

Home Care for People Living with HIV/AIDS: The Power of Our Community

**Integrating Reproductive Health and HIV/AIDS for
Non-Governmental Organizations, Faith-Based
Organizations and Community-Based Organizations**

Volume III

November 2003

cedpa

Home Care for People Living with HIV/AIDS: The Power of Our Community

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**The Centre for Development
and Population Activities**



This publication was supported by the United States Agency for International Development (USAID) under Cooperative Agreement # HRN-A-00-98-00009-00.

The contents of this document do not necessarily reflect the views or policies of the USAID or The Centre for Development and Population Activities (CEDPA).

Abbreviations

ABC	Abstinence, Be Faithful, and Condom Use
AIDS	Acquired Immune Deficiency Syndrome
ARV	Antiretroviral
AUSAID	Australia Agency for International Development
CEDPA	The Centre for Development and Population Activities
CBO	Community-Based Organization
ENABLE	Enabling Change for Women’s Reproductive Health
FBO	Faith-Based Organization
FP	Family Planning
GIPA	Greater Involvement of Persons Living with HIV/AIDS
HIV	Human Immunodeficiency Virus
IEC	Information, Education, and Communication
IDU	Injecting Drug User
IGA	Income Generating Activities
ICPD	International Conference on Population and Development
MSM	Men Who Have Sex with Men
MTCT	Mother-to-Child Transmission
NGO	Non-Governmental Organization
ORS	Oral Rehydration Solution
OVC	Orphans and Vulnerable Children
PLWHA	People Living with HIV/AIDS
RH	Reproductive Health
RTI	Reproductive Tract Infection
STI	Sexually Transmitted Infection

TB	Tuberculosis
UNAIDS	Joint United Nations Programme on AIDS
UNGASS	United Nations General Assembly Special Session on HIV/AIDS
UNICEF	United Nations Children's Fund
VCT	Voluntary Counseling and Testing
WHO	World Health Organization

Acknowledgements

Headquartered in Washington, DC, The Centre for Development and Population Activities (CEDPA) is an international nonprofit organization that seeks to empower women at all levels of society to be full partners in development. Founded in 1975, CEDPA supports programs and training in leadership, capacity building, advocacy, governance and civil society, youth participation, and reproductive health.

The Enabling Change for Women's Reproductive Health (ENABLE) project works to strengthen women's capabilities for informed and autonomous decision making to prevent unintended pregnancy and improve reproductive health. Begun in 1998, ENABLE seeks to increase the capacity of non-governmental organization (NGO) networks to expand reproductive health services and to promote a supportive environment for women's decision making.

ENABLE is implemented under Cooperative Agreement #HRN-A-00-98-00009-00 funded by the United States Agency for International Development (USAID). We would like to thank them for making this series of manuals possible.

Acknowledgement and thanks must be given to the various organizations and individuals whose resources and knowledge helped make this manual possible. Sources for technical information include the Peace Corps, UNAIDS, World Health Organization (WHO), Australia Agency for International Development, and Pact, Inc.

Our thanks go to Lucy Owusu-Darko, Chinwe Onumonu, Ahmed Dery, and John Otugbo for their able assistance and excellent insights in field-testing the manual in Benue State, Nigeria.

We would like to thank the following for their support in the production of this manual series: Peg Marshall, Robert Kelly, Cynthia Green, Victoria Wells, Nancy McCharen, and Rose Amolo for sharing their technical expertise and advice, and Allison Clifford, Annmarie Leadman, Malcolm Lowe, and Annie LaTour for their hard work in formatting and design.

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Overview

The HIV/AIDS pandemic has created a crisis of unprecedented proportion that greatly impacts society as a whole, especially women and their reproductive health. Communities everywhere are struggling to respond. It is our hope that this manual will help communities find the strength to address this crisis.

The International Conference on Population and Development (ICPD) held in Cairo in 1994 was a watershed in the field of reproductive health (RH). In Cairo, the thinking about population and development underwent a major change: from a focus on demographic goals to a greater recognition of the interrelation of population, sustainable development, and economic growth, and to advances in the education, economic status, and empowerment of women. Women's groups, non-governmental organizations (NGOs), faith-based organizations (FBOs), community-based organizations (CBOs), and other members of civil society pressed for a new, holistic interpretation of reproductive health that focused on the individual's needs and desires and the interdependence of individuals and their communities.

Given the call to action from Cairo, CEDPA's ENABLE Project was designed "to strengthen women's capabilities for informed and autonomous decision making to prevent unintended pregnancy and improve reproductive health." Through partner NGO networks, women would have greater access to high-quality, *integrated* reproductive health services and an enabling environment would be promoted.

In a strategic response to the HIV/AIDS pandemic, ENABLE has developed a series of manuals entitled "Integrating Reproductive Health and HIV/AIDS for NGOs, FBOs, and CBOs." Each volume addresses various facets of the pandemic and the issues of sexuality underlying both family planning (FP) and HIV transmission. Priority areas include: (1) integrating HIV/AIDS education, prevention, and care and support activities into ongoing programming; and (2) building capacity in NGO partner programs, networks, and communities affected by the destabilizing effects of the HIV/AIDS pandemic.

Communities that have been hard hit by HIV/AIDS need to be supported in their response to the crisis. Families and community groups that are caring for people living with HIV/AIDS and orphans and vulnerable children often need basic information on HIV/AIDS to keep themselves safe and to help those in their care stay healthy and emotionally positive for as long as possible. This training manual provides the necessary information, as well as tapping into the strength of the community and empowering participants to action. This manual offers people living with HIV/AIDS, orphans and vulnerable children, families, and community members knowledge about healthy living with the virus, about care and support, and about death and dying. Community members are urged to visualize their regions protected against the ravages of HIV/AIDS and to work together to find solutions to the impact of HIV/AIDS on their spheres of influence and action.

A Note on Greater Involvement of Persons Living with HIV/AIDS in Home and Community-Based Care¹

In Paris in 1994, the representatives of 42 countries signed a declaration supporting the greater involvement of people living with or affected by HIV/AIDS (GIPA) as an imperative, ethical, and effective response to the HIV pandemic.

Defining GIPA²

At its most basic, GIPA means two important things—

- Recognizing the important contribution people living with or affected by HIV/AIDS can make in the response to the epidemic
- Creating space within society for people living with HIV/AIDS involvement and active participation in all aspects of that response

This contribution can be made at all levels, from the individual to the organizational, and in all sectors from the social and cultural to the economic and political. In particular, the Paris Declaration emphasizes the role of networks of people living with HIV/AIDS and community-based organizations (CBOs).

Community- and home-based care are often undertaken with the assumption that people living with HIV/AIDS and orphans and vulnerable children are passive recipients of care and support services. But studies have shown that their involvement can enhance those services, and at the same time provide benefits for the NGOs, CBOs, people living with HIV/AIDS, and orphans and vulnerable children. There are four levels of involvement of people living with HIV/AIDS in community and home care programs—

- **Access**—Using the care and support services of NGOs and CBOs
- **Inclusion**—Working as support staff or volunteers, providing peer outreach or home visits
- **Participation**—Providing HIV/AIDS services, either as volunteers or staff, using their experience and training
- **Greater Involvement**—Designing services and managing organizations, often engaging in advocacy activities and public speaking

Their meaningful involvement strengthens NGOs and CBOs by improving providers' attitudes and understanding of issues affecting people living with HIV/AIDS, and by creating a more supportive environment. There is often a greater integration of HIV/AIDS advocacy into the

¹ Gilborn, Laelia. *Meaningful PLWHA Involvement; A Part of the Solution for Home and Community Care*. (Washington, DC: HORIZONS/Population Council, 2003).

² UNAIDS. *From Principle to Practice: Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA)*. (Geneva: UNAIDS, 2002). <http://www.unaids.org/publications/documents/persons/gipa-8.doc>.

work of NGOs and CBOs. Care and prevention activities become more effective by improving perceptions and by putting a human face on the epidemic, thus building synergy between prevention and care and support. It also increases the credibility of the organizations with beneficiaries, donors, and other stakeholders.

There are also challenges when involving people living with HIV/AIDS in service provision. These include disruption of services due to illness and death of a person living with HIV/AIDS, the attendant costs of providing health and life insurance, and increased training costs due to turnover. Organizations also have to beware of “tokenism” or superficial involvement of people living with HIV/AIDS, and the occasional tension that may arise between HIV positive and HIV negative employees. One challenge that many face in care and support is that it can be difficult emotionally for an asymptomatic HIV positive person to work with a person in the final stages of AIDS. NGOs/CBOs also need to be sensitive to gender-specific needs, including the reproductive goals and care burden for women.

The benefits to people living with HIV/AIDS are very important when they are meaningfully involved in care and support programs. Many experience improved psychological and physical health, reduced isolation through peer contact, better access to care, increased knowledge of HIV/AIDS, access to treatment, information on safer sex, better acceptance of their HIV status both by self and family, and increased self-esteem. They also often derive material benefits and paid employment.

Studies have shown other wider benefits from involving people living with HIV/AIDS and orphans and vulnerable children in care and support efforts.³ In Uganda, some areas have experienced greater acceptance at the community level when they are seen to be thriving and active in their own and other’s care, thereby reducing stigma. People living with HIV/AIDS have even become role models in the community for their proactive positive living and planning for the future of their families. This has also increased the demand for voluntary counseling and testing (VCT) and access to care and support services.

There are several key elements that have been identified for creating a supportive environment for people living with HIV/AIDS involvement—

- Non-discriminatory staff attitudes, policies, and procedures
- Psychological support
- Avoiding tokenism by building skills of people living with HIV/AIDS—
 - personal empowerment
 - communication and presentation skills
 - HIV/AIDS knowledge
 - knowledge of the legal aspects of HIV/AIDS

³These findings were drawn from a HORIZONS study funded by USAID entitled, *A Modified Approach to Support for AIDS-Affected Children in Uganda*. Principal investigators were Rebecca Nyonyintono, Makerere University, and Laelia Gilborn at HORIZONS, Population Council.

- skills for organizing and conducting policy dialogue⁴
- Material support
- Gender- and sexuality-sensitive services and opportunities for participation

Any organization or group developing home or community care services should keep these ideas in mind and in practice.

A Note on Caring for the Caregivers

Experience has shown that to effectively fight the HIV/AIDS pandemic, communities need to work together and utilize their resources wisely. One of the greatest resources are those people willing and motivated to care for others who are ill and affected by HIV/AIDS. Caregivers may be family members, volunteers, or health and social workers, but they are on the front line in dealing with the epidemic and they need to be cared for themselves and supported in their work, lest they become overwhelmed by the burden of grief and despair.

Any home-based care program should provide for the needs of its caregivers, by building in support systems for them. These may be as simple as creating opportunities for caregivers to talk with one another to share their experiences, as in a weekly meeting or a “buddy system” (pairing up home-care givers). Other possibilities include respite care for family members caring for people living with HIV/AIDS or orphans and other vulnerable children, day care centers, regular vacation time built into volunteer and professional caregiver schedules, and regular visits with a psychologist to protect the caregiver’s mental health. The type of support given will depend on the resources available in the community, but it is crucial to provide support in order to keep caregivers from “burning out.”

Methodology

Several training methodologies are utilized in this curriculum in order to add variety to sessions and to engage all types of adult learners—

- Demonstration
- Discussion
- Brainstorming
- Small group work
- Role-play
- Presentation/lecture
- Guest speakers

⁴ Ibid.

Evaluation

It is important to get an idea of participants' level of knowledge about HIV/AIDS and home care before the training starts in order to evaluate how much they learn from it. Evaluations also inform the instructors of participants' baseline knowledge, experience, background, and expectations. During the registration process on the first morning of the workshop, give each participant a copy of the questionnaire "What We Know about Home Care for People Living with HIV/AIDS" (see the Appendix page I-376 for instruction and forms). The same questionnaire will be distributed during the evaluation session at the end of the workshop. You can then compare the two to determine what was learned and areas that need to be strengthened or followed up.

At the end of each day, participants will fill out three color-coded cards. On green cards, they will write one thing they have learned today. On pink cards they will write one thing about which they need more explanation. On yellow cards they will write one suggestion for improvement for the facilitator(s). Volunteers from among the participants will collect and summarize the cards, giving feedback to the group the following morning. The training team will meet each day to evaluate the day's work, plan and modify the program as necessary. A final workshop evaluation will be conducted with participants at the end of the workshop (see the "Workshop Final Evaluation" in the Appendix page I-382).

Learning Objectives

By the end of Section One, *The Many Aspects of Care*, participants will be able to—

1. Describe at least five categories of needs of people living with HIV/AIDS and orphans and vulnerable children and possible community interventions to meet those needs
2. Discuss the importance of psychological health of people living with HIV/AIDS and describe some of the issues around VCT and disclosure of status to partners and children, including potential partner violence
3. Identify activities that pose a risk of HIV transmission and at least five examples of ways to prevent HIV infection among caregivers
4. List at least five positive behaviors and hygienic measures in the home that can help people living with HIV/AIDS to live longer, healthier lives
5. Describe symptoms of common illnesses, suggest strategies for managing them in the home, and identify those that require medical attention
6. Depending on the circumstances, discuss where to obtain World Health Organization (WHO) approved oral rehydration solution (ORS) packets or demonstrate the correct method to make ORS and to use a thermometer
7. Describe issues of particular importance to women in the community and home-based care
8. Describe special issues surrounding pregnancy and breastfeeding for HIV positive women

9. Demonstrate at least two ways to help people living with HIV/AIDS and their families to obtain and understand instructions from health care workers
10. Define “antiretroviral therapy” and list at least two benefits and two risks
11. List strategies for helping a person living with HIV/AIDS to prepare to die with dignity and for helping orphans and vulnerable children to heal psychologically and emotionally after the loss of their parent(s)
12. Identify psychological, physical, medical, social, material, and other supports and resources for people living with HIV/AIDS and orphans and vulnerable children in the local community

By the end of Section Two, *The Basics of HIV/AIDS*, participants should be able to—

13. Name three ways HIV can be transmitted and three ways to prevent transmission
14. Describe the stages of HIV progression in the body and define related terms

By the end of Section Three, *Harnessing the Power of the Community*, participants should be able to—

15. Create an action plan and affirm the participant’s commitment for providing support for people living with HIV/AIDS and orphans and vulnerable children in the community and for each other
16. Describe community responses to past challenges and visualize a successful community response to HIV/AIDS

How to Use This Manual

In recognition of the volume of material included in this manual, and considering the different audiences, settings, and circumstances (especially those surrounding people living with HIV/AIDS and orphans and vulnerable children and their caregivers), the manual is designed and organized for flexibility. Prototype-training schedules have been provided, however, alternative exercises and sections have been included for the trainer to choose from depending on the participants’ background. It is important that the caregivers/participants know the basics of HIV/AIDS, including how HIV is transmitted and how to prevent further transmission, in order to protect themselves and reduce stigma. If the participants do not already know this information, the trainer should begin with activities from Section Two, *The Basics of HIV/AIDS*, which offers these basic facts. The trainers will need to evaluate the participant’s knowledge of HIV/AIDS and which areas specifically they lack knowledge in and add the appropriate activities from Section Two. CEDPA has produced an entire series of HIV/AIDS manuals, of which this is just one. If possible, it is recommended that participants attend a training based on Volume I, *Family Planning Plus: HIV/AIDS Basics for NGOs and Family Planning Program Managers* prior to this training. Section Three, *Harnessing the Power of the Community*, consists of activities aimed at mobilizing the community as a whole. If the participants express interest in the care of people living with HIV/AIDS in a broader context and would like to take further action in their community, these activities might be more appropriate.

The four-day training provided is based on the activities and topics only in Section One, *The Many Aspects of Care*. These are directed more specifically to aspects of care, both mental and physical. The manual is meant to be used within a community that is confronting the issues of care and support for people living with HIV/AIDS and orphans and vulnerable children. There should be 15 to 20 participants, from the same community, who are motivated and in positions within that community to make/support positive change in dealing with HIV/AIDS. Family members who are actively caring for a person living with HIV/AIDS, community groups involved in home care, and community leaders that can mobilize and influence the community to take on this work would be ideal participants for this training.

The two-day training is a refresher course for caregivers, with only the core competencies of care included (see example page IIX). This could also be used to give caregivers who cannot spare a full four days a quick overview of the most important aspects of care and to introduce them to resources available to them in the community. These activities can be modified or shortened depending on the facilitators' and participants' needs.

A five-day training can be utilized if the participants are able to attend for this length of period. In this case, the trainers should evaluate their competency in the subjects that will be presented and discuss with participants what they would like to learn. Section Two or Section Three can be added depending on the outcome. Prototype schedules can be found at the beginning of each Section.

Many programs, however, do not conduct the two to five-day trainings exactly as presented in this manual. Instead, trainers use the manual as a model and design their own home-based care training depending on the needs of the participants and the reality of the clients and community members they serve. Alternatively, sections of this manual can be used independently, to give specific skills to home care teams and family caregivers, or to empower a person living with HIV/AIDS and their support groups. Facilitators should feel free to adapt the sessions to meet the needs of the specific audience with whom they are working and design a realistic schedule. Also, in cases where there is difficulty in convening a group workshop, the manual can be used to develop easy-to-use resources for already scheduled meetings and other situations.

Remember, it is important to have full participation of people living with HIV/AIDS as equal partners in all HIV/AIDS activities, so it is assumed that wherever possible, they will be included as participants and facilitators in this workshop. Including people living with HIV/AIDS as active agents in the sessions can be very powerful, as other participants and facilitators can benefit from their insights and experiences.

Home Care for People Living with HIV/AIDS: The Power of Our Community is Volume III of a series of manuals entitled, *Integrating Reproductive Health and HIV/AIDS for Non-Governmental Organizations, Faith-Based Organizations and Community-Based Organizations*. The other two manuals, *Volume I—Family Planning Plus: HIV/AIDS Basics for Non-Governmental Organizations and Family Planning Program Managers* and *Volume II—Faith Community Responses to HIV/AIDS*, are important resource materials for trainers who may want to refer to them for more information in dealing with diverse target groups with different skill levels.

Sample Four-Day Caregiver Care and Support Training

Schedule	Day One	Day Two	Day Three	Day Four
	Registration <i>30 minutes</i>	Recap <i>30 minutes</i>	Recap <i>30 minutes</i>	Recap <i>30 minutes</i>
Session	The Power of Our Community Introductions, Goals, and Objectives Workshop Structure <i>1 hour 30 minutes</i>	Medical Support for People Living with HIV/AIDS (cont.) Common Illnesses Role-Play <i>1 hour 45 minutes</i>	Nutritional Needs for People Living with HIV/AIDS and Their Families We Are What We Eat <i>1 hour</i> Nutritional Needs for People Living with HIV/AIDS <i>1 hour</i>	Preparing for Goodbye Supporting People Living with HIV/AIDS <i>1 hour 30 minutes</i>
Break	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
Session	Breathe in Life, Breathe Out Trouble The Power of Our Community <i>1 hour 30 minutes</i>	Oral Rehydration Solution and Thermometer Use <i>1 hour</i> Seeking Medical Support from a Professional Service Provider Special Medical Concerns for People Living with HIV/AIDS <i>1 hour</i>	Social Support for People Living with HIV/AIDS and Their Families Small Groups on Social Issues <i>1 hour</i> Plenary on Social Issues <i>1 hour 30 minutes</i>	Supporting Orphans <i>1 hour 30 minutes</i>
Lunch	<i>1 hour</i>	<i>1 hour</i>	<i>1 hour</i>	<i>1 hour</i>
Session	Review from Section Two Review of HIV Transmission, Prevention, and Disease Progression <i>1 hour 30 minutes</i>	Strategies for Dealing with Health Professionals <i>45 minutes</i> Antiretrovirals <i>30 minutes</i>	Psychological Support for People Living with HIV/AIDS and Their Families People Living with HIV/AIDS Vignettes <i>1 hour 45 minutes</i>	Closing Evaluation <i>1 hour</i> String Spider Web and Closing Ceremony <i>1 hour</i>
Break	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
Session	The Life Tree Life Tree <i>1 hour 30 minutes</i> Medical Support for People Living with HIV/AIDS Common Illnesses Role-Play <i>1 hour</i>	Physical Support for People Living with HIV/AIDS and Their Families Caring for People Living with HIV/AIDS in the Home <i>1 hour 30 minutes</i>	<i>The previous session can be emotional. Trainers may want to have a counselor present and use the afternoon session for this purpose.</i>	
Evaluation	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
Total Time	<i>8 hours 45 minutes</i>	<i>8 hours 45 minutes</i>	<i>8 hours 30 minutes</i>	<i>6 hours 45 minutes</i>

Sample Two-Day Refresher Training for Caregivers— Core Competencies

Schedule	Day One	Day Two
	Registration <i>30 minutes</i>	Recap <i>30 minutes</i>
Session	Introductions and Workshop Structure <i>1 hour 30 minutes</i>	Common Illnesses of People Living with HIV/AIDS <i>2 hours</i>
Break	<i>15 minutes</i>	<i>15 minutes</i>
Session	Breathe in Life Transmission Facts What's the Fluid? Where's the Door? Prevention Facts <i>2 hours 10 minutes</i>	Oral Rehydration Solution and Thermometer Use <i>1 hour</i>
Lunch	<i>1 hour</i>	<i>1 hour</i>
Session	Condom Carousel Condom Demonstrations <i>1 hour 20 minutes</i>	Special Medical Concerns for People Living with HIV/AIDS <i>1 hour</i> Antiretrovirals <i>30 minutes</i>
Break	<i>15 minutes</i>	<i>15 minutes</i>
Session	Caring for People Living with HIV/AIDS in the Home <i>1 hour</i> Nutrition <i>1 hour</i>	Evaluation <i>1 hour</i> String Spider Web and Closing Ceremony <i>1 hour</i>
Evaluation	<i>15 minutes</i>	<i>15 minutes</i>
Total Time	<i>9 hours 15 minutes</i>	<i>8 hours 30 minutes</i>

Sample Five-Day Training for Caregivers: Sections 1 and 2

Schedule	Day One	Day Two	Day Three	Day Four	Day Five
	Registration <i>30 minutes</i>	Recap <i>30 minutes</i>	Recap <i>30 minutes</i>	Recap <i>30 minutes</i>	Recap <i>30 minutes</i>
Session	Transmission and Prevention of HIV/AIDS Myths and Facts <i>1 hour</i> Transmission Facts <i>30 minutes</i>	The Power of Our Community Introductions, Goals, and Objectives Workshop Structure <i>1 hour 30 minutes</i>	Medical Support for People Living with HIV/AIDS (cont.) Common Illnesses Role-Play <i>1 hour 45 minutes</i>	Nutritional Needs for People Living with HIV/AIDS and Their Families We Are What We Eat <i>1 hour</i> Nutritional Needs for People Living with HIV/AIDS <i>1 hour</i>	Preparing for Goodbye Supporting People Living with HIV/AIDS <i>1 hour 30 minutes</i>
Break	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
Session	What's the Fluid? Where's the Door? <i>30 minutes</i> Prevention of HIV <i>30 minutes</i> Condom Carousel <i>30 minutes</i>	Breathe in Life, Breathe Out Trouble The Power of Our Community <i>1 hour 30 minutes</i>	Oral Rehydration Solution and Thermometer Use <i>1 hour</i> Seeking Medical Support from a Professional Service Provider Special Medical Concerns for People Living with HIV/AIDS <i>1 hour</i>	Social Support for People Living with HIV/AIDS and Their Families Small Groups on Social Issues <i>1 hour</i> Plenary on Social Issues <i>1 hour 30 minutes</i>	Supporting Orphans <i>1 hour 30 minutes</i>
Lunch	<i>1 hour</i>	<i>1 hour</i>	<i>1 hour</i>	<i>1 hour</i>	<i>1 hour</i>
Session	Condom Demonstration <i>1 hour</i> The Immune System and HIV Elephants and Lions Game <i>15 minutes</i>	The Life Tree Life Tree <i>1 hour 30 minutes</i>	Strategies for Dealing with Health Professionals <i>45 minutes</i> Antiretrovirals <i>30 minutes</i>	Psychological Support for People Living with HIV/AIDS and Their Families People Living with HIV/AIDS Vignettes <i>1 hour 45 minutes</i>	Closing Evaluation <i>1 hour</i> String Spider Web and Closing Ceremony <i>1 hour</i>
Break	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
Session	Disease Progression Diagram <i>1 hour</i>	Medical Support for People Living with HIV/AIDS Common Illnesses Role-Play <i>1 hour 30 minutes</i>	Physical Support for People Living with HIV/AIDS and Their Families Caring for People Living with HIV/AIDS in the Home <i>1 hour 30 minutes</i>	<i>The previous session can be emotional. Trainers may want to have a counselor present and use the afternoon session for this purpose.</i>	
Eval	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
Total	<i>7 hours 30 minutes</i>	<i>8 hours 15 minutes</i>	<i>8 hours 45 minutes</i>	<i>8 hours 30 minutes</i>	<i>6 hours 45 minutes</i>

Sample Five-Day Training for Caregivers: Sections 1 and 3

Schedule	Day One	Day Two	Day Three	Day Four	Day Five
	Registration <i>30 minutes</i>	Recap <i>30 minutes</i>	Recap <i>30 minutes</i>	Recap <i>30 minutes</i>	Recap <i>30 minutes</i>
Session	The Power of Our Community Introductions, Goals, and Objectives Workshop Structure <i>1 hour 30 minutes</i>	Medical Support for People Living with HIV/AIDS (cont.) Common Illnesses Role-Play <i>1 hour 45 minutes</i>	Nutritional Needs for People Living with HIV/AIDS We Are What We Eat <i>1 hour</i> Nutritional Needs for People Living with HIV/AIDS <i>1 hour</i>	Preparing for Goodbye Supporting People Living with HIV/AIDS <i>1 hour 30 minutes</i>	Merging the Community Maps <i>30 minutes</i> Action Planning for Our Community Story with a Gap <i>1 hour 30 minutes</i>
Break	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
Session	Breathe in Life, Breathe Out Trouble The Power of Our Community <i>1 hour 30 minutes</i>	Oral Rehydration Solution and Thermometer Use <i>1 hour</i> Seeking Medical Support from a Professional Service Provider Special Medical Concerns for People Living with HIV/AIDS <i>1 hour</i>	Social Support for People Living with HIV/AIDS and Their Families Small Groups on Social Issues <i>1 hour</i> Plenary on Social Issues <i>1 hour 30 minutes</i>	Supporting Orphans <i>1 hour 30 minutes</i>	Group Action Plan <i>1 hour</i>
Lunch	<i>1 hour</i>	<i>1 hour</i>	<i>1 hour</i>	<i>1 hour</i>	<i>1 hour</i>
Session	The Life Tree Life Tree <i>1 hour 30 minutes</i>	Strategies for Dealing with Health Professionals <i>45 minutes</i> Antiretrovirals <i>30 minutes</i>	Psychological Support for People Living with HIV/AIDS and Their Families People Living with HIV/AIDS Vignettes <i>1 hour 45 minutes</i>	Creating Our Community Vision Statement Developing My Own Vision Statement <i>15 minutes</i> Creating Our Community Vision <i>1 hour 30 minutes</i>	Closing Evaluation <i>1 hour</i> String Spider Web and Closing Ceremony <i>1 hour</i>
Break	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
Session	Medical Support for People Living with HIV/AIDS Common Illnesses Role-Play <i>1 hour 30 minutes</i>	Physical Support for People Living with HIV/AIDS and Their Families Caring for People Living with HIV/AIDS in the Home <i>1 hour 30 minutes</i>	<i>The previous session can be emotional. Trainers may want to have a counselor present and use the afternoon session for this purpose.</i>	Community Mapping Creation of Community Maps <i>1 hour 15 minutes</i>	
Eval	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
Total	<i>8 hours 15 minutes</i>	<i>8 hours 45 minutes</i>	<i>8 hours 30 minutes</i>	<i>8 hours 15 minutes</i>	<i>7 hours 15 minutes</i>

Building a Training Team

Ideally, to facilitate the five-day prototype training, using all the activities in the manual, you should build a team of at least three facilitators. Team building is a process. Facilitators should meet to familiarize themselves with the content and discuss it, to choose sessions that each will facilitate and prepare, and to determine appropriate participants. It is important to have a variety of skills among the facilitators, in order to respond to the needs and questions of participants. It is also important to have a daily evaluation with facilitators in order to address concerns, assess progress, and to make any modifications that may be needed in the training.

The facilitator for the technical sessions needs substantial knowledge and experience in HIV/AIDS, perhaps a health or medical professional. Another should have a solid background in counseling or social work, either a trained social worker or other professional counselor, for facilitation of the psychosocial sessions. And finally, someone with experience in community mobilization, perhaps from a local NGO or an activist who is living with HIV/AIDS, would be useful for sessions on community response and action planning. Of course, you may be able to find one person that has two or more of these skills. It is still a good idea to have three or more facilitators to share the sessions, as this is quite a long and intense workshop. Each facilitator should be a skilled presenter and trainer.

Important Things to Remember when Presenting this Training Course

When giving this training course, it is important to be aware of the emotional impact on participants and facilitators. Although the manual is focused on finding the strength within the community to deal with HIV/AIDS with hope and commitment, many of the sessions will be painful and emotionally challenging. Everyone should feel that they are in an environment where they are supported and can explore issues and feelings safely. There should be respect for each other and assurance that all information that is shared will be confidential.

Participants and facilitators may be HIV positive and may experience severe emotional reactions during the course of the training. Even if they are not positive, these sessions may bring up very difficult feelings. It is crucial to be sensitive and supportive to all and understanding of those whose behavior is out of the norm.

Due to the intensity of the subject matter of this workshop, it is recommended that the participants and facilitators take a recreational break of some kind on the third or fourth evening of the workshop. For example, go on some kind of outing together, or have a festive dinner together with dancing, entertainment or games, to release tension and stress and facilitate bonding of the group.

Given the strong feelings and emotions that the process of this training may bring up, not necessarily at the time of the training, it is important for both facilitators and participants to identify someone to whom they can turn in the future to provide support. This training will lay the foundation for the support that caregivers will need to give to each other, as caring for people living with HIV/AIDS and orphans and vulnerable children can be very emotionally draining and burnout is common.

Those participants who commit to continuing this work in the community in the future will need to have regular opportunities to support each other; any program providing these services needs to build in support for caregivers.⁵

Also, as facilitators it is important to remember that our words have power and positive words can reframe the way we, and our communities, think about HIV/AIDS. Positive, non-judgmental messages, both in verbal and non-verbal gestures, can combat stigma and discrimination. Please refer to the “Guidelines for Communicating about HIV/AIDS” on page 1-17 before presenting this training.

How the Manual Is Organized

The manual is divided into three sections and 15 chapters, each chapter dealing with a specific content area. Prototype schedules are provided at the end of this section as a guide. (There are also large sections of this manual that are reference materials, both in “Handouts” and “Trainer Resources,” which can be photocopied for distribution to participants. Because of the volume, you may need to budget extra funds for photocopies.)

Each chapter may contain—

Key Questions. This section allows you to see at a glance what major questions will be addressed in the chapter.

Introduction. This section introduces the major theme of the chapter content and orients the facilitator to the overall lesson plan.

Objectives. The objectives set the learning goals for the sessions in specific, clear, and measurable terms. They can be used to focus your pre-test/post-test material and to orient the participants to the focus of the sessions.

Sample Session Design. The sample lesson plan contains the time required, the content, the methodology used, materials needed and a way to evaluate the participants’ learning. It helps the facilitator to determine whether the content is appropriate for the audience and to make sure that everything is prepared for the session.

Important Terms. This section contains definitions of key words that are necessary for comprehension of the session content. You may want to use them as handouts for participants to help them learn new terms, and then keep as a reference.

Activities and Handouts. This section contains all of the activities included in the sample lesson plan. Each activity has the learning objectives and step-by-step directions on how to conduct the session. Any handouts needed are included after the activity.

Note to Trainers. Denoted by a “notebook” graphic, these contain tips or helpful hints based on experience for facilitators, on how to teach the session, and extra resources that can be used for the session.

Tools for Trainers. The “Tools for Trainers” contain helpful examples or materials that trainers can use in sessions and can be adapted by the trainer to fit various audiences.

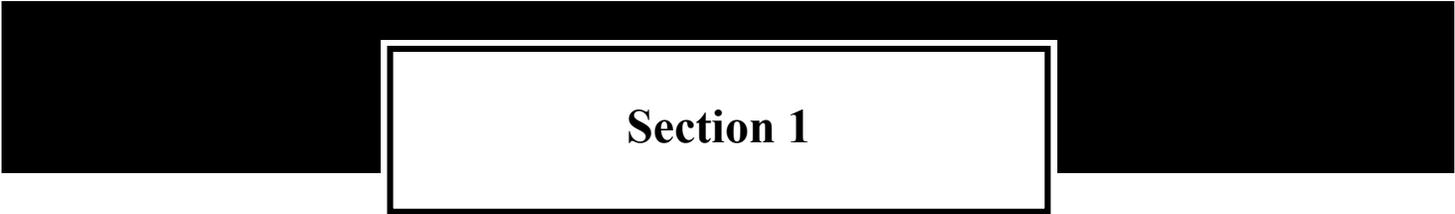
⁵ UNICEF, World Vision, Save the Children (USA) Malawi, and the Ministry of Women, Youth, and Community Services of Malawi. *Starting from Strengths, Community Care for Orphaned Children*. (Malawi: UNICEF, 1998).

References

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<http://www.unaids.org/publications/documents/persons/gipa-8.doc>.

Training Schedule: Section 1

Schedule	Day One	Day Two	Day Three	Day Four
	Registration <i>30 minutes</i>	Recap <i>30 minutes</i>	Recap <i>30 minutes</i>	Recap <i>30 minutes</i>
Session	The Power of Our Community Introductions, Goals, and Objectives Workshop Structure <i>1 hour 30 minutes</i>	Medical Support for People Living with HIV/AIDS (cont.) Common Illnesses Role-Play <i>1 hour 45 minutes</i>	Nutritional Needs for People Living with HIV/AIDS and Their Families We Are What We Eat <i>1 hour</i> Nutritional Needs for People Living with HIV/AIDS <i>1 hour</i>	Preparing for Goodbye Supporting People Living with HIV/AIDS <i>1 hour 30 minutes</i>
Break	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
Session	Breathe in Life, Breathe Out Trouble The Power of Our Community <i>1 hour 30 minutes</i>	Oral Rehydration Solution and Thermometer Use <i>1 hour</i> Seeking Medical Support from a Professional Service Provider Special Medical Concerns for People Living with HIV/AIDS <i>1 hour</i>	Social Support for People Living with HIV/AIDS and Their Families Small Groups on Social Issues <i>1 hour</i> Plenary on Social Issues <i>1 hour 30 minutes</i>	Supporting Orphans <i>1 hour 30 minutes</i>
Lunch	<i>1 hour</i>	<i>1 hour</i>	<i>1 hour</i>	<i>1 hour</i>
Session	Review from Section Two Review of HIV Transmission, Prevention, and Disease Progression <i>1 hour 30 minutes</i>	Strategies for Dealing with Health Professionals <i>45 minutes</i> Antiretrovirals <i>30 minutes</i>	Psychological Support for People Living with HIV/AIDS and Their Families People Living with HIV/AIDS Vignettes <i>1 hour 45 minutes</i>	Closing Evaluation <i>1 hour</i> String Spider Web and Closing Ceremony <i>1 hour</i>
Break	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
Session	The Life Tree Life Tree <i>1 hour 30 minutes</i> Medical Support for People Living with HIV/AIDS Common Illnesses Role-Play <i>1 hour</i>	Physical Support for People Living with HIV/AIDS and Their Families Caring for People Living with HIV/AIDS in the Home <i>1 hour 30 minutes</i>	<i>The previous session can be emotional. Trainers may want to have a counselor present and use the afternoon session for this purpose.</i>	
Evaluation	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
Total Time	<i>8 hours 45 minutes</i>	<i>8 hours 45 minutes</i>	<i>8 hours 30 minutes</i>	<i>6 hours 45 minutes</i>



Section 1

The Many Aspects of Home Care

Chapter 1

The Power of Our Community

“Dr. Sam I. Okware, Uganda’s Deputy Director of Medical Services, was not overstating when he said, ‘Here, nobody is born an individual. If an important person dies, it is not one individual dying; it is a community.’ As the man who pays the school fees for almost all the children of his home village, Dr. Okware’s obligations are much heavier than mine. But in a sense he was speaking for many of us when he remarked, sadly: ‘If I go, the whole village is gone’.”

OMARI HARUNA KOKOLE
ASSOCIATE DIRECTOR OF GLOBAL CULTURAL STUDIES
THE STATE UNIVERSITY OF NEW YORK AT BINGHAMTON

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Chapter 1: The Power of Our Community

Key Questions

- What are our expectations for this workshop?
- What have our communities done in the past to combat problems and crises?
- What can our communities do to care for people living with HIV/AIDS? To take care of orphans and vulnerable children?

Introduction

There were 3.5 million new HIV infections in sub-Saharan Africa in the year 2002, a rapidly growing epidemic throughout Eastern Europe and Central Asia and the continuing spread of HIV/AIDS throughout the rest of the world. It is therefore more important than ever for communities to develop strategies for the care and support of people living with HIV/AIDS and orphans and vulnerable children. In some cases, communities with HIV/AIDS programs have focused all of their efforts on prevention, while the needs of those living with the virus have gone largely unnoticed. With 42 million people living with HIV/AIDS as of December 2002, the needs of these members of the community can no longer be ignored.

People living with HIV/AIDS are doctors, teachers, health workers, extension workers, government officials, farmers, businesspeople, other skilled professionals, mothers, fathers, children, and grandparents. The loss of these vital members of the community has a debilitating impact on the development of every nation, every community. Devastating losses have been noted in agriculture, in education systems, in hospitals, and in all levels of the economy, as people living with HIV/AIDS are lost to illness and death. And yet many people struggle against discrimination in the workplace, and may lose their jobs, their benefits, and the respect of peers due to their HIV status. This stigma may make it more difficult for those who test positive to live openly with the virus, thus holding back prevention efforts and their own ability to remain well.

But perhaps most importantly, people living with HIV/AIDS are parents. They must make difficult decisions about revealing their HIV status to their partners, their families, and especially, to their children. Children, especially girls, may lose valuable time at school, at work, in the fields or family business to help care for sick family members. Families may become helplessly impoverished as incomes are lost, savings are channeled into health care, and the death of parents leaves children orphaned. These orphans may turn to crime or sex work to survive, or may migrate to the cities and become street children—abused, sometimes addicted, and desperately poor. They, in turn, become most at risk for new HIV infection.

This devastating cycle of illness, impoverishment, death, and orphanhood may make the situation of people living with HIV/AIDS and orphans and vulnerable children seem hopeless. Indeed, many communities have developed a fatalistic response to HIV/AIDS—after watching so many families and friends suffer, there is a feeling that nothing can be done to reverse the terrible toll HIV/AIDS has taken on their communities.

But something *can* be done. More and more, communities are coming together to strike back against HIV/AIDS. Using the kinship networks and extended family systems that have long been a part of their histories, community members are coming together to care for the sick, fight for the rights of people living with HIV/AIDS, develop systems to support orphans and vulnerable children, and continue prevention efforts. These areas are witnessing a reversal of some of the terrible trends of the disease, and they are realizing lower infection rates, higher levels of dignity among people living with HIV/AIDS and orphans and vulnerable children, and a re-assertion of the community culture that has sustained their people for many generations.



Note to Trainers—

At the beginning of any workshop, it is helpful to get an idea of what the participants expect to get out of the workshop, in order to make the experience a good and productive one for all involved. This will also help the facilitators to get to know the participants and the participants to get to know and be comfortable with each other. It is important to foster a sense of belonging within the group, and to establish a set of ground rules that all participants can agree to abide by for the duration of the workshop, and to establish the training setting as a safe and confidential place.

To begin a discussion on HIV/AIDS, the facilitator and participants must realize that everyone will not be immediately at ease discussing matters that have to do with sex, illness and dying, subjects that are uncomfortable, may be taboo, and are emotionally challenging. Just the act of recognizing the discomfort some may be feeling often helps to create a more comfortable climate and openness in the group.

The first substantive session, *The Power of Our Community*, sets the tone of hope and power that will characterize the rest of the workshop. Using inspired storytelling, participants think back to a time when their ancestors overcame a challenge, and envision that same strength and power moving through them to overcome the HIV/AIDS pandemic. Participants are reminded of this vision of their community throughout the workshop, and it becomes a source of strength and focus as they continue their HIV/AIDS work.

Chapter 1: The Power of Our Community

Objectives

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

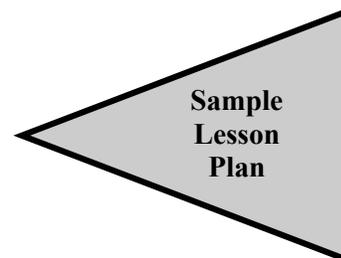
- List participants' expectations for the workshop
- List the group norms for the workshop
- Visualize a successful community response to HIV/AIDS
- Mentally release negative worries, problems, and pressures related to HIV/AIDS
- Demonstrate an empowerment technique to use when necessary to refocus positive energy on HIV/AIDS work
- Describe community responses to past challenges

Home Care: The Power of Our Community

Training Schedule: Section 1

Schedule	Day One	Day Two	Day Three	Day Four
	Registration <i>30 minutes</i>	Recap <i>30 minutes</i>	Recap <i>30 minutes</i>	Recap <i>30 minutes</i>
Session	The Power of Our Community Introductions, Goals, and Objectives Workshop Structure <i>1 hour 30 minutes</i>	Medical Support for People Living with HIV/AIDS (cont.) Common Illnesses Role-Play <i>1 hour 45 minutes</i>	Nutritional Needs for People Living with HIV/AIDS and Their Families We Are What We Eat <i>1 hour</i> Nutritional Needs for People Living with HIV/AIDS <i>1 hour</i>	Preparing for Goodbye Supporting People Living with HIV/AIDS <i>1 hour 30 minutes</i>
Break	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
Session	Breathe in Life, Breathe Out Trouble The Power of Our Community <i>1 hour 30 minutes</i>	Oral Rehydration Solution and Thermometer Use <i>1 hour</i> Seeking Medical Support from a Professional Service Provider Special Medical Concerns for People Living with HIV/AIDS <i>1 hour</i>	Social Support for People Living with HIV/AIDS and Their Families Small Groups on Social Issues <i>1 hour</i> Plenary on Social Issues <i>1 hour 30 minutes</i>	Supporting Orphans <i>1 hour 30 minutes</i>
Lunch	<i>1 hour</i>	<i>1 hour</i>	<i>1 hour</i>	<i>1 hour</i>
Session	Review from Section Two Review of HIV Transmission, Prevention, and Disease Progression <i>1 hour 30 minutes</i>	Strategies for Dealing with Health Professionals <i>45 minutes</i> Antiretrovirals <i>30 minutes</i>	Psychological Support for People Living with HIV/AIDS and Their Families People Living with HIV/AIDS Vignettes <i>1 hour 45 minutes</i>	Closing Evaluation <i>1 hour</i> String Spider Web and Closing Ceremony <i>1 hour</i>
Break	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
Session	The Life Tree Life Tree <i>1 hour 30 minutes</i> Medical Support for People Living with HIV/AIDS Common Illnesses Role-Play <i>1 hour</i>	Physical Support for People Living with HIV/AIDS and Their Families Caring for People Living with HIV/AIDS in the Home <i>1 hour 30 minutes</i>	<i>The previous session can be emotional. Trainers may want to have a counselor present and use the afternoon session for this purpose.</i>	
Evaluation	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
Total Time	<i>8 hours 45 minutes</i>	<i>8 hours 45 minutes</i>	<i>8 hours 30 minutes</i>	<i>6 hours 45 minutes</i>

Chapter 1: The Power of Our Community



Sample Lesson Plan

Time	Content	Methodology	Materials Needed	Evaluation
30 minutes	<p>Introductions and Opening of the Meeting</p> <p>Local practices should guide the opening of the meeting.</p>	<p>Official opening by community leader</p> <p>Introductions of all participants using peer interviews or optional activity</p>	<p>Possibly head table, flowers, water for the speakers, etc.</p>	<p>None</p>
20 minutes	<p>Expectations and Objectives</p>	<p>Facilitator asks participants to consider the single most important thing that they want to take from this workshop and compares these to the objectives</p>	<p>Colored paper</p> <p>Markers</p> <p>Tape</p> <p>Prepared signs on colored paper</p> <ul style="list-style-type: none"> - Expectations - Expectations Met 	<p>Participants' expectations will be used to evaluate the entire training workshop</p> <p>Facilitator(s) can move the written expectations into an "Expectations Met" section as each of the topics gets covered throughout the four days</p>
40 minutes	<p>Group Norms and Workshop Structure</p>	<p>Discussion of the three participant groups, brainstorming</p> <p>Establish group norms</p>	<p>Flipcharts with group sign-ups</p> <p>Blank flipcharts</p> <p>Markers</p> <p>Tape</p>	<p>Abiding by group norms throughout the workshop</p> <p>Active participation in one of three groups</p> <p>Norms established in "Workshop Structure"</p>

Time	Content	Methodology	Materials Needed	Evaluation
<i>10 minutes</i>	Breathe In Life, Breathe Out Trouble Visualization of positive future Release of problems and worries	Facilitator leads a group visualization in which participants breathe in their positive vision for the future of their community and breathe out all of the current problems of the community	None	Active participation in the activity Motivation to fully participate in the workshop
<i>1 hour 20 minutes</i>	The Power of Our Community	Participants meet in groups to discuss successful community responses to past challenges The entire group shares these stories	Flipchart Markers Tape	Active participation in the activity Motivation to fully participate in the workshop

Chapter 1: The Power of Our Community

Activities and Handouts for The Power of Our Community

- **Registration and Pre-Test/Post-Test Questionnaire
(see Appendix page I-377)**
- **Introductions**
- **Expectations and Objectives**
- **Workshop Structure**
- **Breathe In Life, Breathe Out Trouble**
- **The Power of Our Community**

Activity **Introductions**

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

- Name at least one other participant and one facilitator

Time allotted 30 minutes

Preparation Local practices should guide the opening of the meeting. You may want to start with an official opening by a community leader or a prayer from a religious leader. Depending on how well participants know each other, you may want have all participants give their names and tell something about themselves, or use suggested introductory activities below (or use your own activity). Facilitators should participate as well. Some of the optional activities require supplies such as candy, markers, paper, pens, etc.

Optional **Introductory** **activities**

1. Pass around a bowl of candy and let participants take a few pieces each. Then go around the circle and instruct participants to tell one thing about themselves for each piece of candy they took. (Those with a sweet tooth will have to reveal more about themselves!)
2. Create word cards with a general theme (could be HIV or something else relevant to the group), one word for every two participants and facilitators. Cut each word in half and mix up. Pass out a card to each participant. Have participants circulate and find the other half of their word. Participants then briefly interview each other. Regroup and have each word couple introduce each other to the group. (This may require more time, depending on the size of the group.)
3. Have participants break into groups of three and tell each other their names. Give each group a piece of paper and pen and tell them to come up with a list of as many things that they have in common as possible. (These could be physical features like eye color, likes or dislikes, socio-demographic characteristics such as number of children, etc.) Tell them they will have three minutes to do this. When the time is up, have each group introduce themselves and report back their list to the larger group. (This may work best with a group that already knows each other.)

Activity **Expectations and Objectives**

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

- Name one important outcome of the workshop for themselves
- Describe the purpose of the workshop
- List at least two of the objectives of the workshop

Time allotted 20 minutes

Preparation Have a flipchart with “Expectations” at the top and one with the workshop objectives written out. Make copies of the workshop schedule or a flipchart with the schedule. Markers.

Facilitation steps

1. Start by acknowledging that we all have our own hopes, ideas and expectations about what we wish to get out of this workshop. If you had to choose one thing that is most important for you to take away from this workshop, what would it be? Have each person give one expectation. Record each response on the “Expectations” flipchart.
2. After all the expectations have been listed, refer to the “Workshop Objectives” flipchart.
3. Next, compare it with the list of expectations to see if all the expectations will be covered in the process of meeting the objectives.
4. Have participants look at the workshop schedule (hand out copies if you have them). Summarize the expectations listed and indicate which sessions are likely to address these expectations.

Wrap-up If there are unexpected topics listed, use this time to negotiate with the participants, regarding a time or means to include that topic in the workshop if appropriate, or to clarify that something does not fall within the scope of this workshop. Tape the flipcharts from this session on the walls, so that people can refer to them throughout the workshop.

Activity Workshop Structure

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

- Set and agree on the norms that will guide the group’s work
- Set up the overall workshop norms
- Place themselves in a group of their choice
- Discuss ways to provide feedback to facilitators

Time allotted 40 minutes

Preparation Prepare three flipcharts with the names of groups (Climate Control Group, Learning Synthesis Group, and Feedback/Evaluation Group). Prepare cards in three colors and write on each: 1) One thing you have learned today; 2) One thing about which you need more explanation; 3) One suggestion or improvement. Create a “Parking Lot” flipchart. Blank flipcharts, markers.

Facilitation steps

1. Start by suggesting that HIV/AIDS is a difficult topic for many people to discuss. Some people may feel embarrassed or feel it taboo to discuss issues around sex and death, that inevitably arise when dealing with HIV/AIDS. Say that this is okay and that in this training we would like to create a safe place where we can discuss these issues. We will now spend some time laying out ground rules for this.
2. Hand out copies of the “Guidelines for Communicating About HIV/AIDS.” Give participants a chance to read through them and then suggest that, in this training, you would like them to abide by these guidelines. Answer any questions, and then ask if they can accept these guidelines as part of the ground rules. (If someone refuses to follow these guidelines, you may need to negotiate an acceptable compromise.)
3. Next, lead a group brainstorm regarding the ground rules for the workshop. Ask participants to suggest rules that will make the training a safe place where we can discuss things openly and support each other in the process. You will also need to agree upon some rules to make the workshop run well. List suggestions on a flipchart.
4. As participants offer suggestions, the facilitator seeks agreement from the rest of the group before noting the norm on the flipchart. Examples of norms the group might suggest include: we should all be on time, we should encourage everyone to participate, swear to confidentiality, respect each person’s opinion, allow for strong emotional reactions, etc.

5. The facilitator then introduces the three learning groups and explains the roles. The groups are: 1) Climate Control Group – this group will be responsible for keeping track of the feelings of the participants (e.g. when the group is tired, the Climate Control Group should suggest an energizing exercise); 2) Learning Synthesis Group – this group should prepare a summary of the day’s learning, keep track of any outside news that is relevant to the workshop, and report/review to the whole group the next morning; 3) Feedback/Evaluation Group – this group will distribute/collect the feedback cards, analyze them, and summarize the results for the group the next morning.
6. Explain the importance of feedback for the facilitators, and that the daily evaluation will give an opportunity to share learning and participant concerns with everybody.
7. Introduce the way the daily evaluation will be done with color-coded cards: 1) A green card on which participants will write one thing they have learned; 2) A pink card on which participants will write one thing on which they need more explanation; 3) A yellow card on which they will write one suggestion or improvement.
8. Finally, introduce the idea of a “Parking Lot” and hang a flipchart on the wall. This is a place where participants can post concerns, questions and ideas that did not get covered to their satisfaction during sessions (anonymously, if they want). The Parking Lot should be revisited regularly through the course of the workshop to answer the question/concerns, perhaps during the recap in the morning or at the end of the day.

Wrap-up

The facilitator invites the participants to sign up for the three groups. Each group should meet and assign tasks right there and then, during the break or at the end of the evening session. The tasks are: 1) the facilitator of discussion in the group; 2) the reporter; and 3) the timekeeper. The tasks/roles should change everyday; the facilitator encourages the participants to do so, so that each one gains experience in the facilitator, reporter, and timekeeper roles.

Guidelines for Communicating about HIV/AIDS⁶

These guidelines are intended to help ensure accurate, consistent, and positive HIV/AIDS content in talking, educating, or writing about HIV/AIDS, people living with HIV/AIDS, and orphans and vulnerable children. Words have power, and positive words can reframe the way we and our communities think about HIV/AIDS. Positive, non-judgmental messages, both in verbal and non-verbal gestures, can combat stigma and discrimination.

1. Refer to “people living with HIV/AIDS” or “HIV positive persons,” rather than “AIDS patients” or “AIDS sufferers.” “Patient” or “sufferer” implies that people living with HIV or AIDS are sick all of the time, which is not typically the case, plus it takes away hope. Also, refrain from referring to people living with HIV/AIDS as “PLWHA” or other abbreviations, as it dehumanizes individuals to be referred to as an abbreviation.
2. Do not use “AIDS victims,” rather use “people with AIDS.” “Victims” robs people with AIDS of dignity and hope, and inaccurately implies that they are passive about their health.
3. Instead of saying one is “dying from AIDS,” say they are “living with AIDS.” At any given time, we are all “dying” as that is the inevitable outcome of life. People with AIDS can live longer and richer lives, when living positively, and getting support for living positively. Referring to someone as “dying from AIDS” takes away hope.
4. When referring to children living with HIV/AIDS, use non-judgmental, specific wording, such as “the child was born infected,” rather than “the child was innocent, having been born infected.” Designating children as “innocent victims” implies that all other people infected with HIV are “guilty” for having become infected. Also, refrain from referring to orphans and vulnerable children as “OVC” or children affected by AIDS as “CABA” or other abbreviations, as it dehumanizes individuals to be referred to as an abbreviation.
5. Instead of referring to “high-risk groups” use “high-risk behavior.” No group is predisposed to HIV infection and should not be stereotyped as such. What individuals do causes infection, not who they are.
6. When using examples of people living with HIV/AIDS or situations around HIV as illustrations, do not use actual names of anyone in your community. Because of the stigma and discrimination surrounding HIV/AIDS, it is important to protect people living with HIV/AIDS and their families. Confidentiality should be paramount. Only the person living with HIV/AIDS has the right to decide to disclose his or her status to others.

⁶ Pickens, Judith and McKay, Malcolm. *The AIDS Ministry Handbook*. (Seattle: ANIN, 1997.)

Guidelines for Communicating about HIV/AIDS, continued

7. When using examples to teach about HIV issues, be sure to change the situation enough that the community **cannot** identify the persons involved. Often, community members are aware of each other's life situations, and unless the situation is disguised, individuals, families, and the community may be hurt.
8. When there are people living with HIV/AIDS who are open about their status, be the first to share a meal, put your arm around the person, show your acceptance and support through casual touch.
9. Reinforce at every opportunity that AIDS is caused by a virus like measles, colds, and many other diseases. Many illnesses are related to how we live and should not be a reason for judgment or discrimination (there are not "good" or "bad" diseases).

Activity **Breathe In Life, Breathe Out Trouble**

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

- Visualize a successful community response to HIV/AIDS
- Mentally release negative worries, problems, and pressures related to HIV/AIDS
- Demonstrate an empowerment technique to use when necessary to refocus positive energy on HIV/AIDS work

Time allotted 10 minutes

Preparation Arrange the chairs in a circle.

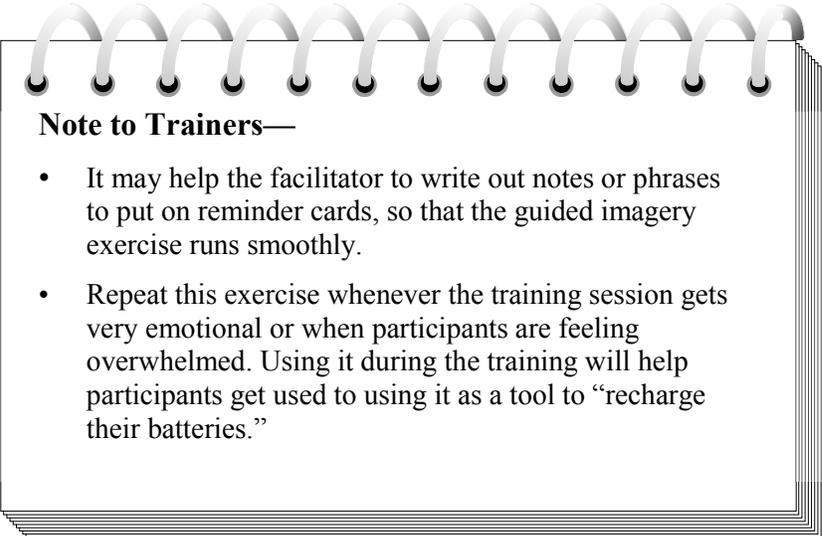
- Facilitation steps**
1. Suggest to the group that the purpose of our time together during this workshop is to create an effective community response to HIV/AIDS. We will be working together this week to address some of the most difficult impacts of HIV/AIDS on the community—the care of people living with HIV/AIDS in the home, the guidance and care of orphans and vulnerable children, and the many effects of HIV/AIDS on the life of the community. Suggest that each of us individually, as well as the community as a whole, has the power to make a positive contribution to this important community issue.
 2. Ask the participants to think about the many problems that HIV/AIDS has created in our families, our communities, and our nations. Suggest that they think about the various people in their own lives who have been touched by this disease and its effects. Allow a few silent moments for participants to remember those who have been affected by HIV/AIDS in their own lives.
 3. Suggest that working with the issue of HIV/AIDS can often be difficult, and it is important that those doing such work continually “recharge their batteries,” so that they can be strong for both their own sakes and for the people with whom they are working. This brief visualization exercise can be a powerful way to “recharge those batteries”—to help us to continually keep a positive image of our goal in mind, and to allow us to expel all of the negative thoughts and feelings that may be weighing us down.
 4. Ask participants to close their eyes. Ask them to imagine their community as they would wish to see it. This may be a fantasy image of the community—with no HIV/AIDS, no orphans, people living healthily and in harmony, and so on. They should not feel constrained by reality, but

should allow themselves to imagine everything that they would wish for their community. Allow a few moments for participants to silently visualize this happy, healthy community.

5. Next, suggest that participants take a deep breath. They should imagine that they are breathing in this beautiful life, this hope, this image of their communities. They should allow that breath to absolutely fill them, as if it is entering every particle of their being—their bodies, their minds, their souls. Allow everyone a chance to take in this deep breath. Ask them to hold it, and to retain that beautiful image of the community.
6. Then ask participants to breathe out, and to imagine that they are expelling from their bodies, their minds, their souls all of the negative issues associated with HIV/AIDS. They should imagine that all of the pain, the bad memories, the community problems, all of these things are leaving them completely—carried away on that exhaled breath.
7. Ask participants to do the exercise again a few more times with you. They breathe in a positive vision of the way they would like life to be, and they breathe out all of the pain and suffering that currently has a hold on the community. Breathe in life; breathe out trouble. Breathe in life; breathe out trouble....

Wrap-up

At the end of the session, suggest that participants pause to “Breathe In Life; Breathe Out Trouble” whenever they are feeling overwhelmed by the work associated with the fight against HIV/AIDS, or whenever they need an extra dose of power and energy. This can be their own personal weapon against HIV/AIDS—breathing in a positive image of a happy, healthy community, and breathing out all of the pain, trouble, and worry that HIV/AIDS has brought to the area.

A graphic of a spiral-bound notebook with a white cover and a silver spiral binding on the left side. The notebook is open, showing a white page with a black border. The text is written on this page.

Note to Trainers—

- It may help the facilitator to write out notes or phrases to put on reminder cards, so that the guided imagery exercise runs smoothly.
- Repeat this exercise whenever the training session gets very emotional or when participants are feeling overwhelmed. Using it during the training will help participants get used to using it as a tool to “recharge their batteries.”

Activity The Power of Our Community⁷

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

- Describe community responses to past challenges
- State an example of a successful community response to HIV/AIDS

Time allotted 1 hour 20 minutes

Preparation Arrange the chairs in a circle, leaving a small gap for the facilitator and a flipchart stand. Identify one clear wall in the training area on which participants' statements may be hung. Paper, pens.

Facilitation steps

1. Suggest that the group keep the positive vision of the community's future in mind as you move into this activity of the session.
2. Say that HIV/AIDS has taken an extraordinary toll on the people and institutions in our area, and ask them how AIDS has affected their community. Let them discuss the impacts for a few minutes. If the following issues are not mentioned, but are relevant to the community, you may want to remind the group that we have watched our loved ones and neighbors get sick and die, leaving numbers of orphans. We have watched as professionals like health workers, teachers, and government officials have died leaving their posts empty. Remind the group of the impact of HIV/AIDS on the development of the nation, as well as on the lives of each and every one of us.
3. HIV/AIDS has indeed wrecked havoc in our area, but suggest that there have been many such challenges to our community in the past. Our ancestors have met challenges great and small, and overcome these challenges, just as we must take it as our responsibility to meet and overcome the challenges posed by HIV/AIDS. Ask the participants to think about a time in the history of our community when we made extraordinary efforts to deal with a great challenge. What did our ancestors, neighbors, or we do to overcome this threat? Ask the participants to think about any stories that they may have been told by grandparents or parents, and to think back to such a time of trouble in the history of the community. Provide a few moments for all participants to think about this. (Given the great oral traditions of many cultures, stories might come from hundreds of years ago. Use a local example of a trying time.)

⁷ Adapted and reprinted with permission of Pact, Inc. *Tool #3: Appreciative Inquiry: Generating Hope in Community Response to HIV/AIDS*. (Washington, DC: Pact, Inc.).

4. Divide participants into groups of no more than four. Provide about 20 minutes for participants to tell these stories in detail. They need not have four different stories, but should think together about the history of their community, and discuss the ways that the community handled a difficult situation in the past.
5. When all groups appear to be finished, bring the large group back together. Invite participants to tell a few of their stories in detail. Many of the stories may be about the same situation, so allow other participants to add any comments as the stories are told.
6. Next, ask participants to think about their stories. What were the strengths, the personal or communal qualities that people showed in the stories that enabled them to overcome these challenges? Brainstorm some of these qualities on the flipchart. (Answers may include courage, selflessness, working together, and so on.)
7. Now ask participants to think about these qualities. What was the deep, life-giving force that was the source of these strengths and qualities? (Answers may include love for community, belief in the power of God, determination to provide children with a bright future, and so on.) Write these ideas on the flipchart.
8. Discuss the following points with the participants: *Given what we know about the strengths, qualities, and inner power of our community, what are our highest hopes for the future? Think about the vision that we just had for our community. What are the three most precious wishes we have for the future of our community?* Then provide participants with paper, and ask them to write these three most precious wishes on the paper.
9. Finally, invite participants to stand and read their three wishes to the group.
10. As participants read, have them state each wish in a strong, affirmative manner. They should begin each statement with “Our children WILL...” or “The community WILL...” (For example, if one of the wishes is for the community’s orphans to be provided with a good education and the prospects for a good job, the participant should say, “Our children will receive a good education and will be able to find a good job.”) Listening to all of these statements framed in such powerful terms can be a very encouraging experience for the group.

Wrap-up

At the end of the session, suggest that participants keep these wishes for the community in mind as a goal throughout the workshop. After break, use these wishes to frame their vision or mission. Later in the workshop, the group will specifically address these wishes, and create community action plans to achieve these goals. Invite participants to post their wish statements on the wall as they leave the training area for the break.

Chapter 2

The Life Tree

“Over the last ten years care needs of people living with HIV/AIDS have become better defined and well articulated by themselves, their families, and their communities. In the late eighties the founders of TASO in Uganda, adopted the slogan ‘living positively with HIV/AIDS’ and spearheaded the process of translating this concept in relation to living with HIV/AIDS in Africa. They were determined to change the predominantly negative attitude towards people with HIV/AIDS, which equated the diagnosis of AIDS to a death sentence. Later, as the reality of AIDS as a fatal condition became clear the need for dignified death became clear. TASO broadened its slogan to ‘living positively and dying with dignity’.”

—NOERINE KALEEBA, FOUNDING MEMBER
THE AIDS SERVICE ORGANIZATION (TASO), UGANDA

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Chapter 2: The Life Tree

Key Questions

- What are the specific needs of people living with HIV/AIDS and orphans and vulnerable children?
- What are some community interventions that may benefit people living with HIV/AIDS and orphans and vulnerable children?

I ntroduction

Perhaps the greatest strength of community members working together in the fight against HIV/AIDS is their own experience with the disease. Many families in every community have already dealt with HIV/AIDS-related illnesses or death of a relative or friend, and the powerful emotions associated with this experience often strengthen the commitment of the community to overcome this epidemic. In high-prevalence communities, it is important to tap into the positive attitudes, knowledge, and experience of community members who have grappled with the disease in their own lives.

Those who have experienced HIV/AIDS firsthand understand that it is not merely a health concern. While people living with HIV/AIDS may have a myriad of health needs, they are also still responsible for the same day-to-day functions in their lives and in the care of their children and extended families as before they were diagnosed. As such, people living with HIV/AIDS and orphans and vulnerable children still have the same needs as every other member of the community—food, shelter, comfort, meaningful work, spiritual expression, and so on. Care and support for people living with HIV/AIDS and orphans and vulnerable children must thus incorporate far more than home-based medical care.

The “Life Tree” session provides a framework through which participants may view the goals and components of supporting and caring for people living with HIV/AIDS and orphans and vulnerable children. Participants brainstorm the myriad of needs using a visual image called the “Life Tree.” This image then becomes the framework for all other sessions in the workshop.

Chapter 2: The Life Tree

O

bjectives

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

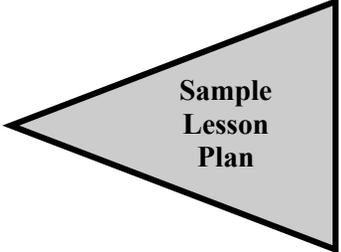
- List at least five categories of the needs of people living with HIV/AIDS
- Describe specific needs of people living with HIV/AIDS and possible community interventions to meet those needs
- Discuss the specific needs of orphans and vulnerable children and possible community interventions to meet those needs
- Describe the strengths of people living with HIV/AIDS and orphans and vulnerable children

Home Care: The Power of Our Community

Training Schedule: Section 1

Schedule	Day One	Day Two	Day Three	Day Four
	Registration <i>30 minutes</i>	Recap <i>30 minutes</i>	Recap <i>30 minutes</i>	Recap <i>30 minutes</i>
Session	The Power of Our Community Introductions, Goals, and Objectives Workshop Structure <i>1 hour 30 minutes</i>	Medical Support for People Living with HIV/AIDS (cont.) Common Illnesses Role-Play <i>1 hour 45 minutes</i>	Nutritional Needs for People Living with HIV/AIDS and Their Families We Are What We Eat <i>1 hour</i> Nutritional Needs for People Living with HIV/AIDS <i>1 hour</i>	Preparing for Goodbye Supporting People Living with HIV/AIDS <i>1 hour 30 minutes</i>
Break	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
Session	Breathe in Life, Breathe Out Trouble The Power of Our Community <i>1 hour 30 minutes</i>	Oral Rehydration Solution and Thermometer Use <i>1 hour</i> Seeking Medical Support from a Professional Service Provider Special Medical Concerns for People Living with HIV/AIDS <i>1 hour</i>	Social Support for People Living with HIV/AIDS and Their Families Small Groups on Social Issues <i>1 hour</i> Plenary on Social Issues <i>1 hour 30 minutes</i>	Supporting Orphans <i>1 hour 30 minutes</i>
Lunch	<i>1 hour</i>	<i>1 hour</i>	<i>1 hour</i>	<i>1 hour</i>
Session	Review from Section Two Review of HIV Transmission, Prevention, and Disease Progression <i>1 hour 30 minutes</i>	Strategies for Dealing with Health Professionals <i>45 minutes</i> Antiretrovirals <i>30 minutes</i>	Psychological Support for People Living with HIV/AIDS and Their Families People Living with HIV/AIDS Vignettes <i>1 hour 45 minutes</i>	Closing Evaluation <i>1 hour</i> String Spider Web and Closing Ceremony <i>1 hour</i>
Break	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
Session	The Life Tree Life Tree <i>1 hour 30 minutes</i> Medical Support for People Living with HIV/AIDS Common Illnesses Role-Play <i>1 hour</i>	Physical Support for People Living with HIV/AIDS and Their Families Caring for People Living with HIV/AIDS in the Home <i>1 hour 30 minutes</i>	<i>The previous session can be emotional. Trainers may want to have a counselor present and use the afternoon session for this purpose.</i>	
Evaluation	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
Total Time	<i>8 hours 45 minutes</i>	<i>8 hours 45 minutes</i>	<i>8 hours 30 minutes</i>	<i>6 hours 45 minutes</i>

Chapter 2: The Life Tree



Sample
Lesson
Plan

Sample Lesson Plan

Time	Content	Methodology	Materials Needed	Evaluation
<i>1 hour 30 minutes</i>	The Life Tree Visual presentation of the strengths and needs of people living with HIV/AIDS and their families	Using a “Life Tree” the size of one wall of the training room, participants brainstorm the strengths and needs of people living with HIV/AIDS and orphans and vulnerable children	Flipchart paper Markers Tape	Creation of “Life Tree” at the end of the session

Chapter 2: The Life Tree

Activities and Handouts for The Life Tree

- **The Life Tree**

Activity **The Life Tree**

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

- List at least five categories of needs for people living with HIV/AIDS
- Describe specific needs of people living with HIV/AIDS and possible community interventions to meet those needs
- Discuss the specific needs of orphans and vulnerable children and possible community interventions to meet those needs
- Describe the strengths of people living with HIV/AIDS and orphans and vulnerable children

Time allotted 1 hour 30 minutes

Preparation Arrange the participants' chairs in a semi-circle around a wall. Cover the wall with flipcharts taped together to form one wall-sized flipchart. Draw the outline of a tree on the wall-sized flipchart.

- Facilitation steps**
1. Say that now we will start to look at the specific needs and strengths of people living with HIV/AIDS and orphans and vulnerable children as we create the “Life Tree.”
 2. Explain that people living with HIV/AIDS have very similar needs, wants, and desires as those who are HIV negative. Although their lives have been permanently changed due to being diagnosed positive, they must still manage the day-to-day functions of their lives and build a future for themselves and their families. In addition, they must also cope with the realities of being HIV positive, and the impact that this new status will have on their lives, their children's lives, and the lives of all who know them. As we have seen from previous sessions, although people living with HIV/AIDS often feel completely alone, their problems are the community's problems. Working together, community members can support and assist people living with HIV/AIDS and orphans and vulnerable children when necessary, and attempt to lessen the impact that HIV/AIDS has on them, and the community as a whole. It is also important to empower these groups by encouraging and allowing them to use their own strengths, skills, and knowledge to help themselves, their families, and the community.
 3. State that the “Life Tree” exercise is meant to help us to visualize the many different needs of people living with HIV/AIDS and their children.

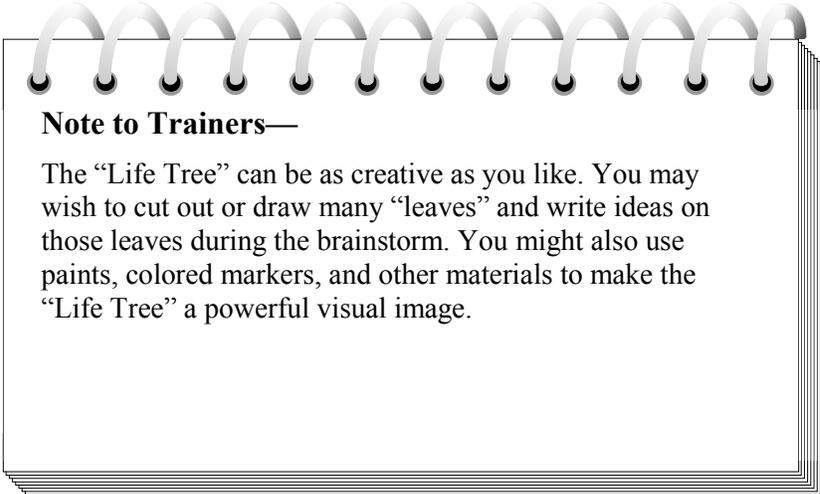
4. Write “People living with HIV/AIDS” at the base of the tree on the wall-sized flipchart. Ask participants to suggest some of the strengths and skills that people already possess that can help them in dealing with the added pressures of being HIV positive. Write these strengths on the trunk of the tree. (Examples might include patience, cheerfulness, business sense, intelligence, education, job skills, hope, etc.)
5. Next, ask participants to think about the many needs of people living with HIV/AIDS. As participants brainstorm these needs, write their ideas on the branches of the “Life Tree.” (See the graphic at the end of the chapter for an example.) Try to sort the needs into various groups—for example, physical needs, social needs, psychological needs, spiritual needs, medical needs, economic needs, and so forth. Use different branches for each group of needs.
6. When participants seem to have run out of ideas, write the names of the various groups of needs along the appropriate branches. Then, taking each of the “branches” in turn, ask leading questions to further brainstorm on the issues surrounding that group. For example, if you are talking about medical needs, and someone says that drugs are a medical need, you might ask questions about drugs. How does a person living with HIV/AIDS get the drugs he/she needs? They need an accessible health center. Write “accessible health center” on the branch. What does the health center need to have in place to be supportive of a person living with HIV/AIDS? The health center must stock appropriate drugs, have health services that address needs of people living with HIV/AIDS at all levels, and so on. Write each of the ideas on the branch. In this way, attempt to understand all of the issues surrounding each group before moving on to the next one.
7. Continue in this way until all possibilities in all groups are exhausted.
8. At this point, suggest that each of the many needs that we have identified may provide a clue as to how communities can actively work to support people living with HIV/AIDS and to reduce the impact of HIV/AIDS on the community. Remind participants that people living with HIV/AIDS have their own skills and strengths, as well. We are not suggesting that they are helpless and that communities must rise up to completely care for them. (In fact, it is important to empower people living with HIV/AIDS as much as possible to do things for themselves and keep active as part of positive living.) Rather, we are suggesting that community members can support people living with HIV/AIDS in meeting their own needs, and later, those community members can take a larger role if needed.
9. Ask participants to look at the many needs we have identified. What are some ways that community members can intervene to meet those needs or to support people living with HIV/AIDS in meeting those needs? Allow participants to share their suggestions. Do not spend too much time discussing each suggestion, but allow many ideas to be heard. Suggest that

we will return to these strategies in later sessions. (You may wish to have a second facilitator record the ideas on a sheet of paper to save for later.)

10. Next, sketch a smaller tree next to the “People Living with HIV/AIDS Life Tree.” Write “Orphans and Vulnerable Children” at the base of the tree.
11. Suggest that although we talked already about people living with HIV/AIDS worrying about meeting the needs of their children, we must not forget to deal specifically with the needs of these children apart from their parents. Orphans and vulnerable children may experience shock, distress, fear, economic hardship, and other issues in ways that are different from their parents. Their needs may also require different interventions than those needed by people living with HIV/AIDS.
12. Following Steps 4 - 9 above, brainstorm a “Life Tree” for the children of people living with HIV/AIDS. Remember to emphasize that children also have their own strengths and skills, and to write them in the trunk of the tree. Also briefly brainstorm proposed interventions to meet the needs of orphans and vulnerable children.

Wrap-up

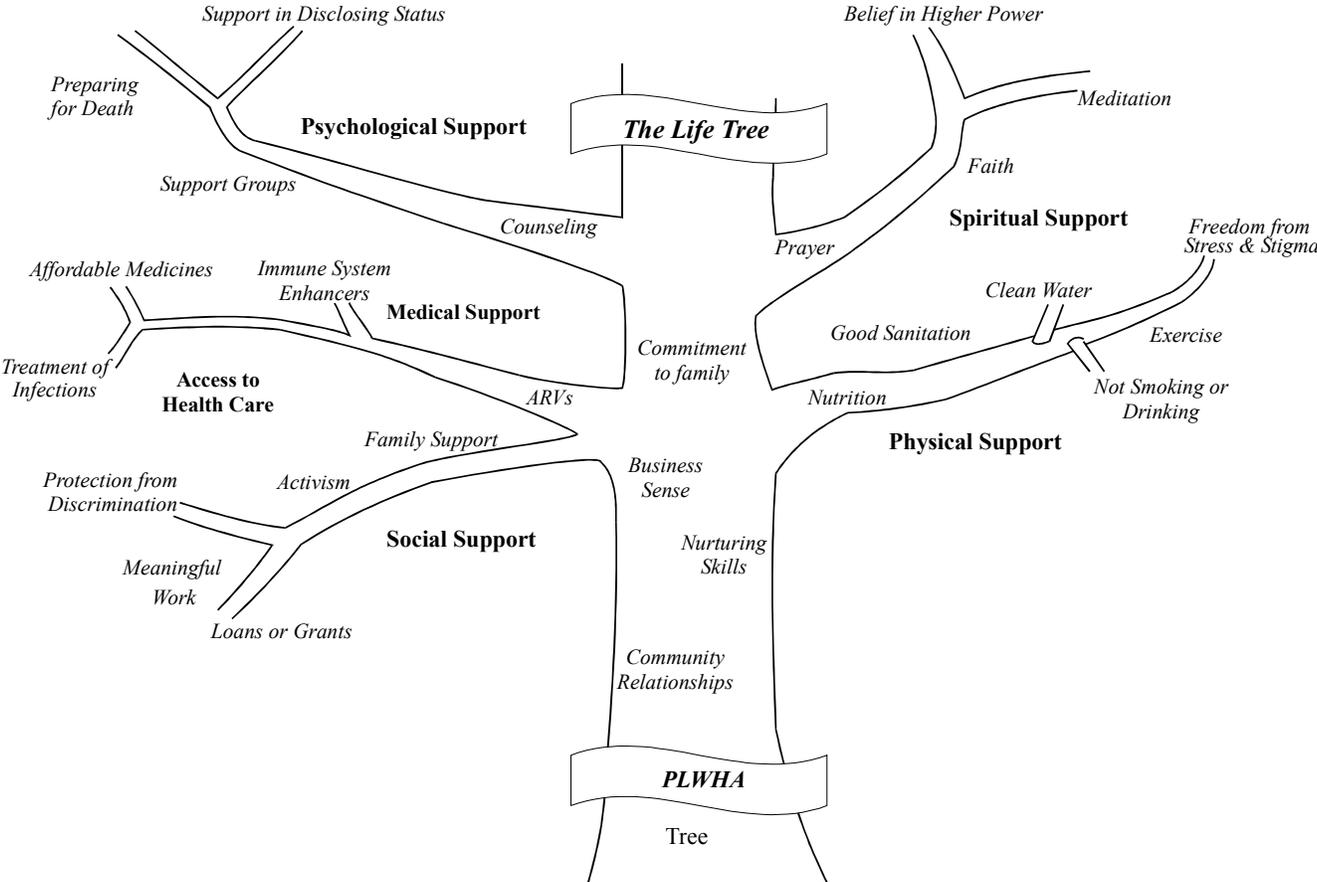
Summarize the session by saying that the strengths and resources of people living with HIV/AIDS and orphans and vulnerable children, combined with the resources and commitment of community members, can make an enormous impact in the way in which HIV/AIDS affects those who are HIV positive and the community as a whole. Say that we will refer to the “Life Tree” throughout the next few days as we begin to think in more detail about the specific issues at work in the lives of people living with HIV/AIDS and orphans and vulnerable children. We will begin by discussing psychological support.



Note to Trainers—

The “Life Tree” can be as creative as you like. You may wish to cut out or draw many “leaves” and write ideas on those leaves during the brainstorm. You might also use paints, colored markers, and other materials to make the “Life Tree” a powerful visual image.

The Life Tree—A Sample



Chapter 3

Medical Support for People Living with HIV/AIDS and Their Families

“Palliative care is a philosophy of care, which combines a range of therapies with the aim of achieving the best quality of life for patients (and their families) who are suffering from life-threatening and ultimately incurable diseases. Central to this philosophy is the belief that everyone has a right to be treated, and to die, with dignity and that the relief of pain – physical, emotional, spiritual, and social is a human right and essential to this process.”

—UNAIDS

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Chapter 3: Medical Support for People Living with HIV/AIDS and Their Families

Key Questions

- What are the symptoms of common illnesses that people living with HIV/AIDS might face?
- What are some strategies for managing such symptoms in the home?
- How can we know which symptoms require medical attention at a health center or hospital?
- Are there traditional remedies that we can use in the home to care for people living with HIV/AIDS?
- What are some specific skills needed by home care givers?

Introduction

Management of illness and alleviation of pain in the home are important aspects of the work of a caregiver. Often family members may be afraid to take on the role of caregiver—believing that only health care professionals are able to treat symptoms and manage pain. However, many of the symptoms that show up in the home can be treated using common sense home remedies.

This session draws on the prior experience of participants so that they will feel less intimidated by home care and more empowered by their own knowledge about treating illnesses in the home. In addition, it strives to bring in local knowledge and traditional healing, before adding more Westernized medical notions of care. Insight is provided regarding the appropriate time to seek medical attention.

The following illnesses and symptoms are discussed in this chapter—

- Anxiety and depression
- Coughing and difficulty in breathing
- Diarrhea
- Fever
- Genital problems
- Mental confusion and dementia
- Mouth and throat problems
- Nausea and vomiting
- Nutrition problems
- Pain
- Skin problems
- Tiredness and weakness

There is a final section on specific skills useful to caregivers, both on making and administering oral rehydration solution (ORS) and using a thermometer to take one's temperature.

Chapter 3: Medical Support for People Living with HIV/AIDS and Their Families

Objectives

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

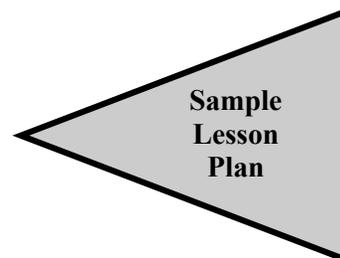
- Describe symptoms of common illnesses
- Suggest strategies for managing such symptoms in the home
- Identify symptoms that require medical attention or referral to a local health center
- State the correct procedure for making ORS
- Demonstrate the correct method for taking and reading someone's temperature

Home Care: The Power of Our Community

Training Schedule: Section 1

Schedule	Day One	Day Two	Day Three	Day Four
	Registration <i>30 minutes</i>	Recap <i>30 minutes</i>	Recap <i>30 minutes</i>	Recap <i>30 minutes</i>
Session	The Power of Our Community Introductions, Goals, and Objectives Workshop Structure <i>1 hour 30 minutes</i>	Medical Support for People Living with HIV/AIDS (cont.) Common Illnesses Role-Play <i>1 hour 45 minutes</i>	Nutritional Needs for People Living with HIV/AIDS and Their Families We Are What We Eat <i>1 hour</i> Nutritional Needs for People Living with HIV/AIDS <i>1 hour</i>	Preparing for Goodbye Supporting People Living with HIV/AIDS <i>1 hour 30 minutes</i>
Break	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
Session	Breathe in Life, Breathe Out Trouble The Power of Our Community <i>1 hour 30 minutes</i>	Oral Rehydration Solution and Thermometer Use <i>1 hour</i> Seeking Medical Support from a Professional Service Provider Special Medical Concerns for People Living with HIV/AIDS <i>1 hour</i>	Social Support for People Living with HIV/AIDS and Their Families Small Groups on Social Issues <i>1 hour</i> Plenary on Social Issues <i>1 hour 30 minutes</i>	Supporting Orphans <i>1 hour 30 minutes</i>
Lunch	<i>1 hour</i>	<i>1 hour</i>	<i>1 hour</i>	<i>1 hour</i>
Session	Review from Section Two Review of HIV Transmission, Prevention, and Disease Progression <i>1 hour 30 minutes</i>	Strategies for Dealing with Health Professionals <i>45 minutes</i> Antiretrovirals <i>30 minutes</i>	Psychological Support for People Living with HIV/AIDS and Their Families People Living with HIV/AIDS Vignettes <i>1 hour 45 minutes</i>	Closing Evaluation <i>1 hour</i> String Spider Web and Closing Ceremony <i>1 hour</i>
Break	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
Session	The Life Tree Life Tree <i>1 hour 30 minutes</i> Medical Support for People Living with HIV/AIDS Common Illnesses Role-Play <i>1 hour</i>	Physical Support for People Living with HIV/AIDS and Their Families Caring for People Living with HIV/AIDS in the Home <i>1 hour 30 minutes</i>	<i>The previous session can be emotional. Trainers may want to have a counselor present and use the afternoon session for this purpose.</i>	
Evaluation	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
Total Time	<i>8 hours 45 minutes</i>	<i>8 hours 45 minutes</i>	<i>8 hours 30 minutes</i>	<i>6 hours 45 minutes</i>

Chapter 3: Medical Support for People Living with HIV/AIDS and Their Families



Sample Lesson Plan

Time	Content	Methodology	Materials Needed	Evaluation
2 hours	<p>Common Illnesses Role-Plays</p> <p>Home remedies, traditional remedies, and medical strategies to deal with common illnesses in the home</p>	<p>Facilitator prepares several participants to role-play the suffering of a person living with HIV/AIDS from particular symptoms</p> <p>Participants discuss possible strategies for helping the person living with HIV/AIDS, using home remedies, traditional solutions, and medical strategies</p>	<p>Prepared role-plays, some with props</p> <p>Flipchart Paper</p> <p>Markers</p> <p>Tape</p> <p>Handouts of suggested responses to common illnesses</p>	<p>Active participation in the exercise</p> <p>Strategies for caring for common illnesses</p>
1 hour	<p>Oral Rehydration Solution and Thermometer Use</p>	<p>Discuss where to find ORS packets or demonstrate how to make ORS, taking and reading temperature, then participants practice the skills</p>	<p>Thermometer(s)—at least one as a sample, or one for each participant; a locally used bottle or container that holds 1 liter of liquid, a large bowl, a teaspoon, clean water, salt and sugar. Copies of “Making ORS” handout</p>	<p>Observed correct mixing of ORS, or correctly stating the steps according to checklist (handout), and correct steps of taking and reading temperature</p>

Chapter 3: Medical Support for People Living with HIV/AIDS and Their Families

Activities and Handouts for Medical Support for People Living with HIV/AIDS

- **Common Illnesses Role-Plays**
- **Oral Rehydration Solution and Thermometer Use**

Activity **Common Illnesses Role-Plays**

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

- Describe symptoms of common illnesses
- Suggest strategies for managing such symptoms in the home
- Identify symptoms that require medical attention or referral to a local health center

Time allotted 2 hours

Preparation It is important to choose participants to perform in the role-plays and to work with them at least a day before this session. Be sure to rehearse each role-play once or twice before this session to ensure that appropriate symptoms are being described by each participant.

As there are many different illnesses described in the “Tools for Trainers” at the end of this chapter, the facilitator(s) will need to choose the most important topics (diarrhea, fever and cough, at the minimum) to be covered in the session, and perhaps provide handouts for all others.

Some of the props or learning aids recommended for this session include: thermometer(s)—at least one as a sample, or one for every participant if possible, samples of ORS, and samples of locally-made toothbrushes, toothpaste, or traditional mouth and teeth cleaners. The following session will demonstrate how to make ORS at home and how to use a thermometer.

Facilitation steps

1. Say that we will now continue to discuss the physical and medical needs of people living with HIV/AIDS. Say that when most people think of home care, they picture caring for particular illnesses in the home. As we know from our discussions up to this point, home care is a much more comprehensive topic, and it covers much more than management of symptoms. Nevertheless, management of illness and alleviation of pain in the home are important aspects of the work of a caregiver, and we will spend the next two sessions looking at these topics in greater depth.
2. Remind the group that it is not necessary for caregivers to have a degree in medicine to provide good care in the home. Often, people are afraid to become involved in home care because they fear that they are not qualified to help people living with HIV/AIDS with their medical needs. In reality, some “common sense” wisdom, along with a bit of special instruction regarding what to look for and when to seek medical attention, is often enough preparation for most home care situations.

3. Say that we have all had to deal with illness in the home in the past. Whether it was taking care of our children when they became sick, assisting with the care of older relatives, or even managing our own illnesses, we have all been involved already in home care in one way or another. Perhaps some of us are even involved in the care of people living with HIV/AIDS at this time. So although we may not be aware of it, we already possess a great deal of knowledge regarding the management of illness in the home. Suggest that we are going to explore that knowledge in this session. Ask participants for examples from their personal experiences.
4. Ask if anyone knows what a “symptom” is, and have her/him explain the definition to the group.
 - A *symptom* is what a person who is ill complains of (that is, what hurts or what is not normal in their body), as opposed to a *sign* that a caregiver can observe.
5. Indicate that we are going to observe a number of “patients” complaining of a variety of different illnesses. For each patient, participants should—
 - Ask any questions necessary to ascertain what symptoms the patient is experiencing
 - Suggest ways to alleviate or treat the symptoms, using any personal, local, and/or traditional knowledge they might possess about these symptoms
 - Attempt to figure out what the underlying cause of those symptoms might be
 - Suggest the appropriate time to seek professional medical treatment
6. Invite the first participant “actor” to come forward and begin his or her prepared role-play. After the participant has acted out his or her symptoms, invite all participants to ask him or her questions, to which he or she should respond in character.
7. Next, ask participants what they would do if they were on a home care visit and a person living with HIV/AIDS was exhibiting these symptoms or if the person’s family was asking what to do in such a case. List all ideas on a flipchart as participants respond. You may also wish to ask what a traditional healer might do to treat such symptoms. List these ideas on the flipchart as well.
8. After participants have exhausted all ideas, validate those items on the list that are recommended for treatment of symptoms. (See suggested “Management of Symptoms” in the “Tools for Trainers” section at the end

of this chapter.) If some items on the list are clearly *not* recommended as treatment, discuss them frankly and explain why it is not a good idea to treat the symptoms in this manner.

9. Next, ask participants what the causes of such symptoms might be. List all of their ideas on a flipchart, before making any clarifications.
10. Lastly, ask participants to suggest when it would be most appropriate to refer this patient to a health center or other professional health worker. What symptoms might occur that would make you consider seeing a doctor or health center? Would anything else compel you to seek medical attention? (Whenever possible, ask the person doing that role-play to act out some of the symptoms that might indicate the need for professional medical attention.) List all of the participants' ideas, and clarify using the information provided in the "Tools for Trainers" section.
11. Continue Steps 5-9 for the rest of the illnesses you wish to cover in this session.

Wrap-up

When summarizing this session, you might wish to suggest that there are perhaps two most important things to remember when providing home-based medical care. They are: 1) what you know, and 2) what you do not know. Caregivers who are clear on their own strengths and limitations will serve their patients well. Pretending to know more than you do can lead to bad advice and may keep patients from getting proper medical attention when they need it.

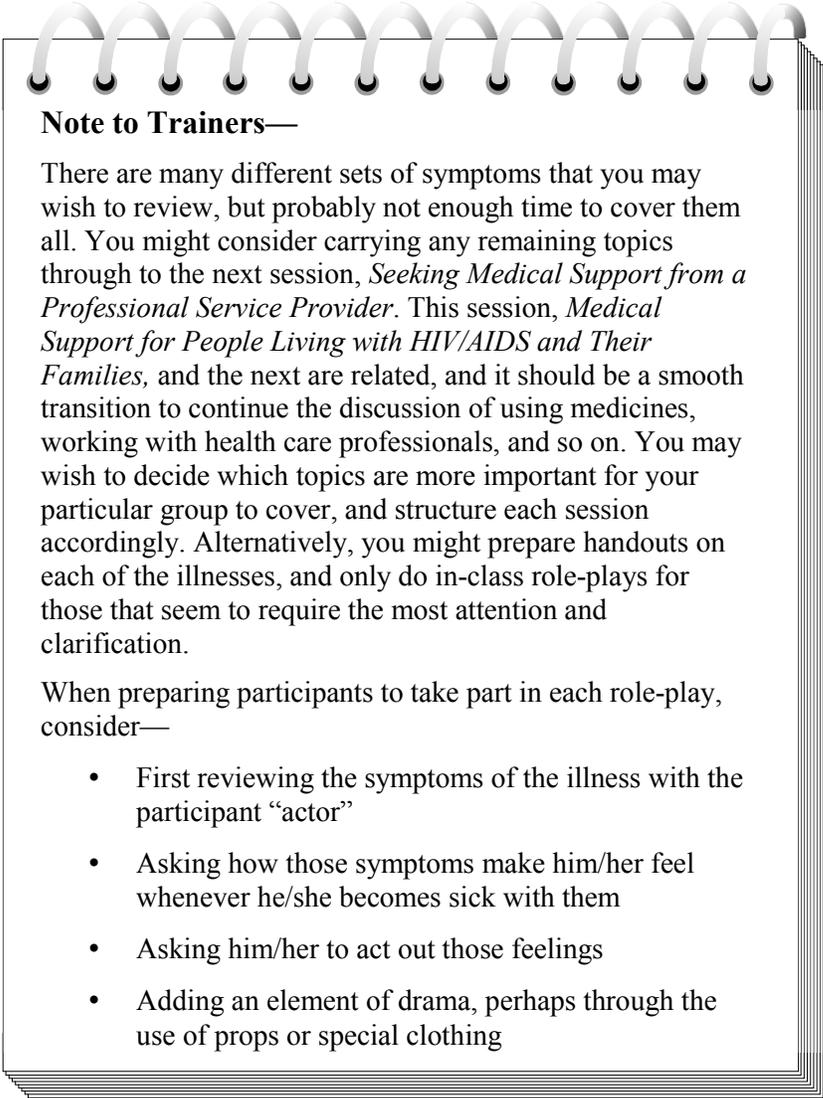
You may also wish to provide handouts on all of the illnesses we have reviewed in this session. If you choose to distribute handouts for illnesses that were not covered, you might wish to take a few minutes to review each of them. Alternatively, suggest to the participants that you will use the first part of the next session to finish this exercise before progressing on to a discussion of the proper uses of medicines.

References

The “Tools for Trainers” section for this chapter was adapted with permission from the World Health Organization. *AIDS Home Care Handbook*. (Geneva: World Health Organization, 1993).

UNAIDS. *AIDS: Palliative Care*. UNAIDS Technical Update. (Geneva: UNAIDS, 2000).

Werner, David and Bower, Bill. *Helping Health Workers Learn*. (Palo Alto: The Hesperian Foundation, 1995).

A graphic of a spiral-bound notebook with a white cover and a silver spiral binding on the left side. The notebook is open to a page with a white background and a thin black border. The text is written in a black serif font.

Note to Trainers—

There are many different sets of symptoms that you may wish to review, but probably not enough time to cover them all. You might consider carrying any remaining topics through to the next session, *Seeking Medical Support from a Professional Service Provider*. This session, *Medical Support for People Living with HIV/AIDS and Their Families*, and the next are related, and it should be a smooth transition to continue the discussion of using medicines, working with health care professionals, and so on. You may wish to decide which topics are more important for your particular group to cover, and structure each session accordingly. Alternatively, you might prepare handouts on each of the illnesses, and only do in-class role-plays for those that seem to require the most attention and clarification.

When preparing participants to take part in each role-play, consider—

- First reviewing the symptoms of the illness with the participant “actor”
- Asking how those symptoms make him/her feel whenever he/she becomes sick with them
- Asking him/her to act out those feelings
- Adding an element of drama, perhaps through the use of props or special clothing

Activity **Oral Rehydration Solution and Thermometer Use⁸**

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

- Correctly state or demonstrate how to make oral rehydration solution (ORS)
- Read a thermometer correctly

Time allotted 1 hour

Preparation This lesson follows directly on the “Common Illnesses Role-Plays” and should help caregivers build some competency-based skills that will improve the quality of their care. Place a table in the front of the room on which you can demonstrate the mixing of ORS. Learning aids recommended for this session include: thermometer(s)—at least one as a sample, or one for every participant if possible, a locally used bottle or container that holds one liter of liquid, a large bowl, a teaspoon, clean water, salt, and sugar.

Facilitation steps

1. Say that we will now learn some practical skills to use in caring for people living with HIV/AIDS. As caregivers, we may use these skills ourselves or we may want to teach them to families of people living with HIV/AIDS. Practice is needed to become competent at performing these skills.
2. Say that as we learned in the last session, one of the most common illnesses that people living with HIV/AIDS experience is diarrhea. They may have diarrhea over long periods of time, and one of the most dangerous aspects of diarrhea is the dehydration that may result from it. Signs of dehydration include feeling irritable or lethargic or if the skin goes back slowly when pinched. Urination will decrease in volume and frequency and its odor will become stronger and unpleasant. It is important that anyone suffering from diarrhea get enough liquids to make up for water lost in their stools. It is key that the caregiver knows when the situation is too dangerous and referral to health professionals is needed.

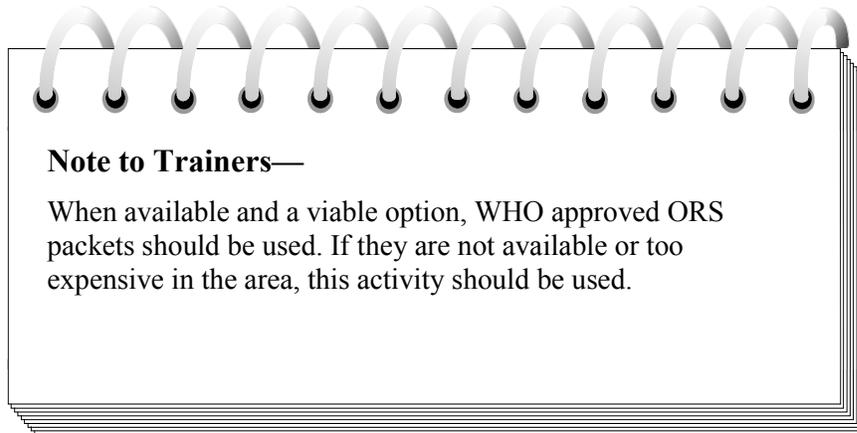
⁸ Werner, David with Thuman, Carol and Maxwell, Jane. *Where There Is No Doctor*. (Palo Alto: The Hesperian Foundation, 1995).

3. Ask if anyone knows the recipe for ORS. If a participant volunteers, have them tell the other participants verbally. If they state the process correctly (see the “Making Oral Rehydration Solution” handout on page 3-51), have them come up to the table and demonstrate making ORS for the group. (If no one volunteers, you will need to demonstrate how to do it.)
4. After the demonstration, ask if someone else would like to come up and try making it. You may have time for several participants to try it, or you may just ask them to state the steps verbally. Continue this until you are sure that everyone understands the process.
5. Next, say that people living with HIV/AIDS often have fevers. Ask participants if anyone knows how to tell if someone has a fever. They should say that you can put the back of one of your hands on the person’s forehead, while putting the back of the other hand on your own forehead, and compare the level of warmth. This is useful, but not very accurate, and sometimes it is important to be able to measure fever carefully and monitor it over time. For this, one needs a thermometer, a small tool used to measure temperature.
6. At this point, bring out the thermometer(s) and distribute to participants or pass it around if it is the only one. Types of thermometers vary, but this exercise is based on using a mercury thermometer, either Celsius or Fahrenheit. If you have no thermometer, distribute copies of the “Thermometer” handout on page 3-50. Ask if anyone knows what is the normal temperature for the human body (98.6 °F or 37 °C). Ask participants to find that point on the thermometer.
7. Have participants now look at the ends of the thermometer. Note that one end has a bulb where the mercury sits. Say that to accurately take someone’s temperature, you must first shake the thermometer, by holding the end away from the bulb, to make the mercury retract into the bulb, so that it is below 35 °C (or 94 °F). This resets the thermometer from any previous reading. Demonstrate shaking and have participants try it.
8. After everyone has shaken their thermometers, say that to take a temperature, you put the thermometer under the tongue of the person who is ill. It is important to do this gently as people living with HIV/AIDS often have sore mouths. They should gently hold it under their tongue, with the mouth closed, for three to four minutes. (Be sure they do not bite down hard on it!) (Alternatively, you can take one’s temperature by placing the thermometer in the armpit and holding the arm down for three minutes, but this will register a bit lower than actual temperature.)

9. After three minutes, slide the thermometer out of the mouth and look carefully at the line of mercury and the number at which it stops. (Sometimes you have to move the thermometer slightly in order to see the mercury line clearly.) This is the person's temperature. When a person is ill, the temperature should be taken four times a day and recorded. Write down the number on a paper by the person's bed with the time and date, in order to keep a record.

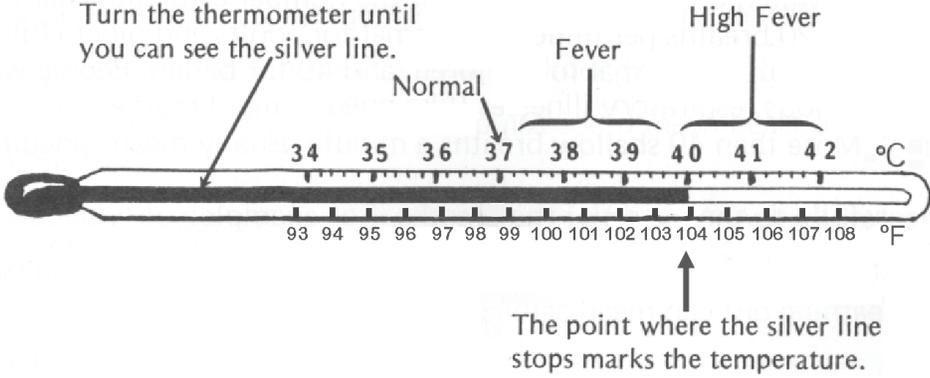
Wrap-up

Have participants practice taking their own temperature. If there is only one thermometer, you will need to demonstrate taking your own temperature and pass around the thermometer so that all participants can read it. Make sure every participant can read the thermometer correctly. Point out and demonstrate that you should wash the thermometer with soap and warm water, or wipe it down with alcohol, every time it is used.



Thermometer⁹

How to read the thermometer



⁹ Ibid.

Making Oral Rehydration Solution

Oral rehydration solution (ORS) has been used all over the world to reduce illness and death due to diarrhea. In many areas, packets of ORS salts are available at health centers and in pharmacies, and should be prepared according to the directions on the packet. It may be much less expensive and quicker to learn to make it at home according to the recipe below. It is important that the solution is made with clean water and tastes no more salty than tears. This recipe can be used as a checklist to verify the competency of those performing the skill.

1. Wash your hands with soap and water.
2. Get a large bowl, a bottle, or container that holds one liter of liquid, and a teaspoon. Make sure they are both clean and dry.
3. Fill the bottle with clean water (boil water for 10 minutes and cool, if necessary) and pour it into the bowl.
4. Add eight level teaspoons of sugar (you can also use honey or molasses).
5. Add one level teaspoon of salt.
6. Stir until all the salt and sugar are dissolved.
7. Taste the solution and make sure that it is no saltier than tears.
8. Pour into a clean and dry cup.

Give the dehydrated person sips of this drink every five minutes. A grown person may need as much as three liters of ORS a day while experiencing diarrhea, a small child may need one liter. You may need to feed it to the person with a spoon if s/he is very weak. You may also add a half a cup of orange juice, green coconut water, or banana to provide potassium. When the patient can eat or drink normally, encourage him/her to drink (clean) water.

Common Symptoms— Anxiety and Depression

Characteristics of Anxiety—

- Loss of appetite
- Shortness of breath
- Trembling
- A sensation that the heart is pounding
- Sweating
- Tingling sensations, for example in the hands
- Feeling faint
- Difficulty sleeping
- A feeling of being out of control
- Difficulty concentrating
- Feeling very worried
- Feeling jumpy

Characteristics of Depression—

- Feelings of hopelessness
- Feeling tired and generally without energy
- Inability to find pleasure and the sense that everything is a chore
- Irritability
- Inability to concentrate and poor memory
- Waking up early in the morning or having trouble getting to sleep at night
- Eating too much or being unable to eat
- Poor judgment
- Sadness, crying
- Thoughts, plans, or attempts at suicide

What to Do in the Home—

- Treatment of anxiety and depression varies from culture to culture.
- In many communities, support for such problems is often provided by trusted elders in the family, through traditional systems, and by religious institutions.
- Revisit the discussion of *Psychological Support for People Living with HIV/AIDS and Orphans and Vulnerable Children* found in Chapter 8. Some of these steps can be useful for helping people living with HIV/AIDS to cope with depression or anxiety in the home. You can give people an opportunity to progress through the stages of grief simply by encouraging them to talk, and then by listening to them. It is not expected that you will have all of the answers; it is enough that you are there. Encourage them to express their thoughts and feelings.
- Help people living with HIV/AIDS and their families to find local support groups. It can be especially comforting and empowering to meet with others who may be dealing with the same issues and feelings.
- Steady diet and sleep patterns should be encouraged.
- Daily vigorous exercise – if possible – is a proven anti-depressant.
- If no support group exists in your community, consider forming one. Work with other caregivers to bring together people living with HIV/AIDS and their families for discussions, meals together, meetings on income generation or other concerns, and so on.
- It can be helpful for people living with HIV/AIDS and orphans and vulnerable children to meet with a professional counselor or with a spiritual advisor.
- When people become ill, help them plan activities on a daily or weekly basis. This can help them to fight the sense that their life is out of control or that they cannot accomplish anything. The important point here is that these plans should be realistic in terms of the person’s abilities and time.
- Encourage people who are ill and their family members to learn how to relax. This is a skill that takes time to master, but it can be very helpful. It is good to have both physical and mental relaxation activities.
- Although alcohol and other “drugs” may seem to help people relax, if used in excess they may actually result in a worsening of the anxiety and depression over time. Therefore, alcohol and other “drugs” should be avoided during times of depression.
- The use of medicines for treating anxiety or depression can be very helpful and may make an enormous difference to someone’s ability to function. However, such medicines can have side effects so their use should be carefully supervised.
- Lastly, sometimes anxiety and depression can be alleviated by working with people around issues of death and dying. See Chapter 9, *Preparing for Goodbye*.

Possible Causes of Anxiety and Depression—

- The diagnosis of HIV infection or AIDS is a crisis for the person, for their families, and for their friends. When people receive the news that they are HIV positive, they can go through a number of stages, as described in Chapter 8, *Psychological Support for People Living with HIV/AIDS and Their Families*. How they react and behave after this initial shock depends on many things, for example how they have dealt with stresses in their life before and what types of support they can get for emotional and social problems.
- When someone is infected with HIV or has AIDS they experience many losses in a very short period of time. Examples of this might include loss of health, loss of physical beauty, loss of job or ability to function in the community, loss of mobility, loss of eyesight. For all these losses a person must grieve and will at times feel very unhappy.
- Anxiety and depression are normal if someone has been told that they are HIV positive or have been diagnosed with AIDS, and they are trying to cope with it. It is when these feelings are very intense or last a long time, so that normal daily activities are interrupted, that they are considered abnormal.
- The physical symptoms experienced with either anxiety or depression can be dramatic and may lead people to think that they are physically ill. Learning to recognize their own symptoms allows people to distinguish between those which are caused by anxiety or depression and those that may indicate the onset of an infection or illness. Possible explanations for symptoms which resemble those of either anxiety or depression include: infections, side effects of some medicines, and malnutrition.

When to Seek Medical Treatment for Anxiety and Depression—

- The person living with HIV/AIDS or their families believe that the anxiety or depression is severe enough that the person may commit suicide, otherwise harm themselves, or harm someone else.
- There is a prolonged disruption in the person living with HIV/AIDS ability to function, such as in sleeping, eating, relating to their family or friends, or going about their daily life, that is not explained by any physical disability they may have.
- Where medical treatment is readily available, a criterion of “two weeks” disruption of normal activities and life is used to determine when a patient should seek treatment.
- Traditional healers can be effective in treating anxiety and depression with herbs, counseling, or a combination of the two.

Common Symptoms— Coughing and Difficulty in Breathing

Symptoms—

- Chronic cough
- Shortness of breath
- Chest pains
- Increased production of mucus (also called sputum)

What to Do in the Home—

- Keep the person active by walking about, turning in bed, and sitting up. This encourages the lungs to drain.
- Other measures that encourage drainage of the lungs include massage or gentle patting on the back over the lungs. This can be done with the person lying face down, his/her head turned to one side resting on a towel to absorb the mucus. Someone in the home can do this, especially for younger children.
- If pain is felt in the chest or ribs during coughing, a pillow or hand should be held tightly over the area that hurts when coughing. This makes the cough less painful.
- During the day it may be beneficial to cough and clear the lungs at least four times a day. Even though coughing may cause discomfort, it is an important way to clean the lungs of the accumulated mucus and disease-causing bacteria.
- Thus, anyone with lung problems should be encouraged to cough. Several points are worth mentioning—
 - The bacteria or infectious agents in the person's sputum can be passed to other people through the air, especially when coughing. When anyone is coughing, they should always cover their mouth with their arm or with a cloth, which can be cleaned or disposed of.
 - All homes and other places where people meet should be ventilated—make sure there is a way in and a way out for fresh air.
- An irritating cough can sometimes be relieved with safe cough remedies, for example—
 - Soothe the throat by drinking tea with sugar or honey.
 - Use a safe, homemade cough syrup. Throughout the world families and herbalists have suggestions for things that soothe coughs.
 - Commercial remedies may also be useful although they are often expensive and usually work no better than home remedies.

Common Symptoms—Coughing and Difficulty in Breathing, continued

- A constant cough can be very tiring and interfere with a person's rest. If coughing keeps someone from being able to sleep at night a cough suppressant can be prescribed. It is important to cough, so do not encourage the use of cough suppressants during the day. They should only be used at night to allow someone to rest.
- Pain in the chest without signs of infection, and difficulty in breathing, are common problems in people with AIDS. Very often the cause is not known. Warm compresses (pads or folded towels) to the area where the discomfort seems to be centered may be helpful. Medicines like aspirin or paracetamol may be useful at times. Paracetamol is safer for children. It is important that the things done to help relieve the pain will also help someone in their efforts to keep active, moving, and coughing.
- When someone is experiencing difficulty in breathing, the following advice might help—
 - Lie with pillows under the head, or with the head of the bed raised on blocks.
 - Sit leaning forward with the elbows on the knees or on a low table.
 - Have someone else there. Difficulty in breathing can be very frightening. Coughing “spells” can sometimes be alleviated by distractions such as games and stories.
- In children with respiratory problems, it is important to clear the nose if it is congested, and especially if the congestion interferes with the ability to eat or to be breast-fed. Dry or thick, sticky mucus can be softened and removed with a wick or twisted piece of cloth moistened in clean salt water (a quarter of a teaspoonful in a cup of clean water).
- In a lung infection with cough, it is important that plenty of fluids are taken: first, to replace the extra fluids lost through the lungs by rapid breathing, and second to help keep the mucus in the lungs from becoming too dry and sticky and more difficult to cough out. Remind parents that fast or difficult breathing in children may be dangerous and needs medical treatment quickly.
- Encourage children with respiratory problems to take more fluids by increasing the frequency of breast-feeding or by giving additional fluids by spoon or cup.

Possible Causes of Coughing and Difficulty in Breathing

Respiratory problems, particularly lung infections, are common and can be quite serious. The most common causes of respiratory problems include—

- Colds and flu
- Bronchitis
- Pneumonia
- Tuberculosis
- Heart problems
- Asthma

When to Seek Medical Treatment for Coughing and Difficulty in Breathing—

- People should be made aware of the signs and symptoms that require medical treatment—
 - The onset of fever or a change in the regular fever pattern of the person who is ill
 - They are in severe pain or discomfort
 - Blood in the sputum
 - A sudden or rapid worsening in their ability to breathe or catch their breath after normal activity
 - A change in the color of their sputum from clear to gray, yellow, or green
- If the problems experienced with coughing, chest pain, or other respiratory symptoms are chronic (lasting more than three weeks) and do not respond to antibiotic treatment, tuberculosis may be the cause and should always be considered.
- In children (particularly below the age of five) respiratory infections can be very serious. All children should be brought to a health care worker for immediate attention if they are—
 - Breathing with difficulty through the mouth or with audible wheezing (squeaking sound as they inhale or exhale)
 - Breathing faster than usual
 - Unable to drink because of problems with breathing

Common Symptoms—Diarrhea

Symptoms—

- Frequent bowel movements
- Stools are usually clear and watery, may be accompanied by pains in the abdomen and cramping
- Stools smell strongly or pass noisily, as well as being loose and watery
- Three or more loose or watery stools in a day

What to Do in the Home—

- Encourage the person to drink more fluids than usual to prevent dehydration. You might wish to ask a health care professional for the most appropriate fluids to drink in your area, but as a rule, some of the best options include unsweetened juices, coconut water, and weak tea or food-based fluids such as gruel, soup, or rice water. The person should be encouraged to drink as much as possible, and may need to force himself/herself to drink even when not feeling thirsty. It may be helpful to keep a glass of clean water nearby and to sip some every five to ten minutes. Make sure to boil water for 10 minutes and cool, if it is possible that the water may not be clean.
- In the case of breast-fed infants with diarrhea, the mother should continue to breastfeed and try to do it more often than normal (at least every three hours). Encourage the mother to drink more than usual, even when she's not feeling thirsty.
- It is especially important to encourage children with diarrhea to drink. Give children under two years old about a quarter to a half of a large cupful of fluid after each loose stool. Give older children one half to one large cupful after each loose stool. You may have to use a spoon to get the child to take enough liquid.
- Encourage those with diarrhea to continue to eat. If people try to stop eating when they have diarrhea, this can cause malnutrition or make existing malnutrition worse. It will not decrease the diarrhea. The fluids taken in do not replace the need for food. It is important for people to take in the nutrients needed to stay strong and prevent weight loss: a strong person will resist illness better. Even if someone does not feel hungry, s/he should eat small amounts of nutritious and easily digestible food frequently. After the diarrhea has stopped, an extra meal each day for two weeks will help to regain any weight lost during the illness.
- It is especially important to encourage young children with diarrhea to eat. Some children will continue to need extra food after the diarrhea has gone for some time to make sure they regain any lost weight. Especially easily digestible foods, usually available, include rice, bananas, and dry bread.

Common Symptoms—Diarrhea, continued

- Advise people to eat foods with the largest amounts of nutrients and calories. These should be mixes of cereal and locally available beans, or mixes of cereal and meat or fish. Oil can be added to these foods to make them more energy-rich. Dairy products, eggs, and bananas are also suitable. Very diluted soups are recommended as fluids, but are not sufficient as foods because they fill you up without providing sufficient nutrients.
- Advise people to avoid—
 - High-fiber or bulky foods, such as fruit and vegetable peels, and whole grain cereals; these are hard to digest
 - Foods or drinks containing a lot of sugar, such as commercial soft drinks, as they can worsen diarrhea
- Prepare foods by cooking well, then mashing or grinding them to make them easier to digest.
- Try to make sure that people take food every three to four hours at least (about six times each day). Food should be given more often to young children with diarrhea.
- Recognize and treat dehydration early. Signs of dehydration include feeling irritable or lethargic or if the skin goes back slowly when pinched. Urination will decrease in volume and frequency and its odor will become stronger and unpleasant. If these signs are noticed, give the patient an ORS, which can be obtained from the local health center. Dissolve the contents of the packet in the amount of clean water indicated on the packet. Not all packets are the same size so people will have to read the instructions to be sure how much water to add. If they use too little water, the drink could make the diarrhea worse. If they use too much water, the drink will be less effective. If clean water is not available, then you may need to boil the water and let it cool before mixing the ORS. The mixture should be stirred well and then drunk the same day it is prepared. If ORS packages are not widely available you should advise people that they can still make a suitable solution at home. You should advise on the recipe for the solution used in your country or the recipe in this manual.
- Discourage the use of medicines at home to control diarrhea.
- For severe stomach cramps that sometimes accompany diarrhea, paracetamol may be helpful.
- Other problems that may accompany diarrhea include—
 - Skin irritation in the rectal area. To prevent or treat sore or broken skin you should advise the person who is ill to—
 - Clean the rectal area gently with water after each bowel movement and pat dry
 - Apply a lotion to help relieve the discomfort and protect the skin

Common Symptoms—Diarrhea, continued

- Sit in warm water containing a little pinch of salt three or four times a day; this may also relieve the discomfort
- Hemorrhoids can develop after the diarrhea has been present for some time. They are caused by a weakening of the walls and blood vessels of the rectum. The tissues around the anus become very sore and itchy. The blood vessels may become very tender and may bleed—small amounts of blood may be noticed in stools or during cleaning of the rectal area. Trying to relax during bowel movements and not straining or pushing too hard to pass the stools can prevent hemorrhoids. Sitting in a bath may help to ease the discomfort and paracetamol can be taken to relieve the pain. Remember to use gloves or other protective gear when bathing someone who may have bleeding hemorrhoids.
- To help someone with diarrhea who cannot get out of bed, use a bedpan or other suitable plastic or metal container. Be sure it is not too high and can be used by slipping it under the person in bed. Empty the contents frequently. Do not use this container for any other purpose once it has been used as a bedpan. Change wet or soiled bedding immediately to prevent damage to the skin.

Possible Causes of Diarrhea—

- Diarrhea is very common in people living with HIV/AIDS.
- There are two types of diarrhea—
 - Acute diarrhea lasts for less than two weeks
 - Persistent diarrhea is when someone has more than three liquid stools a day every day for more than two weeks
- If loose or watery stools also contain blood, the diarrhea is called dysentery.
- The most common causes of diarrhea in people living with HIV are—
 - Intestinal infections from food or water that is not clean and fresh
 - Opportunistic infections related to AIDS
 - Side effects of some medicines

The Two Main Dangers of Diarrhea are Dehydration and Malnutrition—

- Dehydration is the loss of a large amount of water and salt from the body, which if not treated can cause death. In a healthy person, the body regulates the amount of water and salts it needs by a two-way process. It takes in water and salts from the food and drink consumed. It also gets rid of excess water and salts through the stools, urine, and sweat. In a healthy person there is a balance between intake and output. When someone has diarrhea, however, the intestines do not work normally and this balance breaks down. Increased amounts of water and salts are passed into the intestines and the output of water and salts becomes greater than the intake. This results in dehydration. The greater the frequency of diarrhea the more water and salts are lost. Vomiting can also cause dehydration, which often accompanies diarrhea. Dehydration occurs faster in infants and young children, in hot climates, and in people who have fever.
- Diarrhea can cause malnutrition or make it worse because—
 - Nutrients are lost from the body in the stools
 - People with diarrhea often do not feel hungry
 - Some think *wrongly* that they should not eat when they have diarrhea, or even for some days after the diarrhea lessens

To Prevent Diarrhea—

- Drink clean water. Boil water that is to be used in making food or drinks. The water need only boil for a few minutes. Drinking water from a dirty well, or water kept in a dirty container, can cause diarrhea.
- Eat clean, safe food. Eat freshly prepared foods. Make sure that raw foods are washed in clean water and that cooked food, especially meat, has been cooked properly. Badly washed food, or food not protected against dirt, flies, and animals can be unsafe to eat because it can become contaminated with disease-causing organisms. If previously cooked foods are to be eaten, make sure they have been stored safely and reheated thoroughly at a high temperature.
- Clean your hands. This is particularly important. People should always wash their hands after using the latrine or toilet, after helping somebody else use the latrine or toilet, after cleaning soiled children or people who are ill, and before preparing food or drink for themselves or other people.

When to Seek Medical Treatment for Diarrhea

- People are at risk of dehydration and should seek help if they have diarrhea and—
 - Are very thirsty
 - Have a fever
 - Cannot eat or drink properly
 - Do not seem to be getting better
 - Pass many watery stools
 - See blood in the stools
 - Are vomiting and cannot retain fluids
- Help should be sought quickly if signs of dehydration have already developed, such as—
 - The person is extremely thirsty
 - The person is in an irritable or lethargic state
 - The skin returns slowly after pinching
 - In an infant, if the soft spot on the head sinks in
- Remember that traditional healers often have effective herbs to replenish the body's nutrients. Try to verify that the traditional healer is reputable before recommending them.

Common Symptoms—Fever

Symptoms—

- Skin is hot to the touch
- Body aches; feeling uncomfortable all over
- Increased sweating

What to Do in the Home—

- Use a thermometer if one is available and measure the person’s temperature.
- If there is no thermometer available, you can still get an idea of whether or not someone has a fever. Put the back of your hand on the person’s forehead, and put the back of your other hand on your own forehead. If the person has a fever, you should be able to feel the difference.
- To lower a fever—
 - Remove any unnecessary clothing and blankets; fresh air is not harmful and helps to lower the fever.
 - Cool the skin by taking baths or pouring water on it, putting cloths soaked in water on the chest and forehead and fanning the cloths, or just wiping the skin with wet cloths and letting the water evaporate.
 - Provide plenty of water, weak tea, broth, or juice. Someone with a fever will lose more fluids than usual and this can make them feel worse, and can cause them to become dehydrated.
 - Use medicines that reduce fever, for example, aspirin, paracetamol, acetaminophen, or Ibuprofen, usually two tablets every four to six hours. For children, the dose is lower and depends on size (weight) or age. (It is better not to use aspirin for children under six years old.)
- In between bathing and cooling the skin to lower the fever, keep the skin clean and dry.
- Use lotions or powders to prevent skin problems such as rashes, sores, sore areas, or broken areas.

Possible Causes of Fever—

- A fever is not a disease in itself but a sign that there is an infection somewhere in the body. A slight fever can be a sign that the body is “burning off” the infection, but a high fever can be dangerous, especially in small children.

Common Symptoms—Fever, continued

- In people living with HIV/AIDS, fevers often come and go. It is difficult to know whether the fever is a symptom of a treatable infection or whether it is due to the HIV infection itself. The causes of fever can include—
 - AIDS-related opportunistic infections, which might include anything from diarrhea to tuberculosis
 - Endemic diseases, such as malaria
 - HIV infection itself

When to Seek Medical Treatment for a Fever—

- The person has a very high fever (over 100.4 F or 38 C)
- The fever continues for a long time
- The fever is accompanied by coughing and weight loss
- The fever is accompanied by symptoms such as stiff neck, severe pain, confusion, unconsciousness, yellow color in the eyes, sudden severe diarrhea, or convulsions
- The person has recently had a baby or is currently pregnant
- The person lives in an area where malaria is common and the fever has not gone away after one treatment with anti-malarial medicine; discourage people from treating themselves repeatedly with such medicine



Note to Trainers—

Suggestions for the Role-Play—

- Have the participant stand in the sun for a long time, or hold something hot to his/her head and arms in order to better simulate a fever.
- Another option would be to have a role-play in which an infant infected by HIV/AIDS has a fever. In this case, a participant could rush into the training area carrying a very hot doll. (The doll can be left in the sun or covered with a hot cloth prior to the role-play.) This will give participants a chance to more clearly imagine assisting in the care of an infant with fever symptoms.

Common Symptoms—Genital Problems

Symptoms—

- An unusual discharge (a mucus or pus-like substance) from the vagina; may be accompanied by an unpleasant smell, itching, soreness, and sometimes fever
- An unusual discharge from the urethral opening of the penis; may be accompanied by burning when passing urine
- Open sores or ulcers in the genital, groin, or rectal areas, which sometimes start as blisters
- A rash in or around the genital area
- Warts in the genital area or around the anus
- Swollen glands in the groin
- Sense of urgency or pain when urinating (in men or women)
- Painful intercourse (in men or women)

What to Do in the Home—

- If a person feels they may have a sexually transmitted infection (STI), you should first advise them to seek treatment from a health care worker where available. Such treatment should be sought before attempting any kind of home treatment.
- Always advise people to use a condom each and every time they have any sexual contact. It is dangerous for someone who is already infected with HIV to be exposed to other STIs. The use of condoms offers protection from all STIs, and also provides protections to the partners of those with such conditions.
- People with open sores or lesions on the genitals should be advised to—
 - Always use condoms when having any sexual contact
 - Keep the affected area clean with soap and water
 - Between washings, keep the wound dry
 - Watch for signs of infection, and seek help if redness, pus, or swelling is seen, or if the sores become painful
- If herpes is diagnosed, advise the person to bathe the affected area with salt solution consisting of a teaspoonful of ordinary cooking salt in half a liter of clean water. They should do this often, every two or three hours if possible. Between times the affected area should be kept dry. Calamine, talcum, or starch powder may also be applied to the sores. If the person is pregnant, seek care immediately.

Common Symptoms—Genital Problems

- If someone is experiencing candidiasis (yeast infection) repeatedly, the following approach may help to ease discomfort, to prevent the onset of a new infection (which can occur, for example, as a result of taking antibiotics given for another problem), and possibly to reduce the intensity of an existing infection—
 - Apply gentian violet to the vulva and vaginal area or the affected male genital area. To prepare a gentian violet solution, dissolve one or two teaspoonfuls of gentian violet crystals in one liter of clean water. Apply once daily for three days. Gentian violet solutions should be applied internally or externally to the affected area using a soaked piece of clean cotton wool, cloth, or gauze. This should be done for at least three days or until the symptoms improve—if this does not happen then the person must see a health care worker. People should be advised that gentian violet stains clothing and sheets a purple color.
 - A rash on the penis or under the foreskin will often respond to soaking in a diluted salt and water solution. Dissolve a teaspoonful of salt in a glass or jam jar of water. Pull back the foreskin, put the penis in the water and soak for five minutes. Repeat two or three times a day. If this does not work, carry out the same procedure using a gentian violet solution (a half teaspoonful gentian violet in one liter of clean water). If the rash does not clear up in three to four days the person should ask advice from a health care worker.
 - Someone who experiences candidiasis (yeast infection) repeatedly should learn to recognize the signs of an infection and begin the treatment at home while it is still in the early stages.
- If a woman's periods have stopped, always remember that she may perceive this as a loss of capacity to bear children or a loss of femininity and may feel sad or even depressed (assuming this is not due to pregnancy). You can help a person to fight off this loss of self-esteem by reassuring her that cessation of menstruation is experienced by many women for a wide variety of reasons. Women should be encouraged to be with friends, to involve themselves in the people and activities around them, and to remember that they are still worthwhile and have a great deal to give.

Possible Causes of Genital Problems—

- Other STIs and opportunistic infections of the genital area are common in both men and women with AIDS, and may recur on numerous occasions. Considerable evidence suggests that STIs that cause ulcerative lesions promote the transmission of HIV through sex. Effective diagnosis, care, and education about genital problems are, therefore, crucial to both the prevention of HIV transmission and to the care of people living with HIV/AIDS.
- Vaginal infections are important because—
 - They may be passed on to others through sexual intercourse.
 - STIs (e.g. gonorrhea, chlamydia) are particularly likely to spread from the genital area to the upper reproductive tract causing pelvic inflammatory disease. This may even lead to abscesses with severe cramps and pains in the abdomen, with the result that such infections become difficult to treat, even with strong medicine, and can be life threatening. Sterility may result from untreated pelvic infections.
 - They increase the risk of acquiring, or passing on, HIV infection during sex.
 - They may be transmitted to an unborn child during delivery.
- Some advice on ways to avoid vaginal problems—
 - Always use condoms when having any sexual contact. This may prove difficult for women to negotiate with their partners, and the discussion of condoms should be approached sensitively with a woman and her partner(s).
 - Keep the vulva and anal areas clean by washing with water (but avoid soaps that damage this delicate skin).
 - After going to the latrine, wipe the anus in a direction away from the vagina so that feces do not get into the vulva/vaginal region.
 - Avoid washing out the vagina or putting anything (e.g. leaves, herbs) inside unless advised to do so by a health worker.
- Genital warts are very common, are infectious, and can be caught by sexual contact, then passed on to other people the same way. They are often larger, spread more quickly and are more difficult to treat in people living with HIV/AIDS.
- Herpes is a viral infection that many people get around their mouths or genital area. It tends to remain latent (hidden away), under the control of the body's defenses. It occasionally appears as blisters that break down to give painful ulcers, which heal slowly by themselves. In people living with HIV/AIDS, the blisters appear more frequently, spread over a wider area and sometimes do not heal at all. They can be very painful and difficult to treat.

Common Symptoms—Genital Problems

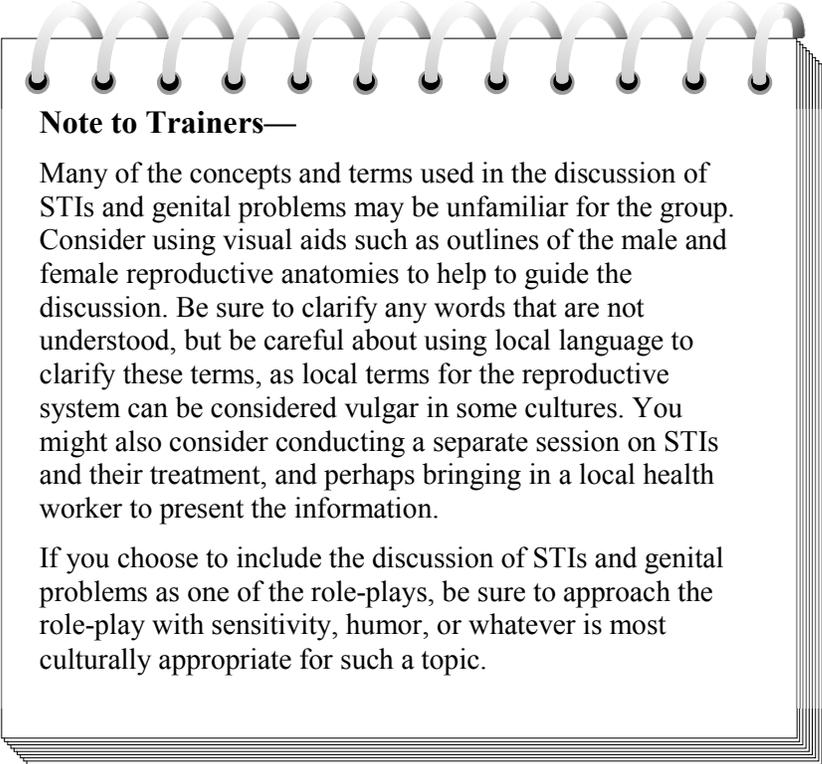
- Candidal (yeast) infections are common, but they are particularly frequent and more difficult to cure in people living with HIV/AIDS. In women, they produce a curdy discharge and cause redness and soreness of the vulva that is accompanied by severe itching. The skin may break down and bleed, particularly if scratched. Candidiasis is also found in men, especially among those who are uncircumcised, and occurs often and severely in men with AIDS. The foreskin and the area underneath it become very sore and red. There may be a yellow discharge under the foreskin. The skin of the penis, scrotum, and around the anus sometimes becomes red, sore, and itchy. Candidiasis is not sexually transmitted but is often brought on by the use of antibiotics for the treatment of other conditions, or simply because the person living with HIV/AIDS has lowered resistance to the fungi that cause it. The organisms are always present in the genital area, but are not normally a problem because the body's defenses keep them from growing out of control.
- Cessation of menstruation and irregular bleeding occur in many illnesses, including AIDS. If a woman loses a lot of weight her periods may stop altogether or become infrequent. Cessation of menstrual bleeding can have many causes (including pregnancy) and is often seen in women with AIDS. This should be assessed in order to plan for the future care of the woman.

When to Seek Medical Treatment for Genital Problems—

- If a person feels they may have an STI, you should first advise them to seek treatment from a health care worker where available. Such treatment should be sought before attempting any kind of home treatment.
- Any woman with abnormal vaginal discharge should be examined by a health worker.
- Any man experiencing pus or mucus discharge from the opening of the urethra should be examined by a health worker.
- Both men and women experiencing genital warts should seek treatment from a health worker as soon as possible. Local treatment of warts provided by a health worker can be effective if applied before the warts are too big. If someone waits too long and the warts become quite big, it may be necessary to have them cut out, a surgical procedure, which has associated risks. Warts that are damaged can become infected.
- If a woman misses one or two periods, she should be encouraged to go to the health center to be examined. If pregnancy is not the cause, then the reason for the cessation of menstruation should, be determined.

Common Symptoms—Genital Problems

- Medical assistance should be sought—
 - If an STI is suspected
 - If difficulty or pain in passing urine is experienced
 - If genital warts are present
 - If genital ulcers are present
 - If there is an unusual vaginal discharge that is foul-smelling, itchy, very plentiful, or green, yellow, or gray in color
 - If a pain develops in a woman's lower abdomen, particularly if it is accompanied by a fever
 - If a woman's periods stop or become irregular or erratic
 - If there is a discharge from the penis
 - If there is swelling and/or pain in the scrotum

A graphic of a spiral-bound notebook with a white cover and a silver spiral binding on the left side. The notebook is open to a page with a white background and a thin black border. The text is written in a black, sans-serif font.

Note to Trainers—

Many of the concepts and terms used in the discussion of STIs and genital problems may be unfamiliar for the group. Consider using visual aids such as outlines of the male and female reproductive anatomies to help to guide the discussion. Be sure to clarify any words that are not understood, but be careful about using local language to clarify these terms, as local terms for the reproductive system can be considered vulgar in some cultures. You might also consider conducting a separate session on STIs and their treatment, and perhaps bringing in a local health worker to present the information.

If you choose to include the discussion of STIs and genital problems as one of the role-plays, be sure to approach the role-play with sensitivity, humor, or whatever is most culturally appropriate for such a topic.



Common Symptoms— Mental Confusion and Dementia

Symptoms—

- The person may describe feeling “dulled” or “slow” in their thinking at first.
- People living with HIV/AIDS may have difficulty thinking clearly. This may be noticed as a problem in concentrating, and losing track of conversations or tasks.
- The person may become irritable, disinterested, or unpredictable.
- The person may start dropping things more often, falling, or may develop slowness in movements, or shakiness. Strength and coordination may be affected.

What to Do in the Home—

- Mental confusion can be a very upsetting and frightening problem for everyone involved. People with these problems may have moments when they realize that they are not able to think as clearly as before and will be aware of actions they have taken that were inappropriate. This is deeply distressing to them. Family members are also often very upset and not sure what to do. Support and guidance from pastors, counselors, and friends will be very important.
- There is no specific treatment for these problems and people must learn to live with them and to make the environment as safe as possible for the person who is ill. Mental confusion in the person, perhaps more than any other symptom, can make caregivers feel like giving up and cause them to feel overwhelmed by the demands of caring for someone they love.
- If it is determined that nothing further can be done, then the family will need to give whatever help they can. This will include protecting the person who is ill from harm.
- Caregivers may need help to occasionally arrange time away from the home. Taking care of a sick family member for 24 hours a day, every day, is very difficult and people need their personal and emotional strength to deal with this.

Common Symptoms—Mental Confusion and Dementia, continued

- To help the functioning of the confused or demented person, people can—
 - Remind the person where he or she is and what time it is—use cues to help, for example—
 - Provide reminders of daily activities in a form the person understands
 - Provide familiar objects in easily visible places, such as pictures, clocks, calendars, and so on
- Keep a calm, accepting and open manner when dealing with the person
- Be aware of their actions and consciously slow down and relax
- Speak slowly
- Use a low-pitched tone of voice—this is reassuring
- Maintain a daily routine including arrivals of visitors/caretakers
- Ask questions that can be answered “yes” or “no”
- Give simple short directions, or explanations to questions
- Be concrete and specific
- Give the person lots of time to respond to questions, directions, or conversation
- Try to interpret the feelings the person is trying to express rather than just the words
- Talk about the distant past—the person’s memory of events that happened long ago may be good and this will be pleasurable
- People should avoid—
 - Arguing, as it will not convince the person and may only upset him or her
 - Directly challenging the person’s delusions or fantasies; it is better to cast doubt in a kindly way
 - Giving the person multiple tasks; instead give the person one thing at a time to do
 - Talking to the person as if he or she is a child
 - Giving choices, as this can be confusing

Common Symptoms—Mental Confusion and Dementia, continued

- To help a confused person who is upset or angry—
 - Change the subject
 - Provide music or switch on a radio
 - Give the person a manual task, e.g. folding clothes
 - Leave the room for a few minutes; the person may forget why he or she is angry
 - Remove the person from an upsetting situation
 - Maintain a quiet environment
 - Set limits
 - Say “no” gently, but firmly
 - Do not challenge or respond to the content of the angry words directed at the caregiver or others

- To prevent accidents in the home, people should—
 - Pay attention to open fires or boiling water
 - Provide canes or walkers for people who are weak or off balance when walking
 - Remove loose and potentially dangerous objects, including rugs
 - Keep walkways clear
 - Avoid rearranging furniture
 - Store poisonous or toxic substances safely out of reach
 - Keep medicines out of reach and only give them according to the prescribed schedule
 - Install handrails or put a chair in showers or tubs
 - Store sharp objects like knives, scissors, razors, and saws safely and out of reach
 - Try not to leave the person who is ill alone and unattended for long periods

Possible Causes of Mental Confusion and Dementia—

- Some degree of mental confusion (or dementia) is common among people living with HIV/AIDS. These symptoms may be caused by infection of the brain with HIV. The mental changes resulting from this may be barely noticeable or they may become a serious disability.
- HIV infection of the brain is the most common cause of mental confusion in people living with HIV/AIDS. However, other possible causes include—
 - The side effects of many medicines
 - Infection with numerous other bacteria, viruses, and parasites
 - Severe depression

When to Seek Medical Treatment for Mental Confusion and Dementia—

- If there is any sudden change in the person's ability to think or move, especially if this is associated with new fever, high fever, headache, or difficulty in breathing.
- If other mental or character changes occur—such changes should be evaluated by a health care worker, who may be able to offer help or provide treatment for the underlying cause.
- A confused and aggressive person can be very difficult to manage at home. There may come a time when the people around them cannot manage and they will need the help of a health care worker in placing the person elsewhere in order to protect the person who is ill or family members.
- A person who has a sudden change in thinking, behavior, or ability should seek help. Some of the sudden mental changes may be treatable and the person will recover. However, if such changes are allowed to continue, they may contribute to the rate of mental deterioration.

Common Symptoms— Mouth and Throat Problems

Symptoms—

- Soreness in the mouth, usually accompanied by white patches on the tongue and surrounding redness
- Blisters and sores on the lips
- Cracks and sores on the mouth
- Problems with the teeth such as inflammation of the gums, tooth abscesses, and infection

What to Do in the Home—

- Poor nutrition can cause problems in the mouth and can make existing problems worse. Encourage people to eat a healthy diet or take vitamin supplements.
- To help prevent problems in the mouth and throat, the mouth can be rinsed with warm salt water (half a teaspoonful of salt in a cupful of clean water), or with a mouthwash solution after eating and between meals. The wash should be swished gently in the mouth then spat out (not swallowed or it may upset the stomach and cause nausea).
- General hints for dealing with a sore mouth—
 - Eat soft foods rather than hard or crunchy foods
 - Eat bland, not spicy, foods
 - Use a straw for liquids and soups. This may help when taking in the food needed while preventing it from touching the sore areas
 - Cold foods, drinks, or ice, if available, may help numb the mouth and relieve discomfort
- You should advise someone with thrush to—
 - Gently scrub the tongue and gums with a soft toothbrush at least three or four times per day, then rinse the mouth with diluted mouthwash, or a salt water or lemon water rinse
 - Suck a lemon if it is not too painful—the acid of the lemon slows down the growth of the fungus
 - Apply gentian violet solution three or four times a day—gentian violet solution is prepared by dissolving one teaspoonful of gentian violet crystals in a half a liter of clean water; again, warn about the purple staining linens and clothing

Common Symptoms—Mouth and Throat Problems, continued

- If necessary, you might use a prescribed anti-fungal oral suspension or lozenge; in some people, thrush affects not only the mouth but the entire esophagus causing pain on swallowing and a burning sensation in the chest
- You should advise someone with herpes simplex sores to—
 - Apply the gentian violet solution described above; although the strong purple color may bother some people, the solution can help in preventing the sores from becoming infected
- To avoid or treat dental problems, encourage people living with HIV/AIDS to make regular visits to a dentist when possible, and to be particularly careful about oral hygiene. They should be sure to brush the teeth and clean between the teeth (using dental floss or toothpicks) to remove food particles. If someone does not have a toothbrush, they can use a tooth-cleaning stick made out of the twig of a tree, or they can tie a piece of towel around the end of a stick, to make a toothbrush. If toothpaste is not available, mixing salt and bicarbonate of soda (or ashes) in equal amounts can make a tooth-cleaning powder. To make it stick, the brush should be wetted before being put in the powder. This mixture works just as well as commercially available toothpaste for cleaning teeth.

Possible Causes of Mouth and Throat Problems—

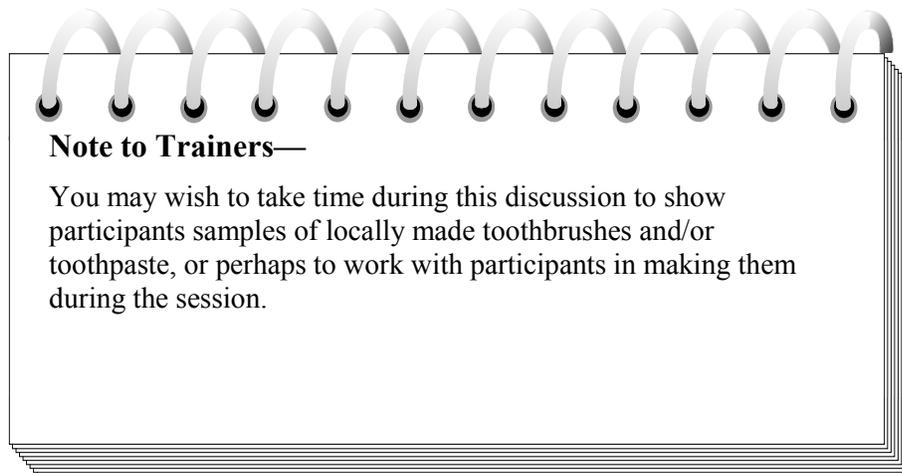
- Soreness in the mouth, usually accompanied by white patches on the tongue, is a common symptom in people living with HIV/AIDS. Sometimes it progresses into the throat and esophagus, causing painful swallowing, thereby interfering with eating and drinking. Other associated problems are blisters and sores on the lips, and dental problems. The following diseases may cause a sore mouth or throat—
 - Thrush (yeast infection), resulting in white patches and surrounding redness, not only in the mouth but possibly in the throat and esophagus; if the white patches scrape off with a brush or a fingernail, it is probably thrush; if it does not, it may be another condition called hairy leukoplakia
 - Oral herpes simplex (blisters and sores on the lips)
 - Malnutrition (cracks and sores on the mouth)
 - Kaposi's sarcoma of the mouth or throat
 - Dental problems

Common Symptoms—Mouth and Throat Problems, continued

- Hairy leukoplakia may look like thrush. However, it does not cause pain, it will not scrub off the tongue or gums, and it commonly makes vertical ridges on the edges of the tongue. It is mentioned here only so that you know that it can be confused with thrush. There is no need for a specific treatment for this condition. It will not interfere with the ability to eat or with a person's general comfort. The main point is to not use too many medicines for thrush if in fact the problem is hairy leukoplakia.

When to Seek Medical Treatment for Mouth and Throat Problems—

- If the person who is ill becomes dehydrated or is unable to swallow properly
- If there are symptoms of esophageal thrush such as a burning pain in the chest or a deep pain on swallowing



Common Symptoms— Nausea and Vomiting

Symptoms—

- Feeling sick to the stomach
- Feeling unable to eat
- Vomiting

What to Do in the Home—

- If a person is having trouble with nausea and vomiting, advise them to—
 - Avoid cooking smells if possible
 - Watch out for dehydration (see the discussion of diarrhea above)
 - Talk to a health care worker, who may prescribe medicine to control the symptoms if they are very severe, in order to allow the person to eat
- If someone is vomiting severely, they should—
 - Not eat any food or drink any fluids for one to two hours
 - Then gradually start drinking room-temperature water, oral rehydration solution, weak tea, or other clear liquids (about two tablespoonfuls an hour for two or three hours), or suck ice in small amounts
 - Then increase the amount of fluids to four to six tablespoonfuls an hour for two to three hours; the amount can be increased as desired but people should force themselves to keep taking fluids to make up for what they have lost
 - As the nausea decreases, people should increase the amount and types of foods they eat; it may be best to start with small quantities of dry, plain foods such as bread, rice, or cassava
 - Frequent care of the mouth will remove the foul taste and freshen it; this can include rinsing the mouth with clean water, or gently scrubbing the tongue and gums with a soft toothbrush or cloth at least three or four times a day, then rinsing with diluted mouthwash or lemon water rinse
 - Ventilating or freshening a room may make a person feel better and less nauseated

Common Symptoms—Nausea and Vomiting, continued

- It is also a good idea for people to identify and reduce the things that seem to make them feel nauseated, such as specific odors, medicines, or foods (high-fat foods, for example)
- A cool compress applied to the forehead, or other things that help someone to relax, may be useful

Possible Causes of Nausea and Vomiting—

- Nausea and vomiting can be an important problem for people living with HIV/AIDS. These symptoms may be caused by—
 - Medicines
 - Infections
 - A problem with the stomach or intestines
 - Kaposi's sarcoma in the intestines
 - HIV infection itself
- In some people, nausea and vomiting are very short-lived, and go away by themselves or after treatment of the cause. In others, they are chronic or long lasting and become a part of daily life.

When to Seek Medical Treatment for Nausea and Vomiting—

- If vomiting occurs repeatedly and fluids cannot be kept down—in such cases the person who is ill is at risk of becoming severely dehydrated.
- If regular vomiting lasts more than 24 hours, particularly if it is accompanied by pain in the abdomen.
- If the person has a fever in addition to the vomiting.
- If the person who is ill vomits violently, especially if the vomit is dark green, brown, or smells like feces.
- If the vomit contains blood.

Common Symptoms—Nutrition Problems

Symptoms—

- Weight loss or “wasting”

What to Do in the Home—

- A person who is ill has an even greater need for food than a healthy person. People should be encouraged to think about the foods that will help make them healthy, rather than worry about foods that are not considered to be good for them. Remember: the same foods that are good for you when you are healthy are good for you when you are sick.
- Encourage people living with HIV/AIDS to eat food from three groups—
 - **Body-building foods.** These include peas or beans, soy beans, groundnuts, nuts, eggs, meat, fish, and milk. These foods are rich in protein, iron, and calcium.
 - **Energy-giving foods.** These include potatoes, yams, cassava, taro, plantains, sugar, wheat, rice, millet, maize, animal fats, and vegetable oils.
 - **Foods that protect the body from infection (vitamin-rich foods).** These include all fruits and vegetables. Dark green leafy vegetables are the most nutritious, then orange-colored vegetables and fruits. Cooking for too long destroys vitamins so these foods should be cooked or steamed lightly, and the cooking water used as a soup or sauce. As mentioned in the diarrhea section of this chapter, correct preparation and storage of foods should ensure that they are clean and safe and do not cause disease. This is especially important for infants.
- General hints for people who are having trouble eating or maintaining their weight and strength—
 - Eat small amounts often; foods that can be eaten with the fingers are easier to manage, particularly if the person is weak
 - To supplement a regular diet of nutritious foods, vegetable oil, or groundnut paste can be added to food
 - Raw vegetables are not very digestible and can easily be contaminated, so they are not a wise choice
 - If someone is experiencing nausea or vomiting, preparing the foods in liquid or semi-liquid form may help
 - If persistent diarrhea is present, use soft or mashed foods and avoid irritating foods, for example hot pepper and raw vegetables
 - Drink plenty of fluids and watch for dehydration

Common Symptoms—Nutrition Problems

- Taking vitamin tablets may be helpful, although eating good foods is always better.
- Certain problems that decrease the appetite or the ability to eat, such as thrush or dental problems, can be treated and action should be taken before the problem gets very bad.
- Loss of appetite or difficulty in eating can be very distressing for the person who is ill and the family as it might make them feel helpless and ineffective. It may help if they can discuss this with a health worker.

Possible Causes of Nutrition Problems—

- AIDS almost always causes severe weight loss, even in people who eat good food. There are many reasons for this including—
 - Not enough nutritious foods available
 - Painful or difficult swallowing because of—
 - Oral or esophageal thrush
 - Mouth sores such as the blisters caused by herpes simplex
 - Kaposi's sarcoma lesions (purple lesions which can occur on gums or palate)
 - Inflammation of the gums or infections of the gums and teeth (redness, pus, or swelling of the gums); these can be caused by a lack of vitamin C (found primarily in citrus fruits and in dark green leafy vegetables)
 - Nausea and vomiting
 - Chronic diarrhea
 - Tuberculosis
 - Depression or anxiety
 - Fever from any cause

When to Seek Medical Treatment for Nutrition Problems—

- If the person who is ill becomes dehydrated or very malnourished
- If the person is suddenly unable to eat
- If the person starts to have severe abdominal pain with or without vomiting

Common Symptoms—Pain

Symptoms—

- Pain in any part of the body
- Strong burning sensation, particularly in the hands or feet
- Pain can be accompanied by swelling

What to Do in the Home—

- In trying to control and relieve pain, people will need to know that pain is also influenced by the person's emotional state and can be frightening. The person who is ill may need extra reassurance and care.
- Encourage people to look out for any clues as to what increases or relieves pain.
- People can take an active role in controlling their pain. For example, by—
 - Learning deep and regular breathing techniques, which may help them to relax
 - Learning to deal with pain through distraction and lessening of their anxiety
 - Taking medicines for pain according to an organized schedule—this can help people to feel more in control and reassure them that the pain will not become too great before medicine is taken
 - Engaging in physical activity or receiving gentle massage—both of these can be helpful for some types of pain
 - Imagining or remembering a favorite place or event
- If a person is experiencing a strong burning sensation, particularly in the hands or feet, it may be due to nerve problems. This type of pain is made worse by extremes of temperature (very cold or very hot), touch (even clothing or bed sheets) and dryness. The pain is sometimes made better by putting the legs and feet in water. If the skin seems to be sensitive, then people should plan things so that all the care and activities that require touching are done at the same time, to allow for periods of rest in between. The person's bed can be lined with soft blankets or cushions.
- If people experience any swelling, they should raise their legs or swollen parts on pillows, or raise the foot of the bed on blocks. They should also keep changing their body position.

Common Symptoms—Pain, continued

- Treatment for pain of all types may include mild medicines for pain (analgesics), which are commonly used in the home, such as aspirin or paracetamol. There are other stronger medicines that people can take for pain but these should only be taken with the advice of a health care worker. It is important that the person who is ill takes the mild pain medicines regularly, at least every eight hours, if the problem is long lasting or chronic. Waiting until the pain is very bad before taking the medicine makes it less likely to work well.
- Caregivers for people living with HIV/AIDS should be advised to do the following to keep the atmosphere as calm as possible—
 - Talk slowly to the person who is ill, and use gentle tones
 - Approach the person slowly and quietly
 - Avoid using bright lights
 - Ask others to be quiet and gentle in the presence of the person who is ill
- People should also be encouraged to talk with the person, and to provide comfort and distraction from the pain, perhaps by—
 - Playing favorite music quietly
 - Reading aloud or telling stories
 - Applying a cool cloth on the forehead, or giving massage
 - Asking what relieves the pain and then doing it
- If the person is unable to move unaided, he/she should be helped to change positions frequently.
- Some people like to be wrapped in a blanket or cloth when they are experiencing pain or to have the painful areas wrapped in cloths or a bandage.
- When someone lifts a child who is in pain, the palms of the hands should be used rather than the fingertips (which can sometimes feel like a pinch).

Possible Causes of Pain—

- For some people in the later stages of AIDS, pain becomes a part of daily life. For others it is only occasional and easily controlled. The causes of pain are many and include—
 - Immobility (not being able to move about on their own)
 - Infections, such as herpes zoster
 - Swelling of the extremities (caused by poor circulation brought on by Kaposi's sarcoma or problems with the heart)
 - Headache alone or associated with meningitis or encephalitis
 - Nerve problems including pain with or without weakness
 - Psychological or emotional causes such as depression and anxiety, which may increase the sense of being in physical pain

When to Seek Medical Treatment for Pain—

- If the pain becomes unbearable or is linked with new symptoms such as a severe headache or weakness.
- If there is a sudden or recent occurrence of pain in the hands or feet. People need to be certain it is not due to another illness or medicines for other diseases.
- If there is a persistent headache lasting over two weeks, a severe headache which is getting rapidly worse and is not relieved by the usual ways of dealing with pain, a headache associated with vomiting, or a headache that affects the person's ability to think or move.

Common Symptoms—Skin Problems

Symptoms—

- Rashes
- Itching skin
- Painful sores on the skin
- Increased dryness of the skin
- Slow healing of wounds
- Boils and abscesses (red, raised, painful lumps on the skin)—usually on the groin, buttocks, armpits, back, and upper legs

What to Do in the Home—

- As a general rule, cleaning the skin frequently with soap and water and keeping it dry between washings will prevent the most common problems.
- Almost all skin problems involve the sensation of itching. Scratching the itching skin with fingernails can make things worse, either by breaking the skin or by introducing or spreading infection. Keeping nails short can avoid this. Try to encourage people not to scratch any type of skin lesion or sore. However, rubbing with the flat of the fingers or gentle slapping can give some relief.
- Itching can be reduced in a number of ways, including—
 - Cooling the skin with water or fanning it
 - Applying lotions such as calamine that are soothing and prevent the skin from becoming too dry
 - Not letting the skin get hot and not applying warmth to itching areas
 - Using effective traditional remedies that are available locally from an herbalist or traditional healer
- If people have trouble with very dry skin, they may have to avoid soaps and detergents and use bath oils and skin creams as much as possible. Vaseline, glycerin, and vegetable or plant oils can be as effective as the more expensive oils and creams sold in the shops.
- To prevent babies, or someone who is confused, from scratching themselves, cut their fingernails very short or put gloves or socks over their hands.

Common Symptoms—Skin Problems, continued

- For children in diapers/nappies who have diarrhea rash or yeast infections, the buttock area will need special care. For example, people should—
 - Leave the baby’s bottom exposed to air as much as possible
 - Soak the baby’s bottom with warm water between diaper changes
 - Do not let the child remain in wet diapers or cloths but remove or change them as soon as they become soiled
 - Avoid wiping the buttocks area; instead squeeze water from a wash cloth or pour water over the area and then pat dry
 - Use simple lotions provided by a health care worker or pharmacist—this may help cure rashes in the diaper area, particularly if they are treated early
 - Do not forget to wash both your hands and theirs afterwards!

Uninfected Wounds—

- Wash the affected areas with clean water—preferably water which has been boiled and cooled—mixed with a little salt (one teaspoonful of salt to one liter of clean water) or gentian violet solution (one teaspoonful of gentian violet crystals in half a liter of clean water).
- Protect by covering with clean gauze bandages or cloth, wrapped loosely.
- Put warm compresses of weak salt water on the area four times a day (one teaspoonful of salt to one liter of clean water).
- If the wound is on the legs or feet, raise the affected area as high and as often as possible. During sleep it should be on pillows. During the day, try to raise the foot for five minutes in every 30 minutes. Walking helps the circulation, but standing in one place or sitting with the feet down for long periods is harmful.

Infected Closed Wounds—

- Once someone notices a red lump under the skin they should start using warm compresses over the area for 20 minutes, four times a day. The warmth of the compresses will help the boil or abscess “mature” or to form and harden and drain its contents.
- If they are having a great deal of pain and the boil or abscess continues to get bigger without draining (i.e. opening out onto the skin), they should seek help. The wound may require drainage and treatment with antibiotics.

Infected Open Wounds—

- If wounds are not cared for properly they can become infected. A wound is infected if—
 - It becomes red, swollen, hot, and painful
 - It has pus either draining from it or visible under the skin
 - It begins to smell bad
- The infection is spreading to other parts of the body if—
 - It causes fever
 - There is a red line running out from the wound
 - The lymph nodes under the skin in the neck, armpits or groin become swollen and tender
- People should attend to infected wounds with one of the following—
 - A salt wash (one teaspoonful of salt in one cupful of clean water)
 - Hot compresses over the wound for 20 minutes, four times a day
- If there is pus or dead tissue, you should show the person how to clean it away.
- Advise people to treat infected wounds as follows—
 - Use a gentian violet solution on the wound before applying dressings
 - If the wound is on a hand or foot, soak it in a bucket of hot water with soap or potassium permanganate (one teaspoonful of potassium permanganate to a bucketful (four to five liters) of clean or boiled water—do not exceed the recommended amount; if the solution is too concentrated it can burn or irritate the skin). Be sure that any compress or water applied to the wound is not too hot, since damaged skin can easily burn
 - When it is not being soaked, keep the infected part at rest and elevated (raised above the level of the heart)
 - If there is dead tissue, hydrogen peroxide can be used to rinse the wound

Washing or Cleaning an Infected Wound and Applying Dressings—

- Use gloves, plastic bags, or a big leaf when handling cleansing cloths or dressings to avoid touching blood from the wound and wash your hands afterwards with soap and water.
- Wash around the edge of the wound first, then wash from the center out to the edges using separate little pieces of clean cloth for each wipe if possible.
- Cover the area with a clean piece of cloth and bandage if the wound has pus or blood. If the wound is dry it can be left exposed to the air—it will heal quicker that way.
- Dressings are used to cover wounds to prevent them from becoming infected, to protect other people from infection, to keep medicines in place or to avoid painful contact with the environment—
 - Never apply a dressing tightly
 - Make sure dressings are clean
 - Change the dressing at least once a day; be sure to look for signs of infection
- After changing the dressing, rinse the soiled cloth and bandages in water and soap and put them in the sun to dry or put them in boiling water for a short period and hang them to dry. If the dressings are not to be reused, always dispose of them properly by burning them or putting them in a pit latrine.
- If soil or dirt gets into the wound it can become infected with a bacteria that causes a serious disease called tetanus (lockjaw). You should therefore ensure that people are fully immunized against tetanus. Even if they have been immunized for tetanus before, they may still need further immunization. Advise people who are not immunized against tetanus to seek medical help immediately if they are wounded or develop open sores.

Shingles—

- **Shingles** (herpes zoster) is a viral infection, which used to be seen only in older people or in those with weakened immunity for various reasons. Now shingles is very common in people living with HIV/AIDS and may be one of the first symptoms they have of HIV infection or of AIDS.
- Shingles begins as a painful rash with blisters, usually on the face, limbs, or trunk. Shingles on the face may affect the eyes, causing pain and blurred vision. The blisters often combine, resulting in a large eroded or broken area, and there may be an intense burning feeling in the affected area. Healing takes place over several weeks and leaves discolored areas on the skin.

Common Symptoms—Skin Problems, continued

- The following measures may be helpful for shingles—
 - Applying calamine lotion twice daily to relieve pain and itching and promote healing
 - Keeping the sores dry and not letting clothes rub on them if possible
 - Wearing clean, loose-fitting, cotton clothing
 - Relieving pain with aspirin or paracetamol, but sometimes the pain may be so severe as to require stronger prescribed medicines, including painkillers and sedatives at night
 - Preventing infection by bathing the sores with warm saltwater three or four times a day or applying gentian violet solution once a day, or antibiotic skin creams or ointments if available
 - Watching for signs of infection of the shingles sores such as redness or pus; if infection occurs treat as indicated for infected wounds above
 - The pain usually diminishes after three or four days. Unfortunately, some people develop a persistent pain and scarring over the affected area. Rubbing creams on the scars or painful areas may help; medicines for pain such as aspirin or paracetamol may also be needed

Allergic Reactions—

- ***Allergic reactions*** to medicines are more common in people living with HIV/AIDS. These often appear suddenly and start as skin rashes, redness, and itchy skin. If people think they may be having a reaction to a medicine they should immediately go to see the health care worker who prescribed it. Medicines that commonly cause reactions in people living with HIV/AIDS include—
 - Anti-tuberculosis medicines
 - Antibiotics
 - Anti-cancer medicines

Kaposi's sarcoma—

- ***Kaposi's sarcoma*** is a cancer of the cells in the blood vessels or lymph system. The cancer may begin as—
 - Discolored (brown or purple) areas on the skin or in the mouth.
 - Enlarged lymph glands that are not painful.
 - Both of these are a type of external cancer (affecting the outside of the body) and are mostly a problem for cosmetic reasons, but the cancer may go on to affect internal parts of the body causing the enlargement of internal organs or bleeding from the lungs or digestive tract. How Kaposi's sarcoma will appear in a specific person and what its course will be are very difficult to predict. Some people have only mild complaints arising from the appearance of the lesions; others may become very ill as a result of the cancer.
- Because of the variety of ways in which Kaposi's sarcoma may appear and because of the numerous parts of the body that may be affected, this disease can be mistaken for many others. Once the diagnosis of Kaposi's sarcoma is made, it indicates that the person has AIDS.
- The specific care needed for the problems caused by Kaposi's sarcoma will depend on where the cancer is situated and on what type of problems it is causing.

Bedsores—

- ***Bedsores*** are caused by the breakdown of the skin due to pressure. It is very important to prevent infections resulting from sores of any type that do not heal adequately, and bedsore are included in this category. These chronic open sores appear in people who are so ill that they cannot roll over in bed, especially those who are very thin and weak. The sores form over bony parts of the body where the skin is pressed against the bedding. They are most often seen on the buttocks, back, hips, elbows, and feet.
- To prevent bed sores in people who are ill you should advise them to—
 - Get out of bed as much as possible
 - Change position, when lying down, every two hours from one side onto the back, from the back onto the other side, and so on in order to prevent prolonged lack of circulation to any one area of the body; this is particularly important if an area of skin is already affected—the person may need help with this in the home if they are very weak
 - Use soft bed sheets and padding, which should be hung to air daily and changed each time the bedding is soiled with urine, stools, vomit, or sweat; straighten the bedding often as lying on wrinkled bedding can hurt the skin

Common Symptoms—Skin Problems, continued

- Put cushions under the body in such a way that the bony parts rub less
- Eat as well as possible; extra vitamins may help
- A bedridden child who has a severe chronic illness should be held often on someone's lap

Possible Causes of Skin Problems—

- Skin problems in people living with HIV/AIDS are common and unfortunately tend to be chronic. They can be controlled with the right treatment, but rarely completely cured. The most common causes of the illnesses listed above include—
 - Yeast infections (thrush, candidiasis)
 - Other fungal infections (ringworm)
 - Bacterial infections
 - Shingles (herpes zoster)
 - Poor hygiene
 - Allergic reactions to medicines or skin irritants
 - Bed sores (caused by lying in one position in bed)
 - Eczema
 - Kaposi's sarcoma

When to Seek Medical Treatment for Skin Problems—

- If pus, redness, or fever (indicating infection) accompany the skin problem
- If the wound has a bad smell, if brown or gray liquid oozes out, or if the skin around it turns black and forms air bubbles or blisters—this might be gangrene, a very dangerous condition; medical help must be sought very quickly
- If there is severe pain from a skin problem, like shingles, and the person is unable to sleep or function during the day
- If shingles affects the eyes
- If there is an allergic skin reaction to a medicine
- If the person is wounded or develops an open sore and they are not fully immunized against tetanus

Common Symptoms— Tiredness and Weakness

Symptoms—

- Weakness and fatigue
- Feeling tired all the time

What to Do in the Home—

- If no treatable infection or other problem is found, it is important for people to learn how to adjust to their limited ability. The following advice may help someone to do this—
 - See what can and cannot be done without help; it can help a family to know when and for what things someone needs assistance, and it helps them to understand that there are still some things the person who is ill can do in the home, while other tasks may have to be given to others
 - Rest should be taken as often as needed
- Help should be asked for, and accepted, from others. People will usually appreciate being told how they can help rather than having to guess and feel uncertain.
- Ways should be found of making some activities easier—for example, sitting rather than standing to bathe or cook; using a bedpan or suitable container rather than going to the toilet or latrine; buying or making a walker, cane, or wheelchair.
- If people living with HIV/AIDS cannot get out of bed at all they will clearly need help—see the above section on skin problems for information on the prevention of bedsores and other problems due to prolonged inactivity. The person helping should be advised to—
 - Move the person's arms and legs gently, several times a day
 - Turn the person from one side onto their back, or to the other side, every few hours
 - Provide a bedpan or suitable container every few hours, or more often if needed, to allow the person to empty their bowels or bladder
 - Keep the person's skin clean and dry
 - When someone is caring for a person who is tired and weak they should—
 - Help with the person's daily needs, such as bathing, going to the toilet or latrine, getting in and out of bed, changing position in bed, eating and drinking
 - Keep the person involved, even if he or she is very weak, in the activities within the home

Common Symptoms—Tiredness and Weakness, continued

- If the person who is ill is weak but moving about, safety precautions can be very important. General safety precautions to be taken in the home are described in detail in the section on mental confusion, but a quick summary follows—
 - Move loose or dangerous objects out of the way
 - Assist the person when walking or make a walking stick or cane for him or her
 - Try not to leave the person alone for long periods

Possible Causes of Tiredness and Weakness—

- AIDS can often make a person feel very tired and weak, particularly in the later stages of the illness. This can have many causes and to some extent is unavoidable. It is important to advise people to do what they can to keep their strength up and not to take on activities that could be dangerous to them (like walking too far). A person's weakness and fatigue could be a result of some or all of the following—
 - HIV infection or HIV-related illnesses (particularly respiratory illnesses)
 - Poor nutrition
 - Depression
 - Anemia.

When to Seek Medical Treatment for Tiredness and Weakness—

- If the person suddenly becomes very weak (for example, unable to walk), particularly if there are also other symptoms such as a high fever, headache, or confusion.

Chapter 4

Seeking Medical Support from a Professional Service Provider

“It is a serious injustice to see that only 1 percent of the 4.1 million people in sub-Saharan Africa who need antiretroviral therapy have access to it. As we work together to close this vast treatment gap, we must also tackle the intolerance and fear that prevents people from accessing the services they need.”

—BEN PLUMLEY
CHIEF EXECUTIVE OFFICE, UNAIDS

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Chapter 4: Seeking Medical Support from a Professional Service Provider

Key Questions

- Why do so many people who have HIV/AIDS also have tuberculosis?
- What are the symptoms of tuberculosis? Can it be treated at home? What can be done to keep family members from getting it?
- What should an HIV positive woman do if she gets pregnant?
- How can people living with HIV/AIDS and caregivers manage medications?
- What are the new “AIDS drugs?” Are they a cure for HIV/AIDS? How do they work?

Introduction

No matter how well caregivers manage symptoms and alleviate pain in the home, there will inevitably come a time when a person living with HIV/AIDS and their families will have to turn to the health care system for assistance. For some families, working with health care professionals may seem frightening. There may be fears around “going to the hospital to die” in some communities; in others, the higher levels of education of health care workers may be threatening. Still others may not be able to afford the cost of health care. It is important to work with the person and their caregivers to ensure that they feel comfortable going to the clinic or hospital, so that they will seek medical attention when it is necessary or when they have special conditions like tuberculosis or pregnancy.

This session seeks to lessen some of the concerns around using the health care system by helping participants imagine the questions and issues they may need to raise with health workers. It also details some of the important issues surrounding tuberculosis and pregnancy, so that people living with HIV/AIDS and their families will be prepared to manage these conditions should they arise.

Lastly, this session tries to make clear some of the misunderstanding about the “AIDS drugs,” or antiretroviral therapy and protease inhibitors. Although antiretroviral drugs (ARVs) are not available in many communities or are so expensive as to be inaccessible in most communities, things are slowly changing. Therefore, it is important that participants understand the basic facts about them for a number of reasons—

- To clear up any mistaken belief that there is a “cure” for AIDS
- To help communities to understand the struggle to obtain safe and affordable ARVs; in many areas, ARVs are often in the headlines or the source of protests, but often community members may not understand the basic issues at work around these drugs
- To identify the benefits of ARVs and the ways in which these drugs slow down disease progression
- To understand the risks and difficulties associated with ARVs

Perhaps most importantly, the time should be taken to dispel the notion that communities without ARVs have no hope in the arena of HIV/AIDS. As we will discuss in Chapter 5, *Physical Support for People Living with HIV/AIDS and Their Families*, there are many behaviors and strategies for keeping people living with HIV/AIDS healthier longer that have nothing to do with ARVs. Indeed, of the many branches on the “Life Tree,” only one details medical interventions. While the positive benefits of obtaining ARVs should not be underestimated, it should be clear that there is still hope for a long, healthy life even without these medicines.

Chapter 4: Seeking Medical Support from a Professional Service Provider

Objectives

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

- Describe the relationship between tuberculosis (TB) and HIV/AIDS
- Describe the relationship between pregnancy and HIV/AIDS
- Discuss symptoms and treatment of TB for people living with HIV/AIDS, including ways to prevent transmission to the rest of the family
- Describe special issues surrounding pregnancy for an HIV positive woman
- List questions that people living with HIV/AIDS and their families might keep in mind when receiving medications or instructions from health care workers
- Define “antiretroviral therapy”
- Describe how antiretroviral drugs (ARVs) lengthen the honeymoon period for people living with HIV/AIDS
- List three benefits and three risks of using ARV therapy
- Discuss local access to ARV therapy

Home Care: The Power of Our Community

Training Schedule: Section 1

Schedule	Day One	Day Two	Day Three	Day Four
	Registration <i>30 minutes</i>	Recap <i>30 minutes</i>	Recap <i>30 minutes</i>	Recap <i>30 minutes</i>
Session	The Power of Our Community Introductions, Goals, and Objectives Workshop Structure <i>1 hour 30 minutes</i>	Medical Support for People Living with HIV/AIDS (cont.) Common Illnesses Role-Play <i>1 hour 45 minutes</i>	Nutritional Needs for People Living with HIV/AIDS and Their Families We Are What We Eat <i>1 hour</i> Nutritional Needs for People Living with HIV/AIDS <i>1 hour</i>	Preparing for Goodbye Supporting People Living with HIV/AIDS <i>1 hour 30 minutes</i>
Break	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
Session	Breathe in Life, Breathe Out Trouble The Power of Our Community <i>1 hour 30 minutes</i>	Oral Rehydration Solution and Thermometer Use <i>1 hour</i> Seeking Medical Support from a Professional Service Provider Special Medical Concerns for People Living with HIV/AIDS <i>1 hour</i>	Social Support for People Living with HIV/AIDS and Their Families Small Groups on Social Issues <i>1 hour</i> Plenary on Social Issues <i>1 hour 30 minutes</i>	Supporting Orphans <i>1 hour 30 minutes</i>
Lunch	<i>1 hour</i>	<i>1 hour</i>	<i>1 hour</i>	<i>1 hour</i>
Session	Review from Section Two Review of HIV Transmission, Prevention, and Disease Progression <i>1 hour 30 minutes</i>	Strategies for Dealing with Health Professionals <i>45 minutes</i> Antiretrovirals <i>30 minutes</i>	Psychological Support for People Living with HIV/AIDS and Their Families People Living with HIV/AIDS Vignettes <i>1 hour 45 minutes</i>	Closing Evaluation <i>1 hour</i> String Spider Web and Closing Ceremony <i>1 hour</i>
Break	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
Session	The Life Tree Life Tree <i>1 hour 30 minutes</i> Medical Support for People Living with HIV/AIDS Common Illnesses Role-Play <i>1 hour</i>	Physical Support for People Living with HIV/AIDS and Their Families Caring for People Living with HIV/AIDS in the Home <i>1 hour 30 minutes</i>	<i>The previous session can be emotional. Trainers may want to have a counselor present and use the afternoon session for this purpose.</i>	
Evaluation	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
Total Time	<i>8 hours 45 minutes</i>	<i>8 hours 45 minutes</i>	<i>8 hours 30 minutes</i>	<i>6 hours 45 minutes</i>

Chapter 4: Seeking Medical Support from a Professional Service Provider

Sample
Lesson
Plan

Sample Lesson Plan

Time	Content	Methodology	Materials Needed	Evaluation
1 hour	Special Medical Concerns for People Living with HIV/AIDS Tuberculosis Pregnancy	Facilitator reads a statement about tuberculosis or pregnancy for people living with HIV/AIDS Participants decide whether the answer is “true” or “false” and stand under the appropriate sign. Each issue is discussed and the correct answer given	Large Signs - “True” - “False” Flipchart Markers Tape List of statements regarding tuberculosis and pregnancy	Correct answers in the “True/False Exercise” Active participation in the exercise
45 minutes	Strategies for Dealing with Health Professionals	Participants generate a list of questions people living with HIV/AIDS might ask a health worker upon receiving medications. These questions are discussed. Strategies for working with the health care system are summarized	Paper and pens for each participant Flipchart paper Tape	Active participation in the exercise Creation of effective question lists
30 minutes	Antiretrovirals Brief description of antiretroviral drugs	Facilitator uses the disease progression diagram in Chapter 12 to help briefly describe how antiretroviral drugs work	Disease Progression diagram(s) in Chapter 12 Flipchart paper Markers Tape	Active participation in the discussion

Chapter 4: Seeking Medical Support from a Professional Service Provider

Activities and Handouts for Seeking Medical Support from a Professional Service Provider

- **Special Medical Concerns for People Living with HIV/AIDS**
- **Strategies for Dealing with Health Professionals**
- **Antiretrovirals**

Activity **Special Medical Concerns for People Living with HIV/AIDS¹⁰**

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

- Describe the relationship between TB and HIV/AIDS
- Describe the relationship between pregnancy and HIV/AIDS
- Discuss symptoms and treatment of TB for people living with HIV/AIDS, including ways to prevent transmission to the rest of the family
- Describe special issues surrounding pregnancy for an HIV positive woman

Time allotted 1 hour

Preparation Before this session begins, it is important to do some research into issues surrounding TB and pregnancy for people living with HIV/AIDS in your local community. Investigate the treatment that is available for TB in your area and the strategies recommended for managing TB in the home. Also, investigate the resources available for HIV positive women who are pregnant. Some issues to explore include the availability of testing, antiretroviral therapy during pregnancy (whether available at a fee or in drug trials, if it is available at all), the possibilities for Caesarian delivery and the possible consequences, the recommendations around breastfeeding, and so forth. Use the information discovered through this local research to create a list of statements for use in this exercise. (It is best to create such a list out of the exact resources and information available locally, but a sample list of statements is listed at the end of the activity to help you get started.)

Prepare two signs, one that reads “True” and one that reads “False.” Hang them on opposite sides of the room, and ensure that the space between them is open and will accommodate the movement of the participants.

¹⁰ The *Special Medical Concerns for People Living with HIV/AIDS* and *Strategies for Dealing with Health Professionals* sections of this chapter were adapted with permission from the World Health Organization (WHO). *AIDS Home Care Handbook*. (Geneva: WHO, 1993).

Facilitation steps

1. Summarize some of the medical issues discussed in the last session. Suggest that there are two medical areas that we have not yet discussed at length that are of special concern. These issues are TB and pregnancy. Both of these conditions require special management for people living with HIV/AIDS. Although TB and pregnancy will usually require the intervention of health care workers, it is important that you, the caregivers, understand the many issues surrounding these two concerns, so that you may better advise and assist the families through these conditions.
2. Say that we may already have a great deal of knowledge about the special issues surrounding TB and pregnancy from our own work or from our experiences in the home. We have chosen to explore these topics by using an exercise that will help us to share the information and knowledge that everyone in the room already possesses.
3. Point out the words on the wall. Indicate that you will read out a statement about TB or pregnancy for people living with HIV/AIDS, and if the participants believe that the statement is true, they should stand under the “True” sign. If they believe it is false, they should stand under the “False” sign. If they are unsure or believe that the answer could be different in various contexts and situations, they might wish to stand in the middle.
4. Read the first statement, and give all participants a chance to choose their answers. When all have chosen, invite a few participants from the “False” side to explain why they have chosen that answer. Do the same for those under the “True” sign. Allow some debate to develop here so that the key issues around the question are thoroughly explored.
5. After all debate has been exhausted, clarify the “correct” answer to the statement and explain it. Ask for questions and ensure that all participants understand before beginning the process again with the next question.
6. Continue in this way until all statements have been finished or until it seems clear that many of the most important issues around pregnancy and tuberculosis for people living with HIV/AIDS have been covered.

Wrap-up

When wrapping up this exercise, remind participants that they are not expected to be experts when it comes to the management of tuberculosis and pregnancy in the home. Both of these conditions require the intervention of the health care system, and it is more important that caregivers understand the major issues, so that they are able to guide families to ask the most useful questions and provide the most helpful care to people living with HIV/AIDS.



Note to Trainers—

There are many ways to structure this discussion about TB and pregnancy for women living with HIV/AIDS. This interactive activity has been chosen because participants may have a hard time sitting and listening to more medical information after the weighty last session. If you wish to have a more formalized discussion around these important topics, however, consider having a charismatic health worker come and present the issues around TB and pregnancy in your area.

Activity **Strategies for Dealing with Health Professionals¹¹**

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

- List questions that people living with HIV/AIDS and their families might keep in mind when receiving medications or instructions from health care workers

Time allotted 45 minutes

Preparation Ensure that plenty of paper is available to each participant. Invite participants to move their seats to any comfortable position, and arrange the flipchart stand where the group can easily see it.

Facilitation steps

1. Referring back to the previous session, suggest that helping people living with HIV/AIDS and their families to manage the issues that come with tuberculosis and pregnancy can be difficult. There are many important points for them and their families to remember when interacting with any health worker, especially when receiving medicines or particular instructions that must be followed. As a caregiver, you can serve as a valuable resource for them and their families. You can foresee some of the issues that may come up and help to prepare the family to ask the appropriate questions and to help them to remember all of the advice given by health care personnel.
2. Indicate that we are going to take some time to think about the issues that may be important for people living with HIV/AIDS and their families to remember when working through the health care system, especially in terms of using medications. Suggest that it is essential when taking any medication to follow the instructions for their safe and effective use. Medicines not taken according to instructions can be useless and even harmful, causing further illness. Remember that there is some danger in the use of any medication. It can be very confusing for a person and his/her family when they are provided with several different medicines, all with different instructions. By thinking about some of the issues beforehand, you can better help the family for which you are providing care.

¹¹ Ibid.

3. If it has not yet been done, distribute paper and pens to all participants. Suggest that participants think about the many issues to keep in mind when taking medicine, or when receiving advice and instructions from health workers. Invite participants to write down every question that they can think of that may be useful to ask a health worker when receiving special medications or instructions. Allow 10-15 minutes for participants to individually write their lists.
4. When participants seem to have finished, invite each participant to turn to a partner and compare lists. Suggest that the pairs take about 10 minutes to review each other's lists, to discuss them, and to add any new questions that may come up.
5. Next, invite all participants to come back together into the larger group. Lead a discussion with the larger group about the types of questions people living with HIV/AIDS and their families should remember to ask when dealing with a health care provider. List the ideas on the flipchart as you discuss them. Some possibilities might include—
 - Why has this medicine been prescribed?
 - How will it help me?
 - What symptoms or illness will it address?
 - How should it be taken? Should it be taken on an empty stomach or with meals?
 - For how long should it be taken? Should I stop taking it after my symptoms go away or should I take it until it is finished? Should I come back for more when it is finished?
 - What side effects, if any, should I watch for? What should I do if I see such side effects?
 - Is there any special care for the medicine that I should remember? Should I keep it in a cool place out of the sunlight? Should I shake it before using it?
 - What if I vomit right after taking the medicine? Should I take more or just wait for my next dose?
 - What if I forget to take my medicine? Should I take two doses once I remember?
 - If prescribing more than one drug, will there be any negative interactions between the drugs? Should I watch for any side effects of this drug interaction?

- Will this medicine affect my ability to have sex?
 - If the person is already taking medication at home, such as birth control pills or painkillers, it is important to ask the health worker if there will be any interactions between those medicines and the ones being prescribed. Health workers often forget to ask questions that deal specifically with women's issues, such as whether or not she is using any birth control method. This can be dangerous, as some drugs will interact negatively with some kinds of birth control, and an unwanted pregnancy may result. It is important to remember to ask, and it is also important to tell the health worker if you are pregnant or might be pregnant whenever he/she is prescribing drugs.
 - If giving medicines to a child, ask for specific directions about how to deliver the medicines and doses appropriate for the child's size and weight.
 - What will happen if I do not take this medicine?
 - Is there another medicine that is just as effective but has fewer side effects, or costs less?
 - Will I have to take this medicine all my life?
 - How will I know if this medicine is working?
6. After thoroughly discussing the questions to ask about medications, ask participants if there are any other points that people living with HIV/AIDS and their families should remember to discuss with health workers during an appointment. Add any ideas to the above list. Some ideas might include—
- A person living with HIV/AIDS and his/her caregivers should be prepared to tell the health worker of any new symptoms or illnesses that they have been having since the last visit. (It may be helpful to keep a running list of questions and issues to discuss with health workers between visits, so they will be prepared when they see the health workers.)
 - If there is a good chance that the person will be seeing a different health worker every time he/she comes for an appointment, it is important to keep a history of illnesses, symptoms, medicines, reactions, and so on, from the time of first diagnosis. This will help the health worker to catch up on the patient's history before treating him or her.
 - For illiterate families, suggest that they draw an outline of the body and map where they feel pain between visits.

7. When wrapping up this part of the exercise, it may be helpful to suggest that people living with HIV/AIDS and their families try to work with the same health care providers every time they visit a clinic or doctor's office, if that is at all possible. Creating and maintaining a relationship with one or two health workers will ensure that they understand the history, particular circumstances, and so on, ultimately ensuring a better standard of care.

Wrap-up

Before transitioning into the discussion of ARVs, suggest that, as caregivers, we can use our creativity and our sense of organization to help people living with HIV/AIDS and their families learn to manage the health system. Remind the group that we can help them feel empowered to participate in their own health care by asking appropriate questions, developing strong relationships with health care providers, and understanding drug dosages and side effects in the home. That sense of empowerment will contribute to the overall psychological and physical sense of well being.

Activity Antiretroviral (ARV) Therapy

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

- Define “antiretroviral therapy”
- Describe how ARV therapy lengthens the honeymoon period for people living with HIV/AIDS
- List three benefits of using ARV therapy
- List three risks of ARV therapy
- Discuss any local access to ARV therapy

Time allotted 30 minutes

Preparation It is a good idea to explore your community’s access to ARV therapy a week or so before this session. Investigate any drug trials, low-cost programs, and so on that may be available in the area or in the nation. Compile this information for distribution to participants or simply prepare it for presentation in this session.

Hang the “Disease Progression Diagram” flipchart located in Chapter 12 on a visible wall, and ensure that the flipchart stand is in full view of the participants. If you did not use this as part of a review session prior to the training, you may want to take a few minutes to explain the diagram.

Facilitation steps

1. Suggest that we will spend the final 30 minutes of our discussion of medical support for people living with HIV/AIDS dealing with the topic of antiretroviral therapy. ARV therapy is the name given for the “AIDS drugs” that we often read about in the newspapers. Sometimes called the “drug cocktail,” or the triple combination therapy, or the “triple cocktail,” ARVs are not often found in our communities as yet, so we will not spend a great deal of time discussing these drugs. As we will discuss in Chapter 7, *Social Support for People Living with HIV/AIDS and Their Families*, there are many issues surrounding access to these expensive AIDS drugs, and activism around these issues may hasten their availability.
2. Suggest that we will limit our discussion to a few major points regarding these new drugs. First, ask participants to summarize the definition of “antiretroviral therapy.” A good definition might be—
 - Antiretroviral therapy is a name for treatment with drugs that stop HIV, the virus that causes AIDS, from reproducing and infecting

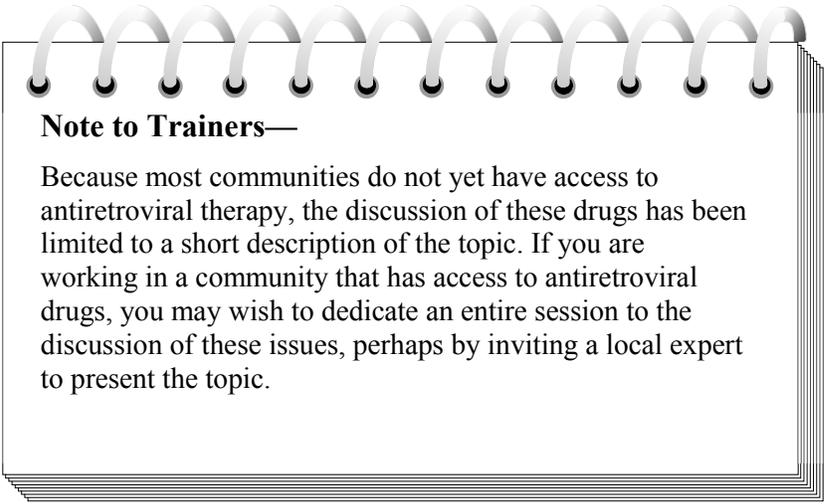
cells in the body. This effect may slow the progression of HIV disease in some people.

3. Using the “Disease Progression Diagram,” invite participants to show you where ARV therapy might be working in the progression of the disease. Point out the red line that symbolizes HIV viral load in the window period and in the honeymoon period (see page 12-314 for definitions). Suggest that ARVs attack HIV as HIV attacks the body throughout this period. These “AIDS drugs” invade HIV and try to keep it from reproducing itself. While the AIDS drugs are fighting the virus, it allows the antibodies to wage a better battle against the disease, and it allows the person to remain healthier longer. Indicate that the honeymoon period can thus continue for years, as HIV is not able to really take hold of the person’s immune system, as it would in a person not taking the ARV therapy.
4. Next, ask participants if ARVs offer a cure for HIV/AIDS. After hearing everyone’s perspectives, remind the group that these new drugs do not offer a cure for AIDS. It can be confusing, because people who are using these drugs look and feel healthy and it is sometimes even hard to find HIV antibodies in their systems. This can make it seem like the drugs have cured these people from HIV/AIDS. This is not true, however, and sooner or later, HIV seems to break through these new drugs, defeating them, and then the person develops AIDS. Because these drugs are so effective, it can take years, even decades, for this to happen, but it is important to emphasize that HIV is not gone from a person’s system, but rather, lying in wait in the bone marrow.
5. Next, ask participants to suggest some of the benefits of getting access to these new drugs. Some ideas might include—
 - Ability to live a longer, healthier life
 - Fewer orphans, because people are living longer
 - Reducing the risk of transmission from mother-to-child during pregnancy, delivery, and during breastfeeding
 - Reducing symptoms of HIV/AIDS
6. After discussing these benefits, ask participants to list some of the risks or drawbacks involved in using these drugs. Some ideas might include—
 - There are many side effects associated with these drugs, some of them quite painful or uncomfortable. These may include nausea, stomach cramps, diarrhea, headache, insomnia, vomiting, tingling around the mouth, muscle loss, high levels of fats, cholesterol, or glucose in the blood, and so on. These can have a negative impact on quality of life.

- ARV therapy sometimes involves taking 10-20 pills at different times of the day. This can sometimes affect quality of life.
- These drugs are very expensive and difficult to keep in supply. Many governments and drug companies are currently arguing about making these drugs available to more people at lower cost.
- Earlier development of drug resistance. This means that the HIV in your bloodstream might begin to figure out how to beat the medicine you are using. This can force someone to change the combination of drugs over and over, but HIV can eventually become resistant to all of them. There is a fear that someone who has developed such resistance may not be able to use any of the newer drugs or therapies.
- People living with HIV/AIDS using these drugs need to be monitored by a health care professional, to deal with side effects and resistance.
- Unknown long-term effects of using these drugs.

Wrap-up

Summarize the discussion of ARVs by providing any information you have collected about availability of ARV therapy in the community or in the nation. If participants want to talk about the issues surrounding access to these drugs, you might wish to defer the discussion until after conducting the activities in Chapter 7, in which we will discuss the various social support issues for people living with HIV/AIDS and orphans and vulnerable children.



Note to Trainers—

Because most communities do not yet have access to antiretroviral therapy, the discussion of these drugs has been limited to a short description of the topic. If you are working in a community that has access to antiretroviral drugs, you may wish to dedicate an entire session to the discussion of these issues, perhaps by inviting a local expert to present the topic.

On Tuberculosis and Pregnancy for People Living with HIV/AIDS

Sample Statements for the “True/False” Exercise

- Everyone, without exception, should seek assessment and health care if coughing for three weeks or more.

True. A cough that lasts more than three weeks should always be assessed for TB.

- Some possible negative reactions to anti-tuberculosis medicines might include reddening of the eyes, unusual itching, or a widespread rash.

True. It is important that those taking anti-tuberculosis medications watch for these signs and seek medical attention if they appear.

- TB is not catching.

False. TB is highly catching, or contagious. It is very important that everyone without exception—should cover their mouth when coughing—especially someone with TB. Further, it is important that everyone—without exception—should avoid being in an unventilated space with a person who has been coughing for more than three weeks. Lastly, all homes, health facilities, workplaces and other places where people meet should be ventilated—to make sure there is a way in and a way out for fresh air. These measures can reduce the risk of transmitting this highly contagious disease.

- There is no cure for TB.

False. TB can be cured with the correct treatment, which must be obtained from a health professional. Do not attempt to treat TB by yourself in the home.

- Once symptoms of TB have stopped, you may stop using anti-tuberculosis drugs.

False. It is important that those with TB take the entire cycle of treatment that has been prescribed to them to ensure that the TB will be totally cured. TB treatments usually include at least two different medicines. If only one is used, the bacterium that causes TB may become resistant (insensitive) to it. Treatment stopped too early is dangerous to both the individual and the community because this, too, can lead to the development of TB bacteria that can resist drugs. It is vitally important to ensure that people take all the medicines they are given for the treatment of TB, and that they complete the full course. Such medicines, if taken properly, will prevent this infection from spreading among people who live together.

On Tuberculosis and Pregnancy for People Living with HIV/AIDS, continued

- If someone has HIV infection, they are more likely to get TB.

True. In many parts of the world, by the time they reach adulthood most people have been infected by the bacterium that causes TB. However, if they are healthy their body's defenses—the immune system—will have prevented the bacteria from causing TB. The damage to the immune system caused by HIV means the immune defenses are weakened and that they can no longer keep the TB bacteria from making a person ill. The TB bacteria, which have remained quiet in the body for years in some people, now cause the disease called TB.

- Some common symptoms of TB are chronic cough, coughing up blood, and losing weight.

True. Other symptoms may include mild fever, sweating at night, a cough lasting more than three weeks which is worse just after waking up, pain in the upper back or chest, and loss of appetite. If someone has AIDS, they may also develop less usual TB symptoms, such as fever without a cough. TB can also infect the lymph nodes, especially in children—most often in the area of the neck and shoulders. Those infected nodes may become large lumps under the skin that open and drain pus, close for a time, then open and drain again.

- HIV infection and AIDS should be considered in every person with TB.

True. Because TB and AIDS have been shown to accompany each other very often, in many areas of the world it is possible that if someone has TB they are also infected with HIV. People with TB should consider asking their health care worker to test them for HIV if this has not already been suggested. (Before using this sample question and answer, it is important to confirm the situation in your local area. It is also important to note that not everyone who has TB necessarily has HIV/AIDS.)

- TB should be suspected if someone has AIDS and has respiratory or chest symptoms.

True. Because the possibility of having TB is so high if a person has AIDS, all people living with HIV/AIDS who have respiratory, chest, or general symptoms, which do not go away within three weeks, should go to a health care worker to be tested for TB. This is particularly true if someone lives in an area where TB is common. As TB is treatable with medicines, is highly dangerous if not treated, and can be passed on to others, it is important for people to get a prompt diagnosis through a sputum examination and/or a chest x-ray.

On Tuberculosis and Pregnancy for People Living with HIV/AIDS, continued

- There is no vaccine for TB.

False. In areas where TB is endemic, all newborn babies and young children (except those with HIV/AIDS) should be immunized against TB with Bacillus Calmette-Guerin (BCG) vaccine. This may cause a spot or slight wound at the point of injection, which will usually heal in some months without any treatment. The vaccine gives good protection against the serious childhood forms of the disease. However, if a child is ill at birth or has clinical symptoms of AIDS, they should not receive BCG vaccine.

- With the proper medication, TB can be cured in a week or two.

False. It can take many months to cure TB completely. When a person is treated at the hospital or clinic, they should then be sent home with enough anti-tuberculosis medicines to last for about one month or at least until their next scheduled clinic appointment. After returning home from the clinic or hospital, they should be seen by a health care worker and given a new supply of medicines every month. A TB patient should take their medications until the entire course is completed, otherwise symptoms will reappear and they will again become infectious to their families.

- A baby born to an HIV-infected mother will always get HIV.

False. Almost all babies born to an HIV-infected mother will test positive for HIV at birth, but this is because the mother's antibodies have been passed to the baby. It may take up to 18 months to be sure if the virus itself has been passed to the baby. Many babies are born to HIV-infected mothers and do not themselves become infected. This can depend on a number of factors, including the amount of HIV in the mother's system at the time of pregnancy.

- Using a condom during pregnancy and breastfeeding can help an HIV-infected mother to reduce the risk of passing HIV to her baby.

*True. The use of a condom helps a pregnant or breastfeeding woman to avoid re-infection with STIs or with HIV. This can substantially reduce the risk of passing HIV to the baby, as the amount of HIV in the body (viral load) can be a factor in transmitting HIV to an unborn baby (fetus) or breastfeeding infant. In fact, if a woman is pregnant or breastfeeding when **first** infected with HIV, her chances of passing the virus on to her baby are greatly increased. It is especially important for husbands and wives to understand this, because often, married couples practice abstinence during later stages of pregnancy or for six weeks or so after birth. It is not uncommon for husbands to seek sexual release outside of marriage during these times, and most important for them to use condoms if they do. Should they contract HIV during these abstinent periods within their marriage, their viral load will be very high when they resume having sex with their wives. This means that they greatly increase the chance of passing HIV on to their unborn or newborn child.*

On Tuberculosis and Pregnancy for People Living with HIV/AIDS, continued

- Once a woman realizes she is HIV positive, it is easy for her to decide not to get pregnant so she will not pass HIV on to a baby.

False. Whether or not a woman is aware of her HIV status, she may often have little control over whether or not she will get pregnant. First, women usually do not have as much decision making authority as men, and sometimes may not be able to make decisions regarding whether or not to have sex, whether or not to use a condom or other family planning method, and so on. Also, in many areas, a woman's standing in the community and that of her family depend on her ability to bear children. In such cases, it may be socially and culturally unacceptable for her to take the steps to avoid becoming pregnant, such as abstaining from sex or using a condom or any other form of birth control. In many areas, safe and legal abortion may not be available as an option for an HIV positive woman who becomes pregnant, and she may resort to unsafe, illegal, or self-induced abortion, putting her life at risk.

- HIV positive women can pass HIV on to their infants in three ways: during pregnancy, during delivery, and through breastfeeding.

True. The most common way to pass HIV to an infant is during delivery (because of the presence of excessive amounts of blood and bodily fluids), and this is one of the reasons that a Caesarian section is recommended (where it can be done safely with minimal chance of post-operative infection). Although most cases of mother-to-child transmission occur during either pregnancy or delivery, studies indicate that about one-third of cases are a result of breastfeeding (see below for recommendations).

- Because breastfeeding might pass HIV on to her child, a woman should not breastfeed if she knows she is HIV positive.

It depends on the situation. Every woman needs to be educated as to the alternatives to breastfeeding in her area. After being provided with all of the choices, it is an individual decision of each woman whether to breastfeed her baby. Some of the issues to be considered include: the availability of an alternative, equally nutritious option for milk, the availability of clean water, the affordability of using this substitute for the entire time for which is it required, the likelihood of malnutrition in her area, and the stigma that may be associated with not breastfeeding. If an HIV positive woman chooses to breastfeed, some of the ways to reduce the risk of transmission include using a condom when having sex throughout the time of breastfeeding, and exclusively breastfeeding (not giving the baby any other food or liquid, not even water) for six months. This means the infant should not be given food while breastfeeding, as it may increase the risk of infection by opening small tears in the child's esophagus. After six months, the child should be weaned abruptly.

On Tuberculosis and Pregnancy for People Living with HIV/AIDS, continued

- An HIV positive woman who becomes pregnant is putting her own health in jeopardy.

True. Pregnancy can be an enormous strain on a woman's body, and pregnancies, especially frequent ones, can shorten a woman's honeymoon period and make her sicker faster. This is why the news that she is pregnant can be especially distressing to a woman, as she fears both that her child will be born infected and that the pregnancy will take a toll on her own health.

- If a woman has AIDS, she is more likely to have a complicated pregnancy.

True. Some of the possible problems include—

- *Miscarriage—loss of the baby during pregnancy*
 - *Fevers and infections*
 - *Premature labor—delivery occurring earlier than it should, often causing the death of the baby*
 - *A smaller baby—the weight at birth of even a full-term baby can be much lower than normal; babies with a low birth weight are more likely to have problems later*
 - *Infections after birth—these are much more common in women with AIDS and can be life-threatening; women who are HIV positive might have unexpected severe infections after delivery which do not respond to the usual treatments with antibiotics*
- After delivery or miscarriage, a woman should seek medical help if she develops a fever.

True. Women should seek medical attention after delivery or miscarriage if they develop a fever, have bad-smelling vaginal discharge, or have vaginal discharge with fresh blood. These may be signs of a dangerous infection. Caregivers can help women to avoid some of these infections by encouraging good hygiene after delivery or miscarriage, especially in the genital area. Washing with soap and water should be done twice daily.

Chapter 5

Physical Support for People Living with HIV/AIDS and Their Families

“...It is becoming increasingly clear to public health officials that home or community care is not about ‘decongestion of hospital beds’ but about the provision of a comprehensive range of medical, nursing, counseling, spiritual, as well as nutritional care, which must exist from hospital to home, (continuum of care). The role of family and community members in this continuum of care has equally been realized, as has the need to support, supervise, and encourage them in their role.”

—NOERINE KALEEBA, FOUNDING MEMBER,
THE AIDS SERVICE ORGANIZATION (TASO), UGANDA

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Chapter 5: Physical Support for People Living with HIV/AIDS and Their Families

Key Questions

- Can family members contract HIV by caring for people living with HIV/AIDS in the home?
- How can we best prevent transmission of HIV to caregivers?
- Can we keep people living with HIV/AIDS healthier by keeping our homes cleaner?
- How can family and community members provide physical support for people living with HIV/AIDS?

I ntroduction

When most people think of home care for people living with HIV/AIDS, managing the physical symptoms of illness is usually the first thing that comes to mind. As we have highlighted in the last few sessions, care and support represents much more than the management of illness. Nevertheless, there may come a time when care for illness becomes necessary in the home. It is therefore important for caregivers to have a basic understanding of the progression of HIV/AIDS in the body, and of ways to intercede to help people living with HIV/AIDS remain healthy at various points in the disease cycle.

Family members often have two primary concerns when caring for people living with HIV/AIDS in the home: 1) ensuring that other members of the family do not contract HIV as a result of caregiving; and 2) ensuring that the person in their care remains as free as possible from infection and further illness.

This session, *Physical Support for People Living with HIV/AIDS and Their Families*, begins with a review of the basic facts of transmission so that caregivers understand how best to prevent HIV

infection in the home. Universal precautions are also reviewed, with specific steps to keep family members safe from HIV transmission as a result of caregiving. Strategies are also discussed to keep the home hygienic so that people living with HIV/AIDS can avoid unnecessary infections.

Another important aspect of home-based care is providing care for the caregivers. For family members, taking care of people living with HIV/AIDS or orphans and vulnerable children can be very emotionally draining and physically tiring. Community home care programs can relieve some of the burden on the family. However, dealing with the inevitability of death and the emotions of families can be very draining to the community home caregiver. Programs need to build in support and opportunities for home-based caregivers to meet with each other to talk about their work, process their own feelings of grief when a person dies, and renew each other and their commitment. The fact that women bear the brunt of home care necessitates community-wide involvement to share the burden, not only by NGOs, FBOs, and CBOs, but also by men. This training can be the first step in that process and we provide an exercise that builds trust and confidence among the participants.

Chapter 5: Physical Support for People Living with HIV/AIDS and Their Families

Objectives

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

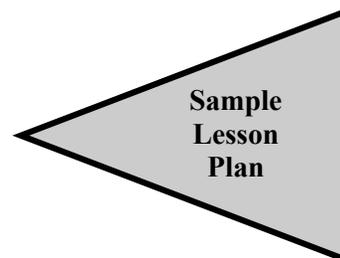
- Identify activities that pose a risk of HIV transmission
- List at least five ways to prevent HIV infection among caregivers
- Identify at least five ways to keep the home hygienic to help people living with HIV/AIDS avoid unnecessary infections

Home Care: The Power of Our Community

Training Schedule: Section 1

Schedule	Day One	Day Two	Day Three	Day Four
	Registration <i>30 minutes</i>	Recap <i>30 minutes</i>	Recap <i>30 minutes</i>	Recap <i>30 minutes</i>
Session	The Power of Our Community Introductions, Goals, and Objectives Workshop Structure <i>1 hour 30 minutes</i>	Medical Support for People Living with HIV/AIDS (cont.) Common Illnesses Role-Play <i>1 hour 45 minutes</i>	Nutritional Needs for People Living with HIV/AIDS and Their Families We Are What We Eat <i>1 hour</i> Nutritional Needs for People Living with HIV/AIDS <i>1 hour</i>	Preparing for Goodbye Supporting People Living with HIV/AIDS <i>1 hour 30 minutes</i>
Break	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
Session	Breathe in Life, Breathe Out Trouble The Power of Our Community <i>1 hour 30 minutes</i>	Oral Rehydration Solution and Thermometer Use <i>1 hour</i> Seeking Medical Support from a Professional Service Provider Special Medical Concerns for People Living with HIV/AIDS <i>1 hour</i>	Social Support for People Living with HIV/AIDS and Their Families Small Groups on Social Issues <i>1 hour</i> Plenary on Social Issues <i>1 hour 30 minutes</i>	Supporting Orphans <i>1 hour 30 minutes</i>
Lunch	<i>1 hour</i>	<i>1 hour</i>	<i>1 hour</i>	<i>1 hour</i>
Session	Review from Section Two Review of HIV Transmission, Prevention, and Disease Progression <i>1 hour 30 minutes</i>	Strategies for Dealing with Health Professionals <i>45 minutes</i> Antiretrovirals <i>30 minutes</i>	Psychological Support for People Living with HIV/AIDS and Their Families People Living with HIV/AIDS Vignettes <i>1 hour 45 minutes</i>	Closing Evaluation <i>1 hour</i> String Spider Web and Closing Ceremony <i>1 hour</i>
Break	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
Session	The Life Tree Life Tree <i>1 hour 30 minutes</i> Medical Support for People Living with HIV/AIDS Common Illnesses Role-Play <i>1 hour</i>	Physical Support for People Living with HIV/AIDS and Their Families Caring for People Living with HIV/AIDS in the Home <i>1 hour 30 minutes</i>	<i>The previous session can be emotional. Trainers may want to have a counselor present and use the afternoon session for this purpose.</i>	
Evaluation	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
Total Time	<i>8 hours 45 minutes</i>	<i>8 hours 45 minutes</i>	<i>8 hours 30 minutes</i>	<i>6 hours 45 minutes</i>

Chapter 5: Physical Support for People Living with HIV/AIDS and Their Families



Sample Lesson Plan

Time	Content	Methodology	Materials Needed	Evaluation
<i>1 hour</i>	<p>Caring for People Living with HIV/AIDS in the Home</p> <p>Review of HIV transmission</p> <p>Protecting caregivers from transmission of HIV</p> <p>Keeping the household sanitary to prevent unnecessary infections</p> <p>The “Glove Game”</p>	<p>Participants brainstorm methods of protecting caregivers and family members from HIV transmission.</p> <p>Participants then discuss hygienic practices for keeping the household sanitary. To review, the group plays the “Glove Game.” Facilitator calls out various activities that may or may not transmit HIV.</p> <p>Participants raise a gloved hand if the activity might transmit HIV, and a bare hand if it will not transmit HIV.</p>	<p>Flipchart</p> <p>Markers</p> <p>Tape</p> <p>Latex gloves or plastic bags</p> <p>Sharps container, if possible</p> <p>List of activities that may or may not transmit HIV</p>	<p>Correct answers to the review game</p>

Chapter 5: Physical Support for People Living with HIV/AIDS and Their Families

Activities and Handouts for Physical Support for People Living with HIV/AIDS and Their Families

- **Caring for People Living with HIV/AIDS in the Home**

Activity **Caring for People Living with HIV/AIDS in the Home**

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

- Identify activities that pose a risk of HIV transmission
- List at least five ways to prevent HIV infection among caregivers
- Identify at least five ways to keep the home hygienic to help people living with HIV/AIDS avoid unnecessary infections

Time allotted 1 hour

Preparation Arrange the chairs so that participants are in a circle with a small gap for the flipchart stand. Be sure to have at least one latex glove for each of the participants for use in the “Glove Game.” It is also helpful to have some heavy plastic or metal container fashioned into a sharps container to use as a visual aid. This can be an actual sharps container or simply an old coffee container. Punch a hole in the plastic top large enough to insert a needle. Lastly, provide at least one example of a barrier available in the local community that can be used if latex gloves are not available (for example, plastic shopping bags). Stress that one’s risk is close to zero, unless one has a cut/sore.

Facilitation steps

1. Welcome the group back to the session and briefly review the “Life Tree.” Remind the group that we are focusing on a few key branches of the “Life Tree.” We will have a discussion for the next few sessions on physical and medical support, getting into psychological support later. Direct the group’s attention to the “physical support” branch of the “Life Tree.” Suggest that when most people think of home care, they think of supporting their physical and medical needs. Emphasize again that, as HIV/AIDS carries a social stigma and has such widespread consequences for the overall well being of the family, home care requires attention to far more than just the needs brought on by illness. Nevertheless, it is important to focus on physical and medical needs as care of people living with HIV/AIDS will necessarily require an understanding of the opportunistic infections brought on by HIV.
2. Suggest that we will spend this session focusing on physical support. Our discussion will start with a brief review of the precautions that a caregiver should take to remain safe from HIV infection and to keep the home healthy and hygienic. Next we will look at nutritional needs and strategies for keeping people living with HIV/AIDS healthy.

3. Suggest that most caregivers have two major concerns. The first is how to prevent HIV transmission from the people living with HIV/AIDS to anyone else in the family or household. The second is how to maintain a safe home environment that does not expose the person living with HIV/AIDS to unnecessary infections.
4. In order to avoid infection, it is important to remember the ways in which HIV is transmitted. Briefly review the ways HIV is transmitted with participants—
 - Vaginal or anal sex
 - Possibly oral sex
 - Sharing needles or other sharp instruments such as razors
 - Blood transfusions of untested blood (emphasize that most countries now test blood for HIV so most sources are safe)
 - Contact with infected blood, semen, vaginal secretions through open cuts/sores
 - From mother to infant during pregnancy, during delivery, or through breastfeeding

Clarify any questions that may come up during this brief brainstorm. Suggest that since HIV is transmitted in such specific ways, it is easy to avoid infection with the virus. (If you find that participants do not have a clear understanding of transmission, or believe certain myths about HIV, such as that it can be transmitted by mosquitoes, be sure and spend the time to go over the basics facts of transmission and dispel the myths. Further information/training sessions can be found in Section 2: *The Basics of HIV/AIDS.*) *Be sure to emphasize that HIV is a very weak virus and cannot survive outside the human body for long. Washing with soap and hot water, or rinsing with a bleach solution easily kills it.*

6. Reinforce to participants that there is no risk of acquiring HIV from people living with HIV/AIDS in a home care situation provided that the caregivers follow a few simple rules. Ask participants to brainstorm these practices, and fill in any remaining points from the following list—
 - When handling blood or any of the fluids that transmit HIV (blood, semen, vaginal fluids, breast milk, and so on), you must create some kind of a barrier between that fluid and your skin. Discuss local barriers that may prove effective in blocking these fluids. Some possibilities may include plastic bags from sugar or other products, thick leaves, latex gloves, and so on.

- Clean up blood spills immediately using gloves or barriers and wipe with a bleach and water solution and let it stand for 20 minutes, then dispose of soiled items in plastic bags.
- If a glove should tear, wash hands with soap and hot water for five minutes.
- Proper disposal of the barrier is also very important, make sure you do not touch the dirty sides of gloves or other barriers when removing them. So is washing your hands thoroughly after the event.
- Wash your hands with soap and water after changing soiled bed sheets and clothing.
- Keep wounds covered. Both caregivers and the person living with HIV/AIDS should cover any open wounds they may have, especially on their hands or other places likely to have contact with other people, their bedding, or clothing. Cover open wounds with a bandage or cloth.
- Keep bedding and clothing clean. This will help keep people who are ill comfortable and prevent skin problems. If you use barriers when handling these fabrics and wash your hands thoroughly, the risk of transmission through contact with soiled bedding or clothing is extremely low. To clean clothing or sheets stained with blood, diarrhea, or other body fluids—
 - Keep them separate from other household laundry
 - Holding an unstained part, rinse off any blood or stool with water—be particularly careful if there are large amounts of blood, such as after childbirth
 - Wash in warm soapy water, or clean with bleach
 - Hang to dry and fold or iron as you would normally
- Do not share sharp skin-piercing instruments. Do not share toothbrushes, razors, needles, or anything else that can cut or come into contact with blood. If it is necessary to share these types of objects, boil them for at least 20 minutes in water prior to use.
- Put used injection needles in puncture-proof containers. (Pass around the sharps container or other sample container.) Do not recap needles, as this is the most common way that health workers have infected themselves.
- If a person you are caring for begins to bleed, hand them a cloth to stop the bleeding themselves until medical help arrives.

- If you are in a situation where blood or other fluids may splatter into your face, for example, if helping with childbirth, cover your eyes with glasses and your nose and mouth with a mask (if possible) or tie a cloth over your mouth and nose.
 - Keep a first aid kit with latex gloves or plastic barriers, bandages, and antiseptic available at your school, home, or work site.
 - If you do become exposed to potential HIV infection, contact a medical officer immediately for possible prophylactic treatment. Be sure not to treat the person whose blood you have touched only as a possible infector, but show concern for their health as well.
7. After reviewing ways to avoid transmission of HIV in the home, move into a discussion of household hygiene. As we know, people living with HIV/AIDS have weakened immune systems, and are less able to fight off infections. It is important to maintain an environment that will cut down on germs that may cause illness. Suggest that there are a few simple health practices that dramatically improve the living environment and help people living with HIV/AIDS remain free from unnecessary infections. Ask participants to brainstorm these practices, and fill in any remaining points from the following list—
- The best way to prevent transmission of infection is to wash your hands frequently with soap and water and to dry them well. Always wash your hands before cooking, eating, feeding another person, and giving medicines. Always wash your hands after using a toilet, changing soiled bed sheets or clothing, doing laundry, blowing your nose, coughing, and so on.
 - Use clean water whenever possible. This may require boiling.
 - Wash bed linen, towels, and clothes with soap and water.
 - Store food properly to prevent it from spoiling and causing infection.
 - Wash drinking cups and utensils before sharing them, especially if someone in the family is sick with a cold, flu, etc.
 - Cover your mouth when sneezing or coughing.
 - Avoid spitting or always spit into a container, and not on the ground.
 - Kiss babies on the top of their heads rather than on the lips.
 - Carefully wash all raw fruits and vegetables with clean water.

- Wash objects that a child or infant frequently puts in its mouth with soap and clean water.
- Dispose of waste properly. This may include using a pit latrine, or burning or burying objects. Be sure to keep dirty objects such as used tissues out of the reach of children.
- If malaria is common in your area, use bed nets (mosquito nets) impregnated with insecticide or a sheet to protect your family while they sleep. Remember to cover the baby's cradle as well. Use insecticide sprays to protect your home and body from any mosquitoes. Drain any standing water that may serve as a mosquito breeding ground.

Wrap-up

To summarize the points discussed in this session, you might wish to play the "Glove Game." Provide each participant with a latex glove (or other barrier found locally, such as a plastic bag). Indicate that they should place the barrier on one of their hands, while leaving the other bare. Say that you will call out different activities or situations. Participants should raise the gloved hand if the activity requires the use of some kind of barrier against HIV infection. They should raise the bare hand if the activity requires no barrier. Before starting the game, demonstrate how many activities one can do while wearing a glove or bag, such as holding a pen and writing and tying one's shoes. A suggested list of situations can be found on the following page.

The Glove Game—Suggested Situations

- When dressing a bleeding wound (glove)
- When shaking hands with a person you know to have AIDS (hand)
- When cleaning blood off of the floor (glove)
- When cleaning vomit or stool from the floor of your home (glove—emphasize that this is mostly a precaution in case there is blood in the vomit or stool, as there is not enough HIV present in vomit or stool to cause infection; but there are other infectious diseases in vomit and stool that one would want to avoid catching)
- When wiping the tears from the face of an HIV positive person (hand)
- When having sex (glove—remind participants that the “glove” is a condom)
- When lifting a person who is ill (hand—unless there are open sores present, check to see first)
- Changing diapers (nappies) of a sick baby (glove—emphasize that this is mostly a precaution in case there is blood in the feces or diarrhea, as there is not enough HIV present in feces or diarrhea to cause infection; but there are other infectious diseases in feces and diarrhea that one would want to avoid catching.)
- When cleaning sheets that have blood on them (glove)
- When bathing a person who is ill (hand—unless there are open sores on the person, check to see first)
- When cleaning the sheets and pillowcases of an HIV positive person (hand)

**Chapter
6**

**Nutritional Needs for People
Living with HIV/AIDS and
Their Families**

“Food isn’t a magic bullet. It won’t stop people dying of AIDS, but it can help them live longer, more comfortable and more productive lives.”

—WILLIAM CLAY
FOOD & AGRICULTURAL ORGANIZATION, FOOD AND NUTRITION DIVISION

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Chapter 6: Nutritional Needs for People Living with HIV/AIDS and Their Families

Key Questions

- What are the basic food groups? Identify examples of local foods that fall into each food group.
- What are the benefits of eating a balanced diet for a person living with HIV/AIDS?
- List the special dietary needs of a person living with HIV/AIDS.
- What can be done in the house to prevent food-borne illnesses?

Introduction

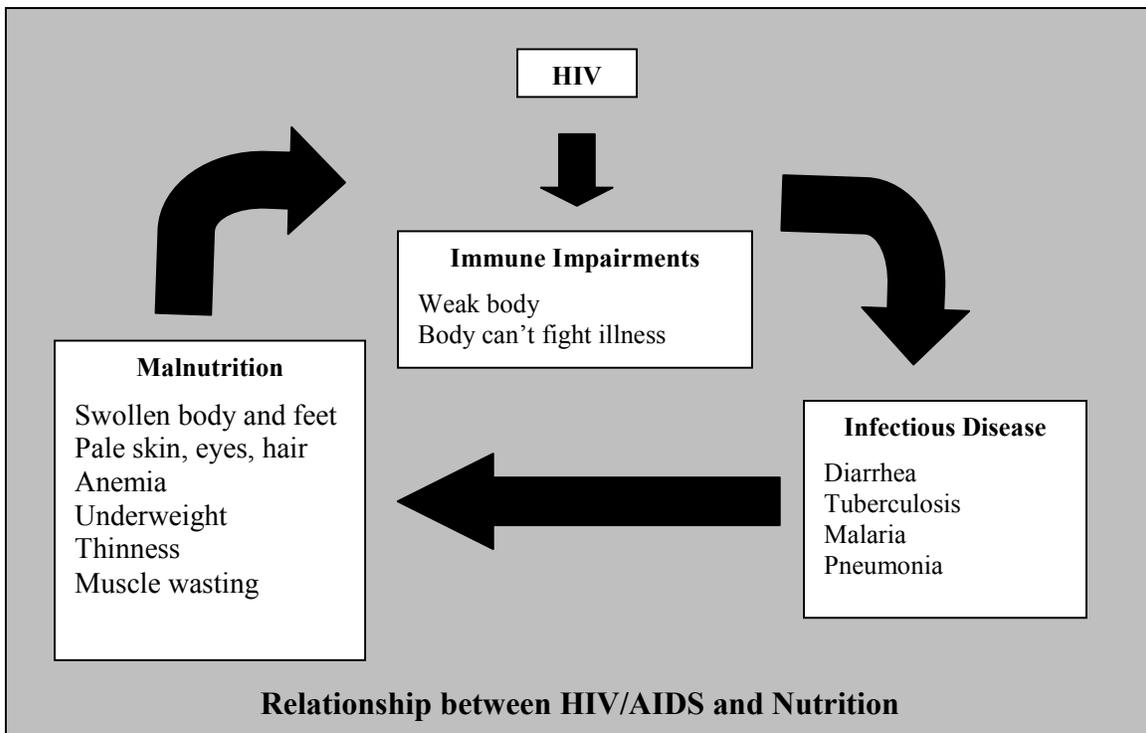
The links between nutrition and infection are well established. Good nutrition is essential for achieving and preserving health while helping the body to protect itself from infections. A well balanced diet provides energy and nutrients our body needs to stay alive, move and work; to build new cells and tissues for growth, maintenance and repair; to fight and resist infections. When the body does not get enough of the right food, it becomes weak and cannot develop or function properly. Similarly, the body cannot effectively fight infections. Extreme cases of no food, or not enough of the right food, will lead to malnutrition.

When a family member is infected with HIV/AIDS, the effects are felt by the entire household. When an adult member (head of household) becomes ill, agricultural production and family income declines, affecting the availability, and access to food. This puts the family at risk for malnutrition and therefore increased vulnerability to infection; time and household resources are consumed in an effort to care for sick family members; and partners risk becoming infected with HIV. Discrimination, social marginalization, and the burdens of childcare magnify their problems.

Providing nutritional care and support for people living with HIV/AIDS is an immediate and essential need that when met, allows HIV/AIDS infected households to live in dignity and security. Good nutritional status is very important for a person infected with HIV as it increases resistance to infection and disease, improves energy, and thus makes a person generally stronger, more comfortable and productive. Education about nutrition is an essential first step in ensuring good nutritional status. People living with HIV/AIDS, household members, and supporting community members learn how to adapt through choice, cultivation, storage, and preparation of food.

Relationship between HIV/AIDS and Nutrition

HIV attacks and impairs the body's natural defense system (immune system) against disease and infection. In the early stages, a person may show no visible signs of illness, but as the disease progresses, bacteria and parasites take advantage of the "opportunity" to further weaken the body and cause various illnesses such as pneumonia, tuberculosis, oral thrush, diarrhea, and weight loss (As discussed in Chapter 3). These infections can lower food intake because they reduce appetite, and can interfere with the body's ability to absorb nutrients from food. As a result a person may become malnourished, lose weight, and become weak. Malnutrition leads to immune impairment, worsens the effect of HIV, and contributes to the rapid progression to full blown AIDS (FANTA Project, *HIV/AIDS: A Guide for Nutrition, Care and Support*). It is important to note here that the amount of time it takes for HIV infection to progress into full-blown AIDS depends on the general health and nutritional status before and during the time of HIV infection (WHO, *FAO Living Well with AIDS*).



Source: Food and Nutrition Technical Assistance Project (FANTA). *HIV/AIDS A Guide For Nutrition, Care, and Support*. (Washington, DC: Academy for Educational Development, 2001).

Caregivers need to be aware of weight loss, a common sign of the onset of clinical AIDS, and ensure that nutritional needs are met. A healthy and balanced diet should be one of the goals of counseling and care for people at all stages of HIV infection. An effective program of nutritional care and support will improve the quality of life of a person living with HIV/AIDS by—

- Maintaining body weight and strength
- Replacing lost vitamins and minerals
- Improving the function of the immune system and the body's ability to fight infection
- Extending the amount of time from infection to the development of AIDS
- Improving response to treatment
- Reducing time and money spent on health care
- Keeping HIV-infected people active, allowing them to care for themselves and their families
- Keeping HIV-infected people productive, able to work, grow food, and contribute to the income of their family

This session aims at teaching caregivers how to better handle the nutritional needs of a family, including those living with HIV/AIDS.

Relationship between Antiretroviral (ARVs) Drugs and Nutrition¹²

Although access to ARVs is limited at this time, there are new commitments by both pharmaceutical companies and governments that promise to make this treatment more widely available. Therefore, the relationship between ARVs and nutrition needs to be considered. Diet can significantly influence the effectiveness of ARV therapy in the treatment of HIV/AIDS. Certain combinations of food and medicine may slow down ARV therapy effectiveness, block nutrient delivery to the body, or cause dangerous side effects. Certain foods can also affect the way ARVs are absorbed by the body. Drug side-effects such as nausea, taste changes, and loss of appetite, may make it harder for the person to eat, while diarrhea and vomiting may increase nutrient loss. People living with HIV/AIDS in resource-limited settings may be unable to follow the best food and nutrition recommendations for ARV therapy due to lack of access to required foods. These factors could in the end interrupt the drug regime, which leads to substantial decline in health, increased occurrence of opportunistic diseases, and faster progression of HIV/AIDS. A person should always receive counseling before starting on drug therapy that touches on all issues surrounding ARVs, including nutrition.

¹² Castleman, Tony, Seumo-Fosso, Eleonore, and Cogill, Bruce. *Food and Nutrition Implications of Antiretroviral Therapy in Resource Limited Settings*. (Washington, DC: AED, 2002).

Chapter 6: Nutritional Needs for People Living with HIV/AIDS and Their Families

Objectives

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

- Describe the importance of eating enough food
- Describe what constitutes a balanced diet
- List the basic food groups and identify examples of local foods that fall into each food group
- Describe the reasons for increased nutrient needs for people living with HIV/AIDS
- Identify the special nutritional needs for people living with HIV/AIDS
- Advise or demonstrate good nutritional practices for people living with HIV/AIDS
- Plan a daily sample menu for a person living with HIV/AIDS, including those displaying symptoms such as diarrhea, lack of appetite, nausea/vomiting, sore mouth, etc.
- Demonstrate proper food hygiene measures to minimize risk of food-borne infections

Important Terms

Absorption	The process whereby nutrients pass into the bloodstream for use by the body
Calorie	Unit of food energy
Candida	The name of a fungus that causes oral thrush - a common infection of the mouth in people with AIDS
Constipation	A condition when the bowels do not function properly and a person has difficulty in passing stools (defecating); this may be caused by a diet low in fiber, a symptom of illness or a side-effect of medicines
Dehydration	The excessive unhealthy loss of water and salts from the body, often during diarrhea
Diarrhea	The frequent passing of watery feces (stools) - at least three in a day
Digestion	The process in the stomach and intestine in which food is broken down and nutrients released into the body
Food security	A situation that exists when all people, at all times, have physical, social and economic access to sufficient, safe and nutritious food that meets their dietary needs and food preferences for an active and healthy life
Healthy and balanced diet	Consumption of an adequate amount and variety of foods including, as appropriate, staples, legumes, animal products, fruit, vegetables, nuts, fat and oils, and sugar/sugar-containing foods, sufficient to meet one's energy and nutrient needs
Kilocalorie	Unit used to measure food energy 1000 units of food energy (1000 calories = 1kcal)
Macronutrients	Macronutrients are the three nutrients that provide calories used for energy in the body; these three nutrients include: carbohydrates, protein, and fat.
Malnutrition	An abnormal condition in the body caused by lack of, too much of or imbalances in energy, protein and/or other nutrients; malnutrition in this manual refers to: a) lack of food energy (undernutrition); and b) lack of nutrients
Micronutrients	The vitamins, minerals and certain other substances that are required by the body in small amounts; they are measured in milligrams or micrograms
Nausea	Feeling unwell and sick in the stomach
Nutrient	Nourishing substance contained in foods that is released during digestion

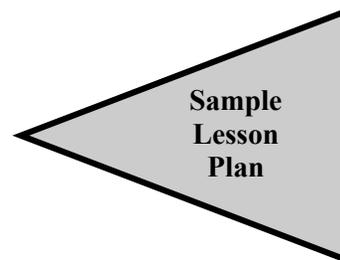
Nutrition	The science of food and how it is used by our bodies to grow, work, play, maintain health and resist disease
Refined cereals	Foods containing cereals such as wheat, rice or maize that have been processed to remove all or part of the husks; refined (processed) foods are low in fiber
Staple foods	Foods that form the main part of the diet, usually cereals such as maize, rice, wheat and millet or root crops, such as yams, cassava and potatoes
T & B cells	T & B cells are types of white blood cells; taking a count of these cells can help diagnosis an immunodeficiency disease, such as HIV, and to monitor a person's response to different therapies (see Chapter 12 for more in-depth definition).
Vitamins	A group of naturally occurring substances that are the micronutrients needed in small amounts by the body to maintain health

Home Care: The Power of Our Community

Training Schedule: Section 1

Schedule	Day One	Day Two	Day Three	Day Four
	Registration <i>30 minutes</i>	Recap <i>30 minutes</i>	Recap <i>30 minutes</i>	Recap <i>30 minutes</i>
Session	The Power of Our Community Introductions, Goals, and Objectives Workshop Structure <i>1 hour 30 minutes</i>	Medical Support for People Living with HIV/AIDS (cont.) Common Illnesses Role-Play <i>1 hour 45 minutes</i>	Nutritional Needs for People Living with HIV/AIDS and Their Families We Are What We Eat <i>1 hour</i> Nutritional Needs for People Living with HIV/AIDS <i>1 hour</i>	Preparing for Goodbye Supporting People Living with HIV/AIDS <i>1 hour 30 minutes</i>
Break	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
Session	Breathe in Life, Breathe Out Trouble The Power of Our Community <i>1 hour 30 minutes</i>	Oral Rehydration Solution and Thermometer Use <i>1 hour</i> Seeking Medical Support from a Professional Service Provider Special Medical Concerns for People Living with HIV/AIDS <i>1 hour</i>	Social Support for People Living with HIV/AIDS and Their Families Small Groups on Social Issues <i>1 hour</i> Plenary on Social Issues <i>1 hour 30 minutes</i>	Supporting Orphans <i>1 hour 30 minutes</i>
Lunch	<i>1 hour</i>	<i>1 hour</i>	<i>1 hour</i>	<i>1 hour</i>
Session	Review from Section Two Review of HIV Transmission, Prevention, and Disease Progression <i>1 hour 30 minutes</i>	Strategies for Dealing with Health Professionals <i>45 minutes</i> Antiretrovirals <i>30 minutes</i>	Psychological Support for People Living with HIV/AIDS and Their Families People Living with HIV/AIDS Vignettes <i>1 hour 45 minutes</i>	Closing Evaluation <i>1 hour</i> String Spider Web and Closing Ceremony <i>1 hour</i>
Break	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
Session	The Life Tree Life Tree <i>1 hour 30 minutes</i> Medical Support for People Living with HIV/AIDS Common Illnesses Role-Play <i>1 hour</i>	Physical Support for People Living with HIV/AIDS and Their Families Caring for People Living with HIV/AIDS in the Home <i>1 hour 30 minutes</i>	<i>The previous session can be emotional. Trainers may want to have a counselor present and use the afternoon session for this purpose.</i>	
Evaluation	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
Total Time	<i>8 hours 45 minutes</i>	<i>8 hours 45 minutes</i>	<i>8 hours 30 minutes</i>	<i>6 hours 45 minutes</i>

Chapter 6: Nutritional Needs for People Living with HIV/AIDS and Their Families



Sample Lesson Plan

Time	Content	Methodology	Materials Needed	Evaluation
<i>1 hour</i>	<p>We Are What We Eat: Healthy and Balanced Nutrition for Growth, Work, and Play</p> <p>Importance of food</p> <p>A balanced diet</p> <p>Basic food groups</p> <p>How local foods fit into these groups</p>	<p>The session will start with a group discussion leading into a discussion of macro- and micro-nutrients</p> <p>Secondly, the participants will work in groups to translate this information into daily meal plans</p>	<p>Markers</p> <p>Flipchart labeled: “Micronutrient” and “Macronutrient”</p> <p>Samples of food packaging or containers</p> <p>Sheets of paper</p> <p>Handout “Healthy and Balanced Nutrition for Growth, Work, and Play”</p> <p>Cards with the words: vitamin, mineral, fat, carbohydrate and protein</p>	<p>Participants should be able to describe the importance of food, a balanced diet, and the basic food groups</p>
<i>1 hour</i>	<p>Nutritional Needs for People Living with HIV/AIDS</p> <p>Nutritional needs for people living with HIV/AIDS</p> <p>Sample menus</p> <p>Proper food hygiene</p>	<p>Group discussion lead by facilitator</p>	<p>Markers</p> <p>Flipcharts</p> <p>Samples of food packaging and containers</p> <p>Handouts: “Healthy and Balanced Nutrition for Growth, Work and Play,” “The Role and Source of Micronutrients,” and “Local Food Pyramids”</p>	<p>Participants will be able to identify a nutritious menu that can be served to people living with HIV/AIDS and describe how to prepare it safely</p>

Chapter 6: Nutritional Needs for People Living with HIV/AIDS and Their Families

Activities and Handouts for Nutritional Needs for People Living with HIV/AIDS and Their Families

- **We Are What We Eat: Healthy and Balanced Nutrition for Growth, Work, and Play**
- **Nutritional Needs for People Living with HIV/AIDS**

Note to Trainers—

The session, *Nutritional Needs for People Living with HIV/AIDS and Their Families*, was designed with a wide audience in mind. This manual is intended to be flexible and adaptable to a variety of settings, therefore, the activities and handouts are very general. The trainer should do research prior to this session to tailor it to the local setting. The local Ministry of Health or NGOs may have nutritional charts, food pyramids, suggested food intake, and recipes that are more appropriate for the local context.

Activity **We Are What We Eat: Healthy and Balanced Nutrition for Growth, Work, and Play**

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

- Describe the importance of eating enough food
- Describe what constitutes a balanced diet
- List the basic food groups
- Identify nutritious local foods that fall into the different food groups

Time allotted 1 hour

Preparation Have markers, flipcharts, samples, or packaging containers of foods from local area, large sheets of white paper, and copies of the handout – “Healthy and Balanced Nutrition for Growth, Work, and Play,” the role and source of selected micronutrients, and local food charts/pyramids with recommended serving sizes (samples of food pyramids from other countries should be available as models for adaptation in case one does not exist locally). Have individual cards with words: “vitamin,” “mineral,” “fat,” “carbohydrate,” and “protein.”

Prepare handouts with pictures of common containers/cans/bottles, body parts (hands, fingers), items used in the community such as pots, showing equivalent serving sizes of local foods. Do some measuring to find equivalent quantities. Use the resource “Making Sense of Serving Sizes” as a guide.

- Facilitation steps**
1. Ask participants to think about a time when they had to do a physical activity when they were very hungry. Then ask how they felt while they did the activity. Was it harder to do than after a full meal? Write down their comments on a flipchart.
 2. Pulls out a flipchart listing the importance of food to our bodies. Go through each of the following points, explaining that food is essential to our bodies to—
 - Develop, replace, and repair cells and tissues
 - Provide nutrients for growth in children
 - Produce energy to keep warm, move, and work
 - Carry out chemical processes such as the digestion of food

- Protect against, resist, and fight infection and recover from sickness
3. Put up two flipcharts: one labeled “Micronutrients” and the other “Macronutrients.” Asks participants if they have heard of them and if so ask them to explain. Participant responses should be recorded. In cases where the participants have not heard of them then the facilitator would have to explain. At the end of the brief explanation stick the cards with the words “vitamins” and “minerals,” under “Micronutrients.” Place cards labeled “carbohydrates,” “fat,” and “proteins” under “Macronutrients.”
 4. Explain that we all need to eat a variety of foods containing the above nutrients in order for our bodies to function. Explain that foods are normally divided into food groups, all of which need to be consumed on a daily basis to provide us with a healthy balanced diet. Ask the group to name the food groups, and explain the role that each of the food groups play in our body functions. Hand out the “Healthy and Balanced Nutrition for Growth, Work, and Play” handout.
 5. Divide the participants into two to three groups, pass out a chart with the following labels: 1) fruits and vegetables; 2) breads and cereals (staples); 3) dairy products, meat, eggs, fish, legumes, and nuts; 4) sugars, oils, and fats; and 5) water.
 6. Ask the participants to draw in and or list different foods available in the local community that fall into each of the above categories.
 7. Each group is also to make two meal plans: 1) a typical one-day meal plan, as it is in their community; 2) an optimal meal plan, that shows the times at which different foods from all the food groups can be consumed to provide a healthy well-balanced diet.
 8. Each group presents their food chart, and their meal plans, explaining the changes made from the first typical one, to the optimal one, giving reasons for the need to adjust.
 9. Summarize all the work with a short discussion on how to move from the “typical” to the “optimal” meal plan. Community/household problems that will hinder changes in behavior such as general lack of types of food, no money, no land, etc., may come up. Be ready with a list of services that may exist in the community that provide assistance for food, agricultural techniques, and income-generating activities that s/he can refer the participants to.

Wrap-up

Do the following—

- Reemphasize the importance of a balanced diet
- Pass out the rest of the handouts
- Answer any final questions that participants may have

Note to Trainers—

The session should be as interactive as possible and allow discussion, especially about the importance of a balanced diet in improving general health, immunity, and growth. Depending on how informed the participants are on food groups, the facilitator can spend either less or more time on the subject. Food groups have also been classified in different ways, in some cases separating the dairy products from meats and legumes, etc. This shouldn't cause a problem so long as all of the above categories are included. Local food guide pyramids can be used as a guide. A larger collage of pictures of real food that make up each of the food groups would make the session more visual and colorful.

Facilitators may want to ask participants to bring in food samples eaten in the community and or collect sample pictures beforehand that can be used in the creation of the group food charts.

Serving sizes may pose a problem, as amounts/serving sizes vary depending on the, measuring instrument being used. Not all people in a community may have measuring scales; furthermore, it is just not practical. It is important for the trainer to use body parts such as hands, fingers, and items commonly used in the community—empty cans, beer/soda bottles—to estimate serving sizes. The handout “Making Sense of Serving Sizes” (page 6-150) is not intended for the participants but as a guide for the trainer to modify to suit the local needs and help participants make sense of the serving sizes being recommended. Important measurements to know are—

1 cup is about the size of a fist

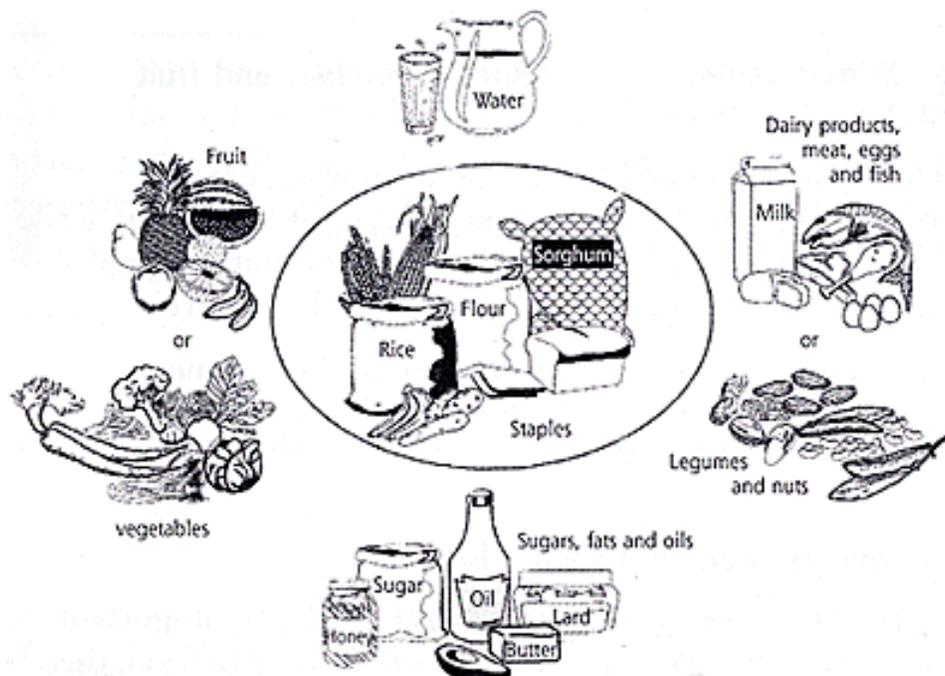
1 cup = 8 ounces = 140-200 grams

5 ml = 1 teaspoon

15-20 ml = 1 tablespoon (dry and liquid respectively)

Healthy and Balanced Nutrition for Growth, Work, and Play

Enjoy a Variety of Foods



Source: WHO/FAO. *Living Well with HIV/AIDS: A Manual on Nutritional Care and Support for People Living with HIV/AIDS*. (Rome: FAO, 2002).

Eat Staple Foods with Every Meal

These foods are relatively cheap and supply not only energy and protein but also small amounts of vitamins and minerals. Staples include cereals, (such as rice, maize, millet, sorghum, wheat, and barley), starchy roots, (such as potatoes, sweet potatoes, cassava, and yams) and starchy fruit (such as plantains).

Eat Legumes if Possible Every Day

These foods include beans, peas, lentils, groundnuts (including peanut butter) and soybeans. When eaten with staple foods, the quality of protein is increased.

Eat Animal and Milk Products Regularly

Foods from animals and fish should be eaten as often as you can afford them. They supply good-quality proteins, vitamins, minerals, and extra energy. All forms of meat, poultry (birds), fish, eggs, and dairy products, such as milk, sour milk, buttermilk, yogurt, and cheese, should be included. If insects, such as caterpillars or grasshoppers, are part of your eating patterns, they also provide good nutrients.

Eat Vegetables and Fruit Every Day

These foods are important for a person to grow well and fight infection. A recommended list is provided below—

Yellow, orange, red, or dark green

Green leafy vegetables (spinach, pumpkin, cassava leaves), green peppers, squash, carrots, yellow peaches, apricots, papaya, and mangoes

Good sources of Vitamin A

Other vegetables and fruit

Tomatoes, cabbage, oranges, mandarins, grapefruit, lemons, guavas, mangoes, passion fruit, pineapples, mulberries, and baobab fruit

Good sources of Vitamin C, which help to fight infection

Use Fats and Oils as well as Sugar and Sugary Foods

Fats, oils, and sugar should be used sparingly, however, they are also good sources of energy and are important for maintaining weight or regaining weight. In moderation, they add flavor to food, thereby stimulating the appetite.

Fats and oils include butter, lard, margarine, cooking oil (vegetable, coconut, palm oil), cream, mayonnaise, and coconut cream. They are also found in avocados, oilseeds (sunflower, groundnut, and sesame), fatty meat, fish, curds, and cheese.

Sugars and sugary foods include honey, jam, table sugar, cakes, and biscuits.

Drink Plenty of Clean and Safe Water

Drink about eight cups of water per day and even more if you are suffering from diarrhea, vomiting, or fever. You can also drink fruit juice, soups, and other beverages. Collect your water from a protected source and store it in a clean container. If the water is not from a protected source it should be boiled for ten minutes and cooled down afterwards before drinking. Avoid drinking tea or coffee with a meal, as they reduce the iron the body gets from your food.

Source: WHO/FAO. *Living Well with HIV/AIDS: A Manual on Nutritional Care and Support for People Living with HIV/AIDS*. (Geneva: FAO, 2000).



The Role and Source of Selected Micronutrients

Micronutrient	Role	Source
Vitamin A	<p>Growth and function of T and B cells (see “Important Terms,” p. 6-144) for immunity; maintenance of certain cells, including the lining of the respiratory and gastrointestinal tracts</p> <p>Vitamin A deficiency is associated with speeded up HIV progression, increased adult mortality, increased mother-to-child transmission, higher infant mortality, and child growth failure</p>	Liver and dairy products, dark green leafy vegetables, kidney, eggs, some fishes, sweet potatoes, pumpkin, palm oil, carrots, and fruits such as papaya
Thiamine Vitamin B1	Important for energy metabolism; support appetite and nervous system functions	Whole grain cereals, beans, meat, fish, chicken, eggs
Riboflavin Vitamin B2	Important for energy metabolism; support normal vision, health, and integrity of skin	Milk, yogurt, meat, green leaves, whole grained cereals, fish, and beans
Niacin Vitamin B3	Essential for energy metabolism; support integrity and health of skin, nervous and digestive systems	Milk, eggs, poultry, peanuts, groundnuts, whole grained cereals, fish
Pyridoxine Vitamin B6	Facilitates metabolism and absorption of fats and protein; helps to make red blood cells	Sweet potatoes, white beans, maize, avocados, cabbage, meat, fish
Cobalamin Vitamin B12	Important for new cell development and maintenance of the nerve cells	Red meat, fish, chicken, shellfish, cheese, eggs, milk, and fermented products
Ascorbic Acids Vitamin C	Important for immune functions and Iron absorption	Oranges and tomatoes
Vitamin E	Protects cell structures and makes it easier to resist disease	Leafy vegetables, vegetable oils, peanuts, egg yolk, vegetables, and liver

The Role and Source of Selected Micronutrients, continued

Micronutrient	Role	Source
Iron	Transports oxygen to the blood; eliminates old red blood cells, and builds new cells	Red meat, poultry, shellfish, eggs, peanuts, groundnuts, lentils, beans, some cereals, and dried fruit
Calcium	Builds strong bones and teeth; important for functioning of the heart and muscle functions, blood clotting and pressure; immune defenses	Milk, green leaves, shrimp, dried fish, beans, lentils, peas, whole grain millet, oil seeds, and okra
Zinc	Reinforces the immune system, facilitates digestion, and transports Vitamin A	Meat, chicken, fish, cereals, and vegetables
Selenium	Prevents impairment of the heart muscle	Seafood, liver, meat, carrots, onions, milk, and eggs
Iodine	Ensures the development and proper functioning of the brain and of the nervous system	Fish and other seafood, salt with iodine
Magnesium	Strengthens the muscles, important for nervous system functions, and is involved in bone development and maintenance of teeth	Cereal, dark green vegetables, seafood, nuts, legumes, and groundnuts

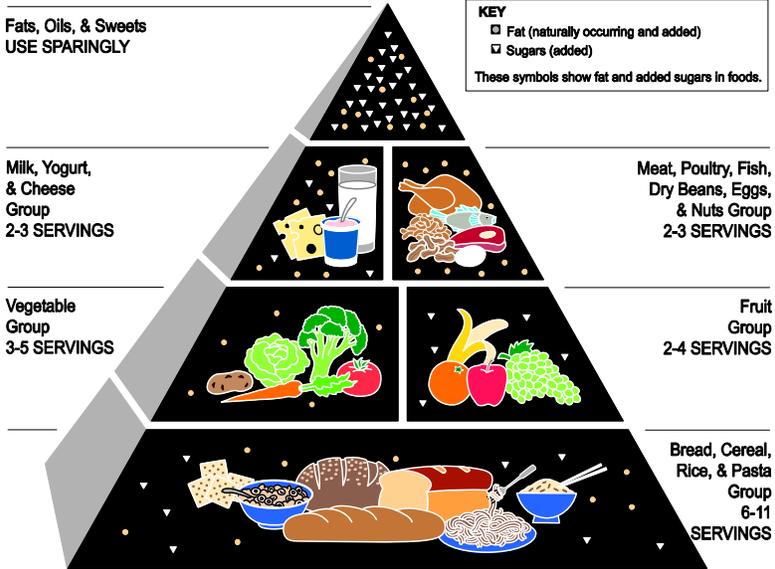
Source: FANTA Project, USAID, and AED. *HIV/AIDS: A Guide for Nutrition, Care and Support*. (Washington, DC: AED, 2001).

The American Food Guide Pyramid

A Guide to Daily Food Choices



Making Sense of Serving Sizes



Source: U.S. Department of Agriculture/U.S. Department of Health and Human Services.

Finding It Hard to Picture What a Serving Size Is?

Below are some ways you can picture a serving size using everyday objects. Using these everyday examples can help show you that you may actually eat more servings from the Food Guide Pyramid than you think!

The Bread, Cereal, Rice, and Pasta Group

- 1 cup of rice or pasta (2 servings) is the size of a fist*
- 1 pancake is the size of the palm of an adult hand
- 1/2 cup cooked rice is the size of a small light bulb
- 1 piece of cornbread is the size of a bar of soap
- 1 slice of bread is the size of an audiocassette tape, palm of hand
- 1 cup of cereal flakes is the size of a fist*

The Vegetable Group

- 1 cup salad greens is the size of a fist*
- 1 baked potato is the size of a fist*
- 3/4 cup tomato juice is the size of a tea cup
- 1/2 cup cooked broccoli is the size of a light bulb
- 1/2 cup serving is the size of 7-8 baby carrots or 3-4 carrot sticks or 1 ear of corn on the cob/ear of maize

Making Sense of Serving Sizes, continued

The Fruit Group

1/2 cup of grapes (15 grapes)	is the size of a light bulb
1/2 cup of fresh fruit	is the size of a light bulb
1 medium size fruit	is the size of a fist*
1 cup of cut-up fruit (2 servings)	is the size of a fist*
1/4 cup raisins	is the size of an egg

The Milk, Yogurt, and Cheese Group

1-1/2 ounces natural cheese	is the size of a 9-volt battery, 3 dominoes
Or	
1 ounce processed cheese (half serving)	is the size of a pair of dice or your thumb

The Meat, Poultry, Fish, Dry Beans, Eggs, and Nut Group

2 tablespoons peanut butter-equal to 1 ounce of meat	is the size of an egg
1 tablespoon peanut butter	is the size of a thumb tip
3 ounces cooked meat, fish, poultry	is the size of a palm of an adult hand
3 ounces grilled/baked fish	is the size of a palm of an adult hand
3 ounces cooked chicken	is the size of a chicken breast or leg and thigh

Fats, Oils and Sweets

1 teaspoon butter, margarine	is the size of a fingertip**
2 tablespoons salad dressing	is the size of a cupped hand

Snack Foods

1 ounce of nuts or small candies	is the size of one handful
1 ounce chips or pretzels	is the size of two handfuls
1/2 cup of potato chips, crackers, or popcorn	is the size of one man's handful
1/3 cup of potato chips, crackers, or popcorn	is the size of one woman's handful

Making Sense of Serving Sizes, continued

Serving Dishes/Utensils

1/2 cup	is the size of a small fruit bowl, a custard cup
1-1/2 cups	is the size of a large cereal/soup bowl
1/2 cup of pasta, noodles	is the size of a small soup bowl
1-1/2 cups of pasta, noodles	is the size of a dinner plate, not heaped

You might want to know that...

- 1 cupped hand holds 2 tablespoons of liquid
- 1 slice of bread is one ounce or 1 serving
- Some rolls or bagels weigh 3-5 ounces or more making them equal to 3-5 servings of bread

*Note: hand and finger sizes vary from person to person! These are only GUIDES.

**Note: your index and middle fingers

Source: Compiled by Ellen Schuster, Oregon State University Information provided by the University of Illinois Extension Office.

Activity **Nutritional Needs for People Living with HIV/AIDS**

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

- Describe the reasons for increased nutrient needs for people living with HIV/AIDS
- Identify the special nutritional needs of people living with HIV/AIDS
- Advise or demonstrate good nutritional practices for people living with HIV/AIDS
- Plan a daily sample menu for a person living with HIV/AIDS, including those displaying symptoms such as diarrhea, lack of appetite, nausea/vomiting, sore mouth, etc.
- Demonstrate proper food hygiene measures to minimize risk of food-borne infections

Time allotted 50 minutes

Preparation Have markers, flipcharts, samples or packaging containers of foods from local area, large sheets of white paper, and copies of the handouts—

- Healthy and Balanced Nutrition for Growth, Work, and Play
- The Role and Source of Selected Micronutrients
- Local food charts/pyramids with recommended serving sizes

Prepare handouts with common containers/cans/bottles, body parts (hands, fingers), items used in community such as pots, showing equivalent serving sizes of local foods. Use the resource “Making Sense of Serving Sizes” (page 6-150) as a guide.

Also prepare four large labels and sticks them on cartons/boxes—

- 7-11 cups breads and cereals
- 3-4 servings milk and milk products
- 3 (3+) meat and meat products, legumes, and nuts
- 5-10 servings of fruits and vegetables

Facilitation steps

1. Start by referring to the “Elephants and Lions” game and how the immune system works hard to fight infection. (This game is located in Chapter 12.) This process increases energy and nutrient needs. Further infection and fever also increase the body’s demand for food. Once a person is infected he/she has to eat more to meet these needs. These increase even further as symptoms increase.
2. Ask the participants what they have noticed about the eating habits of people living with HIV/AIDS in general and the reasons for such behavior. List the responses reinforcing the reasons listed below—
 - Reduced appetite illnesses and medications may reduce the appetite and/or modify the taste of food, thus reducing intake
 - Symptoms such as sore mouth, nausea, and vomiting make it difficult to eat; diarrhea causes poor absorption of nutrients causing rapid weight loss
 - Fatigue, isolation, and depression reduce the appetite and the willingness to make an effort to farm, prepare food, and eat regularly
 - Not eating because there is not enough money to buy food
3. Refer back to the food charts created previously, which display the food groups needed for a balanced diet. Explain that all the food we eat produces energy that is measured in units called kilocalories (kcal). A kcal is simply an amount of energy. 1 gram of protein is equivalent to 4 kcal; 1 gram of fat is 9 kcal; 1 gram of carbohydrates is 4 kcal; 1 gram of alcohol is 7 kcal; and 1 gram of dietary fiber is 3 kcal. All the foods that we eat have some amount of kilocalories, and in a given day, an adult is required to eat approximately 1,500-2,000 kcals. The amount on a given day may vary depending on age, sex, activity level, and health status.

Kilocalorie equivalents of macronutrients—

- 1 gram of protein = 4 kcal
- 1 gram of carbohydrates = 4 kcal
- 1 gram of fats = 9 kcal
- 1 gram of alcohol = 7 kcal
- 1 gram of dietary fiber = 3 kcal

4. Hand out cards with the amount of kilocalories and protein for adults, for pregnant women, for lactating women, and people living with HIV/AIDS to four participants and ask them to come and hang them, one-by-one, on

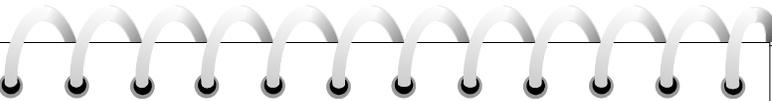
the wall. Under the title “Mean Requirement for Adults,” place cards listing both energy (kcal/day) and protein (g/day). By the end we will have created a similar chart to the one on the following page. Then pass out the handout “Daily Energy and Protein Requirements for Adults and Children,” and go through the rest of the requirements for children of different age groups. Allow for discussion and questions.

5. In front of the group display four large, carton boxes with labels showing: “7-11 Cups Breads and Cereals,” “3-4 Servings Milk and Milk Products,” “3 (3+) Meat and Meat Products, Legumes, and Nuts,” and “5-10 Servings of Fruits and Vegetables” (see resources for labels). Ask for four participants (one for each of the major food groups) to come up, and actually measure out using cups/containers available, demonstrating to the group the daily requirements from each food group. Another participant is asked to come and demonstrate the glasses of water required in a given day. Mention should be made of the sparing use of sugars, oils, and fats. This should be repeated for each food group. Emphasize that people living with HIV/AIDS should eat more in a given day than the average healthy adult.
6. Then, initiate a discussion regarding the increased nutritional requirements for people living with HIV/AIDS. Draw on the boxes at least two to three extra cups for breads and cereals and double the amounts for meat/meat products and vegetables and fruits as the discussion goes on. It should be mentioned that fats and oils should be used to meet the increased energy needs of people living with HIV/AIDS. Pass out the hand out and allow for questions and discussion.
7. Give a lecture to reinforce the importance of gaining weight, eating small but frequent meals, increasing the number of meals and snacks in a day to improve well being, increasing vitamin and mineral intake, using supplements when needed. For people living with HIV/AIDS, maintaining weight may be a more measurable goal.
8. Ask the group to plan a day’s meals, using locally available food, for a person who has AIDS symptoms, indicating the times and intervals of the meals.
9. Two or three volunteers should share with the group their meal plans and reasons for their choices.

Wrap-up

Recap on the following points—

- Re-emphasize the importance of a balanced diet
- Pass out the rest of the handouts of facts
- Answer any remaining questions that participants may have



Note to Trainers—

Prior to facilitating the session, the trainer should find out more about the dietary habits in the community, varieties of local available food, hindrances that prevent healthy eating, and local or national food guide if available. Modifications of the charts may be necessary to suit the local situation. Measuring containers should reflect what is used in the local markets and households. Frequently communities will use beer bottles, empty food cans, etc. for measuring.

The importance of nutrition counseling in any care and support services should be featured throughout the session.

Daily Energy and Protein Requirements for Adults and Children

Mean Requirements for Adults by Characteristic (1500-2000 kcal/day)	Energy kcal/day	Protein grams/day
Adjustment for Activity Level		
Moderately Active		
Males	+ 360	57
Females	+100	48
Very Active		
Males	+850	57
Females	+350	48
Pregnancy	+285	55
Lactation	+500	68
Adults Living with HIV/AIDS	Increase of 10-20%	Increase of 50-100%

* Note how protein requirements do not increase with increased activity but kilocalorie requirements do.

Mean Requirements for Children by Age and Sex		
0-2 months	404	
3-5 months	550	
6-8 months	682	
9-11 months	830	
12-23 months	1092	12
1-3 years	1250	23
3-5 years	1500	26
7-10 years	1710	30
Boys		
10-12 years	2170	50
12-14 years	2360	64
14-16 years	2620	75
16-18 years	2820	84
Girls		
10-12 years	1925	52
12-14 years	2040	62
14-16 years	2135	69
16-18 years	2150	66
If pregnant	+285	+7

Note: The mean requirement is 2070 kcal per day. A moderately active female aged 27 years who is pregnant and HIV positive would require—

Average Activity Level	+ Female	+ Pregnancy	+ HIV Status	= Total
2070	+ 100	+ 285	+ 368	= 2,823 kcals

Source: FANTA Project, USAID, and AED. *HIV/AIDS: A Guide for Nutrition, Care and Support*. (Washington, DC: July, 2001).

Gaining Weight

Weight is gained by eating more food, either by eating larger portions and/or eating more caloric foods, eating meals more frequently, and using a variety of foods. Here are some suggestions for gaining weight—

- Eat more staple foods such as rice, maize, millet, sorghum, wheat, bread, potatoes, sweet potatoes, yams, and bananas.
- Increase intake of beans, soy products, lentils, peas, groundnuts, peanut butter, and seeds, such as sunflower and sesame.
- Include all forms of meat, poultry, fish, and eggs as often as possible. Minced meat, chicken, and fish are easier to digest. Organs (e.g. kidney and liver) can be the least expensive source.
- Eat snacks regularly between meals. Good snacks are nuts, seeds, fruit, yogurt, carrots, cassava crisps, crab crisps, and peanut butter sandwiches.
- Slowly increase the fat content of the food by using more fats and oils, as well as eating fatty foods—oilseeds such as groundnuts, soy and sesame, avocados, and fatty meat. If problems with a high fat intake are experienced (especially diarrhea), reduce the fat intake until the symptoms are over and then gradually increase it to a level that the body can tolerate. Be sure to increase water intake if and when diarrhea occurs.
- Introduce more dairy products such as full-cream milk, sour milk, buttermilk, yogurt, and cheese into the diet.
- Add dry milk powder to foods such as porridge, cereals, sauces, and mashed potatoes. However, do not use coffee and tea whiteners, which do not have the same nutritional benefits as milk. Note that some people may find milk difficult to digest. It should be avoided if it causes cramps, a feeling of being full, or skin rashes.
- Add sugar, honey, jam, syrup, and other sweet products to the food.
- Make meals as attractive as possible.

Recipes following these recommendations for gaining weight are provided, starting on page 6-169.

Increasing the number of meals and snacks in a day. If poor appetite persists or the person is ill, it is a good idea to spread the food intake throughout the day. Snacks should be included in the daily meal plan. A snack is any nutritious food that is readily available and can be eaten without much preparation. Good snacks are nuts, seeds, fruit, yogurt, carrots, cassava chips, crab chips, and peanut butter sandwiches. With at least three meals a day and snacks in between, there is less likelihood of malnutrition or weight loss.

If a person needs to stay in bed, food and water should be kept within easy reach.

Caregivers should ensure that sick members of the family are given preference, fed more frequently and receive extra servings to maintain their weight and strength. Food should be served in an attractive way. Caregivers need to be kind, while frequently encouraging people to eat.

Exercise improves well-being. Regular exercise makes a person feel more alert, helps to relieve stress and stimulates the appetite. Exercise is the only way to strengthen and build up muscles. The body uses muscles to store energy and protein that the immune system can draw upon when required. Exercise is therefore especially important for maintaining the health of people living with HIV/AIDS.

It may be that everyday activities such as cleaning, working in the field, and collecting firewood and water provide enough exercise. If a person's work does not involve much exercise, an enjoyable exercise program should be found that can be part of his or her daily life. Exercise should not be tiring or stressful; gentle muscle-building exercise is recommended. Walking, running, swimming, and dancing are all suitable. People living with HIV/AIDS need to make an effort to find the exercise that they enjoy and that suits their situation.

Preventing weight loss during and after illness. Infection increases the body's requirements for nutrients. Illness also reduces the appetite and the ill person will eat less food, causing weight loss. Recommendations for dealing with poor appetite, diarrhea, vomiting, sore mouth, and nausea are given in Chapter 3.

Early treatment of infection is important to maintain body weight. If infection persists and cannot be cured by nutritional management within a couple of days, advice and treatment should be sought from a doctor, nutritionist, nurse, or local health worker.

Once the infection is over and the person is feeling better, he or she should start eating normally again. It is important to regain the weight lost as soon as possible and to restore the body's nutritional reserves.

Increase vitamin and mineral intake. Vitamins and minerals are essential to keep healthy. They protect against opportunistic infection by ensuring that the lining of skin, lungs, and gut remain healthy and that the immune system functions properly. Of special importance are Vitamin A, Vitamin C, Vitamin E, certain B-group vitamins, and minerals such as selenium, zinc, and iron. A balanced diet should provide enough of these vitamins and minerals.

- **Vitamin A** is important to keep the lining of skin, lungs, and gut healthy. Vitamin A deficiency increases the severity of diseases such as diarrhea while infection will increase the loss of Vitamin A from the body. Good Vitamin A sources are dark green, yellow, orange, and red vegetables and fruit. These include spinach, pumpkin, cassava leaves, green peppers, squash, carrots, amaranth, yellow peaches, apricots, papaya, and mangoes. Vitamin A is also contained in red palm oil, yellow maize, orange and yellow sweet potatoes, egg yolks, and liver.
- **Vitamin C** helps to protect the body from infection and aids in recovery. It is found particularly in citrus fruits such as oranges, grapefruit, lemons, and mandarins. Guavas, mangoes, tomatoes, and potatoes are also good sources of Vitamin C.

- **Vitamin E** protects cells and aids resistance to infection. Foods containing Vitamin E are green leafy vegetables, vegetable oils, peanuts, and egg yolks.
- **Vitamin B-Group** is necessary to keep the immune and nervous systems healthy. Vitamins, however, may be lost from the body through the use of certain medicines for the treatment of tuberculosis. Good food sources include white beans, potatoes, meat, fish, chicken, watermelon, maize, grains, nuts, avocados, broccoli, and green leafy vegetables.
- **Iron** is needed to prevent iron-deficiency anemia. This is a widespread problem in many countries, especially among women and children. Good iron sources are green leafy vegetables, seeds, whole-grain products, dried fruit, sorghum, millet, beans, alfalfa, red meat, chicken, liver, fish, seafood, and eggs.
- **Selenium** is an important mineral because it helps to activate the immune system. Good sources include whole grains such as wholemeal bread, maize, and millet and dairy products such as milk, yogurt and cheese. Meat, fish, poultry, eggs, and other protein-rich foods are also good sources, as are peanut butter, dried beans, and nuts.
- **Zinc** is also important for the immune system. Zinc deficiency reduces the appetite. Sources include meat, fish, poultry, shellfish, whole-grain cereals, maize, beans, peanuts, and milk and dairy products.

Further Recommendations

Since the vitamin content of food can be damaged during cooking, it is better to boil, steam, or fry vegetables for a short time only. Boil vegetables in a little water and use it afterwards for cooking as the water contains considerable amounts of vitamins and minerals. Vegetables will lose some of their vitamins and minerals if soaked for a long time.

The skins and kernels of grains and legumes also contain vitamins, in particular of the B-group. Processed refined grains have lost many of their vitamins, minerals, and proteins so whole grains such as brown bread and unrefined cereals are better sources than white bread and refined cereals. Fortified cereals and bread are preferred because of their higher vitamin content. If a person has diarrhea, however, whole, unrefined grains and cereals should be avoided since this insoluble fiber makes the diarrhea worse. Soluble fiber foods such as bananas are recommended. Fibers are contained in many plant foods. Soluble fiber will bind water in the gut and therefore reduce diarrhea.

Micronutrient Supplementation

When food intake is low, multivitamin and mineral supplements—often in the form of pills—can help to meet increased requirements. However, these supplements are often not available or are expensive, and leave less money for food. It would, therefore, be better to provide a good balanced diet whenever possible rather than buy supplements.

If supplements are considered necessary, the following guidelines should be adhered to—

- Discuss your intake of vitamin and mineral supplements with your health worker or nutritionist.
- Always take vitamin pills on a full stomach. Be consistent and take them regularly.
- It is probably cheaper to take a combined product with minerals rather than several pills containing different vitamins and minerals. However, iron may be a problem for people with HIV/AIDS as it can increase the activity of some bacteria. Supplements that do not contain iron are therefore better.
- Take any vitamin or mineral supplementation according to the advice on the label. More is not better. Taking high doses can cause nausea, vomiting, decreased appetite, and liver and kidney problems, as well as interfere with the immune system. This is particularly true for Vitamin A, Vitamin E, zinc, and iron.
- Micronutrient supplements can be useful but cannot replace eating a balanced and healthy diet.

Source: WHO/FAO. *Living Well with HIV/AIDS, A Manual on Nutritional Care and Support for People Living with HIV/AIDS*. (Rome: FAO, 2002).

Avoiding Food-Borne Illnesses

It is important to store, cook, and handle food safely when caring for people living with HIV/AIDS—avoiding the introduction of harmful bacteria and germs that make them sick. Food safety and hygiene practices include—

Sanitary disposal of feces—

- Use a latrine and keep it clean and free from flies.
- Keep the surroundings clean.
- Wash clothes, bedding, and surfaces that might have been contaminated with feces in hot water with soap.
- Wash hands after defecation.

Personal hygiene—

- Always wash hands with clean water and soap or ashes before, during, and after preparing food or eating, and after visiting the toilet. Dry hands on a clean cloth or towel, or shake dry.
- Cover all wounds to prevent contamination of food during preparation and handling.
- Use safe clean water from protected sources such as treated piped water supplies, boreholes, gravity-fed schemes, and protected wells. If the water is not from a protected source, it should be boiled for 10 minutes before drinking or using. Care must be taken during collection and storage to use clean containers to prevent contamination. Water containers in the home can easily become contaminated by dirty cups and hands that have not been washed.

Hygiene in the kitchen

- Keep all food preparation surfaces clean. Use clean dishes and utensils to store, prepare, serve, and eat food.
- Wash vegetables and fruit with clean water.
- Cover food to prevent both flies and dust from contaminating the food.
- Keep rubbish in a covered bin (and empty it regularly) so it will not cause offensive smells and attract flies, which can contaminate food with germs.
- Germs multiply more quickly in warm food. Storing food in a refrigerator or cool place slows down this growth. Cooking on a high heat can also kill most germs. Food should be eaten as soon as it is cooked.

- Cover and store food in containers away from insects, rodents, and other animals.
- Store fresh food in a cool place or refrigerator where available.
- Cook food thoroughly, but do not overcook vegetables.
- Serve food immediately after cooking to avoid germs multiplying. Do not leave the food standing at room temperature before eating.
- Do not store raw and cooked food together; use containers to avoid contact between them.
- Avoid storing leftovers unless they can be kept in a refrigerator or a cool place. Do not store them for more than one or two days and always reheat them at a high temperature to kill germs before eating.

Animal products

- Cook meat and fish well; meat should have no red juices.
- Wash utensils and surfaces touched by animal products with hot water and soap before preparing other foods.
- Keep meat and fish separate from other foods.
- Eggs should be hardboiled. Do not eat soft-boiled eggs, raw eggs, cracked eggs, or any foods containing raw eggs.

However careful one is, food-borne infections may happen. When a person has serious food poisoning, the caregiver should see a health worker without delay in order to avoid weight loss and further illness. The advice for diarrhea in Chapter 3 will help, but it is important to see a health worker without delay in order to avoid life-threatening dehydration.

Source: WHO/FAO. *Living Well with HIV/AIDS: A Manual on Nutritional Care and Support for People Living with HIV/AIDS*. (Rome: FAO, 2002).

Major Food Groups

Grain Products 5-12 SERVINGS PER DAY	<table style="width: 100%; border-collapse: collapse;"> <tr> <td style="text-align: center; border-bottom: 1px solid black;">1 serving</td> <td style="text-align: center; border-bottom: 1px solid black;">2 servings</td> </tr> <tr> <td style="text-align: center; vertical-align: top;">  1 Slice  Cold Cereal 30 g </td> <td style="text-align: center; vertical-align: top;">  Hot Cereal 175 mL 3/4 cup  1 Bagel, Pita or Bun </td> </tr> <tr> <td style="text-align: center; vertical-align: top;">  Pasta or Rice 250 mL 1 cup </td> <td></td> </tr> </table>	1 serving	2 servings	 1 Slice  Cold Cereal 30 g	 Hot Cereal 175 mL 3/4 cup  1 Bagel, Pita or Bun	 Pasta or Rice 250 mL 1 cup		
1 serving	2 servings							
 1 Slice  Cold Cereal 30 g	 Hot Cereal 175 mL 3/4 cup  1 Bagel, Pita or Bun							
 Pasta or Rice 250 mL 1 cup								
Vegetables and Fruit 5-10 SERVINGS PER DAY	<table style="width: 100%; border-collapse: collapse;"> <tr> <td style="text-align: center; border-bottom: 1px solid black;">1 serving</td> </tr> <tr> <td style="text-align: center; vertical-align: top;">  1 Medium Size Vegetable or Fruit </td> <td style="text-align: center; vertical-align: top;">  Fresh, Frozen or Canned Vegetables or Fruit 125 mL 1/2 cup </td> <td style="text-align: center; vertical-align: top;">  Salad 250 mL 1 cup </td> <td style="text-align: center; vertical-align: top;">  Juice 125 mL 1/2 cup </td> </tr> </table>	1 serving	 1 Medium Size Vegetable or Fruit	 Fresh, Frozen or Canned Vegetables or Fruit 125 mL 1/2 cup	 Salad 250 mL 1 cup	 Juice 125 mL 1/2 cup		
1 serving								
 1 Medium Size Vegetable or Fruit	 Fresh, Frozen or Canned Vegetables or Fruit 125 mL 1/2 cup	 Salad 250 mL 1 cup	 Juice 125 mL 1/2 cup					
Milk Products Servings per Day Children 4-9 years: 2-3 Youth 10-16 years: 3-4 Adults: 2-4 Pregnant and Breast-feeding Women: 3-4	<table style="width: 100%; border-collapse: collapse;"> <tr> <td style="text-align: center; border-bottom: 1px solid black;">1 serving</td> </tr> <tr> <td style="text-align: center; vertical-align: top;">  250 mL 1 cup </td> <td style="text-align: center; vertical-align: top;">  3"x1"x1" 50 g </td> <td style="text-align: center; vertical-align: top;">  2 Slices 50 g </td> <td style="text-align: center; vertical-align: top;">  175 g 3/4 cup </td> </tr> </table>	1 serving	 250 mL 1 cup	 3"x1"x1" 50 g	 2 Slices 50 g	 175 g 3/4 cup	Other Foods Taste and enjoyment can also come from other foods and beverages that are not part of the 4 food groups. Some of these foods are higher in fat or calories, so use these foods in moderation.	
1 serving								
 250 mL 1 cup	 3"x1"x1" 50 g	 2 Slices 50 g	 175 g 3/4 cup					
Meat and Alternatives 2-3 SERVINGS PER DAY	<table style="width: 100%; border-collapse: collapse;"> <tr> <td style="text-align: center; border-bottom: 1px solid black;">1 serving</td> </tr> <tr> <td style="text-align: center; vertical-align: top;">  Meat, Poultry or Fish 50-100 g </td> <td style="text-align: center; vertical-align: top;">  1/3-2/3 Can 50-100 g </td> <td style="text-align: center; vertical-align: top;">  1-2 Eggs </td> <td style="text-align: center; vertical-align: top;">  Beans 125-250mL 1/3 cup </td> <td style="text-align: center; vertical-align: top;">  100 g 1/3 cup </td> <td style="text-align: center; vertical-align: top;">  Peanut Butter 30 mL 2 tbsp </td> </tr> </table>	1 serving	 Meat, Poultry or Fish 50-100 g	 1/3-2/3 Can 50-100 g	 1-2 Eggs	 Beans 125-250mL 1/3 cup	 100 g 1/3 cup	 Peanut Butter 30 mL 2 tbsp
1 serving								
 Meat, Poultry or Fish 50-100 g	 1/3-2/3 Can 50-100 g	 1-2 Eggs	 Beans 125-250mL 1/3 cup	 100 g 1/3 cup	 Peanut Butter 30 mL 2 tbsp			

Note: 1 serving size = to 50-100 grams

Source: Canada's Food Guide to Healthy Eating, Health Canada (<http://www.hc-sc.gc.ca/english>).

Summary of Nutritional Impacts of HIV

HIV infection results in—

- **Poor food intake**
- **Poor nutrient absorption**
- **Chronic infection**
- **Muscle wasting or loss in lean tissue**

Illnesses associated with nutritional impacts—

- **Anorexia**
- **Fever**
- **Thrush**
- **Diarrhea**
- **Nausea**
- **Anemia**

Excerpted from Network of African People Living with AIDS (November 1997)

Source: The FANTA Project, USAID and AED. *HIV/AIDS: A Guide For Nutrition, Care, and Support*. (Washington, DC: AED, 2001).

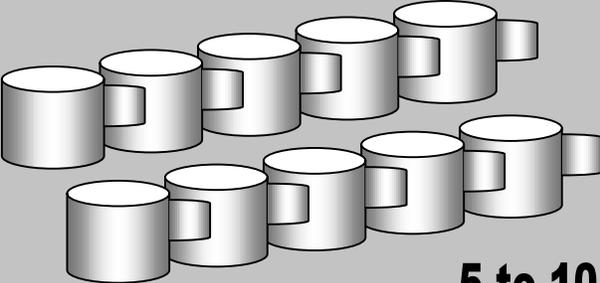


Energy Requirements for HIV Positive People

	HIV Negative Person	HIV Positive Person
Energy Needs	1500-2000 kcal/day	10-15% more energy/day (~400 kcal and 300 kcal for men and women respectively)
Protein Needs	~ 57 grams/day for men ~ 48 grams/day for women	~ 50 –100% more (85 grams for men, 72 grams for women)

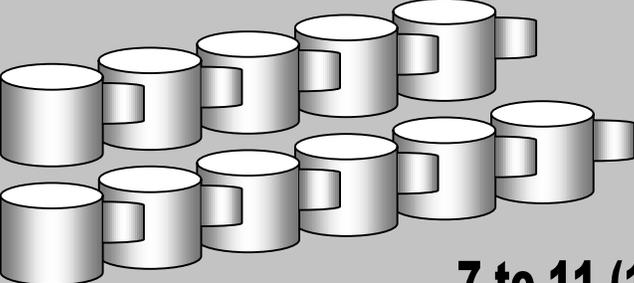
Source: The FANTA Project, USAID, and AED. *HIV/AIDS: A Guide For Nutrition, Care, and Support*. (Washington, DC: AED, 2001).

Labels for Carton Boxes



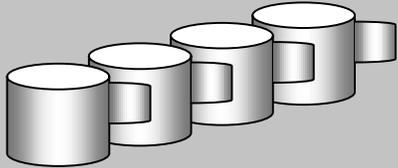
Fruit and Vegetable Food Group

5 to 10 servings a day



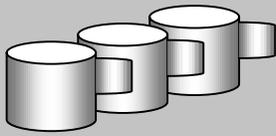
Breads and Cereals Food Group

7 to 11 (11+) servings a day



Milk and Milk Products Food Group

3 to 4 (4+) servings a day



Meat and Meat products Food Group

3(3+) servings a day



Recipes and Food for a Healthy Diet

The service provider or community worker can use the form below to suggest one or more recipes for the household to address a specific complication or disease.

Name	Date
Recipes for (fill in complications such as diarrhea, sore mouth, etc.)	
Complications (specific comments such as diarrhea for x days, foods not advised, etc.)	
Recipes	
Remarks	

Recipes for Gaining Weight and for Combating Diarrhea, Sore Mouths, Nausea, Vomiting, and Other Digestive Problems

The recipes selected below are suggestions for food and drinks that may help to address some of the common complications arising from HIV/AIDS. All recipes should be pre-tested in countries and local situations and be adapted to locally available foods and taste preferences.

People living with HIV/AIDS may have problems in digesting fat (particularly when they are suffering from diarrhea). In these cases, fat should be used in moderation, following the recommendations given.

Beans and Tomatoes (*easy and fast to prepare*)

1 medium size tin baked beans, 1 medium size tin tomatoes or 5 fresh chopped tomatoes, parsley, basil leaves, grated cheese

Mix the beans and tomatoes together. Bring to boil and simmer slowly for ten minutes. Add freshly chopped herbs. Sprinkle grated cheese over before serving.

(You can also add minced meat or chopped leafy greens and simmer together with the vegetables.)

Bean Broth

Beans, water, salt

Boil the beans (using more water than usual) until they are well cooked. Drink the broth or use it to make other soups. Serve to family members who do not have diarrhea.

(You can also boil rice, maize meal, or millet with the broth to add carbohydrates for more energy.)

Beef and Lentils

Minced beef, onion, margarine, lentils (soaked overnight), carrots, salt, pepper, water, spinach or other green leaves, lemon juice

Fry beef and chopped onion in margarine in a large saucepan. When meat is brown add lentils, chopped carrots, salt and pepper. Add water, cover and cook until lentils are tender (about 30 minutes). Add chopped green leaves and boil another ten minutes. Add a squeeze of lemon juice to serve.

Beef Broth

Beef, water, carrot, onion, parsley, salt, pepper

Boil beef in water with chopped vegetables and parsley until beef is well cooked. Season to taste.

Carrot Soup

Carrots, water, salt, cinnamon (optional)

Chop carrots and bring to the boil with water. Cook slowly until carrots are soft and then mash them. Add a pinch of salt and ground cinnamon.

Chicken Stew

Pieces of chicken (raw or cooked), onion, garlic, oil, potatoes, carrots, pumpkin, water, greens

Fry the onion and garlic in a little oil. Add the chicken, potatoes, carrots and pumpkin. Add water just to cover. Bring to boil and then simmer until vegetables are very soft. Mash vegetables and chicken together. Add finely chopped greens before serving.

(If you have a sore mouth, cook the stew without the chicken and mash the vegetables until smooth. Cut the chicken in small pieces, cook separately and then add to the vegetables.)

Corn and Cheese Chowder

2 cups potatoes, 1 cup carrots, 1 cup celery, water, 1 tin corn, milk, 1 cup grated cheese, salt, pepper

Chop potatoes, carrots and celery. Boil slowly in one cup of water for 15 minutes. Add corn and simmer for five more minutes. Add milk and heat until boiling. Remove from heat and add grated cheese and salt and pepper to taste.

Energy Drink

Large clove of garlic, turmeric, finely chopped fresh or ground ginger, water, milk

Boil together all the ingredients. Simmer for ten minutes. Cool slightly. Add a teaspoon of honey or sugar if you like the drink sweet.

(If you have diarrhea or difficulty in digesting milk, replace it with water.)

Fish Curry and Yellow Rice

Fish, onions, garlic, ginger, oil, tomatoes, mild curry powder, any combination of vegetables, water, lemon juice, dried coconut, jam, salt

For the rice: rice, water, turmeric, salt

Chop and fry the onions, garlic and ginger in a little oil until brown. Chop and add the tomatoes. Add the curry powder, fish and vegetables. Cook until soft. Add water if necessary. Add lemon juice, coconut, jam and salt to taste.

(Prepare the rice as you normally do, but add turmeric to the water when you start cooking. It will make the rice yellow.)

Garlic Oil

Crushed garlic, vegetable oil

Put the crushed garlic in the oil. Leave in a warm place for three days. Strain off the garlic. Keep the garlic oil in a cool place. Use for cooking, salads, etc.

Ginger Drink

8 cups clean water, 3 teaspoons ginger, 2 teaspoons sugar, 1 small chopped pineapple

Mix all the ingredients and leave in a warm place for a day in a clean and covered container. Drink the ginger juice.

(You can eat the pineapple.)

Ginger Tea

Ginger, water

Crush ginger in cold water and boil for ten minutes. Place in a covered container, strain the ginger and drink three cups of the liquid per day before meals.

Greens Stew

Greens or other vegetables (such as cabbage, pumpkin, squash, green beans, sprouted beans, and peas), onions, garlic, ginger, cinnamon, coriander or mild curry powder, cayenne (if you like a hot taste), oil, chopped meat (optional; use bones or mince), water, carrots, tomatoes, potatoes, lemon juice

Chop and fry the onions, garlic and spices over medium heat in a little oil. When onions are brown, add the meat and water. Cook meat at a high temperature until well done and soft. Chop and add the vegetables other than the greens. Cover and simmer until the vegetables are soft. Chop and add the greens ten minutes before the dish is ready. Add lemon juice to help digestion.

High Protein Stir-Fry

Chicken, meat (including liver), fish, oil, onions, garlic, cinnamon, ginger, cloves, any combination of vegetables, water, lemon juice

Heat two tablespoons oil in a pan over medium heat. Cut the meat or fish into small pieces and fry with onions, garlic and spices until brown. Add chopped vegetables and 1/4 cup water. Cover and turn heat down to low. Cook for five minutes, so that the vegetables are still crisp. Add a squeeze of lemon juice.

Lentil or Split Pea Soup

Dried lentils or split peas, water, vegetables (carrots, potatoes, greens or other), salt, garlic

Soak lentils or split peas in water overnight. Cook until fairly soft. Add chopped vegetables and cook until soft. Add salt and garlic.

Lentil Porridge

Lentils, peanut butter

Roast lentils and pound. Boil the pounded lentils until soft. Add peanut butter and mix.

(You can use cowpeas or beans instead of lentils.)

Liver Stew

Liver, garlic, margarine or oil, pumpkin, soup mixture (rice, barley, lentils, and split peas), water, thyme, salt, pepper

Cut liver into small pieces and fry with garlic in a little margarine or oil. Add grated pumpkin, soup mixture, water, thyme, salt and pepper. Bring to the boil and simmer for about one hour.

Mixed Beans with Spinach

Mixed beans, water, salt, onions, garlic, margarine or oil, tomatoes, spinach or other green leaves, pepper

Boil beans. Fry chopped onions and garlic in a little margarine or oil. Add chopped tomatoes and boiled beans and bring to boil. Add chopped spinach or other green leaves and pepper. Cover and simmer slowly until the leaves are soft.

Oatmeal Porridge

Oatmeal, milk, butter or margarine, salt, sugar

Cook oatmeal slowly with milk for about 15 minutes. Add a little butter or margarine and a pinch of salt and sugar to taste. Serve warm.

(If you have diarrhea and/or digestive problems, replace the milk with water and omit or reduce the margarine or butter.)

Peanut Sauce with Dried Fish

2 onions, margarine, ginger, 150 g dried fish, 2 tablespoons peanut butter, 1/2 liter milk, salt, pepper, lemon juice, 1/2 tablespoon brown sugar

Fry the chopped onions in a little margarine. Add ginger and fish and fry for ten minutes. Add peanut butter and stir in milk until thick. Add salt and pepper. Add squeeze of lemon juice and sugar before serving. Eat with rice, maize meal, or millet.

Porridge of Baobab Fruit

Baobab fruit, water or milk, sugar

Break the fruit. Sieve to separate the powder from the seeds and threads. Mix powder with water or milk, boil and simmer for 20 minutes. Add sugar to taste.

Pumpkin Soup

Pumpkin or butternut squash, onion, garlic, cinnamon, oil, water, coconut

Chop the pumpkin or butternut, onion and garlic. Fry the onion, garlic and cinnamon in a little oil. Add the chopped pumpkin. Add water and bring to boil. Simmer until the pumpkin is very soft. Before serving, sprinkle coconut on top.

Pumpkin Stew

Pumpkin or butternut, beef

Boil beef with chopped pumpkin until very soft. Mash the pumpkin. Cut the beef into small pieces and add to the pumpkin.

(You can also boil rice, maize meal, or millet with the stew to add carbohydrates for more energy.)

Rice and Spinach Soup

Rice, water, salt, spinach, peanut butter

Add one cup of rice to four cups of salted water. Cover the pot, bring to the boil, and cook until soft (about 40 minutes). Add chopped spinach and two tablespoons of peanut butter when the rice is cooked. Stir and cook slowly for a further ten minutes.

Recipes for Gaining Weight and for Combating Diarrhea, Sore Mouths, Nausea, Vomiting, and Other Digestive Problems, continued

Rice Porridge

Rice, salt, cinnamon, sugar

Add one cup of rice to three cups of salted water. Cover the pot, bring to the boil, and cook slowly for one hour. Add cinnamon and sugar when serving.

Rice Soup

Rice, water, salt

Add one cup of rice to four cups of salted water. Cover the pot, bring to the boil, and cook until soft (about 40 minutes).

(Other ingredients can be added and adjusted according to taste and tolerance, e.g. grated carrots, pumpkin, sweet potatoes or apples; finely chopped garlic and chopped liver.)

Scrambled Eggs with Greens

Eggs, oil, onions, finely chopped dark leafy greens (or sprouts)

Lightly oil a pan over medium heat. Fry the onions until brown. Add greens and cook for three minutes. Add the eggs and scramble with the other ingredients. Cook until egg is firm.

Simple Sprout Stir-Fry

Legume sprouts, vegetable oil, water, lemon juice (optional)

Put a little oil in a pan, add the sprouts and a small amount of water, cover and cook for about ten minutes. You can squeeze lemon juice over the sprouts.

(You can eat with grains, such as rice, maize, oats, barley, millet, or sorghum.)

Sweet Potato Soup

Sweet potatoes, water, salt, grated cheese, yogurt

Peel sweet potatoes, cut them in pieces and cook in a little water until soft. Mash them and add more water to make a soup. Add salt, cheese and yogurt and bring soup to boil, stirring often. Serve.

(If you have diarrhea, omit the cheese.)

Vegetable Stew with Meat

Meat, onions, leeks, carrots, potatoes, oil, water, garlic, salt, pepper

Cut meat and vegetables in small pieces. Fry meat until brown, add onions and leeks and fry together. Then add the other vegetables, water, and chopped garlic, and cook until tender. Season to taste with salt and pepper.

Apple Sauce

Apples, water, sugar, cinnamon

Peel and slice apples and bring to boil with a little water. Cover and cook slowly until tender. Mash apples until smooth and add sugar and cinnamon.

Avocado Dip

Mashed avocados, yogurt or thick sour milk, lemon juice, finely chopped raw onion, garlic, and tomato

Mix all ingredients together.

Banana and Papaya Milkshake

Banana, papaya, milk, sour milk or yogurt

Mash fruit together well or blend in a blender and mix with milk, sour milk or yogurt.

Cowpea Paste

1 1/2 cups boiled cowpeas, water, salt, 1 tablespoon grated onion, 1 teaspoon margarine, 1 tablespoon lemon juice

Boil the peas in water with a little salt until very soft. Mash to make a smooth paste. Add onion, margarine, and lemon juice, and mix.

(You can also use bambara nuts or beans.)

Peanut Sauce

1/2 cup finely chopped onions, crushed garlic cloves, 1 1/2 tablespoons oil, 1/2 cup boiling water, 1 cup peanut butter, juice and rind of 1/2 lemon, 1/2 tablespoon grated fresh ginger, honey or sugar, 1/2 teaspoon cayenne (if you like a hot taste), 1 1/2 cups milk

Fry the onions and garlic in oil until brown. Stir in all the other ingredients, except the milk. Cook the sauce over medium heat until smooth. Slowly stir in the milk. Cook for a few more minutes.

Sour Cabbage Water

Chopped raw cabbage, water

Wash and soak one cup of cabbage in three cups water. Cover tightly and leave for two to three days. Strain the water from the cabbage, throw the cabbage away and store the water in a cool place or refrigerator. It is ready to drink when it starts to bubble.

Drink 1/2 cup three times a day for all digestive problems.

(You can make a second batch by pouring 1/2 cup of the first batch into the second batch and letting it stand for one day only.)

White Sauce

1 tablespoon of margarine, 1 tablespoon flour, 1 cup milk or broth (see recipe for beef broth)

Melt margarine in a pan. Remove from heat and blend in flour. Return to heat and stir until cooked. Slowly add milk or broth and whisk until smooth and thick.

Tea for Colds, Coughs, Sore Throats, and Flu

For the teas below to have the greatest impact, it is best to prepare them fresh three times a day and drink them hot. However, if this is not possible, prepare them in the morning and heat them up or even drink them cold during the day.

Garlic Tea (for sore throats)

Chop 3-4 cloves garlic. Add to one cup boiling water. Boil for ten minutes. Cover and allow it to cool. Add honey or sugar to taste. Drink one cup three times a day.

Recipes for Gaining Weight and for Combating Diarrhea, Sore Mouths, Nausea, Vomiting, and Other Digestive Problems, continued

Ginger and Cinnamon Tea (for chesty colds or coughs)

Add 1/2 teaspoon chopped fresh ginger to one cup boiling water. Boil slowly for ten minutes. Add 1/4 teaspoon ground cinnamon. Cover and allow to stand for five minutes. Strain. Drink one cup three times a day. Start drinking the tea as soon as you feel a cold coming.

Guava Tea (for a persistent cold)

Add a guava, a squeezed lemon, and a eucalyptus leaf to a cup of boiling water. Cover and allow it to stand for five minutes. Drink three times a day.

Lemon Tea (for flu)

Squeeze a lemon. Add the juice to 1/2 a cup water that has boiled and cooled slightly. Add sugar or honey to taste. Drink one cup as hot as possible three times a day.

Onion Tea (for a blocked and runny nose)

Put 1/4 onion into a cup of boiling water. Cover and leave for five minutes. Strain. Throw the onion away. Drink one cup three times a day.

Thyme Tea (for dry coughs)

Add 1/4 teaspoon dried thyme leaves to one cup boiling water. Cover and leave for five minutes. Strain. Drink one cup three times a day.

Cough Syrups

For adults:

Mix one part honey with one part lemon juice and one part cane spirit. Shake or stir well. Take one teaspoon three times a day.

(An alternative is to mix one part honey with one part lemon juice. Add two finely chopped garlic cloves. Shake or stir well. Take one teaspoon three times a day.)

For children:

Mix one part honey with one part lemon juice and add one-part water. Shake or stir well. Give children one teaspoon three times a day.

Extracts for Sore Throats

Use three drops of either extract below on the back of the tongue. This will disinfect the throat. Start using the extract as soon as you feel a sore throat coming. Continue using the drops every two to three hours until you feel no more pain.

(You can also use the extract to prepare cough syrup.)

Eucalyptus Extract

Fill a clean empty bottle with eucalyptus leaves. Press them well down with a knitting needle or stick to pack in as many leaves as possible. Fill up with alcohol (40 percent proof). Press again to release any air. Close the bottle. Leave in a dark place for two weeks. Strain before using.

Thyme Extract

Use 20 g dried thyme leaves (or one refill packet). Add 100 ml alcohol (40 percent proof). Keep in a closed bottle in a dark place for two weeks. Strain before using.

Fever Remedies

Neem Tea

Cut a fresh twig from a neem tree. Remove the leaves and boil the bark in water; the bark can also be chewed.

How to Sprout Seeds for Eating

Sprouts are seeds that are starting to grow into a new plant.

Advantages of sprouted foods—

- They increase the vitamin, mineral, and protein content of foods
- They contain many live enzymes that help food to be digested
- They cut down on cooking time
- They are an easy and cheap way to obtain fresh food

Method of sprouting foods—

- Put the amount of seed shown in the chart in a jar
- Fill the jar half full with clean and safe water
- Use a tight rubber band to secure cheesecloth or mesh over the jar
- Soak seeds overnight (or as shown in the chart)
- Drain water
- Put the jar down at an angle so that the water can drain off (a dish rack is perfect for this)
- Keep the jar in the dark until sprouting begins
- Rinse the sprouts to remove the shells twice a day, with clean and safe water, morning and evening; if it is very hot, rinse more often
- Place in a cool place or refrigerator ready to eat
- Eat the sprouts after the length of time shown in the chart

Grow different kinds of sprouts such as alfalfa, beans, lentils, peas, sorghum, and sunflower, but grow them in different jars, since they need different times to sprout. All sprouts can be eaten raw in salads, sandwiches and in scrambled eggs, for example, and can be cooked in stews and soups.

Sprouting Chart

Type of seed	Amount of seed per jar	Time to soak seeds	Approximate time until ready to eat	Length of sprout when ready to eat
Alfalfa	3-4 tablespoons	4 hours	4-6 days or until seeds develop green leaves	3 cm
Beans	1 cup	Overnight	4-7 days	1 cm
Groundnuts/ Peanuts (whole)	1 cup	Overnight	1-2 days	Swell, do not sprout
Lentils	1 cup	Overnight	2-5 days	1/2-1 cm
Maize	1 cup	Overnight	3-4 days	1 cm
Peas	1 cup	Overnight	2-5 days	1 cm
Sorghum or Millet	1 cup	Overnight	2-3 days	1/2 cm
Sunflower (without husks)	1 cup	Overnight	1-3 days	1/2-1 cm

Source: WHO/FAO. *Living Well with HIV/AIDS: A Manual on Nutritional Care and Support for People Living with HIV/AIDS*. (Rome: FAO, 2002).



Form to Monitor Food Intake over One Week

This form can help you to monitor your food intake. Fill it in carefully every day, noting the amount you eat each time. List all the amounts of food you eat daily for every day of the week. Review the form or discuss it with your nutritionist, doctor, nurse, local health worker or counselor after one week. Compare the sheets from week to week to see if you are eating less from one week to another. This will help you to see if your food intake is going down, even if you do not feel that you are eating less. If you find that you are eating less, identify the reasons (e.g. diarrhea, sore mouth, feeling weak) and follow the guidelines provided to increase your food intake.

Meal	Breakfast <i>7am</i>	Snack <i>10am</i>	Lunch <i>1pm</i>	Snack <i>4pm</i>	Supper <i>7pm</i>	Bedtime <i>10pm</i>
Monday						
Tuesday						
Wednesday						
Thursday						
Friday						
Saturday						
Sunday						

References

WHO/FAO. *Living Well with HIV/AIDS: A Manual on Nutritional Care and Support for People Living with HIV/AIDS*. (Rome: FAO, 2002).

The FANTA Project, USAID, and AED. *HIV/AIDS: A Guide For Nutrition, Care, and Support*. (Washington, DC: AED, 2001).

Boyle, Marie A and Morris, Diane H. *Community Nutrition In Action: An Entrepreneurial Approach, Second Edition*. (Minneapolis: West/Wadsworth Publishing Co., 1999).

Health Canada. Using the Food Guide.

http://www.hc-sc.gc.ca/hpfb-dgpsa/onpp-bppn/food_guide_rainbow_e.html

Chapter 7

Social Support for People Living with HIV/AIDS and Their Families

“My husband’s death was my initial motivation to fight AIDS. The energy to fuel my actions was provided by anger and frustration at the stigma, rejection, and isolation of people with AIDS by their families and by health care workers. AIDS in my family opened doors and windows into other people’s lives, homes, and communities.

People with HIV/AIDS have been my teachers, my friends, and my inspiration. Their situations have humbled me greatly, and have dwarfed my own experience making me realize the relative advantages with which I have had to face my tragic loss.”

—NOERINE KALEEBA, FOUNDING MEMBER
THE AIDS SERVICE ORGANIZATION (TASO), UGANDA

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Chapter 7: Social Support for People Living with HIV/AIDS and Their Families

Key Questions

- How can activism or meaningful work help people living with HIV/AIDS live healthier and longer lives?
- Why would ending discrimination against people living with HIV/AIDS make a difference in the pandemic? And, more specifically, in the lives of people living with HIV/AIDS?
- What does income generation have to do with care and support of people living with HIV/AIDS and orphans and vulnerable children?
- Are there any strategies to keep children, especially girls, in school when their caregivers become sick?
- What is the “double burden” of women and girls?

Introduction

One of the thickest “branches” on the “Life Tree” involves social support for people living with HIV/AIDS and their families. Often, social issues are given less attention than medical issues, but the reality is that social, cultural, political, and economic factors play as much a part in overall wellness for people living with HIV/AIDS as managing illness and pain.

Meaningful involvement of people living with HIV/AIDS in the community and home-based care has been shown to improve the quality of life for many. There is a tendency to focus on people living with HIV/AIDS as passive clients or patients, rather than to involve them as care and support providers and decision makers with unique qualifications. Similarly, communities tend to narrowly focus on an individual orphan or vulnerable child and only after their parents are dead, rather than intervening earlier in the context of AIDS-affected children, and involving their parents in preparing for the child's future.¹³

Social issues pertinent to people living with HIV/AIDS and orphans and vulnerable children will vary in different communities and cultures, and it is important that the facilitator focus on issues appropriate to each participant group in this session. Six topics that people living with HIV/AIDS and orphans and vulnerable children may encounter are highlighted—

- **Activism.** There are a great many injustices around the issue of HIV/AIDS, including unfair inheritance laws, lack of access to safe and affordable drugs, discrimination in insurance laws, housing, work, and so on. One of the ways people living with HIV/AIDS have coped with their anger around these unfair practices is to mobilize to fight them. Many of the gains made around discrimination and access to drugs have come from the work of committed activist groups organizing to promote change.
- **Importance of Work.** Although some might argue that work contributes to stress, most people living with HIV/AIDS have identified work as an important survival strategy. In many cases, work can provide feelings of economic security and self-worth. In some cases, it also provides access to health insurance.
- **Discrimination/Stigma.** Perhaps because of the taboo against speaking about sexuality in some communities, the stigma associated with HIV/AIDS can often be stronger than that associated with any other illness or disease. People living with HIV/AIDS often suffer in silence rather than confront the shame, rejection, job loss, isolation from family and friends, loss of housing, and discrimination that can accompany an HIV positive result. It is crucial to change community norms around HIV/AIDS to reduce the stigma and ensure human rights.
- **Income Generation.** Since most people living with HIV/AIDS become HIV positive and develop symptoms during their most economically productive years, health problems often translate into financial problems for the entire family. The loss of income due to job loss, sick time, or inability to work in the family fields, combined with the increased need for resources to help keep people living with HIV/AIDS healthy, can represent a double economic burden for families. It is important for communities and families to develop strategies to generate income for people living with HIV/AIDS and orphans and vulnerable children.

¹³ Gilborn, Laelia. *Meaningful PLWHA Involvement: A Part of the Solution for Home and Community Care*. (Washington, DC: HORIZONS/Population Council, 2003).

- **Removal of Children from the Educational System.** The loss of income and the need for resources associated with living with HIV/AIDS can lead to severe economic hardship for families. This situation can drive children out of school. Children may need to work in the fields, factories, market, or even as sex workers to ensure family survival during this difficult time. Upon the death of their parents, these children can become among the most impoverished, and may be forced to turn to crime, living on the street or sex work to survive. In some communities, keeping children in school may be the only avenue to a better life. Community members must develop strategies to help children stay in school while also implementing care programs for people living with HIV/AIDS.
- **Double Burden of Women and Girls.** Women and girls are more vulnerable to HIV infection for a variety of biological and socio-cultural reasons. In addition to increased vulnerability to infection, their roles as the primary caregivers in their families places women and girls at the heart of every community's response to the HIV/AIDS pandemic. This is the "double burden of women and girls" often referred to by those working with HIV/AIDS. Communities must develop action plans to support women and girls in caring for themselves, caring for their families, remaining in school, and planning for their futures.

Chapter 7: Social Support for People Living with HIV/AIDS and Their Families

Objectives

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

- Describe important social issues surrounding HIV/AIDS, for example activism, the importance of work, discrimination, income generation, removal of children from the education system, and the double burden of women and girls
- Suggest strategies for supporting social issues important to people living with HIV/AIDS and orphans and vulnerable children

Home Care: The Power of Our Community

Training Schedule: Section 1

Schedule	Day One	Day Two	Day Three	Day Four
	Registration <i>30 minutes</i>	Recap <i>30 minutes</i>	Recap <i>30 minutes</i>	Recap <i>30 minutes</i>
Session	The Power of Our Community Introductions, Goals, and Objectives Workshop Structure <i>1 hour 30 minutes</i>	Medical Support for People Living with HIV/AIDS (cont.) Common Illnesses Role-Play <i>1 hour 45 minutes</i>	Nutritional Needs for People Living with HIV/AIDS and Their Families We Are What We Eat <i>1 hour</i> Nutritional Needs for People Living with HIV/AIDS <i>1 hour</i>	Preparing for Goodbye Supporting People Living with HIV/AIDS <i>1 hour 30 minutes</i>
Break	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
Session	Breathe in Life, Breathe Out Trouble The Power of Our Community <i>1 hour 30 minutes</i>	Oral Rehydration Solution and Thermometer Use <i>1 hour</i> Seeking Medical Support from a Professional Service Provider Special Medical Concerns for People Living with HIV/AIDS <i>1 hour</i>	Social Support for People Living with HIV/AIDS and Their Families Small Groups on Social Issues <i>1 hour</i> Plenary on Social Issues <i>1 hour 30 minutes</i>	Supporting Orphans <i>1 hour 30 minutes</i>
Lunch	<i>1 hour</i>	<i>1 hour</i>	<i>1 hour</i>	<i>1 hour</i>
Session	Review from Section Two Review of HIV Transmission, Prevention, and Disease Progression <i>1 hour 30 minutes</i>	Strategies for Dealing with Health Professionals <i>45 minutes</i> Antiretrovirals <i>30 minutes</i>	Psychological Support for People Living with HIV/AIDS and Their Families People Living with HIV/AIDS Vignettes <i>1 hour 45 minutes</i>	Closing Evaluation <i>1 hour</i> String Spider Web and Closing Ceremony <i>1 hour</i>
Break	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
Session	The Life Tree Life Tree <i>1 hour 30 minutes</i> Medical Support for People Living with HIV/AIDS Common Illnesses Role-Play <i>1 hour</i>	Physical Support for People Living with HIV/AIDS and Their Families Caring for People Living with HIV/AIDS in the Home <i>1 hour 30 minutes</i>	<i>The previous session can be emotional. Trainers may want to have a counselor present and use the afternoon session for this purpose.</i>	
Evaluation	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
Total Time	<i>8 hours 45 minutes</i>	<i>8 hours 45 minutes</i>	<i>8 hours 30 minutes</i>	<i>6 hours 45 minutes</i>

Chapter 7: Social Support for People Living with HIV/AIDS and Their Families

Sample
Lesson
Plan

Sample Lesson Plan

Time	Content	Methodology	Materials Needed	Evaluation
<i>1 hour</i>	<p>Small Group Discussions on Social Issues</p> <p>Activism around health care for people living with HIV/AIDS</p> <p>Importance of work</p> <p>Discrimination/stigma</p> <p>Income generation</p> <p>Children's removal from education system</p> <p>Double burden of women and girls</p>	Each small group is given a social issue to explore around HIV/AIDS and start to come up with strategies to support people living with HIV/AIDS and orphans and vulnerable children on the issue	<p>Flipchart paper</p> <p>Markers</p> <p>Tape</p>	Participation in plenary discussion later in the session
<i>1 hour 30 minutes</i>	<p>Plenary Discussion</p> <p>Social issues around HIV/AIDS</p> <p>Strategies for providing support</p>	Groups present their findings, and the large group discusses strategies to support the social needs of people living with HIV/AIDS and orphans and vulnerable children	<p>Flipchart Paper</p> <p>Markers</p> <p>Tape</p>	Inclusion of strategies in action plans created at the end of the workshop

Chapter 7: Social Support for People Living with HIV/AIDS and Their Families

Activities and Handouts for Social Support for People Living with HIV/AIDS and Their Families

- **Small Group Discussions on Social Issues**
- **Plenary Discussion on Social Issues**

Activity **Small Group Discussion on Social Issues**

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

- Describe important social issues surrounding HIV/AIDS, for example activism, the importance of work, discrimination, income generation, removal of children from the education system, and the double burden of women and girls
- Suggest strategies for supporting social issues for people living with HIV/AIDS and orphans and vulnerable children

Time allotted 1 hour

Preparation First, identify some of the major social issues surrounding HIV/AIDS in your community (some examples are listed in the objectives above, but try to determine the most critical for people living with HIV/AIDS and orphans and vulnerable children in your area). Write out the issues, one each on a separate sheet of flipchart paper. Have plenty of blank flipchart paper and markers.

Facilitation steps

1. Summarize the group's work up to this point. Suggest that we have spent the last several sessions focusing on some of the most important aspects of the "Life Tree." Although there are many elements of the "Life Tree" that we have not discussed in any great detail, we have taken time for a general overview of some of the most important issues in the lives of people living with HIV/AIDS and orphans and vulnerable children. Remind that group that, although physical and medical needs are paramount, it is important not to neglect other important aspects of wellness. This session will focus on the many ways in which people living with HIV/AIDS and orphans and vulnerable children can be supported in their social needs.
2. Divide the group into as many small groups as you have social issues (not more than six). Distribute a flipchart with a social issue to each small group. Instruct the group to do the following—
 - Each group should study their topic and answer the following questions—
 - What is happening around this issue in their community?
 - How does the issue relate to HIV/AIDS, people living with HIV/AIDS, or orphans and vulnerable children? Describe the social issue and all of the implications it may have.

- What strategies can we come up with to support people living with HIV/AIDS and/or orphans and vulnerable children with the issue?
 - Each group should choose someone to present the group's discussion.
 - Reporter for the group should list highlights of their discussion on flipchart paper.
3. Write the above questions on a flipchart, and make sure that the participants understand the task. Allow the remainder of the hour for participants to form groups and prepare to report on their issue. Once groups are formed, pass out flipchart paper and markers to each group.

Wrap-up

When all groups appear to have finished their discussions, bring the entire group back together. Discuss any final questions that participants may have before moving on to the next session.

Activity **Plenary Discussion on Social Issues**

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

- Describe important social issues surrounding HIV/AIDS, for example activism, the importance of work, discrimination, income generation, removal of children from the education system, and the double burden of women and girls
- Suggest strategies for supporting social issues in the lives of people living with HIV/AIDS and orphans and vulnerable children

Time allotted 1 hour 30 minutes

Preparation Arrange the chairs in a semi-circle around a blank wall or flipchart.

Facilitation steps Welcome participants back and have them join their small groups and get some flipchart paper. Explain that we will now process the social issues that we discussed in small groups earlier in the day as one large group. Invite one group at a time to—

- Tape its discussion notes to the wall or flipchart, and describe the social issue they discussed yesterday
- Present the group's findings on social issues, along with any strategies they came up with for supporting these issues in the lives of those with whom we work
- Lead a group discussion on the social issues addressed, and the strategies for supporting people living with HIV/AIDS and orphans and vulnerable children

(Decide on the amount of time for each group depending on the number of groups.)

Wrap-up Before summarizing the session, invite participants to review all of the issues on the wall. Are these the most important social issues at work in the lives of people living with HIV/AIDS and orphans and vulnerable children in our community? Are some more important than others? What other issues might we have included? Summarize by suggesting that many of the social issues we have discussed—the reduction of stigma, the importance of meaningful work, and so on—can enhance the lives of people living with HIV/AIDS and may even help them to live longer, healthier lives.

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- Callahan, Kathleen. *Impact of HIV/AIDS on Women and Girls, WID/GAD Newsletter*. (Washington, DC: Peace Corps, 2001).
- Fox, Susan. *Investing in Our Future: Psychosocial Support for Orphans and Vulnerable Children*. UNAIDS Case Study. (Geneva: UNAIDS, 2001).
- Gilborn, Laelia, *Meaningful PLWHA Involvement; A Part of the Solution for Home and Community Care*. (Washington, DC: HORIZONS/Population Council, 2003).
- Mota, Ruth. *Strategies for Survival, AIDS in the World II*. Edited by Mann, Jonathan and Tarantola, Daniel. 1996.
- World Health Organization. *AIDS Home Care Handbook*. (Geneva: WHO, 1993).

Social Support Issues—Activism

Points for Discussion

- There are a great many injustices around the issue of HIV/AIDS, including unfair inheritance laws, lack of access to safe and affordable drugs—both ARVs and drugs to combat opportunistic infections—discrimination in insurance laws, housing, work, and so on. One of the ways people living with HIV/AIDS have coped with their anger around these unfair practices is to mobilize together and fight them. Many of the gains made around discrimination and access to drugs have come from the work of committed activist groups organized to promote change. (You might wish to provide examples, such as the recent gains made in South Africa around access to affordable ARVs to address mother-to-child transmission.)
- Rather than becoming depressed and frustrated due to injustice and discrimination, organizing with others can help people living with HIV/AIDS feel more in control of their destinies. Feeling empowered and supported by others in an activist environment can reduce stress and build strength in people living with HIV/AIDS—thus helping them to live longer, healthier lives.
- In addition to helping individual activist, the work of these committed organizations can help to achieve important legal and social changes for all the people living with HIV/AIDS and orphans and vulnerable children.

Possible Strategies to Support People Living with HIV/AIDS and Orphans and Vulnerable Children

- Identify local AIDS activist organizations to put people who need their services in touch with them.
- Research issues around discrimination, access to drugs, and so on in your community. Help people living with HIV/AIDS and orphans and vulnerable children to understand these issues.
- Use “World AIDS Day” or other national holidays as an opportunity to bring out issues and facts relating to HIV/AIDS to the general public. Use conferences and large events that draw media attention, and/or get local/national celebrities and people living with HIV/AIDS to speak about AIDS-related issues.
- Talk to local policy makers, leaders, and celebrities about the issues regarding people living with HIV/AIDS and orphans and vulnerable children.
- If no AIDS activist community exists in the area, consider helping people living with HIV/AIDS to organize a local activist group.
- Consider organizing a workshop for the community around issues of AIDS advocacy and activism.

Social Support Issues— The Importance of Work

Points for Discussion

- Although some might argue that work can contribute to stress, most people living with HIV/AIDS have identified work as an important survival strategy. In many cases, work can provide feelings of economic security and sometimes access to health insurance. In addition, work can promote feelings of self-worth by making people living with HIV/AIDS continue to feel valuable and productive.
- Many people living with HIV/AIDS fear that a positive test result will lead to job loss or discrimination and stigma while on the job. In some cultures, one's work can serve as a primary part of identity, particularly for men. Losing the opportunity to work can shatter one's self-esteem and lead to anxiety regarding access to income and insurance. These fears can serve as a deterrent to testing for HIV.
- Continuing to work can be a distraction from the fears and anxieties associated with a positive result.

Possible Strategies to Support People Living with HIV/AIDS and Orphans and Vulnerable Children

- Remember to explore issues of work with people living with HIV/AIDS. Encourage them to continue to work when possible and spend time listening to their fears around discrimination, stigma, or job loss.
- Work with people living with HIV/AIDS on an action plan regarding work during the various stages of their disease progression. Help look forward to issues such as when and if to inform employers of their status, how to manage work responsibilities or coverage when ill, strategies for when they can no longer work, and so forth.
- Should people living with HIV/AIDS lose their jobs due to discrimination or have to quit for health reasons, encourage them to consider volunteer work or association with an activist group. To continue financial support, seek out income generation projects through local businesses or NGOs that may be done in the home.
- Including people living with HIV/AIDS in community and home-based care programs can make them more effective and relevant. Improving perceptions and personalizing the epidemic can strengthen the synergy between care and prevention.

Social Support Issues— Discrimination/Stigma

Points for Discussion

- Perhaps because of the taboo against speaking about sexuality in some cultures, the stigma associated with HIV/AIDS can often be stronger than that associated with any other illness or disease. Throughout the history of the pandemic, HIV/AIDS has been called a “punishment from God,” the “gay men’s plague,” or blamed on bar girls, drug users, and other marginalized members of society. Ignorance about the ways in which HIV is transmitted has led to fear of infection, which has led communities and even families to isolate those infected with HIV.
- People living with HIV/AIDS suffer in silence rather than confront the shame, rejection, job loss, isolation from family and friends, loss of housing, and discrimination that can accompany an HIV positive result. This silence can make it difficult for them to receive the comfort, medicine, and care they require to live longer, healthier lives. In addition, women may fear violence or abandonment from their partners or family members should they disclose an HIV positive status.
- Sometimes people living with HIV/AIDS can internalize the stigmatization that goes with their diagnosis. They may feel that they deserve this disease and this shame and guilt can lead to unhealthy feelings and depression.

Possible Strategies to Support People Living with HIV/AIDS and Orphans and Vulnerable Children

- Perhaps the most important support that one can provide around issues of stigma and discrimination involves working to change community norms around HIV/AIDS. This may require educating community members about HIV/AIDS, especially influential community members such as spiritual leaders, teachers, and government officials. An active and outspoken organization can serve as a catalyst in changing community norms about HIV/AIDS.
- Set an example of acceptance and caring by openly speaking with and casually touching people living with HIV/AIDS and orphans and vulnerable children in an appropriate manner. For example, shake hands with them, put your arm around them, hug a child or let them sit on your lap, if it is culturally appropriate.
- Explore the issues of stigma and discrimination. It may be helpful to talk about the community norms around HIV/AIDS, the possible consequences of living openly as a person living with HIV/AIDS, an orphan, or vulnerable child, and the positives and negatives associated with this decision. Thus informed, people living with HIV/AIDS can make their own educated decisions regarding disclosure of their status.

Social Support Issues—Discrimination/Stigma, continued

- It is imperative that all caregivers respect the confidentiality of people living with HIV/AIDS and orphans and vulnerable children. If they have made the decision to keep their status a secret, the caregivers should respect those wishes and make every effort to ensure this confidentiality.
- Working against discrimination in inheritance laws, housing, employment, and health insurance can serve to combat discrimination as well as boosting feelings of empowerment and control.

Social Support Issues— Income Generation

Points for Discussion

- Since most people living with HIV/AIDS become HIV positive and develop symptoms during their most economically productive years, health problems often turn into financial problems for the entire family. The loss of income due to job loss, sick time, or inability to work in the family fields, combined with the increased need for resources to help keep people living with HIV/AIDS healthy, can represent a double economic burden for families.
- It can be especially difficult for families to witness the devastating illnesses of people living with HIV/AIDS that might be prevented or cured if resources were available, for example, nutritious foods, basic medicines, or antiretroviral drugs.
- The loss of income and the need for resources can drive children out of school. Children may be sent to work in fields, factories, at the market, or even as sex workers so that the family can survive. Early marriage for girls may also be viewed as a practical solution to economic problems.
- A family's savings can be completely used while caring for a person living with HIV/AIDS, leaving only debts and financial problems for orphans and remaining family members. The fear of leaving children penniless can lead to extreme anxiety for the person living with HIV/AIDS, which further impacts on their quality of life.
- Extended families who take orphaned children into their households often face an enormous financial burden. If the perceived economic burden is too great, extended families may feel forced to abandon them. Many of the orphans and vulnerable children may feel they have nowhere else to turn and become street children.

Possible Strategies to Support People Living with HIV/AIDS and Orphans and Vulnerable Children

- Promote voluntary counseling and testing (VCT) to detect HIV positive people while they are still healthy.
- If possible, work with people soon after they learn of an HIV positive result. Help them and their families to measure their current financial situation, to consider a savings plan, and to plan for the various stages of disease progression. Also, work with them to help foresee their financial needs and to strategize early on the best ways to meet them.

Social Support Issues— Income Generation, continued

- Encourage people living with HIV/AIDS to plan for the future of their children while they are still healthy. This may involve legal issues such as turning over the deeds to property to the children's names or making a will. It may also involve choosing guardians for the children and working with those guardians on a plan for the future of the children. This planning can reduce the anxiety for all concerned. In fact, studies have shown that succession planning (including writing wills, appointing future guardians, and disclosing sero-status to children, especially older children) has reduced stigma and increased acceptability of succession planning (even in communities where speaking of one's death is taboo). It has even increased community demand for VCT and access to care and support services.
- Recognize that there is a genuine need to help people living with HIV/AIDS and their families to meet their increased financial burdens. Develop a community plan to address the situation. This may involve community income generation projects, such as community gardens, fundraisers, crafts or cottage industries, and so forth. Proceeds can be given to households to pay the costs of health care or given to orphans and vulnerable children for school fees, food, clothing, and other needs.
- Many donor agencies and local community organizations support micro-finance or loan revolving-fund schemes. Work with people living with HIV/AIDS and orphans and vulnerable children to consider these organizations.
- Link people living with HIV/AIDS to centers where they can access antiretrovirals (ARVs).

Social Support Issues—Removal of Children from the Education System

Points for Discussion

- The loss of income and the need for resources associated with living with HIV/AIDS can lead to severe economic hardship for families. In many cases, several family members may be infected with HIV, which increases the need for resources and decreases the amount of income available to the family. These realities can drive children out of school. Children may be sent to work in fields, factories, the marketplace, or even as sex workers so that the family can survive. Early marriage for girls may also be viewed as a practical solution to economic problems.
- The illness of parents may lead to role reversals within the family, as the children try to take on the roles of breadwinners and caregivers. These responsibilities can have a number of negative effects on the children, including loss of education, fear of the future, psychological damage, drug addiction, depression, and so on.
- In some cases, children may even be forced to trade sex for food or money, thus putting them at risk for violence, STIs, and HIV/AIDS.
- While children are still in school, problems in the home may cause their performance to suffer. In some cases, the children of people living with HIV/AIDS may also suffer stigma or discrimination at the hands of other students or even teachers.
- A family's savings can be completely used up while caring for a person living with HIV/AIDS, leaving only debts and financial problems for orphans and remaining family members. The fear of leaving children penniless can lead to extreme anxiety, which further impacts on their quality of life.
- Extended families who take orphaned children into their households often face an enormous financial burden. If the perceived economic burden is too great, extended families may feel forced to abandon them. Many of these children may feel they have nowhere else to turn and become street children. In other cases, they may be treated as servants or even abused by extended family households. They may be kept out of school and made to work in the fields or in the home to earn their place in the household.

Possible Strategies to Support People Living with HIV/AIDS and Orphans and Vulnerable Children

- Encourage people living with HIV/AIDS to plan for the future of their children while they are still healthy. This may involve legal issues such as turning over the deeds to property to the children's names or making a will. It may also involve choosing guardians for the children and working with those guardians on a plan for the future of the children. This planning can reduce the anxiety for all concerned. In fact, studies have shown that succession planning (including writing wills, appointing future guardians, and disclosing sero-status to children, especially older children) has reduced stigma and increased acceptability of succession planning (even in communities where speaking of one's death is taboo). It has even increased community demand for VCT and access to care and support services.
- Be sure to involve orphans and vulnerable children in planning for their futures, including working with them to choose a guardian, to develop a plan to keep them in school, or to learn skills for future income generation.
- Recognize that there is a genuine need to help people living with HIV/AIDS and their families to meet their increased financial burdens. Develop a community plan to address this situation. This may involve community income generation projects, such as community gardens, fundraisers, crafts or cottage industries, and so forth. Proceeds can be given to households to pay the costs of health care or given to orphans and vulnerable children for school fees, food, clothing, and other needs.
- Assist in establishing a special endowment or trust to provide scholarships to orphans and vulnerable children so they are able to continue with school.
- Many donor agencies and local community organizations support micro-finance or loan revolving-fund schemes. Work with people living with HIV/AIDS and orphans and vulnerable children to investigate these organizations.
- Establish community vocational training programs for orphans and vulnerable children, so that they will have skills to support themselves upon the deaths of their parents.
- Develop training programs to help teachers to understand the psychological and emotional issues that may trouble orphans and vulnerable children. Understanding that behavioral problems may be related to trauma or fear at home can help teachers feel better able to deal with these issues.
- Acknowledge the changing roles of children and help them to talk about these issues. At the same time, try to provide space for "kids to be kids." Try to structure a schedule of caregiving that includes time for children to get away, to play, and to spend time with other children their own ages.

Social Support Issues—Double Burden of Women and Girls

Points for Discussion

- Women and girls are more vulnerable to HIV infection than men and boys for many biological and social reasons. Some of the social issues that increase the vulnerability of women and girls to infection include—
 - Gender roles that do not permit women to participate in sexual or reproductive decisions
 - Girls’ initiation rites that could include female genital cutting or young girls’ sexual initiation by an older male
 - High value placed on virginity, which encourages some girls to resort to anal sex to preserve theirs
 - Taboos related to speaking about sex and sexuality
 - Men’s preference for “dry sex,” which can encourage women to put drying agents in the vagina that can cause tearing
 - Social practice and acceptance of men visiting sex workers, even after marriage
 - Bride price or marriage rites that give women a property value and delay marriage
 - Extreme poverty that encourages the exchange of sex for money, school fees, or food
 - Belief that a man can cure AIDS by sleeping with a virgin
 - Lack of educational, vocational, or economic opportunities
 - Lack of female-controlled prevention methods like microbicides, or a belief that condoms do not work or are contaminated with the virus
 - Violence against women, including sexual abuse, rape, and trafficking
- In addition to their increased vulnerability to infection, their roles as the primary caregivers in their families and communities place women and girls at the heart of every community’s response to the HIV/AIDS pandemic. This is the “double burden” of women and girls often referred to by those working with HIV/AIDS.
- Women provide home-based care for family members who fall ill due to AIDS, while at the same time increasing their involvement in economic activities to support the family. Women themselves may often be infected with HIV themselves, but not as sick as the family member, adding to the double burden of keeping themselves healthy along with the family member.

Social Support Issues—Double Burden of Women and Girls, continued

- Girls are often forced to abandon school to assist in providing care for the sick and/or to serve as caregivers for younger children as their mothers take on income-generating responsibilities.
- Compounding the greater risk and responsibility women confront in the face of HIV/AIDS is their further marginalization upon the death of the male head-of-household. Property laws in many areas still return land and household possessions to the man's family upon his death, leaving women and children with little hope for the future. This hardship and misery, coupled with the stigma associated with HIV/AIDS, makes women even more vulnerable to hunger, disease, and lack of social support.

Possible Strategies to Support People Living with HIV/AIDS and Orphans and Vulnerable Children

- Organize with the community to change laws that discriminate against women, especially inheritance laws. Support programs that address violence against women.
- Encourage community leaders, religious leaders, and others who have power in the community to challenge societal norms such as violence against women and older men taking young girls as sexual or marriage partners and to sanction those who engage in them. Encourage the use of “ABC” prevention methods.
- Educate community members about the “double burden” on women and girls. Work with community members to develop action plans to support women and girls in caring for themselves, caring for their families, remaining in school, and so on.
- Provide opportunities to girls that are often not available to them, such as leadership training, vocational skills training, or scholarships to school. Life skills programs and girls' clubs can help girls to learn to negotiate for their own rights, to feel empowered, to communicate their own needs, and to enhance self-esteem.
- Work with local schools to arrange non-traditional schooling options for girls who are caring for families affected by HIV/AIDS. Some possibilities include alternative school hours, tutoring programs, and so on.
- Develop a strong community home care program for people living with HIV/AIDS. This community support may be the difference between a girl's removal from school and her graduation from it.

Chapter 8

Psychological Support for People Living with HIV/AIDS

“After I delivered [my fourth baby], they tested my child, too. Then the doctor just told me that they had taken our blood and the results for both of us were positive. When I broke the news to my husband, he left me that very same night, after calling me names and accusing me of being unfaithful and a prostitute. I later learned that he had already been tested and was HIV positive but didn’t have the courage to tell me. I confided my HIV status to my sister, a nurse. Because of stigmatization and discrimination, she told me not to tell anyone else. I kept quiet but felt as if everybody knew that I was HIV positive. I was so lonely, isolated, and afraid of leaving my children without any information on AIDS. I spent most of my time crying and the loss of my child at five months made my condition worse. Fortunately, I didn’t have to give up my job because it was my only source of support.”

—WINNIE CHIKAFUMBWA
FOUNDER, NATIONAL ASSOCIATION OF PEOPLE
WITH HIV/AIDS IN MALAWI (NAPHAM)

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Chapter 8: Psychological Support for People Living with HIV/AIDS

Key Questions

- What does voluntary counseling and testing (VCT) normally involve? How important is it to the psychological well being of people living with HIV/AIDS?
- What are some of the issues around disclosing one's HIV status to a partner? Are the issues different for women and men? In what ways?
- What are some of the issues involved in disclosing HIV status to one's children? To one's extended family?
- How can support groups help people living with HIV/AIDS and orphans and vulnerable children?

Introduction

Communities can support people living with HIV/AIDS by developing positive, empowering, and confidential testing facilities to determine HIV status. Making the decision to get tested for HIV may be a difficult one for most people—the fear and anxiety of suspecting HIV infection, coupled with perceived stigma around HIV/AIDS, may keep many individuals from seeking to know their HIV status. It is a particularly difficult decision for women, because in many areas, women are blamed for HIV infection, may be beaten, be abandoned, lose their children, or be thrown out of the house, even when they have only had one sexual partner—their husband. And yet it is clear from the experiences of communities around the world that knowing one's HIV status can be a first step to stronger prevention programs, greater advocacy, and better health care for people living with HIV/AIDS and orphans and vulnerable children. It is important, therefore, for communities to ensure that the rights and confidentiality of all are protected in the

VCT process, especially women, and that appropriate psychological support is given before, during, and after testing.

Empowering post-test and follow-up counseling are especially important for those who have tested positive for HIV. Some of the important issues that can be raised in these sessions include—

- Assisting people living with HIV/AIDS in developing strategies around disclosure of test results to partners, children, and extended family
- Assessing any risk of violence or abandonment around disclosure of results—especially for women
- Referrals to both formal (hospital groups) and informal (church groups) support groups (where available)

Appropriate psychological support may be the strongest foundation for care and support. Once these groups begin to view their status in terms of hope, positive action, and personal control, they may be better able to make appropriate decisions regarding health care, economic situations, and preparing for death and dying. Working with traditional healers and perhaps training them to serve as counselors for HIV/AIDS can provide another rich source of support for people living with HIV/AIDS and orphans and vulnerable children.

There are many important topics to cover when discussing psychological support with participants, including—

- The importance of positive, confidential VCT and support cannot be underestimated.
- One of the biggest hurdles for those diagnosed as HIV positive is telling their partners, their families, and especially their children.
- It is important to remember that for women, these feelings of pain and anxiety at disclosing their news can be compounded by fear of physical abuse, loss of their children and property, or abandonment by their male partners. Men may face other issues when deciding to disclose their positive status, such as accusations of infidelity, anger, ostracism, etc. Disclosure of negative status also has implications that the individual should consider. It should always be left to the individual to decide to disclose his/her status.
- It is crucial to support children in managing their fear, grief, and anxiety at the news of their parent's status.
- A support group can be a powerful anchor in the lives of people living with HIV/AIDS and orphans and vulnerable children.

The approach used in this session is to raise these issues through the personal stories of people living with HIV/AIDS themselves. Although this approach can sometimes be painful, it has proven to represent the most powerful entry into a discussion of care and support.

Chapter 8: Psychological Support for People Living with HIV/AIDS

Objectives

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

- Discuss the importance of VCT to the psychological health of people living with HIV/AIDS
- Describe some of the issues around disclosing HIV status to a partner, including potential partner violence, loss, or abandonment
- Demonstrate an understanding of the issues involved in disclosing HIV status to children
- Discuss the importance of support groups to the psychological health of people living with HIV/AIDS and orphans and vulnerable children

Important Terms

Voluntary Testing and Counseling (VCT) Terms

Pre-Test Counseling The first part of VCT, pre-test counseling, involves a counseling session followed by the blood test to detect HIV antibodies. During the pre-test session, the counselor should attempt to assess the client's risk for HIV infection, describe exactly what the test is looking for and what it will mean, discuss what the client will do if the result is positive, and provide information about risk reduction.

Post-Test Counseling It is during the post-test counseling session that the client gets the HIV test result. If the test is negative, the counselor will spend some time discussing the window period, and should recommend that the client return in three months for another test. She or he should also discuss risk reduction, and offer condoms and guidance on how to use them. If the test is positive, the counselor should listen to the client's reactions, answer his or her questions, provide referrals to support groups and guidance around how to live healthy with HIV and should offer condoms and guidance on how to use them. The counselor may also recommend a follow-up counseling session once the client has had a chance to process the news.

Shared Counseling In shared counseling, the client is invited to bring a trusted friend or relative to the post-test counseling session. This support person receives the result along with the client, and helps the client to cope with the news. Shared counseling involves the client's own support system, so that he or she will have someone to talk to at home in the days to come. The support person can also be helpful in breaking the news to other family members and friends, but the decision to disclose status should always be left to the individual.

Voluntary Counseling and Testing (VCT) This is a phrase commonly used to refer to going for an HIV antibody test. It is a confidential process, in which an individual is counseled about the nature of HIV, and can make an informed choice about whether or not to be tested for HIV. VCT can be an important first step in living healthy with HIV/AIDS, and knowing one's status can be a powerful tool for preventing the spread of HIV.

Reactions to Voluntary Counseling and Testing

Acceptance After some time, a person with a positive result will usually begin to accept their situation. This will help the person to feel better and to begin to take better care of themselves.

Anger A response to an HIV positive test that may include blaming oneself, blaming the person suspected of infecting you, blaming the person delivering the result, or even blaming God. This may be the most difficult reaction to deal with, but it is important to try not to take it personally, but to help the person talk about their feelings.

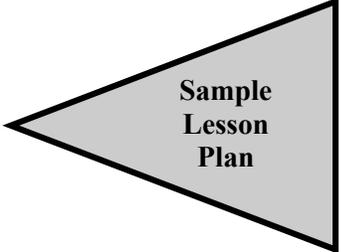
Bargaining	A person with HIV or AIDS may try to bargain, thinking, “God will cure me if I stop having sex,” or “I won’t ever be unfaithful again if I get well.”
Denial	Another common response to a positive result. Sometimes the person may not believe that the result is true or that they are really HIV positive. This may be a subconscious way to protect oneself from the fear and pain associated with the threats posed by HIV/AIDS. It is important not to become angry or impatient with such a person, but to help him or her to understand the test and its results.
Depression	A common response to learning one is HIV positive. Symptoms may include sleeping a lot, not wanting to eat, not wanting to talk, crying, and sadness. Depression can make someone very weak in mind and body. It is important to recognize the signs of depression and try to get the person to visit with friends, stay busy with important things, do something to help others, and think about their children and friends who still need them. If the symptoms of depression do not go away or get worse, it may be necessary to refer the person to a doctor or a counselor.
Fear	People with a positive result may fear death, losing a job, losing children, discrimination, and other things. Talking with the person or referring them to a support group may help him or her to work through these fears.
Hope	It is important for a person with a positive result to move into a place of hope. People living with HIV/AIDS can hope for many things—to live a long time, to remain healthy a long time, to hope for better medicines to fight the disease, to hope for success on their jobs or with their activities, to hope for a happy life after death, and so on. Hope is an important part of lengthening one’s honeymoon period and remaining healthy longer with HIV/AIDS.
Loneliness or Isolation	Another common reaction to a positive HIV test result. This feeling may come and go and may be lessened by support from family, friends, and the community.
Self-Consciousness	Another possible reaction to a positive test result. The person may feel that everyone is looking at them or talking about them. They may want to hide or feel unworthy. Encourage them to get involved in community events and to stay active. Remind them that people with HIV/AIDS are valuable members of the community like everyone else.
Shock	A common reaction to a positive result to an HIV test. The person may be so surprised and confused that they may not know what to do. It is important that the person have someone that they trust around at this time.

Home Care: The Power of Our Community

Training Schedule: Section 1

Schedule	Day One	Day Two	Day Three	Day Four
	Registration <i>30 minutes</i>	Recap <i>30 minutes</i>	Recap <i>30 minutes</i>	Recap <i>30 minutes</i>
Session	The Power of Our Community Introductions, Goals, and Objectives Workshop Structure <i>1 hour 30 minutes</i>	Medical Support for People Living with HIV/AIDS (cont.) Common Illnesses Role-Play <i>1 hour 45 minutes</i>	Nutritional Needs for People Living with HIV/AIDS and Their Families We Are What We Eat <i>1 hour</i> Nutritional Needs for People Living with HIV/AIDS <i>1 hour</i>	Preparing for Goodbye Supporting People Living with HIV/AIDS <i>1 hour 30 minutes</i>
Break	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
Session	Breathe in Life, Breathe Out Trouble The Power of Our Community <i>1 hour 30 minutes</i>	Oral Rehydration Solution and Thermometer Use <i>1 hour</i> Seeking Medical Support from a Professional Service Provider Special Medical Concerns for People Living with HIV/AIDS <i>1 hour</i>	Social Support for People Living with HIV/AIDS and Their Families Small Groups on Social Issues <i>1 hour</i> Plenary on Social Issues <i>1 hour 30 minutes</i>	Supporting Orphans <i>1 hour 30 minutes</i>
Lunch	<i>1 hour</i>	<i>1 hour</i>	<i>1 hour</i>	<i>1 hour</i>
Session	Review from Section Two Review of HIV Transmission, Prevention, and Disease Progression <i>1 hour 30 minutes</i>	Strategies for Dealing with Health Professionals <i>45 minutes</i> Antiretrovirals <i>30 minutes</i>	Psychological Support for People Living with HIV/AIDS and Their Families People Living with HIV/AIDS Vignettes <i>1 hour 45 minutes</i>	Closing Evaluation <i>1 hour</i> String Spider Web and Closing Ceremony <i>1 hour</i>
Break	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
Session	The Life Tree Life Tree <i>1 hour 30 minutes</i> Medical Support for People Living with HIV/AIDS Common Illnesses Role-Play <i>1 hour</i>	Physical Support for People Living with HIV/AIDS and Their Families Caring for People Living with HIV/AIDS in the Home <i>1 hour 30 minutes</i>	<i>The previous session can be emotional. Trainers may want to have a counselor present and use the afternoon session for this purpose.</i>	
Evaluation	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
Total Time	<i>8 hours 45 minutes</i>	<i>8 hours 45 minutes</i>	<i>8 hours 30 minutes</i>	<i>6 hours 45 minutes</i>

Chapter 8: Psychological Support for People Living with HIV/AIDS



Sample
Lesson
Plan

Sample Lesson Plan

Time	Content	Methodology	Materials Needed	Evaluation
2 hours (or more)	<p>People Living with HIV/AIDS Vignettes and Discussion</p> <p>Voluntary counseling and testing</p> <p>Disclosing status to partner</p> <p>Potential partner violence or abandonment</p> <p>Disclosing status to children</p> <p>Support groups</p>	<p>HIV positive participants (or guests) tell brief vignettes about specific issues in their own lives; each vignette is followed by a discussion of the issues involved</p>	<p>Flipchart</p> <p>Markers</p> <p>Tape</p>	<p>Active participation in the activity</p> <p>Participants referencing psychological issues throughout rest of the workshop</p>

Chapter 8: Psychological Support for People Living with HIV/AIDS

Activities and Handouts for Psychological Support for People Living with HIV/AIDS

- **People Living with HIV/AIDS Vignettes and Discussion**

Activity **People Living with HIV/AIDS Vignettes and Discussion**

Objective

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

- Explain voluntary counseling and testing (VCT)
- Discuss the importance of VCT to the psychological health of people living with HIV/AIDS and others affected
- Describe some of the issues around disclosing HIV status to a partner, including potential partner violence or abandonment
- Demonstrate an understanding of the issues involved in disclosing HIV status to children
- Discuss the importance of support groups to the psychological health of people living with HIV/AIDS and orphans and vulnerable children

Time allotted 2 hours (or more)

Preparation

It is important to take extra time in preparing for this session, as you will want to achieve a smooth flow between the brief vignettes of HIV positive participants and the ensuing discussions. It is important to have at least one man and one woman, as their experiences will differ due to gender issues. If you have people living with HIV/AIDS at your workshop, you may wish to meet with them the night before this session (or during lunch if that is not possible). [*If people living with HIV/AIDS are brought in just for this session, you will want to meet with them a day or two before this session, and then probably again on the day of the session.*] You may want to describe the specific issues you want to get at in the session, and to discuss the speakers' experiences with the various issues. Then choose specific vignettes from the participants to be shared with the larger group in this session. Encourage the speakers to keep their vignettes brief, as this can often be a challenge. Be sure to ask the HIV positive speakers if there are other issues that you have missed that have been pertinent in their own lives, and to add them to the topics of this session. (You may also find that some topics are not an issue in terms of the experience of your participants, and you should stay open to removing those issues from the session.)

In terms of room arrangement, you may want to consider a circle of chairs, with a small gap for the flipchart stand. You might position all the speakers who are living with HIV/AIDS near the front of the circle (by the flipchart), or you may find it is more effective to leave them scattered among the participants, so that they tell their stories from within the group.

It is important to be sensitive to the stress levels in the group during this session. Feel free to use the “Breathe In Life” exercise as needed during and at the end of this session. It is an excellent opportunity to practice the release of stresses.

Facilitation steps

1. Recap the “Life Tree” session briefly. Suggest that we will spend the next few days dealing with a few of the specific categories involved in care and support for people living with HIV/AIDS and orphans and vulnerable children. Refer to the “Psychological Support” branch, and indicate that we will begin by discussing these issues, as they are often the most important at the beginning of an HIV positive diagnosis.
2. Suggest that the care and support of a person living with HIV/AIDS begins even before he/she comes in for an HIV test. The decision to get tested is a very important one, and the possible consequences must be considered. Community support for getting tested can reduce stigma and discrimination and other negative outcomes, such as partner violence or abandonment of those who get testing. The importance of a positive, confidential VCT experience cannot be underestimated. Point out that the decision to be tested—regardless of results—can make a person vulnerable to stigma, discrimination, violence, or abandonment.
3. Invite the people living with HIV/AIDS that you have chosen to speak on VCT to begin his or her vignette/s. Allow 10-15 minutes for the story. After the vignette, lead a discussion around the issue of VCT, noting important points on the flipchart. Whether the story is of a positive or a negative counseling experience, use it to raise some of the following key issues in the discussion that follows.

Voluntary Counseling and Testing

- The **reasons a person decides to get tested** can play into their state of mind or their readiness to cope with a positive result. Some people suspect that they might be infected already and may be more prepared than someone who has been tested unexpectedly. No one should be forced to have an HIV test. It is important that the person has control over the decision to get tested in the first place. There may be negative consequences for getting tested, especially for women, so all testing services should take care to ensure safety.
- The **environment of the testing site** is important. Was it a private, confidential discussion or were many people around? Was information available about the test at the site?

- The attitude, compassion, and communication skills of the **counselor** are probably the most important factor in an empowering VCT session. The counselor should remain nonjudgmental, positive, and hopeful, while at the same time listening and acknowledging the feelings of the client. It is important that the counselor listen to the client's feelings and fears without attempting to give advice or just make them feel better. (You may wish to review pre- and post-test counseling with the group at this time, using some of the definitions in the "Important Terms" section of this chapter.) Working with traditional healers and perhaps training them to serve as counselors for HIV/AIDS can reduce stigma around the myth of bewitchment.
 - In some communities, **shared counseling** is practiced. Shared counseling emphasizes the support of the family or community from the very beginning. The client chooses a trusted family member or friend to accompany him or her to the pre- and post-test counseling sessions. The counselor gives the result to both the client and the companion and involves the companion in helping the client cope with the positive result.
 - There are a number of **possible reactions** to a positive test result. These are listed in the beginning of this chapter under "Important Terms." (You may want to go through these possible reactions one by one, and emphasize that these reactions can happen at any time after diagnosis, not just during the VCT session. Participants need to know about these possible reactions to prepare for their home care work.)
 - Confidential VCT may not be achieved in one visit. It may take many visits before the client can decide to be tested.
 - Negative results also have implications that a person will have to deal with and may want to seek some of the same post-test counseling options or support from family members. It will now be a priority to remain HIV negative and it is important that the person is counseled on prevention methods. This may be difficult depending on their situation, such as being married to an HIV positive spouse.
4. After about 20 minutes of discussion around VCT, invite the person living with HIV/AIDS who has been chosen to speak on disclosing HIV status to a partner to speak. Allow 10-15 minutes for the story. After the vignette, lead a discussion around the issues involved in disclosure of HIV status to a partner. Be sure to ask leading questions to cover at least the following points.

Disclosure of HIV Status to a Partner

- It is important to disclose one's status to a partner or partners so that the couple can prevent infection or re-infection, plan for the future of the family and attempt to avert mother-to-child transmission of HIV.
- Sometimes the very decision to test can suggest problems with trust in the relationship or can be construed as an admission of risky sexual behavior. As such, clients may fear that disclosure of HIV results will call the relationship into question.
- Women may feel that they need permission from their sexual partners to take the HIV test at all. Taking the test without their partner's consent and then disclosing positive results can lead to fear of violence or rejection for the female partner. In addition, those tested are far more likely to disclose their test results if their partner knows beforehand that they are going to take the test. Therefore, outreach efforts aimed at education around HIV/AIDS might begin to target strategies for communicating with one's partner about the HIV test.
- Violence can often be a very real part of life for female clients, and, as such, the possibility of it should be addressed during the VCT session and beyond. Women may often need a great deal of support to deal with the issue of violence around disclosure of HIV status. The decision to disclose status should always be left to the individual. Strategies to disclose status safely can be discussed in women's groups, with clergy, and among the community in general. (If you have statistics regarding partner violence in your community, you may wish to include them here.)
- Greater community awareness of HIV and the presence of support groups often make it easier for a person to disclose their HIV status to a partner. As such, community programs to target stigma and discrimination around HIV/AIDS can help reduce the anxiety around disclosure.
- Although many women fear being blamed for the result, or may worry about physical abuse or abandonment, studies seem to indicate that reactions are usually not so negative. Despite this research, some women may still be in a risky situation around disclosure of results, so the counselor should work with all women to create safe disclosure strategies. Counselors should also keep in mind that they should encourage, but not force, disclosure, as only the woman involved truly understands the reactions that may accompany such disclosure.

- Because of the risk of violence in the lives of (especially) women, VCT counselors should be trained to ask questions about partner violence, to honor client confidentiality, and to strategize about safe disclosure plans.
 - Working on community interventions to change norms around violence, as well as legal recourse for the victims of violence, may be the most powerful tools in supporting those who wish to disclose their HIV status to their partners.
5. The discussion around disclosure of status to a partner, especially in terms of women's fear of disclosure, can be animated, but try to ensure that it does not go over 25-30 minutes. Next move on to a discussion on disclosing one's HIV status to children. Invite the participant to tell their story about how they disclosed their status to their children, or the difficulties that have prevented them from disclosing their status. Allow 10-15 minutes for this vignette, before leading a discussion that includes at least the following points.

Disclosure of HIV Status to Children

- Parents must overcome many barriers and taboos in order to disclose HIV status to children. These may include the stigma associated with HIV/AIDS itself, or traditional customs that discourage adults from discussing sex or death with those younger than themselves. Parents may wish to avoid the embarrassment that comes with discussing HIV/AIDS and potential questions about how they became infected. As there may also be fear in some societies around the myth of bewitchment, parents may also wish to protect their children by keeping their status a secret. Parents may debate whether disclosing their status will help or hurt their children. Working with traditional healers and perhaps training them to serve as counselors for HIV/AIDS can reduce stigma around bewitchment.
- Parents must come to accept their HIV status before they can feel comfortable guiding their children through the news.
- Parents should be aware that children might suspect their illness and maybe even their HIV positive status. Children are keen observers, but often do not know how to interpret what they see. Consequently, children may fear that the illness is much worse than it is or that they themselves have caused their parent's illness. Children may fear that their parent may die immediately. It is important to make some decision about disclosure to children before the parent's illness begins to cause anxiety in the child that may manifest itself in the child's performance at school, behavioral problems, or the child's overall wellness.

- The age of the child may influence whether or not the parent/s choose to disclose their status to them. Children around seven years old are usually mature enough to understand death and they may have heard about HIV/AIDS by that time. Often, children at this age do not yet understand the stigma and discrimination around HIV/AIDS.
- Discussing HIV infection and transmission with all family members, including children, can help them to protect themselves from potential infection that may come from caring for their sick relative.
- It is important to remember that the decision to disclose to children is the persons alone. As a counselor or care provider, you may provide the person living with HIV/AIDS as many facts and as much support as you can, but ultimately, it is an intimate and personal decision. It is the parent's right to choose how and when to disclose their status to their children, and you can only help them to understand the effect that disclosure or non-disclosure may have upon the children.
- Once parents decide to disclose their status to their children, it is important that they emphasize—
 - The parent's HIV infection is not the child's fault, nor is any other illness that comes from that infection.
 - The parent clarifies that their HIV status means, illness and death, and possibly many years of a normal life. Depending on their age, children should be told what will happen to the children after the parent/s deaths. Children should be educated about the progression of the disease, so that they will understand that their parent/s can live healthily with the virus. As much as possible, parents should emphasize a hopeful outlook—that they will live positively with HIV/AIDS.
 - They remember that the entry of HIV/AIDS into a household can often substantially change the child's role in the family. Children may become caregivers for the sick, may have to take on additional housework or income generation responsibilities, and may suffer withdrawal from school or other youthful pursuits.
- The best person to prepare a child for the death of a parent is that parent. Many adults believe that not talking to children about death is a way of protecting the child, but in fact, it is often a way of protecting the adults from a painful discussion. It is important to remember that even if an adult is not talking to a child about death

and illness, they are still communicating about it—but in a negative way.

- It is important to keep the lines of communication open with children about HIV/AIDS so that they can continue to feel included and sure of the situation as the disease progresses and as the circumstances of their lives change. More information about talking to children about death and dying will be discussed in the “Preparing for Goodbye” session later in the workshop.
6. Next move on to a discussion on disclosing one’s HIV status to the extended family. Invite the participant/s to tell their story about how they disclosed their status to their extended family members, or the difficulties that have prevented them from disclosing their status. Allow 10-15 minutes for this vignette, before leading a discussion that includes at least the following points.

Disclosure of HIV Status to Extended Family

- The extended family is important in many cultures. It often provides a safety net to those family members who experience difficult situations or unforeseen emergencies. Disclosure of HIV positive status to extended family members can help the person deal with various issues, including provision of social, emotional, and economic support.
- Sometimes it is easier for a person to disclose his/her status to a member of his/her extended family, such as a brother, sister, mother, father, aunt, uncle, or some other member that he/she is particularly close to and whom he/she trusts. That family member may be able to help the person living with HIV/AIDS to tell other members of the family. The decision to disclose, however, always remains the positive individual’s right and responsibility.
- However, sometimes when members of the extended family find out someone is HIV positive, they can react in very cruel ways. They may feel that the individual has brought shame or disgrace on the family. They may be frightened that they too will contract HIV and will shun the family member who is ill, refusing care and even food. Some family members may even throw the person out on the street and disown him/her and his/her children.
- Working with traditional healers and perhaps training them to serve as counselors for HIV/AIDS can reduce stigma around the myth of bewitchment.

7. Lastly, invite a person living with HIV/AIDS to talk about the importance of support groups or peer groups in their lives or in the lives of their children. Allow 10-15 minutes for this vignette, and then lead a discussion that includes the following points.

Support Groups for People Living with HIV/AIDS and Orphans and Vulnerable Children

- Support groups can help people living with HIV/AIDS and orphans and vulnerable children overcome their feelings of isolation and can provide an outlet for their fears and anxieties. Support groups can also provide valuable strategies for dealing with problems arising from being HIV positive.
- In areas where there are active support groups, there also appears to be less stigma in the community around HIV/AIDS and VCT.
- Because parents can often be preoccupied with their own grief or with illness, it can often be difficult to provide enough support to their children. A peer group can provide a forum for the children to discuss their fears openly with other children who are also affected by HIV/AIDS.
- In situations in which you are the support person for a person living with HIV/AIDS or an orphan or vulnerable child, try to remember to—
 - Actively listen, without feeling that you always have to provide advice.
 - Understand what the person is feeling, but do not assume you can understand fully.
 - Ask questions.
 - Respect people and their feelings; do not feel that you have to change them.
 - Try not to distance yourself from their pain by denying their emotions or providing advice; these messages imply that there is something wrong with the way the person is feeling and that you are uncomfortable dealing with their issues.
 - Respect confidentiality and privacy.
 - Provide correct information; admit when you do not know information, and offer to find out.
 - Encourage people living with HIV/AIDS and orphans and vulnerable children to find spiritual outlets for their pain and grief. Prayer, meditation, attending religious services, or speaking with a spiritual advisor can all help in finding answers

to the difficult questions around life and death, and can bolster one's feelings of power and hope during the battle with HIV/AIDS.

- Try not to become impatient or angry. If you feel yourself losing patience, acknowledge that as a caregiver, you will also need support and a respite from these issues.
- Offer to help. This may include helping with physical ailments, picking up supplies or food, helping with the children or with household chores, or helping the person living with HIV/AIDS to plan for the future.
- Be sure to have your own emotional support. Dealing with chronically ill people and death is extremely difficult and you need to care for your own mental and emotional health, in order to be an effective caregiver.

Wrap-up

In summarizing the session, emphasize that psychological support may be the backbone of care. Often, caregivers will focus on providing physical or medical care, but forget stopping to talk or really listen to the needs of those affected by HIV/AIDS. It is important to support people living with HIV/AIDS and orphans and vulnerable children to retain a hopeful state of mind, while listening to and helping to address the realities of coping with HIV/AIDS. Suggest that participants keep these issues in mind throughout the workshop as we move on to a discussion of physical, medical, and social support. Psychological support issues underlie all of the topics we will discuss, and we should always keep in mind this holistic approach to caring for people living with HIV/AIDS and orphans and vulnerable children.

References

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Note to Trainers—

It is important to have full participation of people living with HIV/AIDS as equal partners in all activities. So it is assumed that wherever possible, there are HIV positive participants and/or trainers in this workshop. Including them as active agents in this session can be particularly powerful, as other participants can benefit from their experiences with VCT, disclosure of results, and issues around support.

If there are no HIV positive participants or facilitators at the workshop, the second best thing would be to bring in people living with HIV/AIDS, perhaps from a local support group. If you decide to do that, consider inviting them to be with you for lunch and throughout the day so that they and the participants will become more comfortable with each other. It will also be doubly important to spend time outside the workshop preparing these guests for the vignettes if you choose this option.

If it is impossible to have people living with HIV/AIDS at the workshop, you might consider using the Case Studies at the end of this chapter. If you choose to use Case Studies, you may wish to divide participants into four groups—each with a different case study—and ask them to come up with the issues involved in that story. All groups can then report out in plenary, after which you can highlight any missing issues.

Women tend to have an especially hard time disclosing their status to a partner due to fear of physical abuse or abandonment. It may be a good idea to choose a female living with HIV/AIDS for the second vignette on disclosure of status to a partner, so that you can easily raise these issues. If a male living with HIV/AIDS is your only option, be sure to raise these issues anyway.

Always keep in mind that participants in the workshop may either think they are infected or know they are infected and not be ready to disclose their status.

Psychological Support for People Living with HIV/AIDS and Their Families

Case Study 1—Testing

Things were going just fine until Joseph's brother was in an accident. The family rushed to the hospital, and a few of the brothers were asked to donate blood for surgery. After a few hours, one of the nurses asked to see Joseph in the office. She sat him down and explained that they were not able to use his blood because it was "bad." Joseph did not understand and asked her to explain. She told him he had HIV in his blood, and that he must have counseling so that he can tell his sexual partner, have safer sex, and begin living a positive and healthy life with the virus. Joseph was very angry. He was not sick at all, yet, here she was telling him he was going to die! Joseph stormed out of the office and went off to the bottle-store (or bar). He began to drink heavily and to think about what the nurse had said. He started to wonder about his girlfriend. Did she give him this terrible thing? He got angrier and angrier as he drank and thought about who might have done this to him. He stormed off to meet his girlfriend and confronted her about her sexual behavior.

- What were some of the positive and negative aspects of the way that Joseph was tested and counseled?
- What were some of Joseph's reactions to the news that he was HIV positive? What do you think was responsible for these reactions?
- Would there have been a more positive way for the counselor to approach her discussion with Joseph? What might have been improved? What could not have been avoided? What should have been the correct procedure for testing and releasing the result?

Psychological Support for People Living with HIV/AIDS and Their Families

Case Study 2—Disclosure to Partner(s)

What a difficult year it has been. First, Mercy's new baby seemed so small and sick. The baby seemed to come down with one illness after another—ear infections, diarrhea—and he just did not seem to grow any bigger. The visit to the health clinic was no help—the doctor said she thought the baby might have AIDS. Mercy refused to have the baby tested, but when the baby died, she felt sure that her family had been found by this disease. Then when Mercy started feeling weak and tired all the time herself, she grew worried that she too was infected and that she may have passed this disease on to her little baby. When she finally went to the clinic and tested positive, she was terrified. How could she confess this result to her husband? He would be so angry that she went for the test without asking him about it. What would he say? Would he beat her? Send her back to her family?

- What are Mercy's fears about disclosing her status to her husband?
- As a counselor or support person, how might you help Mercy decide on a safe way to disclose her status to her husband? What are some of the things you might emphasize to her?

Psychological Support for People Living with HIV/AIDS and Their Families

Case Study 3—Disclosure to Children

Edith is frightened. After the death of her baby sister, she began to suspect that something might really be wrong with her mother. Her grandmother and aunt always stopped their whispering when she walked into a room, but the last time, Edith overheard them say that they did not know what would happen to the children once their mother died. Edith can not understand why everyone is hiding the truth from her. She has started to daydream a lot in school—thinking about her mother and father and what might be making them sick. She wonders if it has something to do with her. She took over the cooking when her mother was pregnant—maybe she somehow made them sick with her food? Or maybe the family is bewitched? All Edith knows is that she is terrified that her parents will die and leave all of the children orphans. Where will they live? Who will care for them? What will they eat?

- How is Edith reacting to the situation in her family?
- What are some of the positive and negative aspects of explaining her parents' HIV status to Edith and the other children?
- How might Edith's parents approach disclosing their status to their children?
- How could Edith find answers to her questions?

Psychological Support for People Living with HIV/AIDS and Their Families

Case Study 4—Support for People Living with HIV/AIDS and Orphans and Vulnerable Children

It has been hard for the whole family to deal with the community's reactions to the news that Papa is HIV positive. The children are often embarrassed at school—they think that everyone is always looking at them and talking about them. Mama fears that the ladies from the church think that she is HIV positive, too, and that she somehow caused Papa's illness. She tries to talk about it to her sisters, but they always tell her that everything is going to be all right, or they give her advice that is not realistic. Mama knows that her children are feeling isolated, but she does not know what to do to help them. One day, the counselor at the hospital suggests that Mama go to a support group for people living with HIV/AIDS that operates from the community center. He even suggests that she send her children to a peer group for young people. She was very worried about going to the support group because she thought that the community would talk about her even more. But after a few visits, she began to feel better about the situation. The people in the group seem to be having the same problems and worries as she and her husband. And the children say it is a relief to know that other children are living with this problem too.

- How did Mama react to the help of her sisters? Why was their approach to helping her not effective?
- What are some of the benefits of joining a support group for people living with HIV/AIDS and orphans and vulnerable children? Are there any drawbacks?
- If you were the caregiver or support person for the family, how might you approach their anxieties about their situation? What might you say or do to support them?

Chapter 9

Preparing for Goodbye

“Let’s walk with 13- year old Linda—two kilometers to a well in the heat of the Ugandan mid-day sun to fill a jerry can of water (which weighs nearly as much as Linda). Linda is small for her age, largely due to the fact that there has not been enough to eat in the family since the arrival of this chronic illness, which took her father a year ago and is now ravaging her mother...

Linda has many fears and anxieties for the future, and she has reason to be anxious. She will spend many days caring for her mother until she dies. When her mother is gone Linda and her siblings will be left alone to fend for themselves—joining the growing number of child-headed households in Africa. Without parental guidance, the chance of Linda joining the cycle of HIV infection and her siblings ending up on the street is very high.”

—NOERINE KALEEBA, FOUNDING MEMBER
THE AIDS SERVICE ORGANIZATION (TASO), UGANDA

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Chapter 9: Preparing for Goodbye

Key Questions

- What are some of the issues, anxieties, or fears that may come up for people living with HIV/AIDS while thinking about their deaths?
- What are some strategies that can help people living with HIV/AIDS die with dignity?
- What are some of the fears and anxieties that may come up for orphans and vulnerable children upon the loss of their parents?
- What strategies can be put in place to lessen the impact of HIV/AIDS on orphans and vulnerable children?

Introduction

Perhaps the most difficult topic to explore around HIV/AIDS or any chronic illness is death and dying. In many communities all over the world, the topic of death is avoided, perhaps because it is a cultural taboo, or because we fear that we are inviting death if we discuss it. Sometimes we fear that discussing death will upset or depress people living with HIV/AIDS and their children. But in reality, they often spend a great deal of time thinking about death, especially in the final stages of HIV/AIDS. Having the courage to talk about death and dying can often be the most compassionate support you can provide.

Some of the major issues that may trouble people living with HIV/AIDS when they think about death and dying might include: fear of a painful death, possibility that there is no afterlife, sadness at leaving their families and children, worrying about money or resources, fearing that their lives were meaningless, and so forth. This session encourages participants to develop strategies to support people living with HIV/AIDS as they encounter these issues.

Talking to children about death and dying may be difficult for caregivers and even more so for their HIV positive parents. In many societies, it is not considered appropriate to discuss dying with children, and in some cases, it may even be taboo. But the children may feel sadness, grief, confusion, fear, and even anger at the potential loss of their parent(s) and their normal way of life. It is important that community members and people living with HIV/AIDS themselves develop support systems to meet the unique needs of orphans and vulnerable children. This session challenges participants to focus on the issues of death, dying, and grieving for both people living with HIV/AIDS and orphans and vulnerable children.

Chapter 9: Preparing for Goodbye

O

bjectives

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

- List some of the issues, anxieties, or fears that may confront a person living with HIV/AIDS while thinking about their deaths and the future of their families
- List strategies for helping a person living with HIV/AIDS prepare to die with dignity
- Describe a “Memory Book”
- Describe the process for writing and registering a will according to local laws
- List some of the issues, anxieties, or fears that may confront children upon the loss of their parent(s)
- List strategies for helping orphans and vulnerable children to heal psychologically and emotionally after the loss of their parent(s)
- List strategies for supporting the material and social needs of children after the loss of their parent(s)
- Describe an “AIDS Quilt”

Home Care: The Power of Our Community

Training Schedule: Section 1

Schedule	Day One	Day Two	Day Three	Day Four
	Registration <i>30 minutes</i>	Recap <i>30 minutes</i>	Recap <i>30 minutes</i>	Recap <i>30 minutes</i>
Session	The Power of Our Community Introductions, Goals, and Objectives Workshop Structure <i>1 hour 30 minutes</i>	Medical Support for People Living with HIV/AIDS (cont.) Common Illnesses Role-Play <i>1 hour 45 minutes</i>	Nutritional Needs for People Living with HIV/AIDS and Their Families We Are What We Eat <i>1 hour</i> Nutritional Needs for People Living with HIV/AIDS <i>1 hour</i>	Preparing for Goodbye Supporting People Living with HIV/AIDS <i>1 hour 30 minutes</i>
Break	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
Session	Breathe in Life, Breathe Out Trouble The Power of Our Community <i>1 hour 30 minutes</i>	Oral Rehydration Solution and Thermometer Use <i>1 hour</i> Seeking Medical Support from a Professional Service Provider Special Medical Concerns for People Living with HIV/AIDS <i>1 hour</i>	Social Support for People Living with HIV/AIDS and Their Families Small Groups on Social Issues <i>1 hour</i> Plenary on Social Issues <i>1 hour 30 minutes</i>	Supporting Orphans <i>1 hour 30 minutes</i>
Lunch	<i>1 hour</i>	<i>1 hour</i>	<i>1 hour</i>	<i>1 hour</i>
Session	Review from Section Two Review of HIV Transmission, Prevention, and Disease Progression <i>1 hour 30 minutes</i>	Strategies for Dealing with Health Professionals <i>45 minutes</i> Antiretrovirals <i>30 minutes</i>	Psychological Support for People Living with HIV/AIDS and Their Families People Living with HIV/AIDS Vignettes <i>1 hour 45 minutes</i>	Closing Evaluation <i>1 hour</i> String Spider Web and Closing Ceremony <i>1 hour</i>
Break	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
Session	The Life Tree Life Tree <i>1 hour 30 minutes</i> Medical Support for People Living with HIV/AIDS Common Illnesses Role-Play <i>1 hour</i>	Physical Support for People Living with HIV/AIDS and Their Families Caring for People Living with HIV/AIDS in the Home <i>1 hour 30 minutes</i>	<i>The previous session can be emotional. Trainers may want to have a counselor present and use the afternoon session for this purpose.</i>	
Evaluation	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
Total Time	<i>8 hours 45 minutes</i>	<i>8 hours 45 minutes</i>	<i>8 hours 30 minutes</i>	<i>6 hours 45 minutes</i>

Chapter 9: Preparing for Goodbye

Sample Lesson Plan

Time	Content	Methodology	Materials Needed	Evaluation
1 hour 30 minutes	<p>Supporting People Living with HIV/AIDS</p> <p>Accepting death and dying with dignity</p> <p>Preparing children</p> <ul style="list-style-type: none"> - Memory Books - Choosing a guardian - Inheritance provisions 	<p>Participants think about strategies for helping people living with HIV/AIDS prepare to die with dignity.</p> <p>Participants write those ideas on individual cards. The cards are placed on one wall. A large group discussion explores the ideas and uses them to generate additional strategies.</p>	<p>Half sheets of paper in two different colors (one color for people living with HIV/AIDS, one color for orphans and vulnerable children)</p> <p>One marker for each participant</p> <p>Tape</p> <p>Flipchart paper</p> <p>Samples of—</p> <ul style="list-style-type: none"> - Memory Books - Will - Inheritance laws <p>(if available and appropriate)</p>	<p>Active participation in the session</p> <p>Strategies generated and accepted by the group</p>
1 hour 30 minutes	<p>Supporting Orphans</p> <p>Honoring Memories</p> <ul style="list-style-type: none"> - AIDS Quilts - Use of drawings - Community support for orphans and orphans and vulnerable children 	<p>Participants think about strategies for helping children deal with the death of their parents and to manage their new status.</p> <p>Participants write those ideas on individual cards. The cards are placed on one wall. A large group discussion explores the ideas and uses them to generate additional strategies.</p>	<p>Half sheets of paper in two different colors (one color for people living with HIV/AIDS, one color for orphans and vulnerable children)</p> <p>One marker for each participant</p> <p>Tape</p> <p>Flipchart Paper</p> <p>Samples of—</p> <ul style="list-style-type: none"> - AIDS Quilts - Children's drawings <p>(If appropriate and available)</p>	<p>Active participation in the session</p> <p>Strategies generated and accepted by the group</p>

Chapter 9: Preparing for Goodbye

Activities and Handouts for Preparing for Goodbye

- **Supporting People Living with HIV/AIDS**
- **Supporting Orphans and Vulnerable Children**

Activity **Supporting People Living with HIV/AIDS**

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

- List some of the issues, anxieties, or fears that may confront people living with HIV/AIDS while thinking about their deaths and the future of their families
- List strategies for helping people living with HIV/AIDS to prepare to die with dignity
- Describe a “Memory Book”
- Describe the process for writing and registering a will according to local laws

Time allotted 1 hour 30 minutes

Preparation A week or more before this session, spend some time exploring local laws around inheritance, making a will, and guardianship. Attempt to obtain any documents, forms, or sample wills that may help participants to understand the process for registering a will. In addition, work with local orphan-care organizations to acquire a sample copy of a “Memory Book,” or if that is not possible, you may wish to create a sample yourself.

On the day of the session, arrange the chairs in a semi-circle around a blank wall. Ensure that each participant receives a bright colored marker and several half-sheets of colored paper. You may also wish to tear many pieces of tape and array them along the wall to facilitate the taping during the session.

Facilitation steps

1. There are often a number of false ideas, or myths about death and dying. Ask participants if there are any common proverbs or sayings about death in their community. (Some examples might be: “A man who will not talk about his death is a fool.”) Discuss common themes or reasons why someone might believe certain myths about death. Suggest that because there is no cure for HIV/AIDS, caregivers, people living with HIV/AIDS and the community must deal with issues of death and dying. It is often difficult for groups to speak openly about death and dying, but it is perhaps the most important and courageous discussion that a group can have in working with HIV/AIDS.
2. Now that we have explored various branches of the “Life Tree” from psychological to physical support, from medical to social support, we must focus our remaining “Life Tree” session on preparing to die. Suggest that sometimes we avoid the topic of death, either because it is a cultural

taboo, or because we somehow believe we are inviting death to come if we discuss it. Sometimes we think it is better to avoid discussing death because we fear it will upset or depress them to talk about it. But in reality, most people living with HIV/AIDS spend a lot of time thinking about and possibly worrying about death, especially in the final stages of AIDS. Having the courage to share these thoughts and fears with them can relieve the isolation they may feel in confronting their own deaths.

3. Since the focus of care up until this point has been positive and hopeful, sometimes it can be difficult to know when to begin to discuss death and dying. Suggest that it is important to emphasize that we are planning for a time that may be far or near, and that we are not suggesting that death is coming quickly. It may be difficult to decide when to shift from images of life and hope to a discussion of acceptance and dying with dignity. Some signs might include—
 - When medical treatment is no longer available or is no longer effective
 - When the person says he or she is ready to die (It is important to differentiate between someone who is ill and accepting death and someone who has been depressed and is clearly not that sick; the latter should be encouraged not to give up and should be helped to manage his/her depression)
 - When the body's vital organs begin to fail
4. Suggest that many of us in this group have had personal experiences with the deaths of those closest to us. Perhaps we have lived with or cared for someone in the final stages of AIDS or another terminal illness. Perhaps we are HIV positive ourselves and sometimes worry about what will happen to our loved ones when we die. No matter what our relationship to death, there is a great deal of expertise in this group that may help us to think through strategies for supporting people living with HIV/AIDS as they strive to die with dignity.
5. Ask participants to take a moment to think about the different issues that may be of importance to people living with HIV/AIDS as they think about their own deaths and as they think about the future of their families after they die. What issues may be uppermost in their minds as they prepare to say goodbye? What anxieties or fears might they have in the face of death?
6. Suggest that participants write down each issue that they think of on a separate half-sheet of paper. They should continue to write new cards until they have exhausted all ideas.
7. When participants seem to have finished, invite them to come up and tape their cards to the blank wall.

8. When all cards are along the wall, invite participants to take 15 minutes to read all of the ideas presented. If they see any similarities in the cards, they should feel free to move them around on the wall to arrange them in logical groups. They should also feel free to add any ideas using new cards. Although each group may have totally different ideas, some of the possibilities might include—
 - Fear of a painful death
 - Possibility that there is no afterlife; that “this is it”
 - Feeling like there is so much “unfinished business”
 - Sadness at missing key moments in the lives of their children or families
 - Worries about money or resources
 - What will happen to the children? Worries about the children becoming orphans, street children, and so forth
 - Fear that they will not be remembered; that their lives were meaningless
 - Worry that they will not have a chance to say goodbye
 - Fear that they will not go to heaven
 - Worry that there will not be enough money for a proper funeral
9. After 15 or 20 minutes, ask participants to take their seats. Ask the group which ideas stood out for them, which need more clarification, and so forth.
10. Lead a large group discussion around the ideas on the wall—reading a few and then discussing them with the group. Throughout the discussion, ask participants to consider any strategies that we might employ as caregivers to support people living with HIV/AIDS with these issues. List these strategies on a flipchart. Some possibilities include—
 - Listen. Allow the person living with HIV/AIDS to feel comfortable talking with you about their thoughts about death and dying. Although it may be uncomfortable at first, it will be easier as you go along, and it may be a great comfort to the person.
 - Arrange visits with a spiritual leader of the person’s faith. Spirituality, prayer, and meditation may be especially important for a person living with HIV/AIDS at this time.

- Ask the person if they wish to contact any family or friends who live outside the neighborhood and help to contact or send letters to this person.
- Arrange visits with a trained counselor if the person living with HIV/AIDS would feel more comfortable talking with someone outside of their circle of family and friends.
- Put the person living with HIV/AIDS into contact with a support group. As the participants in a support group are often confronting the same issues, they may feel more comfortable discussing these issues in such a group.
- Assure the person that management of pain will be a priority at the time of their deaths. Meet with health care workers to discuss these issues, so that they can be assured that they will have as little pain as possible at the time of death.
- Gather information about local inheritance laws and share that knowledge with the person living with HIV/AIDS. Work together to develop a plan for the inheritance of any property. This may involve writing a will together or putting them in touch with someone to help them write and register a will. (At this point, distribute any copies of inheritance laws, documents, sample wills, and so forth. Briefly discuss these documents and anything you might have found out about the inheritance process.)
- Encourage the person to talk with his/her children about their deaths. People often try to avoid talking with children about death or allowing them to express their feelings about death—usually because it is assumed that children will not understand death, because there is a fear that children will be frightened, or because it makes adults uncomfortable. This is a mistake that might lead to the feelings of guilt, depression, confusion, loss of control, anxiety, or fear in the children. Talking about death and dying can be a positive experience for both them and their children. It is especially important for older children to talk with their parents. It gives both the opportunity to say goodbye, to ask questions, to give advice for the future, and to help the children to begin to let go. It is often said that the best person to prepare a child for a parent's death is that parent.
- Suggest that the person work with their children in choosing a guardian(s). They can use the time while they are still healthy to discuss guardianship with the extended family, to choose the guardian(s), and even to allow the child to spend some days or weeks with the guardian(s). Planning for the future in this way can

ease anxiety and can lead to a smoother transition for the children upon the parent's death.

- Encourage the person to create a Memory Book for their children. Originating in Uganda, the Memory Book is a journal of facts and memories for children who are facing the loss of a parent. The Memory Book is a way for the parent to impart important memories to the children—about the history of the family, facts about the parent(s), family traditions, favorite memories, and so forth. It can include stories, pictures, photographs, or anything else, under headings such as “My favorite memories of you,” “How I met your father,” “Family traditions and events,” “Special family recipes,” advice on a variety of issues the child will have to deal with, and so on. The Memory Book is a comfort to the person living with HIV/AIDS because it is a way for them to live on in their children's memories. It is a comfort because it increases the children's sense of belonging and allows children to keep the memories of their family alive even if they must relocate to another area. People can complete the Memory Book on their own and then discuss it with the children, or they can create the books together with their children. It is important that the Memory Book be discussed with the children while the parent is still alive, so that the children can ask questions about the family history, talk about loss or feelings of grief, and seek advice. The Memory Book can also be a way to disclose HIV status to the children or to talk with them about HIV prevention for themselves. (If you have a sample Memory Book, pass it around for the participants to see it as you are having this discussion.)
- In the final stages of dying—
 - Keep the person comfortable
 - Manage pain using pain medication; be sure to give in regular doses, not only when pain is at its worst
 - Use relaxation techniques such as encouraging deep breathing, giving back rubs or body massages
 - Continue basic physical care such as keeping the person clean and dry, preventing skin problems, and so on
 - Encourage communication with the family and community; help them to use this time to say goodbye, to heal old wounds, to give advice to children, and so on
 - Provide physical contact by touching, hugging, and holding hands
 - Arrange for counseling or spiritual guidance

- Ensure that the guardian chosen for the children is there during the final stages to help comfort both the children and the person
- Help people living with HIV/AIDS to stay as independent as possible—
 - Accept the person’s own decisions such as refusal to eat or get up
 - Respect requests, for example regarding visitors
 - Ask them what they are feeling; listen and allow the person to talk about how they feel
 - Accept the person’s feelings of anger, fear, grief, and other emotions
 - Work with the person on funeral arrangements and other last-minute preparations that may ease anxiety about what will happen after they die

Wrap-up

Summarize this segment of the session by asking for any final comments about supporting people living with HIV/AIDS in managing death and dying. Suggest that we will now move into a discussion of working with children after the loss of their parent(s).

Activity **Supporting Orphans and Vulnerable Children**

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

- List some of the issues, anxieties, or fears that may confront orphans and vulnerable children upon the loss of their parent(s)
- List strategies for helping orphans and vulnerable children to heal psychologically and emotionally after the loss of their parent(s)
- List strategies for supporting the material and social needs of children after the loss of their parent(s)
- Describe an “AIDS Quilt”

Time allotted 1 hour 30 minutes

Preparation About a week before this session, you may wish to explore all of the local and national support systems for orphans and vulnerable children. Find out about any support groups, camps, community organizations, and so forth that work with orphaned children, and prepare a handout of contact information for the group. In addition, attempt to acquire a panel of an AIDS Quilt to use as a sample, or, if that is not possible, collect photographs of AIDS Quilts to use as samples. Lastly, samples of children’s drawings (from local orphan-care organizations) would be useful as examples during the session.

The room arrangement and supplies will be the same as with the first half of the session. Chairs should remain arranged in a semi-circle around a blank wall (although half of it should now be covered with the papers from the “People Living with HIV/AIDS” exercise). Ensure that each participant receives a bright colored marker and several half-sheets of colored paper—use a different color than that used for the “People Living with HIV/AIDS” exercise. You may also wish to tear many pieces of tape and array them along the wall to facilitate the taping during the session.

Facilitation steps

1. Welcome the group back from break. Indicate that we will spend the next session focusing on caring for orphans and vulnerable children after the loss of their parent(s). Suggest that our roles as caregivers continue after the death of the parent as we strive to help the families overcome their grief, manage financial and other arrangements and transition the children into new homes and situations.
2. Ask participants to take a moment to think about the different issues that may be of importance to children after the loss of their parent(s). What issues may be on their minds after their parent dies? What anxieties or fears might they have? What material or social needs might they have?
3. Suggest that participants write down each issue that they think of on a separate half-sheet of paper. They should continue to write new cards until they have exhausted all ideas.
4. When participants seem to have finished, invite them to come up and tape their cards to another section of the blank wall.
5. As in the last exercise, when all cards are along the wall, invite participants to take 15 minutes to read all of the ideas presented. If they see any similarities in the cards, they should feel free to move them around on the wall to arrange them in logical groups. They should also feel free to add any ideas using new cards. Although each group may have totally different ideas, some of the possibilities might include—
 - Sadness, grief, or anger at the loss of the parent(s)
 - Feelings of guilt or that they somehow are responsible
 - Fear or anxiety about their care. Who will feed them? Where will they live? Who will take care of their school fees? Will their new guardian(s) be kind or cruel?
 - Worry that relatives will snatch their property or anything left to them by their parents
 - Fear about the future
 - Stigma or discrimination from the community because their parent(s) died of AIDS or anxiety that the community will think they are also infected with HIV
 - Fear about being infected with HIV or worry that they, too, will die of AIDS
 - Nightmares or bad memories of parent's illness and death

6. After 15 or 20 minutes, ask participants to take their seats. Ask the group which ideas stood out for them, which need more clarification, and so forth.
7. Lead a large group discussion around the ideas on the wall—reading a few and then discussing them with the group. Throughout the discussion, ask participants to consider any strategies that we might employ as caregivers to support orphans and vulnerable children with these issues. List these strategies on a flipchart. Some possibilities include—
 - Offer to help the extended family to make any arrangements for the funeral or for the transitioning of the children. Invite the new guardian(s) of the children to accept your help and continued care. Since you were involved in the care of the parent(s) during the time of illness and death, you may be an important link to the parents' memory for the children during this transitional period and thereafter.
 - Visit the children's new home as often as possible or as often as is appropriate. Offer to help with practical matters or just spend time listening to the needs of the children or of the extended family.
 - Where possible, mobilize the community to assist in offsetting the cost of food, clothing, or school fees for the children. As much as possible, work with the community to provide resources so that children are able to remain with their extended families. Investing money and resources into the extended family can keep orphans and vulnerable children from becoming street children, from involvement with crime or violence, or from having to exchange sex for food or shelter. But remember that assisting only orphans can create further stigmatization. Attempt to involve *all* children in any special community support schemes.
 - Provide connections to counselors, spiritual advisors, or other support systems for the children to help them to manage their feelings of grief, guilt, and sadness. Investigate any support groups and try to connect children to these groups. The death of a parent can often leave children feeling a profound sense of loss, abandonment and guilt. Children may require special emotional and psychological support to help them to manage these feelings.
 - If life skills camps, girls' clubs, boys' clubs, vocational training, or other opportunities exist in the community, help the children to become involved in them. Also, try to provide opportunities for the children to play or to "get away from it all."
 - Talk to teachers or other school leaders to help them to better understand the situation. Helping teachers to understand the trauma

suffered by the children can better prepare them to deal with any problems that may arise.

- Training programs or HIV/AIDS information sessions in schools, churches, with traditional healers, or in other venues may be helpful in changing community norms about HIV/AIDS. This may help reduce stigma and discrimination of orphans and vulnerable children.
- Help children to understand how HIV is transmitted and assure them of their own HIV status. Answer any questions they may have about HIV/AIDS, and offer to facilitate testing if necessary to relieve children's fear of being infected.
- Listen to the needs of children. Talk to them about their situation, their fear and anxieties, their hopes. Sometimes, especially with younger children, drawings can be helpful in evoking some of the grief and sadness they may wish to discuss. This can be as simple as inviting the child to draw a picture of their home life, or of their parent(s), and so forth. Ask the children to describe the picture to you, or ask specific questions about the picture to help the children to begin to open up. (At this point, show any samples you may have of children's drawings, and guide the group through a discussion of the pictures.)
- Involve the children in decision making about their futures. Ask them what they want to do about school, vocational training, play, and so forth, so that they can feel more in control of their own lives. Involving older children in the care of younger children can help them to feel more responsible and keep them from engaging in risk behavior.
- Give children many opportunities to talk about and to honor their lost parent(s). You may do this by looking through the Memory Book together, writing your own story about their parent(s) into their Memory Book, or you may work with the children to create an AIDS Quilt. An AIDS Quilt is created by the children and/or remaining family members to memorialize the lost parent(s). It can be made out of anything—fabric or clothing that was special to the parent, photographs, favorite items, religious symbols, and so on—anything that evokes the lost parent and allows the children to honor them. You can use the time taken to work on the quilt to help children to talk about their parent(s), to discuss their feelings of grief and loss, and to help them to remember them. (At this point, show participants the AIDS Quilt or pictures of AIDS Quilts as an example.) Alternatively, in some cultures, planting a tree is used in much the same way as an AIDS Quilt and can be suggested as a remembrance.

Wrap-up

Summarize the session by inviting any final comments or discussion regarding supporting people living with HIV/AIDS in death and dying and in supporting children upon the loss of their parent(s). Suggest that these issues are perhaps the most difficult and the most crucial of our many responsibilities as caregivers for people living with HIV/AIDS and orphans and vulnerable children. Successfully managing this difficult period requires the support of the entire community.

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Chapter 10

Closing

“Let’s build on what we have learned—

- *That we are not powerless against AIDS*
- *That prevention and care are two sides of the same coin, they have to be taken together*
- *That programs must not only give people information but also options, and skills, and programs must focus on young people*
- *That political leadership, involvement of people and communities, as well as international solidarity, are key ingredients to a successful anti-AIDS campaign.”*

*—NOERINE KALEEBA, FOUNDING MEMBER
THE AIDS SERVICE ORGANIZATION (TASO), UGANDA*

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Chapter 10: Closing

Key Questions

- What have we learned in this workshop?
- What are we *personally* committed to doing to ensure the care and support of people living with HIV/AIDS and orphans and vulnerable children in our communities?

I ntroduction

It is not possible to overestimate the impact of an entire community mobilized to provide care and support for people living with HIV/AIDS and orphans and vulnerable children. From the creation of a community vision statement to outlining the specific action plans for a care and support program, this training workshop has provided an opportunity to envision a powerful community response to the HIV/AIDS pandemic, complete with the knowledge and information necessary to get started. The final session of this workshop is intended as a summary and reflection upon the work of the group over the past few days so that the participants may feel further committed and motivated to begin the real work once the sessions have ended. The “String Spider Web” activity is a positive representation of the commitment in the community that begins to work on HIV/AIDS issues together. This powerful image will remain with participants throughout their HIV/AIDS work, and it may serve to inspire them and to support each other when their work becomes difficult.

It is important to evaluate what has been accomplished in any workshop in order to have meaningful input into programs and communities. We need to look at what the participants have learned, how well the facilitators presented the material and at the workshop overall, to help us improve future trainings. A final evaluation form is presented before the closing ceremony. It will be important to do a follow-up evaluation in the future to determine whether the participants did indeed become effective/competent caregivers and if this resulted in better care for the person they cared for at home, and to provide refresher training if needed.

Chapter 10: Closing

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bjectives

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

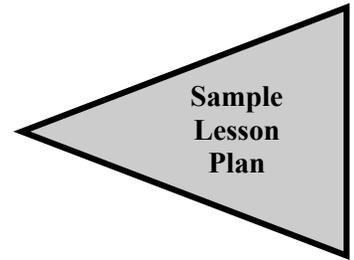
- Reflect upon the group's work
- Affirm their commitment to caring for people living with HIV/AIDS and orphans and vulnerable children

Home Care: The Power of Our Community

Training Schedule: Section 1

Schedule	Day One	Day Two	Day Three	Day Four
	Registration <i>30 minutes</i>	Recap <i>30 minutes</i>	Recap <i>30 minutes</i>	Recap <i>30 minutes</i>
Session	The Power of Our Community Introductions, Goals, and Objectives Workshop Structure <i>1 hour 30 minutes</i>	Medical Support for People Living with HIV/AIDS (cont.) Common Illnesses Role-Play <i>1 hour 45 minutes</i>	Nutritional Needs for People Living with HIV/AIDS and Their Families We Are What We Eat <i>1 hour</i> Nutritional Needs for People Living with HIV/AIDS <i>1 hour</i>	Preparing for Goodbye Supporting People Living with HIV/AIDS <i>1 hour 30 minutes</i>
Break	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
Session	Breathe in Life, Breathe Out Trouble The Power of Our Community <i>1 hour 30 minutes</i>	Oral Rehydration Solution and Thermometer Use <i>1 hour</i> Seeking Medical Support from a Professional Service Provider Special Medical Concerns for People Living with HIV/AIDS <i>1 hour</i>	Social Support for People Living with HIV/AIDS and Their Families Small Groups on Social Issues <i>1 hour</i> Plenary on Social Issues <i>1 hour 30 minutes</i>	Supporting Orphans <i>1 hour 30 minutes</i>
Lunch	<i>1 hour</i>	<i>1 hour</i>	<i>1 hour</i>	<i>1 hour</i>
Session	Review from Section Two Review of HIV Transmission, Prevention, and Disease Progression <i>1 hour 30 minutes</i>	Strategies for Dealing with Health Professionals <i>45 minutes</i> Antiretrovirals <i>30 minutes</i>	Psychological Support for People Living with HIV/AIDS and Their Families People Living with HIV/AIDS Vignettes <i>1 hour 45 minutes</i>	Closing Evaluation <i>1 hour</i> String Spider Web and Closing Ceremony <i>1 hour</i>
Break	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
Session	The Life Tree Life Tree <i>1 hour 30 minutes</i> Medical Support for People Living with HIV/AIDS Common Illnesses Role-Play <i>1 hour</i>	Physical Support for People Living with HIV/AIDS and Their Families Caring for People Living with HIV/AIDS in the Home <i>1 hour 30 minutes</i>	<i>The previous session can be emotional. Trainers may want to have a counselor present and use the afternoon session for this purpose.</i>	
Evaluation	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
Total Time	<i>8 hours 45 minutes</i>	<i>8 hours 45 minutes</i>	<i>8 hours 30 minutes</i>	<i>6 hours 45 minutes</i>

Chapter 10: Closing



Sample Lesson Plan

Time	Content	Methodology	Materials Needed	Evaluation
<i>1 hour</i>	Workshop Final Evaluation	Facilitators explain the importance of feedback from the participants to improve future trainings Participants fill out questionnaire and evaluation forms to assess their learning and the workshop	Copies of the Final Evaluation form and Post-Test Questionnaire Pens Envelope to collect forms	Active participation in filling out forms
<i>1 hour</i>	String Spider Web and Closing Ceremony Reflections Affirmations Presentation of certificates	Facilitator leads participants in reflections on the workshop using the “String Spider Web” activity Participants create a web connecting the entire group together while discussing their own commitment to HIV/AIDS work and their feelings about the workshop	String, Yarn, or Twine (large spool) Certificates of Participation in the workshop Gift (optional)	Active participation in the exercise Personal commitment to become involved in care and support for people living with HIV/AIDS in community and to support each other in that work

Chapter 10: Closing

Activities and Handouts for Closing

- **Workshop Final Evaluation**
- **String Spider Web and Closing Ceremony**

Activity **Workshop Final Evaluation**

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

- Evaluate their own learning in the workshop
- Evaluate the workshop structure and facilitation

Time allotted 1 hour

Preparation Make enough copies of the “Workshop Final Evaluation” forms and “What We Know about Home Care for People Living with HIV/AIDS Post-Test Questionnaires” for all participants. (Locate these in the Appendix.) Two envelopes for collecting the evaluations and post-tests. Pens/pencils.

Facilitation steps

1. Invite participants to sit where they can write comfortably. Say that we have almost finished our work together, but now we must look carefully at what we have gotten out of this workshop.
2. Explain that in order to inform programs and community activities for caregivers, it is important that we assess this workshop. We need to look at both what we have learned and how well the information has been presented by the facilitators. We also need to know if the content was appropriate for participants. This is crucial for us to improve future trainings.
3. Explain that the “Workshop Final Evaluation” form is anonymous—we do not need the participant’s name on it. This will enable them to be honest and candid in their answers. It is important that they answer fully.
4. Say that in addition, participants will receive a questionnaire just like the one they filled out during the registration at the beginning of the workshop. They should answer all the questions as best they can. This is an important way for you, the facilitators, to see how well you presented the material in the workshop. The participants should put their name on this one (or the same sign that they used on the first questionnaire). This way facilitators can analyze the learning of individual participants as well as the knowledge of the group, compared to their knowledge prior to training.
5. Hand out copies of the Workshop Final Evaluation form and Post-Test Questionnaire.

Wrap-up Have participants put completed evaluation forms in one envelope and questionnaires in another envelope.

Activity **String Spider Web and Closing Ceremony**

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

- Reflect upon the group’s work
- Affirm their commitment to caring for people living with HIV/AIDS and orphans and vulnerable children

Time allotted 1 hour

Preparation A large ball of string, twine, or yarn will be needed for the “String Spider Web” activity. If you will be distributing certificates and/or gifts to the workshop participants, ensure that they are ready for this session. Keep a large open space available so that all participants can stand in a circle.

- Facilitation steps**
1. Say that our time together in this workshop has come to a close, but that our commitment to each other, and to caring for people living with HIV/AIDS and orphans and vulnerable children in our communities, will continue. Indicate that we will now take our final moments together to reflect upon the workshop and to affirm our commitment.
 2. Invite participants to stand up and form a circle. Indicate that we will be creating a “string spider web,” a visual representation of the strength of our link to each other. Indicate that when a person receives the string, he or she should reflect upon the aspects of the workshop that were most important for him or her, and state one thing that he or she is committed to doing to support people living with HIV/AIDS and orphans and vulnerable children. After speaking, the participant should toss or roll the string to a participant at the other side of the circle, while still holding the other part of the string taut.
 3. The facilitator should begin the circle and also end the circle. He or she should speak a bit about the training and offer one commitment for working with people living with HIV/AIDS and orphans and vulnerable children in the future. The facilitator will then hold onto one part of the string, and toss the roll to a participant across the circle.
 4. Continue in this way until every participant has spoken and the string has been returned to the facilitator. At this stage, the circle should be joined by a “spider web” of string. Speak a bit about the symbolism of this web—that we are all connected to each other by our commitment to HIV/AIDS, and that we are strong as long as we maintain this community approach to our work. Relax one part of the string a bit, and watch the entire web sag.

Suggest that if one member of the circle wavers in commitment to this work, it has an impact on all. Point out that this group will also provide strength and support to each other during the hard work that we will be involved in. Enjoin the group to remember this image in the weeks and months to come as we continue to work together to create a supportive community of care for people living with HIV/AIDS and orphans and vulnerable children and for each other.

Wrap-up

Use the final 15 minutes or so of the workshop to distribute any certificates or gifts to the participants. You may also wish to invite a speaker to close the workshop.

Section 2

The Basics of HIV/AIDS

About this Section

Section 2, *The Basics of HIV/AIDS*, has been included to provide general information on the HIV/AIDS pandemic, modes of transmission, and methods for prevention. The knowledge of participants should be assessed, either verbally or with a written questionnaire, to determine what level the group is at in terms of HIV/AIDS awareness. A variety of activities have been included in this section and they can all be used or selectively chosen depending on the group's needs. If the group needs only a brief review, reference the training schedule in Section 1, *The Power of Our Community*. This schedule includes a one and a half-hour review and outlines what activities to use, but again, these can be adjusted to cater to the group. The training schedule below is an example of a more in-depth review, lasting just over one day. If Sections 1 and 2 are done together, the entire workshop would be five days. If the group requires even further background information on HIV/AIDS, please reference CEDPA's training manual, *Integrating Reproductive Health and HIV/AIDS for NGOs, FBOs and CBOs Volume I: Family Planning Plus*, which offers a four-day training on basic knowledge of HIV/AIDS.

Home Care: The Power of Our Community

Training Schedule: Sections 1 and 2

Schedule	Day One	Day Two	Day Three	Day Four	Day Five
	Registration <i>30 minutes</i>	Recap <i>30 minutes</i>	Recap <i>30 minutes</i>	Recap <i>30 minutes</i>	Recap <i>30 minutes</i>
Session	Transmission and Prevention of HIV/AIDS Myths and Facts <i>1 hour</i> Transmission Facts <i>30 minutes</i>	The Power of Our Community Introductions, Goals, and Objectives Workshop Structure <i>1 hour 30 minutes</i>	Medical Support for People Living with HIV/AIDS (cont.) Common Illnesses Role-Play <i>1 hour 45 minutes</i>	Nutritional Needs for People Living with HIV/AIDS and Their Families We Are What We Eat <i>1 hour</i> Nutritional Needs for People Living with HIV/AIDS <i>1 hour</i>	Preparing for Goodbye Supporting People Living with HIV/AIDS <i>1 hour 30 minutes</i>
Break	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
Session	What's the Fluid? Where's the Door? <i>30 minutes</i> Prevention of HIV <i>30 minutes</i> Condom Carousel <i>30 minutes</i>	Breathe in Life, Breathe Out Trouble The Power of Our Community <i>1 hour 30 minutes</i>	Oral Rehydration Solution and Thermometer Use <i>1 hour</i> Seeking Medical Support from a Professional Service Provider Special Medical Concerns for People Living with HIV/AIDS <i>1 hour</i>	Social Support for People Living with HIV/AIDS and Their Families Small Groups on Social Issues <i>1 hour</i> Plenary on Social Issues <i>1 hour 30 minutes</i>	Supporting Orphans <i>1 hour 30 minutes</i>
Lunch	<i>1 hour</i>	<i>1 hour</i>	<i>1 hour</i>	<i>1 hour</i>	<i>1 hour</i>
Session	Condom Demonstration <i>1 hour</i> The Immune System and HIV Elephants and Lions Game <i>15 minutes</i>	The Life Tree Life Tree <i>1 hour 30 minutes</i>	Strategies for Dealing with Health Professionals <i>45 minutes</i> Antiretrovirals <i>30 minutes</i>	Psychological Support for People Living with HIV/AIDS and Their Families People Living with HIV/AIDS Vignettes <i>1 hour 45 minutes</i>	Closing Evaluation <i>1 hour</i> String Spider Web and Closing Ceremony <i>1 hour</i>
Break	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
Session	Disease Progression Diagram <i>1 hour</i>	Medical Support for People Living with HIV/AIDS Common Illnesses Role-Play <i>1 hour 30 minutes</i>	Physical Support for People Living with HIV/AIDS and Their Families Caring for People Living with HIV/AIDS in the Home <i>1 hour 30 minutes</i>	<i>The previous session can be emotional. Trainers may want to have a counselor present and use the afternoon session for this purpose.</i>	
Eval	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
Total	<i>7 hours 30 minutes</i>	<i>8 hours 15 minutes</i>	<i>8 hours 45 minutes</i>	<i>8 hours 30 minutes</i>	<i>6 hours 45 minutes</i>

**Chapter
11**

**Transmission and Prevention
of HIV/AIDS**

*“Prevention can save many millions of lives... We need to
inform, inspire, and mobilize...”*

*—KOFI ANNAN
SECRETARY GENERAL, UNITED NATIONS*

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Chapter 11: Transmission and Prevention of HIV/AIDS

Key Questions

- What bodily fluids contain HIV?
- How is HIV transmitted from person to person?
- How do I know if I have been at risk of HIV transmission?
- Are there social and cultural issues that might influence HIV transmission?
- What cultural expectations and roles make women more vulnerable to HIV/AIDS? Which make men more vulnerable?

Introduction

Before we can address the care and support of people living with HIV/AIDS and orphans and vulnerable children, it is important to determine the level of awareness and knowledge of HIV/AIDS among the caregivers. In recent years, one of the worst impacts of HIV/AIDS is the loss of knowledge about the ways that the disease is transmitted and prevented. The loss of teachers, doctors, and parents has meant that the very people who might teach young adults and children about HIV/AIDS have been killed by the disease themselves—leaving no one behind to teach the children about the very illness that claimed them. Most new infections are occurring among young adults aged 15-24, with over half being girls. Nations and communities all over the world must step up their efforts at prevention campaigns. Essential to care and support is knowledge of how the disease is transmitted and prevented.

As this session will show, enough HIV is contained in the following fluids to make transmission possible: blood, semen, vaginal fluids, and breast-milk. (There are other fluids that have enough HIV to transmit infection, such as amniotic fluid, but these only pose a risk to health workers and others who attend births, and are not dealt with in this session.) HIV can be transmitted from person to person in the following ways—

- Vaginal or anal sex
- Possibly oral sex
- Sharing needles or other sharp equipment such as razors
- Blood transfusions of untested blood and blood products
- Mother to infant during pregnancy, delivery, or breastfeeding

The following chart details the main mode(s) of transmission for adults living with HIV/AIDS in these regions—

Region	Main Modes of Transmission
Sub-Saharan Africa	Heterosexual
North Africa and Middle East	Heterosexual, injecting drug use
South and Southeast Asia	Heterosexual, injecting drug use
East Asia and Pacific	Injecting drug use, heterosexual, men who have sex with men
Latin America	Men who have sex with men, injecting drug use, heterosexual
Caribbean	Heterosexual, men who have sex with men
Eastern Europe and Central Asia	Injecting drug use
Western Europe	Men who have sex with men, injecting drug use
North America	Men who have sex with men, injecting drug use, heterosexual
Australia and New Zealand	Men who have sex with men

Source: UNAIDS. *AIDS Epidemic Update*. (Geneva: UNAIDS, 2001). <http://www.unaids.org>

As a disease largely transmitted through sexual contact, HIV/AIDS cuts right to the core of intimate, personal relationships. HIV/AIDS points up many of the expectations placed on men and women because of their gender roles, as many of the cultural expectations of men and women, boys and girls, may make them more vulnerable to HIV infection.

For example, the following social stereotypes and cultural expectations may place men and boys at risk for HIV infection—

- The assumption that men and boys should be risk-takers may make them more likely to have sexual intercourse without a condom, or more likely to inject drugs
- The stereotype that men and boys are always seeking sexual activity or need sex to survive may make them take a number of sexual partners or have sex when they have STIs
- The idea that men should always be strong may keep them from visiting a doctor or clinic when they are showing signs of an STI. Since STIs greatly increase the risk of HIV transmission, this places men and their partners at higher risk of contracting HIV

Due to biological make-up, women are already more vulnerable to HIV transmission, cultural expectations however, can put women and girls at even greater risk. Consider the following examples—

- Where women and girls are considered subordinate to men, they may not have the right to make decisions regarding when to have sex, with whom, whether or not to use a condom, whether or not to get pregnant, and so on
- In some cultures, there are taboos associated with not breastfeeding one's baby, making it difficult for an HIV positive mother to attempt to avoid MTCT by choosing not to breastfeed

HIV/AIDS is not only a health concern, but also includes issues of gender, socioeconomic status, educational levels, and cultural practices. We will explore how these issues impact men and women differently.

There are also assumptions and expectations made about people living with HIV/AIDS. Often, people think that once someone is diagnosed HIV positive, the person no longer has any sexual needs or rights. In fact, we are sexual beings from cradle to grave, and an HIV positive person may want to continue having sex and loving relationships, as is their human right. But they must also take responsibility to protect others from infection and themselves from reinfection. They will need to know *how* to prevent transmission. As more people learn their status through voluntary counseling and testing (VCT) *before* they become sick with AIDS, this will become more important and is key to reducing the spread of HIV. In this session, in addition to the basics of transmission and prevention, some implications of VCT are discussed.

Whereas transmission and prevention are arguably the most important topics for those seeking to prevent HIV infection, the “Disease Progression” is perhaps the most important topic for people living with HIV/AIDS and those taking care of them. Understanding the progression of HIV/AIDS in the body can offer a great deal of hope those coping with HIV infection, because it explains the following crucial links to a longer, healthier life—

- The significance of the “honeymoon period,” or the time before HIV develops into AIDS
- The influence of co-factors in moving HIV infection more quickly into AIDS, and especially how to live more positively and lengthen the honeymoon period
- The significance of avoiding reinfection with the virus and avoiding infection with opportunistic diseases, especially STIs
- The prevention of MTCT by avoiding reinfection with the virus during pregnancy and while breastfeeding
- The effect of frequent pregnancies on the honeymoon period and the importance of family planning
- Ways to lengthen the honeymoon period, even without access to antiretroviral (ARV) drugs

The tone of this session should be one of empowerment. In many communities, the lack of access to expensive ARV drugs has left people living with HIV/AIDS feeling helpless and disempowered in the face of their HIV infection. Although ARV drugs certainly lead to longer, healthier lives for those infected with HIV, there are still many ways for infected people to control the progression of the virus in their bodies using locally available resources. Information about disease progression, along with an understanding of the many aspects of positive well being, can help those living with HIV/AIDS and those who care for them to regain control of their own health. Early VCT can be an important entry point into care and support services and preventive behavior. This session represents that powerful new direction for communities that have been hit hard by the pandemic, as they continue the fight for access to ARV therapy. Access to ARV drugs will become an increasingly pivotal issue as generic production improves and cost decline. Therefore, as access improves, involving local clinicians and traditional healers in this session will be even more relevant.

Chapter 11: Transmission and Prevention of HIV/AIDS

Objectives

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

- Identify myths and facts about HIV/AIDS
- Define “transmission,” “portal of entry,” and “dual protection”
- Identify at least five ways in which HIV is transmitted
- Determine whether or not HIV can be transmitted by specific activities
- Describe the “ABCs” of HIV prevention
- Describe the stages of sexual development
- Determine the risk of sexual transmission and decide which prevention strategy would be best in various situations
- Explore the power dynamics of sexual decision making and risk taking
- List the steps for proper use of male and female condoms
- Demonstrate proper use of male and female condoms

Important Terms

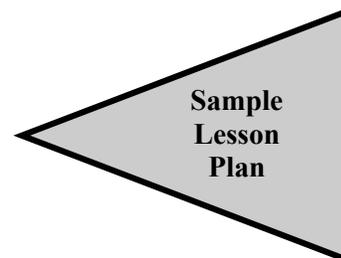
Dual Protection	Dual Protection is defined as protection from pregnancy, STIs, and HIV/AIDS through: 1) the use of a condom alone, 2) the use of a condom plus another contraceptive method, 3) abstinence, 4) use of contraception between uninfected monogamous couples, and 5) avoidance of all types of penetrative sex.
Portal of Entry	An opening in the skin or mucous membrane that HIV can pass through; a “door” into the body; examples include cuts, sores, or the soft tissue of the vagina, penis, and so on.
Synovial Fluid	Synovial fluid is normally a viscous (thick), straw colored substance found in small amounts in joints, bursae, and tendon sheaths.
Transmission	Passing a virus (like HIV) from one person to another.

Home Care: The Power of Our Community

Training Schedule: Sections 1 and 2

Schedule	Day One	Day Two	Day Three	Day Four	Day Five
	Registration <i>30 minutes</i>	Recap <i>30 minutes</i>	Recap <i>30 minutes</i>	Recap <i>30 minutes</i>	Recap <i>30 minutes</i>
Session	Transmission and Prevention of HIV/AIDS Myths and Facts <i>1 hour</i> Transmission Facts <i>30 minutes</i>	The Power of Our Community Introductions, Goals, and Objectives Workshop Structure <i>1 hour 30 minutes</i>	Medical Support for People Living with HIV/AIDS (cont.) Common Illnesses Role-Play <i>1 hour 45 minutes</i>	Nutritional Needs for People Living with HIV/AIDS and Their Families We Are What We Eat <i>1 hour</i> Nutritional Needs for People Living with HIV/AIDS <i>1 hour</i>	Preparing for Goodbye Supporting People Living with HIV/AIDS <i>1 hour 30 minutes</i>
Break	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
Session	What's the Fluid? Where's the Door? <i>30 minutes</i> Prevention of HIV <i>30 minutes</i> Condom Carousel <i>30 minutes</i>	Breathe in Life, Breathe Out Trouble The Power of Our Community <i>1 hour 30 minutes</i>	Oral Rehydration Solution and Thermometer Use <i>1 hour</i> Seeking Medical Support from a Professional Service Provider Special Medical Concerns for People Living with HIV/AIDS <i>1 hour</i>	Social Support for People Living with HIV/AIDS and Their Families Small Groups on Social Issues <i>1 hour</i> Plenary on Social Issues <i>1 hour 30 minutes</i>	Supporting Orphans <i>1 hour 30 minutes</i>
Lunch	<i>1 hour</i>	<i>1 hour</i>	<i>1 hour</i>	<i>1 hour</i>	<i>1 hour</i>
Session	Condom Demonstration <i>1 hour</i> The Immune System and HIV Elephants and Lions Game <i>15 minutes</i>	The Life Tree Life Tree <i>1 hour 30 minutes</i>	Strategies for Dealing with Health Professionals <i>45 minutes</i> Antiretrovirals <i>30 minutes</i>	Psychological Support for People Living with HIV/AIDS and Their Families People Living with HIV/AIDS Vignettes <i>1 hour 45 minutes</i>	Closing Evaluation <i>1 hour</i> String Spider Web and Closing Ceremony <i>1 hour</i>
Break	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
Session	Disease Progression Diagram <i>1 hour</i>	Medical Support for People Living with HIV/AIDS Common Illnesses Role-Play <i>1 hour 30 minutes</i>	Physical Support for People Living with HIV/AIDS and Their Families Caring for People Living with HIV/AIDS in the Home <i>1 hour 30 minutes</i>	<i>The previous session can be emotional. Trainers may want to have a counselor present and use the afternoon session for this purpose.</i>	
Eval	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
Total	<i>7 hours 30 minutes</i>	<i>8 hours 15 minutes</i>	<i>8 hours 45 minutes</i>	<i>8 hours 30 minutes</i>	<i>6 hours 45 minutes</i>

Chapter 11: Transmission and Prevention of HIV/AIDS



Sample Lesson Plan

Time	Content	Methodology	Materials Needed	Evaluation
30 minutes	<p>Myths and Facts about HIV/AIDS</p> <p>Clarification of common myths about HIV/AIDS</p> <p>Provision of a few basic facts about HIV/AIDS</p> <p>Needs assessment to assist facilitator in understanding participants' level of HIV/AIDS knowledge</p>	<p>Participants move under "True" or "False" sign in response to facilitator's statements about HIV/AIDS</p>	<p>Prepared signs "True" "False" List of myths and facts</p>	<p>Active participation in the activity</p> <p>Verbalized understanding of the "correct" answers</p>
30 minutes	<p>Transmission Facts</p> <p>Introduction to "transmission"</p> <p>Listing modes of transmission</p> <p>Introduction of "What's the Fluid? Where's the Door?" test</p> <p>Discussion of "portal of entry"</p>	<p>Facilitator introduces the concept of "transmission," then leads a group brainstorm regarding ways in which HIV is transmitted from one person to another</p> <p>Facilitator introduces the "What's the Fluid? Where's the Door?" test, and describes "portal of entry"</p>	<p>Flipchart Markers Tape Prepared flipchart Cutouts of a door and a drop of blood with the phrases— "What's the Fluid?" and "Where's the Door?"</p>	<p>Proper placement of the cards in the next exercise</p>

Time	Content	Methodology	Materials Needed	Evaluation
<i>30 minutes</i>	<p>What's the Fluid?</p> <p>Where's the Door?</p> <p>Review of specific activities and discussion of whether they pose the risk of transmitting HIV</p>	<p>Participants are asked to reach under their chairs, and remove the card that is placed there</p> <p>Participants are asked to walk up to the front of the room, one-by-one, and place the cards under the proper heading; while doing so, they should answer, "What's the Fluid? Where's the Door?"</p>	<p>One card for each participant marked with a—</p> <p>"Transmit" or "Does Not Transmit"</p> <p>Tape</p>	<p>Proper placement of the cards and correct identification of the fluid and the portal of entry</p>
<i>1 hour</i>	<p>Prevention Facts ("ABCs" and Human Sexuality)</p>	<p>Brainstorm on "ABCs" of prevention</p> <p>Participants discuss human sexuality and determine risk and prevention options for common situations</p>	<p>Have three flipcharts with "A," "B," and "C" written at the top</p> <p>Copies of the handout, or a flipchart of "Sexuality and Sexual Development"</p>	<p>Active participation in the risk assessment and "ABC" choice activity</p>
<i>20 minutes</i>	<p>Condom Carousel</p>	<p>Demonstrate greater comfort in handling condoms</p> <p>Clarify common questions about condom use</p> <p>Define dual protection</p>	<p>Male condoms blown up and tied with pieces of paper with condom myths and facts written on them, radio or tape player</p>	<p>Participants able to define "dual protection," able to answer questions about condoms correctly</p>
<i>1 hour</i>	<p>Condom Demonstrations</p>	<p>Participants observe correct demonstration of male/female condom application, then practice doing it themselves in pairs</p>	<p>Penis models or equivalent (bananas, broomsticks, etc.), enough male and female condoms for each participant to demonstrate correct application, female condom models, if available, if not, use half clenched fist for demonstration</p>	<p>Each participant observed applying male and female condom on model correctly, according to steps listed in handout</p>

Chapter 11: Transmission and Prevention of HIV/AIDS

Activities and Handouts for Transmission and Prevention of HIV/AIDS

- **Myths and Facts about HIV/AIDS (Needs Assessment)**
- **Transmission Facts**
- **What's the Fluid? Where's the Door?**
- **Prevention of HIV ("ABCs" and Human Sexuality)**
- **Condom Carousel**
- **Condom Demonstrations**

Activity **Myths and Facts about HIV/AIDS (Needs Assessment)**¹⁴

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

- Identify common myths about HIV/AIDS
- State key facts about HIV/AIDS

Time allotted 30 minutes

Preparation Write a list of common community myths about HIV/AIDS, along with some basic facts about HIV/AIDS. It is best to develop your own list from the experiences of your community, but an example is provided in the handouts, to help you get started.

Prepare two signs, one that reads “True” and one that reads “False.” Hang them on opposite sides of the room, and ensure that the space between them is open and will accommodate the movement of the participants.

Facilitation steps

1. Say that before we can get into the specifics of caring and supporting people living with HIV/AIDS, we, as caregivers and community members, need to have clear and accurate information about HIV/AIDS, including how it is transmitted and prevented. Suggest that because HIV/AIDS is such an important issue for a community, there are often a number of false ideas, or myths about HIV/AIDS. It is important to be able to recognize these myths, and help our fellow community members to understand the real facts about the disease, so that we may all better protect ourselves and care for those who are infected.
2. Point out the words on the wall. State that you will read out a statement about HIV/AIDS, and if the participants believe that the statement is true, they should stand under the “True” sign. If they believe it is false, they should stand under the “False” sign.
3. Read the first statement, and give all participants a chance to choose their answer. When all have chosen, invite a few participants from the “False” side to explain *why* they have chosen that answer. Do the same for those

¹⁴ Adapted and reprinted with permission of Peace Corps from *Life Skills Manual*. pp. II-27 to II-30. (Washington, DC: Peace Corps, 2000.)

under the “True” sign. Allow some debate to develop here—this will help the facilitator to get an idea about the level of knowledge around HIV/AIDS in the group, and will point out some of the key issues to be clarified in the sessions to follow. In addition, this exercise will help the facilitator to get a sense of the group leaders, as personalities begin to assert themselves during the debate. (It is important to make sure that all participants have a chance to speak. Make sure that people living with HIV/AIDS, women and others, possibly of lesser status in the community, are involved in the activity.)

4. After all debate has been exhausted clarify the “correct” answer to the statement and explain it. Ask for questions and ensure that all participants understand before beginning the process again with the next question. (It is not necessary to go into great detail regarding each answer here, as many of these issues will be addressed in the sessions to follow.)
5. Continue in this way until all questions are exhausted, the time for the exercise is exhausted, or the participants are exhausted (from moving around).

Wrap-up

At the end of the activity, suggest that participants keep some of these myths and facts in mind throughout the sessions to follow. Point out that sometimes facts about HIV/AIDS can be a bit confusing, and it is important that we all feel free to ask questions throughout the workshop and make clear anything that we do not understand.

Myths and Facts about HIV/AIDS

It is important that the trainer(s) spend some time before the workshop compiling a list that represents some of the common myths around HIV/AIDS in the local community. The examples provided below are merely suggestions to help get you started. Brief explanations are provided below each statement to assist with discussion after the participants have chosen their answers.

Myths

You can be cured of HIV/AIDS if you have sex with a virgin.

This myth is not only false, but attempting it also greatly increases the risk of transmitting HIV to young girls and boys, and also puts them at risk of coercive sex and rape. (The origins of this myth are not clear, but are based on an idealized female character of virgin purity, and it reinforces the idea of the male as predator.)

Mosquitoes can transmit HIV/AIDS.

Because mosquitoes take blood from various people, it is often believed that they can transmit HIV from person to person. There are many things that a facilitator can say to refute this myth—

- Mosquitoes do not inject blood into a person when they bite.
- Mosquitoes take blood into the “stomach,” and it does not remain in their stingers.
- HIV stands for “Human Immunodeficiency Virus.” This is a virus that can only survive in humans—once it is taken in by a mosquito, the virus dies.
- If HIV were transmitted in this way, we would see cases of AIDS in all ages—from infants to grandparents, the way we see malaria in all ages. Instead, most cases of HIV/AIDS are among sexually active people of reproductive age.

There are new medicines that can cure AIDS.

Although there are new medicines, called antiretrovirals (ARV) and protease inhibitors that can help someone to live a great deal longer with HIV, these medicines neither eliminate the HIV virus from the body nor cure AIDS. The virus is still in the body, and although the antibodies may be at an undetectable level, it still may be reproducing in the bone marrow of the infected person.

Myths and Facts about HIV/AIDS, continued

A condom has small holes that HIV can pass through.

Although male and female condoms are not 100 percent effective, usually because they are not used correctly or consistently, they have been proven very effective against the transmission of HIV. In studies where one partner was infected and the other was not, and where condoms were used consistently and correctly, the other partner did not get infected.

A baby born to an HIV-infected mother will always get HIV.

Almost all babies born to an HIV-infected mother will test positive for HIV at birth, but this is because the mother's antibodies have been passed to the baby. It may take up to 18 months to determine whether the virus itself has been passed to the baby. Many babies are born to HIV-infected mothers and do not become infected. This can depend on a number of factors, including the amount of HIV in the mother's system at the time of pregnancy, and other issues that we will discuss in a later session.

Drinking local gin can cure AIDS.

There is no cure for AIDS. Drinking alcohol can lead to poor judgment and risky behavior, such as unprotected sex. HIV weakens the immune system, and drinking alcohol may hasten the onset of AIDS.

Facts

Although many people do not have access to expensive drugs to treat HIV/AIDS, there are medicines that can be used to slow down the disease and to keep us healthier longer.

Medicines used to treat infections and diseases like tuberculosis, malaria, STIs, and so on, can help us to remain healthier longer with HIV/AIDS. It is very important to get treated for any illness promptly to help one's body stay strong to fight HIV infection.

Someone with an untreated STI has a higher risk of becoming HIV infected.

Untreated STIs greatly increase one's risk of becoming HIV infected for a number of reasons—

- *Sores and lesions from STIs create more "doors" for HIV to pass through.*
- *Having a discharge, as with STIs such as gonorrhea or chlamydia, means that more white blood cells are present. Since white blood cells are hosts for HIV, it means that more virus can be transmitted or received when discharge is present.*
- *Women often do not have symptoms of STIs or can not see lesions/sores because they are inside the vagina, which puts women at even higher risk.*

Myths and Facts about HIV/AIDS, continued

A person can have a negative test for HIV and still be infected with the virus.

The HIV test looks for antibodies, not for HIV itself. Since it can take anywhere from two weeks to three months for most people to develop antibodies against HIV, you may test negative during those weeks before your body has been able to produce antibodies. This is called the “window period,” and it is the time when someone is most highly infectious.

Using condoms when having sex during pregnancy and breastfeeding can help an HIV-infected mother to reduce the risk of passing HIV to her baby.

The use of a condom helps a pregnant woman to avoid infection with STIs or re-infection with HIV. Viral load, or the amount of HIV in the body, is highest when initially infected, therefore reducing the risk of re-infection during either pregnancy or while breastfeeding, keep the mother healthier and protect the baby.

You cannot know if someone is HIV positive.

People who are HIV positive can live a healthy life for years without any visible signs of infection. The only way to confirm a person is HIV positive is through self-disclosure after having an HIV antibody test. In the later stages of disease progression, when a person has AIDS, there are more physical signs.

Women are more vulnerable to HIV transmission.

Even without considering social and cultural factors, women have a higher risk of HIV infection due to their biological make-up. The soft tissue walls of the vagina are very susceptible to tearing, therefore, creating an entry point for the HIV virus to enter the body.

Activity Transmission Facts¹⁵

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

- Define “transmission”
- Identify at least five ways in which HIV is transmitted
- Define “portal of entry”

Time allotted 30 minutes

Preparation Prepare two flipcharts. The first should read “What’s the Fluid?” and have a colorful cutout of a drop of blood taped to the top. The second should read “Where’s the Door?” and have a colorful cutout of a door on the top.

Facilitation steps

1. Suggest that as caregivers it is important to know how HIV is transmitted and prevented, so that we can protect our families, our community, and ourselves. It is also important so that we can break down the stigma and discrimination, which are based on fear and ignorance of the facts. Say that it is very clear how HIV is transmitted, and it is also clear how it can be prevented.
2. Ask participants to brainstorm which fluids in the body are capable of transmitting HIV. Record the correct answers on the “What’s the Fluid?” flipchart. When answers are given that cannot transmit HIV, record them in a separate box at the bottom to be dealt with later. The correct answers include blood, semen, vaginal secretions, and breast-milk. (Also other secretions include amniotic fluid, synovial fluid (see Important Terms), cerebral-spinal fluid, etc., but these will probably only come up if you are conducting a session with health workers.) Fluids that do not transmit HIV include vomit, stool/feces, saliva, tears, sweat, and urine. After all of the correct answers have been given, be sure to indicate that while fluids like vomit, diarrhea, saliva, tears, sweat, and urine do contain HIV, there is *not enough* HIV in them (unless they are bloody) to transmit the virus from one person to another. However, many of these fluids may transmit other diseases, so care should be taken with them.

¹⁵ Adapted and reprinted with permission of Peace Corps from the *Life Skills Manual*, pp. II-51 to II-55. (Washington, DC: Peace Corps, 2000.)

3. Next, point out that in addition to a fluid infected with HIV, one also needs a “door” into the body for HIV to pass through. This “door” is sometimes called a “portal of entry.” It is the place where the virus may enter. Ask participants to think of possible “doors” that may allow HIV into the body, and write the answers on the “Where’s the Door?” flipchart. Some suggested answers include cuts, sores, soft tissues of the vagina, tip of the penis, anus, mouth, eyes, or nose.
4. State that we can always tell whether or not it is possible for HIV to be transmitted by asking ourselves two questions—
 - What is the fluid?
 - Is one of the fluids that can transmit HIV present?
 - Where’s the door?
 - Is there a portal of entry for the virus to pass through?
5. Ask participants to brainstorm some of the most common ways for HIV to be transmitted. These include—
 - Vaginal or anal sex
 - Possibly oral sex
 - Sharing needles or other sharp equipment such as razors
 - Blood transfusions of untested blood (emphasize that most countries now test blood for HIV so most sources are safe)
 - From mother to infant during pregnancy, delivery, or breastfeeding

Wrap-up

Summarize the activity by emphasizing that it is clear how HIV is transmitted.

Review the fluids that can transmit HIV, and the “doors” through which HIV can enter. Remind participants that they can now put any activity to the “What’s the Fluid? Where’s the Door?” test if they are unsure whether the activity may put them at risk for HIV transmission. In the next exercise, we will practice this test by reviewing a number of activities that may or may not transmit the virus.

Activity **What's the Fluid? Where's the Door?**¹⁶

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

- Determine whether or not HIV can be transmitted by specific activities
- List activities that can and activities that cannot transmit HIV

Time allotted 30 minutes

Preparation Create cards with a number of different activities on them. (Suggested activities are listed on the following page.) Ensure that there is one card for each participant. Before the session (preferably before the day begins or during the break), tape the cards under the participants' chairs. Tape two signs at the front of the room, one reading "Can Transmit HIV," and one reading "Cannot Transmit HIV."

Facilitation steps

1. Remind participants of the transmission facts that we have just learned, and say that we will now practice using the "What's the Fluid? Where's the Door?" test.
2. Ask participants to reach under their chairs and pull out the activity cards taped there. Say that the cards were placed randomly and that the card they have has nothing to do with them personally. Give participants a moment to read their cards. Ask them to think about whether that activity might transmit HIV or not.
3. Invite participants to come up to the front of the room, one-by-one, with their activity cards. Each participant should read his or her card, tell what fluid is present that might contain HIV, and what door is present through which HIV might pass. The participant should then tape the card under the "Can Transmit HIV" or "Cannot Transmit HIV" section. After the participant chooses, ask for feedback from the entire group. Clarify any questions or incorrect answers.
4. Repeat this process until all participants have completed the exercise.

Wrap-up Summarize the activity. Suggest that participants can always tell whether or not an activity is a risk behavior for HIV transmission by using this simple test.

¹⁶ Adapted and reprinted with permission of Peace Corps from the *Life Skills Manual*, pp. II-51 to II-55. (Washington, DC: Peace Corps, 2000.)

What's the Fluid? Where's the Door?

Below are some suggested activities for the “What’s the Fluid? Where’s the Door?” exercise. Be sure to write out one card for each participant.

Can Transmit HIV

- Vaginal sex
- Anal sex
- Blood transfusion of untested blood
- Sharing needles
- Contact with blood of an infected person
- Breastfeeding
- Mother-to-infant during delivery
- Mother-to-infant during pregnancy
- Contact with semen
- Contact with vaginal fluids
- Cleaning up blood spill without using gloves

Cannot Transmit HIV

- Living with a person infected by HIV
- Eating from the same dish as an HIV-infected person
- Hugging a person with HIV
- Kissing a person with HIV
- Shaking hands with a person with HIV
- Proper use of a condom during sex
- Eating a chicken raised by someone with HIV
- Sharing a drinking cup with an HIV-infected person
- Letting someone cry on your shoulder
- Stepping on a nail outside
- Cleaning up vomit with gloves

Activity **Prevention of HIV (“ABCs”) and Human Sexuality**

- Objective** By the end of this session, participants will be able to—
- Describe the “ABCs” of HIV prevention
 - Describe the stages of sexual development
 - Determine the risk of sexual transmission and decide which prevention strategy would be best in various situations
 - Explore the power dynamics of sexual decision making and risk taking

Time allotted 60 minutes

Preparation Have three flipcharts with “A,” “B,” and “C” written at the top. Make copies of the “Human Sexuality and Sexual Development” handout, or prepare a flipchart with the definition of sexuality and stages of sexual development on it.

- Facilitation steps**
1. Say that the last activity was a brief introduction to the issues around HIV prevention, and that this session will deal with the topic in more detail.
 2. Go through each of the ways that HIV is transmitted with the participants, and brainstorm possible ways to prevent such transmission. Begin with transmission through blood contact and brainstorm some suggestions for preventing such transmission. Indicate that this topic, so important to caregivers, will be covered in detail in another session, when we deal with “universal precautions.”
 3. Briefly discuss mother-to-child transmission (MTCT). Allow a few suggestions here, but indicate that we will also be covering that topic later. We are putting off this discussion until that time, because this is one of the more complicated topics in HIV prevention. It will be easier to understand the issues surrounding MTCT after we have talked more about the immune system and how it is affected by HIV/AIDS. (See “Special Medical Concerns for People Living with HIV/AIDS” on page 4-101.)
 4. Suggest that because it can be difficult to discuss sexual matters openly, often conversations and even education or information about HIV/AIDS focus more on the non-sexual ways that the virus is transmitted and prevented. While these issues are certainly important, we must be realistic and understand that the majority of HIV infections come from sexual

contact. (Use the statistics for your country here.) For this reason, we will devote this session to preventing the transmission of HIV through sexual activity. We will need to discuss human sexuality frankly and the different risks that individuals face throughout their lives as sexual beings.

5. Start by saying that humans are sexual beings from before birth to death. Hand out copies of “Human Sexuality and Sexual Development” or go over prepared flipchart. Briefly discuss the definition of sexuality and stages of sexual development. Point out that even people living with HIV/AIDS still have sexual needs and desires. In fact, having a healthy sexual life, including intimacy, is important for emotional health and positive living. It is very important for everyone, whether HIV positive or negative, to understand their risk for transmission and how to prevent it.
6. Introduce the “ABCs” of prevention, “Abstinence, Be Faithful and Condoms.” It is very likely that many participants will be familiar with these concepts.
7. Ask participants to brainstorm what “Abstinence” means, and list their ideas on the flipchart with “A” at the top. They may come up with something like “no sex,” “never having sex,” or “waiting to have sex until you are married.” Probe for further elaboration, such as how long might one go without sex to consider it “being abstinent.” Are there situations where that length of time might change? What is the risk for sexual transmission of HIV using abstinence? (Abstinence is the only 100 percent sure way not to transmit/contract HIV sexually.) What kinds of sexual or intimate acts would one have to refrain from to be abstinent? (Just vaginal sex? anal sex? oral sex? hugging? kissing? masturbation of self or partner? massage? etc.) How comfortable are most people with abstinence as a prevention method? Are there particular groups who might be most comfortable using abstinence for prevention? Are there alternative that would make it easier for one to abstain? (Many cultures and religions consider masturbation to be wrong. In the face of the HIV/AIDS crisis, perhaps this should be rethought. In any case, children and especially adolescents, need to understand that there is no mental or physical harm in masturbation—and it will not kill you, as AIDS will!)
8. Brainstorm the definition of “Being Faithful.” Write participants’ suggestions on the flipchart with “B” at the top. Possible examples might include, “being faithful within marriage,” “zero-grazing,” or “being faithful with a tested, faithful partner.” What are the problems of using being faithful as one’s prevention method? (Can one be sure that one’s partner is faithful? Testing is only a reflection of a partner’s HIV status at that moment, not forever. Married women in Africa and other areas have become HIV positive while being monogamous with their husbands.) What is the risk of transmission of HIV using “B?” (You can only be absolutely sure about your own behavior, therefore a risk may remain.) What are some advantages to using “B?” (If a person is sure that both

his/her partner and self are HIV negative and faithful, then there is no need to use condoms, and can get pregnant if that is wanted, etc.) What factors must be in place for this method to work? (Examples might include trusting that one's partner is also faithful, getting tested before deciding to use this method and testing again in three months to make sure one is not infected before having unprotected sex, and so on). Say that we will discuss testing a bit more in upcoming sessions.

9. Now discuss "C" or "Condoms." Point out that condoms must be used consistently and correctly to be effective in preventing transmission of HIV. (If they are used correctly every time one has sex, studies have shown that they are over 90 percent effective in preventing transmission of HIV.) Ask how easy it is to get condoms in this area. Who has access to condoms and why? Do youth have access financially and socially/culturally to condoms? Do women and girls have access financially and socially/culturally to condoms? How can one learn to use them correctly? Who should initiate condom use? Can married couples use them? What about people living with HIV/AIDS? Say that we will learn more about condoms and how to use them in the next activity.
10. Now place the A, B, and C flipcharts in three different areas of the room. Explain that you will read out situations where one would need to choose A, B, or C. (See Trainer Resource, "ABC Situations" starting on page 11-291.) Participants should then move to the area that they think would be a good choice (A, B, or C) for each situation. Once people have moved, ask a participant from each group to explain what the risk is in the situation and why they think A, B, or C is a good choice. Are there other possible choices? Allow debate to develop between groups. Probe for the level and kinds of risks involved in each situation. Also discuss whether the person in the situation has the power to choose A, B, or C, and what alternatives they might have.

Wrap-up

Summarize the activity by suggesting that because we are sexual beings, A, B, or C may be appropriate for various people at various points in their lives. The important thing is to always be actively practicing one of them. Sometimes we can think of it as three boats in a raging sea that is HIV infection. We can change boats, but we must always be in one of the boats or another—"Abstinence," "Being Faithful with a Faithful, Tested, HIV Negative Partner," or "Condom Use—every time, all the time."

“ABC” Situations

These are some suggested situations where individuals would need to choose being **A**bstinent, **B**eing faithful, or using **C**ondoms, to avoid the risk of transmission of HIV. You can use these or make up some situations that are common in your community. Participants should decide if A, B, or C is the best choice given the situation, and discuss why they think so, and the implications of the choice. Be sure the issues in *Italics* below the situation are covered in the debate.

- A fifteen-year old girl in love with a sixteen-year old boy she wants to marry.

Proof of fertility

Economic security

Does she have the power to choose?

- An adolescent boy out drinking with friends meets a woman at the bar.

Proof of masculinity

Peer pressure

Loss of judgment

Does he have the power to choose?

- A married woman who suspects her husband is being unfaithful.

Social norms

Trust in relationship

Desire for pregnancy

Possible violence from husband if woman says no to sex or asks for condom

Does she have the power to choose?

- Widowed older man who wants a new young wife.

Would society frown on this?

Proof of masculinity

Proof of fertility

Does he have the power to choose?

“ABC” Situations, continued

- Widowed woman who is inherited by her brother-in-law.

Customary practice

What if she knows he has AIDS?

Does she have the power to choose?

- A person living with HIV/AIDS who is married.

Is the person obliged to disclose status? If male? If female?

Can one disclose one's status safely? What are possible consequences?

Does a person living with HIV/AIDS have the power to choose?

What options might one have for healthy and safe expression of sexuality?

- A married man whose wife is pregnant or has just had a baby.

Traditional postpartum abstinence used as justification for not being faithful

(Point out that the risk for MTCT is much higher if primary HIV infection occurs during pregnancy or breastfeeding.)

Alternatives for intimate contact between married couples besides vaginal/anal intercourse

Does he have the power to choose?

Human Sexuality and Sexual Development¹⁷

Sexuality refers to an expression of who we are. It involves a person's thoughts, feelings, and sexual expression and relationships, as well as the biology of the sexual response system.¹⁸

Many believe that people living with HIV/AIDS are no longer interested in sex or should stop enjoying sex after they know their status. Most, however, still have sexual needs and desires. In fact, having a healthy sexual life, including intimacy, is important for emotional health and positive living. It is very important for everyone, whether HIV positive or negative, to understand their risk for transmission and how to prevent it, and to take responsibility for their sexual health and that of their partner.

Sexual Development through the Life Cycle¹⁹

Many people cannot imagine that all people, including babies, children, teenagers, adults, and old people are sexual beings. Some believe that sexual activity is reserved for those just in early and middle adulthood, and teenagers often feel that adults are too old for intercourse or "having sex." However, sexuality is much more than just sexual intercourse.

Sexuality includes an individual's attitudes, fantasies, dreams, thoughts, beliefs, perceptions, experiences, and behaviors that could result in any type of erotic stimulation. It is part of who a person is and involves his or her thoughts, feelings, forms of sexual expression and relationships, as well as the biology of the sexual response system (EngenderHealth, 2002). We are sexual beings throughout our lifetime.

Sexuality in Infants and Toddlers

Children are sexual even before birth. Males can have erections while still in the uterus, newborn boys can have frequent erections, and infants often touch and rub their genitals because it provides pleasure. Boys and girls can experience orgasms from masturbation, but boys do not ejaculate until puberty. By about age two, children know their sex. They are aware of differences between genitals and in how boys and girls urinate.

¹⁷ The Centre for Development and Population Activities (CEDPA). *Reproductive Health Awareness*. (Washington, DC: CEDPA, 2003).

¹⁸ EngenderHealth, *Sexuality and Sexual Health Online Minicourse*.
<http://www.engenderhealth.org/res/onc/sexuality/understanding/index.html>

¹⁹ The Centre for Development and Population Activities (CEDPA). *Reproductive Health Awareness*, pp 5-5 –5-8. (Washington, DC: CEDPA, 2003).

Sexuality in Children Ages Three to Eight

Preschoolers are interested in everything about their world, including sexuality. They may practice urinating in different positions. They are very affectionate and enjoy hugging other children and adults. They begin to be more social and may imitate adult social and sexual behaviors, like holding hands or kissing. Many young children “play doctor” during this stage, looking at other children’s genitals and showing off their own. This is normal curiosity. By age five or six, however, most children become more modest and private about dressing and bathing.

Children of this age are aware of marriage or “living together,” based on their family experience. They may role-play being married or having a partner while they “play house.” They model behavior they see in the home and “try on” various roles. Most young children talk about marrying or living with a person they love when they get older. School-age children may play sexual games with friends or siblings of their same sex, touching each other’s genitals or masturbating together. Most sex play at this age occurs because of curiosity.

Sexuality in Pre-Adolescent Children (ages nine to 12)

Puberty, the time when the body matures, begins between the ages of nine and 12 for most children, though later maturation may be perfectly normal. Girls begin to grow breast buds and pubic hair as early as age nine or 10. Boys’ development of the penis and testicles usually begins between the ages of 10 and 11. After puberty, pregnancy can occur. Children become more self-conscious about their bodies at this age and often feel uncomfortable undressing in front of others, even a parent of the same sex.

Masturbation continues and increases during these years. Pre-adolescent boys and girls do not usually have much sexual experience, but they often have many questions. They have usually heard about intercourse, petting, oral and anal sex, homosexuality, rape, and incest, and they want to know more about these things. The idea of actually having intercourse, however, is unpleasant or strange for most pre-adolescent girls and boys.

Homosexual experiences are common at this age. Boys and girls tend to play with friends of the same sex and often explore sexually with them. Masturbating together and looking at or caressing each other’s genitals is common among boys and girls. Such same-sex behavior is usually unrelated to a child’s sexual orientation.

Some group dating may occur. Pre-adolescents may attend girl/boy parties, dance, and play kissing games. By age 12 or 13, some young adolescents will pair off and begin dating or “making out.” In some urban areas, boys experience vaginal intercourse at this age. Girls are usually older when they begin having vaginal intercourse. However, it is not uncommon for young teens to practice sexual behaviors other than vaginal intercourse, like petting to orgasm and oral intercourse. The age for many of these norms is affected by the society in which they live.

Sexuality in Adolescents (ages 13 to 19)

Once children reach puberty, their interest in genital sex increases and continues through adolescence. There is no way to predict how a particular teenager will act sexually. As a group, most adolescents explore relationships with one another, fall in and out of “love,” and participate in sexual behaviors before the age of 20. In many cultures, girls are expected to marry during this age range to prevent sexual experimentation outside of marriage. In other cultures, girls are expected not to marry and not to have sexual relations during this age.

Adult Sexuality²⁰

Adult sexual behaviors are extremely varied. In most cases, they remain a part of an adult’s life until death. Early adulthood is a time for both men and women to find a partner, establish their career, and start a family if they so choose. It is a time when they must balance the needs for their own sexual gratification with a partner’s sexual needs, along with family and work needs.

At around age 50, women experience menopause, which affects their sexuality. Their ovaries no longer release eggs and produce estrogen. They may experience several physical changes—vaginal walls become thinner and intercourse may be painful, there is less vaginal lubrication, and the entrance to the vagina becomes smaller. Regular sexual activity tends to slow the rate of these changes. On the other hand, freedom from risk of pregnancy can be very liberating and stimulate a rise in sexual desire and pleasure.

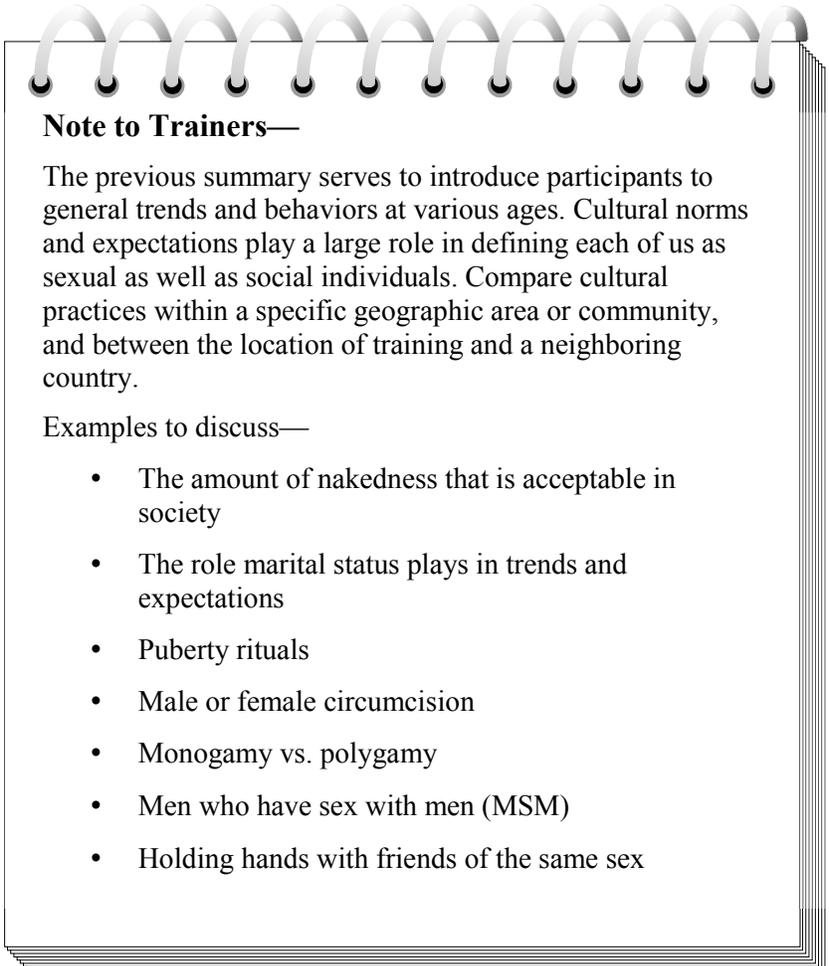
Adult men also experience some changes in their sexuality, but not at such a predictable time as menopause. Men’s testicles slow down their testosterone production between ages 40 and 45. Erections occur more slowly. Men also become less able to have another erection after an orgasm. It may take up to 24 hours to sustain another erection. The amount of semen released during ejaculation also decreases, but men are capable of producing a baby even when they are very old—some men have become fathers in their 90s! Many older men have an enlarged prostate gland in their later years, which may interfere with their ability to urinate.

Although adult men and women do go through some sexual changes as they age, they do not lose their desire or their ability for sexual expression. Even among the very old (those age 80 and older), the need for touch and intimacy remains, although the desire and ability to have sexual intercourse may wane.

We truly are sexual beings from birth to death.

Source: The description of sexual development throughout the life cycle was adapted from *Advocates for Youth*. 1995, pp. 127-128.

²⁰ The Centre for Development and Population Activities (CEDPA). *Reproductive Health Awareness*, pp 9-6—9-8. (Washington, DC: CEDPA, 2003).

A graphic of a spiral-bound notebook with a silver spiral binding at the top. The notebook page is white with a thin black border and contains text. The text is formatted with bold headings and bullet points.

Note to Trainers—

The previous summary serves to introduce participants to general trends and behaviors at various ages. Cultural norms and expectations play a large role in defining each of us as sexual as well as social individuals. Compare cultural practices within a specific geographic area or community, and between the location of training and a neighboring country.

Examples to discuss—

- The amount of nakedness that is acceptable in society
- The role marital status plays in trends and expectations
- Puberty rituals
- Male or female circumcision
- Monogamy vs. polygamy
- Men who have sex with men (MSM)
- Holding hands with friends of the same sex

Activity Condom Carousel²¹

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

- Demonstrate greater comfort in handling condoms
- Clarify common questions about condom use
- Define dual protection

Time allotted 20 minutes

Preparation Begin by writing common questions about condom use on small slips of paper and folding the paper very small. (Suggestions regarding condom questions can be found after this activity. See the Tool for Trainers starting on page 11-302.) Completely unroll one latex condom for each question. Drop one question into each condom. Blow the condoms up like balloons and tie them off. You will need a radio or tape player. Be sure to have music queued for the activity. If necessary, ask a volunteer from among the participants to be responsible for turning the music on and off.

Facilitation steps

1. Say that often people rely on being faithful even when it might not be the method of prevention most likely to protect them from HIV infection. For example, Esi would have been safer using condoms than being faithful. Sometimes this is due to discomfort with the idea of condom use, and sometimes it may come from misinformation about condoms.
2. State that it is natural for anything that is completely new to be a bit uncomfortable to talk about or to use. Before deciding to use condoms, it is important to become more familiar with them. The next two activities are designed to help us to become more comfortable with handling condoms, to gather more information about condoms, and to give us an opportunity to practice their most effective use.
3. Say that the first exercise is the “Condom Carousel.” This activity will allow us a chance to become familiar with the look, feel, and smell of condoms while we discuss common questions about condom use.

²¹ The “Condom Carousel” activity was adapted with permission of Peace Corps from *Life Skills Manual*, Appendices 28-29. (Washington, DC: Peace Corps, 2000).

4. Invite participants to stand in a circle. Say that you will circulate a condom blown up like a balloon while the music is playing. Participants should pass it around the circle until the music stops. Whoever is holding the condom balloon when the music stops should break it, take out the slip of paper inside, and answer the question for the group.
5. Clarify any misconceptions about the questions. If a participant finds a particular condom balloon hard to break, be sure to point out how strong condoms are and how difficult it is to break them! Also remember to point out how large the condom can be when it is blown up, and link this to the myth that condoms are too small.
6. Continue until all balloons have been used, then invite the participants to sit down.

Wrap-up

When summarizing, take a moment to ask participants how comfortable they felt touching or holding the condoms. For some, this may have been the first time to have such contact. Ask for any comments or questions. Allow time for the participants to express any discomfort or negative feelings they might have about condoms or condom use. When the discussion is winding down, say that we will now move on to a deeper discussion on how condoms are used.

Activity **Condom Demonstrations**

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

- List the steps for proper use of male and female condoms
- Demonstrate proper or correct use of male and female condoms

Time allotted 1 hour

Preparation Ensure that you have enough male condoms for each participant. Be sure to provide some condom demonstration models (wooden penises, bananas, bottles, and so on)—it works best when there is one model for each pair of participants. Make copies of the “How to Use a Male Condom” for each participant, or write the steps on a flipchart for participants to copy later.

Provide enough female condoms for all participants, and at least one female condom demonstration model for each pair of participants. Provide photocopied handouts of the “Steps for Using a Female Condom.”

Before the session begins, place a condom or two at each participant’s seat. Put one condom demonstration model near each pair of participants. Do not hand out the “Steps for Condom Use” until the end of the session.

Facilitation steps

1. Move immediately from the “Condom Carousel” activity to a discussion about the proper use of a condom. Suggest that practicing proper use of a condom can often clear up many of the mistaken beliefs and fears about condom use.
2. Invite one of the participants to come to the front of the room and guide us through the proper steps for using a male condom using one of the models. Suggest that fellow participants provide feedback and advice should the volunteer need it. Correct any wrong information about the steps.
3. Next, suggest that participants take a moment to open one of the condoms at their seats. Ask participants to practice the steps for putting on a condom in pairs. Each participant should have one chance to explain the steps for putting on a condom to their partner. Each pair will thus go through the demonstration twice.

4. Move on to a discussion of the female condom. Say that there is a shared responsibility between men and women for condom use, be it for disease prevention, family planning, or both, which is called “dual protection.” Point out that sometimes women do not have the decision making power in a relationship, and thus they may not be able to convince a partner to use a condom. In cases like these, the use of a device like the female condom may give the woman more power over condom use.
5. Pass female condoms out to all participants, and encourage them to take the condoms out of the wrapper and to explore them. Tell them that female condoms are not made of latex like a male condom, but of polyethylene (rubber), which is a stronger material than latex and less likely to break. Show them that the female condom comes covered with some lubricant. Another advantage is that you may insert the female condom up to eight hours before a sexual encounter, so that you can always be prepared and protected. Also be sure to point out that the female condom covers a wider surface area than the male condom, which may offer women greater protection against other STIs.
6. Say that there are also some negative aspects to the female condom, including a higher cost or a lack of availability in some areas, and the awkwardness of application. Some people have also said that the female condom makes some noise during sex. However, if you put the female condom inside several hours before the sexual encounter, it will cut down on the noise.
7. Ask if any of the participants would like to volunteer to demonstrate the proper steps in using a female condom on a model. This may be the first time that some participants have seen the female condom, so be prepared to demonstrate it yourself. Distribute female condom demonstration models (see Note to Trainers below), ensuring that each pair of participants gets one. Encourage the group to follow along with you, using their own models, as you demonstrate.
8. Demonstrate the use of the female condom, following the “Steps for Using a Female Condom” and “How to Use a Female Condom” at the end of this chapter. Provide some time for the participants to practice in pairs.

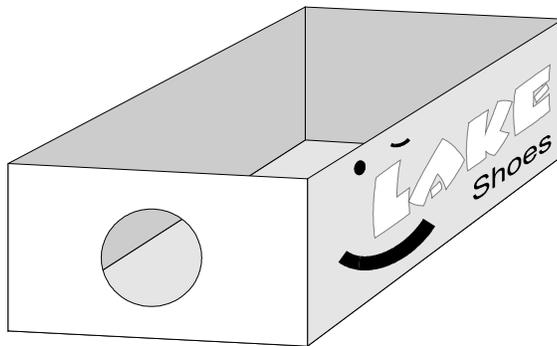
Wrap-up

To finish up the discussion regarding condom use, review the steps and distribute the handouts to each participant. Remind the group that condom use is one of a few ways to protect yourself from sexual transmission of HIV. You may want to discuss the advantages and disadvantages of female versus male condoms. However, stress that each person must make her or his own decision about which method of protection is best for her or his situation.

Note to Trainers—

You may start by opening a discussion about condoms and the reasons that people think they do not work. Point out that most condom failure is due to inconsistent or improper use. By actually going through the steps of proper condom use with real condoms, they can learn and even be able to teach others, how to properly use a condom. This can be empowering, but it may also be one of those areas where they have to be open to new experiences in order to fight against HIV.

Also, there is not a good, lightweight, portable, anatomically correct female models appropriate for use in the community. It is possible to make a rough model by cutting a four to five centimeter (1.5 to 2 inches) hole in a small box (e.g. a shoebox) to demonstrate condom insertion.



Condom Carousel—Sample Questions

It is important to compile a list from the community of common questions or concerns regarding condom use. The suggestions below are intended merely as examples. Each of the statements or questions should go on a separate piece of paper. Facilitators may review the answers to the questions, which are included in italics.

- How many times can you use a male/female condom?

Each male condom should only be used one time and then thrown away. It is very dangerous to attempt to use a condom more than once, as it will be filled with semen, and possibly infected with STIs or HIV.

*The situation is somewhat different for female condom. The World Health Organization (WHO) does **not** recommend or promote reuse of a female condom. However, recognizing the urgent need for risk reduction, WHO recently released a draft protocol for the reuse of female condoms. The protocol says that a female condom can be disinfected using a 1:20 solution of household bleach and water for one minute, then washed with soap and water, hung to dry, and re-lubricated. This may occur up to five times without damage. Check for leaks by filling the condom with water and observing it. Female condoms **can** be lubricated with petroleum-based oil (e.g. Vaseline) (WHO, 2002).*

- It is safer to wear two condoms instead of just one, whether it is a male and a female condom or two male condoms. It is double the protection. True or false?

False. You should only use one condom at a time. Using two may increase the friction and cause condoms to break. Also, using two condoms may reduce the sensation, and the couple may be tempted not to use condoms at all the next time.

- Petroleum jelly (Vaseline, or local brand name) is a good lubricant to use with a male latex condom. True or false?

False. Petroleum jelly or any other oil-based lubricant should not be used with a male condom. These substances can cause condoms to break. Use a water-based lubricant, such as K-Y Jelly or local brand. (However, as stated above, Vaseline or oil-based lubricants can be used with female condoms. See WHO, 2002 above for female condoms.)

- If a man/woman uses a condom for more than two years, he can become infertile. True or false?

False. Condom use has never been shown to cause infertility. This is a myth.

Condom Carousel—Sample Questions, continued

- Only men can receive free condoms. True or false?

False. Free condoms are available to both men and women at (insert local source for free or inexpensive condoms).

- What is dual protection?

*Protection from pregnancy, and HIV and STIs, either through the use of a condom alone or the use of a condom plus another family planning method. Abstinence also provides dual protection, as does avoiding penetrative sex (CEDPA's manual *Female Condom and Dual Protection*).*

- Condoms are too small for men in our area. True or False?

False. Condoms stretch to fit any size penis.

- Condoms are too big to be used by adolescents. True or False?

False. Condoms are very elastic and can fit both small and large penises.

- Condoms can (do) sometimes transmit HIV. True or False?

False. Well-made and properly stored latex condoms do not permit HIV cells to pass through.

- Why are condoms good for married couples to use?

They can be used by married couples for dual protection, both from disease and pregnancy. If one partner has engaged in risk behavior, it can protect the other partner. Condoms can also be used if one or both partners are HIV positive, in order to protect the other partner from infection or re-infection, and to possibly reduce the risk of transmission to an unborn child or breastfeeding infant.

- Condoms encourage immoral sexual behavior. True or False?

False. Epidemiological studies from several countries have consistently demonstrated that neither the number of partners nor frequency of non-monogamous sexual intercourse increases with the use of condoms.

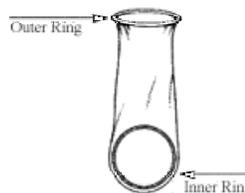
Steps for Using a Female Condom

- Purchase or pick up female condoms long before you will need them. Make sure they are available in case of a sexual encounter and practice insertion prior to sexual activity.
- If you are expecting a sexual encounter, you may insert the female condom up to eight hours before you have sex. (Optional)
- Insert the female condom, before you and your partner begin any sexual activity.
- Wash your hands with soap before you begin.
- Check the expiration date before opening the package.
- Open the package carefully, and be sure not to tear it with your nails or your teeth.
- Find a comfortable position, perhaps by standing with one leg up on a chair, or by lying on your back with both legs up, or by sitting with knees apart.
- Rub the condom to spread the lubricant over the entire thing.
- You will notice two rings on the female condom—one of these rings stays on the outside of the pubic area, while the other sits up against the cervix (the entrance to the uterus or womb).
- Squeeze the smaller ring and insert it into the vagina as far as it will go. When you release the ring it will snap open to cover your cervix.
- Push the condom up with your finger to make sure that it is not twisted and that it is properly in place.
- During sex, hold the outer ring of the condom in place while guiding the penis into the vagina.
- To remove the condom after sex, twist the outer ring and pull it out while still lying down. Be careful not to spill any semen.
- Tie the condom and dispose of it in a place where children are not likely to play. Do not flush down the toilet.

How to Use a Female Condom²²

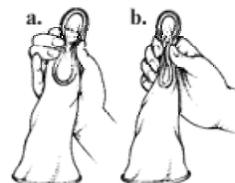
1. Open End (Outer Ring)

The open end covers the area around the opening of the vagina. The inner ring is used for insertion and to help hold the sheath in place.



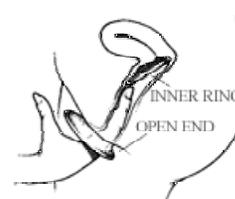
2. How to Hold the Sheath

Hold inner ring between thumb and middle finger. Put index finger on pouch between other two fingers, or just squeeze.



3. How to Insert the Condom

Squeeze the inner ring. Insert the sheath as far as it will go. It's in the right place when you can not feel it. Do not worry—it can not go too far, and IT WILL NOT HURT!



4. Make Sure Placement Is Correct

Make sure the sheath is not twisted. The outer ring should be outside the vagina.



5. Removal

Remove before standing up. Squeeze and twist the outer ring. Pull out gently. Dispose with trash, not in toilet.



Use more lubricant if—

- The penis does not move freely in and out
- The outer ring is pushed inside
- There is noise during sex
- You feel the female condom when it is in place
- The female condom comes out of the vagina during use

Remove and insert a new female condom if—

- The female condom rips or tears during insertion or use
- The outer ring is pushed inside
- The penis enters outside the pouch
- The female condom bunches inside the vagina
- You have sex again

²² Adapted from CEDPA's *Reproductive Health Awareness Manual*, p. 21. (Washington, DC: CEDPA, 2003).

How to Use a Male Condom²³

IMPORTANT: Whenever possible, show clients how to put on and take off a condom. Use a model, a stick, a banana, a soda pop bottle, or two fingers to demonstrate putting on the condom. Suggest to a new user that he practice putting on a condom by himself before he next has sex. You may also want to encourage women to practice putting a condom on a model.

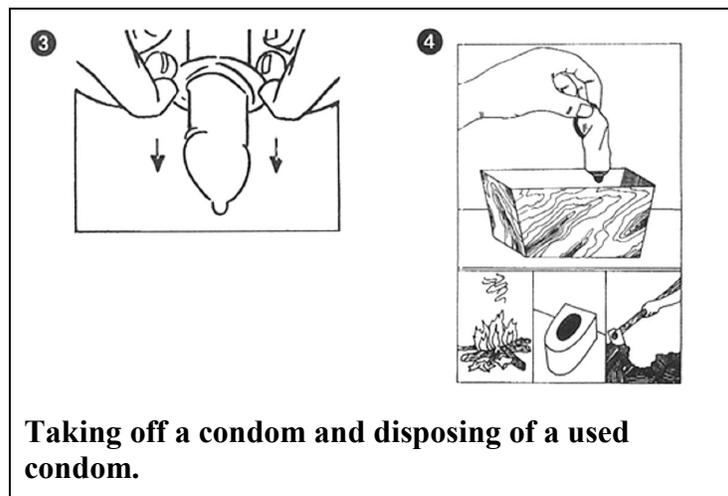
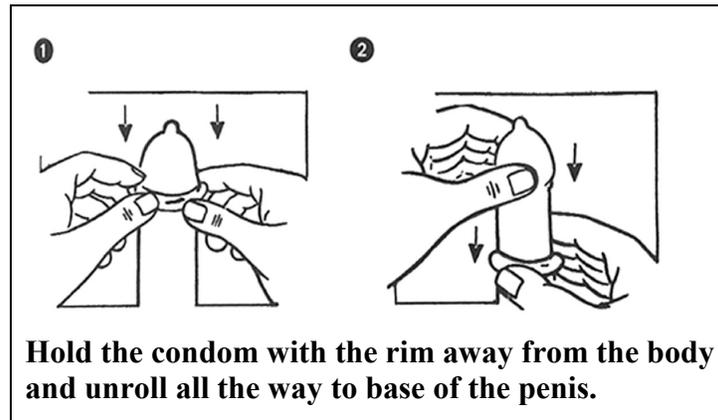
- Purchase or pick up condoms long before you need them.
- Store condoms in a cool place, away from direct sunlight and heat.
- Always have condoms available, even when you are not likely to have sex.
- Before using any condom, check the expiration date. Do not use condoms beyond their expiration date.
- Check that the condom has not been left too long in the sun by feeling for an air pocket in the wrapper.
- Open the package carefully. Take care not to use long nails or your teeth to open the packet, as this may cause a tear in the condom.
- Pinch the tip of the condom to prevent air from being trapped. Air at the tip can cause the condom to burst.
- Hold the condom so that the rolled rim is facing up, away from the penis.
- Pull the foreskin back if the penis is uncircumcised.
- Place the condom on the tip of the erect penis.
- Unroll the condom all the way to the base of the penis. The condom should unroll easily. If it does not, it is probably backward. Turn it over and try again. If using the condom to avoid passing on an STI, throw away the condom that was on backward and start over with a new one.
- Any lubricant used should be water-based. Good lubricants include a spermicide (except nonoxynol 9), glycerin, and specially made products. Water can also be used. They help keep condoms from tearing during sex. Natural vaginal secretions also act as a lubricant. Do not use lubricants made with oil, most of them damage condoms. Do NOT use cooking oil, baby oil, coconut oil, mineral oil, petroleum jelly (such as Vaseline), skin lotions, suntan lotions, cold creams, butter, cocoa butter, or margarine.
- After ejaculation, hold the rim of the condom to the base of the penis so it will not slip off. Pull your penis out of the vagina before completely losing your erection.

²³ Adapted from CEDPA's *Reproductive Health Awareness Manual*, p. 20. (Washington, DC: CEDPA, 2003.)

How to Use a Male Condom, continued

- Remove the condom carefully, being careful not to spill the contents on your partner.
- Tie a knot at the top of the condom, and throw the condom away in a pit latrine, burn it, or bury it. Do not leave it where children will find it and play with it. And, do not flush it down a toilet.
- Do not use a condom more than once. Always use a brand new condom whenever having sex.

Putting on a Condom



References

Marshall, Peg and Aumack Yee, Kimberly. *Reproductive Health Awareness: A Wellness, Self-Care Approach*. (Washington, DC: CEDPA, 2003).

Peace Corps. *Life Skills Manual*. (Washington, DC: Peace Corps, 2001).

Chapter 12

The Immune System and HIV

“People who know their HIV status are more likely to change their behavior to protect themselves and others,” said Health Minister Brian Chituwo on Zambian President Kenneth Kaunda’s decision to go for an HIV/AIDS test.

“Voluntary counseling and testing also helps to break the stigma linked to HIV/AIDS and provides a link to care and support services for those who are HIV positive.”

—BRIAN CHITUWO, HEALTH MINISTER, ZAMBIA

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Chapter 12: The Immune System and HIV

Key Questions

- How does HIV progress to AIDS in the body?
- What are some of the symptoms of HIV or AIDS?
- What is the “window period?” The “honeymoon period?”
- Are there ways to prevent mother-to-child transmission?
- What are the recommendations for prevention of mother-to-child transmission?
- Can certain behaviors lengthen the time that an HIV infected person can live healthily with the virus?
- How can people with HIV/AIDS live longer and healthier lives?

Introduction

Whereas transmission and prevention are arguably the most important topics for those seeking to prevent HIV infection, the “Disease Progression” session is perhaps the most important topic for people living with HIV/AIDS and those who care for them. Understanding the progression of HIV/AIDS in the body can offer a great deal of hope to those coping with HIV infection, because it explains the following crucial links to a longer, healthier life—

- The significance of the “honeymoon period,” or the time before HIV develops into AIDS
- The influence of co-factors in moving HIV infection more quickly into AIDS, and especially how to live more positively and lengthen the honeymoon period
- The significance of avoiding reinfection with the virus and avoiding infection with opportunistic diseases, especially STIs
- The prevention of mother-to-child transmission (MTCT) by avoiding reinfection with the virus during pregnancy and while breastfeeding
- The effect of frequent pregnancies on the honeymoon period and the importance of family planning
- Ways to lengthen the honeymoon period, even without access to antiretroviral (ARV) drugs

The tone of this session should be one of empowerment. In many communities, the lack of access to expensive ARV drugs has left people living with HIV/AIDS feeling helpless and disempowered in the face of their HIV infection. Although ARV drugs certainly lead to longer, healthier lives for those infected with HIV, there are still many ways for infected people to control the progression of the virus in their bodies using locally available resources. Information about disease progression, along with an understanding of the many aspects of positive well-being, can help those living with HIV/AIDS and those who care for them to regain control of their own health. Early VCT can be an important entry point into care and support services, and preventive behavior. This session represents that powerful new direction for communities that have been hit hard by the pandemic, as they continue the fight for access to ARV therapy. Access to ARV drugs will become an increasingly pivotal issue as generic production improves and costs decline. Therefore, as access improves, involving local clinicians and traditional healers in this session will be even more relevant.

Chapter 12: The Immune System and HIV

Objectives

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

- Describe the role of the immune system in one's body
- Discuss the impact of HIV on the immune system
- Define the terms: window period, honeymoon period, AIDS, opportunistic infections/diseases, and co-factors
- Describe the stages of HIV progression in the body
- List at least three recommendations for preventing MTCT of HIV
- List at least five co-factors that can make an HIV positive person develop AIDS faster
- List at least five positive behaviors that can lengthen the honeymoon period and keep an HIV positive person healthy longer
- Describe the importance of treating opportunistic infections to staying healthy

Important Terms

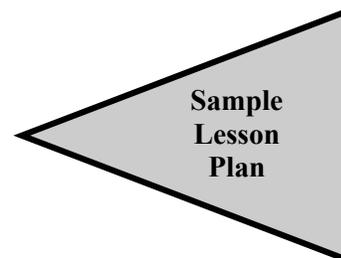
AIDS	Acquired Immune Deficiency Syndrome. A cluster of opportunistic diseases brought on by an immune system weakened by HIV.
B Cells	A white blood cell that exists in your bone marrow and secretes antibodies.
Co-Factors	Factors that can shorten an HIV positive person's honeymoon period and move that person more quickly into AIDS. Some examples are: poor nutrition, re-infection with HIV, infection with STIs and/or other diseases, stress and isolation, smoking, drinking too much, and using drugs.
HIV	Human Immunodeficiency Virus. The virus that weakens the immune system, ultimately leading to AIDS.
Honeymoon Period	The time between the end of the window period to the beginning of disease symptoms associated with AIDS. It is called the honeymoon period because the persons are living in relative harmony with their virus. They may have a few minor symptoms, but usually do not look ill. During this time, their antibody level is high, and their viral load is low. Although they can still pass the virus to others, they are less infectious than during the window period and once they reach the stage of full-blown AIDS. During the honeymoon period, pregnant women have less chance of passing HIV to their babies.
Opportunistic Diseases or Opportunistic Infections	Infections or diseases that may not affect an HIV negative person, but due to the immune-deficiency in the HIV positive person, the microbes take the opportunity to cause disease. Examples include pneumonia, tuberculosis, Kaposi's sarcoma, fungal infections (thrush), and cervical cancer.
T4 Cells	T4 Cells, also called "Helper T-Cells" are white blood cells that help other cells destroy infective organisms.
T8 Cells	T8 Cells, also called "Suppressor T-Cells" are white blood cells that suppress the activity of other lymphocytes so they do not destroy normal tissue.
Window Period	The time between infection with HIV and when a person develops enough antibodies to show up positive on the HIV test—usually between two weeks and three months. During this period, a person has a high viral load and is very infectious because no antibodies are controlling the virus. The person's test is still negative at this time because the test detects antibodies, not the virus.
Viral Load	The viral load is the amount of HIV RNA in the blood stream. RNA is the part of HIV that knows how to make more virus.

Home Care: The Power of Our Community

Training Schedule: Sections 1 and 2

Schedule	Day One	Day Two	Day Three	Day Four	Day Five
	Registration <i>30 minutes</i>	Recap <i>30 minutes</i>	Recap <i>30 minutes</i>	Recap <i>30 minutes</i>	Recap <i>30 minutes</i>
Session	Transmission and Prevention of HIV/AIDS Myths and Facts <i>1 hour</i> Transmission Facts <i>30 minutes</i>	The Power of Our Community Introductions, Goals, and Objectives Workshop Structure <i>1 hour 30 minutes</i>	Medical Support for People Living with HIV/AIDS (cont.) Common Illnesses Role-Play <i>1 hour 45 minutes</i>	Nutritional Needs for People Living with HIV/AIDS and Their Families We Are What We Eat <i>1 hour</i> Nutritional Needs for People Living with HIV/AIDS <i>1 hour</i>	Preparing for Goodbye Supporting People Living with HIV/AIDS <i>1 hour 30 minutes</i>
Break	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
Session	What's the Fluid? Where's the Door? <i>30 minutes</i> Prevention of HIV <i>30 minutes</i> Condom Carousel <i>30 minutes</i>	Breathe in Life, Breathe Out Trouble The Power of Our Community <i>1 hour 30 minutes</i>	Oral Rehydration Solution and Thermometer Use <i>1 hour</i> Seeking Medical Support from a Professional Service Provider Special Medical Concerns for People Living with HIV/AIDS <i>1 hour</i>	Social Support for People Living with HIV/AIDS and Their Families Small Groups on Social Issues <i>1 hour</i> Plenary on Social Issues <i>1 hour 30 minutes</i>	Supporting Orphans <i>1 hour 30 minutes</i>
Lunch	<i>1 hour</i>	<i>1 hour</i>	<i>1 hour</i>	<i>1 hour</i>	<i>1 hour</i>
Session	Condom Demonstration <i>1 hour</i> The Immune System and HIV Elephants and Lions Game <i>15 minutes</i>	The Life Tree Life Tree <i>1 hour 30 minutes</i>	Strategies for Dealing with Health Professionals <i>45 minutes</i> Antiretrovirals <i>30 minutes</i>	Psychological Support for People Living with HIV/AIDS and Their Families People Living with HIV/AIDS Vignettes <i>1 hour 45 minutes</i>	Closing Evaluation <i>1 hour</i> String Spider Web and Closing Ceremony <i>1 hour</i>
Break	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
Session	Disease Progression Diagram <i>1 hour</i>	Medical Support for People Living with HIV/AIDS Common Illnesses Role-Play <i>1 hour 30 minutes</i>	Physical Support for People Living with HIV/AIDS and Their Families Caring for People Living with HIV/AIDS in the Home <i>1 hour 30 minutes</i>	<i>The previous session can be emotional. Trainers may want to have a counselor present and use the afternoon session for this purpose.</i>	
Eval	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
Total	<i>7 hours 30 minutes</i>	<i>8 hours 15 minutes</i>	<i>8 hours 45 minutes</i>	<i>8 hours 30 minutes</i>	<i>6 hours 45 minutes</i>

Chapter 12: The Immune System and HIV



Sample Lesson Plan

Time	Content	Methodology	Materials Needed	Evaluation
20 minutes	<p>Elephants and Lions Game</p> <p>Effect of HIV on the immune system</p> <p>Difference between HIV and AIDS</p>	Participants act out a role-play to illustrate the effect of HIV on the immune system	Sticky paper or pieces of tape, signs labeled “Body,” “Immune System” and “Various Opportunistic Infections” on them	<p>Active participation in the activity</p> <p>Application of concepts in disease progression activity</p>
1 hour 20 minutes	<p>Disease Progression Diagram</p> <p>Definition of concepts: window period, honeymoon period, incubation period, co-factors, and reinfection</p> <p>Phases of HIV infection in the body over time</p> <p>Effects of opportunistic diseases</p> <p>Prevention of MTCT</p>	Using ribbons or tape on the wall, participants craft a diagram showing the progression of HIV in a body over time; participants affix key terms on the diagram at the appropriate points	<p>Three different colors of ribbon or tape</p> <p>Masking Tape</p> <p>Prepared cards—</p> <ul style="list-style-type: none"> - Window period - Honeymoon period - Incubation period - Chills - Fever - Cough - Weight loss - Diarrhea - Yeast infections - Cervical cancer - Herpes zoster (shingles) - Tuberculosis - Dementia - Pneumonia - Kaposi’s sarcoma - AIDS <p>Blank cards</p>	<p>Proper placement of the cards throughout the exercise</p> <p>Correct presentation of the “Disease Progression Diagram”</p>

Chapter 12: The Immune System and HIV

Activities and Handouts for The Immune System and HIV

- **Elephants and Lions**
- **Disease Progression Diagram**

Activity Elephants and Lions Game²⁴

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

- Describe the difference between HIV and AIDS
- Describe the role of the immune system in one’s body
- Discuss the impact of HIV on the immune system

Time allotted 20 minutes

Preparation Ensure that the chairs are arranged in a large circle, with plenty of room inside the circle for a group of participants to move around. Have several pieces of sticky paper or tape (enough for each “lion” to have three or more). Make signs saying, “Body,” “Immune System,” (enough for each of the adult elephants), and several with names of diseases on them, including “Tuberculosis,” “Malaria,” “Diarrhea,” “Syphilis,” and “Gonorrhea,” etc. (but not HIV) enough for all the lions to each have one. Tape.

- Facilitation steps**
1. Say that we have been discussing how HIV is transmitted and ways to prevent such transmission. Now we will move to a deeper discussion of exactly what happens once HIV has already entered the body.
 2. Suggest that we will do a short activity to get us started and to help us to think more clearly about the impact of HIV on our bodies. This activity is called the “Elephants and Lions Game.”
 3. Stand in the center of the circle, and ask for one volunteer. Have the volunteer stand in the center of the circle with you. Indicate to everyone that this person is the baby elephant.
 4. Ask for six more volunteers (this number can be higher depending on the size of your group). These volunteers are the adult elephants. Their job is to protect the baby elephant. They should form a circle around the baby elephant, facing out, away from the baby elephant, and link arms or join hands. To show them the importance of their job, the facilitator should try to touch the baby elephant—you will find that the adult elephants quickly get the point and close ranks to avoid attack.

²⁴ The *Elephants and Lions Game* was adapted and reprinted with permission of Peace Corps from the *Life Skills Manual*. (Washington, DC: Peace Corps, 2001)

5. Now, ask for four or five more volunteers (or more depending on the size of your group). These people are the lions. Give each lion several pieces of sticky paper or tape. Their job will be to attack the baby elephant—they should try to put the pieces of sticky paper or tape onto the baby elephant.
6. When the facilitator says “Go!” the lions should try to attack the baby elephant. Let this go on for about 30 seconds—until the baby elephant has at least one piece of sticky paper or tape stuck to it from the lions—but the baby elephant should not be hurt.
7. Now ask the following questions (the volunteers should stay where they are)—
 - What is the baby elephant? What does the baby elephant represent?
 - Answer: The baby elephant is the human body (tape the sign saying ‘Body’ to the baby elephant). Point out that this could be *any* human body; man, woman, young, old.
 - What are the adult elephants? What do they represent?
 - Answer: The adult elephants are the immune system. Their job is to protect the body from invading diseases. (Tape ‘Immune System’ signs to the adult elephants.)
 - So, what are the lions? What do they represent?
 - There may be a few people who say that the lions represent HIV. That is not so. Ask another person to try to tell you the meaning of the lions.
 - Answer: The lions stand for the diseases, illnesses, and infections that attack a person’s body.
8. Now go very dramatically to each of the lion volunteers—one by one. Say, “These diseases, such as tuberculosis (give the volunteer the ‘Tuberculosis’ sign), malaria (give another the ‘Malaria’ sign), diarrhea (give another the ‘Diarrhea’ sign and so on,) attack the human body, but are they able to kill the human body?” The answer should be “no.” Diseases or germs attack the human body every day, but the immune system (point to the adult elephants) manages to fight them off and protect the body. The human body might get sick (such as the sticky paper or piece of tape that reached the baby elephant), but it does not die, because the immune system is strong.
9. The facilitator continues, “But suppose I am HIV. I come to this body (touch the baby elephant), and I attack the immune system.” At this point, the facilitator should touch three of the adult elephant volunteers and ask

them to sit down. Touch each person as you remove him or her, acting as if HIV is slowly killing the immune system.

10. The facilitator continues, “Now, what will happen to the baby elephant when the lions come?” The answer should be that the baby elephant will be hurt even more when the lions come back.
11. Again the facilitator moves from one adult elephant volunteer to another, acting as if HIV is killing the adult elephants and telling the volunteers to sit down. Do this until only one or two are left. Indicate that HIV has continued to attack this body’s immune system, until only a very little bit of it is left. Ask participants what will happen now when the lions return? Will the remaining adult elephants, what is left of the immune system, be able to protect the baby elephant, or the body?
12. Once more, tell the lions to attack (putting sticky paper or tape onto the baby elephant) on the word, “Go!” The lions are now able to easily get to the baby elephant. Make sure the volunteer does not get hurt! Stop the attack.
13. Thank all volunteers and ask them to sit down.

Wrap-up

Summarize the activity by reminding participants that HIV has killed the immune system. This lack of an immune system makes it possible for many common diseases like tuberculosis, diarrhea, and so forth, to attack a person’s body at once. Gradually all of these diseases come together, to cause a person’s death rather than just make the person ill. This is called AIDS.

To be sure people have understood, you might ask, “Does HIV kill a person?” They should say, “No—the diseases kill a person.” Or “No, HIV kills the immune system, AIDS kills a person.” Lastly, have someone describe the difference between HIV and AIDS.

Activity Disease Progression Diagram²⁵

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

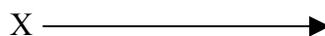
- Define the terms *window period*, *honeymoon period*, *incubation period*, *AIDS*, *opportunistic infections*, and *co-factors*
- Describe the stages of HIV progression in the body
- List some co-factors that can make an HIV positive person develop AIDS faster
- State two ways to help prevent MTCT

Time allotted 1 hour 20 minutes

Preparation Prepare cards with the following phrases written in large print on them—Window Period, Honeymoon Period, AIDS, Herpes Zoster, Cervical Cancer, Tuberculosis, Pneumonia, Dementia, Cough, Chills, Fever, Weight Loss, Thrush, Diarrhea. Either tape these cards under participants' chairs or distribute them before the exercise. Arrange the chairs in a semicircle around a prominent wall. Ensure that the wall is completely blank, or use several blank flipcharts taped together, so that the “Disease Progression Diagram” may be constructed on it (see the tool for trainers on page 12-329). Have three different colors of tape or ribbon available, perhaps red, blue, and green. When constructing the diagram, make everything big and bold so that all participants can see it.

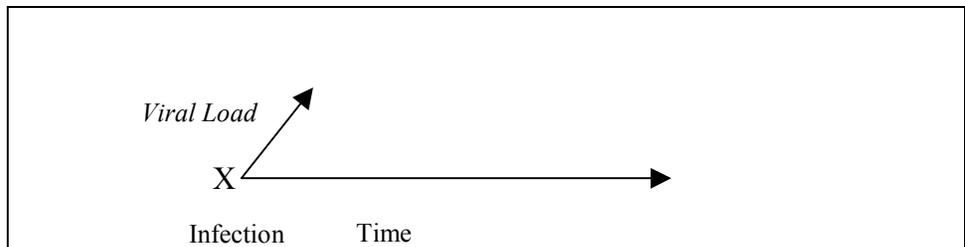
Facilitation steps

1. Say that we have seen the effects of HIV on the immune system, but we will now turn our attention of how it acts in the body once someone has been infected.
2. Stretch a length of the green tape (or ribbon) in a horizontal line along a large stretch of wall, or on the flipcharts taped together. (—————▶) Suggest that this is a timeline and that it represents the time from the moment one gets infected to when one develops AIDS and beyond. Make a large X with the red tape on the time line to the far left. Indicate that this X represents the day that one is infected with HIV.

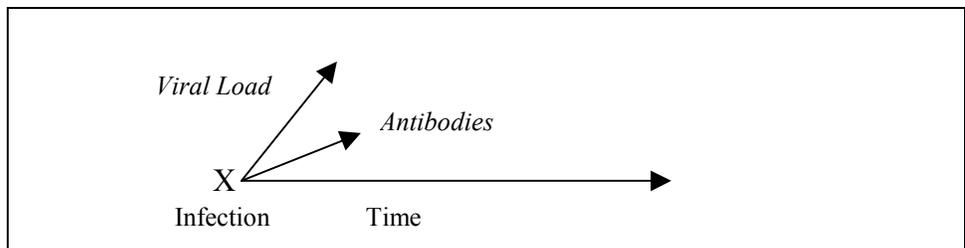


²⁵ The “Disease Progression Diagram” session was adapted and reprinted with permission of Peace Corps from the *Life Skills Manual*. (Washington, DC: Peace Corps, 2001).

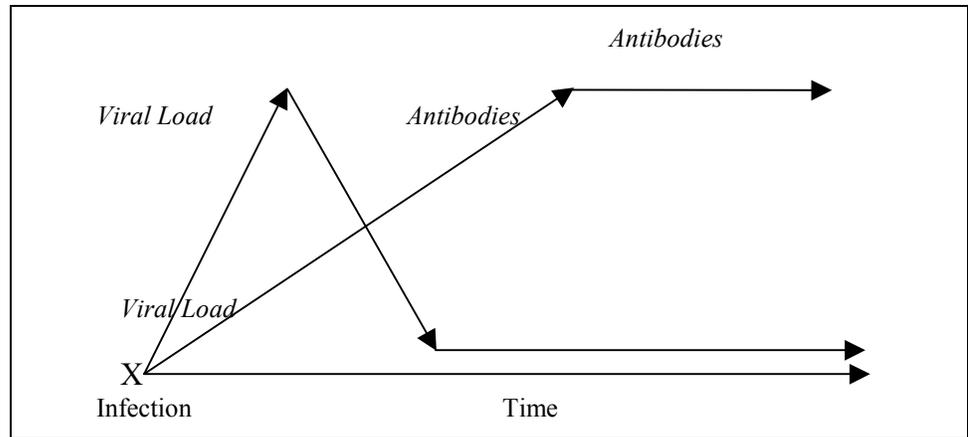
3. Ask participants to remember the “Elephants and Lions Game.” What happens in the body when HIV first enters? Allow participants to discuss the effect of HIV on the immune system.
4. Say that when a person is first infected, they have a high viral load because the immune system has not had a chance to fight the virus. Beginning at the red X, use the red tape to draw a line at about a 70-degree angle from the timeline. Indicate that this line represents the HIV viral load in a person’s body when one is first infected.



5. Ask participants what happens with the immune system when all of this virus is dumped into the body. The T4 cells are taken over, but still call for the T8 cells and the B cells. (See “Important Terms” for definition.) The B cells begin to make antibodies to fight the HIV in one’s system. Use the blue tape to represent the climbing antibody count in a person’s system. The tape should begin at the red X at about a five degree angle, and steadily climb until it is at about a 45 degree angle from the timeline.



6. Ask participants what they think will happen to a person’s viral load when the antibodies are beginning to fight the virus like this. They should indicate that the viral load will decline as the antibodies fight the virus. Use the red tape to illustrate this, taking it down from the peak and dropping it toward the timeline. It should intersect with the blue antibody line about halfway up from the timeline. Do not allow the HIV viral load to go completely down, but level it off until it is parallel with the timeline. (See the sample “Disease Progression Diagram” on page 12-329.)



7. Indicate that the antibody count will climb and level off as well. Use the blue tape to draw a parallel line well above the red HIV viral load line.
8. Point out that the level of antibodies and viral load actually fluctuate and one of our goals is to keep the antibody level high and the viral load low by promoting healthful co-factors (e.g. good nutrition) and diminishing harmful cofactors (e.g. exposure to STIs).
9. Point to the intersection between the red and the blue lines. Indicate that this is a very important time for an HIV positive person. Ask if anyone knows why. Explain that before this point is when a person can test negative for the virus. Remind participants that the HIV test can only pick up antibodies to HIV—the test cannot find HIV itself. So at first, if someone has the virus and goes for testing, it may appear that he or she is not infected. But in fact, the person is infected but has not yet developed enough antibodies to be spotted on the test. This time period is known as the “Window Period.” Ask the participants to take a look at the cards in their hands or under their chairs. If someone has the “Window Period” card, he or she can come up and place it on the timeline now.
10. Talk about the window period a bit. Ask participants why the window period is such an important time. Answers might include—
 - *A person does not know that s/he is infected, so s/he may keep engaging in risky behavior.*
 - *A person has a high viral load at this time, and this is the time when he or she is the most likely to infect someone else.*
 - *If a person gets the test at this time and does not come back to be tested again, he or she may think that there is no HIV infection.*

11. Point out that another big issue about the window period involves MTCT of HIV. If a woman becomes or is pregnant during the window period, her body will have a high viral load, so she will be more likely to transmit HIV to her infant. Also, if a woman is breastfeeding during the window period, she is more likely to transmit HIV to her infant. What does this tell us about some of the ways to lessen the risk of MTCT of HIV?

- *A woman should either abstain from sex or use a condom when she is pregnant or breastfeeding in order to reduce the risk of MTCT.*

12. Before moving on, ask participants if they know how long the window period is likely to last. Write each answer on a card and paste it in the window period section of the diagram. The answer should be two weeks to six months, although 95 percent of people will test positive if they have been infected after three months.

- Why is this important to remember for VCT?

A person who has engaged in risky behavior needs to act as though s/he has been infected; that is, not continue the behavior and practice safer sex, and get tested. It is important to always practice safe behavior, but especially from this point on. Even if s/he tests negative s/he will need to have a second test three to six months after the risk behavior, in order to make sure that s/he is HIV negative.

- When and why should someone get tested? Answers may include—

- If s/he or her/his partner has engaged in unprotected or unsafe sex
- If s/he has had sex with multiple partners
- If s/he has been cut by a knife or needle used by someone who is possibly infected
- If s/he, her/his partner, or her/his children are unexplainably or chronically ill
- If s/he is afraid s/he has been infected; some people just want to know

- What are the benefits of being tested?

- To learn one's antibody status, if s/he is HIV positive or HIV negative

- What are the consequences of knowing one's status?
 - An HIV positive person can begin to take better care of her/himself immediately, take measures to live positively, make plans for the future of her/his family, and take precautions to not infect others and to take care not to be re-infected
 - An HIV negative person may have a sense of relief, and can change her/his behavior so as not to become infected in the future

- What are the consequences of not knowing your status?
 - You may always be worried that you may be infected, and may not know what precautions to take, and may not be able to plan for the future
 - Believing that you are positive when in fact you are negative
 - Believing that you are negative when in fact you are positive

(Ask participants to compare and contrast the effects of these last two scenarios.)

13. Ask participants to look at their cards again. Would an HIV positive person have had any symptoms of HIV infection during the window period? If any of the participants have cards showing such symptoms, they should come up and place them on the timeline now. Some of the possible symptoms of initial HIV infection might be chills, a fever or a cough; something like a cold or mild flu. But remind participants that these are symptoms for many different illnesses, so it is very difficult to realize that HIV might be involved. Most people do not notice these symptoms at all.

14. Again draw participants' attention to the diagram. At this point in the diagram, the antibody count has risen, and the viral load has dropped. What time in a person's life do they think this represents? Remind the group that people with HIV can be healthy and well for years after the first infection. This is because the body is battling HIV infection and for the time being, the antibodies are winning. Ask participants if they know the name for this time period. It is called the "honeymoon period" because this is a time when people are living in relative harmony with the virus. A person may get sick, but the immune system is still able to fight off the infection. Ask the person with that card to come up and place it on the timeline now.

15. During the honeymoon period, a person looks and feels as healthy as any other person. Why is this an important thing to remember? Some answers might include—

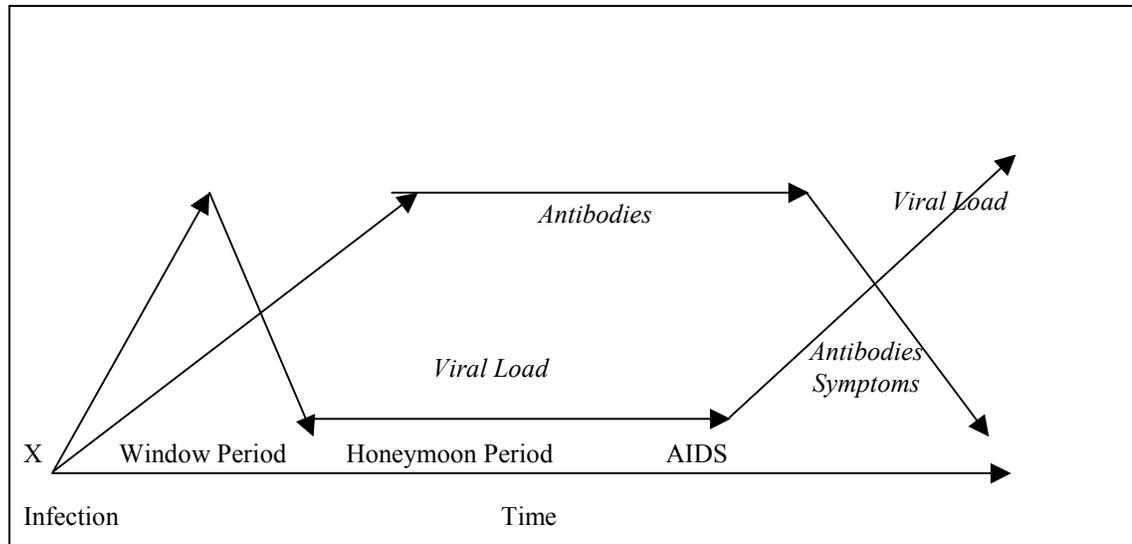
- *Others might think that a person is not infected because he/she looks and feels healthy and decide not to protect themselves against HIV*
- *A person might not protect him- or herself against new infections or other diseases because he/she looks and feels healthy*
- *They might not plan for the future*

It is important to remember that, during this time, a person will test positive for HIV on a test.

16. Suggest that sometimes the names that scientists give to these phases are not easy to think about or to remember. Are there better ways to think about infection, the window period, or the honeymoon period? One possibility is to think about infection as planting the seeds. For a time, there is no evidence that seeds have been planted—this is like the window period. Before we begin to see sprouts, the seeds germinate. This is like the honeymoon period. And just like with planting seeds, sooner or later a bud and then an entire plant comes up. In terms of our timeline, that period is known as AIDS.

17. Invite participants to think now a bit about someone they have known who was HIV positive AND when they first started to get a bit sick. Many HIV positive persons get tuberculosis, for example, but they get treatment for it, and get better. But later they fall ill again. What do you think is happening in that person's immune system at this time? (If necessary, remind participants of the "Elephants and Lions Game.")

18. Suggest that now the virus starts to win the battle against the antibodies. The viral load again begins to climb, and the antibody count begins to drop. Use red and blue tape to illustrate this on the diagram. The red line should begin to climb, and the blue line should begin to drop.



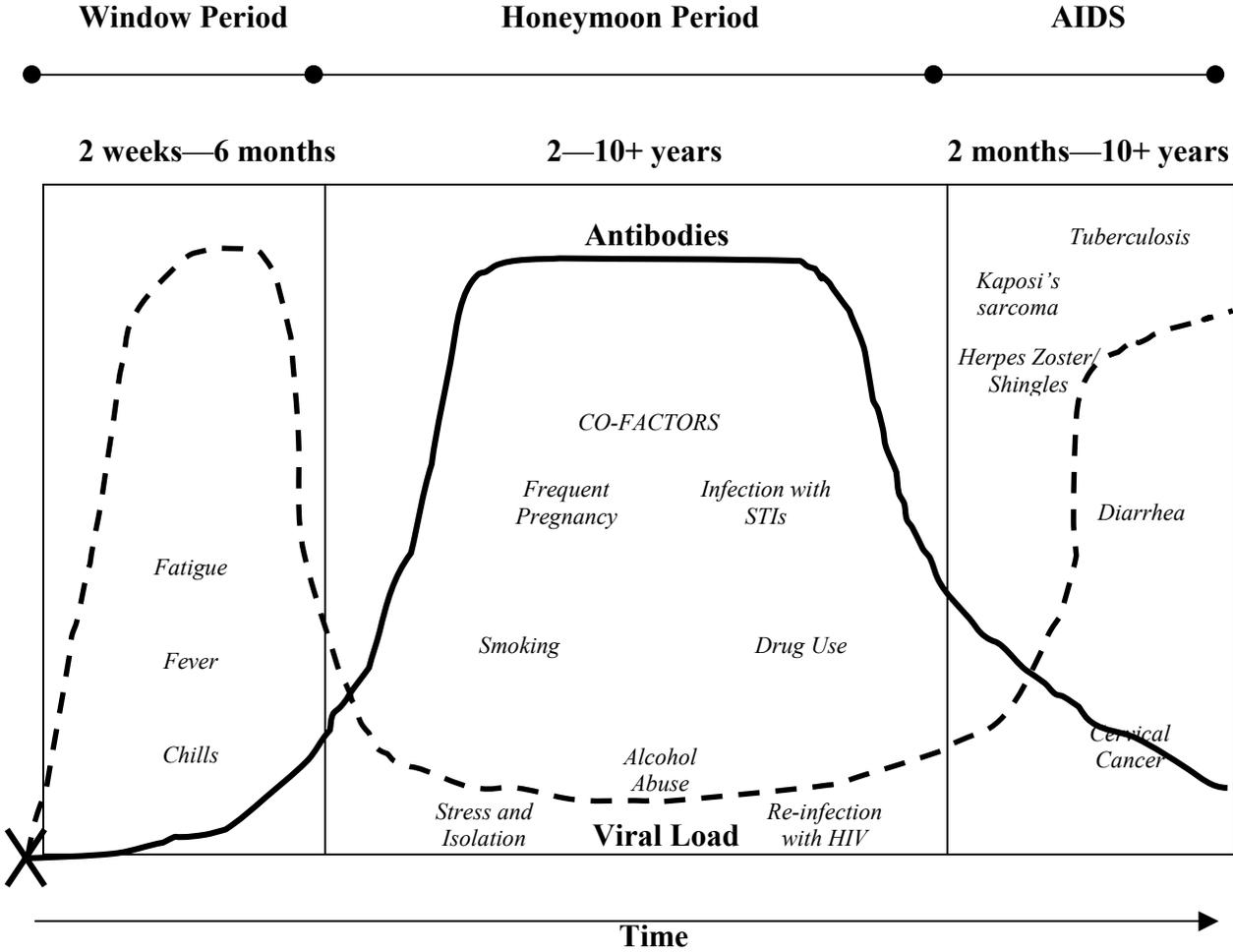
19. Point to this new point on the diagram, where the rising red line intersects with the falling blue line. Ask participants to tell you the name of this time period. This is when a person has begun to develop AIDS. Ask the participant with that card to come up and place it on the timeline now.
20. Say that when the viral load starts to climb, it means that the antibodies are dropping. The T4 cells are losing their battle and the immune system is getting weaker and weaker. Ask participants what will begin to happen to the person now. They should say that s/he will begin to get sick with different infections such as diarrhea, tuberculosis, malaria, and so on, because her/his immune system is not strong enough to stop those diseases. Ask participants with such diseases on their cards to come up and place them on the timeline. Indicate that these diseases are often called “Opportunistic Infections,” because HIV has given them the opportunity of the weakened immune system to take a hold of the person’s body.
21. You may need to take some time to describe each of the opportunistic infections. Diseases such as herpes zoster (shingles), Kaposi’s sarcoma, tuberculosis, pneumonia, cervical cancer, and dementia should be placed on the part of the timeline that represents AIDS. Other cards, such as weight loss, yeast infections, and so on, should be placed toward the end of the honeymoon period. These symptoms may be present at that time as the body gets weaker. Also, any STIs that you chose to place on the cards would be sprinkled throughout the honeymoon period and the AIDS period on the diagram. Tell participants that one gets sicker and sicker at this point, until the various diseases in one’s system finally cause death.

22. Now that the diagram is almost finished, ask participants how long the honeymoon period lasts. Listen to a variety of answers based on people's experiences. (Answers could be anywhere from two to ten years or more.) Finally, indicate that the honeymoon period is the hopeful part of this diagram. This is the part of the diagram at which people have the most control over what happens to their bodies. A number of factors can shorten the honeymoon period, and make people become ill with AIDS-related infections faster. And there are a number of ways that people can lengthen their honeymoon period, so that they remain healthier longer. Stress that the honeymoon period is becoming longer and longer as we learn more and implement healthy behaviors.
23. Ask participants to brainstorm some of the things that can make people develop AIDS faster. Write ideas on individual cards and paste them in the honeymoon period section of the diagram. Some examples are re-infection with HIV, STIs, infection with other diseases (such as malaria, diarrhea, and so on), pregnancy, poor nutrition, poor water quality, lack of exercise, smoking, drinking too much, stress, depression and isolation, using drugs, fatigue, and so on. Indicate that these are called co-factors; they are factors that can lessen the honeymoon period and move an HIV positive person more quickly into AIDS. Take time to clarify any co-factors that are unclear for participants.

Wrap-up

Ask a participant or two to guide the group through a summary of the "Disease Progression Diagram." Ask other participants to define some of the terms, such as window period, honeymoon period, incubation period, AIDS, viral load, co-factors, and so on. Say that just as there are ways to shorten the honeymoon period and make someone sicker faster, there are also ways to lengthen the honeymoon period. We will soon discuss how to keep ourselves healthy for a long period of time with HIV infection.

Completed Disease Progression Diagram



Section 3

Harnessing the Power of the Community

About This Section

Section 1, *The Many Aspects of Home Care*, gives very specific information on how to deal with HIV/AIDS at the family level. However, to combat the HIV/AIDS epidemic it will take a multi-level response. Section 3, *Harnessing the Power of the Community*, looks at how communities as a whole can mobilize and respond to the epidemic. This can be used in conjunction with Section 1 to create a more holistic five-day training or can be used alone as a one-day training. The schedule below lays out the five-day combined schedule with all the activities outlined. However, all training schedules should be modified and organized to meet the needs of the entire group.

Home Care: The Power of Our Community

Training Schedule: Sections 1 and 3

Schedule	Day One	Day Two	Day Three	Day Four	Day Five
	Registration <i>30 minutes</i>	Recap <i>30 minutes</i>	Recap <i>30 minutes</i>	Recap <i>30 minutes</i>	Recap <i>30 minutes</i>
Session	The Power of Our Community Introductions, Goals, and Objectives Workshop Structure <i>1 hour 30 minutes</i>	Medical Support for People Living with HIV/AIDS (cont.) Common Illnesses Role-Play <i>1 hour 45 minutes</i>	Nutritional Needs for People Living with HIV/AIDS We Are What We Eat <i>1 hour</i> Nutritional Needs for People Living with HIV/AIDS <i>1 hour</i>	Preparing for Goodbye Supporting People Living with HIV/AIDS <i>1 hour 30 minutes</i>	Merging the Community Maps <i>30 minutes</i> Action Planning for Our Community Story with a Gap <i>1 hour 30 minutes</i>
Break	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
Session	Breathe in Life, Breathe Out Trouble The Power of Our Community <i>1 hour 30 minutes</i>	Oral Rehydration Solution and Thermometer Use <i>1 hour</i> Seeking Medical Support from a Professional Service Provider Special Medical Concerns for People Living with HIV/AIDS <i>1 hour</i>	Social Support for People Living with HIV/AIDS and Their Families Small Groups on Social Issues <i>1 hour</i> Plenary on Social Issues <i>1 hour 30 minutes</i>	Supporting Orphans <i>1 hour 30 minutes</i>	Group Action Plan <i>1 hour</i>
Lunch	<i>1 hour</i>	<i>1 hour</i>	<i>1 hour</i>	<i>1 hour</i>	<i>1 hour</i>
Session	The Life Tree Life Tree <i>1 hour 30 minutes</i>	Strategies for Dealing with Health Professionals <i>45 minutes</i> Antiretrovirals <i>30 minutes</i>	Psychological Support for People Living with HIV/AIDS and Their Families People Living with HIV/AIDS Vignettes <i>1 hour 45 minutes</i>	Creating Our Community Vision Statement Developing My Own Vision Statement <i>15 minutes</i> Creating Our Community Vision <i>1 hour 30 minutes</i>	Closing Evaluation <i>1 hour</i> String Spider Web and Closing Ceremony <i>1 hour</i>
Break	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
Session	Medical Support for People Living with HIV/AIDS Common Illnesses Role-Play <i>1 hour 30 minutes</i>	Physical Support for People Living with HIV/AIDS and Their Families Caring for People Living with HIV/AIDS in the Home <i>1 hour 30 minutes</i>	<i>The previous session can be emotional. Trainers may want to have a counselor present and use the afternoon session for this purpose.</i>	Community Mapping Creation of Community Maps <i>1 hour 15 minutes</i>	
Eval	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
Total	<i>8 hours 15 minutes</i>	<i>8 hours 45 minutes</i>	<i>8 hours 30 minutes</i>	<i>8 hours 15 minutes</i>	<i>7 hours 15 minutes</i>

Chapter 13

Creating Our Community Vision Statement

*A new generation
To protect and love
Hear them singing, playing, laughing,
Let's give them everything in truth and love
Take the message, across the frontiers,
Break the barriers; we'll fight together
The doors are open; we'll lead the struggle
We won't lie down in defeat; we'll fight on
Today it's me, tomorrow someone else
It's you and me; we've got to stand up and fight
We'll shed a light on the fight against AIDS
Let's come on out; let's stand together; fight AIDS
In times of joy, in times of sorrow,
Let's take a stand and fight on to the end
With open heart let's stand up and speak out to the world
We'll save some lives; save the children of the world.
Let's be open,
Advise the young ones.*

—PHILLY BONGOLE LUTAAYA
MUSICIAN AND ONE OF THE FIRST
HIV POSITIVE AFRICANS TO SPEAK OUT, UGANDA

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Chapter 13: Creating Our Community Vision Statement

Key Questions

- What is our community committed to doing in order to support people living with HIV/AIDS?
- What is our community committed to doing in order to support orphans and vulnerable children?
- How will our communities work together to fight the HIV/AIDS pandemic?

I ntroduction

Over the course of the HIV/AIDS pandemic, there have been many individuals who have risked everything to speak out about living with the virus. Despite stigma, discrimination, rejection by loved ones, isolation from the community—these courageous individuals chose to talk about their HIV status in an effort to help others living with the virus and to change community norms about HIV/AIDS. These heroes have made great advances in reversing discrimination, ensuring care, and focusing global attention on the pandemic.

But the real power of the early work of these pioneers lies with the mobilization of entire communities in the fight against HIV/AIDS. It is only when community members work together to emphasize prevention of HIV/AIDS, provide care and support, and advocate for the rights of the infected and affected, that true change can be achieved on a community and national scale. When community members work together, feel more empowered to speak openly about living healthy with the virus, at-risk groups feel more supported in seeking prevention methods, and orphans and vulnerable children are enabled to balance the needs of the ill with planning for their own future.

In Chapter 1, *The Power of Our Community*, participants were challenged to look at the powerful histories of their community and to bring that source of strength and hope into the fight against HIV/AIDS. This session, *Creating Our Community Vision Statement*, continues that momentum

by asking participants to imagine a successful community response to HIV/AIDS. Participants are then asked to create their own vision or mission statement for their community's response to the pandemic. The remainder of this chapter is devoted to merging these vision statements into an overall vision or mission statement for the entire community. The group commits to its community vision, and this vision statement becomes a backdrop and motivator for the group's HIV/AIDS work.

Chapter 13: Creating Our Community Vision Statement

Objectives

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

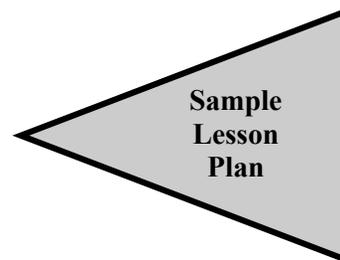
- Describe a positive vision of the future of the community
- Commit to a common vision for their community response to HIV/AIDS

Home Care: The Power of Our Community

Training Schedule: Sections 1 and 3

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Chapter 13: Creating Our Community Vision Statement



Sample Lesson Plan

Time	Content	Methodology	Materials	Evaluation
<i>20 minutes</i>	<p>Developing My Own Vision Statement</p> <p>Individual statements of a vision for the future of the community</p>	Participants generate ideas and individually write their own vision statements for the future of the community	<p>Paper</p> <p>Pens</p> <p>Flipchart paper</p> <p>Markers</p> <p>Tape</p>	Identifying important aspects of participants' personal commitment in the community vision statement developed by the end of the session
<p><i>1 hour</i></p> <p><i>40 minutes</i></p>	<p>Creating Our Community Vision Statement</p> <p>Creation of a community vision statement</p>	Participants gather in larger and larger groups to merge their vision statements; by the end of the process, one vision statement is created, to which all members of the group commit	<p>Flipchart</p> <p>Markers</p> <p>Tape</p> <p>Paper</p> <p>Pens</p> <p>Sticker symbols—enough for each participant to receive five (or pieces of colored tape)</p>	<p>Commitment to the community vision/mission</p> <p>Referring to the community vision throughout the workshop</p>

Chapter 13: Creating Our Community Vision Statement

Activities and Handouts for Creating Our Community Vision Statement

- **Developing My Own Vision Statement**
- **Creating Our Community Vision Statement**

Activity **Developing My Own Vision Statement**

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

- Describe a positive vision of the future of the community

Time allotted 20 minutes

Preparation Provide paper and pen to each participant.

Facilitation steps

1. Begin by saying that we will use our wishes and hopes for the future from the previous exercise to design a community vision or mission statement. This statement will help us direct our energies in positive ways as we begin to design an action plan around HIV/AIDS in our community. Some examples of visions for the community might be: the community cooperating together without fighting among factions, or without leaving anyone out of the discussion; or calling on the strengths of the ancestors to empower the community.
2. Ensure that each participant has paper and a pen. Say that we will begin our task of developing a community vision statement by coming up with ideas for our own personal vision statement for the community. If you were going to personally write a vision or mission, something that could really happen, for the community's response to HIV/AIDS, what would you include? What are the strengths that the community shares? What are the challenges it faces? What are your hopes for the manner in which the community will meet those challenges?
3. Ask that the participants take a few minutes to write down short responses to these questions. After organizing the most important issues to include, participants should take another 10 minutes or so to write their own version of a vision or mission statement for the community.

Wrap-up Rather than wrapping up this activity immediately move into the next phase of the activity.

Activity **Creating Our Community Vision Statement**²⁶

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

- Commit to a common vision for their community response to HIV/AIDS

Time allotted 1 hour 40 minutes

Preparation Provide plenty of paper and markers for this activity. During the early merges, participants will be using pen and paper, but as the groups get larger, they will need plenty of flipchart paper and markers. Ensure that a wall is cleared for posting the final versions of the vision statement. Provide five sticker symbols (or pieces of colored tape) for each participant.

- Facilitation steps**
1. After all participants have finished writing their own personal vision or mission statements, say that we will now begin to develop a community vision out of the many different versions that we currently have before us.
 2. Suggest that it can often be a complicated and time-consuming process to attempt to create a vision or mission statement, as it can be difficult for a large group of people to sit down and agree on exact wording. We are going to attempt to merge or combine our vision statements using a less complicated process, and we hope that this style will lead to the fullest inclusion of everyone's individual hopes for the group's vision or mission.
 3. Ask participants to form pairs. Provide extra paper to each pair, and ask each pair to attempt to merge their vision statements into one statement with which they can both agree. They should read each other's vision statements, and attempt to join the two vision statements together into one new vision or mission statement.
 4. After the pairs seem to have completed this process, bring two sets of pairs together. Now, ask the groups of four to create one vision statement out of the two vision statements that are currently before them.
 5. Continue this process, joining two groups together and asking them to merge their vision statements, until you are left with two or three vision statements. These groups should write their final vision statements in large print on flipchart paper so that everyone in the group can see them clearly.

²⁶ Adapted and reprinted with permission of Pact, Inc. *Tool #3: Appreciative Inquiry: Generating Hope in Community Response to HIV/AIDS*. (Washington, DC: Pact, Inc.)

6. Post the two or three vision statements, and provide participants with five sticker symbols or pieces of colored tape each. Provide participants with time to move to each of the vision statements and read them, or have volunteers read them out to the group. After they have finished reading all of the statements, say that they should “vote” on the vision or mission statement that they like the most. If they like some parts of one and also parts of another, they can split their votes. For example, they might put three stickers on one vision statement, and two sticker symbols on another. Or they may put all five dots on one vision statement.
7. Bring the large group back together. Note the vision statement with the most stickers. Discuss the content of that statement. If there is another statement with many stickers, ask participants to point out the parts of that vision statement that they would like included in the version that received the most votes. Be sure to ask participants if they are comfortable before you make any changes to the vision statements.

Wrap-up

By the end of this process, all participants should feel comfortable with the vision statement that has been created. Ask if all participants can commit to this vision or mission for the community’s response to HIV/AIDS. Make any last changes necessary to gain everyone’s commitment. Invite one of the participants to read the newly developed vision-statement. If some of the group members are especially creative, suggest that they re-write the new vision statement, perhaps with pictures or graphics, to post on the wall of the training room or wherever the community group meets.

Sample Community Vision (Mission) Statement²⁷

A community vision or mission statement should arise solely from the ideas of the community members. The following example is only provided as a guide for the facilitator:

“We are the people of the San River Valley. The rich earth and sparkling water of this valley are part of us and we are part of them. Neither slavery, nor war, nor disease can destroy us. Each child born in this community is a promise of the future. We mothers, fathers, children, teachers, workers, and healers are strong. We know HIV/AIDS is trying to destroy us, and we are united in our efforts to find out how this terrible disease is passed on and how to protect ourselves, and our loved ones, from infection. We believe in the strength and compassion of our neighbors and our leaders, and we will help each other care for the sick, bury the dead and take care of the children they leave behind. Together we will speak out about this killer to our local and national leaders and we will cry for help from every corner of this world. Our spirit and determination are unbreakable. We will face this killer and do whatever is called for to save our people.”

²⁷Adapted and reprinted with permission of Pact, Inc. *Tool #3: Appreciative Inquiry: Generating Hope in Community Response to HIV/AIDS*. (Washington, DC: Pact, Inc.)

Chapter 14

Community Mapping—Our Community's Resources

“When my husband died of AIDS, I found it difficult to make ends meet. I decided to grow tomatoes, but did not have enough money to start the project. When I had almost given up hope, I got into conversation with some women in my village who were in a similar situation as myself. One of them suggested we pool our resources to support one another. The plan worked out quite well. I am now able to take better care of myself and my family. Our group’s plan also ended up being an inspiration to other women in the village.”

—ANONYMOUS, TANZANIA

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Chapter 14: Community Mapping—Our Community's Resources

Key Questions

- Which of our community resources may help with the care and support of people living with HIV/AIDS and orphans and vulnerable children?
- What economic or material support exists in our community? How can we tap into it?
- In what ways can our community provide psychological, physical, medical, and social support for people living with HIV/AIDS? For orphans and vulnerable children?

Introduction

In the beginning of this training program, participants were urged to visualize their home areas at the end of a successful community response to HIV/AIDS. Using the power of past community responses to other crises, participants were encouraged to imagine that same positive energy being brought to bear on the HIV/AIDS pandemic. This session, *Community Mapping—Our Community's Resources*, is the first of two sessions that focus on the specific planning that can help to make this vision a reality.

Community mapping is a powerful tool often used in development projects for the purposes of assessment. Community members from various stakeholder groups create a map of the community that may detail property ownership, specific landmarks, health facilities, schools, and so forth. It is believed that the ways in which community groups create their maps may indicate a great deal about their priorities and the issues of particular importance to them in the community. For example, if a community group chooses to place a mosque or a church at the center of their community map, it may indicate that religion is of central importance in the lives of that group.

This session uses the tool of community mapping in a slightly different manner. Participants are divided into interest groups, focusing on specific topics around care and support of people living with HIV/AIDS and orphans and vulnerable children—for example, psychological support, medical support, and so on. They are then urged to think about the resources in the community that may be helpful in furthering their particular topic and to create a community map illustrating the people, institutions, and organizations that can be mobilized to assist with that issue. After each of the interest groups has created its particular map, all of the maps are merged together to create a guide to the many resources that can be used in the community response to care and support.

Chapter 14: Community Mapping—Our Community's Resources

Objectives

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

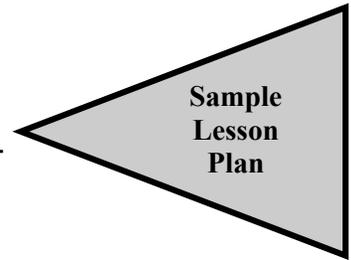
- Identify psychological, physical, medical, social, and other supports and resources for people living with HIV/AIDS in the local community
- Identify psychological, physical, medical, social, and other supports and resources for orphans and vulnerable children in the local community

Home Care: The Power of Our Community

Training Schedule: Sections 1 and 3

Schedule	Day One	Day Two	Day Three	Day Four	Day Five
	Registration <i>30 minutes</i>	Recap <i>30 minutes</i>	Recap <i>30 minutes</i>	Recap <i>30 minutes</i>	Recap <i>30 minutes</i>
Session	The Power of Our Community Introductions, Goals, and Objectives Workshop Structure <i>1 hour 30 minutes</i>	Medical Support for People Living with HIV/AIDS (cont.) Common Illnesses Role-Play <i>1 hour 45 minutes</i>	Nutritional Needs for People Living with HIV/AIDS We Are What We Eat <i>1 hour</i> Nutritional Needs for People Living with HIV/AIDS <i>1 hour</i>	Preparing for Goodbye Supporting People Living with HIV/AIDS <i>1 hour 30 minutes</i>	Merging the Community Maps <i>30 minutes</i> Action Planning for Our Community Story with a Gap <i>1 hour 30 minutes</i>
Break	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
Session	Breathe in Life, Breathe Out Trouble The Power of Our Community <i>1 hour 30 minutes</i>	Oral Rehydration Solution and Thermometer Use <i>1 hour</i> Seeking Medical Support from a Professional Service Provider Special Medical Concerns for People Living with HIV/AIDS <i>1 hour</i>	Social Support for People Living with HIV/AIDS and Their Families Small Groups on Social Issues <i>1 hour</i> Plenary on Social Issues <i>1 hour 30 minutes</i>	Supporting Orphans <i>1 hour 30 minutes</i>	Group Action Plan <i>1 hour</i>
Lunch	<i>1 hour</i>	<i>1 hour</i>	<i>1 hour</i>	<i>1 hour</i>	<i>1 hour</i>
Session	The Life Tree Life Tree <i>1 hour 30 minutes</i>	Strategies for Dealing with Health Professionals <i>45 minutes</i> Antiretrovirals <i>30 minutes</i>	Psychological Support for People Living with HIV/AIDS and Their Families People Living with HIV/AIDS Vignettes <i>1 hour 45 minutes</i>	Creating Our Community Vision Statement Developing My Own Vision Statement <i>15 minutes</i> Creating Our Community Vision <i>1 hour 30 minutes</i>	Closing Evaluation <i>1 hour</i> String Spider Web and Closing Ceremony <i>1 hour</i>
Break	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
Session	Medical Support for People Living with HIV/AIDS Common Illnesses Role-Play <i>1 hour 30 minutes</i>	Physical Support for People Living with HIV/AIDS and Their Families Caring for People Living with HIV/AIDS in the Home <i>1 hour 30 minutes</i>	<i>The previous session can be emotional. Trainers may want to have a counselor present and use the afternoon session for this purpose.</i>	Community Mapping Creation of Community Maps <i>1 hour 15 minutes</i>	
Eval	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
Total	<i>8 hours 15 minutes</i>	<i>8 hours 45 minutes</i>	<i>8 hours 30 minutes</i>	<i>8 hours 15 minutes</i>	<i>7 hours 15 minutes</i>

Chapter 14: Community Mapping— Our Community’s Resources



Sample Lesson Plan

Time	Content	Methodology	Materials Needed	Evaluation
1 hour 30 minutes	<p>Creation of Community Maps</p> <p>Graphic image of community resources in the fight against HIV/AIDS</p> <p>Gallery Walk</p>	<p>Groups create maps detailing community resources in various aspects of the fight against HIV/AIDS</p> <p>Participants then walk about the room looking at all the community maps</p>	<p>Flipchart Paper</p> <p>Markers</p> <p>Tape</p> <p>Glue</p> <p>Assorted supplies including string, buttons, rocks, leaves, and so on</p>	<p>Active participation in the session</p> <p>Community resources detailed in the action plans</p>
30 minutes	<p>Merging the Community Maps</p> <p>Discussion of community resources</p> <p>Creation of one large community map</p>	<p>Facilitator leads a discussion regarding the findings on the community maps and attempts to pull the work of all groups into one large community map</p>	<p>Large outline of the community on a flipchart</p> <p>Prepared community maps</p> <p>Flipchart paper</p> <p>Markers</p> <p>Tape</p>	<p>Active participation in the session</p> <p>Community resources detailed in the action plans</p>

Chapter 14: Community Mapping—Our Community's Resources

Activities and Handouts for Community Mapping—Our Community's Resources

- **Creation of Community Maps**
- **Merging the Community Maps**

Activity **Creation of Community Maps**

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

- Identify psychological, physical, medical, social, and other supports and resources for people living with HIV/AIDS in the local community
- Identify psychological, physical, medical, social, and other supports and resources for orphans and vulnerable children in the local community

Time allotted 1 hour 30 minutes

Preparation Clear one large wall in the training area for hanging the community maps. Ensure that groups will have enough open room at a table or along the floor to create the community maps. Collect supplies for use in mapmaking, including flipchart paper, tape, markers, glue, rocks, shells, string, buttons, leaves, and other appropriate local resources. Lastly, post the “Life Tree” (from Chapter 2) and the “Community Vision Statement” in an area of the training room that can be seen by the whole group.

Facilitation steps

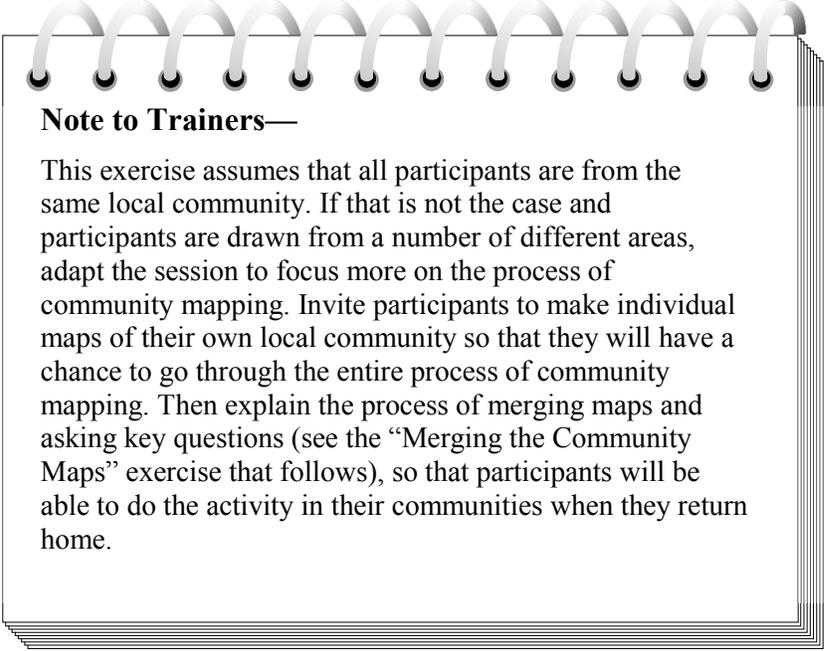
1. Referencing the “Life Tree,” briefly review the work of the group up until this point in the workshop. Suggest that we have spent a great deal of time discussing ways to support people living with HIV/AIDS and orphans and vulnerable children—psychologically, physically, medically, socially, and in preparing for death and for becoming orphans. We spent our earlier session working together on a community vision statement and reminding ourselves of difficult moments in our community’s history that we have been able to overcome. Our final sessions together will return to a focus on our community’s commitment to lessen the impact of HIV/AIDS on people living with HIV/AIDS and orphans and vulnerable children.
2. Invite participants to think about the many needs that we have identified for supporting people living with HIV/AIDS and orphans and vulnerable children during the various stages of disease progression. In thinking about the community, in which we live and work, what resources are available to help us with these various aspects of care? Certainly everyone in this room is an important resource. Are there other people, institutions, material things, or possibilities that can also serve as supports?
3. Divide the participants into six groups—psychological support, physical support, medical support, social support, dying with dignity, and working with orphans and vulnerable children. (You may need to adjust these

groups based on the number of participants.) Ensure that each of the six groups has enough supplies at their table or area to create community maps.

4. Indicate that we are going to draw maps of our community. We will begin by drawing landmarks, including churches, buildings, traditional healers, health centers, and so on. We will continue to flesh out our maps with everything that we can think of, so that we will have a mini-version of our community on the papers in front of us. While creating its map, each team should keep in mind its topic, whether it be psychological support, physical support, working with orphans and vulnerable children, and so on. Create the map thinking about all the resources that the community has available for that particular topic. Draw in or use the supplies to create the various resources in the community that can be brought to bear on that particular topic. The teams should focus only on the topic that they have been given, and each team should think about every possible available support for their topic that might exist in the community. Teams need not limit themselves to what currently exists, but may think about the specific people or organizations that may be mobilized to help with their topic. It is important that the teams be very specific about what resources exist and where, or which people or community groups living in which areas can do particular tasks to help support people living with HIV/AIDS and orphans and vulnerable children.
5. Ensure that participants understand the task, and then allow about an hour for teams to create their maps. Be sure to spend some time with each of the teams to ensure understanding of the mapping process. Remind each team to create a title for its map that includes the topic it is exploring.

Wrap-up

When all teams appear to have finished their maps, invite them to tape their maps to the blank wall. Then invite participants to spend about 15 minutes walking about the room reading and observing all of the community maps.

A graphic of a spiral-bound notebook with a white cover and a silver spiral binding on the left side. The notebook is open to a page with a white background and a thin black border. The text is written in a black, sans-serif font.

Note to Trainers—

This exercise assumes that all participants are from the same local community. If that is not the case and participants are drawn from a number of different areas, adapt the session to focus more on the process of community mapping. Invite participants to make individual maps of their own local community so that they will have a chance to go through the entire process of community mapping. Then explain the process of merging maps and asking key questions (see the “Merging the Community Maps” exercise that follows), so that participants will be able to do the activity in their communities when they return home.

Activity **Merging the Community Maps**

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

- Identify psychological, physical, medical, social, and other supports and resources for people living with HIV/AIDS in the local community
- Identify psychological, physical, medical, social, and other supports and resources for orphans and vulnerable children in the local community

Time allotted 30 minutes

Preparation To make this part of the session move a bit faster, you may wish to create a large outline of a community map posted on the wall. Another possibility would be to take the most readable, clearest community map generated by the teams and add information from all teams to that map.

Facilitation steps

1. Begin by asking participants to take their seats. Then invite any comments about the community maps and the process of creating them. What was difficult about this task? What was easy about it? Are there similarities among the maps? What stood out?
2. Using the clearest community map, or using a blank community map, begin the process of merging all maps into one. Invite one representative from each group to describe the team's map. While the representative is speaking, note important resources, support people, or other ideas on the main map. Use different colored markers to represent different topics, and draw a small key at the bottom of the map as a guide. For example, you might use blue to represent physical support, purple to represent working with orphans and vulnerable children, and so on. The aim is to make the final map easy to read and to ensure that it clearly represents the work of all of the groups.
3. After all teams have presented their maps and you have made all notes on the main map, invite the entire group to look at the main map again. Is there any overlap? Are there particular people or resources that were employed by more than one team? If there is overlap, is it possible for the same people and resources to handle the various issues, or is there a need to look further for additional support? Have we truly exhausted all possibilities for resources and support? Are there any questions that this process has left unanswered? Discuss gaps and brainstorm ways that these could be filled.

Wrap-up

Draw the session to a close when participants seem comfortable with the final map. Suggest that we will refer to this map during our next session as we begin to make specific plans to address community support for people living with HIV/AIDS and orphans and vulnerable children.

Chapter 15

Action Planning for Our Community

“Successful home and community care programs have some key characteristics. These programs—

- *Uphold the rights and dignity of people infected and affected by HIV/AIDS.*
- *Ensure involvement and active participation of family and community members, particularly people living with HIV/AIDS and affected children.*
- *Provide for equal partnership and mutual respect between the community and the facilitating NGO/CBO or government department.*
- *Improve quality of life of infected and affected family and community members, for example affected children, elderly parents, and the immediate bereaved family.*
- *Build capacity and ensure continued momentum.*
- *Build on the realities of ‘living with HIV/AIDS’ while maintaining hope based on community collective action.*
- *Maximize community use of community resources and mechanisms while identifying and using additional external ones as needed.”*

—NOERINE KALEEBA, FOUNDING MEMBER
THE AIDS SERVICE ORGANIZATION (TASO), UGANDA

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Chapter 15: Action Planning for Our Community

Key Questions

- What specific steps will we take to provide psychological support for people living with HIV/AIDS and orphans and vulnerable children in our communities? Physical and medical support? Social support?

Introduction

The second of two action planning sessions, “Action Planning for Our Community” allows participants to begin to develop specific strategies to implement care and support projects for people living with HIV/AIDS and orphans and vulnerable children. Using the same topic area as in the “Community Mapping—Our Community’s Resources” session, participant groups are invited to detail the specific steps they will take when they have returned to their larger community to implement the strategies detailed throughout the workshop. The groups are invited to see their action planning as a “story with a gap.” They are asked to first look at the state of their topic as it currently stands—for example, the psychological supports currently available to people living with HIV/AIDS and orphans and vulnerable children. They are then encouraged to remember the group vision statement—the image of a successful community response to HIV/AIDS. Their action planning will then “fill the gap” as they are invited to list the steps and strategies that could move the community from its current situation to a more positive one. This use of storytelling is especially powerful in that it allows participants to feel the positive emotions that would come with a successful response to HIV/AIDS in their areas.

Chapter 15: Action Planning for Our Community

Objectives

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

- Create an action plan for providing psychological, physical, medical, and social support in the community for people living with HIV/AIDS
- Create an action plan for providing psychological, physical, medical, and social support in the community for orphans and vulnerable children

Home Care: The Power of Our Community

Training Schedule: Sections 1 and 3

Schedule	Day One	Day Two	Day Three	Day Four	Day Five
	Registration <i>30 minutes</i>	Recap <i>30 minutes</i>	Recap <i>30 minutes</i>	Recap <i>30 minutes</i>	Recap <i>30 minutes</i>
Session	The Power of Our Community Introductions, Goals, and Objectives Workshop Structure <i>1 hour 30 minutes</i>	Medical Support for People Living with HIV/AIDS (cont.) Common Illnesses Role-Play <i>1 hour 45 minutes</i>	Nutritional Needs for People Living with HIV/AIDS We Are What We Eat <i>1 hour</i> Nutritional Needs for People Living with HIV/AIDS <i>1 hour</i>	Preparing for Goodbye Supporting People Living with HIV/AIDS <i>1 hour 30 minutes</i>	Merging the Community Maps <i>30 minutes</i> Action Planning for Our Community Story with a Gap <i>1 hour 30 minutes</i>
Break	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
Session	Breathe in Life, Breathe Out Trouble The Power of Our Community <i>1 hour 30 minutes</i>	Oral Rehydration Solution and Thermometer Use <i>1 hour</i> Seeking Medical Support from a Professional Service Provider Special Medical Concerns for People Living with HIV/AIDS <i>1 hour</i>	Social Support for People Living with HIV/AIDS and Their Families Small Groups on Social Issues <i>1 hour</i> Plenary on Social Issues <i>1 hour 30 minutes</i>	Supporting Orphans <i>1 hour 30 minutes</i>	Group Action Plan <i>1 hour</i>
Lunch	<i>1 hour</i>	<i>1 hour</i>	<i>1 hour</i>	<i>1 hour</i>	<i>1 hour</i>
Session	The Life Tree Life Tree <i>1 hour 30 minutes</i>	Strategies for Dealing with Health Professionals <i>45 minutes</i> Antiretrovirals <i>30 minutes</i>	Psychological Support for People Living with HIV/AIDS and Their Families People Living with HIV/AIDS Vignettes <i>1 hour 45 minutes</i>	Creating Our Community Vision Statement Developing My Own Vision Statement <i>15 minutes</i> Creating Our Community Vision <i>1 hour 30 minutes</i>	Closing Evaluation <i>1 hour</i> String Spider Web and Closing Ceremony <i>1 hour</i>
Break	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
Session	Medical Support for People Living with HIV/AIDS Common Illnesses Role-Play <i>1 hour 30 minutes</i>	Physical Support for People Living with HIV/AIDS and Their Families Caring for People Living with HIV/AIDS in the Home <i>1 hour 30 minutes</i>	<i>The previous session can be emotional. Trainers may want to have a counselor present and use the afternoon session for this purpose.</i>	Community Mapping Creation of Community Maps <i>1 hour 15 minutes</i>	
Eval	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
Total	<i>8 hours 15 minutes</i>	<i>8 hours 45 minutes</i>	<i>8 hours 30 minutes</i>	<i>8 hours 15 minutes</i>	<i>7 hours 15 minutes</i>

Chapter 15: Action Planning for Our Community

Sample
Lesson
Plan

Sample Lesson Plan

Time	Content	Methodology	Materials Needed	Evaluation
<i>1 hour 30 minutes</i>	Story with a Gap Action planning	Participants divide into the same groups as in Chapter 14. The facilitator tells a “Story with a Gap” about the state of the community now, and the vision of the community that the group has created. Groups must design an action plan for their topic to fill in this gap.	Flipchart Markers Tape Copies of the “Community Vision Statement” from Chapter 13 Copy of the “Community Maps” from Chapter 14	Active participation in the session Development of concrete action plans
<i>1 hour</i>	Group Action Plan Presentation of action plans	Each group “fills in the gap” by detailing an action plan for the community on their topic	Flipchart Markers Tape	Active participation in the session Development of concrete action plans

Chapter 15: Action Planning for Our Community

Activities and Handouts for Action Planning for Our Community

- **Story with a Gap**
- **Group Action Plan**

Activity Story with a Gap

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

- Create an action plan for providing psychological, physical, medical, and social support for people living with HIV/AIDS
- Create an action plan for providing psychosocial and material support for orphans and vulnerable children

Time allotted 1 hour 30 minutes

Preparation Provide each participant with a copy of the “Community Vision Statement” created in Chapter 13. In addition, post the “Community Vision Statement” flipchart on the wall, along with the “Community Maps” created in Chapter 14.

- Facilitation steps**
1. Summarize the group’s work up to this point. Suggest that we will soon bring our workshop to a close, but that first we must spend some time attempting to bring together all of our strategies and ideas into a concrete action plan for our community.
 2. Ask participants to get back into the topic teams they were a part of in Chapter 14 when we created community maps. Ensure that all of the teams have an adequate supply of flipchart paper and markers for their action planning. In addition, distribute the “Community Vision Statement” handouts.
 3. Suggest that we will structure our action planning by thinking of it as a “Story with a Gap.” We know the current situation of our communities with respect to HIV/AIDS and especially care and support. Remind the group of the conversations we had during the sessions about the pressures and problems facing people living with HIV/AIDS and orphans and vulnerable children at the current time in our communities. Use those to tell the first part of the story—the state of our communities at this moment with respect to care and support.
 4. After participants have discussed the current state of the community, invite them to take a look at the “Community Vision Statement” handout. You may wish to ask someone to read the statement aloud. Suggest that we have decided through this community vision statement and through our community mapping exercise exactly what kind of services, support, and resources we would like to provide. We have a vision for how our community will look when we have put these services, resources, and

supports into place. At the moment a gap exists between where we currently are and where we would like to be. Suggest that our action planning can list steps to fill that gap.

5. Invite teams to think about their topic areas. They should first think about the state of their topic (whether it be medical support for people living with HIV/AIDS, working with orphans and vulnerable children, and so on) at the present time. They should then think about the strategies we have discussed in the past several days to provide services, resources, and support around that topic. They will then have their “story with a gap.” They can tell a story about their topic as it stands now and about how they would like to see their topic in the future. They must now begin to fill this “gap” through action planning.
6. As groups begin to plan, encourage them to use all of the resources available from the past sessions to help them. They might reference their community maps and the specific issues we discussed around their topics. They might wish to think about the exact steps that need to be taken, the people that need to be contacted, and the tasks that need to be done in order to complete each step. Suggest that the more specific their action plans are, the more likely they will be implemented successfully. Encourage the teams to set timelines for the activities and tasks on their action plans.
7. The steps or objectives needed to reach the goal, or the way they would like to see their community in the future, must be specific and measurable. Each step or objective should be assigned to a specific person or group (one of the identified resources in the community) to be responsible for making sure that it gets done. All of these things should be written down, so that the community’s members can refer to the plan and monitor progress toward the ultimate goal. An action plan should be flexible so that one could add steps or objectives, as conditions change or unforeseen opportunities arise. Some groups have never before made an action plan; it may be useful, if this is a new concept, to distribute the handout “Action Planning Guidelines” on page 15-372 and go over the steps involved.
8. Ask participants if they have any questions. When the process is clear, invite the teams to take about one hour to create their action plans. Remind teams to choose someone to record all of their plans and someone else to report the findings to that larger group.

Wrap-up

When all teams appear to have finished their action plans, move directly into plenary.

Activity **Group Action Plan**

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

- Create an action plan for providing psychological, physical, medical, and social support for people living with HIV/AIDS
- Create an action plan for providing psychological, physical, medical, and social support for orphans and vulnerable children

Time allotted 1 hour

Preparation Bring all of the chairs into a half circle around a blank wall or a flipchart stand.

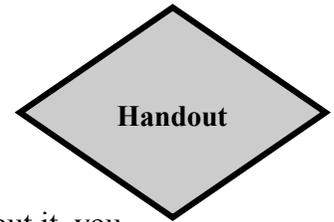
Facilitation steps

1. Invite all participants to take a seat in the large group circle. Suggest that we will take the rest of the session time to review the action plans of each group and to add any suggestions that we may have in each topic area.
2. In turn, invite a presenter from each of the teams to post the flipcharts from his or her group and to briefly describe the action plan created by the team. After each presentation, invite the larger group to give any feedback they may have about the team’s action plan. Use this time to ensure that the tasks are specific and realistic. Ask for clarification regarding time lines. Ask the group to appoint one person to be responsible to carry out these action plans—perhaps to serve as the chair of a committee on the topic, with the other team members serving on the committee.
3. Continue in this manner until all teams have had a chance to resent their action plans.

Wrap-up When summarizing the action planning session, invite each of the teams to fill in their “story with a gap.” For example, a presenter might first tell the story of the current state of care and support for orphans and vulnerable children in the community, after which he or she will quickly run through the action plans created by the team, and finally finish off with a much more positive story about the future of care and support for orphans and vulnerable children. You might suggest that the presenters tell the story as if it is something that happened in the past, so that the story will mirror the stories that were told during Chapter 13. For example, the “working with orphans and vulnerable children” team might say—

“Many years ago, our community was almost devastated by HIV/AIDS. So many parents were dying, leaving children orphaned. Extended families could no longer absorb so many children, and many of them began to live on the street. There was poverty and pain everywhere, until we decided to do something about it. The community got together and began to make plans to support these orphans. An orphan care committee was set up to raise funds for school fees. Community members shared food and resources with extended families that cared for orphans, so that the children could remain in their family homes. Teachers changed some school schedules to better help children to get a good education, and the local carpenters set up free training programs so that some orphans could learn a skill. Now, the community cares for its orphans by itself, and the orphans are helped to avoid risk behaviors and to become strong, productive members of the community.”

Action Planning Guidelines²⁸



Once you have identified an issue and made a commitment to do something about it, you need to plan what action you are going to take.

Some points to remember when making action plans—

- Plans need to be explicit and detailed. Write an action plan using lots of action words.
- A timeline must be included in the action plan. Be sure to list a start/complete date for each step in the plan. This will help everyone to keep on track. The dates can be changed or adjusted as the plan progresses.
- Assign tasks or steps to specific individuals who will be responsible for making sure that they are done on time.
- Write the action plan. This will allow members to refer to the plan and facilitate sharing information and progress. This does not mean that the plan cannot be changed as needed. Plans need to be flexible.
- Plans also need to be revised to address new or unforeseen challenges or opportunities. Monitor the organization's progress over time against the plan to appreciate what has been accomplished and determine what steps still need to be taken to reach the goal. Action planning is a process.

Action plans are designed to help you reach a goal. How you decide to go about this is your strategy. There may be many steps involved in your strategy. Breaking it down into steps and setting objectives will help. An objective is an incremental step towards your goal. Sound objectives are crucial to the planning process. Depending on its quality, an objective can bring either clarity or confusion to the rest of the planning process. A good objective is SMART.

Criteria for Setting Objectives

S - specific

M -measurable

A - achievable

R - realistic

T - time-bound

(Be sure people living with HIV/AIDS are involved in all steps.)

²⁸ The Centre for Development and Population Activities (CEDPA), *Gender, Reproductive Health, and Advocacy: A Trainer's Manual* (Washington, DC: CEDPA, 2000).

Action Planning Guidelines, continued

Sample Action Plan

Goal	Strategy	Objective	Responsibility	Timeline
Result to be achieved	Steps or activities that illustrate how to reach the goal	Specific, measurable, achievable, realistic and time-bound	Who will accomplish that objective	When the implementer will accomplish that objective

The action planning process requires cooperation among individuals and groups. Individuals may want work in small groups to determine specific activities. Groups can then meet to negotiate and agree on an action plan. It is important to write down all the steps with start/finish dates and names of the individuals responsible. The plan can be modified over time. When an activity or objective is completed, make sure to monitor the results and adjust the plan if necessary.

Appendix

Activities and Handouts for Assessment and Evaluation

- **What We Know about Home Care for People Living with HIV/AIDS**
- **Pre-Test/Post-Test Questionnaire Key**
- **Pre-Test/Post-Test Questionnaire**
- **Workshop Final Evaluation Form**

Activity **What We Know about Home Care for People Living with HIV/AIDS**

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

- Assess the base of knowledge among participants

Time allotted 20 minutes

Preparation A pre-test/post-test questionnaire and the answer keys are located at the end of this appendix. Make enough copies of the questionnaires for all the participants to fill out one of each. Some participants may not be familiar with a written testing format, so you will have to adapt the questionnaires to meet their needs. Questionnaires should be based on the content of the training. If you modify the content, you will need to modify the questionnaires to reflect the changes. The pre-test questionnaire should be handed out to participants as they arrive and they can complete it as part of the registration process. The post-test questionnaire should be distributed during the final evaluation session.

Facilitation steps

1. Pass out the questionnaires and instruct participants to answer all of the questions to the best of their ability, without discussion among themselves.
2. Before starting the introduction part of the workshop and at the end of the registration period, collect all the pre-test questionnaires.
3. At the end of the workshop, collect the post-test questionnaires in a separate envelope from the Final Evaluation forms.

Wrap-up Explain that you will look over the questionnaires, but they will not be graded or returned. Emphasize that it will help you to be a better trainer.

5. List three things that caregivers can do in the home to prevent a person living with HIV/AIDS from getting common illnesses. (Chapter 3)

Wash hands before cooking, eating, feeding another person, touching a people living with HIV/AIDS and giving medicines

Cover your mouth when sneezing or coughing

Store and cook food properly to prevent it from spoiling and causing infection

6. Name three ways to provide psychological support for persons living with HIV/AIDS. (Chapters 8)

Start a support group for people living with HIV/AIDS or orphans and vulnerable children

Counseling from a professional or spiritual counselor

Listen to their worries and fears

Help them plan for the future

7. Name three material or social needs of a person living with HIV/AIDS. (Chapter 7)

Meaningful work

Protection from stigma and discrimination

Financial loans or grants

8. Name three material or social needs of orphans and vulnerable children. (Chapters 7 and 9)

Education

Healthcare

Friendship

Play

9. Name three things a caregiver can do to help people living with HIV/AIDS to take medication and talk to healthcare workers. (Chapter 4)

Make a list of questions to ask the provider.

Make a drawing to indicate when to take medication

Keep notes about symptoms that have developed since the last visit to a health care worker.

10. Name three common illnesses of people living with HIV/AIDS that a caregiver can manage in the home. (Chapter 3)

Anxiety and depression

Coughing and difficulty in breathing

Diarrhea

Mouth and throat problems

* It is important to check the overall level of knowledge on these basic questions before the sessions on physical support for people living with HIV/AIDS. If a majority of participants cannot answer these questions correctly, you may want to include some sessions on HIV transmission and prevention from CEDPA's *Family Planning Plus: HIV/AIDS Basics for NGOs and Family Planning Program Managers Manual*.



Workshop Final Evaluation

Location: _____

Date: _____

The final evaluation form consists of several questions intended to get your assessment of the workshop, including content, structure, and methodology of the training. Please answer the questions as fully as possible. We invite your honest and candid opinions. Your input will be important for improving future workshops.

Following are the workshop objectives. Please rate how well you think the objective was achieved on a scale of 1 to 10, with 10 being “fully achieved” and 1 being “did not achieve.”

By the end of the workshop, the participants will be able to—

- a. Describe community responses to past challenges and visualize a successful community response to HIV/AIDS

1 2 3 4 5 6 7 8 9 10

- b. Describe at least five categories of needs of people living with HIV/AIDS and orphans and vulnerable children and possible community interventions to meet those needs

1 2 3 4 5 6 7 8 9 10

- c. Discuss the importance of psychological health of people living with HIV/AIDS and describe some of the issues around VCT and disclosure of status to partners and children, including potential partner violence

1 2 3 4 5 6 7 8 9 10

- d. Identify activities that pose a risk of HIV transmission and at least five examples of ways to prevent HIV infection among caregivers

1 2 3 4 5 6 7 8 9 10

- e. Describe the stages of HIV progression in the body and define related terms

1 2 3 4 5 6 7 8 9 10

- f. List at least five positive behaviors and hygienic measures in the home that can help people living with HIV/AIDS to live longer, healthier lives

1 2 3 4 5 6 7 8 9 10

g. Describe symptoms of common illnesses, suggest strategies for managing them in the home, and identify those that require medical attention

1 2 3 4 5 6 7 8 9 10

h. Describe special issues surrounding pregnancy for HIV-positive women

1 2 3 4 5 6 7 8 9 10

i. Demonstrate at least two ways to help people living with HIV/AIDS and their families to manage taking medicines at home and instructions from health care workers

1 2 3 4 5 6 7 8 9 10

j. Define “antiretroviral therapy” and list its benefits and risks

1 2 3 4 5 6 7 8 9 10

k. List strategies for helping people living with HIV/AIDS prepare to die with dignity and for helping orphans and vulnerable children to heal psychologically and emotionally after the loss of their parent(s)

1 2 3 4 5 6 7 8 9 10

l. Identify psychological, physical, medical, social, material and other supports and resources for people living with HIV/AIDS and orphans and vulnerable children in the local community

1 2 3 4 5 6 7 8 9 10

m. Create an action plan and affirm their commitment for providing support for people living with HIV/AIDS and orphans and vulnerable children in the community

1 2 3 4 5 6 7 8 9 10



Session Ratings

Please rate each session on a scale of 1 to 10, with 1 being the lowest and 10 being the highest possible rating, by writing the number in the space provided after the session title. Rate each session according to how important and useful the session was to you.

Session	Rating
1. Introductions and Workshop Structure	_____
2. The Power of Our Community	_____
3. The Life Tree	_____
4. Common Illness Role-Plays	_____
5. Special Medical Concerns for People Living with HIV/AIDS	_____
6. Antiretrovirals	_____
7. Caring for People Living with HIV/AIDS in the Home	_____
8. Nutritional Needs for People Living with HIV/AIDS and Their Families	_____
9. Group Action Plan (Social Support for People Living with HIV/AIDS)	_____
11. Psychological Support for People Living with HIV/AIDS and Their Families	_____
12. Supporting People Living with HIV/AIDS	_____
13. Supporting Orphans	_____
14. Disease Progression Review	_____
15. Strategies for Using Medications	_____
16. Creating Our Community Vision Statement	_____
17. Creation of Community Maps	_____
18. Merging Community Maps	_____
19. Story with a Gap	_____
20. Group Action Plan (Action Plans)	_____

Please make comments or suggestions about how specific sessions could be improved. If you rated any session a “5” or below, please indicate the session and briefly explain why—

(Feel free to use the back of this form.)

1. Overall, I found the workshop—

Very Useful

Useful

Not Useful

Comments

2. Which topics did you find most helpful?

1

2

3

Comments

3. Which topics did you find least helpful?

1

2

3

Comments

4. Which training activities helped you learn the most?

1

2

3

Comments

5. Was the time adequate for the workshop objectives?

Just Adequate

Too Short

Too Long

Comments

6. List the training materials that were most useful.

1

2

3

Comments

7. List the training materials that were least useful.

1

2

3

Comments

8. Are there specific ideas, tools or skills that you did not get from this training workshop that you need to improve your skills?

Yes

No

If yes, list them

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