

ADVANCED MODULE 19: PLHIV Support Groups



DURATION: 330 minutes (5 hours, 30 minutes)

Note: The duration will be longer if the optional activity in *Session 19.4* is included. Trainers can adjust the methodology and content to make this Advanced Module shorter or longer as needed.



LEARNING OBJECTIVES:

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

- Discuss the overall goals and objectives of peer support groups
- Understand different types of support groups that may be helpful for PLHIV and their families
- Plan a support group meeting, including making an agenda and working with co-facilitators
- Effectively facilitate a support group meeting



CONTENT:

Session 19.1: Introduction: Why Do We Need Support Groups?

Session 19.2: Planning Support Group Meetings

Session 19.3: Facilitating Support Group Meetings

Session 19.4: Classroom Practicum on Support Groups

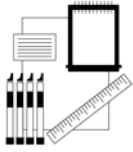
Session 19.5: Module Summary



METHODOLOGIES:

- Large group discussion
- Brainstorming
- Interactive trainer presentation
- Small group work
- Case studies

- Observation (optional)
 - Role-play
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MATERIALS NEEDED:

- Flip chart
 - Markers
 - Tape or Bostik
 - Case study cards for *Sessions 19.2* and *19.4*
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WORK FOR THE TRAINER TO DO IN ADVANCE:

- Read through the entire Module and make sure you are familiar with the training methodologies and content.
 - Organize for participants to attend and observe a support group meeting (optional).
 - Prepare case study cards for *Sessions 19.2* and *19.4*.
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SESSION 19.1: Introduction: Why Do We Need Support Groups? (30 minutes)



TRAINER INSTRUCTIONS

Methodologies: Large Group Discussion, Brainstorming, Interactive Trainer Presentation

Step 1: Review the Module learning objectives.

Step 2: Lead a discussion to introduce the Module and get a sense of participants' experiences with support groups. First, ask participants to raise their hand if they have participated in a support group meeting. Then, ask participants to raise their hand if they have facilitated a support group meeting. Use these questions to guide the group discussion and fill in, as needed, from the content below:

- *What type of support group did you attend or facilitate?*
- *What were your experiences with the support group? What was good? What was not good?*
- *Is/was being a support group member helpful to you? Why or why not?*
- *What do you think Peer Educators can do to start or improve support groups in the health facility or in the community?*

Step 3: Ask participants to brainstorm on the different types of people that would benefit from support groups and the range of topics that could be discussed in support group meetings. Record on flip chart and fill in, as needed, from the content below. Remind participants that while support groups may have many functions, the most important is that they provide psychosocial and emotional support to members.

KEY INFORMATION

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 improve and better manage their situation, share challenges and discuss solutions. Members support each other to implement decisions made in order to meet their psychological, social, physical and medical needs.

- Very often people living with HIV feel isolated and alone. Meeting other people living with HIV can reduce isolation and encourage PLHIV to live more fully and positively.

- Support groups can help increase the uptake of health facility services, such as HIV testing, PMTCT and HIV care and treatment. Support groups can help members to better understand clinical services, give them support to seek and adhere to different services and bring family members for services.
- Support groups also offer a way to link health facility services and community-based services for their members. For example, health care providers can speak about HIV services as part of community-based support group meetings. Or, leaders of community-based organizations can speak about the services they offer at health facility-based support group meetings.

Depending on the specific program, Peer Educators may play an important role in starting support groups in health facilities or in the community, facilitating support group meetings and/or helping others organize them and recruit members for them.

More on support groups:

- There are many kinds of support groups.
- Some support groups may be designed to be ongoing – with members coming and going in and out of the group over time.
- Other support groups may have a specific number of topics to cover, after which members are “graduated” out of the support group.
- Some support groups may be held at health facilities and others may be held in the community (for example, at schools, community centers, PLHIV association offices or in someone’s home).

Here are some of the different types of support groups:

- **Adherence support groups:** People who are all starting ART or who are at a similar stage in their treatment (either preparing to begin ART, starting ART or having been on ART for a while) may find it helpful to meet each other for mutual support. Groups can be women only, men only or mixed. It is best that they are led by someone enrolled in care and treatment, such as a Peer Educator.
- **Mothers support groups:** Mothers living with HIV and those with HIV-exposed or HIV-infected children may want to have their own support group. Mothers support groups can provide needed psychosocial and emotional support to members and also help mothers understand and access key HIV and PMTCT services, such as ARVs for members and their children. 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.
- **Parents and caregivers support groups:** People caring for HIV-exposed or HIV-infected children need extra support. Groups may want to discuss nutrition, weaning support for breastfeeding mothers, challenges and solutions to adherence with the children, disclosure to children and pressures from friends and family.
- **Adolescent support groups:** Adolescents living with HIV face special challenges and may want to form their own support groups. These groups may involve recreational activities (sports, crafts, drama, etc.), as well as time for discussion and mutual support. It is best if a young person can help lead this type of support group.
- **Play groups for children:** Children living with HIV and their caregivers may benefit from groups where children of similar ages can play together, where there is play therapy and where caregivers have a chance to share and talk. These groups often involve child-friendly activities, such as drawing, art and music.

- **Couples support groups:** Couples, including those where both people are living with HIV as well as discordant couples, may wish to form support groups. Couples can share common concerns and challenges and support one another to live positively with HIV.
- **Post-test clubs:** These groups are for anyone who has been tested for HIV. Therefore, they do not require participants to identify their status when joining. They often focus on promoting HIV information and education in the community, but they also provide a social environment for the members to meet each other and discuss any important issues, including how to stay negative, being in a discordant couple etc.
- **Groups for other specific populations:** Other groups of people with common characteristics may wish to form their own support groups. This could include sex workers support groups, support groups for men who have sex with men or others. 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.

Remember: The goal of support groups is to offer psychosocial and emotional support to their members. While some support groups may decide to organize income generation, micro-lending or other activities, there should always be a focus on psychosocial support to one another.

SESSION 19.2: Planning Support Group Meetings (110 minutes)



TRAINER INSTRUCTIONS

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

- Step 1:** Discuss the importance of learning more about the support groups that already exist in the community and at health facilities before starting new support groups. Ask participants what Peer Educators can do to learn more about existing support groups and what specific questions they would ask about existing support groups. Fill in, as needed, using the information below.
- Step 2:** Ask participants if they think it is better to hold support group meetings at health facilities or in the community. Discuss the pros and cons of community- and health-facility-based support groups and remind participants that they should talk with clients about where they would prefer to attend a support group meeting.
- Step 3:** Ask participants to brainstorm the key steps to plan a support group. Record on flip chart. Supplement the discussion by reviewing the key steps needed to plan a support group (below).
- Step 4:** Break participants into 4 small groups. Give each small group flip chart, markers and one of the pre-prepared case study cards, including the list of questions beneath each case study. Ask the groups to find a quiet place to read through their case study, discuss the questions and prepare an agenda for the meeting. Give the groups about 40 minutes to work together. Trainers should sit in to provide support to each of the small groups.
- Step 5:** Bring the large group back together. Ask each of the small groups to spend about 10 minutes presenting their scenario, a summary of their discussion and the proposed agenda for their support group meeting. Encourage discussion and inputs from the group. Tell participants that later in the training they will revisit these support group meeting agendas in the same small groups.

Step 6: Close the session by reminding participants that they should talk with other members of their multidisciplinary team and the Peer Educator program managers to learn more about their expected role in starting and facilitating support groups.

KEY INFORMATION

Learn what support groups already exist in the community and at health facilities:

An important first step is for Peer Educators to see what support groups already exist in the community and in health facilities and where there are gaps to fill. Peer Educators can meet with existing support group organizers and get information including the following:

- Who is the support group for?
- How many regular members are there?
- How often does the group meet?
- Where does the group meet?
- Are there mainly men, women, children or parents or is there a mix of people?
- How does someone become a member?
- Who facilitates the support group?
- What does the group talk about?
- Are there other activities, like income generation?
- Are there fees to come to the support group?
- Are there linkages between the group and the hospital, health centers and VCT centers?
- What gaps are there? Needs to be filled?

Consult with key informants to understand more about what support groups are needed:

Peer Educators can meet with local PLHIV associations, community-based organizations, other members of the multidisciplinary team at the health facility and clients to get a better sense of what kinds of support groups are needed and where gaps exist.

- Consult with the rest of the multidisciplinary care team on what types of support groups are needed based on their interactions with clients and challenges faced.
- Ask clients what kinds of support groups they are interested in, when they could come to a meeting, where they would like the meeting to be held and what kinds of things they would like to talk about (e.g. adherence strategies, stigma, disclosure, etc.).

Decide who the support group is for:

- Who will be invited to attend?
- What is the ideal number and type of participants? It is recommended that support groups not have more than 25-30 people in the same meeting so that everyone can participate. Larger support groups can break off into smaller support groups if needed.

Define the goals and objectives 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?

**Example of support group goals and objectives:
Health-facility-based family support groups (FSGs) in Uganda**

Goal: To strengthen the provision of PMTCT services to HIV-positive antenatal/ postnatal mothers and their families by providing an opportunity to meet and support each other psychologically, socially and to link them with HIV prevention, care and treatment services.

General objective: To bring together HIV-positive antenatal/postnatal mothers and their families to receive support to follow through with PMTCT interventions and to access and adhere to HIV prevention, care and treatment.

Specific objectives: The specific objectives of the Family Support Groups are for members to help each other to:

- Disclose to each other and to friends, relatives, partners and children in order to build a personal support system.
- Accept and understand their HIV-status and learn how to live positively.
- Make informed decisions about safe motherhood, including:
 - Antenatal care
 - Swallowing of ARVs by mothers and their babies
 - Birth planning and safe delivery
 - Safe infant feeding
 - Postnatal care
 - Family planning
- Encourage partners and other family members to get tested for HIV.
- Learn how and when to access CTX prophylaxis and ART.
- Prepare for adherence to ARVs.
- Link and access HIV prevention, care, treatment and support services, including community social services.

Make a plan to recruit support group members:

- How will you let people know about the support group?
- Will members of the multidisciplinary team at the health facility refer people to the support group?

Decide on the location of the support group meetings:

- Consider the location of the support group – can it be held at the health facility? Is this convenient or should it be located in the community? Be sure the location offers some privacy and is convenient for members.
- If support group meetings are held at a health facility, will members be able to get HIV services before/after the meeting? For example, if there is a mothers support group meeting at the health facility, will members be able to have their babies tested for HIV that day?

Select convenient days and times for the support group and decide how often the group will meet:

- What time and how often will the groups be held? Do most participants work during the day or do they have household chores that they need to do at certain times of the day? Is 1 hour enough or is 2 hours better?
- Can children come and, if not, will there be someone to watch them while their parent or caregiver attends the meeting?

- Will the group meet once each month? More often? Less often?

Decide who will lead the support group meetings and who will be invited to speak:

- Who will run the support group and what will be the topics to discuss? Will nurses or other health facility staff have a role in the meeting? Peer Educators may lead the support group or they may support other facilitators.
- What will be the role of the support group members? (It should be participatory.)
- If you are facilitating, what are you going to say at the beginning? It is good to practice this beforehand and make some small notes, if needed, to remember the key points.
- Will there be a secretary to record decisions made at the meeting? If yes, she or he should ideally be nominated by group members.
- Will there be guest speakers?

Plan the logistics of the meeting:

- 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?

Make an agenda for the meeting:

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
- Health talk by invited guest or facilitator (the health talk can be a time to share information with support group members on a specific topic and also dispel myths and rumors)
- Testimonials by members related to the specific topic
- Questions and answers
- Open discussion and sharing
- Review of key messages
- Plan for the next meeting
- Closing (song, prayer, dance, etc.)

Case studies for small group work

Case Study 1:

You and another Peer Educator are starting a support group at your health facility. You have learned that most of your clients do not belong to a support group, but that they would be interested in joining one. The group will meet once per month.

Discussion questions and tasks for small groups:

1. What steps would you take to plan the support group?
2. What are the goals of the group? Who is the group for?
3. What do you want members to gain from participating in the group?
4. How will you recruit support group members and advertise the first support group meeting?
5. How will you work with other members of the multidisciplinary team?
6. Develop an agenda for the first support group meeting, which will be held in the training room of the health facility where you work.

Case Study 2:

The PMTCT nurse at your health facility notices that many of her clients are not coming back to the clinic on time for their appointments, especially after they deliver their babies. The nurse comes to you because she wants you to help organize a mothers support group at the clinic. She wants the member mothers to support one another during and after pregnancy and she also thinks it would be helpful to include a short, 15-minute health talk during each of the support group meetings.

Discussion questions and tasks for small groups:

1. What are some of the things you would want to discuss with the nurse? What about with PMTCT clients?
2. What are the goals of the mothers support group?
3. What do you want the members to gain from the group?
4. How would you recruit support group members?
5. Develop an agenda for the first mothers support group meeting, which will be held in the antenatal clinic waiting area. Include a short health talk on a specific topic.

Case Study 3:

A local PLHIV association has monthly support group meetings in their office. The president of the support group asks you to come to lead the next meeting, which will focus on adherence to HIV care and treatment. About 25 men and women are expected to attend the meeting.

Discussion questions and tasks for small groups:

1. What information would you want to know from the support group president?
2. How would you plan for the meeting?
3. What do you hope members will gain from this meeting?
4. Develop an agenda for the meeting (the meetings last about 90 minutes).

Case Study 4:

You and another Peer Educator try to learn more about support groups in the community so you can refer your clients. You learn that there was a strong support group in the community run by a local church. The support group had about 30 active members, but in the past year, the group has not met regularly and members often miss meetings. After talking with other members of the multidisciplinary team and some of your clients, you decide that you should try to work together and improve this community support group instead of starting a new one.

Discussion questions and tasks for small groups:

1. What things would you want to find out about the support group and its members?
2. What are some of the reasons you think the support group is not as active as it used to be?
3. What steps would you take to improve the support group?
4. How will you convince people to return to the support group?
5. Develop an agenda for a support group meeting.

SESSION 19.3: Facilitating Support Group Meetings (50 minutes)



TRAINER INSTRUCTIONS

Methodologies: Large Group Discussion, Interactive Trainer Presentation, Brainstorming

Step 1: Ask participants who have facilitated a support group meeting to share some of their recommendations on how to be a good support group facilitator. Open up the discussion to all participants. Use the following questions to guide the discussion and fill in, as needed, from the information below:

- *What is the role of a support group facilitator?*
- *What makes a good support group facilitator?*
- *What things should facilitators avoid?*
- *How should facilitators manage quiet support group members? What about controlling very talkative members?*

Step 2: Read the following scenario out loud to participants and then discuss, using the questions below as a guide. Fill in, as needed, with the information below.

A nurse at the ART clinic where you work asks you to facilitate this month's PLHIV support group meeting because she is going to be away at a training.

- *What questions would you ask the nurse?*
- *How would you prepare for the support group meeting?*
- *What would you do to be a good meeting facilitator?*
- *What would you do after the meeting?*

Step 3: Ask participants to think about their own experiences as support group members and as PMTCT and ART clients. Ask participants if they think a short health talk would be a good agenda item for some support groups and discuss. Next, ask them to brainstorm possible health talk topics that could be useful to support group members. A list of topics can be found below, but there are no right or wrong answers. Remind participants to always seek feedback and inputs from support group members to learn what they want to discuss at their meetings.

Step 4: Remind participants that they may be asked to facilitate a support group meeting or support other facilitators. They may also be asked to be a guest speaker at meetings in the community. It is important to ALWAYS plan ahead, be prepared and use good communication skills!

KEY INFORMATION

Make an agenda and stick to it!

- Careful planning is key to the success of support groups in the long-term.
- When members feel the meetings are organized and useful, they will come back. On the other hand, if support group meetings are unorganized, there is no clear purpose for the meeting or members do not find the meetings useful, they will probably not come back.
- Respect members' and facilitators' time. Make sure meetings start and end on time.

Make sure to plan new learning opportunities for support group members:

- Everyone is busy. Make sure each support group meeting offers something new and useful to members.
- One way to do this is to include 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. This is also a good way to improve linkages between support group members and health facility services. Health talks should be kept short and simple (about 15-20 minutes is recommended) so that support group members have time to discuss their feelings, questions and concerns. You might conduct the health talk or ask a nurse or other "expert" to lead the health talk.
- Get feedback from support group members on topics they would like to discuss during the meetings and incorporate these into the agenda.

Ideas for health education topics that can be incorporated into support group meetings

(Remember that not all support group meetings need to include health talks.)

- Having a safe pregnancy, labor and delivery
- Positive living
- Disclosure to adults
- Disclosure to children
- Dealing with stigma
- Care for HIV-exposed babies. HIV testing for babies and children
- Safer infant feeding
- Adherence for adults
- Adherence for children
- Preventing opportunistic infections
- Nutrition
- Planning for our family's future (memory books, will-making, etc.)
- Domestic violence
- Family planning and dual protection
- Good hygiene
- Preventing new HIV infections

Set up the room so that everyone is comfortable and can participate:

- Encourage participants to sit in a semi-circle to make it more comfortable to talk and less like a classroom. The person leading the meeting should be part of the semi-circle.
- Facilitators should not stand behind a desk or other furniture.
- If possible, provide tea or a light snack for members and facilitators. If health care workers or other guests are invited, encourage them to eat and socialize with members.

Remind participants about confidentiality:

- Support group members will only feel open to discuss their experiences and feelings if they know there is confidentiality.
- It is always a good idea to remind support group members at the start of each meeting that what is said during the meeting is not repeated in the community. Facilitators should always respect this as well!

Be a good facilitator:

- 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 this is “their” meeting.
- Be sure to plan the meeting agenda ahead of time and practice what you are going to say.
- 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 inputs for the next meeting agenda.
- Interact with participants and engage them by moving around the room, asking questions and asking people to share personal stories/concerns, etc.
- Encourage participants to share their own experiences and concerns.
- Make eye contact with all members of the group.
- Pay attention to people who seem shy or quiet and emphasize that everyone’s personal experiences, questions and concerns are important.
- Try to discourage people from dominating the discussion. If this is happening, you could say, *“You have shared so many helpful ideas and experiences with us – let’s hear from some other members now.”*
- Stick to the agenda and keep time!

Offer on-going support and referrals to participants:

- 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 after the meeting.
- Seek support and inputs from other multidisciplinary team members and other experts on topics that you are unsure about, you are uncomfortable with or are beyond your area of expertise. Remember, it is always better to say you do not know the answer to a question and to ask someone who does rather than give wrong information.
- There may be situations where support group members need assistance right away (for example, if they are mentally distressed, suicidal, violent or the victim of violence). In these cases, Peer Educators should practice shared confidentiality and alert other members of the multidisciplinary team to these issues right away.

Keep records of the meeting:

- Always keep an attendance record. Remember that this should be kept confidential and not widely shared.
- Ask someone to take simple notes at the meeting (or you can do this yourself after the meeting has finished). Note what topics were discussed, key concerns of members and any next steps. Also note the date, time and location of the next meeting.

SESSION 19.4: Practicum on Support Groups (130 minutes)



TRAINER INSTRUCTIONS

Methodologies: Observation (optional), Small Group Work, Role-Play, Large Group Discussion

Step 1: Note: If possible, take participants to observe a support group meeting, either in the community or in a health facility, as part of the practicum. Be sure to introduce participants to the support group leaders and members and explain why they are observing. After returning to the classroom, debrief on what participants observed at the meeting and what they would have done the same or differently. If it is not possible to observe an actual support group meeting during the training, encourage participants to do so after the training has finished.

Divide participants into the same 4 small groups they were in for the support group planning activity in *Session 19.2*.

Step 2: Give each group flip chart paper and markers, and make sure each has the same pre-prepared case study card they used in *Session 19.2*. Tell participants that they will now work in small groups to facilitate the support group meeting that they planned earlier in the day. Encourage the groups to find a quiet place where they can sit together away from distraction. Give the groups about 40 minutes to plan how to facilitate the meeting and to practice. At least one trainer should work with each small group if possible.

Step 3: After about 40 minutes, bring the large group back together. Give each small group about 20 minutes to role-play how they would facilitate portions of their specific support group meeting, with other participants acting as support group members. Discuss what was done well and what the facilitator(s) could have done better after each role-play. Have participants refer to the tips on facilitation in *Session 19.3* to guide their Feedback.

Step 4: Debrief the practicum by asking participants to reflect on their experiences leading the support group meetings. Remind participants that support groups are intended to provide psychosocial and emotional support to members and, in some cases, to help to understand and access key health care services. Ask participants to discuss their specific role in starting and leading support groups with the rest of the multidisciplinary team and Peer Educator Program managers.

KEY INFORMATION

See the case studies in *Session 19.2*.

Note: Some of the preceding information in this Module was adapted from the following sources:

The Republic of Uganda Ministry of Health. (2006). *National guidelines for implementation of family support groups in prevention of mother-to-child transmission of HIV*. Kampala, Uganda: Republic of Uganda Ministry of Health.

SESSION 19.5: Module Summary (10 minutes)

Learn more here



TRAINER INSTRUCTIONS

Methodologies: Large Group Discussion, Interactive Trainer Presentation

- Step 1:** Ask participants what they think are the key points of this Module. What information will they take away from the Module?
- Step 2:** Summarize the key points of the Module using participant feedback and the content below.
- Step 3:** Ask if there are any questions or clarifications.
- Step 4:** Review the learning objectives with participants and make sure all participants are confident with their skills and knowledge in these areas.
- Step 5:** If there are areas participants do not fully understand or in which they need more help, go back and review the session before moving to the next Module.

KEY INFORMATION



THE KEY POINTS OF THIS MODULE INCLUDE:

- Peer Educators play an important role in starting support groups in the health facility or in the community, facilitating support group meetings and helping others organize and recruit members for support groups.
- While there are many different types of support groups, they all should aim to provide psychosocial and emotional support to their members.
- In peer support groups, members help each other to improve and better manage their situation, share challenges and discuss solutions. Members support each other to implement decisions taken in order to meet their psychological, social, physical and medical needs.
- Careful planning is one of the keys to successful support groups. This includes having clearly defined goals and objectives for the groups and an agenda for each meeting.
- Including short health talks as part of support group meetings is one way to share information with members and encourage them to seek health services. This is also a way to get other multidisciplinary team members involved in the support group.
- Support group meetings should always be participatory and everything that is said during the meeting should be kept confidential.
- Good facilitation skills are important to successful support group meetings.
- It is important to provide support group members with information and referrals for ongoing psychosocial support, clinical care and other services.