

Module 5

Providing Psychosocial Support Services for Adolescents

Session 5.1: The Psychosocial Needs of Adolescent Clients

Session 5.2: Assessing Psychosocial Support Needs

Session 5.3: Peer Support in Psychosocial Services for Adolescents

Learning Objectives

After completing this module, participants will be able to:

- List common psychosocial needs of both adolescents in general and ALHIV specifically
- Identify strategies to support adolescent clients and caregivers in dealing with stigma and discrimination
- Recognize psychosocial challenges among most-at-risk ALHIV and provide support and referrals
- Conduct a psychosocial assessment with adolescent clients and caregivers to better determine their specific psychosocial needs and the types of support they require
- Provide adolescents and caregivers with ongoing, age-appropriate psychosocial support services, including referrals
- Understand the importance of peer support in meeting adolescents' psychosocial support needs



Session 5.1

The Psychosocial Needs of Adolescent Clients

Session Objectives

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Overview of Psychosocial Support

Definition of psychosocial support and well being:

- **“Psycho-”** refers to the mind and soul of a person (involving internal aspects, such as feelings, thoughts, beliefs, attitudes, and values).
- **“Social”** refers to a person’s external relationships and environment. This includes interactions with others, social attitudes, values (culture), and the influence exerted by one’s family, peers, school, and community.
- **Psychosocial support** addresses the ongoing emotional, social, and spiritual concerns and needs of people living with HIV, their partners, and their caregivers.
- **Psychosocial well being** is when a person’s internal and external needs are met and he or she is physically, mentally, and socially healthy.

Psychosocial well being is part of the mental health spectrum. Psychosocial support for ALHIV and families is discussed in this module and mental health, more generally, is discussed in Module 6.

Psychosocial Support Needs of ALHIV

All adolescents have unique psychosocial needs, which are different from those of children and adults. This is because adolescence is a unique stage of life that is characterized by:

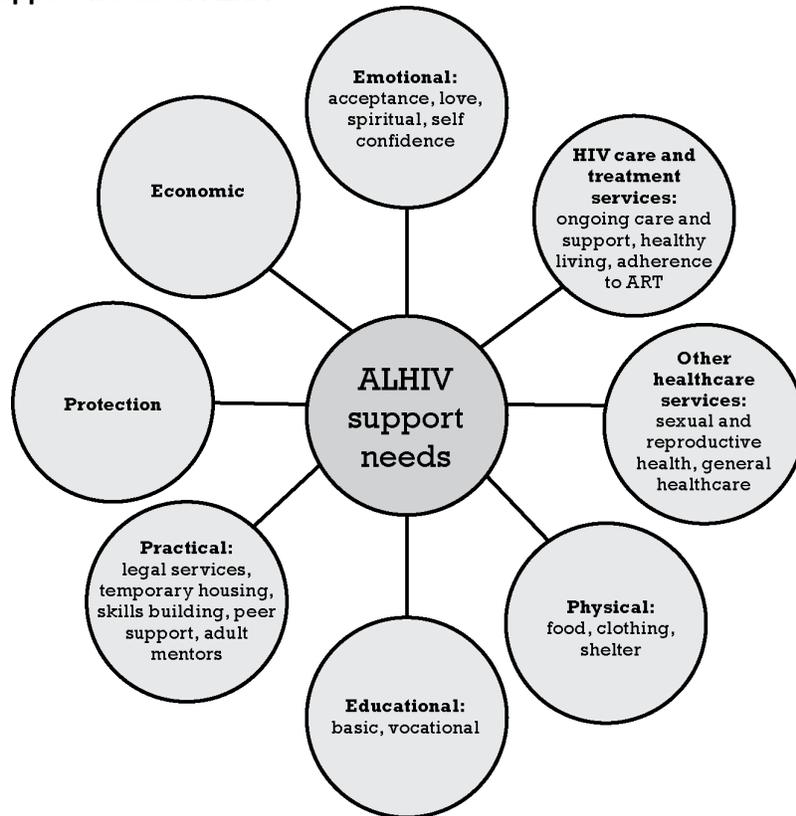
- Significant physical, emotional, and mental changes
- Risk-taking behavior and experimentation
- Sexual desire, expression, and experimentation
- Insecurity/confusion
- Anxiety
- Reactive emotions
- Criticism of caregivers or elders
- A focus on body image
- A sense of immortality
- A need to challenge authority figures while also still needing their support

Remember: ALL adolescents need support coping with normal developmental issues, such as wanting to feel normal and accepted and wanting to fit in with peers.

On top of the psychosocial needs and challenges that all adolescents face, ALHIV may also experience HIV-related stressors, vulnerabilities, and challenges that can result in the need for extra support. Adolescent clients may require extra support in the following areas, (among others):

- Understanding and coming to terms with their own HIV-status
- Understanding and coming to terms with family members' HIV-status
- Grieving the illness or loss of parents and/or siblings and coping with added responsibilities at home
- Coping with cycles of wellness and poor health
- Long-term adherence to both care and medicines
- Disclosure to friends, family members, and sexual partners
- Sexual and reproductive health, including disclosure to partners, practicing safer sex, using family planning, and making childbearing decisions
- 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, such as anxiety, depression, and substance abuse (see Module 6 for more information about mental health and ALHIV)

Figure 5.1: Support needs of ALHIV



Note: This figure was adapted from: Uganda Ministry of Gender, Labour, and Social Development. (2005). *Integrated care for orphans and other vulnerable children: A training manual for community service providers*.

Providing psychosocial support to ALHIV and their caregivers is important because:

- All adolescents need support coping with normal developmental issues, such as wanting to feel normal and accepted and wanting to fit in with peers.
- On top of the psychosocial needs and challenges that all adolescents face, ALHIV may also experience HIV-related stressors and, in some cases, additional vulnerabilities and challenges.
- Psychosocial support can help clients and caretakers gain confidence in themselves and in their coping skills.
- Adequate psychosocial support can increase clients' understanding and acceptance of all comprehensive HIV care and support services.
- Psychosocial well being is associated with better adherence to HIV care and treatment.
- HIV can be a chronic stressor that places ALHIV and their families at risk for mental health problems. Mental health and physical health are closely related (see Module 6).
- Ongoing psychosocial support may help prevent ALHIV from entering the “most-at-risk” category (discussed later in this session) or from developing more severe mental health problems.

Overview of Stigma and Discrimination

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

To stigmatize someone: Labeling or seeing a person as inferior (less than or below others) because of something about him or her. A lot of times people stigmatize others because they do not have the right information or knowledge. People also stigmatize others because they are afraid.

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.

There are different kinds of stigma:

- **Stigma toward others:** Having a negative attitude about others because they are different or assumed to be different (for example, a boy with HIV who feels isolated at school because of the stigmatizing attitudes of his peers)
- **Self-stigma:** Taking on or feeling affected by the cruel and hurtful views of others. Often, self-stigma can lead to isolating oneself from family and community (for example, H___ is HIV-positive and is afraid of “giving the disease” to her family, so she keeps to herself and eats her meals alone.).
- **Secondary stigma:** When people are stigmatized because of their association with PLHIV. This may include community health workers; doctors and nurses at the HIV clinic; children of parents with HIV; and the caregivers and family members of PLHIV (for example, when a child’s friends no longer play with her at school or around the community because people have heard that one of her family members is living with HIV).

There are different forms of discrimination:

- Facing violence at home or in the community
- Not being able to attend school
- Being kicked out of school
- Not being able to get a job
- Being isolated or shunned from the family or community
- Not having access to quality health or other services
- Being rejected from a 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 deter access to HIV prevention, care, and treatment services for many people. Stigma and discrimination can prevent people living with HIV, including adolescents, and their families from living a healthy and productive life.

Effects of Stigma and Discrimination

Stigma and discrimination can:

- Keep ALHIV from accessing care, treatment, counseling, and community support services (because they want to hide their status)
- Cause a great deal of anxiety, stress, and/or depression
- Make adolescents feel isolated and as if they do not fit in with peers
- Make it difficult for ALHIV to succeed in school
- Result in poor adherence to medications
- Make it hard for people to tell their partner(s) their status
- Make it hard for people to discuss safer sex with partners
- Make it hard for parents to disclose their own HIV-status to their children and also for caregivers to tell HIV-infected children their HIV diagnosis
- Discourage pregnant women from taking ARVs or accessing other PMTCT services
- Prevent people from caring for PLHIV in their family, in the community, and in health care settings
- Impact some adolescents more than others. For example, orphans living with HIV may encounter hostility from their extended families and community and may be rejected, denied access to schooling and health care, and left to fend for themselves.

Strategies to Deal with Stigma and Discrimination

Individual strategies for dealing with stigma:

- Stand up for yourself!
- Educate others.
- Be strong and prove yourself.
- Talk to people with whom you feel comfortable.
- Join a support group.
- Try to explain the facts.
- Ignore people who stigmatize you.
- Avoid people who you know will stigmatize you.
- Taking and adhering to ART and other medicines reduces stigma around HIV, helps normalize HIV, and allows the community to see HIV as a chronic disease. People who openly take ART can reduce stigma around the disease.

Strategies for dealing with stigma within health care settings:

- Make sure PLHIV and ALHIV, such as Peer Educators, are part of the care team. This includes making sure that they attend regular staff meetings, trainings, and other events.
- Make sure young people are given opportunities to evaluate clinical services and that feedback is formally reviewed by managers and health workers.
- Ensure that there are linkages with community-based youth groups and support groups for ALHIV; refer adolescents to these groups.
- Talk openly with other health workers about your own attitudes, feelings, fears, and behaviors. Support each other to address fears and avoid burnout.
- When you witness discrimination in the health care setting, challenge it. For example, if you see a colleague being rude to a client with HIV, talk to this colleague on a one-to-one basis after the client leaves. Tell him or her what you saw and how you think the situation could have been handled differently.
- Report to the manager any discrimination in the clinic setting that is directed toward PLHIV or their families.
- Listen to clients when they talk about their feelings and concerns about stigma and discrimination and report what you learn back to other health workers.
- Work with other members of the multidisciplinary team to identify where stigma and discrimination exist in the clinic and work together to make changes.

Overview of Most-at-Risk ALHIV^{1,2}

Worldwide, all adolescents are vulnerable and at-risk because:

- Young people’s behavior is less fixed than that of adults. Drug use and certain sexual practices are sometimes experimental and may or may not continue.
- Young people are less likely than older adults to identify themselves as drug users or sex workers. This makes them both harder to reach with programs and less responsive to communication addressed to groups with specific identities.
- Young people are more easily exploited and abused.
- Young people, especially girls, are the most common victims of gender-based violence or GBV (see Module 10 for more information).
- Many young women are also vulnerable to transactional sex and its consequences (see box below).
- Young people have less experience coping with marginalization and illegality.
- Young people may be less willing to seek out services — and providers may be less willing to provide them with services — due to concerns about the legality of behaviors and informed consent.
- Young people are often less oriented toward long-term planning and thus might not think through the risks that are related to the choices they make.
- Many adolescents are living without parental guidance or support.
- There is a lack of accessible health, social, educational, and legal resources for adolescents.
- Adolescents might live in societies or communities where laws, cultural practices, or social values force young people to behave in ways that place them at risk. Examples include the presence of homophobia, female genital cutting, or norms that encourage adolescent girls to have sex with older men.

Transactional sex: putting young women at risk

Transactional sex is the exchange of sex for money, goods, or services. Significant age disparities are common in partners who engage in transactional sex. Among other factors, concerns about HIV have prompted older men to seek younger sexual partners because they assume these partners are less likely to be HIV-infected. Young women are often willing to participate in these partnerships for emotional reasons; perceived educational, work, or marriage opportunities; monetary and other material gifts; or basic survival. They often fail to realize their vulnerability to abuse, exploitation, reproductive health risks, and HIV. **Transactional sex puts girls and young women at risk of physical and emotional abuse, exploitation, and a range of sexual and reproductive health problems.**

Most-at-risk ALHIV include young people who are both HIV-positive and particularly vulnerable or at risk, such as those who are homeless, homosexual or bisexual, trans-gendered, disabled, imprisoned, caregivers, orphans, migrants, refugees, gang members, sex workers, or injecting drug users. Most-at-risk adolescents may live in especially difficult circumstances and typically experience enormous challenges in meeting their own basic needs for food, shelter, and safety.

“Most-at-risk” refers to behaviors, while **“vulnerability”** refers to the circumstances and conditions that make most-at-risk behaviors more likely.

Young people who most need support often have the most difficulty accessing services and adopting behaviors that will protect them from HIV. The behaviors that put them at risk (for example, exchanging sex for money, food, or shelter) are usually heavily stigmatized, frequently take place in secret, and are often illegal.

Existing policies and legislation, lack of political support, and other structural issues often prevent most-at-risk adolescents from receiving the services they need. This contributes to the further marginalization of these young people and undermines their confidence in health and social services, as well as their willingness to make contact with service providers.

Most-at-risk ALHIV may require increased psychosocial support due to extreme challenges, such as:

- Displacement
- Severe social exclusion and isolation
- Stigma and discrimination
- Extreme poverty
- Substance abuse
- Physical or sexual abuse/violence
- Exploitation
- Migration
- Stigma, discrimination, violence, and fear of arrest due to sexual orientation
- Chronic mental health issues, psychiatric disorders, and learning disorders
- Disabilities
- A stressful past: many situations and events that push youth into vulnerable circumstances in the first place (like parental illness and death, lack of substitute parental care, abuse, etc.) may have a lasting impact on their well being

Non-violence: a human right

Ensure that all clients, particularly those who are most-at-risk, recognize that they have a right to say "no" to sex and a right to live in a world without abuse. Encourage them to recognize that violence and forced sex is not only wrong but also unethical and punishable by law.

Session 5.2

Assessing Psychosocial Support Needs

Session Objective

After completing this session, participants will be able to:

- Conduct a psychosocial assessment with adolescent clients and caregivers to better determine their specific psychosocial needs and the types of support they require

Conducting a Psychosocial Assessment

See *Appendix 5A: Psychosocial Assessment Tool*.

Tips to remember during the psychosocial assessment process:

- Emphasize that all information is confidential and private, but that health workers may share some of the information with other providers in the clinic to ensure the best care for the client.
- Conduct the assessment in a space that has visual and auditory privacy.
- Involve the adolescent during all phases of the assessment process.
- Respect the dignity and worth of the adolescent at all times.
- Do not talk down to the adolescent. Use good listening and learning skills, as discussed in Module 4.
- Always be positive! Offer lots of encouragement and praise throughout the assessment.
- Be patient! Allow the adolescent to speak for him- or herself. Allow the client to express his or her views and to describe his or her experiences.
- Respect the adolescent's coping skills and his or her ideas and solutions to problems.
- Do not judge! Make adolescents feel comfortable instead of fearful that they will be punished or judged — especially if they openly discuss challenges.
- Offer to include caregivers' and/or family members' input into the assessment as needed and agreed upon by the adolescent, while simultaneously protecting the confidentiality of information.
- Keep good records. Always keep a copy of the psychosocial assessment in the client's file.

Family-centered care versus client confidentiality

It is important to ensure the inclusion of caregivers and other family members in care. However, it is equally important that private information discussed during an individual session with an ALHIV remains confidential and is not shared with caregivers (unless the adolescent specifically consents). **Unless clients have a guarantee of confidentiality, they will be unwilling to discuss personal issues.**

Overview of Coping Strategies

Health workers should use the 5 “A’s” when conducting psychosocial assessment with clients: **ASSESS**, **ADVISE**, **AGREE**, **ASSIST**, and **ARRANGE**. Note that the 5 “A’s” were also covered in Module 3; these are part of the WHO IMAI guidelines on working with clients with chronic conditions, including HIV. See Table 5.1 for a review of the 5 “A’s.”

Table 5.1: Using the 5 “A’s” during clinical visits with adolescents, including psychosocial and counseling sessions (the 5 “A’s” were also covered in Module 3)

The 5 “A’s”	More Information	What the Health Worker Might Say
ASSESS	<ul style="list-style-type: none"> 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’s (caregiver’s) knowledge, beliefs, concerns, and behaviors 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 	<ul style="list-style-type: none"> <i>What would you like to address today?</i> <i>What can you tell me about _____?</i> <i>Tell me about a typical day and how you deal with _____?</i> <i>Have you ever tried to _____? What was that like for you?</i> <i>To make sure we have the same understanding, can you tell me about your care and treatment plan, in your own words?</i> <i>Many people have challenges taking their medicines regularly. How has this been for you?</i>
ADVISE	<ul style="list-style-type: none"> 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.) 	<ul style="list-style-type: none"> <i>I have some information about _____ that I’d like to share with you.</i> <i>Let’s talk about your risk related to _____. What do you think about reducing this risk by _____.</i> <i>What can I explain better?</i> <i>What questions do you have about _____?</i>
AGREE	<ul style="list-style-type: none"> Negotiate WITH the client about the care and treatment plan, including any changes Plan when the client will return 	<ul style="list-style-type: none"> <i>We have talked about a lot today, but I think we’ve agreed that _____. Is this correct?</i> <i>Let’s talk about when you will return to the clinic for _____.</i>
ASSIST	<ul style="list-style-type: none"> 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 	<ul style="list-style-type: none"> <i>Can you tell me more about any obstacles you’ve faced with _____ (for example, taking your medicines regularly, seeking support, practicing safer sex)?</i> <i>How do you think you can overcome this obstacle?</i> <i>What questions can I answer about _____?</i> <i>I want to make sure I explained things well — can you tell me in your own words about _____?</i>
ARRANGE	<ul style="list-style-type: none"> 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 	<ul style="list-style-type: none"> <i>I would like to see you again in _____ for _____. It’s important that you come for this visit or let us know if you need to reschedule.</i> <i>What day/time would work for you?</i>

Sources:

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

WHO. (2010). *IMAI one-day orientation on adolescents living with HIV.*

Note: If, during the “ASSESS” phase, a health worker thinks the adolescent client has serious issues that threaten his or her life or immediate safety (such as homelessness, thoughts of suicide, signs of severe depression, violence, etc.), these issues must be addressed IMMEDIATELY.

- In these emergency cases with most-at-risk adolescents, working through the 5 “A’s” should not be the priority.
- Instead, the health worker should focus on the client’s immediate safety and well being.
- Note that in these emergency situations, health workers may need to break confidentiality in order to take actions that are in the best interest of the adolescent and that ensure his or her immediate safety.
- Managing emergency situations is discussed further in Module 6.

Once the health worker has assessed that there are no emergency issues threatening the client’s immediate safety and well being, the health worker 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.

Examples of coping strategies include:

- Talking about a personal problem with someone trusted, such as a friend, family member, counselor, or Peer Educator
- Seeking help from clinic staff, especially if sad, depressed, or anxious for a long period of time (see Module 6 for more information about mental health and ALHIV)
- Joining a support group
- Changing one’s environment, taking a walk, or listening to music
- Seeking spiritual support
- Attending a cultural event, like traditional dancing or singing
- Participating in recreational activities, like sports or youth clubs
- Returning to a daily routine, including doing household chores (e.g. cooking) or going to school
- Doing something to feel useful, like helping a sibling with homework

Helping clients express themselves and encouraging them to tell their stories and to share their problems also helps them to:

- Feel a sense of relief
- Reduce feelings of isolation
- Think more clearly about what has happened
- Feel accepted, cared for, and valued
- Develop confidence
- Build self esteem
- Explore options or solutions to make better decisions
- Prevent bad feelings from coming out as aggressive behavior
- Maintain needed support from family members and other adults

An important part of helping adolescents cope with issues is encouraging their caregivers to strengthen their relationship with them. Health workers can suggest that caregivers:

- Spend time with and listen to the adolescent.
- Let the adolescent know that their feelings are normal and “OK.” Encourage them to talk and express feelings and thoughts. Listen actively.
- Communicate unconditional love and acceptance.
- Help the adolescent plan daily or weekly activities.
- Involve the adolescent in family activities as much as possible.
- Relax. It is important for both the adolescent and the family to learn to relax both physically and mentally.
- Get enough rest and eat well.
- Get professional help from a counselor or social worker.
- Be aware of changes in behavior or mood and look for signs of mental illness, including alcohol and other substance use (discussed more in Module 6).
- Talk to someone; family members may also be depressed and need help.
- Get help from a support organization in the community.
- Continue their regular religious or spiritual practices.

Exercise 1: Assessing Psychosocial Support Needs: Case studies in small groups and large group discussion

Purpose	To discuss how to assess the psychosocial needs of adolescents using <i>Appendix 5A: Psychosocial Assessment Tool</i> and by applying the 5 “A’s”
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Refer to *Appendix 5A: Psychosocial Assessment Tool* and the 5 “A’s” in Table 5.1.

Case Study 1:

A 17-year-old woman named T___ 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 T___ today?*

Case Study 2:

A 12-year-old boy named M___ 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 M___?*

Case Study 3:

K___ 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 last year, K___ 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 K___?*

Session 5.3

Peer Support in Psychosocial Services for Adolescents

Session Objective

After completing this session, participants will be able to:

- Understand the importance of peer support in meeting adolescents' psychosocial support needs

Importance of Peer Support for ALHIV

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.

The engagement of ALHIV as Adolescent Peer Educators can play an important role in improving adherence and service quality. See Module 12 for more information on the benefits of adolescent peer education programs and on how to implement such programs.

Adolescent Peer Educators can help improve services for ALHIV

Full participation of Adolescent Peer Educators in the health facility and in outreach services can expand the clinic's ability to provide quality care to adolescents by allowing already overburdened health workers to concentrate on more technical tasks.

It should be noted, however, that there are some significant differences between Adult and Adolescent Peer Educators, ranging from their availability to their attention span, brain function, and decision-making. Thus, expectations of Adolescent Peer Educators and their supervisory structures must also be different from those of Adult Peer Educators, expert clients, and lay counselors. Adolescents, usually self-conscious because of their age, inexperience, and outsider status, try hard to fit into adult environments. When they are successful, it can be easy to forget that they are not adults. However, when they are under stress, the mask of adulthood may slip, revealing their youth along with their **need for close supervision and guidance.**

Depending on the context and program, Adolescent Peer Educators can play a number of important roles in HIV service delivery, including but not limited to (see Module 12 also):

- Providing counseling and long-term support (related to adherence preparation, adherence follow-up, disclosure, positive living, positive prevention, etc.)
- Providing psychosocial support to clients and family members
- Leading health talks and group education sessions with ALHIV, caregivers, treatment supporters, and others
- Assisting clients with disclosure
- Linking young pregnant women living with HIV to ANC and PMTCT services
- Assisting clients with referrals from place to place, within or between health facilities
- Providing referrals and linkages to community-based services and support
- Tracing clients who miss appointments or who have been lost to follow-up
- Serving as a communication link between clients and health workers
- Participating in HIV-related outreach and education activities in the community
- Assisting with the design and delivery of peer support groups for ALHIV and their caregivers

Peer support can help address ALHIV's psychosocial support needs by (see Module 12 also):

- Helping them feel that they are accepted and valuable members of the group, and by reducing their sense of isolation
- Helping them solve their own problems
- Providing them with emotional support
- Promoting learning, sharing, and skill building around disclosure, adherence, and dealing with stigma and discrimination
- Maintaining their motivation and commitment to HIV care and treatment (since peer support can be more powerful than adult support or personal desire alone)
- Effectively engaging most-at-risk adolescents, who tend to lack positive support networks

Peer Support Groups for ALHIV³

Peer support groups are groups of people who come together because they share a common situation. In peer support groups, members help each other to better manage their situations, to share challenges, and to discuss solutions. Members support each other to implement decisions made to meet their psychological, social, physical, and medical needs.

- Support groups help people meet others living with HIV, which can reduce isolation and provide people with encouragement to live more fully and positively.
- A support group can be a safe place for someone who needs to talk about personal issues, experiences, struggles, and thoughts.
- Adolescents benefit from support groups because they trust information that they get from peers.
- Support groups can help members better understand clinical services, give them support to seek and adhere to care, and provide support for integrating family members into care.
- Support groups also offer ways to link members to community-based services. For example, health workers or leaders of community-based organizations can talk about the range of services their organizations offer during support group meetings. Also, support group members typically share with each other their experiences with local service providers and swap advice on how to navigate each program (what the ideal time to arrive is to reduce wait time, which documents to bring to the initial appointment, etc.).
- Support groups may also give income-generating, vocational, or educational assistance; or they may have savings and loan programs that can benefit members.
- Depending on the specific program, Adolescent Peer Educators may play an important role in starting support groups, facilitating support group meetings, and/or helping others organize them and recruit members. Adolescent Peer Educators in any of these roles benefit from support and mentoring (this is discussed more in Module 12).

There are many different types of useful support groups:

- **Adolescent support groups:** ALHIV may want to form their own support groups to discuss some of the special challenges they face. These groups may involve recreational activities (sports, crafts, drama, etc.) as well as time for discussion. It is best if they are led by an adolescent enrolled in care and treatment, such as an Adolescent Peer Educator.
- **Playgroups for younger adolescents:** Children living with HIV and their caregivers may benefit from groups where children of similar ages can play together and where caregivers have a chance to share and talk. These groups often involve child-friendly activities, such as games, drawing, art, and music.
- **Young mothers support groups:** Young mothers living with HIV and those with HIV-exposed or HIV-infected children may want to have their own support group. Young mothers support groups can provide needed psychosocial and emotional support and can help mothers understand and access key HIV and PMTCT services. These groups can also address concerns specific to mothers, such as safer infant feeding, care of HIV-exposed babies, and the importance of adherence to PMTCT and ART services.
- **Couples support groups:** Couples, including discordant couples as well as those where both partners are living with HIV, may wish to form support groups. Couples can share common concerns and challenges, and can support each other to live positively with HIV.
- **Post-test clubs:** These groups are for anyone who has been tested for HIV; they do not require participants to disclose their status. They often focus on promoting HIV information and education in the community and they also provide a social environment for members to meet each other and to discuss important issues, such as how to stay negative, being in a discordant relationship, etc.

- **Groups for other specific populations:** Other groups of people with common characteristics may wish to form their own support groups. This could include support groups for sex workers, men who have sex with men, street youth, orphans, or other vulnerable groups. In some places, there are support groups just for single people to meet other singles living with HIV. In areas with a diverse population, groups of people that have the same ethnicity or speak the same language may wish to form their own support groups.

Health education and related topics that can be incorporated into support group meetings:

- Positive living
- Adherence
- Disclosure
- Sexual and reproductive health
- Relationships and sexuality
- Preventing new HIV infections and positive prevention
- Preventing opportunistic infections
- Coping with school
- Finding work
- Strategies to reduce gender-based violence
- Dealing with stigma
- Nutrition
- Getting help for mental health problems
- Dealing with dying and the death of a friend or family member
- Managing disabilities



Module 5: Key Points

- Psychosocial support addresses the ongoing emotional, social, and spiritual concerns and needs of PLHIV, their partners, their family, and caretakers of children living with HIV.
- All adolescents need support coping with normal developmental issues, such as wanting to feel normal and accepted and wanting to fit in with peers.
- In addition to the psychosocial needs and challenges that all adolescents face, ALHIV may also experience HIV-related stressors and additional vulnerabilities and challenges.
- Stigmatizing someone, which means having a negative attitude toward a person we think is not “normal” or “right,” often leads us to treat them unfairly (or discriminate against them). Stigma and discrimination deter many people from accessing HIV prevention, care, and treatment services.
- Health services for young people need to be adapted to identify and meet the needs of most-at-risk adolescents.
- Health workers play a key role in assessing clients’ and caregivers’ psychosocial needs.
- Health workers can use the Psychosocial Assessment Tool (in *Appendix 5A*) to help assess clients’ (and caregivers’) psychosocial needs and to help them come up with their own solutions.
- Health workers should remember the 5 “A’s” when conducting a psychosocial assessment: **ASSESS, ADVISE, AGREE, ASSIST, and ARRANGE.**
- If a health worker thinks an adolescent client has serious issues that threaten his or her life or immediate safety, these issues must be addressed **IMMEDIATELY.**
- An important part of helping adolescents cope with issues is encouraging their caregivers to strengthen their relationship with them.
- Peer support is an important source of psychosocial support for ALHIV.
- Health workers have a role in initiating and facilitating peer support groups — and in linking ALHIV with existing support groups.

Appendix 5A: Psychosocial Assessment Tool

How to Use This Tool

This Psychosocial Assessment Tool was developed to support a range of providers (trained counselors, lay counselors, doctors, nurses, and others) 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 them prioritize needs, and helps give direction to ongoing counseling 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 enrollment in HIV care and treatment services and annually after that**. Health workers 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 the health worker 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 to decide on effective next steps, to decide on 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 and treatment programs and the ongoing support of adolescent clients and their families. Each clinic should have an up-to-date list of community support services (such as Adolescent Peer Educators, adherence supporters, ALHIV associations, food support, education and job training programs, 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 counseling 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 counseling session/clinic appointment: Schedule a follow-up counseling 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 Form³

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? <i>Explore and discuss client's coping strategies</i>	
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? <i>Assess risk of depression and need for referral</i>	
4. How often in the last week have you used cigarettes, alcohol, or other drugs? <i>Assess for harmful coping strategies, such as drug/alcohol use, provide counseling and referrals</i>	
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? <i>Counsel on disclosure</i>	
6. Who do you feel close to? Who can you go to for emotional support? <i>Counsel on importance of social support</i>	
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? <i>Make referrals as needed</i>	
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)? <i>Counsel and discuss support services; consider gender-based violence services, if appropriate</i>	
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? <i>Screen for sexual risk-taking and counsel on safer sex, dual protection, etc.; give condoms</i>	
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? <i>Assess living situation</i> <i>If not living with parents, ask: Where are your parents? When did this happen? How did this affect you?</i>	
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? <i>Assess school/work situation</i>	
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? <i>Refer to social worker and community-level support</i>	

Appendix 5B: Starting/Planning a Peer Support Group⁴

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, counselors, social workers, and/or Peer Educators 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 participant? 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 come to an 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 the 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 1 hour enough or is 2 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 semi-circle (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.

Make sure to 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 5C: Facilitating a Peer Support Group⁴

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 semi-circle to make it feel less like a classroom and more comfortable to talk.
- The person leading the meeting should be part of the semi-circle 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: we will respect others' opinions, we will not interrupt, we will allow everyone a chance to speak, we will 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 the 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 counselor as a co-facilitator. Decide what role the co-facilitator will play during the meeting.
- 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 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 7 listening and learning skills when leading a support group meeting:

7 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 judging.
- 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 5D: 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; scorekeeping method
- **Play:** Divide the participants into 2 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 3 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 center 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 counselor 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.

References

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⁴ 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.