

HIV Prevention, Treatment Care & Support - A Training Package for Community Volunteers

Module 8



CARING FOR CARERS



Southern Africa
HIV/AIDS Information
Dissemination Service



World Health
Organization



International Federation
of Red Cross and Red Crescent Societies

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Introduction

Module Eight: Caring for Carers aims to provide CBVs with the knowledge and skills to care for themselves and other caregivers, including child carers and carers living with HIV by exploring the following topics:

- What Caring Means
- Impact of Caregiving: Rewards and Challenges
- Caring for Carers: Practical Steps
- Special Considerations in Caring for Carers

Materials to be used in this module:

1. Module Eight: Caring for Carers (this module)
2. Participant's Handbook
3. Facilitator's Guide
4. Evaluation Tools for the manual

Training time for this module is approximately 8 hours 30 minutes.

For a detailed discussion on the training methodology, evaluation techniques and glossary of important terms used for this module, facilitators should refer to the Facilitator's Guide.

The evaluation tools used in this module include:

Evaluation of Module Content

1. Participants Evaluation
2. Facilitator Evaluation

Participant Evaluation Tools:

1. Pre and Post Test Questionnaire
2. Demonstration of Core skills

Upon completion of this module, participants should demonstrate the following core skills:

1. Discuss “caring for carers” with clients and their families and why it is important in their community. **Session One; Tool 4**
2. Recognise ways in which they show stress as an individual and identify signs of stress in other caregivers. **Session Two; Tool 4**
3. Demonstrate techniques with clients and primary caregivers for coping with stress through self-care. **Session Three; Tool 7**
4. Conduct a community awareness meeting on the needs of child carers. **Session Four, Tool 3**
5. Refer carers living with HIV or carers who do not know their status to the appropriate services in your community. **Session Four; Tool 4**

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1 Session One: What Caring Means

Purpose: The purpose of Session One is to explore the knowledge and attitudes of CBVs surrounding the different types of care, different types of carers and the importance of caring for carers in your community.

Objectives:

By the end of this session, CBVs should be able to:

1. Describe the role and rights of a caregiver in their community.
2. Describe the concept of “caring for carers” with clients and their families and why it is important in their community.
3. Explain the type of caregiver (primary, secondary, volunteer) their role in the community represents.
4. Discuss what motivates them as individuals to provide care in the community.

Duration: 2 hours

Required Materials: Flipchart, markers.

Objective	Content	Time	Methodology
Describe the role and rights of a caregiver in their community	1. What does caring for PLWHA mean?	30 minutes	Mini Lecture Tool One (K): Group Discussion
Discuss “caring for carers” with clients and their families and why it is important in their community.	2. What Does Caring for Carers Mean?	30 minutes	Tool Two (ST): Self Reflection and Role Play
Explain the type of caregiver (primary, secondary, volunteer) their role in the community represents	3. Types of Caregivers	20 minutes	Mini Lecture Tool three (K): Group Discussion
Discuss what motivates them as individuals to provide care in the community	4. Volunteer Caregivers	30 minutes	Mini Lecture Tool Four (A): Self Reflection and Group Discussion

1. What does caring for PLWHA mean? (30 minutes with Tool 1)

There are many different forms of caring for PLWHA. Caring involves helping PLWHA with their physical, emotional, spiritual and social needs in a culturally sensitive manner with human dignity and respect.

Caring for PLWHA can include:

- Providing emotional and spiritual support to PLWHA and their families
- Providing HIV and AIDS care and support
- Provide education on nutrition, hygiene and preventive care
- Providing basic nursing care (feeding, bathing, dressing, toileting)
- Helping PLWHA with daily living (household chores, errands, transport)
- Acting as health care advocate for your client (link with community for resources, clinics and other health services, communicate with health professionals)
- Supervision of ART, TB, pain medication and other treatments (giving medications, monitoring use, educating and monitoring adherence)
- Reducing stigma and discrimination by treating PLWHA with dignity and respect
- Mobilizing support for HIV and AIDS in the community
- Providing information on HIV, AIDS and ART
- Making referrals for PLWHA when and if they are required

Tool 1: Role of Caregivers



Review the list of roles provided by writing each on a flipchart. Ask participants:

1. Can you identify any other roles they play as caregivers that are not listed?
2. Which roles listed above do you find difficult to perform?
3. Are there any roles specific to the community or culture?
4. How might being involved in ART interventions change your role as a caregiver?

2. What does Caring for Carers mean? (20 minutes with Tool 4)

Caring for Carers is a term used to describe recognising that caring can produce stresses and strains on Caregivers. Caring for Carers involves ensuring the mental and physical well-being of people who provide care in the community and helping Caregivers to relieve stress and lead a healthy lifestyle.



Tool 2: Defining Caring for Carers

PART A: Read the definition of caring for carers aloud and divide participants into groups of four. Have group members sit in a circle and explore their experiences with being a caregiver and how support provided through the concept of caring for carers may have been needed.

PART B: As a group define caring for carers and discuss why this is important in your community. Divide participants into pairs and conduct a brief role-play on how participants would explain the concept to clients and families. Role plays should include defining caring for carers and why it is important.

Facilitator's Note: In assessing this core skill at the end of this module, have participants complete Part B only. Assess the effectiveness of participant explanations by using the following checklist:

- Has the participant provided a suitable definition of caring for carers?
- Has the participant explained why caring for carers is important in a way that clients and families will find meaningful?

3. Types of Caregivers (20 minutes)

There are many different types of caregivers. Different caregivers can address the different aspects of the 'holistic' care of PLWHA. Holistic care involves supporting the physical, emotional, spiritual and social needs of PLWHA.

a) Primary Caregivers (5 minutes)

Primary Caregivers are people who provide the day-to-day home-based care activities for PLWHA, usually a family member or friend.

Primary Caregivers for PLWHA can include:

- Relatives
- Spouses/partners
- Children
- Faith based organisation members
- Friends
- Other PLWHA.

b) Secondary Caregivers (15 minutes with Tool 3)

Secondary caregivers are people often thought of as 'specialists' of certain types of care who are trained for the care they provide.

Secondary Caregivers for PLWHA can include:

- Health professionals
- Behavioural health specialists
- Social workers
- Spiritual counsellors.



Tool 3 : What Kind of Caregiver are you?

Engage participants in a discussion of what type of caregiver category, 'primary' or 'secondary', they feel they fall into.

The role of caregivers can be different from country to country, or even community to community. Review the list of characteristics for primary and secondary caregivers and ask CBVs to identify which applies to their own role in the community

For example, a CBV might be living with HIV or AIDS, a friend of her client AND has received special training for caring. What 'type' of caregiver does this make her?

Exercise is meant to illustrate that community caregivers are often both primary and secondary, and provides background for point 4.

4. Volunteer Caregivers (30 minutes)

Volunteer Caregivers, such as Community-Based Volunteers (CBVs), are the backbone of community care for PLWHA around the world. Just as many CBVs discovered in Tool Three, Volunteer Caregivers like CBVs represent a wonderful mix of 'Primary' and 'Secondary' caring for PLWHA.

a) Characteristics of people identified as Volunteer Caregivers (10 minutes)

Volunteer Caregivers, like CBVs, are chosen for their work because they are community members who have shown an interest and willingness to help others in their community.

Characteristics that organisations look for in Volunteer Caregivers are:

- Good listeners
- Non-judgmental
- Trustworthy and able to maintain confidentiality
- Able to get along with others
- Empathetic
- Self-confident
- Committed
- Good will to help
- Role-models in their community

Can CBVs think of any other special characteristics they feel they have?

b) What motivates Volunteer caregivers? (20 minutes with Tool 4)

People have many different personal reasons for becoming a Volunteer caregiver. There is no one 'best reason' for people to choose to volunteer.

Reasons frequently cited for choosing to volunteer include:

- Religious duty
- Compassion for those suffering
- PLWHA who feel a sense of commitment to others who are HIV positive
- Experience
- Learning new skills
- Volunteering makes one feel good
- Hope of promotion to paid employment.

Tool 4: What Motivates Volunteer Caregivers



Ask each participant to make a list of things that motivate them as an individual to act as a Volunteer Caregiver. Explain that the reasons why people choose to volunteer are personal and that there is no 'wrong' answer.

Ask participants to compare their list with those items listed in 2 b) and share any motivational factors they have listed that are different from those on that list. Add any new factors to this list.

As a group, discuss any motivational factors participants feel are specific to the country or culture in your area.

2

Session Two: Impact of Caregiving Rewards and Challenges

Purpose: The purpose of Session Two is to explore the impact of caregiving including rewards associated with being a CBV, and the definition, causes and impact of CBV Burnout.

Objectives:

By the end of this session, CBVs should be able to:

1. Describe the personal rewards of caregiving in their community
2. Explain the difference between stress and burnout
3. Recognise ways in which they show stress as an individual and identify signs of stress in other caregivers.
4. Describe the causes and strategies for alleviating stress specific to their community with clients and family members.
5. Demonstrate an understanding of how caregiver burnout can affect the quality of care for PLWHA in their community.

Duration: 2 hours 30 minutes

Required Materials: Flipchart, markers.

Recommended Preparation:

- Make copies of Handout 8-1 'Signs of Stress' for distribution in section 2. B)

Objective	Content	Time	Methodology
Describe the personal rewards of caregiving in their community	1. Rewards of Caregiving	30 minutes	Mini Lecture Tool One (A): Group Activity
Explain the difference between stress and burnout	2. Caregiver Burnout	1 hour	Mini Lecture Tool Two (A): Group Activity Tool Three (K): Group Discussion
Recognise ways in which they show stress as an individual and identify signs of stress in other caregivers.			Mini Lecture Tool Four (K): Self Reflection and Group Activity
Describe the causes and strategies for alleviating stress specific to their community with clients and family members	3. Causes and Effects of Caregiver Burnout.	1 Hour	Tool Five (PS): Group Discussion
Demonstrate an understanding of how caregiver burnout can affect the quality of care for PLWHA in their community			Tool Six (K): Group Activity

1. Rewards of Caregiving (30 minutes with Tool 1)

When people speak of caregiving, people often only speak of how and why it is difficult. The many rewards of caring that CBVs experience are often left out.

Caring...

- Brings a sense of mission and purpose to the life of Carers
- Presents a chance to develop self-knowledge and new skills
- Builds a sense of personal effectiveness by demonstrating competence under difficult circumstances
- Creates positive feelings of loving, caring and feeling needed
- Makes people feel like they have made a difference and contributed to their Client's well being

Another reward of caring can be the recognition that caregivers receive in the community for the important service they provide. It is important that facilitators consider how are CBVs recognised for their work in your community and how or if this may need to be improved.



Tool 1 : Rewards of Caregiving

Part 1, Group Work: Divide participants into three groups to create a list of rewards from caring for PLWHA. Ask CBVs to specifically list how ART interventions might increase the rewards they achieve through caregiving.

Part 2, Group Discussion: create master list of rewards and keep posted where all participants can see it through for rest of the module.

2. Caregiver Burnout (1 hour 30 minutes)

a) Impact of HIV and AIDS on the Lives of Caregivers (30 minutes with Tool 2)

Before discussing caregiver burnout it is important for caregivers to explore the way that HIV and AIDS impact caregiving activities in their community and how their own lives are affected.



Tool 2 : Impact of HIV and AIDS on the Lives of Caregivers

Facilitator's Note: A 'card' is a separate piece of paper or board on which participants will write individual answers. These cards will then be placed under the appropriate flipchart heading.

Provide participants with six cards. Ask participants to write down the two main ways that HIV and AIDS influence each of the topics below.

1. The impact of HIV and AIDS on their ability to provide care.
2. Ways in which caring for PLWHA can place stress on caregivers.
3. How HIV and AIDS impact their personal life.

Facilitator's Note: While participants are writing their answers create three separate flipcharts, each having a heading reflecting the three topics of discussion.

Ask each person to present their answers, sticking the pieces of paper that relate to each topic under the appropriate heading.

b) What is Caregiver Burnout? (20 minutes with Tool 3)

Caregiver Burnout results from stress that is built up over time until a carer is no longer able to cope. Burnout is not something that happens in one moment or even in one day. It is the result of feeling stress over a period of time. If not dealt with, this stress can combine to impact negatively on a caregiver's mental or physical health; damage his/her relationships; and ultimately, his/her ability to care for PLWHA effectively.

Stress is defined as feelings of being emotionally, physically or mentally overwhelmed and drained when faced with a certain situation, event or person.

Important things to understand about stress are that:

- Stress is something that can be managed
- Everyone feels stress sometimes
- Different people feel stress for different reasons
- No one responds to stress in the same way
- Stress combines in some people to produce burnout.

Psychologists define Burnout using three separate emotional signs:

- Feeling emotionally overextended and feeling as though you lack the energy to face another day
- Feeling “used up” and not caring about work like you used to or treating others negatively
- Growing sense of inadequacy, not feeling as though you are “good enough” to care effectively.



Tool 3 : Burnout vs. Stress

It is important for CBVs to understand the difference between burnout and stress. Probe this issue by asking the question: What is the difference between stress and burnout?

As participants provide answers ensure the following points are addressed:

- Stress is something that everyone feels almost every day for different reasons
- Because caregiving involves addressing the emotional and physical needs of people who can be very sick, caregivers can experience a great deal of stress.
- Burnout is the result of stress that is not dealt with and builds up over a long period of time, affecting the way caregivers may feel emotionally or physically.
- Burnout will ultimately affect the ability of caregivers to care effectively.

Facilitator's Note: It may be useful to agree on an analogy that is suitable to your context that will help participants to remember the difference between stress and burnout. For example, stress can be seen as a rolling snowball, growing bigger and bigger if stress is not dealt with until the snowball is so big that it stops moving (burnout). Or, stress can be seen as tiny rocks falling from a hill, as stress builds more rocks fall (larger boulders) until there is nothing left to support the hill and an avalanche occurs (burnout).

c) Recognizing Burnout (40 minutes with Tool 4)

Caregiver Burnout can take many forms, and it is important that CBVs recognize the signs of burnout in themselves and in fellow caregivers.

Having one or more of the symptoms below does not necessarily mean that a person is burnt out. It does mean, however, that they are suffering from some form of stress that can become burnout if left unattended.

Like most problems, coping with stress is best done by addressing it in the open and seeking out methods of helping you cope with stress. Session Three will offer some strategies for preventing and reducing burnout that CBVs can and should use.

Distribute copies of Handout 8-1 Signs of Stress and review each sign as a group.

Signs of Stress that could result in Burnout include:

Physical	Emotional	Behavioural
<ul style="list-style-type: none">• Backaches• Change in eating patterns• Diarrhoea• Elevated blood pressure• Excessive fatigue• Bowel disturbances• Sleeplessness• Muscle Tension• Weight loss or gain• Constipation• Headaches	<ul style="list-style-type: none">• Anger and frustration• Depression• Not feeling good enough, feeling guilty or helpless• Loss of interest in and commitment to work• Loss of confidence and self - esteem• Feeling restless• Mood swings• Excessive worry about the future• Feeling overwhelmed• Afraid to grieve	<ul style="list-style-type: none">• Always late• Neglecting duties• Tearfulness• Emotional outbursts• Withdrawal from family or friends• Difficulty getting on with people• Loss of quality in work performance• Decreased ability to make good judgements• Increased drug or alcohol use• Resisting change• Resignation from caring activities



Tool 4: Signs of Stress

PART A: Recognising how you show stress.

Ask participants to reflect on the ways in which they feel they show stress based on the items listed under each of the three categories. Encourage them to add any additional ways that they feel they might show stress not listed.

PART B: Recognising stress in others.

Separate CBVs into three groups. Assign each group one category into which stress can fall:

1. Physical
2. Emotional
3. Behavioural

Ask each group to review each of the items listed and present three real-life examples of how they have seen other caregivers show this type of stress (without using names).

Facilitator's Note: Emphasise to participants that being able to recognise **stress** in themselves and others is an important way to prevent burnout.

*In assessing this core skill at the end of the module, participants should demonstrate the ability to describe the physical, emotional and behavioural signs of stress.

3. Causes and Effects of Caregiver Burnout (1 hour)

a) Factors Contributing to Caregiver Burnout (30 minutes with Tool 5)

There are many different reasons why caregivers feel stress. Stress can be felt as a result of the impact of caregiving on the personal life of CBVs, because of aspects of their job or special factors of dealing with HIV and AIDS in their homes and community.

Some Causes of Stress for CBVs Related to their Caring Duties

- Heavy workloads
- Lack of incentives
- Fear of infection
- Inadequate support or supervision from their umbrella organisation
- Lacking the ability to refer clients to services they need
- Lack of medication such as ARVs and materials they need for caring (such as gloves or sanitation equipment)
- Lack of clarity about what they are expected to do
- Lack of recognition for their work
- Interpersonal problems with their client
- Lack of space and privacy while caring
- Feeling unable to make important decisions that affect their clients and their work
- Feeling powerless to change some aspect their clients' problems
- Not feeling as though they can input their own unique solutions for caring

Some Causes of Stress for CBVs Related to their Feelings or Knowledge

- Being faced with death and dying
- Feeling bereavement and grief
- Stigma associated with HIV and AIDS
- Secrecy and fear of disclosure among PLWHA
- Emotional attachment to PLWHA and their families
- Fear from witnessing the impact of HIV and AIDS for Caregivers who are also PLWHA
- Knowledge that AIDS is incurable
- Lack of knowledge that results in Carers not know what to do to help
- Feeling powerless to change some aspect their clients' problems
- Not feeling as though they can input their own unique solutions for caring

Some Causes of Stress for CBVs Related to their Personal Lives

- Financial hardship
- Personal demands competing for attention with caring demands
- Dealing with illness within their own families.

Tool 5 : Causes of Stress in your Community

Every community is different and may provide unique situations that cause stress in CBVs.

As a group, create a list of 'causes of stress for CBVs in _____' and ask CBVs to list specific factors in your community that might increase the stress off Caregivers (some factors may be similar to listed on the previous page). Ask CBVs how being involved in caring for PLWHA could increase their stress.

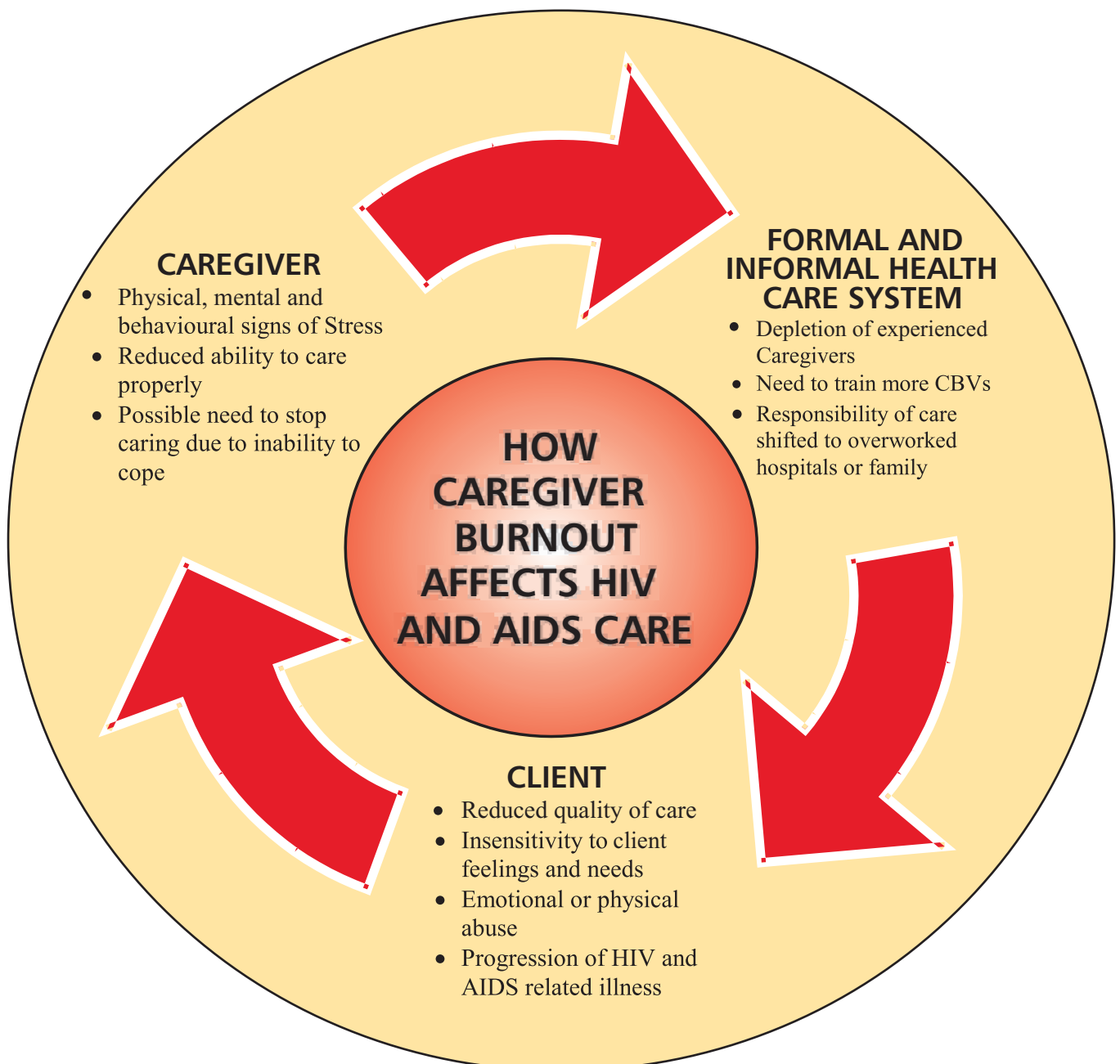
Once the list has been made, identify any methods of alleviating these stressors in your community.



b) Impact of Caregiver Burnout (30 minutes with Tool 6)

Caregiver Burnout does not only affect CBVs. It creates a cycle of effects that could impact on the entire support system for PLWHA.

The cycle diagram below shows the circular process of how caregiver burnout affects care for PLWHA





Tool 6 : Impact of CBV Burnout

Separate participants into three groups. Give each group one of the aspects in the cycle of effects:

1. Caregiver
2. Health Care System
3. Client

Ask each group to create a list of specific ways that burnout of CBVs might impact each group in your community.

3

Session Three: Caring for Carers: Practical Steps

Purpose: The purpose of Session Three is to discuss specific tools for caring for carers, including strategies for reducing and managing stress and protecting the health and well-being of CBVs.

Objectives:

By the end of this session, CBVs should be able to:

1. Discuss appropriate coping strategies for dealing with stress in your community with clients and their families.
2. Describe the benefits of caregiver support groups.
3. Organise the creation of a caregiver support group in your community if none exists.
4. Demonstrate techniques with clients and primary caregivers for coping with stress through self care.

Duration: 2 hours

Required Materials: Flipchart, markers.

Recommended Preparation:

- Make copies of Handout 8-2 'Five Strategies for Self Care for distribution in Section 2
- Review each of the strategies for Self Care in section two and practise each tool prior to the session
- Make copies of Handout 8-3, 'Stress Pledge for Better Health', to distribute to CBVs in Tool 4
- Make copies of the 'Basic Steps for Starting a Support Group' in Handout 8-4 to distribute to participants during section 5 a).
- If participants have not already received it through training in Module 7, make copies of Handout 7-4: Universal Precautions for distribution at the end of the session.

Objective	Content	Time	Methodology
	1. Assessing Caregiver Burden		Mini Lecture
Discuss appropriate coping strategies for dealing with stress in your community with clients and their families	2. Five Strategies for Preventing and Reducing Burnout Through Self-Care	2 hours	Mini Lecture Tool One (ST): Case Study and Group Discussion *Debriefing Tool Two (ST): Group Discussion *Change Approach to Caregiving Tool Three (ST): Demonstration *Body Relaxation Tool Four (ST): Group Discussion *Stress Pledge
Describe the benefits of caregiver support groups.			Tool Five (K): Group Discussion
Organise the creation of a caregiver support group in your community if none exists.			Tool Six (ST): Group Activity
Demonstrate techniques with clients and primary caregivers for coping with stress through self care.	3. Sharing Strategies for Self-Care		Tool Seven (ST): Group Discussion and Role Play

1. Assessing Caregiver Burden

While we reviewed the signs of stress in terms of physical, psychological and behavioural symptoms in Session Two, a short review of signs of stress are:

- Loss of interest in and commitment to work
- Loss of punctuality and neglect of duties
- Feelings of inadequacy, helplessness and guilt
- Loss of confidence and self-esteem
- Tendency to withdraw from clients and colleagues
- Loss of sensitivity in dealing with clients
- Loss in quality of performance in work
- Irritability
- Difficulty getting along with people
- Tearfulness
- Loss of concentration
- Sleeplessness
- Excessive fatigue
- Depression
- Bowel disturbance.

2. 5 Strategies for Preventing and Reducing Burnout through Self-Care (2 hours)

People deal with stress in many different ways. The ways in which people deal with stress are often called **Self-Care**. Self-Care can be described as thoughts and activities that people use to deal with stress. Coping can involve something as simple as going for a walk to clear your head, reading a good book or talking with friends or other CBVs about the stress you feel.

In addition to the personal coping methods each of us use, specific tools for coping with the stress of caregiving have been developed.

Distribute the '5 Strategies for Self-Care' handout located in Handout 8-2. Encourage CBVs to use this handout as a reminder of the methods for reducing stress. CBVs should also be encouraged to share these strategies with the primary caregivers of clients during their next home visit.

1) Coping Strategies (30 minutes with Tool 1)

Coping Strategies for reducing stress involve 'acting' on your stress by gathering information, planning and taking real steps to help you cope. Coping strategies involve doing something about your stress instead of just worrying about it.

Ways that CBVs can use coping strategies include:

- Educate yourself (clients status, understanding HIV, AIDS and ART)
- Ask questions (its OK to say 'I don't understand, can you please explain?')
- Keep a daily journal
- Discuss your problems and feelings with a friend
- If you are feeling very stressed and are unable to cope - seek professional help
- Get rest, listen to what your body is telling you
- Debriefing - by discussing care-related problems with your supervisor or other CBVs as they occur
- Make use of your spiritual support system
- Engage in recreational activities outside of work.



Tool 1: Using Coping Strategies in ART

Replace the term X with a local name'

Read the following case study to CBVs that deals with a situation in helping implement ART that might cause stress:

Your client, X, began taking ARVs a few months ago. He has started feeling better and has decided that he is now 'cured of HIV'. He confided in you that he has stopped taking his ARVs every day, and only takes them when he starts to feel unwell. You are very worried that if he continues not taking his medication he will get very sick and you will be blamed.

As a group, think of some coping strategies that CBVs could use to help X and relieve the Stress you are under.

Facilitator's Note: Ensure the strategies developed by the group highlight the following issue:

- The importance of debriefing as a coping strategy. By talking to a supervisor about this problem or other problems, caregivers can reduce the burden they feel when faced with a problem with a client that is causing them stress.

2) Change Your Approach to Caregiving (20 minutes with Tool 2)

Everyone can get in 'a rut' with their job and find themselves in the same negative situations over and over again. By changing the approach to caregiving, CBVs can obtain a fresh perspective on their work that may help them to solve problems more effectively and reduce stress.

Ways that CBVs can change their approach to Caregiving include:

- Establish realistic goals of what you can and cannot do and talk to your supervisor about needing to make changes in your work
- Divide tasks into manageable parts (small acts of care)
- Learn how to adjust the pace of caregiving
- Ask others to help
- Take time away-time off
- Encourage self-care by the client and family.

Tool 2 : Changing Approach To Caregiving



Ask participants to think of other ways that CBVs in your community could change their approach to Caregiving to help relieve Stress.

Discuss the suitability of each approach suggested and write them down as additional methods under the heading 'Specific Approaches in _____'

3) Relaxation Techniques (30 minutes with Tool 3)

Relaxation Techniques involve engaging in activities or thought processes that help you to relax and let go of built up stress.

Ways that CBVs can use Relaxation Techniques to reduce stress include:

- Visualisation (pleasant images and feelings)
- Take a “Worry Break” (take 10 min each day to put all worries into a box, close it and do not open it again until the next day)
- Deep breathing (in through nose, out through mouth)
- Do things YOU enjoy (socialising, listening to music, reading)
- Body relaxation
- Exercise.

Tool 3 : Body Relaxation



Activity: Ask each participant to sit somewhere comfortable. Provide the following instructions using a calm, relaxing voice:

- Close your eyes
- Breathe through your nose and out through your mouth using slow, controlled breaths.
- Be aware of where your body holds stress (tense shoulders, neck, clenched hands).
- Focus on relaxing your stressed parts while breathing, drop your shoulders downwards, relax your hands, and breathe out slowly.
- Practice these steps until tension reduces.

Encourage CBVs to use body relaxation as a stress reduction technique on their own in their own homes when feeling stressed.

4) Strive for Good Health (30 minutes with Tool 4)

Positive living is just as important for CBVs as for their clients. Positive living is a term commonly used to describe steps taken by PLWHA that enhance their lives and improve their health, but is equally important for CBVs.

When people are stressed, they often engage in unhealthy or risky behaviours. Striving for good health involves caring for yourself, thinking positive thoughts, being good to your body and releasing stress in positive rather than negative ways.

Ways in which CBVs can strive for good health and reduce stress are:

- Stop or reduce unhealthy behaviours (smoking, drinking and drug abuse increase stress in the long run)
- Ensure your basic needs are met where possible (eat 3 meals a day, drink water, sleep 7-9 hours a day, exercise)
- Welcome all your emotions and express them appropriately.

The “Stress Pledge for Better Health” is a tool for CBVs to use that will help them identify what causes them stress, encourage them to stop behaviours that can increase or make stress worse, make time for things they enjoy and to strive to engage in healthy thoughts and behaviours that will help relieve stress.

Tool 4: Self Affirmation with Stress Pledge



Distribute copies Handout 8-3, Stress Pledge for Better Health.

Read the pledge aloud as a group.

Encourage carers to create their own Stress Pledge, including specific factors that may affect their lives. CBVs can change their Stress Pledge as their stress changes.

Facilitator's Note: When feeling stressed CBVs should be encouraged to read their stress pledge. This will help them to manage their stress by identifying the source of stress and affirming healthy thoughts and behaviours that will help them cope with their stress.

Stress Pledge for Better Health

**In order to control my stress and improve my health,
I pledge, where necessary to be aware and do the following:**

To find out...

- Who normally upsets me
- What normally upsets me
- Where I normally get upset
- When I normally get upset
- Why I normally get upset

To stop...

- My intake of alcohol and/or illicit drugs
- Smoking
- Or restrict the intake of coffee, chocolate and/or tea

To make time...

- For regular physical examinations
- For relaxation, every day!
- To get enough sleep
- To have fun doing things that I enjoy
- Exercise in a frequent, consistent and appropriate manner

To strive to...

- Feel good about me and have confidence in myself
- Reward myself when a job is well done
- Laugh
- Be flexible
- Learn to let go
- Not be afraid to cry
- Accept that I can be wrong at times
- Be realistic in establishing my priorities and goals
- Seek and accept help from others when I need it
- Take on only what I can manage at any one point in time
- Say NO when the demands placed on me are too great to handle
- Surround myself with people who are supportive of me
- Have and relate to a 'spiritual contact' each day

5) Build a Support Network (50 minutes with Tool 5 and 6)

A **Support Network** involves people in your life with whom you can talk openly and honestly about things that trouble you. A Support Network often includes people who you feel understand you and what you are going through.

The Support Network of CBVs can include:

- Family members, relatives and friends
- Other caregivers
- Faith communities
- Caregiver support groups
- Support groups for PLWHA.



Tool 5: Benefits of Caregiver Support Groups

Task one: discuss the Support Networks available to Caregivers in your location. Suggest that if there is no caregiver support group available, the participants may wish to form one themselves.

Task Two: Create a list of the benefits of caregiver support groups. Add any additional responses given by CBVs not included on the list below.

Benefits of caregiver support groups:

- Become better informed on HIV and AIDS, new treatments and community resources
- Share problems and brainstorm possible solutions
- Lessen stigma associated with HIV and AIDS
- Arrange **respite care** with other caregivers for holidays and rest periods
- Obtain recognition for caregiving efforts.

a) Starting a Support Group (30 minutes with Tool 6)

In Tool 5, caregivers have been equipped with knowledge regarding the benefits of caregiver support groups. It is important that caregivers consider starting their own support group if none exists in your community. The following are some basic steps for starting a peer support group. Distribute the handout of 'Basic Steps for Starting a Support Group' located in Handout 8-4 and read through each step with participants.

STEP ONE: Deciding the “Mission Statement” for your support group.

- Deciding the purpose or function of your support group will help you to organise. For example
 - Will this be a group that aims to provide support for volunteer caregivers?
 - Will it be a group that aims to provide support to carers living with HIV?
 - Will it be a support group for female/male carers?
- An example of a mission statement is: The mission of the ____ support group is to provide support and respite care for PLWHA who provide care in the community”.

STEP TWO: Deciding who your support group “members” will be.

- Develop the 'criteria for membership' which can be information such as:
 - Who will your support group members be? For example, deciding if the support group will be for CBVs only or for all caregivers in the community including the Primary caregivers of your clients.
 - What sort of characteristics should group members have? For example, you may want support group members who have experience providing care, understand principles of confidentiality..etc.
 - What is the maximum number of members you think your support group should have?

STEP THREE: Deciding when and where to hold support group meetings.

- Deciding when and where support group meetings will be held is important information that should be provided to people before joining your support group, as it will address issues such as:
 - Will support group meetings be held during working hours?
 - Will support group meetings be held at a location that group members can reach (i.e., availability of transportation, walking distance from their homes)?
 - How many times a month will meetings be held?

STEP FOUR: Developing Guidelines for Support Group Meetings

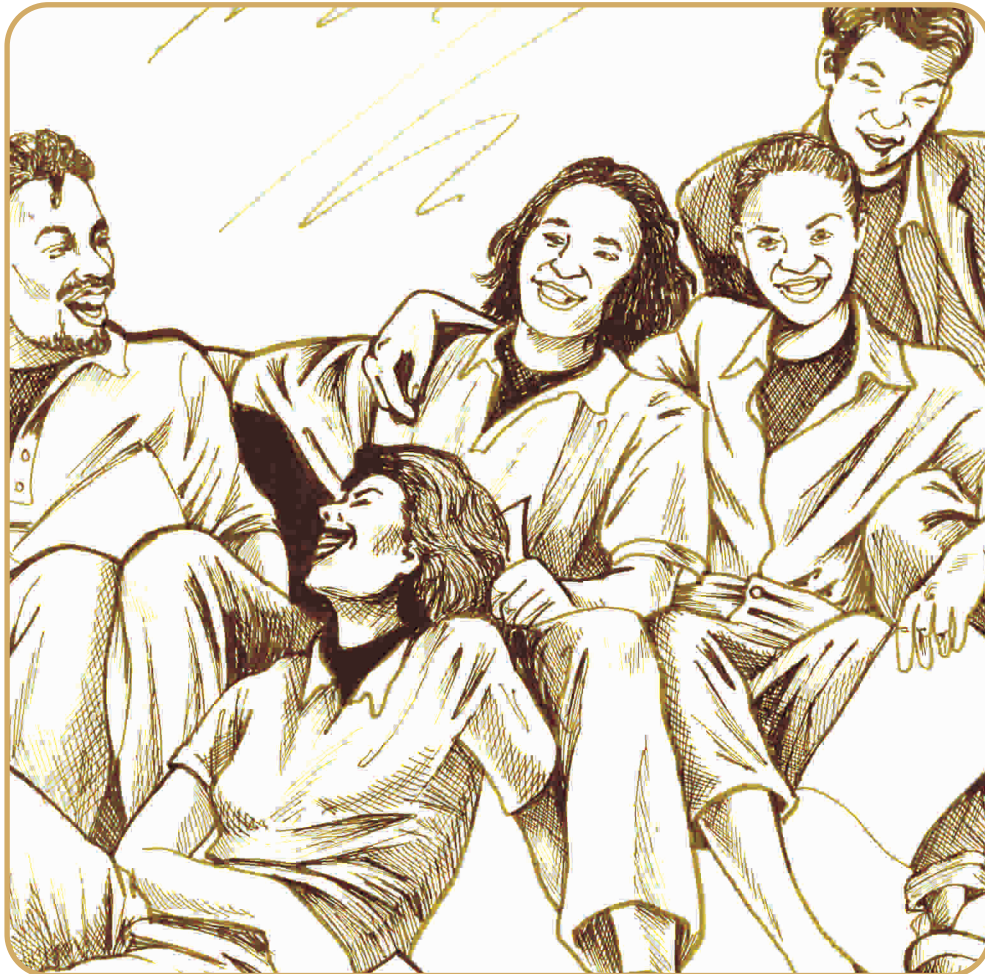
- Developing guidelines for support group meetings will help to ensure that your support group provides reaches it's “Mission Statement” and provides the type of support you want to give to group members.

The following are guidelines for peer support groups which CBVs can use or adapt to suit their needs:

Suggested Guidelines for formal peer support	
Meetings lasting about one hour should be held as frequently as possible (usually every week)	In extreme circumstance, such meetings might be held daily
All members should attend meetings whenever possible	Attending this meeting should be as important as doing good work.
Each week a different member takes the role of a facilitator	All members should gain insight from being in this role
The meeting should begin with the facilitator presenting the agenda, based on items previously requested by the members	Members may add something to the agenda later if time allows
Each item on the agenda is presented by the person who is requesting input	Each peer gives their input based on their own experiences
Finally, the person who received the input gives each peer feedback on the effect or influence of their input	In this way peers are made aware of the person's reaction to their input and communication flow is maintained in all directions. At times peers will want to discuss or debate each other's input which is only natural. This should not be done, however, until each peer has given a chance to give their input without interruption and has received their feedback. Otherwise, The process will get side-tracked and never be completed.

STEP FIVE: Hold Regular Meetings and Strengthen Your Support Group

- Engage group members in discussions that assess whether support group activities are meeting the individual needs of members
- Know of additional resources in the community to help with group activities
- Create working committees within your support group tasked with compiling additional information
- Network with other support groups and organisations working within HIV and AIDS and/or home based care
- Learn strategies for resolving conflict within the support group.



Tool 6: Starting a Support Group in Your Community



If CBVs have decided that they would like to form their own support group, review each of the basic steps for starting a support group and gain group consensus on the following items:

1. The support group “Mission Statement”
2. Criteria for group membership.
3. Where and when to conduct support group meetings.
4. Guidelines for support group meetings.
5. How to strengthen your support group.

Facilitator's Note: Another important way that CBVs can engage in self-care is to always follow universal precautions when caring for clients. Following Universal Precautions will reduce stress associated with fear of infection. If participants have not already received it, distribute copies of Handout 7-4: Universal Precautions and review as a group.

3. Sharing Strategies for Self-Care (30 minutes with Tool 7)

Now that CBVs are equipped with strategies for self-care, it is important that they share these strategies with the primary caregivers of their clients and clients themselves. By assisting clients and families to reduce stress, CBVs may find that the level of stress they experience from caring activities also reduces.



Tool 7: Sharing Self-Care Strategies With Client Households

PART A: Review the '5 Strategies for Self-Care' handout as a group and identify:

1. Strategies for self-care that would be useful and appropriate for clients and primary caregivers.
2. Strategies for self-care that would be inappropriate for clients and primary caregivers.

PART B: Divide participants into pairs. Have participants role-play self-care techniques identified as being useful and appropriate to clients and their primary caregivers.

Facilitator's Note: Ensure each role-play does not just involve explaining the methods, but actually has CBVs demonstrate self-care techniques (such as body relaxation, how to use the Stress Pledge for Better Health).

4 Session Four: Special Considerations in Caring for Carers

Purpose: The purpose of Session Four is to explore special considerations in caring for carers including caring for child carers and caring for caregivers living with HIV.

Objectives:

By the end of this session, CBVs should be able to:

1. Demonstrate an awareness of the effects of caring on child carers and the special needs of children providing care in your community.
2. Conduct a community awareness meeting on the needs of child carers.
3. Refer carers living with HIV or carers who do not know their status to the appropriate services in your community.

Duration: 2 hours

Required Materials: Flipchart, markers.

Recommended Preparation:

- Determine what support is available for carers living with HIV in your community in preparation for Tool 4

Objective	Content	Time	Methodology
Demonstrate an awareness of the effects of caring on child carers and the special needs of children providing care in your community.	1. Caring for Child Carers	1 hour 30 minutes	Mini Lecture
Conduct a community awareness meeting on the needs of child carers.			Tool One (A): Group Activity Tool Two (K): Group Activity
Refer carers living with HIV or carers who do not know their status to the appropriate services in your community.	2. Caring for Carers Living with HIV	30 minutes	Tool Three (ST): Dramatisation Tool Four (ST): Group Discussion and Role Play

1. Caring for Child Carers (1 hour 30 minutes)

a) The Effects of Caring on Children (30 minutes with Tool One)

Children are often the least acknowledged, but most affected, carers in the home. It is important for CBVs to consider how child carers may be affected.

Tool 1: The Possible Impact of Caring on Children



PART A: Divide participants into small groups of 3-4. Provide each group with a flipchart and ask them to write down ways in which they think children providing care for sick family members could be impacted. Ask participants to pay attention to particular ways that children are effected that is different than the effects of caring on adults.

PART B: Ask each group to share their responses and create one flipchart entitled "The Impact of Caring on Children in _____".

Facilitator's Note: The impact of caring on children differs in many places. Following this group activity, review the section below as a group and determine which of the effects listed could apply to children providing care in your community.

Possible effects of providing care on children:

- **Educational effects:** reduced time spent at school, school drop outs to meet demands of caring for sick parent or sibling
- **Social effects:** child carers often miss important social opportunities such as sports, play and socialising with peers
- **Emotional effects:** watching a parent or family member suffer with illness is difficult for children. As child carers have usually not received formal training they can be left wondering "Am I doing this right?", "Am I doing enough?"
- **Physical effects:** children face physical limitations in providing care (such as moving someone who is bedridden) which can impact their health and growth.
- **Financial effects:** children faced with the responsibility of caring are often also faced with the responsibility to care for the family's financial needs. Poverty and illness often lead children to engaging in risky behaviour in exchange for money (sex workers, child labour) that can put them at risk and increase their vulnerability to HIV infection.

b) The Needs of Child Carers (30 minutes with Tool 2)

The first step in caring for child carers is recognising the needs of child carers in your area.



Tool 2: Needs of Child Carers in Your Area

Based on the list of impacts of caring upon child carers created in Tool One, as a group, identify the needs of children created by each effect. As participants identify the needs of children, they should also be linking these needs to existing programmes and services in the community that could assist child carers.

For example, based on the list above, possible needs could include:

- o Offering support to child carers in caring activities, enrolling households with child carers in community-based HBC programmes
- o School support, school fees, uniforms, books
- o Psychological and social support, counselling, self-care strategies, support groups, faith based programmes
- o Training in HBC, age-appropriate skills-building activities
- o Income-generation support, through support groups or school-based Activities
- o Food security support, backyard gardens, food distribution

c) Developing Community Awareness About Caring for Child Carers (30 minutes with Tool 3)

Part of the reason communities find it difficult to provide assistance for child-headed households, or households in which children are acting as caregivers is that they are often not 'visible' within community networks. A good way for CBVs to encourage caring for child carers is to create community awareness about the challenges and needs of child carers.



Tool 3: Creating Community Awareness About Caring for Child Carers

Ask participants to dramatise how they as a group would lead a community meeting to raise awareness about the needs of child carers. In developing their drama, each group should consider:

- Who would be important people in the community to invite to this meeting?
- What organisations or services in the community identified in Tool Two should be present?
- How would you involve child carers in this process?

Facilitator's Note: To assess this core skill at the end of this module, participants should cover the following important topics:

- The effects of caring on child carers
- The needs of child carers
- Intervention strategies for child carers
- Linking child carers with community services that can provide support

2. Caring for Carers living with HIV (30 minutes with Tool 4)

PLWHA are known to make excellent caregivers for other PLWHA as they have a good understanding of what it is like to live with HIV and the emotions experienced by clients in the same situation.

CBVs who know their HIV status should be given special consideration for care if they are HIV positive. CBVs who do not know their HIV status should be supported to make use of HIV Testing and Counselling services.

PLWHA who are carers should be encouraged to adapt health-seeking behaviours through the timely treatment of OIs and access to ARVs when and if they are available.

Tool 4: Caring for Carers Living with HIV

PART A: As a group discuss how carers living with HIV in your community **are supported** by addressing the following topics:

1. How are PLWHA that are carers currently being provided with support in your community?
2. What are additional ways that PLWHA that are carers could be further supported?
3. How could CBVs that do not know their status be supported to make use of HIV Testing and Counselling services?

PART B: Divide participants into pairs and role play how CBVs would refer another carer to the appropriate support services in their community. For example, carers living with HIV to health care, support groups...etc; carers who do not know their status to HIV Testing and Counselling services.

Facilitator's Note: In assessing this core skill, participants should be able to role play giving other carers information on:

- Support services in the community to refer caregivers living with HIV.
- HIV Testing and Counselling services available in the community for CBVs who do not know their HIV status.

To end this module on a positive and encouraging note, engage participants in a short discussion of:

- How did this module help you?
- What part of this training will assist you in your caring activities?
- Is there anything else about caring for carers you would like to discuss?
- Reaffirm to participants the important role they play in helping people in the community.
- Commend participants for their efforts and encourage them to continue providing their excellent service in the community.

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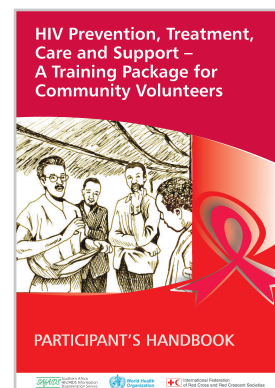
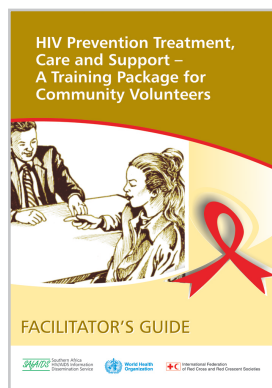
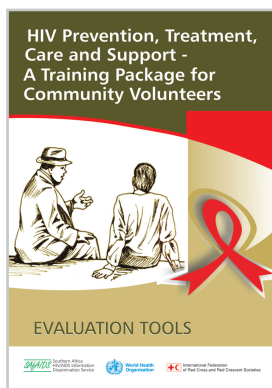
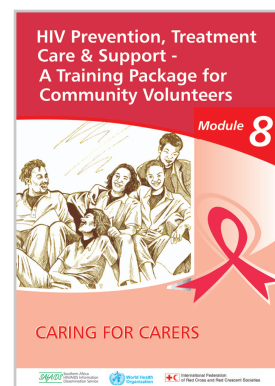
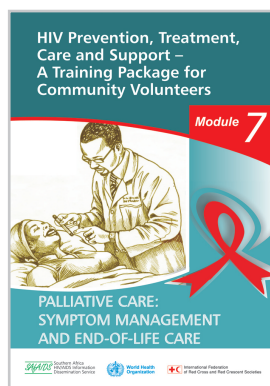
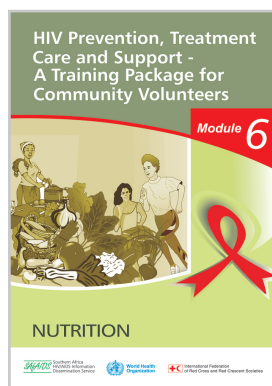
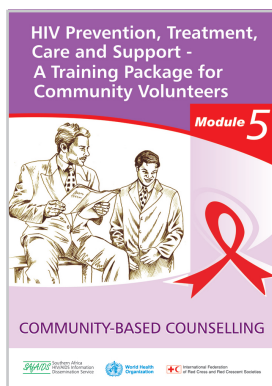
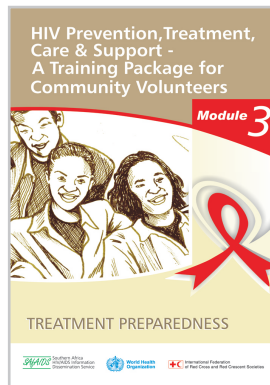
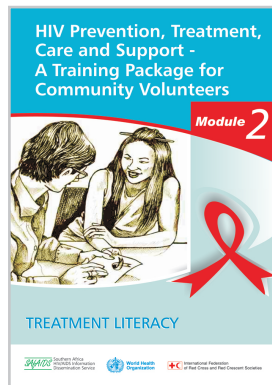
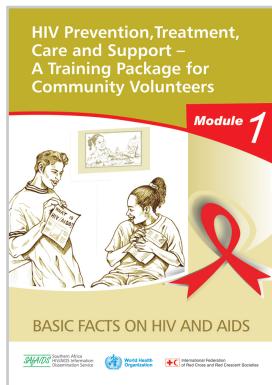
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