



AYFHS Modular Training

MODULE 4: Treatment Support: Disclosure in the family, school and in relationships



Training Certification Reminder

- Attendance
- Pre and post test scores
- Between training, site support and data review.
- Reflect on the application and use of training content in the facility;
 - Module 1: Friendly health services for adolescents and young people
 - Module 2: Test & Treat for Adolescents and differentiated models of care
 - Module 3: Undetectable: Adherence counseling for adolescents and young people

What has been accomplished? Why?



Module 4 Overview: 3 hours

TIME	TOPIC
15 min	Welcome & Opening
10	Pre Test
30 min	Introduction to Aging with HIV
30 min	National Guidance on the Disclosure Process & Steps
5 min	Break
15 min	Overcoming Barriers to Disclosure for Young Patients
60 min	Practicing Skills to Support Disclosure Using Role Play
15 min	Next Steps: Improving disclosure support in our facility
5 min	Closing



Welcome

REVIEW GROUND RULES

- Participate
- Ask for clarification if unclear
- Provide constructive comments and share professional experience
- Cell phones on silent for 3 hours
- Prepare for success and certification
 - Participate in all trainings & pass test
 - Demonstrate use in the facility



Learning Objectives

- Define treatment support
- Define disclosure and its steps
- Understand the disclosure guidelines in Lesotho
- Identify ways to support patients to determine who, when & how to disclose HIV status
 - At ART initiation and with parents/caregivers or treatment supporters
 - At school
 - To boy/girl friends and before marriage
- Practice disclosure sessions using real cases



Pre Test

- 10 minutes given to answer a multiple choice test on the topic area.
- At the end of the training, you'll be given a post-test to check your learning





Halima
16 years old
Tanzania

Reflecting on Halima's Story

- How did it feel to watch the video? What did you notice?
 - What issues around disclosure did you pick up from this video?
 - What could be the reasons why Halima's parents did not disclose to her?
 - If you were Halima's provider how would you have handled the situation?
 - Can this happen in Lesotho? Why or why not?
 - What is the situation in this facility?



Disclosure

Process that involves age-appropriate information which will enable adolescents and young people to understand their HIV diagnosis, how it was acquired and to come to terms with living with HIV.

- It is an ongoing process and is not a one-off event.
- Disclosure of HIV infection to and by adolescents requires due consideration: **why, where, when, who** and **how?**
- It requires planning, sensitivity and understanding from ART initiation and life stages of the patient.



Types of disclosure

- **Prepared Disclosure** The HCW, the caregiver and the child are fully prepared for the disclosure process
- **Unprepared Disclosure** Either the health care provider, the primary caregiver or the child are not fully prepared for the disclosure process
- **Involuntary Disclosure** The primary caregiver is forced into disclosing to the child due to circumstances.
- **Accidental Disclosure** The child becomes aware of their illness purely through an incident that is accidental.
- **Complete Disclosure Process** The child is guided through a process, from the stage of non-disclosure to the stage of health-promoting disclosure within a children's rights framework



Disclosure Guidelines in Lesotho

- Disclosure is important for promoting the client's adherence to treatment, prevention and care plan.
- All patients should be disclosed to (full disclosure) by age 10 years prior to initiation on treatment.
 - The adolescent should hear about their HIV status from the caregiver or parent, with a HCW's support if needed.
- All patients should be encouraged to disclose their status to family, sexual partners, household members and supportive community members.
- Disclosure helps to fight stigma in communities (and normalize HIV.)



Definition: Treatment Supporters

- Are trusted people who can help ALHIV achieve their treatment goals and overcome challenges outside of the facility
- Treatment supporters can change over time; based on the stage of life of a young person
- ALHIV have the right to decide who and when to disclose their HIV status.
- Treatment supporter will need to be disclosed in order for them to give full support to the client



What are the potential benefits of disclosure?

- Enables adolescents to gain more knowledge and understanding of HIV
- Encourages adolescents to take more responsibility for their own care
- Builds a relationship of honesty, trust and support between the client, parent/caregiver and healthcare workers
- Potentially assists in improving:
 - Adherence
 - Access to support services
 - Family communication
 - Emotional well-being
 - Retention in care
- And more ...



What are potential challenges of disclosure?

Study	Negative impacts noted
Corneli et al., 2009	Some youths expressed emotional difficulties from disclosure, including sadness, discouragement and fear
Hejoaka, 2009	* Improved adherence; children maintained concealment strategies and secrecy.
Oberdorfer et al., 2006	Some reported sadness, anger and rebellion
Petersen et al., 2010	Negative effects and emotional difficulties included: distress, fear, perceived stigma, internalized stigma, withdrawal from peers, and perceived shortened future. Accepting family social support helped to address these challenges
Vaz et al., 2010*	Negative effects and emotional difficulties included: sadness, worry and perceived stigma; some children reported relief after disclosure and felt disclosure was important.



Steps to Disclosure Job Aid

1. Not disclosed: Ask the ALHIV to bring their caregiver or parent to their next clinic appointment. If not available, plan a home visit.
2. Separate caregiver session
3. Partial disclosure session
4. Full disclosure session
5. Post disclosure sessions



Lesotho Disclosure Guidelines

For older children and adolescents (10-19 years old)

- It is recommended that they should have full disclosure by age 10 if already in care, or as diagnosed with HIV
- Discuss and plan disclosure with parents/caregivers
- First determine what they already know;
 - A provider may ask if they know why they are coming to clinic/getting blood drawn?
- There is a need for a child assessment to be sure the approach is developmentally and age-appropriate



School: who, when & how to disclose

- Who are possible treatment supporters in schools?
 - Someone who can be trusted with private information for help with ART.
- When do ALHIV need to disclose HIV status in schools?
 - When treatment adherence is affected by the school schedule or programs.
 - When the patient decides to disclose his/her status to others.
- How to disclose at school?
 - Decide if the caregiver should assist in the discussion to ensure privacy.
 - Talking about HIV in general or inquire about other ALHIV in the school with the person to test their reaction.
 - With confirmed confidentiality, discuss the student's need and as appropriate disclose.



Partners: when, who to disclose to

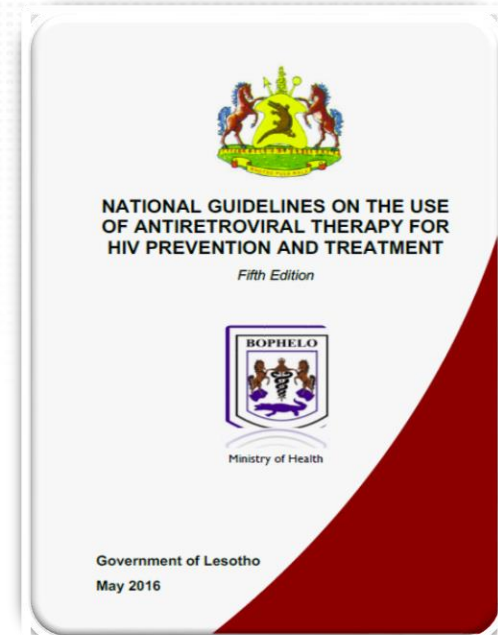
- When do AYPLHIV need to disclose HIV status to sexual partners?
 - When they put another person at risk for HIV infection or themselves for re-infection. (unprotected sex)
 - When the patient has a detectable viral load and engages in behaviour that can transmit HIV.
- Who should AYPLHIV disclose to when in sexual relationships?
 - It is the right of the patient to decide who to disclose to, when & how.
 - Encourage disclosure for committed relationships – prior to marriage or when the patient discusses pregnancy intentions or plans.



Lesotho Disclosure Guidelines

- **For young children (5-9 years)**
 - Simple information in a language they can understand
- **Discuss**
 - Nature of illness
 - How they can care for themselves
 - The near future

Note that diagnosis and prognosis are not a priority at this stage

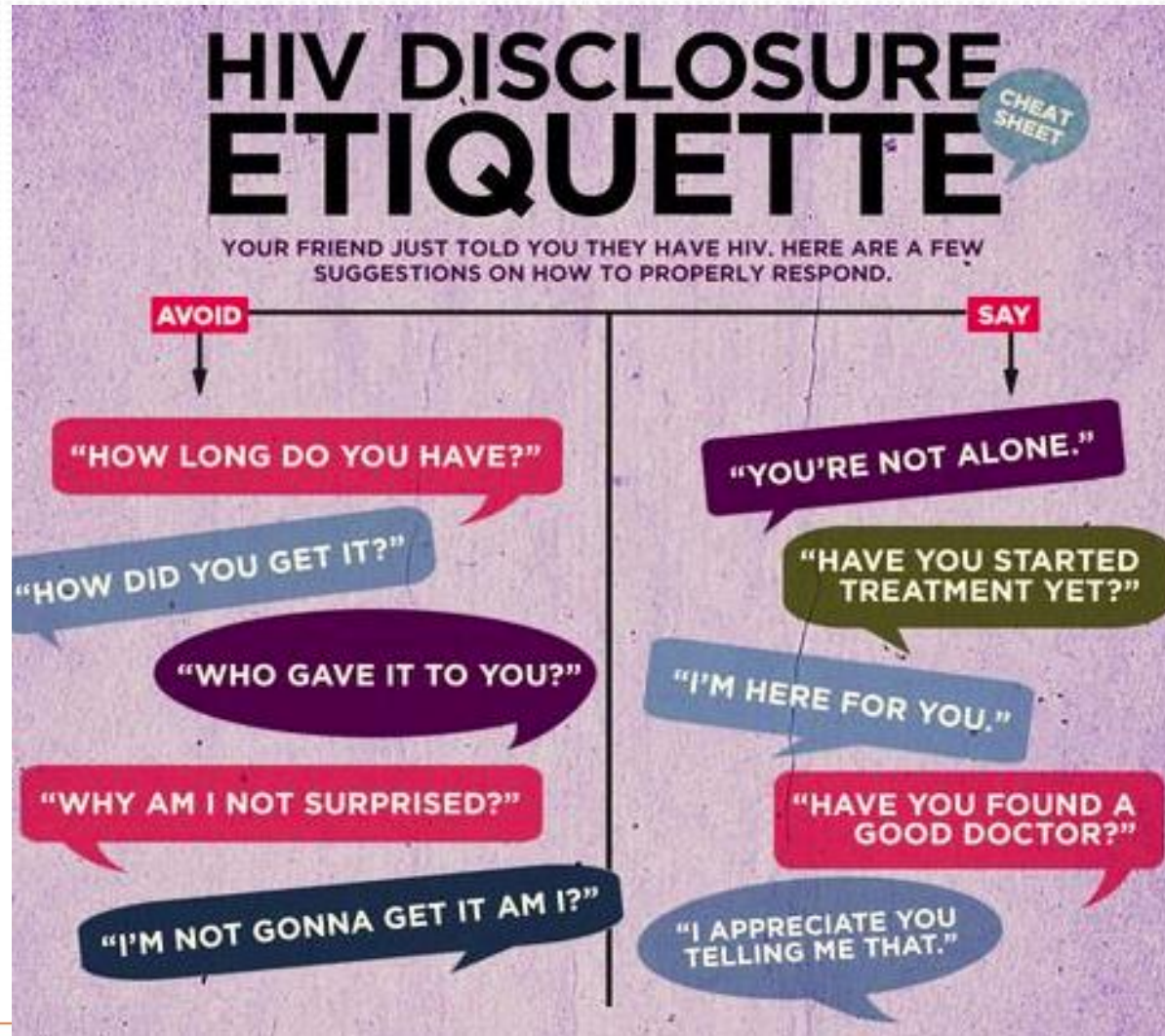


Partners: how to disclose

- Decide if the HCW (counsellor or another) can assist in the discussion for support and safety.
- Make a plan for the process of disclosure.
 - Discuss possible ways to disclose to a sexual partner/spouse/committed boy/girl friend.
 - Talk about HIV with the person to find out if he/she knows their status.
 - Find out how he/she feels about HIV infection or knows anyone living with HIV.
 - Consider going for partner testing together.
 - Practice with patient on how he/she will disclose.
 - Consider any possible reactions and how to respond to them – positive or negative.



Disclosing to Friends



Basket Role Play

PRIVATE &
CONFIDENTIAL

- Take a slip of paper; complete the information and place it back in the basket.
- Each slip is asking you to identify something from experience; about a challenging patient living with HIV between the ages of 10-24 years.
- *Please do not include identifying information in the details.*

Area	Patient details
Age	
Sex	
On ART for ___ time Viral load _____	
Medical history notes	
Social support	
Adherence status	
Disclosure support needs	



Small Group Role Play

- **Provider role;** treat it like a routine clinic visit.
- Test new language to use with the patient.
- Use the slip as your ‘file/record/chart review’
- **Patient role;** choosing a character to portray from the basket.
- Attempt to mimic the patient; with common language and body language.

Other group members play an **observer role**.

Refer to handouts and give feedback after answering:

- What went well?
- What could have been improved?



Process Role Play:

- What happened in your role plays? Was it easy to complete the exercise? Why or why not?
 - How was it to play the patient role?
- What do we learn about real clients from our discussions? (positive and negative)
- What can we take into our work in the clinic?



If the parent/caregiver is not ready to disclose, the process cannot be forced but provide follow-up counselling with the parent/caregiver, exploring their fears and anxieties around disclosure.

The healthcare provider should be patient, kind and understanding but emphasise the rights of the child, which includes the right to know their HIV status as stipulated in the patient's charter

At every visit, check if the child or adolescent has been disclosed to?

ASK

- Do you know why you come to this clinic? OR Do you know why you take these tablets?
- If the adolescent responds that it is because they have HIV, do not assume that they know what HIV is or that they have been properly disclosed to. Rather, follow up with more questions of clarity.
- Check their understanding of HIV. This is an opportunity for you to provide HIV education.

EXPLAIN:

- What HIV is
- The different ways HIV is transmitted
- How HIV and ART works and how taking their ART every day can help them stay healthy
- The possibility of side effects
- That they can still have sex, children and future

Next Steps for Enhanced Treatment Support for ALHIV

- What are the immediate next steps to ensure all adolescents in care complete disclosure?
- What needs to be prepared and reviewed?
- Who will assist with this? How?

Make notes on the Module Report.



Review Learning Objectives; Can we?

- Define a treatment supporter
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 - At school
 - To boy/girl friends and before marriage
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Closing

- Thanks
- Attendance
- Next clinic support visit and continuation of modules

