School schedules (schedule not flexible, boarding schools)
- Long distances to travel
- Lack of disclosure
- Lack of funds for transportation to clinic
- Long waiting time at the clinic
- Unfriendly environment at clinic
- Need to take care of a family member
- Too sick to leave the house and reach the clinic
- Forgot when the next appointment is
- Feel well and do not want to go to the clinic
- Do not understand importance of returning to the clinic at the right times
- Do not understand when or why the next visit was scheduled
- Prefer to use traditional medicines

- Travelled for long visit, seasonal work or holiday
- Worried that a family member, neighbour or other clients will see them going to the clinic or at the clinic
- Drug fatigue and pill burden
- Religious beliefs
- Embarrassed or ashamed about adherence challenges
- Unreported death

8.4.2 Strategies to follow-up with clients who have missed visits

8.4.2.1 Ways to identify clients who have missed visits

There are many tools that can be used to see who has missed an appointment, usually filled by designated staff, which include:

- Appointment registers
- ART register
- CTC 1 and 2 cards
- Facility register for tracking clients with missed appointments
- CTC2 database

8.4.2.2 Approaches to trace adolescents back to clinic

Once there is a list of adolescents who have missed appointments, it will be easy to know who needs a follow-up. Every health facility should have a system to identify clients who have missed appointments and follow them up to bring them back into care.

Check the adolescent file to see if they have contact information listed and if they have given consent to be called or visited at home. If the adolescent has not contacted the clinic to reschedule or come to the clinic within three days of the appointment, conduct follow-up using CBHC and other supporting staff.

Major strategies to track clients are:

- Phone call or SMS to the client or the client's treatment supporter
- Home visit by a community health worker or peer educator linked to the health facility
- Home visit by peer educators

In case of phone call or SMS to the client or the client's treatment supporter:

- If consent has been given for an SMS or phone call, a member of the multidisciplinary team may send an SMS or call the client who has missed an appointment
- If the client does not have a phone, and he or she has given consent, treatment supporter can also be called

Each clinic should have standard procedures for sending SMS or calling clients who miss appointments, including what to say, how to log the SMS or call and what to do if you do not reach the person. Each clinic should also have a logbook where SMS and phone calls are recorded.

In case of home visit by a community health worker or peer educator linked to the health facility:

- It is a good idea for health facilities to be linked with community health workers, local NGOs and PLHIV associations to help with client follow-up
- If clients have given consent for a home visit, peer educators or other members of the multidisciplinary team can meet regularly with community outreach workers to discuss which clients have missed appointments, the type of appointment missed and a plan for follow-up home visits

Community health workers and peer educators can work closely together to make sure clients are given proper adherence counselling in the hope that they will return to care as soon as possible.

Home visit by peer educators:

- Some programmes may ask peer educators to conduct home visits (alone or with other members of the multidisciplinary team) with clients who have missed appointments
- Remember, a home visit should only be conducted if a client has given consent. Clients who have not consented to home visits should not receive them
- Peer educators should learn more about the home visit policies and procedures at their clinic

8.4.3 Key points

- Major strategies to track clients are:
  - Phone call or SMS adolescent/treatment supporter
  - Home visit by a community health worker or peer educator linked to the health facility
  - Home visit by peer educators
  - Communicating with the multidisciplinary team
- Always keep adolescent information confidential during follow-up SMS, phone calls or home visits.
- Never disclose that the person is living with HIV or is receiving HIV care to anyone but the client or the treatment supporter.

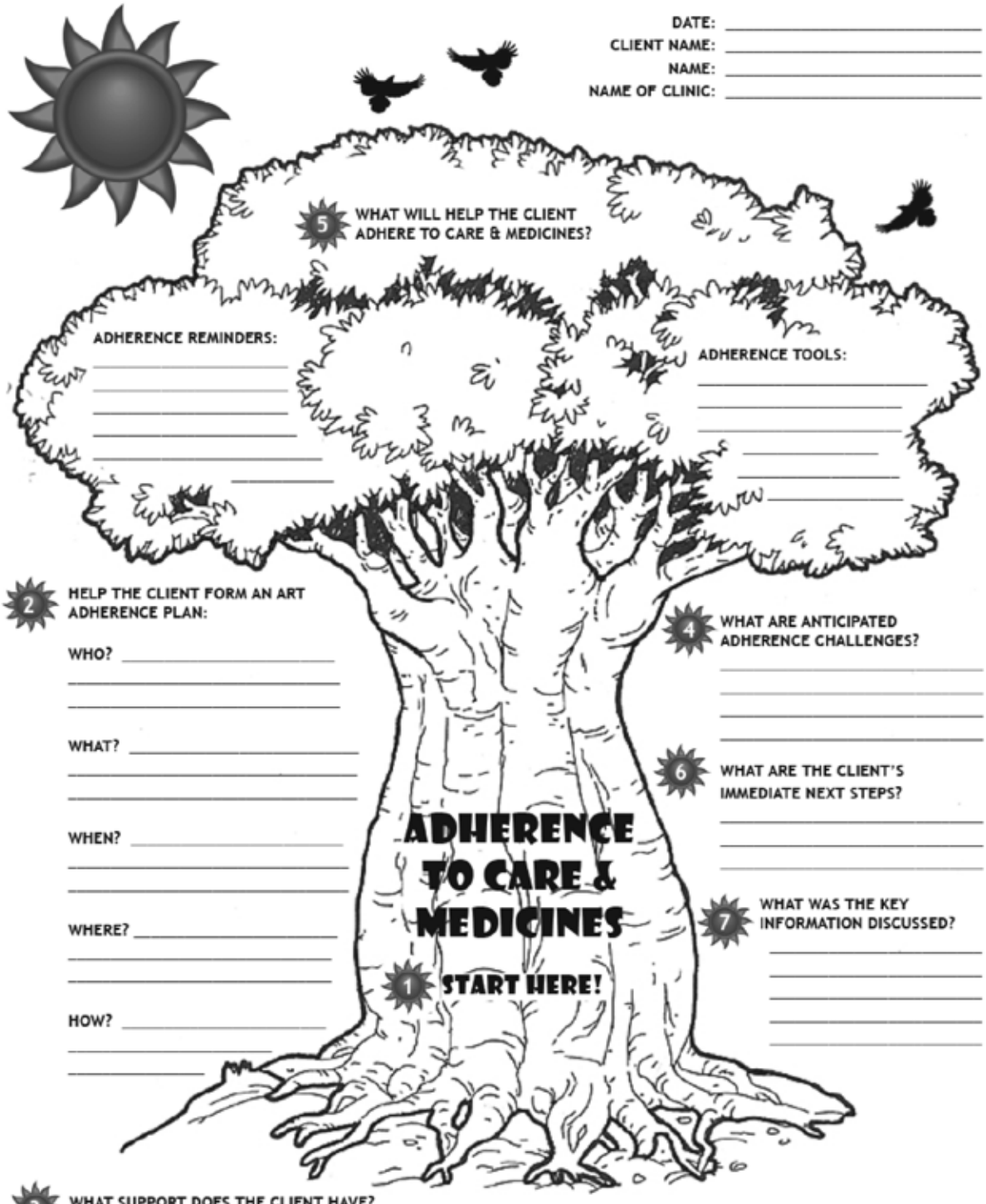
Appendix 8A: Adherence support tree

Instructions for the adherence support tree:

Each instruction below goes with a number on the adherence support tree. You should follow these instructions in order.

1. Start on the trunk. Begin by explaining what we mean by adherence to treatment and why near-perfect adherence is important.
2. Continue by helping the client make an ART adherence plan: address the *are you committed*? question and the WHO, WHAT, WHEN, WHERE and HOW of the medicines. The lines to the left of the tree are spaces for writing down important information related to the client's adherence plan.
   - **Are you ready to take your medicines?** If the response to this question is no, then consider delaying ART initiation.
   - **Who** will help you remember to take your medicine every day at the same time? Is there someone who can help you come to the clinic for appointments?
   - **What** medicines are you taking? What is the dose of each and how often will you take each medicine? What will you do when you are about to run out of your medicines? What will you do if you miss a dose of your medicine?
   - **When** will you take your medicines? (Establish a routine.)
   - **Where** will you take your ART (e.g., at school, at home, at work, etc.)? Where will you store your ART?
   - **How** will you remember to take your medicines every day and at the same time? When you are at school or work? When you are away from home? When you are with your family? When you are with your friends? How will you know that you have taken your doses so you don't miss any or take them twice?
3. Ask the client to imagine him or herself as a tree. His or her roots are 'where you come from, your home, your family, and your community,'and 'what supports and grounds you.' Ask the client who will support him or her with the adherence plan and write this under peers, family and community in the roots of the tree. Also write down if the client has a treatment buddy.
4. Discuss the possible challenges to adherence in the client's (and caregiver's) life. Write these under 'what are the anticipated adherence challenges?'
5. The branches are the client's adherence strategies. These are things he or she can do to have perfect adherence, like using reminders, having routines, having a treatment buddy, etc. Give the client practical suggestions and help him or her plan ways of remembering to take medicines and to come to the clinic for appointments.
6. Always plan a follow-up session and record any action points under 'immediate next steps.' Tell the client that you will always be available to talk more with him or her. Adherence and follow-up to the adherence plan should be discussed during every clinic visit.
7. Lastly, summarize the main points that were discussed during the adherence support session, talk about any necessary referrals and arrange another time to talk (if necessary).

ADHERENCE SUPPORT TREE



DATE: _____

CLIENT NAME: _____

NAME: _____

NAME OF CLINIC: _____

5 WHAT WILL HELP THE CLIENT ADHERE TO CARE & MEDICINES?

ADHERENCE REMINDERS:

ADHERENCE TOOLS:

2 HELP THE CLIENT FORM AN ART ADHERENCE PLAN:

WHO? _____

WHAT? _____

WHEN? _____

WHERE? _____

HOW? _____

4 WHAT ARE ANTICIPATED ADHERENCE CHALLENGES?

6 WHAT ARE THE CLIENT'S IMMEDIATE NEXT STEPS?

7 WHAT WAS THE KEY INFORMATION DISCUSSED?

ADHERENCE TO CARE & MEDICINES

1 START HERE!

3 WHAT SUPPORT DOES THE CLIENT HAVE?

FAMILY: _____

PEERS: _____

COMMUNITY: _____

Appendix 8B: Adherence preparation and support guides

How to use these guides:

These adherence preparation and support guides were developed to assist a range of providers (trained counsellors, APEs, doctors, nurses, pharmacists, community health workers and others) who work with ALHIV and their caregivers. These guides can help providers work with their clients (and caregivers) to understand the importance of adherence to HIV care and treatment throughout their life; to ensure understanding of the care and medications plan; to identify potential adherence challenges; and to come up with practical solutions. **The adherence guides should be adapted to reflect national HIV care and treatment guidelines, as well as the specific clinic, community and cultural contexts in which they are used, including the age and situation of the individual adolescent client.** It may be helpful to translate the guides into the local language.

Often, adherence preparation is not tailored to the specific needs and concerns of adolescents. In some cases, adolescents are referred to adult ART clinics – which may not be youth-friendly – for adherence counselling and preparation. Many programmes stipulate that clients participate in a series of group and individual counselling and preparation sessions before starting ART.

Included here is one adherence preparation and support guide to assess adolescents' readiness for ART and one to assess the readiness of caregivers. The forms should be adapted as needed and used during adherence counselling sessions according to the needs and situation of the client (and caregiver). Completed adherence assessment forms should be kept in the client's file and referred to during follow-up visits.

Basic information:

Write the client's name and file number at the top of the form. Be sure to sign and date the form at the end of each session and ensure that the form is kept in the client's clinic file.

Questions to ask the client/caregiver:

The questions in this section allow the health worker to discuss specific care, medication and adherence issues with the adolescent client/caregiver. The questions should be used to identify areas where the client/caregiver may need additional information and support, but should not be used to 'score' a client's knowledge and readiness to begin ART. It is important to allow time for the client/caregiver to respond to each question. Adolescent clients and caregivers should always be made to feel comfortable asking questions and expressing potential adherence challenges and they should never be judged or punished. Remember to write down any important information from their responses, as this will help to decide on next steps, to identify important areas for follow-up and to support the client's adherence over the long term.

Client/caregiver requires more counselling and support in these areas:

In this space, write down specific areas in which the adolescent client/caregiver needs ongoing adherence counselling and support. Refer to this section of the form during follow-up counselling appointments and clinic visits. Even if a client has questions about his or her care and medicines or is facing specific adherence challenges, this is usually not a reason to delay initiation of ART. Instead, these issues should be viewed as important areas for ongoing counselling and support.

Adherence preparation/support guide for assessing adolescents' readiness for ART

Client's name _____ **Client's age** _____ **Client's file#** _____
Caregiver and/or treatment buddy's name _____

Questions to ask the adolescent:	Notes
1. Can you tell me what peer support group or group education sessions you have attended here at the clinic?	
2. Can you explain why you need to take ART?	
3. Who have you spoken to/who knows about your HIV status?	
4. What do you expect from taking ART?	
5. How do you feel about taking medicines every day for your lifetime?	
6. Can you tell me the names of the medicines you will be taking and when you will take them (how many pills, what times of day)?	
7. Can you tell me some possible side effects of your ART? What will you do if you have side effects?	
8. Can you explain what happens if you do not take all of your ART every day, at the same time?	
9. Who can help you come to the clinic for appointments and help you take your medicines every day? What is his or her name and contact information?	
9a. Has he or she been to the clinic with you?	
9b. What might make it difficult for you to come to this clinic for your appointments?	
10. How will you remember to come for your clinic appointments?	
11. How will you remember to take your medicines the right way, at the same time, every day?	
12. Are you taking any medicines other than the ones prescribed to you by the doctor or nurse (including traditional or herbal medicines)?	
13. Where will you store your medicines?	

Questions to ask the adolescent:	Notes
14. What will you do if you are about to run out of your medicine(s)? What about if you are going to be away from home, like when you are at school?	
15. What will you do if you miss a dose of your medicine?	
16. What questions do you have about the plan for your care and your medicines?	
17. Do you feel ready to start taking these medicines?	

Client requires more counselling and support in these areas (List):

Signature of person completing assessment _____ **Date** _____

Adherence preparation/support guide for assessing caregivers' readiness for ART

Client's name _____ **Client's age** _____ **Client's file#** _____

Caregiver and/or treatment buddy's name _____

Questions to ask the caregiver:	Notes
1. Can you tell me what support group or group education sessions you and your child have attended here at the clinic?	
2. Can you explain why your child needs to take ART?	
3. Who knows about your child's HIV status?	
4. What do you expect from your child taking ART?	
5. How do you feel about your child taking medicines every day for his or her lifetime?	
6. Can you tell me the names of the medicines your child will be taking and when he or she will take them (how many pills, what times of day)?	
7. Can you tell me some possible side effects of your child's ART? What will you do if your child has side effects?	
8. Can you explain what happens if your child does not take all of his or her ART every day, at the same time?	
9. Who will help your child come to the clinic for appointments and help him or her take his or her medicines every day? What is your contact information/ other supporters' contact information?	
9a. *If someone other than the caregiver:* has he or she been to the clinic with your child?	
10. What might make it difficult for your child to come to this clinic for his or her appointments?	
11. How will your child remember to come for his or her clinic appointments?	
12. How will your child remember to take his or her medicines the right way, at the same time, every day?	
13. Is your child taking any medicines – other than the ones prescribed to him or her by the doctor or nurse (including traditional or herbal medicines)?	
14. Where will you store your child's medicines?	
15. What will you do if you are about to run out of medicine(s)? What about if you or your child will be away from each other or away from home, like when he or she is at school?	

16.	What will you do if your child misses a dose of the medicine?	
17.	What questions do you have about the plan for your child's care and medicines?	
18.	Do you feel that you and your child are ready to start taking these medicines?	

Caregiver requires more counselling and support in these areas (LIST):

Signature of person completing assessment _____ Date _____

Adapted from *ICAP, (2010).Improving retention, adherence and psychosocial support within PMTCT services A toolkit for health workers.*

Appendix 8C: Adherence assessment guides

How to use these guides:

These adherence assessment guides were developed to support a range of providers (trained counsellors, APEs, doctors, nurses, pharmacists, community health workers and others) who work with ALHIV and their caregivers. Routine adherence assessments help identify and solve specific adherence challenges in a timely manner. **The adherence assessment guides should be adapted to reflect national HIV care and treatment guidelines, as well as the specific clinic, community and cultural contexts in which they are used and for different ages of adolescent clients.** It may be helpful to translate the guides into the local language.

Included here is one adherence assessment guide to be used with adolescents enrolled in HIV care and treatment and one to be used with caregivers. The guides should be used at every follow-up and refill visit to ensure that the adolescent client and caregiver understand the care and medication plan, and that the client is taking his or her medicines the correct way, every day (and/or that the caregiver is giving the client his or her medicines the correct way, every day). Completed adherence assessment forms should be kept in the client's file and referred to during follow-up visits.

Basic information:

Write the client's name, age and file number, as well as the caregiver or treatment buddy's name, at the top of the form. Then, tick the box corresponding to the type of visit. Be sure to sign and date the form at the end of each session, and ensure that the form is kept in the client's clinic file.

Questions to ask the client/caregiver:

The questions in this section allow you to discuss and assess adherence. It is important to allow time for the client/caregiver to respond to each question. Adolescent clients and caregivers should always be made to feel comfortable expressing adherence challenges and should never be judged or punished. Remember to write down any important information from their responses, as this will help to decide on next steps, to identify important areas for follow-up and to support the client's adherence over the long term. If possible, you should meet with the client and caregiver separately to identify and address any discrepant responses. Meeting separately is especially important as young clients enter middle and late adolescence.

Other assessment measures and next steps:

This is the section where you will make a plan with the adolescent client/caregiver to ensure that the client keeps up good adherence or develops strategies to improve adherence.

- **Other adherence assessment measures** Depending on standard procedures at the clinic, you may do a pill count and/or review the client's medicine diary or calendar. Record the results in the space provided.
- **Specific adherence challenges identified by the adolescent client, caregiver and health worker** Based on the answers to the questions asked in the first section of this form, discuss the specific challenges to adherence that the client is having. Together, discuss possible solutions to each challenge.
- **Referrals made** If there is an outside organization, such as a youth support group or a home-based care programme that could help support the client (and the caregiver and family) to overcome his or her challenges to adherence, refer the adolescent client (and/or caregiver) to

that organization and indicate the name and specific service in this part of the form. In some cases, the client (or caregiver) may need to be referred for other facility-based services, like for an appointment with a trained counsellor or for a session with the pharmacist to explain dosing.

- **Next steps and follow-up plan** Identify which solutions and next steps the client/caregiver thinks are feasible and manageable. For each solution, list the necessary steps the client or you will need to take and a timeline for each. Also, make an appointment for a follow-up visit and record the date on the form. This section of the form can be used as a starting point for adherence assessment during follow-up visits.

Adherence assessment for adolescents taking ART

Client's name _____ **Client's age** ____ **Client's file#** _____

Caregiver and/or treatment buddy's name _____

Tick one: ☐ 2-week follow-up ☐ 1-month follow-up ☐ monthly refill ☐ 3-month refill

Questions to ask the adolescent client:	Notes
1. Can you tell me more about how you took your medicines this past month (or 2 weeks)? Do you know the names of the medicines? How many pills do you take? At what time of day?	
2. I would like you to think about the last 7 days. How many pills did you take late in the last 7 days? What were the main reasons you took them late? For twice daily regimens, was it the morning or the evening dose(s) that you took late?	
3. How many pills did you miss in the last 7 days? What were the main reasons you missed them? For twice daily regimens, was it the morning or the evening dose(s) that you missed?	
4. How did the medicines make you feel? For example, did you have any side effects?	
5. Can you tell me about any changes you noticed (such as in your health) or challenges you had with your medicines?	
6. What support or reminders do you have to help you take your medicines at the same time, every day?	
7. What questions do you have about your care or your medicines?	

Other assessment measures and next steps:	Notes
Results of pill count, if applicable:	
Review of medicine diary or calendar, if applicable:	
Specific adherence challenges identified by the adolescent client, caregiver and health worker: (discuss possible solutions to each)	
Referrals made:	
Next steps and follow-up plan:	Next appointment date: _____

Notes:

Signature of person completing assessment _____ **Date** _____

Adherence assessment for caregivers of adolescents taking ART

Client's name _____ **Client's age** ____ **Client's file#** _____

Caregiver and/or treatment buddy's name _____

Tick one: ☐ 2-week follow-up ☐ 1-month follow-up ☐ monthly refill ☐ 3-month refill

Questions to ask the caregiver:	Notes
1. Can you tell me more about how your child took his or her medicines this past month (or 2 weeks)? Do you know the names of the medicines? How many pills does he or she take? At what time of day?	
2. I would like you to think about the last 7 days. How many pills did your child take late in the last 7 days? What were the main reasons he or she took them late? For twice daily regimens, was it the morning or the evening dose(s) that he or she took late?	
3. How many pills did your child miss in the last 7 days? What were the main reasons he or she missed them? For twice daily regimens, was it the morning or the evening dose(s) that he or she missed?	
4. How did the medicines make your child feel? Did your child have any side effects from the medicines? Can you describe them?	
5. Can you tell me about any changes you or your child noticed (such as in your child's health) or challenges your child had with his or her medicines?	
6. What support or reminders does your child have to help him or her take his or her medicines at the same time, every day?	
7. What questions do you have about your child's care or medicines?	

Other assessment measures and next steps:	Notes
Referrals made:	
Next steps and follow-up plan:	Next appointment date: _____

Notes:

Signature of person completing assessment _____ **Date** _____

MODULE 9:

COMMUNITY LINKAGES AND SUPPORT SERVICES FOR ALHIV

Total module time: 2 hours 15 minutes

Module 9: Objectives

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

- Explain the importance of facility–community linkages
- Describe the common challenges to creating strong facility–community linkages in support of ALHIV and their caregivers, and strategies to overcome these challenges
- Describe community-based support services that ALHIV and their caregivers may need

Session 9.1

Total time taken: 45 minutes

Importance of facility–community linkages

Learning objectives

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

- Explain the importance of facility–community linkages
- Describe the common challenges to creating strong facility–community linkages in support of ALHIV and their caregivers, and strategies to overcome these challenges
- Describe community-based support services that ALHIV and their caregivers may need

9.1.1 Importance of facility–community linkages for ALHIV

9.1.1.1 Health facility–community linkages

A community is made up of members of the population served by the health facility. Community can form a significant component in the delivery of quality HIV services including counselling, adherence support, development of a referral framework and dissemination of information. Planning for quality HIV care and treatment should involve linkages between health facilities and communities in order to maximize the quality and continuum of care. From the facility, clients can be linked with community services or support groups.

Community services include Home and community based care, income generating activities (IGA), legal support, adherence support, information, education, communication and spiritual support.

Support groups include Family and caregiver support group, peer support groups for ALHIV, vocational support groups, adherence educational support group, agricultural clubs, religious groups and post-test clubs.

It is important to link health facility services with services offered at the community level to enhance the care of adolescents. To facilitate this linkage,you should understand the community services and groups in the catchment area. As a health care provider, you need to know the general characteristics of the community support structures that you will link the adolescents to, so as to avoid rejection or conflict of interest.

9.1.1.2 Functions of facility–community linkages

Community participation can serve to:

- Raise awareness, disseminate information and reduce stigma
- Improve treatment and care outcomes by providing supportive services
- Help health care workers to refer adolescents and their families to community-based organizations that can assist them
- Facility–community linkages should be facilitated by health care workers and trained community-based health service (CBHS provider)

There are community-based services available for ALHIV in most places, but groups often do not know about each other or do not know how they can work together. It's important to link health facility services and services offered at the community level to enhance the care of adolescents.

9.1.1.3 Role of the CBHS provider

In order to provide a continuum of care and support to ALHIV and their caregivers/families, you must actively help them get the services they need – at the health facility, in the community and at home.

The general tasks of the CBHS provider include:

- Intensifying early identification of HIV positive client
- Promptly linking HIV positive clients to care and treatment clinics
- Supporting ART adherence and retention
- Tracking clients who have missed appointments
- Facilitating effective community and facility referral and linkages
- Community sensitization and mobilization on adolescent-friendly service

9.1.2 Challenges and strategies in establishing facility–community linkages

9.1.2.1 At facility level

The challenges that health workers face at facility level include:

- Health workers may not be aware of community-based services
- Absence of two-way referrals between facilities and community
- Fragmented/uncoordinated services or non-adolescent-friendly services
- Shortage of human resource, lack of stock of commodities and medicines
- Lack of guidelines and job aids

The facility has to facilitate mechanisms for exchange of information or to formalize two-way referrals with communities. The facility is responsible for planning and coordinating adolescent-friendly services including linkages with the community.

At community level:

Challenges which might spring up at community level while establishing facility–community linkages include:

- Community organizations/leaders may not be aware of adolescent HIV services at the health facility
- Community organizations/leaders may not trust facility-based services or may prefer traditional medicine
- There may not be any community services specifically for ALHIV
- Social and cultural norms, beliefs/religions and gender inequalities
- Lack of knowledge about HIV or the needs of ALHIV among teachers and/or caregivers
- High transportation costs between the community and the health facility

At schools/institutions:

The following are the challenges at schools/institutions which may hinder good linkages:

- Inadequate HIV knowledge among teachers/facilitator
- Schools/institutions may not be aware of community-based services
- There may be no mechanism to exchange information or to formalize two-way referrals between facilities and schools/institutions
- Schools/institutions fear bad reputation

9.1.2.2 Strategies to improve facility–community linkages

At Facility level:

- Understanding and documenting available services and serving organizations in the community
- Facilitating regular meetings with community stakeholders
- Meeting with community leaders to talk with them about ALHIV and the importance HIV care and treatment services
- Starting support groups for adolescents

Facilities should facilitate regular meetings with stakeholders to:

- Share information about the needs of ALHIV
- Discuss available services
- Discuss how to facilitate inter-agency linkages and referrals

Facilities can learn about community organizations and their services by:

- Visiting these organizations to find out what services they offer
- Setting up formal or informal two-way referral systems

At community level:

- Participating in community meetings to discuss HIV, ALHIV and HIV care and treatment
- Training/orienting community-based peer educators, youth group members and community health workers

- Involving young community members openly living with HIV in strengthening facility–community linkages
- Developing a directory of available ALHIV services and establishing referral, linkage system and network

You should learn what community organizations and services are available by:

- Visiting organizations to find out what services they offer.
- Setting up formal or informal two-way referral system

At schools/institutions:

- Training teachers and sensitizing them about HIV management
- Sharing with schools and institutions a directorate of available services and support groups in the area for ALHIV
- Establishing referral and linkage system
- Facilitating elimination of stigma and discrimination
- Establishing facility-schools arrangements for ALHIV clinic visit, for example, specific clinic hours for adolescent students

Health facilities should work with neighbouring schools and institutions to raise awareness of HIV management and establish linkages and referral systems.

9.1.3 Key points

- Linkages to community resources and support are important to help ALHIV and their caregivers get the services and support they need across the continuum of HIV care.
- Health workers should stay up-to-date on which services are available for ALHIV and their caregivers/families and maintain a directory of these services to facilitate referrals.

Session 9.2

Total time taken: 1 hour

Creating a community resource directory

Learning objectives

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

- Create a community resource directory for community services

9.2.1 Community resource directory for community services

9.2.1.1 Creating a community resource directory

HIV community resource directory refers to a document which shows services for PLHIV available in the community. As a health care provider, you may not know all the organizations providing adolescent care services at the community level. However, you can gather this information by organizing meetings for organizations in your community to meet on a routine basis for the purpose of identifying, coordinating and enhancing the available package of services for ALHIV. This can enhance strong facility–community linkages and a coordinated referral system.

Each clinic should establish two-way referral systems to and from the organizations in the directory. Work with adolescents to map available resources in the community for ALHIV and their families. Regularly update the community resource directory.

The directorate should include days/times services are offered, fees, documentation required at the time of initial visit, address, phone number, contact person, etc. Post copies in the clinic waiting room and make copies available in exam and counselling rooms. Designate specific people to update the resource directory regularly.

A good way of knowing where to refer clients is for each health facility to develop and regularly update a community resource directory. Consult CHACC when establishing the resource directorate.

9.2.1.2 Community services

- ALHIV support groups
- Nutritional and food support
- Home-based care and adherence support
- Education and counselling
- Social grants
- Support accessing supplies
- Condom distribution outlets
- Support for child-headed households and OVC
- Education and life skills
- Job preparation and placement
- Spiritual support
- Income generating programmes
- Legal support

9.2.2 Key points

- To ensure good facility–community referrals, it is essential that we develop, maintain and use an up-to-date community resource directory.
- Designate specific people to update the resource directory regularly.

Session 9.3

Total time taken: 30 minutes

Adolescent participation and peer education programmes

Learning objectives

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

- Describe the importance of meaningful adolescent involvement
- Describe effective strategies for involving adolescents in service delivery
- Explain the key components of implementing a successful adolescent peer education programme

9.3.1 Importance of meaningful adolescent involvement

9.3.1.1 Adolescent involvement – service delivery

For successful and meaningful adolescent involvement:

- It is critical to ensure that services are designed and implemented to meet adolescents' needs and require commitment from every member of the multidisciplinary team
- ALHIV may have their own support groups where they discuss topics. These discussions are led by an APE. Peer educators play an important role in initiating, organizing, facilitating and mentoring support groups
- Adolescent peer education offers many benefits to HIV care and treatment programmes

Participation of ALHIV in all aspects of HIV programmes is critical to ensure that services are designed and implemented to meet client needs. Involvement of adolescents and affected communities in clinical services help people to draw on their own experiences to increase effectiveness and appropriateness of services. One way to formally involve adolescent clients in clinical services (planning, implementation and evaluation) is through involvement of APEs.

9.3.2 Effective strategies for involving adolescents in service delivery

9.3.2.1 APEs (APE)

APEs (APE) can complement the work of health care workers and play an important role in improving client adherence and service quality through peer education. Peer education refers to sharing of information and experiences among individuals who have something in common. Peer education is an effective tool for promoting healthy behaviours among adolescents.

9.3.2.2 Benefits of peer education

The benefits of peer education include:

- It offers a safe environment- people trust others in the same situation as themselves
- Improves retention in care, adherence to treatment, linkages, positive living and access to quality service
- Increases community participation and advocacy
- Prepares adolescents for future job opportunities
- Increases access to services
- Offers a closer sense of connection for adolescent clients

9.3.2.3 Qualifications of peer educator for ALHIV

Expected qualities of a peer educator for ALHIV are as follows:

- Older adolescent
- Living positively with HIV
- Adherent to care and medication
- Open minded and non-judgmental
- Respectful and tolerant of different perspectives
- Basic literacy and numeracy skills
- Good interpersonal and communication skills
- Committed to work with other ALHIV
- Available to work at the clinic (no conflict with school/work)
- Represent age, ethnicity, social economic status, gender language and other features of ALHIV in the clinic

APEs can play important roles in direct service delivery, as well as in planning, monitoring, evaluating and participating in quality assurance activities at the facility. As ALHIV and service recipients themselves, APEs can give meaningful feedback to health care programmes, offer insights into the best ways to retain young people in care and support their adherence to ART.

9.3.2.4 Ensuring that expectations are realistic

- Keep expectations,assigned responsibilities and tasks of peer educators realistic (e.g., an APE should not be expected to provide professional-level counselling)
- Provide follow-up training and ongoing mentoring and supervision
- Make boundaries very clear to APE
- Make sure that the programme has explicit rules and that APE are supervised and supported to adhere to them

In involving peer educators avoid:

- Having adolescents present but with no clear role, training, support or supervision
- Asking adolescents their opinions but not taking these opinions seriously
- Assigning tasks to adolescents that adults do not want to do, like filing or cleaning

Health facilities should always use a developmental approach when involving adolescents in programme delivery.

9.3.3 Key components of implementing a successful adolescent peer education programme

9.3.3.1 Key steps in implementing a facility-based adolescent peer education programme

The key steps in implementing a facility-based adolescent peer education programme include:

1. Conducting a participatory situational analysis and needs assessment
2. Engaging stakeholders in participatory program design
3. Defining program indicators, setting targets and developing tools
4. Developing a detailed budget and workplan
5. Recruiting APEs based on selection criteria
6. Adapting or developing a training curriculum
7. Training APEs
8. Engaging health facility teams to roll out peer education activities
9. Providing on going support, supervision and mentoring to APEs
10. Continuously monitoring, evaluating and adjusting the programme

9.3.4 Key points

- Adolescents should be involved in clinical services (planning, implementation and evaluation) is through involvement of APEs.
- APEs can give meaningful feedback to health care programmes, offering insights into the best ways to retain young people in care and support their adherence to treatment.
- Adolescent-centred peer education is a powerful approach to improve the quality of adolescent-friendly services.

Appendix 9A: Community resource directory template

DISTRICT NAME _____ FACILITY NAME _____
DATE _____

Name of organization	Services provided for youth/ families	Geographic areas covered	Contact person	Phone number and address	Other*
1.					
2.					
3.					
4.					
5.					
6.					
7.					
8.					
9.					
10.					

* 'Other' might include, for example, hours of opening, fees, documentation needed at initial visit, information about how to get there (transportation, bus line, directions if difficult to find), etc.

MODULE 10:

ADOLESCENTS, HIV AND MENTAL HEALTH

Total module time: 2 hours 30 minutes

Module 10: Objectives

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

- Describe mental health related to ALHIV
- Manage common mental illnesses among ALHIV
- Provide basic mental health support to ALHIV

Session 10.1

Total time taken: 45 minutes

Overview of mental health and mental illness among ALHIV

Learning objectives

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

- Define mental health and mental illness
- Describe mental illnesses commonly seen among ALHIV
- Provide basic mental health services to ALHIV

10.1.1 Mental health related to ALHIV

10.1.1.1 Mental health

Mental health refers to the psychological or emotional well-being of an individual. It involves four main aspects of mental functioning, which are:

- Appropriate awareness of self
- Awareness of one's abilities
- Ability to work productively in school or communities
- Ability to contribute to community

Healthy development during childhood and adolescence contributes to good mental health and can prevent mental health problems later in life.

10.1.1.2 Mental illness

- Problems of mental health emerge in late childhood and early adolescence
- Poor mental health among adolescents is associated with several health and social outcomes such as;
  - Higher alcohol, tobacco and illicit substance use
  - Adolescent pregnancy
  - School dropout rates
  - Risky behaviours

- Mental health problems among adolescents include depression, anxiety, conduct disorders and eating disorders
- Depression is the largest cause of the burden of disease among adolescents

Adolescents who suffer from depression are more likely to be non-adherent to their medication and have other self-care issues, thus requiring extra attention in both assessment and planning of their care.

10.1.2 Common mental illnesses among ALHIV

10.1.2.1 Mental illness

Mental illness refers to any disease or condition affecting the brain that significantly influences or disrupts a person's thinking, feeling, mood, ability to relate to others and daily functioning. It is characterized by the presence of one or both of the following over time:

- Persistent and severe subjective distress (or discomfort)
- Moderate or severe impairment in functioning (not being able to 'get through' day-to-day activities)

Mental health problems that do not meet the threshold for mental illness can be addressed through general counselling.

Although the exact cause of most mental illnesses is not known, it is becoming clear through research that many are caused by a combination of factors. This module focuses specifically on mental illnesses. Refer to Module 4 for more information on basic counselling and communication skills; Module 7 for more on psychosocial assessment, support information and skills; and Module 11 for more on positive living and positive prevention information.

10.1.2.2 Common mental illnesses seen in adolescents

ALHIV are susceptible to a number of mental illnesses, which can be broadly classified into the following categories:

- Depression
- Alcohol and substance use disorders
- Anxiety disorders (persistence fear or worry that is out of proportion with a person's current life circumstances)
- Behavioural disorders (violent behaviour, aggression and impulsivity)

Suicide is the most severe consequence of mental illness. While severe depression is most commonly associated with suicide, other mental illnesses may also increase an adolescent's risk of suicide.

Mental illnesses vary in severity and can create barriers to adolescents achieving self-protection and the expected degree of independence. Mental illnesses can also interfere with an adolescent's HIV care, including retention, adherence, positive living and positive prevention.

10.1.2.3 Importance of mental health services for ALHIV

Recognizing possible mental illness and providing ALHIV with mental health services is important because:

- Primary mental illnesses usually begin in childhood, adolescence or early adult life
- A person's mental health significantly influences his or her adherence to HIV care and treatment
- Mental health status influences the course of HIV disease and makes it more difficult to engage in positive living and positive prevention

The presence of one mental illness predisposes a person to the onset of other mental disorders (for example, it is not unusual to see a depressed adolescent who also abuses alcohol).

Untreated mental illnesses can disrupt adolescent development by interfering with the ability to work, attend school and form social relationships. Untreated mental illnesses can also result in suicide.

10.1.2.4 Challenges in providing mental health services to adolescents

Challenges in providing mental health services to adolescents include:

- Insufficient number of mental health specialists to provide services, training and supervision
- Limited information on the prevalence of mental health disorders in African countries
- Lack of validated and context-appropriate screening tools
- Few treatment options available in most settings
- Very limited data available on the treatment of psychiatric disorders in ALHIV
- High levels of social stigma and discrimination faced by individuals, families and communities in relation to mental illness

10.1.3 Basic mental health support to ALHIV

10.1.3.1 Solutions to challenges in improving mental health for ALHIV

Health workers can provide mental health support to adolescents by:

- Recognizing that ALHIV are at risk for mental illness and knowing the array of mental illnesses that are seen in adolescents
- Including mental health in routine care by conducting regular psychosocial assessments, assessing a client's mental health needs, checking in with caregivers about changes they have observed, etc.
- Using clinical skills and observations during routine visits to identify possible signs of mental illness
- Knowing the signs of mental illness and how to refer clients for further assessment and care
- Using simple mental health screening tools

- Distinguishing urgent mental illness from less pressing mental health concerns
- Providing appropriate mental health referrals and follow-up care and support
- Considering the impact of mental illness on an adolescents' HIV care, including adherence
- Respecting and listening to the adolescents', caregivers', care supporters' (peer, relatives, etc.) beliefs about the origin and treatment of mental illness
- Discouraging the use of alcohol,tobacco and drugs among adolescents

10.1.4 Drugs/alcohol and adolescence

Adolescents often face challenges and temptations related to drugs and alcohol. People sometimes drink or use drugs to take away their worries; however, this usually makes them feel worse in the long term. Drug and alcohol use may lead to addiction, which is when a person's body starts to need the substance. People who are addicted to drugs and alcohol often do not eat well. Health workers can help adolescents avoid alcohol and other forms of substance use in the first place.

Not everyone who uses drugs becomes addicted, however alcohol and other forms of substance use can cause problems for ALHIV, whether they get addicted or not. Health workers can help adolescents avoid alcohol and other substance use by watching for signs of alcohol and substance use and screening when necessary. Health workers can help clients who are using or abusing drugs and alcohol by providing counselling, support and referrals.

10.1.4.1 Predictors of abuse

The common predictors of substance abuse include:

Family factors	Observing parents or family members using or abusing drugs or alcohol; genetic risk factors; parental absence; inconsistent discipline; lack of communication within family; conflict between parents and adolescents; death of parents due to HIV; family breakup
Peer factors	Spending time with peers who use alcohol and drugs is perhaps the strongest predictor of adolescent substance use and abuse
Mental health problems	There is a strong link between mental health problems and substance abuse
Response to stress	Feeling out of control, feeling hopeless, having a lack of direction in if

10.1.4.2 Consequences of alcohol and other substance use among adolescents

The risks and problems associated with alcohol and substance use are:

- Poor adherence to HIV care and treatment
- School-related problems
- Risky sexual practices
- Delinquent behaviour and juvenile crime

- Developmental problems
- Physical and mental consequences

Physical and mental consequences involve:

- Short-term consequences like memory loss
- Long-term consequences like cancer, heart and respiratory failure, stomach ailments, central nervous system damage and sexual impotence

Substance use may interact with depression and contribute to suicide,accelerate HIV disease progression and increase risk of violence or accidental death.

10.1.4 Key points

- Healthy development during childhood and adolescence contributes to good mental health and can prevent mental health problems.
- Mental disorders vary in severity and create barriers to adolescents achieving self-protection and the expected degree of independence.
- Mental illness can interfere with an adolescent's HIV care, including retention, adherence, positive living and positive prevention.

Session 10.2

Total time taken:
1 hour 45 minutes

Management of common mental illness among ALHIV

Learning objectives

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

- Describe the mental health assessment process for ALHIV
- Describe the basic management of anxiety in ALHIV
- Describe the basic management of depression in ALHIV
- Describe the basic management for mental health emergencies

10.2.1 Mental health assessment process in ALHIV

10.2.1.1 Mental health assessment

Diagnosing a specific mental illness can be difficult and requires specialized training. However, all health workers should know how to recognize the signs of the presence of a serious mental illness and accordingly refer adolescents for further assessment and care.

Assessment of mental health includes:

1. Reviewing the client's recent and past history (somatic symptoms, client's clinical and ART history)
2. Making observations about appearance and presentation, attitude and behaviour, mood and emotions, speech, thinking, perception, level of alertness and orientation, and social and intellectual skills of the client
3. Conducting regular mental health assessments

If the review of history and observations reveal possible problems, ask a few simple follow-up questions that are specific to the problems reported or observed, such as:

- *What is making you cry?*
- *You look frightened today – did something scare you?*
- *What are you feeling angry about?*
- *You are usually so nicely dressed – is something wrong?*
- *Have you noticed how quickly you are speaking?*

Further steps are to be taken by health worker once history and observation has revealed possible signs of mental illness.

Older adolescents may demonstrate more pronounced difficulties with schoolwork, truancy, running away from home and substance abuse. Mental illness interferes with their sense of well-being and/or the ability to carry out usual activities. You should also review clients' clinical and ART history as they may contribute to mental health changes/problems.

Delirium is a serious medical (i.e., not psychological) condition that can be present with signs of mental illness, such as delusions, hallucinations and agitation. However, delirium is not common among adolescents. Prior to concluding that an adolescent has a primary mental illness, first assess whether the adolescent has delirium and is in urgent need of medical care.

10.2.1.2 Importance of psychosocial assessments in diagnosing mental illnesses

Regular psychosocial assessments can:

- Reveal things about the client's mood, mood changes, coping, daily habits, alcohol and drug use and support systems
- Identify areas for additional follow-up and support and reveal possible signs of mental health problems that may require further assessment

Be reminded that the presence of mental illnesses in clients can vary from culture to culture and person to person. There are also differences in younger versus older adolescents *(Refer **Module 7** for more information on psychosocial assessment.)*

10.2.2 Basic management of anxiety and depression in ALHIV

10.2.2.1 Depression

Depression is a feeling of intense sadness, including feeling helpless, hopeless and worthless that usually lasts from days to weeks, accompanied by a loss of interest in activities that usually give pleasure. It is one of the most common mental illnesses in outpatient clinics but is often overlooked. It is also the largest cause of burden of disease among adolescents.

Very few adolescents will present a straightforward complaint of depression. Majority of the adolescents will present other complaints and may never mention their depressed mood unless questioned specifically about the symptoms. If the adolescent presents a vague somatic (body) complaint or numerous complaints that do not fit any clear clinical pattern, consider depression as a diagnosis.

10.2.2.2 Common symptoms of depression

S	Sleep disturbance
I	Interest/pleasure reduction
G	Guilty feelings or thoughts of worthlessness
E	Energy changes/fatigue
C	Concentration/attention impairment
A	Appetite/weight changes
P	Psychomotor disturbances
S	Suicidal thoughts
Plus depressed mood	
Five of these nine symptoms must be present to make a diagnosis.	

10.2.2.3 Management of depression

Counselling is essential in all age groups but often, access is limited. Conducting some counselling in routine clinical visits is an option, although this may require more time.

10.2.2.4 Management of suicidal thoughts or self-harm

- Evaluating whether the person has attempted a medically serious act of self-harm or suicide:
  - ☐ Ask about past self-harm attempts
  - ☐ Look for signs of poisoning, intoxication and self-injury
  - ☐ Treat symptoms medically but with the advice of a mental health expert
  - ☐ Closely monitor the person to prevent further self-harm
  - ☐ Do not leave the person alone or unsupervised
- Evaluating whether there is an imminent risk of self-harm or suicide:
  - ☐ Ask about current thoughts or plans to commit suicide or self-harm
  - ☐ Look for signs of severe emotional distress, hopelessness, agitation, uncommunicative behaviour or social isolation
- Treat or refer the client to a psychiatric hospital

If risk of suicide or self-harm is imminent:

- Remove access to means of self-harm
- Create a secure and supportive environment and ensure that the person is not left alone
- Transfer the client to a psychiatric hospital, accompanied by a family member or any other reliable escort, including, if available, a health worker
- Adolescents with suicidal thoughts may still be at risk of suicide even after treatment has begun

Tables 10.1–10.4 *summarize basic information on common categories of mental illness, including basic definitions, possible signs and symptoms you should watch out for and suggestions for what to do if you observe these signs and symptoms.*

Table 10.1: Depression – Tips for health workers

Possible signs and symptoms of depression	■ Depressed mood, feelings of helplessness or hopelessness ■ Really tired with no energy ■ Cannot find good in anything ■ Does not enjoy things (loss of interest or pleasure) ■ Sleeps too much or not enough ■ Gets angry for no reason ■ Cannot eat or eats too much ■ Does not feel like being social with friends or family ■ Feelings of guilt or low self-worth ■ Poor concentration ■ Talks about running away ■ Thinks about suicide ■ Talks of self-injury or has had prior episode(s) of self-injury ■ Prior attempts or expressions of suicide
What the health worker can do	■ Symptoms of depression are very common among adolescents. They are often transient and respond to support from friends, family and health workers ■ If problems are mild, try psychosocial counselling and support strategies (see Modules 4 and 5) ■ Refer client to trained counsellor or another mental health care provider, peer support group or group/individual therapy, if available ■ Ask about alcohol and drug use (see below) ■ Review the client's HIV history, recent changes in disease status and ART regimen (including any dosing changes or new medications) ■ Screen the client for depression using the screening tools in *Appendix 10B: Sample screening tools for depression and suicide* ■ If depression is severe, does not improve or worsens, refer client to a mental health care provider **Screen for suicide risk. Clients require urgent intervention if:** ■ They indicate that they might hurt themselves or another person, or if they show any evidence of self-harm ■ Their families cannot cope with them anymore ■ They are thinking about, threatening or have attempted to kill themselves ■ If suicidal, ensure immediate safety and refer to the nearest psychiatric hospital; provide constant supervision during transfer (see the section on 'Managing psychiatric emergencies' below for more information).

Table 10.2: Alcohol and substance use disorders – Tips for health workers

Possible signs and symptoms of alcohol and substance use disorders	■ Sudden changes in personality without another known cause ■ Loss of interest in favorite hobbies, sports or other activities ■ Sudden decline in performance or attendance at school or work ■ Changes in friends and reluctance to talk about new friends ■ Deterioration of personal grooming habits and personal hygiene ■ Difficulty paying attention or forgetfulness ■ Sudden aggressive behaviour, anger, nervousness or giddiness ■ Increased secretiveness, heightened sensitivity to being asked questions ■ Sudden changes or unexplained problems with adherence to medications or missed appointments
What the health worker can do	■ Provide general education and counselling on risk reduction and behavioural change. For example, assess the safety of the client and others while client is under the influence of alcohol or drugs (if operating a motor vehicle, having sex, etc.) and provide risk reduction counselling ■ Provide referrals for individual and group counselling and treatment (e.g., Alcoholics Anonymous) ■ Review the client's HIV history, recent changes in disease status and ART regimen (including any dosing changes or new medications) ■ Screen for alcohol misuse,drug use,abuse upon initial intake and whenever suspected, based on medical history, reports from family/ partner, client's behaviour in the clinic, or findings from psychosocial assessments. (See *Appendix 10C: Screening for Alcohol Dependency with the CAGE Questionnaire* and *Appendix 10D: The Drug Abuse Screening Test*) ■ Be patient and accepting of the client's situation; recovery can be a gradual process ■ Provide ongoing support and follow-up at every visit ■ See Module 9 for more information

Table 10.3: Anxiety disorders – Tips for health workers

Possible signs and symptoms of anxiety disorders	■ Cannot eat ■ Cannot breathe or has frequent shortness of breath ■ Panic attacks (may include shaking, sweating, fast heartbeat, difficulty breathing) ■ Tingling in the hands or feet ■ Chronic headaches ■ Trouble sleeping; nightmares ■ Cannot concentrate on anything ■ Feels jumpy, stressed out or restless ■ Feels overwhelming sense of worry ■ Fearful of participating in normal activities
What the health worker can do	■ Symptoms of anxiety are very common among adolescents. They are often transient and respond to support from friends, family and health workers ■ If problems are mild, try psychosocial counselling and support strategies (see Modules 4 and 5) ■ Refer client to peer support groups and group/individual therapy, if available ■ Teach client relaxation techniques and explore other coping mechanisms to manage anxiety ■ Review the client's HIV history, recent changes in disease status and ART regimen (including any dosing changes or new medications) ■ If anxiety is severe, interferes with the client's functioning and/or does not improve or worsens over time, refer client to a mental health provider

Table 10.4: Behavioural disorders – tips for health workers

Possible signs and symptoms of behavioural disorders	■ Frequent defiance of authority ■ Arguing and refusing to obey rules at home and at school ■ Failure to take responsibility for bad behaviour or mistakes ■ Resentment, looking for revenge ■ Regular temper tantrums **In older children/adolescents:** ■ Aggressive behaviours that threaten/harm people or animals ■ Behaviours that destroy property ■ Stealing, bullying or lying ■ Serious violations of rules at home or at school **Adolescents with attention deficit hyperactivity disorder (ADHD) often exhibit the following symptoms:** ■ Trouble paying attention and concentrating ■ Difficulty in organizing activities ■ Easily distracted and fails to finish tasks ■ High activity level ■ Cannot sit still ■ Impulsivity ■ Cannot wait for a turn ■ Interrupts when others are talking or doing something
What the health worker can do	■ Counsel the client, focusing on self-regulation ■ Counsel caregivers, focusing on improving parenting skills and giving advice on how to create a structured home environment ■ Review the client's HIV history, recent changes in disease status and ART regimen (including any dosing changes or new medications). ■ Talk with a mental health specialist about prescribing medication ■ Provide referrals to local support services

10.2.3 Basic management for mental health emergencies

10.2.3.1 Psychiatric emergencies

- Attempted suicide
- Substance abuse
- Depression
- Psychosis
- Violence
- Rapid changes in behaviour

Sometimes an adolescent may act in a violent or agitated manner, making it necessary to provide immediate management. Each health facility should develop standard operating procedures on the management of psychiatric emergencies, train all health workers in following these procedures and ensure that they are implemented.

10.2.3.2 Managing psychiatric emergencies

How to manage a client who is violent or very agitated:

- Protect the client from harming himself or herself, you or others
- Ensure that you are in a quiet area where there is no audience
- Use space to protect yourself
- Get help from other colleagues, security or family members
- Approach the client in a calm and confident manner
- Speak in a calm and reassuring way.
- Be non-confrontational, non-judgmental and deflect criticism.
- Keep your own emotions in check.
- Be aware of potential weapons and remove unsafe objects
- Consider sedation with diazepam or haloperidol

A note on restraining patients In some places, it is currently or was previously customary practice to restrain violent or agitated patients, such as by using hand and feet restraints. The global community recognizes such extreme restraint as both cruel and unnecessary. You should not restrain patients in this way unless it is absolutely necessary to protect the patient.

Exercise 3: Case study 1

Follow instructions provided by facilitators.

Mario is an 18-year-old client who was recently diagnosed with HIV. Mario missed his last appointment two weeks ago, but has come to the clinic today. He tells you that he is too busy with 'life' to come to the clinic and he appears shaky and nervous. You conduct a psychosocial assessment, during which you learn that Mario recently was fired from his job and spends most nights getting drunk with his friends to 'forget about everything'.

- *What are the main mental health concerns for this client? Is there an emergency situation?*
- *What additional information would you want to know about the client (mental health status, HIV care, adherence, positive prevention)? Are there any tools you would use to gather more information?*
- *How would you proceed with this client in your facility (what would you do, what referrals would you make)?*

Exercise 3: Case study 2

Nora is 16 years old. She has been on ART and has been coming to the clinic for many years. As a child, she maintained good grades in school and was described by her grandmother as being helpful around the house. Recently, however, Nora's relationship with her family has deteriorated. She is not eating or sleeping regularly, she goes through periods of extreme anger followed by periods of complete withdrawal, and has run away from home to live with

her boyfriend twice in the past year. Nora says, "Life is not worth living if I can't be with my boyfriend". Her grandmother is very concerned that Nora is going to do something to hurt herself.

- *What are the main mental health concerns for this client? Is there an emergency situation?*
- *What additional information would you want to know about the client (mental health status, HIV care, adherence, positive prevention)? Are there any tools you would use to gather more information?*
- *How would you proceed with this client in your facility (what would you do, what referrals would you make)?*

Exercise 3: Case study 3

Paul is a 14-year-old boy with HIV. He and his aunt arrive at the clinic for a routine check-up. Paul's aunt tells you that she is worried about her nephew because he often seems to get agitated and jumpy. He does not want to go to school or play with his friends like he used to. He also has 'episodes' usually at night or right before he is supposed to leave for school in the morning, where he has trouble breathing and sweats. Paul was living with his mother until she died two years ago.

- *What are the main mental health concerns for this client? Is there an emergency situation?*
- *What additional information would you want to know about the client (mental health status, HIV care, adherence, positive prevention)? Are there any tools you would use to gather more information?*
- *How would you proceed with this client in your facility (what would you do, what referrals would you make)?*

Exercise 3: Case study 4

Blanka is 13 years old and comes for a routine visit with her mother. When you do a clinical check-up with Blanka, you notice that she is having trouble paying attention, that she is suspicious when you ask her questions, and that her clothes and hair are unkempt (which is unusual). At one point, she mentions 'a voice' that is telling her to do bad things that she doesn't want to do and then she starts crying. You then meet with Blanka's mother, who tells you that Blanka has "turned into a different person" during the last few months. She cannot focus at school, seems suspicious when anyone wants to talk with her, she hides her medications, she does not care about her appearance any more and her behaviour in general just seems off.

- *What are the main mental health concerns for this client? Is there an emergency situation?*
- *What additional information would you want to know about the client (mental health status, HIV care, adherence, positive prevention)? Are there any tools you would use to gather more information?*
- *How would you proceed with this client in your facility (what would you do, what referrals would you make)?*

10.2.4 Key points

- When adolescent presents vague somatic (body) complaints or numerous complaints that do not fit any clear clinical pattern, consider depression as a diagnosis.
- All health workers can identify signs of possible mental illness, assess the severity of the signs and symptoms and discuss them with the team by using simple screening tools like the BATHE technique.
- There are many challenges to providing mental health care in resource-limited settings, but there is also a lot we can offer to adolescent clients and caregivers, including ongoing support, emergency management and referrals to mental health care.

Appendix 10A: Tips for health workers on identifying possible mental illness

√	Categories	Signs of a possible mental illness that may require follow-up
1. Ask the client and caregiver about:		
	Present history (reported by client or caregiver)	■ Reports symptoms of mental illness or mental distress ■ Reports new problems with functioning at home, school, work or new problems with friends and family ■ Reports a dramatic change in behaviour and/or a major decrease in psychological functioning (e.g., used to be very calm, now violent; used to do well in school, now falling behind; used to be friendly, is now withdrawn, etc.) ***Note:*** *Review the client's HIV history, recent changes in disease status and ART regimen (including dosing or medicine changes)*
	Past history (reported by adolescent client or caregiver)	■ Reports a past history of mental distress; problems with functioning at home, school, work or problems with friends and family ■ History of psychiatric hospitalization, treatment or psychotropic medication use ■ History of school failure ■ History of severe behavioural disturbances ■ History of mental illness in the family
2. Observe and ask for the caregivers' observations of the client:		
	Appearance and presentation	■ Hygiene and grooming are poor ■ Comes across as frightening or frightened ■ Has alcohol on his or her breath or appears intoxicated ■ Does not make eye contact ■ Crying, shouting or laughing uncontrollably
	Attitude and behaviour	■ Restless, belligerent, or uncooperative ■ Making threats ■ Unwilling or unable to speak ■ Behaving in odd and unusual ways
	Mood and emotions	■ Seems frightened, sad or angry ■ Unusually happy for no apparent reason
	Speech, thinking and perception	■ Speaking very rapidly or overly loud ■ Whispering or speaking very softly ■ Saying things that make no sense ■ Saying things that are unlikely to be true ■ Claiming to hear voices or to see visions of people/things that are not there

√	Categories	Signs of a possible mental illness that may require follow-up
	Level of alertness and orientation	■ Having trouble staying alert and attentive ■ Drowsy ■ Confused about things such as where he or she is or the time of day
	Social and intellectual skills	■ Lacks verbal, behavioural, and/or social skills that would be expected of someone his or her age ■ Behaving like a much younger child/adolescent
3. Conduct regular psychosocial assessments and document major findings (see Module 5)		
	Conduct a psycho-social assessment (at enrollment, annually and when the client's situation changes significantly)	■ Major changes in mood ■ Experiencing chronic sadness or anxiety ■ Changes/problems in sleeping, eating or other routines ■ Harmful coping strategies, including use of alcohol or drugs ■ Problems in school, with friends or with family members

Appendix 10B: Sample screening tools for depression and suicide

Patient health questionnaire-2 (PHQ-2)

This simple questionnaire can be used as an initial screening test for a major depressive episode.

Over the past two weeks, how often have you been bothered by any of the following problems?

Little interest or pleasure in doing things

0 = Not at all

1 = Several days

2 = More than half of the days

3 = Nearly every day

Feeling down, depressed or hopeless

0 = Not at all

1 = Several days

2 = More than half the days

3 = Nearly every day

Total point score: _____

Score interpretation:

PHQ-2 score	Probability of major depressive disorder (%)	Probability of any depressive disorder (%)
1	15.4	36.9
2	21.1	48.3
3	38.4	75.0
4	45.5	81.2
5	56.4	84.6
6	78.6	92.9

Source: *Kroenke, K., Spitzer, R.L., and Williams, J.B (2003). The Patient Health Questionnaire-2 Validity of a two-item depression screener. Med Care, 411284–92.*

PHQ-9 Questionnaire, modified for adolescents

Name _____ **Clinician** _____

Medical record or ID number _____ **Date** _____

How often have you been bothered by each of the following symptoms during the past two weeks?

	(0) Not at all	(1) Several days	(2) More than half the days	(3) Nearly every day
1. Feeling down, depressed, irritable or hopeless?				
2. Little interest or pleasure in doing things?				
3. Trouble falling asleep, staying asleep or sleeping too much?				
4. Poor appetite, weight loss or overeating?				
5. Feeling tired or having little energy?				
6. Feeling bad about yourself or feeling that you are a failure or that you have let yourself or your family down?				
7. Trouble concentrating on things like school work, reading or watching TV?				
8. Moving or speaking so slowly that other people couldn't have noticed? Or the opposite – being so fidgety or restless that you were moving around a lot more than usual?				
9. Thoughts that you would be better off dead or thoughts of hurting yourself in some way?				

10. In the past year, have you felt depressed or sad most days, even if you felt okay sometimes?

☐ Yes ☐ No

11. If you are having any of the problems on this form, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?

☐ Not difficult at all ☐Somewhat difficult ☐ Very difficult ☐Extremely difficult

12. Has there been a time in the past month when you have had serious thoughts about ending your life? ☐ Yes ☐ No
13. Have you ever, in your whole life, tried to kill yourself or made a suicide attempt? ☐ Yes ☐ No

Score _____

Administering the PHQ-9 questionnaire:

- This questionnaire can be used with patients between the ages of 12 and 18 and takes less than five minutes to complete and score.
- It can be administered and scored by a nurse, medical technician, physician assistant, physician or other office staff.
- Patients should be left alone to complete the questionnaire in a private area, such as an exam room or the private area of a waiting room.
- Patients should be informed of their confidentiality rights before administering this questionnaire.
- Depression screening should be conducted annually.

Scoring:

- For every X:

Not at all	= 0
Several days	= 1
More than half the days	= 2
Nearly every day	= 3

- Add scores of all 'X'ed boxes.
- Total score of 11 or above indicates a positive screen.
- Regardless of the total score, endorsement of serious suicidal ideation OR past suicide attempt (questions 12 and 13) should be considered a positive screen.

Total score: depression severity

1–4:	Minimal depression
5–9:	Mild depression
10–14:	Moderate depression (score of 11 or above = positive score)
15–19:	Moderately severe depression

Interpreting the screening results:

- Patients who score positive on the questionnaire should be evaluated by their primary provider to determine if the depression symptoms they expressed on the screen are significant, causing impairment and/or warrant a referral to a mental health specialist or follow-up treatment by the provider.
- It is recommended that the provider inquire about suicidal thoughts and previous suicide attempts with all patients that score positive, regardless of how they answered these items on the questionnaire.
- For patients who score negative, it is recommended that the provider briefly review with the patient the symptoms marked as 'more than half days' and 'nearly every day'.
- The questionnaire indicates only the likelihood that a youth is at risk for depression or suicide; its results are not a diagnosis or a substitute for clinical evaluation.

Depression severity:

- The overall score provides information about the severity of depression, from minimal to severe depression.
- The interview with the patient should focus on their answers to the screen and the specific symptoms with which they are having difficulties.
- Additional questions also explore dysthymia, impairment of depressive symptoms, recent suicide ideation and previous suicide attempts.

Source: *Spitzer, R.L., Williams, J.B., Kroenke, K., et al (2005). Patient Health Questionnaire modified for teens (PHQ-9).*

Appendix 10C: Screening for alcohol dependency with the CAGE questionnaire

✓	Screening for alcohol dependency
	1. Use the CAGE questionnaire
	■ Have you ever felt that you should **C**ut down on your drinking?
	■ Have people **A**nnoyed you by criticizing your drinking?
	■ Have you ever felt bad or **G**uilty about your drinking?
	■ Have you ever had an **E**ye-opener – a drink first thing in the morning to steady your nerves or get rid of a hangover?
	2. If the client responded 'yes' to 2 OR MORE of the above questions, then he or she may have alcohol dependency.
	3. Give feedback on the results of the screening; provide support and referrals.
	■ Provide information about the hazards of drinking (including poor adherence to HIV care and treatment). ■ Involve the adolescent's caregiver(s), if appropriate and if the adolescent gives consent. ■ Emphasize the benefits of changing and assess the client's level of motivation to change. ■ If the client wants to change his or her drinking behaviour, discuss goals and provide advice and encouragement. ■ Provide referrals to a support group and for further counselling. If needed, find a facility that may be able to help the patient overcome physical dependency and, if necessary, detoxification to treat delirium tremens (severe alcohol withdrawal).

Source: *Ewing, J.A (1984.) Detecting alcoholism The CAGE Questionnaire. J. Am. Med. Assoc, 2521905–1907.*

Appendix 10D: The Drug Abuse Screening Test (DAST)

✓	Screening for drug abuse
	Use the DAST questionnaire. Ask: In the last 12 months…:
	1. Have you used drugs other than those required for medical reasons?
	2. Have you abused prescription drugs?
	3. Do you abuse more than one drug at a time?
	4. Can you get through the week without using drugs?
	5. Are you always able to stop using drugs when you want to?
	6. Have you had 'blackouts' or 'flashbacks' as a result of drug use?
	7. Do you ever feel bad or guilty about your drug use?
	8. Do your parents (or spouse) ever complain about your involvement with drugs?
	9. Has drug abuse created problems between you and your parents (or spouse)?
	10. Have you lost friends because of your use of drugs?
	11. Have you neglected your family because of your use of drugs?
	12. Have you been in trouble at work/school because of your use of drugs?
	13. Have you lost a job because of drug abuse?
	14. Have you gotten into fights when under the influence of drugs?
	15. Have you engaged in illegal activities in order to obtain drugs?
	16. Have you been arrested for possession of illegal drugs?
	17. Have you experienced withdrawal symptoms (felt sick) when you stopped taking drugs?
	18. Have you had medical problems as a result of your drug use (for example, memory loss, hepatitis, convulsions, bleeding, etc.)?
	19. Have you gone to anyone for help for a drug problem?
	20. Have you been involved in a treatment programme, especially related to drug use?
	Score the questionnaire.
	■ Score 1 point for each 'yes' response, EXCEPT for the following two questions: ■ Can you get through the week without using drugs (4)? ■ Are you always able to stop using drugs when you want to (5)? For these two questions, score 1 point for 'no' responses. ■ **If the client's score is 6 OR MORE, then he or she may have a substance use problem.** ■ **If the client's score is 16 OR MORE, this may indicate very severe substance abuse.**

✓	Screening for drug abuse
	Give feedback on the results of the screening, provide support and referrals.
	■ Supply information about the hazards of drug use (including poor adherence to HIV care and treatment). ■ Involve the adolescent's caregiver(s), if appropriate and if the adolescent gives consent. ■ Emphasize the benefits of changing and assess the client's level of motivation to change. ■ If the client wants to change his or her behaviour related to drug use, discuss goals and provide advice and encouragement. ■ Provide referrals to a support group and for further counselling. If needed, find a facility that may be able to help the patient overcome physical dependency and provide counselling and support.

Source: *Gavin, D.R., Ross H.E., and Skinner, H.A (1989). Diagnostic validity of the Drug Abuse Screening Test in the assessment of DSM-III drug disorders. Brit J Addict, 84(3), 301–307.*

MODULE 11:

NUTRITIONAL CARE AND SUPPORT AMONG ALHIV

Total module time: 1 hour 30 minutes

Module 11: Objectives

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

- Describe common nutritional issues among ALHIV
- Explain the nutritional assessment process among ALHIV
- Describe nutritional counselling among ALHIV
- Outline measures to be used in preventing drugs and alcohol use among ALHIV

Session 11.1

Total time taken:
1 hour 30 minutes

Nutritional care and support among ALHIV

Learning objectives

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

- Describe common nutritional issues among ALHIV
- Explain the nutritional assessment process among ALHIV
- Describe nutritional counselling among ALHIV
- Outline measures to be used in preventing drug and alcohol use among ALHIV

11.1.1 Common nutritional issues among ALHIV and assessment process

11.1.1.1 Nutrition in adolescents

Adolescence is a time of rapid change and growth that increases the need for macro and micronutrients, hence the need for a balanced diet. Physical changes that require extra nutrition include rapid changes in weight, height, the onset of menarche for girls and increase in fat and muscle mass. Growth in adolescence depends on adequate nutrition, including both the quantity and quality of the food and the ability to digest, absorb and utilize food. HIV infection has a great impact on the overall health, growth and development of adolescent girls as well as on childbirth in later adulthood.

A balanced meal is defined as a meal which contains all food groups; cereals, green bananas, roots (cassava, ming'oko, etc.) and tubers (yams, potatoes, etc.), pulses, animal-source food, fruits, vegetables, sugar, honey, fats and oils. Sugar, honey, fats and oils are the food items which can be added in the food to improve taste and provide energy. It is recommended that a person should drink at least eight glasses (1.5 litres) of water a day.

You should assist adolescents or caregivers in exploring food types available in their local setting that fit in the three food groups.

Good nutrition for ALHIV helps to:

- Improve and speed up recovery from HIV-related illnesses
- Strengthen the immune system, thus enhancing the body's ability to fight diseases

- Prevent weight loss and malnutrition
- Help the individual to maintain better health so as to cope with possible infections
- Improve effectiveness and tolerance to drug treatments
- Improve the quality of life

11.1.1.2 Common nutritional issues for adolescents

- Many adolescents face food insecurity
- Many adolescents develop bad eating habits, such as eating a lot of junk food, skipping meals and having erratic eating patterns
- Some ARVs may cause adolescents to lose their appetite while some may cause changes in physique, such as lipodystrophy
- People living with HIV are encouraged to include foods from different food groups in each meal
- You should help ALHIV understand why it is important to avoid junk food like soft drinks, sweets and potato chips/crisps. You can do so by explaining that junk food costs a lot of money while having little nutritional value.

It is always best to eat fresh, natural foods which are also usually cheaper than packaged and pre-prepared food.

11.1.1.3 Nutritional issues for ALHV

It is very important that you perform nutrition assessment at every clinic visit and refer the client to a nutritionist if there are any concerns.

Good nutrition enables ALHIV to strengthen their immune system, manage HIV-related complications and increase protection from infections. Being HIV-positive means that ALHIV are at greater risk of becoming malnourished.

Infection changes the way our body breaks down sugar, fat, protein, vitamins and minerals, thereby increasing the body's need for these nutrients. Malnutrition along with HIV can worsen the body's immune system and lead to development of more severe infections.

11.1.1.4 Nutrition care and support for ALHIV

Nutrition Care and Support is a package that should include:

- *Nutrition assessment*
- *Nutrition counselling*
- *Micronutrient supplementation (if needed)*
- *Food support (if needed)*
- *Food safety and hygiene*
- *Psychosocial support*
- *Referral to other relevant health care services*

Nutritional assessment for ALHIV

The goal is to determine whether nutritional problems exist and, if so, their severity and probable causes. This involves dietary intake and nutritional status assessments of the following kinds:

- **Anthropometric assessment** Weight, height, BMI or MUAC, where applicable
- **Clinical assessment** For stunting, wasting/ obesity,anaemia,etc.
- **Biochemical assessment** Blood sugar, lipid profiles, haemoglobin levels,etc, where available
- **Dietary assessment**

Nutritional counselling, education and advice should always be adapted to the realities of a particular client's situation.

Commonly used anthropometric measurements for assessment of nutritional status are:

- Weight for Age (WFA)
- Height for Age (HFA)
- Weight for height/length (WFH)
- Mid-upper arm circumference (MUAC)
- Body mass index (BMI) – A normal BMI is 18.5 – 24.9 kg/m^2. A BMI <18.5 denotes underweight; that between 25.0 and 29.9 kg/m^2 is overweight, and > 30.0 kg/m^2 is obesity. For patients with BMI < 18.5 nutritional education is required and food supplementation is to be recommended, if any.

  Formula for calculating BMI

  BMI = weight (kg) ÷ height^2 (m^2)

Dietary intake assessment involves indicators like:

- Amount and type of food eaten
- Eating frequency
- Food preferences and dislikes
- Food taboos
- Eating problems (lack of appetite, nausea, etc.)
- Food availability including locally available foods

Clinical assessment involves observing for bilateral pitting oedema, wasting, extensive skin lesions and paleness in the palms, eyelids, tongue and on the nail beds.

11.1.3 Nutritional counselling among ALHIV

11.1.3.1 Nutritional counselling in ALHIV

This includes:

- Adequate food intake
- Consumption of a variety of foods
- Prompt treatment of opportunistic infections and any ailments such as malaria

- Girls to have iron and folic acid supplements to compensate for loss in menses
- Pregnant adolescents need additional energy and nutrients to support their growth and that of the developing foetus

Adolescents require adequate dietary intake with increased calories to support hormonal and physical changes that come with this stage of development. Their energy needs further increase with the stage of HIV infection. Support clients with nutritional problems and work with them/their caregivers to address these problems with home-based nutrition interventions.

Prompt treatment of symptoms can help clients adhere to their care and treatment plan, which in turn can prevent or reduce many symptoms. Use non-judgmental and youth-friendly counselling and communication skills.

Refer to national guideline for management of HIV and AIDS (2017) for more information on nutritional monitoring and assessment.

11.1.3.2 Nutritional requirements for ALHIV

ALHIV need additional energy because of altered metabolism and nutrient malabsorption. ALHIV with no AIDS-related symptoms (WHO stage I) 10 per cent more energy (about 210 additional kcal/day, equivalent to one cup of porridge).

HIV-infected adolescents with AIDS-related symptoms (WHO stages II, III and IV) 20%–30% more energy (420–630 kcal/day, depending on severity of symptoms). The requirements may be even higher if the HIV-infected adolescent suffers from opportunistic infections or is pregnant or lactating.

The requirements will vary from one client to another depending on the regular weight and nutrition monitoring. Multiple micronutrient supplements (containing iron/folate, zinc, selenium, vitamins A, B, C, etc.) for ALHIV are to be recommended by you.

If diet is insufficient, pregnant/post-partum adolescents with HIV might need multiple micronutrient supplements.

11.1.3.3 Maternal nutrition for ALHIV

Good nutrition for pregnant and lactating ALHIV improves health and infant survival. Support optimal nutrition for pregnant and lactating ALHIV considering the increased nutrient needs. To support lactation management for lactating ALHIV,do the following:

- Identify safer infant feeding practices in the context of HIV
- Demonstrate proper breastfeeding techniques

11.1.3.4 Nutritional counselling and support to ALHIV and caregiver

- Provide practical counselling and education on good nutrition, gardening, purchasing locally available foods and how to store and prepare food.
- Provide ALHIV with multivitamins according to national guidelines.
- Work with the care team to link the ALHIV clinic to agricultural and food support organizations.
- Link ALHIV to community-based agricultural, nutritional, animal husbandry and other programmes.

11.1.3.5 Common signs and symptoms associated with HIV

Common signs and symptoms associated with HIV are anorexia, diarrhoea, fever, nausea and vomiting, anaemia, wasting, mouth sores and oral thrush. Manage symptoms with dietary practices, especially for illnesses that may interfere with food intake, absorption and utilization. It is important to counsel ALHIV to seek prompt treatment for all opportunistic infections and other diseases.

All of the recommendations for nutritional support and management of symptoms should be combined with routine clinical care and treatment.

Refer to *Appendix 11A and review together with nutritional management of common symptoms related to advanced HIV infection.*

Exercise 1: Case study 1

During a routine visit, Almisha, a 16-year-old young woman, tells you that she has been feeling sad a lot lately and hardly ever feels hungry anymore. You also notice that she does not appear to have bathed in several days. She tells you that she has been living with HIV her whole life and isn't sure what is causing her to feel so down.

- *How will you proceed with Almisha?*
- *How will you assess the major issues?*
- *What things will you discuss with the client and/or caregiver?*
- *How will you counsel the client? What are some of the key 'positive living' points that you should make?*

Exercise 1: Case study 2

Egnadra is a 16-year-old who recently found out that she has HIV. She comes to the clinic every month but is always quiet. One of the APEs mentioned that he saw her hanging out with some older men outside of a store. She was smoking a cigarette and sharing some beer.

- *How do you plan to talk to Egnadra about positive living when she comes for her next clinic visit?*
- *How will you assess the major issues?*
- *What things will you discuss with the client and/or caregiver?*
- *How will you counsel the client? What are some of the key 'positive living' points that you should make?*

11.1.3 Key points

- Good nutrition is an important component of healthy living, health workers should provide regular weight and nutritional monitoring and counselling as part of ALHIV routine care.
- Health workers should counsel and support adolescents and caregivers on nutritional matters and also work with them to address those using home-based nutritional interventions.
- Be aware of the resources available to clients in the clinic and community and link clients with several of them.

Appendix 11A: Nutritional management of common symptoms related to advanced HIV infection

Note: *All of the recommendations for nutritional support and management of symptoms should be combined with routine clinical care and treatment, including ART.*

Sign/symptom	Nutritional recommendations and management
Major weight loss (sometimes called 'wasting')	■ Eat small meals often. Try to include 'body building' foods (protein) with each meal. ■ Eat snacks during the day if possible (such as groundnuts, boiled eggs and avocados). ■ Eat more 'energy giving' foods (like rice, maize meal, bread and porridge). ■ Eat more beans, lentils, peas and groundnuts. ■ Try to eat more meat, fish and eggs. ■ Use more fats and oils in food, especially 'good fats' like avocados and nuts. ■ Eat more dairy foods (like milk and yogurt). ■ Add dry milk powder or pounded groundnuts to foods (like porridge and cereals). ■ Add sugar, honey, syrup or fruit jam to foods. ■ Try to eat more of your favorite foods. ■ Adhere to your care and treatment plan, including ART. ■ ALHIV may experience changes in their body shape. This is a long-term side effect that can be caused by ART. Some ALHIV may develop more fat in their stomach, breasts or other areas and may lose fat in their face, arms and legs. These side effects may be confused with weight gain or weight loss.

Sign/symptom	Nutritional recommendations and management
Diarrhoea	■ Eat soups and drink safe water, rice water, thin porridge and weak tea to avoid dehydration. ■ Drink oral rehydration solution (ORS). ■ Eat small amounts of food many times a day. ■ Eat foods like millet, bananas, peas and lentils to help retain fluids. ■ Eat foods like rice, bread, millet, maize, porridge, boiled potatoes, sweet potatoes and crackers, which are easy to digest. ■ Eat soft foods like bananas, squash, cooked and mashed green bananas, paw-paws, mashed sweet potatoes and mashed carrots. ■ Eat eggs, chicken or fish for protein. ■ Adhere to your care and treatment plan, including ART. **Stay away from:** ■ Strong citrus fruits (like oranges and lemons) ■ Dairy products, such as milk – try fermented products instead, like yogurt or sour milk ■ Caffeine (coffee and tea) ■ Alcohol ■ Fried foods ■ Very sugary foods ■ Extra oil, butter or lard ■ Gas-forming foods (like cabbage, onions and carbonated soft drinks)
Nausea and vomiting	■ Drink fluids (especially clean water) to prevent dehydration. ■ Eat bland soups. ■ Eat fruit, such as bananas. ■ Eat lightly salty and dry foods (like crackers or bread) to calm the stomach. ■ Drink herbal teas and lemon juice in hot water. ■ Eat small amounts of food many times a day. ■ Adhere to your care and treatment plan, including ART. **Stay away from:** ■ Spicy or fatty foods ■ Caffeine (coffee and tea) ■ Alcohol

Sign/symptom	Nutritional recommendations and management
Mouth and throat sores or infection	■ Eat soft mashed foods, such as scrambled eggs, cooked carrots, sweet potatoes, bananas, soup, paw-paws and porridge. ■ Eat cold foods or foods at room temperature. ■ Drink liquids, such as beef broth or lentil/pea soup. ■ Rinse the mouth with clean, warm salt water before and after eating. ■ Use cinnamon tea as a mouthwash. ■ Suck on clean ice, if available, to relieve pain. ■ For thrush, eat fermented foods (like plain yogurt and sour milk). Sucking on a lemon and eating garlic can also help. ■ See the nurse or the doctor and adhere to your care and treatment plan, including ART. **Stay away from:** ■ Spicy or salty foods, which can irritate mouth sores ■ Strong citrus fruits and juices, which can irritate mouth sores ■ Sugary foods and drinks ■ Rough foods like toast and raw vegetables ■ Alcohol
Loss of appetite	■ Eat small, frequent meals throughout the day. ■ Eat nutritious snacks between meals. ■ Take walks before meals if possible – fresh air helps to stimulate appetite. ■ Avoid smoking – it reduces appetite. ■ Add seasonings, especially herbs, to food to give it more flavour. ■ Try rinsing out the mouth after meals. ■ Use lemon, raw tomatoes or tonic water to stimulate the taste buds. ■ Chew food well and move it around the mouth to stimulate taste buds. ■ Avoid strong-smelling foods. ■ Eat with others as much as possible. ■ Adhere to your care and treatment plan, including ART.
Taste changes (can sometimes be caused by ARVs and other medications)	■ Change the sweetness, saltiness or sourness of food by adding sugar, salt, jam or lemon (also increases the taste). ■ Try different herbs and spices. ■ Eat more fish or chicken, as meat can often have a metallic taste. ■ Eat lentils, beans or split peas. ■ Brush teeth after eating to remove any aftertaste. ■ Adhere to your care and treatment plan, including ART.

MODULE 12:

ADOLESCENT SEXUAL AND REPRODUCTIVE HEALTH SERVICES

Total module time: 2 hours 45 minutes

Module 12: Objectives

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

- Define sexuality, sexual orientation and sexual identity
- Describe attitudes, values and beliefs about adolescent sexuality and how these may affect their work with adolescents.
- Explain potential effects of HIV on sexuality among adolescents

Session 12.1

Total time taken: 45 minutes

Attitudes, values and beliefs about adolescent sexuality and HIV

Learning objectives

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

- Define sexuality, sexual orientation and sexual identity
- Describe attitudes, values and beliefs about adolescent sexuality and how these may affect their work with adolescents.
- Explain the potential effects of HIV on sexuality among adolescents

12.1.1 Definitions of key terms

12.1.1.1 Key terms

Sex refers to the biological characteristics that define humans as female or male.

Sexuality is the central aspect of being human and refers to an individual's capacity for sexual feelings. Sexuality encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction.

Note: *Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships.*

Even we, as health workers, sometimes find it difficult to talk about sex and sexuality. Being able to comfortably talk about sex and sexuality within a professional context is the first step towards being able to initiate SRH discussions with clients. Our first priority as health workers is to provide care and support to our clients. This means never judging them or making them feel abnormal.

Note: *If you do not talk about sex and sexual behaviours with adolescents, they may not get the information, skills and supplies they need to protect themselves and their partners.*

Sexual orientation is about who you're attracted to and want to have relationships with.

Sexual health is a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity.

Note: *Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences free of coercion, discrimination and violence.*

For sexual health to be attained and maintained, the sexual rights of all people must be respected, protected and fulfilled.

Sexual rights: The fulfilment of sexual health is tied to the extent to which human rights are respected, protected and fulfilled.

Note: *Sexual rights embrace certain human rights that are already recognized in international and regional human rights documents,other consensus documents and in national laws.*

Rights critical to the realization of sexual health include:

- Right to equality and non-discrimination
- Right to be free from torture,cruelty, inhumane,or degrading treatment and punishment
- Right to privacy
- Right to the highest attainable standard of health (including sexual health) and social security
- Right to marry, start a family and enter into marriage with the free and full consent of the intending spouse, and right to equality in and at the dissolution of marriage
- Right to decide the number and spacing of one's children
- Right to information, as well as education
- Right to freedom of opinion and expression
- Right to an effective remedy for violations of fundamental rights

12.1.2 Overview of sexuality in adolescence and effects of HIV on sexuality among ALHIV

12.1.2.1 Overview of sexuality in adolescence

Sexuality emerges during adolescence,which in many cases, is also a time when sexual activity begins. You should never assume that adolescent clients have no sexual desires or that they are not sexually active. ALHIV also have sexual desires and are or want to be sexually active.

Members of the multidisciplinary care team should talk about sexuality and SRH with adolescent clients and offer non-judgmental sex education as well as SRH counselling and services.

12.1.2.2 Effects of HIV on sexuality among ALHIV

- ALHIV may have:
  - Lower self-esteem compared to their peers as well as increased anxiety about their sexuality, sexual relationships and sexual and reproductive health
  - Concerns about if/how they can have safe sexual relationships; they often have fears related to disclosure
- ALHIV may begin looking different due to late or slow onset of puberty
- ALHIV are vulnerable to many illnesses, conditions and drug side effects
- Adolescents who acquire HIV through sexual abuse may have unresolved issues stemming from trauma related to the abuse

You should encourage ALHIV to pursue their dreams including education, career goals,and fulfilment of their sexual desires

12.1.3 Key points

- Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships.
- HIV can have both psychological and physical effects on the sexuality of ALHIV.
- HIV can affect the emerging sexuality of adolescents in a number of ways, including worsening their body image and self-esteem.

Session 12.2

Total time taken: 30 minutes

Adolescent reproductive health services

Learning objectives

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

- Describe reproductive health services for ALHIV

12.2.1 Reproductive health services for ALHIV

12.2.1.1 Key terms

Reproductive health is a state of complete physical, mental and social well-being, and not merely the absence of disease or infirmity, in all matters relating to reproductive system, its functions and processes pertaining to both women and men.

Reproductive rights are the basic rights of all couples and individuals to decide freely and responsibly the number and spacing of their children, to have the information and means to do so, to attain the highest standard of SRH and to make decisions concerning their reproductive health free of discrimination, coercion and violence.

Sexual and reproductive health rights (SRHR) can be understood as the rights for all, whether young or old, woman or man of any sexual orientation, HIV-positive or negative, to make choices regarding their own sexuality and reproduction, provided their choices respect the rights of others to bodily integrity. These definitions also include the right to access information and services needed to support these choices and optimize health.

12.2.1.2 Reproductive health services for ALHIV

The range of reproductive health services should include the following:

- Information and counselling on reproductive health, sexuality and safe sex
- Testing services for HTS , STI and pregnancy
- Management of STIs, PMTCT, HIV/AIDS
- Focused antenatal care, care during childbirth and postnatal care
- Post-abortion care
- Contraception, including emergency contraception

- Condom promotion and provision
- GBV and VAC
- Other related health issues, such as substance abuse, injuries, mental health, chronic diseases, etc.
- Nutrition
- Referral services

12.2.1.3 SRH value clarification

Value is defined as a person's principles or standard of behaviour and their judgment of what is important in their life. The purpose of SRH value clarification is to encourage teens to clarify and explore their personal attitudes and values and to become comfortable with listening to, and understanding opinions different from their own.

All members of multidisciplinary teams caring for ALHIV should:

- Explore their own attitudes, values and prejudices related to adolescent sexuality
- Assess how these attitudes, values and prejudices could affect their ability to provide effective HIV care and treatment services to adolescent clients

You should be sensitive to the emerging feelings of your adolescent clients and encourage them to talk openly and honestly in the clinic setting.

An important part of adolescent HIV care and treatment is assessing and responding to the SRH needs of clients. To be able to do this, you must be comfortable talking about sexuality and SRH with ALHIV. They must also be knowledgeable about common SRH issues adolescents face and the SRH services and information adolescents need.

12.2.1.4 Exercise 2: Value clarification statements on SRH services

Here is the list of value statements to practise:

- Deliberately hurting other people is never okay
- Treating people differently because of who they love is wrong
- Treating people differently because of their HIV status is wrong
- Bisexuality is a myth; no one is really bisexual; they're just confused
- Everyone should have the same rights, irrespective of sex, race/ethnicity, gender identity or HIV status
- It is illegal to give contraceptive methods to adolescents ALHIV
- It is not advised for ALHIV to get married and have a family

Follow the instructions provided by facilitators.

12.2.2 Key points

- The range of SRH services include information and counselling, testing and management of HIV and STIs, reproductive and child health, family planning,nutrition, GBV and referrals.
- SRH value clarification aims at encouraging adolescents to clarify and explore their personal attitudes and values.

Session 12.3

Total time taken: 45 minutes

Supporting adolescent clients to practise safe sex

Learning objectives

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

- Describe safe sex and unsafe sex
- Describe safe sex practices and skills for adolescents
- Describe Sexual risk screening and counselling
- Conduct Sexual risk screening

12.3.1 Overview of safe and unsafe sex practices and skills for adolescents

12.3.1.1 Safe sex

Safe sex refers to sexual practices that do not expose a person to sexually transmitted infections, HIV or pregnancy. These include a range of measures that people can undertake to protect themselves and their partner(s) from HIV, STIs and unintended pregnancy. In other words, safe sex practices are those that prevent passing of body fluids from one person to another.

Safe sex reduces the risk of transmitting HIV without reducing intimacy or pleasure. Safe sex also applies to oral, anal and other sexual practices.

12.3.1.2 Safe sex practices

Adolescents can practise safe sex by:

- Hugging
- Kissing on the cheek (carries no risk of HIV transmission)
- Using condoms
- Practising fidelity
- Massaging

- Rubbing against one other with clothes on
- Sharing fantasies
- Mutual masturbation

PLHIV on ART should still practise safe sex – even when taking ART, there is a risk of acquiring new HIV infections. You should inform clients of the additional benefits of excellent adherence: not only does good adherence improve the quality and length of the client's life, but it reduces the risk of transmission of infection to his or her uninfected sexual partner.

12.3.1.3 Unsafe sexual practices

These are practices which increase the chance of an adolescent contracting or transmitting disease (HIV or other STIs)) or increase the chance of the occurrence of unwanted pregnancy. Unsafe sexual practices include:

- Oral, vaginal or anal sexual contact without a condom
- Not using contraceptive methods or using them inconsistently
- Having multiple sexual partners or changing sexual partners frequently
- Having sex under coercion or the influence of alcohol or drugs

You should counsel the adolescent on how to avoid risky sexual behaviours and emphasize the need to practise safe sex.

12.3.1.4 Reasons why adolescents may not practice safe sex

Adolescents may not practise safe sex for several reasons:

- Lack of adequate or accurate information about safe sex
- Lack of knowledge about methods to practise safe sex and where, how or when to use these methods
- Lack of awareness of pleasurable alternatives that involve safe sex behaviours and practices
- Health worker attitudes towards contraception may prevent distribution of protective methods to adolescents
- Peer pressure
- Social and economic factors
- Trans generational sex (sex between adolescents and adults)
- Sexual abuse

12.3.2 Sexual risk screening, counselling and risk assessment

12.3.2.1 Sexual risk screening and counselling

Sexual risk screening assists health workers in assessing whether a client is sexually active and, if so, with whom and what risks he or she is taking.

Risk reduction counselling focuses on reducing clients' risk of HIV, other STIs and unwanted pregnancy by helping them choose a strategy that is right for them. These may include abstinence, delayed sexual debut, reducing the number of sexual partners and condom use.

Sexual risk screening should start before the adolescent is sexually active. By the time adolescents are 12 years old, begin meeting with them separately from their caregivers for at least part of each appointment. This should be done with the caregiver's consent. Counselling sessions should also include information about early treatment of STIs, adherence to the ART regimen and disclosure strategies.

Follow these rules:

- Establish trust between your adolescent client and yourself to make him or her feel comfortable enough to ask questions and raise concerns with you
- Keep all client information confidential unless there is an emergency or a health risk that requires intervention
- Use good communication and counselling skills to build rapport with clients
- Avoid making assumptions or judgments about the client in regards to his or her knowledge, behaviours and sexual orientation
- If a discussion is awkward, respect a client's cues that further talk is unwanted

Adolescent clients and caregivers decide what information can and cannot be kept confidential. Emphasize that you will protect client confidentiality unless there is an emergency or a health risk that requires intervention. You should avoid using any labels not used by the client first,and let the client know that local law may require disclosure under other circumstances, for instance, cases of child sexual abuse.

You should remember to observe non-verbal communication cues such as crying, silence, awkward smiling, etc. Consider the environment where screening and counselling is happening, and if need be, consider postponing the discussion, changing the venue/time or referring to other counsellor.

Table 12.1: Sexual risk screening

✓	Questions for the client
	1. Is the client sexually active?
	■ *Some adolescents have sex with their partners. Are you having sex?* If the response is no, go to Table 10.2. If yes, proceed to section 2 of this table.
	2. If yes, with whom?
	■ *Are you having sex with men, women or both?* ■ *How many partners do you have right now? How many partners have you had in the past year?* ■ *What is the HIV status of your partner(s)?* ■ *Does your partner know you have HIV?*

✓	Questions for the client
	3. What are the client's sexual practices?
	■ Do you have vaginal sex? Oral sex? Anal sex? ■ What family planning method did you use the last time you had sex? ■ When was the last time you used a condom? ■ Has anyone caused you harm in the past; for example, hurt you physically or made you have an unwanted sexual encounter? ■ Have you ever used cigarettes, alcohol or other drugs? If so, how often in the last week have you used cigarettes, alcohol or other drugs?

Table 12.2: Risk reduction counselling

✓	Questions for the client
	1. Assess knowledge
	■ How is HIV transmitted from one person to another? ■ How can a person prevent transmission of HIV during sex? ■ What is your plan to protect your partner from getting HIV when you have sex? ■ Did you know that even if both partners have HIV, it is important to practice safe sex and use condoms? Do you know why?
	2. Discuss options for sexual risk reduction
	■ There are a number of ways to reduce risk of HIV, other STIs and unwanted pregnancy, which include: ■ Abstinence ■ Intimate touching without exchange of bodily fluids ■ Reducing number of sexual partners ■ Disclosing your HIV status and negotiating sexual practices ■ Correctly and consistently using condoms (for male–female couples, ideally with another form of hormonal contraception) ■ STI screening and treatment (HIV is transmitted more easily in the presence of other STIs). ■ Maintaining maximal suppression of HIV through excellent adherence to ART, if eligible. ■ Avoiding alcohol, marijuana, party drugs and other substances that impair good judgment and prevention practices.
	3. If an option, discuss abstinence
	■ Abstinence means not having sex. If you are abstinent, you cannot get STIs or get re-infected with HIV, and you cannot have an unplanned pregnancy. ■ Is abstinence an option for you? ■ If you choose abstinence, you should have a backup plan as well, just in case you change your mind. What will be your backup plan?

✓	Questions for the client
	4. Discuss condoms
	■ Demonstrate steps for putting on a condom (male and female) and offer to supply the client with condoms. ■ Help client improve condom negotiation skills by: ■ Responding to the clients questions and concerns ■ Reassuring the client that it can be difficult to bring up the topic of condoms with a partner ■ Suggesting that he or she discuss condoms BEFORE they are needed (rather than in the heat of the moment)
	5. Role play to encourage condom use
	■ If partner asks: "But you have never suggested we use condoms before" *Client can say: "I went to the clinic today and my health worker told me that I really need to use condoms for my health and to prevent an unintended pregnancy." (Or, the client may have another reason to explain changing his or her mind.)* ■ If partner asks: "You don't love me enough to have sex without a condom?", *Client can say: "It is because I love you and I love myself that I want to keep us both safe."* ■ If partner says: "You must want to use a condom because you have been messing around with other people", *Client can say: "Before we met, we both had other partners and I want to be sure that neither of us brings anything into this relationship".*
✓	**Questions for the client**
	6. Encourage disclosure
	■ Encourage disclosure to partners, work with clients to facilitate the disclosure process and offer the possibility of meeting with the client and partner together to help the client with disclosure (see Module 7).

12.3.2.2 Conducting risk assessment

To guide adolescents in assessing risk, ask questions such as:

- Do you have a boyfriend/girlfriend?
- Have you ever had sex with your boyfriend/girlfriend?
- Are you having sex with men, women or both?
  - For girls, ask if they are having sex with boys or girls
  - For boys, ask if they are having sex with boys or girls
- How many partners do you have right now? How many partners have you had in the past year?
- How do you practise your sexual activities?
- Did you use a condom last time you had sex? Do you use a condom every time you have sex?
- Are you currently taking any contraceptives? Which ones? Did you use contraceptives last time you had sex?

- Have you had any abnormal discharge (colour, amount or smell), pain when urinating, any sores or bumps in or around your genitals or anus?
- Have you ever experienced sexual contact against your will?
- For girls, have you had your first menstrual period? If yes, when was your last period?
- For girls, have you ever been pregnant? What were the pregnancy outcomes?
- Do you know your own HIV status? Does your partner know your HIV status? Do you know the HIV status of your partner(s)?
- Have you ever used alcohol or drugs? If so, how often in the last week have you used alcohol or drugs?

12.3.2.3 Risk reduction counselling

Risk reduction counselling is an important task of a health worker. It is crucial to explore and understand whether the adolescent has correct knowledge of sexual risk reduction and discuss options for practising the same. Topics that can be discussed include:

- Knowledge about HIV and risk behaviour
- Options for sexual risk reduction
- Abstinence
- Condoms
- Disclosure

Abstinence means not having sex, and it is important to tell the adolescent that abstinence is the only way to avoid getting STIs/ HIV and pregnancy.

12.3.3 Key points

- PLHIV on ART should still practise safe sex – when taking ART, there is still a risk of acquiring new HIV infections.
- Sexual risk screening should start before a client is sexually active.
- Even if a client is not yet sexually active, prepare him or her with facts including how condoms can prevent HIV transmission, re-infection, STIs and unintended pregnancy.
- Risk reduction counselling focuses on reducing clients' risk of HIV, other STIs and unwanted pregnancy by helping them choose a strategy that is right for them.

Session 12.4

Total time taken: 45 minutes

Contraception, pregnancy, STIs and CECAP in ALHIV

Learning objectives

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

- Describe contraceptive methods for ALHIV
- Describe counselling for pregnancy services among ALHIV
- Describe counselling PMTCT services among ALHIV
- Describe cancer of the cervix screening for adolescents

12.4.1 Overview of contraception for ALHIV

12.4.1.1 Contraception for ALHIV

You should encourage sexually active adolescents to use contraceptive services by adopting a positive attitude, ensuring privacy, confidentiality and providing convenient hours of services. Some facts to keep in mind:

- Adolescents are medically eligible to use contraception
- Adolescents have been shown to be generally less tolerant of side effects than older adults, which is one reason why they have higher discontinuation rates
- Method of choice may also be influenced by factors such as sporadic patterns of intercourse, need to conceal sexual activity and type of ART used
- Counsel the adolescent and offer/refer them where they can get the method of contraception of their choice

Remember that you should always follow the national family planning guidelines when providing contraceptive counselling and support and prescribing a contraceptive method.

Refer to *Appendix 12A: Contraception considerations for people living with HIV.*

12.4.1.2 Providing contraception to ALHIV

Important considerations:

- Medical eligibility

- Effectiveness in preventing pregnancy and HIV/STI
- Appropriateness to social circumstances and lifestyle
- Conformity with the prevailing laws of the country
- Age is a factor to be taken into account when considering the use of:
  - Sterilization: Early age is a key risk factor for subsequent regret, both for women and men
  - Progestin-only injectable is not suitable for ALHIV under 18 as it is linked to hindrance of bone development
  - Intrauterine devices are not the first method of choice for those under 20, as the risk of expulsion is higher in young, nulliparous women

Adolescents who are sexually active need contraceptive information and services to prevent them from having early and unwanted pregnancies. For all methods except condoms and emergency contraceptive pills, condoms should be recommended and provided for dual protection.

Table 12.3: Summary of contraceptive options for ALHIV

Male and female condoms		
Advantages	**Disadvantages**	**Summary**
■ Provides protection from both pregnancy and STI (including HIV) transmission and acquisition ■ Highly effective when used consistently and correctly ■ Does not interfere with medications	■ Correct and consistent condom use may be difficult to achieve and failure rates can be high ■ Partner involvement is required; need to negotiate their use	■ Good method for adolescents ■ Requires demonstration of proper use
Combined oral contraceptives (COCs) and progestin-only oral contraceptive pills (POPs) – pills taken daily*		
Advantages	**Disadvantages**	**Summary**
■ Highly effective when taken daily and on time ■ POPs may be a good choice for adolescents who cannot tolerate the estrogen in COCs or are breastfeeding ■ Does not interfere with sex	■ Failure rates are highest for adolescents due to confusion about how to take the pills ■ Side effects can include nausea, weight gain, breast tenderness, headaches, spotting ■ Cannot be taken by clients on rifampicin ■ ARVs may adversely affect the efficacy of low-dose COCs and/or increase their side effects	■ Women taking ARVs who want to use COCs should be counselled about the importance of taking COCs on time every day and about consistent condom use ■ POPs are safe for adolescents but because they must be taken at exactly the same time every day, they are not the best choice

Injectable – 'shot' given every 2–3 months*		
Advantages	**Disadvantages**	**Summary**
■ Highly effective when used correctly ■ Does not interfere with sex ■ As it is an injection, there are no pills to take (i.e., reduced pill burden)	■ Side effects can include spotting at first, then amenorrhea and weight gain	■ Can be used by ALHIV without restrictions ■ Remind adolescent when to return for next injection
Emergency contraceptive pills (ECP) – 2 doses of pills taken within 120 hours of unprotected sex		
Advantages	**Disadvantages**	**Summary**
■ Reduces risk of pregnancy after unprotected sex by 75% ■ Safe for all women, including those living with HIV and those taking ART	■ For emergency use only ■ Side effects can include nausea, vomiting, cramps, headache, breast tenderness and changes in the menstrual cycle	■ Should be widely and easily available to ALHIV ■ Provide counselling for adopting a regular contraceptive method as well as condom use for dual protection
Hormonal implants – small rods inserted under skin, last 3–7 years*		
Advantages	**Disadvantages**	**Summary**
■ Highly effective ■ Can be reversed ■ Does not interfere with sex	■ Effectiveness of implants may be reduced by ARVs ■ Side effects can include nausea, weight gain, and changes in the menstrual cycle ■ Usually need to be inserted and removed at a family planning clinic	■ Can be used by ALHIV who do not take ART ■ Can be used by ALHIV on ART, but they should use condoms as a back-up method ■ Provide counselling to prepare client for possibility of irregular bleeding
Intra-uterine device (IUD) – device inserted into uterus, lasts up to 12 years*		
Advantages	**Disadvantages**	**Summary**
■ Highly effective ■ Does not interfere with sex	■ Should not be initiated in a woman with AIDS who is not taking ART ■ Side effects can include heavy bleeding, discharge, cramping and pain during the first months ■ Usually needs to be inserted and removed at a family planning clinic	■ Appropriate for adolescents in stable, mutually monogamous relationships ■ Not recommended for ALHIV with advanced HIV disease or AIDS, especially if not on ART

Male and female sterilization – surgery*		
Advantages	**Disadvantages**	**Summary**
■ Safe and effective ■ Free of side effects ■ Does not interfere with sex	■ Permanent and requires surgery	■ Permanent methods are not recommended for adolescents
Lactational amenorrhea method (LAM)*		
Advantages	**Disadvantages**	**Summary**
■ Temporary, natural contraceptive option for women who are less than 6 months postpartum, who are exclusively breastfeeding, and whose periods have not yet returned	■ Most adolescents will not be breastfeeding (unless they have infants), so this is not a likely option for ALHIV	■ Appropriate only for adolescents who have given birth within the past 6 months and who are exclusively breastfeeding
Fertility awareness methods*		
Advantages	**Disadvantages**	**Summary**
■ No health risks or side effects	■ Requires a woman to identify her fertile days, which takes time and effort ■ Requires considerable commitment, calculation, and self-control, both by the woman and her partner	■ A difficult method for most adolescents to implement correctly and consistently ■ Not reliable for pregnancy prevention ■ Do not recommend
** Health workers should recommend and provide condoms for dual protection.*		

Adapted from: *Senderowitz, J., Solter, C., and Hainsworth, G. (2002, revised 2004). Comprehensive reproductive health and family planning training curriculum: Module 16: Reproductive health services for adolescents, Unit 7. Watertown, MA: Pathfinder International.*

12.4.2 Counselling for pregnancy and PMTCT services among ALHIV

12.4.2.1 Counselling for planned pregnancy for ALHIV

You should explain to clients and their partners the ways and number of times people living with HIV can safely have children. Ideally, they should:

- Educate adolescents about the risks of pregnancy during adolescence
- Counsel ALHIV on pregnancy and the PMTCT services before they become pregnant
- For girl ALHIVs, it is better if their CD4 is above 500, they have undetectable viral load and are healthy.
- It is important for ALHIV to adhere to ART
- Child spacing should be at least 2 years

Remember that you should follow up-to-date national PMTCT and ART guidelines when providing services to pregnant ALHIV, their partners and families.

12.4.2.2 Risks of adolescent pregnancy

Health risks for girls include:

- Pregnancy complications (obstructed delivery, prolonged labour)
- Pre-eclampsia
- Anaemia
- Complications associated with unsafe abortion
- Premature birth and low birth weight
- Spontaneous abortion and stillbirth, especially among adolescents < 15 years of age
- Mother-to-child transmission

Adolescents are not fully developed and their bodies may not be prepared to handle childbearing. Pregnant adolescents have a greater risk of obstructed delivery and prolonged labour, which in turn increases risk of haemorrhage, infection and fistula.

Psychological, social and economic risks:

- Stigma from family, friends, community members and other health workers, causing emotional distress and barriers to needed care
- Pregnancy often means expulsion from school
- Changes in academic aspirations and career choices (girls and boys)
- Changes in future marriage prospects (girls)
- In order to support their children, some adolescents resort to low-paying and risky jobs (such as prostitution) or early-marriage
- Compared to older fathers, adolescent fathers are less likely to have plans for a future job and more likely to have anxiety, be homeless or living in very unstable households

Early marriages that result from unplanned pregnancies are frequently unhappy and unstable. Some men refuse to take responsibility, which can contribute to hardship for the adolescent mother and child. If parents are unprepared to raise the child, child-rearing problems like abuse or neglect may occur. Fathers of children born to adolescent mothers are also more likely to earn less, get less education and experience depression.

12.4.2.3 Challenges in offering SRH, pregnancy and PMTCT services to adolescents

ALHIV have a host of additional challenges in dealing with pregnancy, apart from the general ones like difficulty adhering to ART, difficulty giving the infant medicines every day, fears about having an HIV-infected baby and guilt about possibly passing HIV to the infant.

These extra challenges include:

- Limited access to youth-friendly SRH, pregnancy and PMTCT information and services
- Low knowledge of adolescents' SRH rights among health care providers
- Difficulties in disclosure of their HIV status

- Challenges related to safe infant feeding
- Gender disparity and unfavourable sociocultural practices
- Health facilities lack privacy, not having staff of the same sex, having health workers with negative attitudes, stigma and discrimination, and lack of confidentiality

Exercise 1: Case study 1

Panda is a 19-year-old young man who comes to the ART clinic regularly. You learn from one of the adolescent peer educators at your clinic that Panda has been bragging that he has been with 'about 10 women' but never uses condoms because they are 'good girls' who don't insist on using them. When you offer him some condoms at the end of his next appointment, he says he doesn't need them. He says that he has a steady girlfriend now because he is feeling pressure from his family to 'get serious.'

- How do you proceed with Panda?

Exercise 1: Case study 2

Kendlwa is a 17-year-old young woman living with HIV. She is on ART and is doing very well. She has a boyfriend who knows about her HIV status and is accepting of it. Kendlwa used to take oral contraceptives, but stopped taking them recently because she said they made her feel nauseous and gain weight. Kendlwa and her boyfriend usually use condoms, but they have had sex a few times without them. Kendlwa and her boyfriend do not want children right now, but they talk about getting married and having children in the future, once she finishes school. Kendlwa is getting a lot of pressure from her family to never have kids because of the risk that they would be HIV-infected.

- How would you proceed with Kendlwa?

Exercise 1: Case study 3

Emmille is 19 years old and was perinatally infected with HIV. She has been adherent to ARVs for many years. She has come to the clinic today for a check-up and during the visit, she tells you that she thinks she is pregnant. She is happy to be pregnant, but is afraid that her baby will become HIV-infected. She is also worried about how her ARVs might be affecting her unborn child and tells you that her boyfriend – who is not infected with HIV – told her to stop taking them so they won't hurt the baby.

- How would you proceed with Emmille? (Assume that her pregnancy test is positive.)

12.4.3 Cancer of the cervix screening for adolescents

12.4.3.1 ALHIV and sexually transmitted infections (STIs)

You should assume that all adolescent clients are sexually active or will be sexually active soon and conduct regular screenings of STI. They should conduct thorough physical examinations, ensure privacy and follow medical ethics. They should give feedback in a non-judgmental manner (for example, saying "I see you have a sore here, does it hurt?").

Adolescents who are sexually active may not practise safe sex and as such are at an increased risk of contracting STIs. At every visit, ask the adolescent client about STI symptoms:

Girls	Boys
Abnormal vaginal discharge	Urethral discharge
Painful urination	Painful urination
Sores/bumps around the genitals	Sores/bumps around the genitals/anus
Lower abdominal pain	

12.4.4 Diagnosis and treatment of STIs

Information from the physical examination should be used in combination with the client's history to make a syndromic diagnosis and manage the client as per the national STI treatment guidelines.

- Client history and physical examination should be used to make syndromic diagnosis
- Management of the cases should follow national STI treatment guidelines
- Counsel adolescent to avoid sex until they are cured
- Counsel adolescent to advice their partner to seek medical care for evaluation and possible treatment
- Conduct risk reduction counselling
- Counsel adolescent to complete medication even if they feel better

12.4.5 Cervical cancer screening for ALHIV

- Cervical cancer is rare before the age of 30. Women between 25–49 years are the primary target for screening according to the national guidelines for prevention and management of cervical cancer.
- Women below the age of 25 should only be screened if they are at high risk of the disease (early sexual exposure, multiple sexual partners, previous abnormal screening or CIN or are HIV-positive)
- All adolescent girls at high risk of cervical cancer should be screened regularly as per the national guidelines
- Offer HPV vaccine to adolescent according to national guidelines

12.5.5 Key points

- Health workers should counsel adolescents on using contraceptive methods if they are sexually active.
- Counsel ALHIV on pregnancy and the PMTCT services before they become pregnant.
- All adolescents who are sexually active should be screened for STI symptoms.
- All adolescent girls at high risk of cervical cancer should be screened regularly as per the national guidelines.

Appendix 12A: Contraception considerations for people living with HIV

(Including contraindications with ARVs and common opportunistic infection drugs)

Essential principles of FP counselling in HIV services:	**Key messages for FP counselling in HIV services:**
■ Every HCT, ART and PMTCT client should be assessed for FP need ■ Quality FP counselling and services should reinforce clients' ability to limit HIV transmission to HIV-negative partners and infants ■ HCT, ART and PMTCT clients have the right to make their own FP choice, including safer pregnancy for HIV-positive women (using risk reduction measures like ARVs and exclusive breastfeeding), if desired	■ Dual method use – using condoms and a contraceptive method for good protection from infection and unintended pregnancy – should be included in FP counselling for clients living with HIV ■ Generally, HIV-positive clients can use most contraceptive methods (even if on ART)

	HIV-related treatments and conditions								
FP Options	**NNRTIs**		**NRTIs (AZT, D4T, 3TC, ABC, TDF)**	**Ritonavir or Ritonavir-Boosted Protease Inhibitors**	**Rifampicin (common for TB)**	**Certain Anti-Convulsants (Carbama zepine, Phenytoin, Barbituates)**	**Systemic Anti-Fungals (Azoles)**	**Untreated Chlamydia and/or Gonorrhea**	**Clinical AIDS/not doing well on ART**
	NVP	**EFV**							
Male/ Female Condoms									
COCs				X	X	X			
POPs				X	X	X			
Implants									
EC									
DMPA Injectables									
NET-EN Injectables									
IUD Insertion								X	X
Tubal Ligation									
Vasectomy									

FP Options	HIV-related treatments and conditions								
	NNRTIs		NRTIs (AZT, D4T, 3TC, ABC, TDF)	Ritonavir or Ritonavir-Boosted Protease Inhibitors	Rifampicin (common for TB)	Certain Anti-Convulsants (Carbama zepine, Phenytoin, Barbituates)	Systemic Anti-Fungals (Azoles)	Untreated Chlamydia and/or Gonorrhea	Clinical AIDS/not doing well on ART
	NVP	EFV							
Natural Family Planning									
Fertility Awareness									
Client Desires Safer Pregnancy		X				X	X	X	X

Legend

	Method appropriate for client; No reservation of drug interaction
	Possible reduced contraceptive effect or increased side effects of hormonal method; Recommend dual method use with condoms and perfect use of method
X	*Do not use the method*

Adapted from: *Pathfinder International. FP/HIV Integration provider reference tool: Family planning considerations specific to HIV-positive clients. Watertown, MA: Pathfinder International.*

MODULE 13:

SUPPORTING THE TRANSITION TO ADULT CARE

Total module time: 1 hour 30 minutes

Module 13: Objectives

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

- Describe key considerations when transitioning ALHIV from adolescent care to adult care

Session 13.1

Total time taken:
30 minutes

Key considerations when transitioning ALHIV from adolescent care to adult care

Learning objectives

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

- Explain the meaning and importance of transitioning ALHIV from adolescent care to adult care
- Describe the role of the health care workers in transitioning ALHIV from adolescent care to adult care
- Explain the challenges faced by ALHIV and health care workers in transitioning ALHIV from adolescent care to adult care
- Explain key considerations in transitioning ALHIV from adolescent care to adult care

13.1.1 Definition and importance of transitioning ALHIV from adolescent care to adult care

13.1.1.1 Health care transition for ALHIV

Health care transition is a process of supporting ALHIV graduate from adolescent HIV care into adult HIV care and services. It is an active process that attends not only to HIV care and treatment needs, but also to psychosocial, academic and vocational needs of the adolescents as they move from adolescent/child- to adult-focused care. As ALHIV grow into adulthood, it becomes necessary for them to transfer to adult care settings and take responsibility for their own health and disease management. Health care transition should facilitate transition in other areas of life as well, like work, community and school/institute.

This transition aims at:

- Increasing adolescents' overall ability to advocate for themselves
- Adequately manage their own care and treatment

13.1.1.2 Importance of transitioning ALHIV into adult care

Planned and organized health care transition helps ALHIV to:

- Establish new relationships with care providers while developing the knowledge and skills necessary to manage their own health
- Cope with unique challenges during the transition process, including:
  - Stigma and the need to disclose their HIV status
  - Neurocognitive impairments and mental health problems associated with HIV
  - Recognition that they face the risk of transmitting HIV
- Adhere to ARVs in adult HIV care settings

ALHIV may need to disclose their HIV status to friends, family and adult care providers. They may recognize the risk of transmitting HIV to future sexual partners and possibly children. Adherence to ARVs can be significantly affected as adolescents try to accommodate into new adult care settings. Adherence can also be affected by psychosocial issues such as depression and substance abuse as adolescents grow into adulthood and become more aware of their HIV status.

13.1.1.3 Transition from paediatric to adult care

The goal of transition is to ensure the provision of uninterrupted, coordinated, developmentally and age-appropriate comprehensive care before, during and after the transition. ALHIV may face challenges in transitioning to adult care. These challenges affect ALHIV, their caregivers and health workers in adolescent and adult clinics.

The goal of transitioning from paediatric to adult care can be explained by using the following key terminologies:

- **Uninterrupted:** The longevity and quality of life of PLHIV depends on continuous and uninterrupted supply of ARVs and other medications
- **Coordinated:** Having a transition plan before transition takes place is necessary. The transition plan should address any special care needs of ALHIV, such as the need for psychosocial support, counselling, appointment reminders, social support and income generation support
- **Developmentally appropriate:** Developmental issues for adolescents in transition to be considered are: taking more responsibility for themselves, wanting to be accepted and to fit in with peers,and learning to navigate their emerging sexuality and new intimate relationships
- **Age-appropriate:** Access to age-appropriate care and support for ALHIV helps sustain effective treatment
- **Comprehensive care:** This involves a multidisciplinary team approach involving adult care providers, peer educators and counsellors, tailored to the individual's specific needs

13.1.2 Role of health workers, challenges and key considerations in transitioning ALHIV from adolescent care to adult care

13.1.2.1 Challenges for ALHIV

Challenges faced by ALHIV during transition period include:

- **Balancing complicated care:** ALHIV has to manage multiple medications and appointments by themselves while dealing with different health workers and health services
- **Leaving a familiar care network:** ALHIV may feel reluctant to leave a familiar care setting and feel uncertain about how to manage a new clinic setting with new providers
- **Psychosocial and developmental challenges:** ALHIV,already coping with the typical changes and worries of adolescence, may additionally struggle with disclosure and adherence too
- **Systemic challenges:** Adult clinics typically lack specific adolescent-friendly services, and maybe crowded compared to adolescent or paediatric care settings.

13.1.2.2 Role of the health worker

The role of a health care worker during an ALHIV's transition period is:

- To provide ALHIV and their caregivers with support before and during transition to adult care
- To help ALHIV increase their capacity to manage their own care
- To help ALHIV advocate for themselves in the clinical setting
- To screen ALHIV for health problems and problem behaviours
- To support ALHIV in healthy development

Support to ALHIV and caregivers may include:

- Providing them with correct information and advice on transitioning to adult care
- Providing disclosure and adherence counselling
- Linking ALHIV to income generating activities and other age-appropriate services such as family planning, etc.

Health workers should:

- Help ALHIV set and achieve goals for independence and self-management of care
- Encourage ALHIV to develop as much independence as possible

13.1.2.3 Challenges for health workers

Challenges facing health workers during transition period include:

- Inadequate knowledge on how to communicate with adolescents
- Staff shortages and increased workload in health facilities resulting in them paying no attention to ALHIV's specific needs

- Poor infrastructure in health facilities, resulting in failure to provide adolescent-friendly facilities
- Adolescent reluctance to transition to adult care

13.1.2.4 Key considerations for the transition of ALHIV to adult care

- Adolescents require support both within and outside the clinic setting.
- The transition to adult care often occurs parallel to an adolescent's emotional and physical maturation.
- Reaching the overall goal of helping adolescents achieve independent management of their own care is a gradual process.
- Some caregivers will need assistance with understanding their changing role as the focus of care shifts towards a confidential relationship between the adolescent and the health worker.

Adolescents should be encouraged to take greater ownership over their health care, behaviour, lives and adherence. This shift should take a multi-disciplinary approach; effective transition must allow adolescents to undergo physical and emotional changes that impact much more than just their clinical care.

Support to adolescents during transition should, whenever possible, involve caregivers and family. ALHIV may have different forms of developmental delays and will depend on support from their caregivers. Not every adolescent will be able to reach 100% independence from his or her caregivers. This is particularly true for adolescents with moderate or severe developmental delays.

13.1.3 Key points

- Adolescents attending paediatric or adolescent HIV care, at a certain age towards adulthood, have to transition to adult HIV care.
- The goal of transition is to ensure the provision of uninterrupted, coordinated, developmentally and age-appropriate comprehensive care before, during and after the transition.
- This transition to adult care can be difficult for adolescents, caregivers and health care workers.
- Taking on a greater role in self-care and self-advocacy may be challenging for adolescents, and they should be supported through a multi-disciplinary approach.

Session 13.2

Total time taken:
30 minutes

Preparing and empowering adolescents to transition into adult care

Learning objectives

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

- Describe the transitioning approaches of ALHIV to adult care
- Use transition tools for ALHIV

13.2.1 Transitioning approaches of ALHIV to adult care

13.2.1.1 Preparing and empowering adolescents to transition into adult care

Programmes and facilities may not adequately plan for client transition to adult care. The kinds of approaches which are liable to result in failure to prepare and empower ALHIV to transition include:

- An abrupt transfer to adult services
- Maintaining adolescents in the paediatric clinic longer than appropriate
- LTF (Lost to Follow-Up) to care
- Adherence challenges

Helping all ALHIV achieve greater independence to manage their care is essential, because unsuccessful transition can result in:

- High rates of youth lost to care
- Adolescents developing weaker immune systems
- Increased morbidity and mortality
- The possibility of adolescents developing drug resistance

13.2.1.2 Helping ALHIV prepare for transition

Transition requires an individualized, developmental approach – not all ALHIV will be ready to transition at the same age. Begin the process early, working as a team with the adolescent client, his or her caregivers and other members of the multi-disciplinary team.

The transition should:

- Enhance the adolescent's autonomy
- Cultivate a sense of personal responsibility
- Facilitate self-reliance and self-efficacy
- Boost the adolescent's capacity for self-care and self-advocacy

In each of these stages,you should consider each adolescent's developmental stage and readiness in the following areas:

- **Autonomy:** Independence or freedom, of the will and of actions
- **Personal responsibility:** The idea that adolescents choose, start or otherwise cause their own actions
- **Self-reliance:** The reliance on one's own efforts and abilities
- **Self-efficacy:** The confidence in one's own ability to achieve intended results

Older adolescents should be encouraged to take responsibility in making and keeping appointments and adhering to medicines by using appointment and medicine calendars.

Some innovative strategies that health workers and programmes can undertake to support transition include:

- Orienting adult HIV providers to adolescent-friendly services and needs of ALHIV
- Bringing adult providers to the adolescent's clinic for joint weekly clinical sessions so they can get to know more about adolescent clients and their unique needs
- Having a provider from the adolescent's clinic attend the adult clinic on a regular basis for 'transition sessions'

At facility level, the following can also be done:

- Identifying and orienting adult providers on the necessity of youth-friendly services through meetings, orientations and trainings
- Transferring the client's medical records to the new clinic and holding a case conference to discuss key issues
- Accompanying the adolescent to the adult clinic for an orientation

Some ways that health workers and adolescent peer educators can help ALHIV prepare for the transition process:

- Reviewing the adolescent's medical history with him or her and encouraging them to ask questions
- Ensuring that the adolescent understands diagnosis, medications, adherence and how to live positively
- Promoting linkages to adolescent peer support groups as well as support groups at the adult clinic

- Transitioning adolescents to adult care in cohorts or groups
- Organizing health talks for transitioning adolescent clients

The measures which health workers and peer educators perform in preparing ALHIV for the transition process can be adopted both at facility level and at the community level. The following steps can be taken to ensure smooth transition:

- Involving peer educators, social workers and counsellors when planning for an adolescent's transition, especially for most-at-risk ALHIV
- Connecting ALHIV to other community-based services

A significant objective of the transition process is to help older ALHIV become more involved in their care. Ideally, they should be able to:

- Know when to seek care for symptoms or emergencies
- Identify symptoms and describe them
- Negotiate multiple providers and different types of clinic visits
- Establish a good working relationship with health service providers
- Ask questions relevant to their treatment and know when and how to ask for help
- Have full understanding of their care and treatment plan, including the medicines they are taking
- Get the results of every test and understand it
- Join an ALHIV support group
- Follow-up on all referrals

13.2.2 Transition tools for ALHIV

13.2.2.1 Support tools for ALHIV transition

It is possible for adolescents to have a smooth transition to adult care. Transition tools can help health care workers and ALHIV prepare for and carry out the transition to adult care. Health care workers should be familiar with and use the 'Transition Checklist' when helping ALHIV transition to adult care.

Table 13.1: A self-care and transition timeline for ALHIV

10–12 years old	13–16 years old	17–19 years old
■ Encourage caregivers to fully disclose details of their condition to the child ■ Solicit direct conversation with the adolescent ■ Increase one-to-one meetings and counselling sessions with the adolescent ■ Begin to explain medications and adherence ■ Deal with early adherence issues and challenges ■ Link adolescent to support groups	■ Assist adolescent with a calendar for appointments and medicines ■ Ensure that the adolescent understands diagnosis, needed medications, adherence, health precautions, positive living, and positive prevention	■ Enforce responsibility in making and keeping appointments ■ Provide ALHIV with copies of medical records and other forms or documents required by the adult clinic ■ Review the client's medical history with them ■ Encourage questions about the adolescent's care plan, treatment regimen and possible changes ■ Transfer medical records to new provider, highlight key issues ■ Visit the adult clinic with adolescent client

Exercise 1: Case study 1

Panache is a 16-year-old ALHIV. In a few months, he is moving to a new town with no paediatric clinic and will have to start getting care and treatment at an adult clinic. He is nervous about this change because he does not know the staff there and will now have to deal with a large, crowded clinic.

- What fears or concerns do you think this adolescent has about transitioning to adult care?
- What could health workers do to prepare this adolescent for his or her transition to adult care?
- What follow-up could health workers provide once the adolescent has enrolled in the adult clinic?

Exercise 1: Case study 2

Megna is an ALHIV who is 19 years old. She has been receiving services from the adult clinic for the past year. Today, Megna has returned to the adolescent clinic to see you. When you ask her about her care and treatment, she tells you that she stopped taking her ARVs 3 weeks ago. When you try and discuss this situation with her in more detail, she cries and tells you that she doesn't like the people at the adult clinic.

- What fears or concerns do you think this client has about transitioning to adult care?
- What could health workers do to prepare this client for his or her transition to adult care?
- What follow-up could health workers provide once the adolescent has enrolled in the adult clinic?

Exercise 1: Case study 3

Brenia is 20 years old and a client at the paediatric clinic where you work. Her auntie supports

her and usually brings her for clinic visits. Brenia has been diagnosed with some learning problems and developmental delays and although she should transition to the adult clinic soon because of her age, you have some concerns about her development and ability to independently manage her own care. You are afraid she will get 'lost' at the adult clinic.

- What fears or concerns do you think this client has about transitioning to adult care?
- What could health workers do to prepare this client for his or her transition to adult care?
- What follow-up could health workers provide once the adolescent has enrolled in the adult clinic?
- What might be some of the implications of Brenia's developmental delays for her transition to adult care?

13.2.3 Key points

- To prepare for the transition from paediatric to adult clinic, older ALHIV need support from a multidisciplinary care team and family members.
- Ideally, health workers from paediatric and adult clinics should collaborate and solve problems together during a client's transition.
- As ALHIV transition to the adult clinic, you can help them advocate for themselves, be involved and understand their care and treatment.
- Planning and preparing for transition with the adolescent and ensuring that adult clinic staff understand the special needs of ALHIV leads to a smooth transition and ensures that the client receives adolescent-friendly services at the adult clinic.

Appendix 13A: Transition checklist for health workers

This checklist contains the key points related to preparing older adolescents for transition to adult care. This checklist is meant to assist you and all members of the multidisciplinary care team by outlining the basic steps involved in supporting adolescents with the transition process. It provides suggested subjects for discussion, although additional areas may be identified to meet an individual's needs. In the 'Actions' section, you should record major actions undertaken, referrals made or information given to the adolescent or caregiver during the discussion.

✓	Important steps and suggested activities to facilitate the transition process	Actions and comments
	1. Introduce the transition	
	Introduce and discuss transition during adolescent support group meetings and group sessions.	
	Discuss transition during clinical checkups and individual counselling sessions with adolescent clients.	
	Discuss transition with caregivers during group or individual sessions.	
	2. Encourage the adolescent to assume increasing responsibility for his or her health care management	
	Make sure the adolescent understands his or her health condition, care plan and medications.	
	Talk about the transition and transfer to the adult clinic, discuss expectations and answer questions.	
	Talk about general coping, positive living and building supportive relationships.	
	Give caregivers an opportunity to discuss their feelings about transition and any concerns.	
	3. Assess the client's ability to make independent health care decisions, his or her readiness for the transition and determine additional support needs	
	Assess the client's understanding of his or her care and transition process.	
	Assess the caregiver's understanding of the client's care and transition process.	
	Encourage the adolescent to make his or her next clinic and refill appointment.	
	Initiate any needed referrals, including referrals to support groups.	
	4. Provide anticipatory guidance	
	Review plans for the client's continued adherence to care.	
	Review the client's adherence to medicines and ensure that he or she has a medicine calendar.	
	Ensure the client knows where to access help if he or she has questions about the new clinic.	

✓	Important steps and suggested activities to facilitate the transition process	Actions and comments
	5. Implement the transfer to an adult clinic	
	Give copies of reports and tests to caregivers so they have their own copies.	
	Transfer medical records to the adult clinic and ensure that the client also has a copy.	
	Discuss the adolescent's care with health workers at the adult clinic.	
	Provide orientation to the adolescent, ideally together with a health worker at the adult clinic.	
	Follow up after the transfer (for example, schedule a follow-up visit with the adolescent, encourage peer educators to visit the adult clinic, etc).	
	6. Other activities that may help health workers and ALHIV plan for the transition process	
	Arrange for ALHIV to meet with adolescent clients who have already transitioned to adult care.	
	Schedule a visit to the adult clinic so adolescents can learn more about the services and health workers there before the transfer takes place.	
	Invite adult providers to the paediatric clinic for a weekly session so they can get to know more about adolescent clients and their needs. And/or, have providers from the paediatric clinic hold regular transition sessions at the adult clinic.	
	Refer ALHIV to attend a support group session with other transitioning adolescents.	
	Suggest that the adolescent start journaling or using a transition workbook.	
	Use a comprehension assessment tools like a quiz or a questionnaire about HIV and adherence to care and treatment in order to assess transition readiness.	

MODULE 14:

MONITORING, EVALUATION AND QUALITY IMPROVEMENT

Total module time: 2 hours 30 minutes

Module 14: Objectives

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

- Explain the importance of routinely monitoring adolescent HIV care and treatment activities
- Describe how information from monitoring and evaluation (M&E) can be used to support programme improvement
- Describe the purpose of quality improvement (QI)
- Define and describe supportive supervision

Session 14.1

Total time taken:
1 hour 45 minutes

Monitoring and evaluation

Learning objectives

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

- Discuss the importance of routinely monitoring adolescent HIV care and treatment activities
- Discuss how information from monitoring and evaluation (M&E) can be used to support programme improvement

14.1.1 Importance of routinely monitoring adolescent HIV care and treatment activities

14.1.1.1 Definition of monitoring and evaluation

Monitoring is routine tracking of programme interventions through collecting, analysing and reporting data to assess progress against set plans. It involves measuring what is being done and routinely checking the quality of the services.

Monitoring and evaluation (M&E) is the standardized process by which data is collected, compiled and evaluated on a routine basis. This data can be used to monitor progress in the implementation of adolescent care and treatment services at facility, district and national levels, so that problems can be identified early and corrected quickly.

Health workers play a vital role in the monitoring process by regularly recording, compiling and reporting data to determine, for example:

- Number of adolescents enrolled in HIV care
- Number of adolescents receiving ART
- Number of adolescents retained in care over time
- Types of clinical and support services offered to adolescents

Remember that facility-level reports are aggregated up to district and national levels, and that they also form a part of international progress reports.

M&E of adolescent HIV care and treatment programmes can help to:

- Assess whether a programme is meeting its targets
- Identify and improve problem areas in the implementation of adolescent services

Routine M&E is necessary to gather information on care and treatment programme outcomes, such as:

- Is the programme retaining adolescent clients in care?
- Are all eligible adolescents receiving ART?
- Are routine lab tests and clinical follow-up visits being conducted on schedule?

REMEMBER

- Programme/project outcomes are usually the cumulative tally of individual outcomes
- M&E data can be used to monitor progress in the implementation of adolescent care, treatment and support services at the facility, district and national levels

14.1.1.2 Disaggregating data

Disaggregation involves distributing collected data by age, sex, pregnancy and breastfeeding. Adolescent data should be disaggregated using the following age groups:

- Ages 10–14 years
- Ages 15–19 years

This gives us detailed information and allows for more meaningful interpretation of programme outcomes. Often, routine reporting disaggregates data into two age categories: under-15 and over-15. However, tools that will break adolescent age categories are under development and will be released soon.

14.1.1.3 Indicators

Indicators are summary measures used to help indicate the status of a programme's activities. ALHIV care and treatment indicators are established at the national level, and cover service delivery, quality of care and management related information. Indicators can be calculated at the facility, district or national levels, depending on need and how the data will be used.

Health facilities can develop their own indicators to monitor progress towards national indicators and towards other gaps identified for that specific health facility. Indicators may need to be revised periodically as they reflect a certain time frame (e.g., month, quarter). It is therefore important to measure changes in indicators over time.

Some examples of indicators are:

- Number of HIV-infected adolescents (aged 10–19) enrolled in care
- Number of adolescents who initiated ART
- Number of adolescents currently receiving ART
- Number of adolescents who had a change of therapy
- Number of adolescents for whom ART was discontinued
- Number of adolescents lost to follow-up
- Number of adolescents transferred to other facilities
- Number of adolescents who have died
- Number of adolescents who have become pregnant

14.1.1.4 Targets

Targets are specific goals established before a new programme or service is implemented, and re-established on a regular basis thereafter. Targets must have a numerator and a denominator.

For example: 'To ensure that 95% of eligible adolescent clients initiate ART.'

- Numerator – Number of adolescent clients initiated ART
- Denominator – Number of eligible adolescent clients

14.1.1.5 Definition of evaluation

Evaluation is the process of tracking changes in indicators that reflect service delivery and determining whether pre-established targets have been reached.

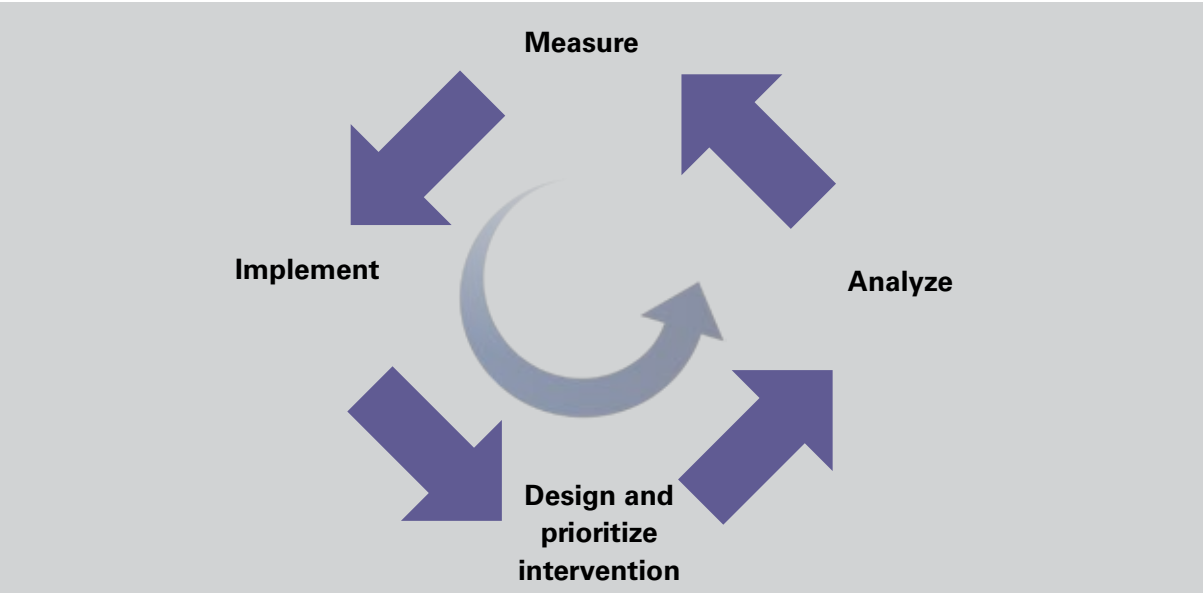
Its implications involve:

- Helping us understand what indicators are really telling us
- Helping us take a closer look at outcomes of interest and answering questions about what these outcomes mean
- Typically conducted at specific time periods (e.g., at the end of a year), whereas monitoring happens on a more regular basis
- At its simplest, will demonstrate to what extent planned activities are actually realized by comparing targets with indicator measurements (e.g., what percentage of the target for ART initiation did the programme reach last year?)

Evaluation can also involve using research methods to systematically investigate a programme's effectiveness. One might use evaluation to answer the following questions about the programme:

- Are adolescents enrolled in a peer support group more likely to return for scheduled appointments compared to adolescents who do not participate in peer support groups?
- Are adolescents enrolled in the programme experiencing a better quality of life?
- Has the programme reduced the number of adolescents hospitalized for HIV-related illnesses?

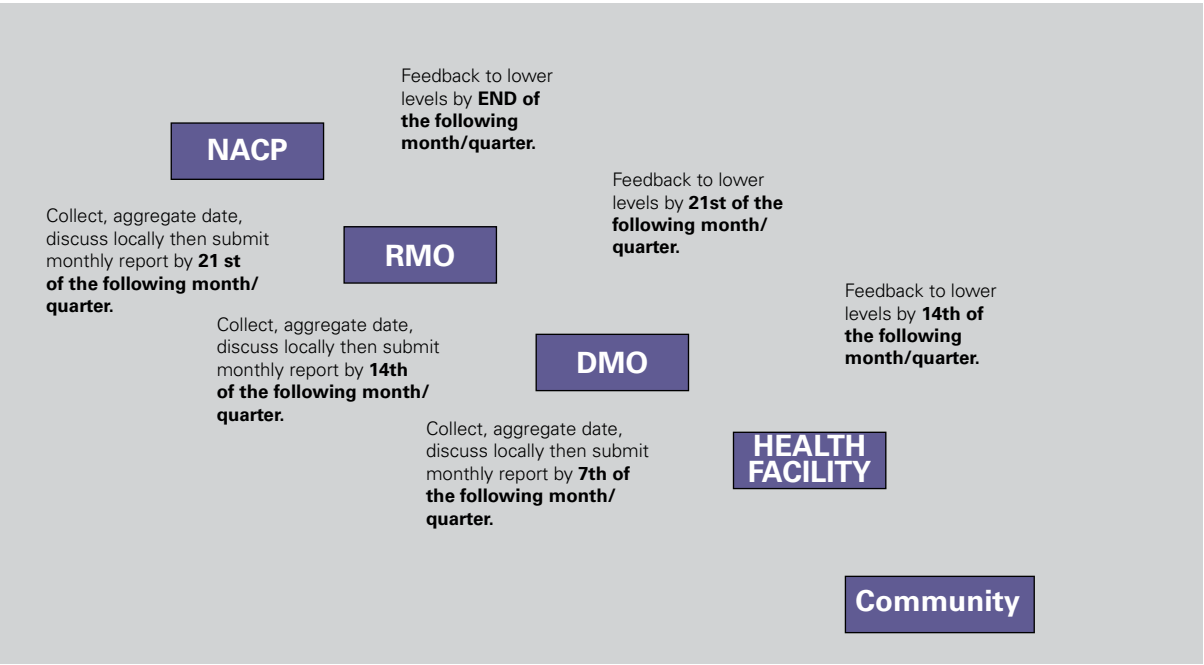
M&E is a CONTINUOUS process



Evaluations should be conducted regularly in order to keep track of the changes that occur as the adolescent HIV programme is implemented and maintained. This will enable programme staff to identify areas of programme strengths and weaknesses, and to respond to weaknesses by investigating and correcting problems.

14.1.1.6 Reporting steps/flow

The flow diagram shows how reports move, and the timeline from community/health facility to the district, regional and national levels.



NOTE:

- It is important to abide by set deadlines as they have national and international implications.
- Data should be used for decision making at different levels.

14.1.1.7 Common tools used

- CTC 2 Card
- CTC 1 Card
- Pre-ART register
- ART register
- Cohort analysis register
- Appointment book
- Tracking register
- CBHS register
- Pharmacy register
- HTC register
- Forms:
  - Request form
  - Referral form
  - Continuation form
- Reports:
  - Cross-sectional reports
    - Monthly
    - Quarterly – age aggregation changed to cover adolescents
    - HTC monthly summary forms
- Cohort analysis report form

More explanation of the above tools

- CTC 2 card is the patient record at the CTC. All patient information is included in this form.
- CTC 1 card is Patient ID card containing the history of medications the patient is taking.
- Pre-ART register lists ALL patients in HIV care in a facility.
- ART register is for patients on ART. Patients move from the pre-ART register to the ART register once they get started on ARV therapy.
- Cohort analysis register is for groups of patients who started ART in the same month/quarter of the same year.
- Appointment book provides return date and time for the clients.
- Tracking register is used for follow-up of defaulted clients.
- CBHS register records clients who do not show up on the day of their appointment.
- Pharmacy register records prescriptions for ARVs.
- HTC register records clients tested for HIV.
- Request form provides for all laboratory investigations requested for the client.
- Referral form is used for transferring clients to another section or facility.
- Cross-sectional report collects reports from pre-ART and ART registers on a quarterly basis.

14.1.2 Use of M&E information for programme improvement

14.1.2.1 Data use

Monthly summary forms should lead to discussions on how improvements can be made at the health facility to meet targets more efficiently.

Such improvements will require discussion of the following:

- What is the problem?
- How will we address the problem?
- What is our plan?
- How will we know if the plan is working?

14.1.2.2 Data collection and forms for adolescents

There is no separate data collection and reporting system for adolescents. This is why it is particularly important that data is appropriately disaggregated by age. Health facilities should use regular national forms for HIV care and treatment.

Effective M&E systems require record keeping that is:

- **Accurate:** In other words, correct and true
- **Reliable:** Completed the same way every time
- **Standardized:** Recorded using the same tools in every clinic in the country
- **Recorded:** By following established guidelines

Important points to remember about data collection are:

- Systems for documenting care and treatment activities must maintain client confidentiality
- It is the responsibility of all staff members who complete registers or summary forms to ensure that data is accurate, complete and that data collection protocols are followed

Exercise 1: Small group work (part 1)

Follow instructions provided by facilitators.

- Review the data in Table 14.1.

Table 14.1: Sample data for Exercise 1

Quarterly adolescent HIV care and treatment summary report for Mji Mwema Clinic			
Number of adolescents enrolled in care	**2016, Q4**	**Target***	**% of target**
■ Females, aged 10–14	100		
■ Males, aged 10–14	95		
■ Females, aged 15–19	150		
■ Males, aged 15–19	165		
■ Total	510	550	

Number of adolescents receiving ART	2016, Q4	Target*	% of target
■ Females, aged 10–14	75		
■ Males, aged 10–14	70		
■ Females, aged 15–19	102		
■ Males, aged 15–19	120		
■ Total	367	350	
Number of new adolescent clients	**2016, Q4**	**Target***	**% of target**
■ Females, aged 10–14	1		
■ Males, aged 10–14	2		
■ Females, aged 15–19	22		
■ Males, aged 15–19	12		
■ Total	37	40	
Number of adolescent clients who missed appointments	**2016, Q4**	**Target***	**% of target**
■ Females, aged 10–14 (75 had appointments this quarter)	20 (27%)		
■ Males, aged 10–14 (70 had appointments this quarter)	23 (33%)		
■ Females, aged 15–19 (95 had appointments this quarter)	37 (39%)		
■ Males, aged 15–19 (105 had appointments this quarter)	42 (40%)		
■ Total (345 had appointments this quarter)	122	10% of those in care, max.	
Number of adolescent clients attending support group meetings	**2016, Q4**	**Target***	**% of target**
■ Females, aged 10–14	55		
■ Males, aged 10–14	45		
■ Females, aged 15–19	120		
■ Males, aged 15–19	130		
■ Total	350	50% of those in care	
Number of support group meetings held at the clinic	**2016, Q4**	**Target***	**% of target**
■ For 10–14 year olds	6		
■ For 15–19 year olds	10		
■ For caregivers	3		
■ Total	19	9	

Number of active adolescent peer educators at the clinic	2016, Q4	Target*	% of target
Number of active adolescent peer educators at the clinic	15	6	
* If a cell is blank, it means that sub-targets have not been stated.			

Part 1 of small group work

- Calculate the 'percentage of target' in the last column based on the data provided.
- Discuss the following questions:

1. For which indicators is Mji Mwema Clinic doing good and meeting its targets? How do you know?
2. For which indicators is Mji Mwema Clinic NOT meeting its targets? How do you know?
3. If the number of adolescents enrolled in care in Q4 (the 4th quarter) of 2015 was 450 and the number of adolescents receiving ART was 290, would you say the clinic is doing better or worse enrolling clients in ART in 2016?
4. Which areas should the staff of Mji Mwema Clinic focus on improving?

Part 2 of small group work

Identify one of the areas that needs improvement at Clinic XX and discuss:

- What is the problem?
- How should we (assuming we are the managers at Clinic Make Believe) address the problem?

14.1.3 Key points

- Routine monitoring of adolescent HIV care and treatment activities helps to identify problems early so that they can be corrected quickly.
- Monitoring and evaluation (M&E) of information can be used to support programme improvement by comparing programme outcomes of interest against the set targets.

Session 14.2

Total time taken: 45 minutes

Quality improvement and supportive supervision

Learning objectives

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

- Describe the purpose of quality improvement (QI)
- Define and describe supportive supervision

14.2.1 Purpose of quality improvement

14.2.1.1 Definition of quality improvement (QI)

Quality is the standard of a thing measured against another thing of a similar kind. It indicates the degree of excellence of that thing.

Quality improvement is the means by which activities are routinely evaluated for the purpose of checking whether services are following established guidelines and standard operating procedures (SOPs). It may also be referred to as quality assurance (QA).

QI is different from M&E. It should be a routine, ongoing part of the normal functioning of health facilities and incorporate procedures in which staff at all levels is involved.

QI uses scientific principles and tools to understand and address system deficiencies in order to produce efficient healthcare delivery processes through redesign. QI is the process of assessing whether services conform to specified internal or external standards.

The purpose of QI is to identify problems (in service delivery, data or both) so that they can be corrected, thereby improving services for adolescent clients and their families.

14.2.1.2 Methods to assess quality

It is often necessary to use a variety of methods to assess programme quality. Standard monitoring tools capture only a fraction of the services provided to adolescents and provide no information on the quality of those services. For example, forms and registers do not give us information on the youth-friendliness of the services or the quality of psychosocial support, adherence and counselling sessions.

14.2.1.3 Areas evaluated by QI activities

QI activities might examine/evaluate:

- Quality of adolescent-friendly services
- Compliance with national guidelines, SOPs and protocols for HIV care and treatment
- Adequacy of space and attention to privacy and confidentiality
- Linkages to ongoing support and community-based services

QI activities include:

- Periodic reviews of records, followed by staff feedback
- Direct observation of clinical procedures and counselling sessions
- Periodic assessments of adolescent-friendly services
- Interviews with staff to obtain feedback on specific indicators
- Individual interviews or of focus groups with ALHIV
- Individual interviews or of focus groups with caregivers of ALHIV
- Exit interviews or surveys completed anonymously by clients
- Evaluation of physical space, client flow and time
- Meeting with service representatives where ALHIV and caregivers are referred

14.2.1.4 How often should QI be conducted?

It is important to set up an established time-frame for health facility management teams to discuss QI findings and issues in their regular meetings, and plan the way forward.

During initial implementation, it is best to schedule reviews daily or weekly. As services become established, reviews should become a formal part of overall programme monitoring activities at designated intervals, starting from monthly and progressing to quarterly reviews.

14.2.2 Overview of supportive supervision

14.2.2.1 Definition of supportive supervision

Supportive supervision is a process that promotes quality at all levels of the health system by strengthening relationships within the system, focusing on the identification and resolution of problems, optimizing the allocation of resources, promoting high standards, team work and bettering two-way communication.

The goal of supportive supervision is to promote and maintain the delivery of high-quality health services.

Supportive supervision is an important component of responding effectively to QI findings. It is an approach in which supervisors work with staff to:

- Establish goals
- Monitor performance

- Identify and correct problems
- Pro-actively improve the quality of services

QI is the most effective when the focus is on providing guidance and mentorship, and using group problem solving to help health workers overcome barriers.

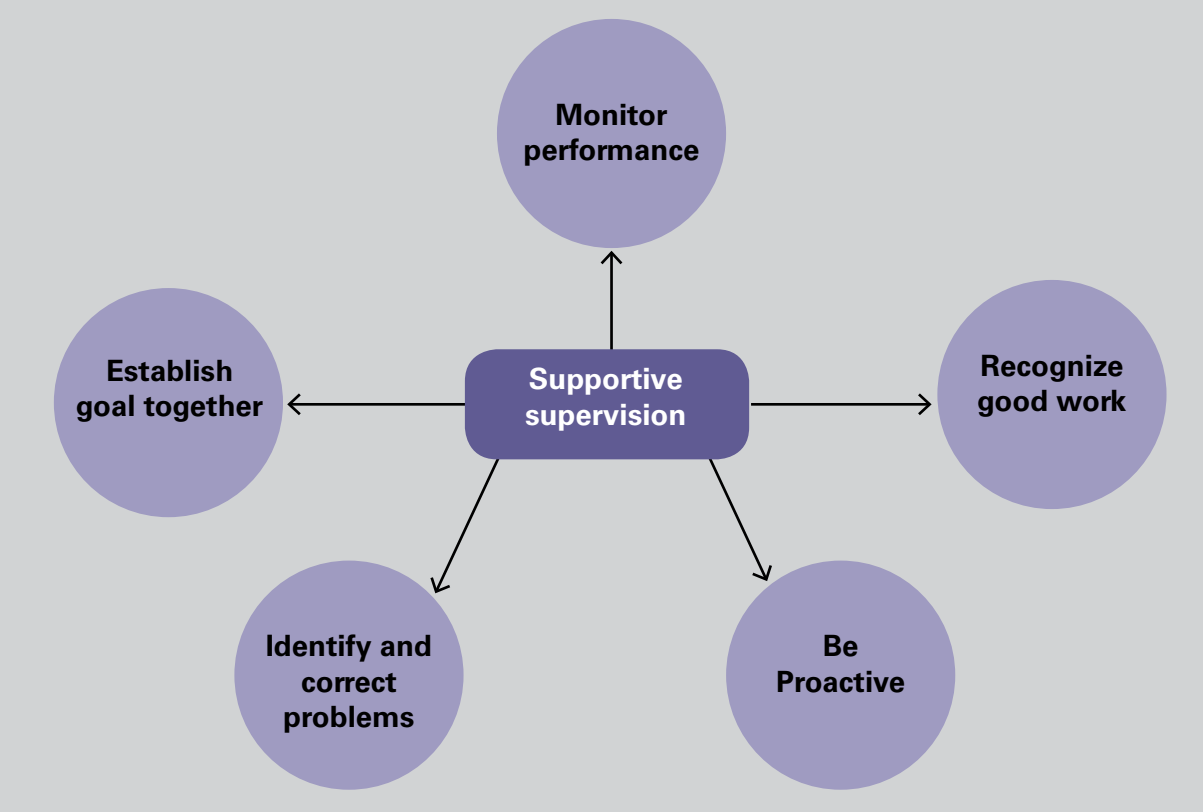
14.2.2.2 Aims of supportive supervision

The aims of supportive supervision are to:

- Obtain information on programme functioning and quality
- Improve performance of health workers by providing one-to-one support
- Acknowledge good practices by providing positive feedback
- Involve supervisors, health workers and volunteers to improve service provision
- Facilitate on-site, participatory problem-solving
- Involve youth in giving feedback and improving service provision
- Ensure that the programme is successful in meeting the needs of ALHIV/caregivers
- Motivate staff and volunteers

Once a deficiency in service provision is identified, supportive supervision must be established as quickly as possible to prevent poor practices from becoming routine.

14.2.2.3 Supportive supervision process



The process of supportive supervision includes:

- Routine monitoring of the performance of adolescent HIV services in the health facility through data collection and review
- Recognizing good work by appreciating and documenting success stories so that they can be applied to other health facilities
- Being proactive in controlling any indication of failure in the way of achieving set targets, rather than complaining or waiting for help
- Identifying and correcting issues arising from service delivery as early as possible. This has to be the role of every health worker in the clinic team
- Establishing goals together after every supportive supervision. The clinic team, together with the supervisor, should agree on the fate of the issues identified

14.2.3 Key points

- Quality improvement (QI) is the means by which activities are routinely evaluated to check whether services offered are following established guidelines and SOPs.
- QI should be a routine, ongoing part of the normal functioning of health facilities.
- A variety of methods may be used to conduct QI.
- An important component of responding effectively to QI findings is to provide supportive supervision.
- Supportive supervision requires collaboration between the supervisor and staff to establish goals, monitor performance and identify and correct problems.

MODULE 15:

ACTION PLANNING, COURSE EVALUATION AND CLOSURE

Total module time: 1 hour 45 minutes

Module 15: Objectives

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

- Review key steps and considerations of initiating or scaling up adolescent HIV care and treatment services
- Identify potential challenges to implementing adolescent HIV care and treatment services at their site and potential solutions to these challenges
- Start developing a site-specific action plan to initiate or improve adolescent HIV care and treatment services
- Discuss whether or not the training objectives were achieved
- Reflect on the concerns, expectations and strengths of the participants discussed on the first training day
- List next steps, including training follow-ups and supportive supervision
- Complete the post-training test
- Evaluate the training and give suggestions for improvement

Session 15.1

Total time taken: 30 minutes

Site-specific adolescent HIV care, treatment implementation and action planning

Learning objectives

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

- Review key steps and considerations of initiating or scaling-up adolescent HIV care and treatment services
- Identify potential challenges to implementing adolescent HIV care and treatment services at their site and potential solutions to these challenges
- Start developing a site-specific action plan to initiate or improve adolescent HIV care and treatment services

15.1.1 Scaling-up adolescent HIV services

15.1.1.1 Key steps for initiating or scaling-up adolescent HIV services

Launching or maximizing quality HIV services for adolescent clients is a thorough four-step process that involves:

- Conducting a needs assessment
- Developing an action plan
- Presenting the action plan to managers, health workers and youth
- Regularly revisiting the action plan to assess progress

Setting up youth-friendly services is a start, but in order to really meet the needs of ALHIV clients, quality and evidence-based HIV care must be provided within the context of youth-friendly services.

15.1.1.2 Characteristics of youth-friendly services

- Health worker characteristics
- Health facility characteristics
- Programme design characteristics

There are many ways to improve the youth-friendliness of services. Additional resources and staff are often not required, and sometimes even small changes can have a big impact.

15.1.2 Site-specific action plan to initiate adolescent HIV care and treatment services

Exercise 1

Following instructions provided by facilitators on developing an action plan.

Exercise 1: Debriefing

- It is important to start a specific action plan when everything learned during the training is still fresh in your mind
- Share the action plan with colleagues, managers and supervisors and ask for feedback
- Update the action plan regularly, perhaps every 3 to 6 months at first

Session 15.2

Total time taken: 30 minutes

Reflection on training objectives, concerns, expectations and strengths

Learning objectives

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

- Discuss whether or not the training objectives were achieved
- Reflect on the concerns, expectations and strengths discussed on the first day of the training
- List next steps, including training follow-ups and supportive supervision

15.2.1 Achievement of training objectives

15.2.1.1 Adolescent HIV care and treatment training objectives

1. Describe the stages and characteristics of adolescence along with the unique needs and challenges of adolescent clients.
2. Implement strategies to make HIV-related services youth-friendly.
3. Define and implement the package of HIV-related care and treatment services for adolescents.
4. Demonstrate effective communication and counselling skills with adolescent clients.
5. Conduct psychosocial assessments and provide ongoing psychosocial support services to adolescent clients.
6. Describe the importance of mental health services for adolescent clients, recognize when a mental health problem may exist and provide appropriate referrals and support.
7. Provide developmentally appropriate disclosure counselling and support to adolescents, and where appropriate, to their caregivers as well.
8. Describe develop mentally appropriate adherence preparation and ongoing adherence support to adolescent clients and caregivers.
9. Conduct sexual risk screening and provide non-judgmental, comprehensive counselling on sexual and reproductive health to adolescent clients.

10. Describe nutritional requirements, care and support for ALHIV.
11. Provide basic, non-judgmental contraceptive counselling and services to adolescent clients.
12. Describe the key components of sexual and reproductive health services for adolescents and provide referrals and support along the continuum of care.
13. Describe ways to link adolescents with needed facilities and community-based support services.
14. Describe and implement activities to meaningfully involve adolescent clients in clinical services, such as through adolescent peer education programmes.
15. Prepare and support adolescent clients throughout the transition to adult care,
16. Describe how monitoring and evaluation can be used to support adolescent HIV programme improvements.
17. Demonstrate core competencies in adolescent HIV care and treatment services in a clinical setting.
18. Develop a site-specific action plan for implementing adolescent HIV care and treatment services.

Be reminded that on going support, mentoring and technical assistance will be provided to help you and your team implement the skills, knowledge and action plans developed during this training.

15.2.2 Concerns, expectations, strengths and next steps

15.2.2.1 Concerns, expectations and strengths

- **Strengths**
  - Would anyone like to add to the strengths list?
- **Concerns**
  - Would anyone like to discuss their current perspective on the concerns listed during the 'Getting to know each other' exercise?
- **Expectations**
  - Were your expectations met during the training? What areas remained lacking?

Session 15.3

Total time taken: 45 minutes

Post-test, training evaluation and closing

Learning objectives

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

- Complete the training post-test
- Evaluate the training and give suggestions for improvement

15.3.1 Training post-test, evaluation and suggestions

15.3.1.1 Training post-test

The objective of this post-test is to find out what the group as a whole knows about adolescent HIV care and treatment, and how much the group's knowledge has improved since the pre-test. Results of the pre- and post-tests will help improve future trainings and will provide information on ongoing mentoring and supervision needs.

Appendix 15A: Adolescent HIV care and treatment action planning and implementation template

Objective	What is the specific activity?	Who is responsible?	What resources or support are needed?	When will the action happen?	Means of verification
Conduct a needs assessment of adolescent HIV services currently being provided.	1.				
	2.				
	3.				
Anticipated challenges to implementing this objective and possible solutions: 1. 2.					

Objective	What is the specific activity?	Who is responsible?	What resources or support are needed?	When will the action happen?	Means of verification
Provide training/ orientation to staff and volunteers.	1.				
	2.				
	3.				
Anticipated challenges to implementing this objective and possible solutions: 1. 2.					

Objective	What is the specific activity?	Who is responsible?	What resources or support are needed?	When will the action happen?	Means of verification
Make the health facility friendlier for adolescent clients	1.				
	2.				
	3.				
Anticipated challenges to implementing this objective and possible solutions: 1. 2.					

Objective	What is the specific activity?	Who is responsible?	What resources or support are needed?	When will the action happen?	Means of verification
Involve youth in programme design and service delivery	1.				
	2.				
	3.				
Anticipated challenges to implementing this objective and possible solutions: 1. 2.					

Objective	What is the specific activity?	Who is responsible?	What resources or support are needed?	When will the action happen?	Means of verification
improve the quality of adolescent clinical care and treatment services	1.				
	2.				
	3.				
Anticipated challenges to implementing this objective and possible solutions: 1. 2.					

Objective	What is the specific activity?	Who is responsible?	What resources or support are needed?	When will the action happen?	Means of verification
Develop and/ or improve appointment and tracking system	1.				
	2.				
	3.				
Anticipated challenges to implementing this objective and possible solutions: 1. 2.					

Objective	What is the specific activity?	Who is responsible?	What resources or support are needed?	When will the action happen?	Means of verification
Develop peer support programmes and support groups for ALHIV	1.				
	2.				
	3.				
Anticipated challenges to implementing this objective and possible solutions: 1. 2.					

Objective	What is the specific activity?	Who is responsible?	What resources or support are needed?	When will the action happen?	Means of verification
Develop strong referral systems and establish linkages	1.				
	2.				
	3.				
Anticipated challenges to implementing this objective and possible solutions: 1. 2.					

Objective	What is the specific activity?	Who is responsible?	What resources or support are needed?	When will the action happen?	Means of verification
Develop and implement data collection reporting, monitoring and evaluation systems.	1.				
	2.				
	3.				
Anticipated challenges to implementing this objective and possible solutions: 1. 2.					

Endnotes:

1. Janie Lacy. Did You Know That…? Available at: http: //janielacy.com/orlando-counseling-services/teens/body-image/

2. Mail online. (July 26, 2011.) 90% of teens unhappy with body shape. Available at: http: //www.dailymail.co.uk/news/article-205285/90-teens-unhappy-body-shape.html

3. Schley, A., Colton, T., Schoeneborn, A., and Abrams, E. (2011).Positive voices, positive choices: A comprehensive training curriculum for adolescent peer educators, Version 1.0. ICAP.

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