DAY 5

◎ Care of People Living with HIV/AIDS

Day 5 focuses on people living with HIV/AIDS. The impacts of HIV/AIDS on individuals, families, communities and societies are explored. A holistic approach to care of PLWA is presented, addressing lifestyle, emotional, practical and medical needs. In addition, the role of support groups is examined, using a group of university students as a case study. At the end of the session, participants are provided the opportunity to write messages of encouragement to the student group. The course concludes by summarizing approaches to HIV/AIDS using the HIV/AIDS tree as a model.

Learning objectives

By the end of Day 5, participants will be able to:

- ◎ Explain the term "PLWA"
- ◎ Analyze the impacts of HIV/AIDS
- ◎ Describe the components of comprehensive care
- ◎ Understand issues impacting treatment options
- ◎ Appreciate the value of support groups for PLWA
- ◎ Acknowledge the role of PLWA in addressing HIV/AIDS

Resource materials

Manual:

- International Rescue Committee. (2003) Protecting the Future: HIV/AIDS Prevention, Care and Support among Displaced and War-Affected Populations. Chapters 10 and 14.

Handouts:

- Course notes: Experiences of managing a support group.
- From: EngenderHealth. (2001) HIV and AIDS online minicourse. Common side effects of antiretroviral drugs. www.EngenderHealth.org

Additional resources:

- Food and Agriculture Organization. (2002) Living well with HIV/AIDS. www.fao.org
- WHO. (undated) Caregiver booklet: A guide for patients, family members and community caregivers. www.who.int/entity/3by5/publications/documents/en/IMAI_Caregiver.pdf
- WHO. (2002) Community home-based care in resource-limited settings. A framework for action. www.who.int/entity/hiv/pub/prev_care/pub14/en
- UNAIDS. (2001) Best practice collection. Reaching out, scaling up: Eight case studies of home and community care for and by people with HIV/AIDS. www.unaids.org/html/pub/publications/irc-pub02/jc915-reachout_en_pdf.pdf
- AIDSCAP. (2003) HIV/AIDS care and support projects: using behavior change communication techniques to design and implement care and support projects. www.fhi.org/en/HIVAIDS/Publications/manualsguidebooks/BCC+Handbooks/HIV_CARESUPPORT_BCC_Hndbks.htm
- WHO. (2004) Scaling up antiretroviral therapy in resource-limited settings: treatment guidelines for a public health approach. www.who.int/entity/3by5/publications/documents/arv_guidelines/en
- UNAIDS. (2000) AIDS: palliative care. Technical update. www.unaids.org/html/pub/publications/irc-pub05/jc453-pallicare-tu_en_pdf.pdf
- International HIV/AIDS Alliance. (2000) Care, Involvement and Action: Mobilising and supporting community responses to HIV/AIDS care and support in developing countries. www.aidsalliance.org
- Family Health International. (2003) HIV/AIDS Care and Treatment: A Clinical Course for People Caring for Persons Living with HIV/AIDS. www.fhi.org/en/HIVAIDS/Publications
- WHO. (2003) Saving Mothers, Saving Families: the MTCT-Plus Initiative. www.who.int/hiv/pub/prev_care/pub40/en/
- WHO. (2003) Antiretroviral Therapy in Primary Health Care: Experience of the Khayelitsha Programme in South Africa. www.who.int/hiv/pub/prev_care/en/South_Africa_E.pdf
- International HIV/AIDS Alliance. (2003) Building Blocks: Africa-wide briefing notes, a series of booklets on psychological support, health and nutrition, economic strengthening, education and social inclusion, for communities working with orphans. www.aidsalliance.org

Teaching materials

PowerPoint:

5.4a Medical care of PLWA
5.4c Antiretroviral therapy
5.4d(i) Introduction to debate
5.4(ii) ARVs in resource-poor settings
Teaching aids Day 5

Posters:

- Infected and affected (In PowerPoint: Teaching aids Day 5)
- Holistic approach (Make from diagram in text: 5.4a)
- AIDS is not a death sentence (In PowerPoint: Teaching aids Day 5)
- Mandela's speech (In PowerPoint: Teaching aids Day 5)

Audio-visual:

- Audio CD: Tracks 09 to 16
- Video: A red ribbon around my house

Other:

- Case studies from "A Broken Landscape"
- Research on drug availability in local setting – by a participant or facilitator

DAY 5 - Session plan

Time	Topic		Materials
30 min	**5.1**	**Introduction**	HIV/AIDS tree; Flipchart
10 min	5.1a	Presentation: **Linking prevention and care**	Flipchart
	5.2	**Care of people living with HIV/AIDS**	
5 min	5.2a	Activity: **Who are PLWA?**	Flipchart; Poster: Infected and affected
	5.3	**What are the impacts of HIV/AIDS?**	
45 min	5.3a	Activity: **Understanding the impacts of HIV/AIDS**	Case studies from "A Broken Landscape"; Flipchart; HIV/AIDS tree
	5.4	**Addressing the needs of PLWA**	
30 min	5.4a	Presentation: **A holistic approach to care of PLWA**	Posters: Holistic approach; AIDS is not a death sentence; Audio CD; PowerPoint
30 min	Break		
15 min	5.4a	Cont.	
10 min	5.4b	Activity: **Assessing the availability of treatment options other than ARVs**	Flipchart; Research on local drug availability
15 min	5.4c	Presentation: **Antiretroviral therapy**	PowerPoint
30 min	5.4d(i)	Activity: **Debating the introduction of ARVs**	PowerPoint
	5.4d(ii)	Presentation: **ARVs in resource-poor settings**	PowerPoint
	5.5	**Support group case studies**	
25 min	5.5a	Activity: **UWC student group on support group**	Audio CD; Flipchart
15 min	5.5b	Activity: **UWC counselor on support group**	Audio CD; Flipchart
10 min	5.5c	Activity: **Messages to UWC group**	
60 min	Lunch		
	5.5d	Presentation: **How can we control the HIV/AIDS tree?**	HIV/AIDS tree; poster: Mandela's speech
	5.5e	Activity: **Profile of a woman living with HIV/AIDS**	Video: A red ribbon around my house
	5.5	**Conclusion**	
		Closing ceremony	

5.1 Introduction

- Brief overview of previous day with review of wall displays. Feedback on pre- and post-tests and evaluations.
- Select host team for the day
- Pre-test
- Overview of the day

5.1a PRESENTATION: *Linking prevention and care*


Presentation – 10 minutes.
Materials: Flipchart

So far, we have primarily discussed ways of preventing the spread of HIV. (Point to wall displays.) Today, we are going to focus on the care of people living with HIV/AIDS. However, prevention and care are closely linked. *(Ask participants what they see as the links.)*

Examples:

- BCC initiatives can lead people to access VCT services. Through VCT, if they are HIV-positive, people can access services for care and support. If they are HIV-negative, going through the VCT process may increase their sense of vulnerability and responsibility, and therefore may lead to safer sexual behavior.
- Well-designed BCC activities can reduce the fear and stigma surrounding HIV/AIDS, and can thus increase people's desire to know their status. Reduced stigma makes disclosure of their HIV status easier for PLWA and improves their quality of life as they become more accepted and understood in their families and communities. PLWA who have disclosed their status and are living productive lives, can have a powerful impact on increasing awareness and reducing stigma.
- Treatment of opportunistic infections and treatment of HIV using ART results in longer, healthier lives for PLWA. The fact that positive measures are available to PLWA is a powerful motivating factor for HIV testing. If HIV/AIDS is no longer seen as a "death sentence," but rather as a manageable chronic illness, stigma and fear are also reduced.
- Early diagnosis and treatment of infectious diseases that are common among HIV-infected people, e.g., STIs, TB, results in increased protection of both PLWA and the rest of the community.
- If women learn that they have HIV/AIDS through BCC programs and VCT services, they can access information and services that will reduce the chance of passing on HIV to their unborn or new-born children.
- Increased availability of care and increased visibility and acceptance of people with HIV/AIDS can make the broader population more aware of HIV/AIDS and can promote discussion and openness which in turn can increase safer behavior.
- Care and support keeps PLWA healthier longer, thus keeping families socially and economically stable and reducing the vulnerability of women and children.

An example of how prevention and care are mutually reinforcing:
In Khayelitsha, a poor neighborhood of Cape Town, South Africa, Médecins sans Frontières (MSF) provides care for PLWA through treatment of opportunistic infections and provision of ART. A recent survey of nine sites around South Africa found that Khayelitsha had the highest rates of HIV testing, and the highest levels of condom use. In the district, VCT uptake increased from fewer than 1,000 HIV tests in 1998 to more than 12,000 in 2002. The number of HIV support groups in Khayelitsha also increased dramatically from 4 in 1998 to 22 in 2002.

HIV/AIDS tree: Add prevention and care sections to HIV/AIDS tree.

5.2 Care of people living with HIV/AIDS

Activity

5.2a *Understanding the range of people impacted by HIV/AIDS*


Plenary - 5 minutes.
Materials: Flipchart
Poster: Infected/affected (In PowerPoint: Teaching aids Day 5)

Facilitator...

...asks:

Who are PLWA?

Those infected and those affected.

Who are those infected?

- People who have been diagnosed with HIV or AIDS. (Some may find the test result or clinical diagnosis so difficult to accept that they do not believe it.)
- People who have not been diagnosed but think they may be HIV positive, e.g., their partner is diagnosed with HIV; or they become ill and know enough about HIV/AIDS to suspect that this could be the cause.
- People who have no idea they have HIV. This is most people.

Who are those affected?

- Partners
- Children
- Family
- Friends
- Colleagues
- Care givers (community workers, health care workers, social workers)
- Wider community/nation
- **You and me**

5.3 What are the impacts of HIV/AIDS?

Activity

5.3a *Understanding the impacts of HIV/AIDS*



Work in small groups.
Discussion - 15 minutes. Feedback - 30 minutes.
Materials: Case study handouts
Flipchart

Case studies from "A Broken Landscape": pp. 46-47; 50-51; 60-61; 90-91; 98-99; 100-101; 104-105; 110-111; 114-115; 134-135; 152-155; 172-173.

Distribute case studies among groups.

Facilitator...

Activity 5.3a cont'd

...introduces:

Read the case studies and draw on the issues described, as well as your own knowledge and experience, to identify:

- Impacts of HIV/AIDS on emotions and mental health.
- Impacts of HIV/AIDS on families.
- Impacts of HIV/AIDS on communities and society.

Note any factors that could be particularly significant or perhaps different in conflict-affected situations.

...notes:

- **Impacts on emotions and mental health:**
  Stress, sadness, guilt, wanting to die, denial, hopelessness, anger, frustration, fear of illness and death, fear of stigma and rejection, fear about future of partner and children, fear of infecting others.
- **Impacts of AIDS on families/communities/society** (adapted from Actionaid webpage: www.actionaid.org)

Income:

- Increased consumption needs for food, medication, transport and care.
- Depleted household assets: items are often sold to pay for treatment.
- Decrease in income as people become too sick to work.
- Problems for economy with loss of workforce and productivity. (According to the World Bank, if 10 percent of adults are infected, national income growth can shrink by one-third. A recent World Bank study predicted that South Africa will face complete economic collapse within three generations if the country does not take effective measures to combat AIDS.)

Nutrition and food security:

- People with HIV/AIDS have high energy requirements and need a high-quality diet.
- Illness and reduced incomes lower the productivity of subsistence agriculture and increase food insecurity.

Education:

- The supply of education is threatened by illness and death among teachers.
- Children drop out of school to care for sick relatives or to work to compensate for income lost through family illness.

Social:

- Relationships break down.
- Stigma, discrimination and rejection: PLWA may be cast out by families or lose jobs or be refused insurance or loans; family members of PLWA may be stigmatized and isolated.
- Women take on greater burdens of caring and face greater economic insecurity when wage earners fall ill.
- Due to some local laws or customs, women may lose house or land rights when their husbands die.
- Local customs may force women to marry their husband's brother, further spreading HIV.
- Older people are often left to care for dying family members and orphans.
- There are increasing numbers of orphans and children made vulnerable by HIV/AIDS. It is estimated that AIDS has orphaned at least 14 million children in Africa. Families and communities who care for them are strained, and there are increasing numbers of child-headed households and street children.
- Children are deprived of the care and opportunities to learn skills usually acquired in supportive family and community settings.
- Girls are more likely to be kept out of school to care for sick relatives or to go to work, entrenching existing gender inequities.

Health care:

- Health care facilities become overwhelmed by AIDS patients.
- Health systems experience loss of health care workers to burnout, illness and death.
- Increased health care needs result in increased costs to governments.

Activity 5.3a cont'd

Security:

- Poverty, hunger and high numbers of street children may lead to increased crime.
- National security may be threatened by lack of development, decreasing social support, loss of confidence in the government and increasing fear and hopelessness.

Conflict-affected situations:

- The HIV/AIDS epidemic is in itself a major crisis, undermining the strength of communities' traditional coping mechanisms. When further crises such as natural disasters, crop failures, conflict and displacement are added, coping mechanisms may be overwhelmed.
- People weakened by HIV/AIDS may not be able to flee disasters, or are an added burden to family members during flight.
- Displaced people often leave home with very few possessions and thus have very little for selling or bartering to ensure survival as well as covering the additional needs of sick relatives.
- Malnutrition is often associated with conflict and displacement and further weakens the immune system of PLWA.
- Stress, overcrowding and unhygienic conditions increase vulnerability to opportunistic infections.
- However, the presence of humanitarian aid as a result of disasters can also bring opportunities to assist people affected by HIV/AIDS.

HIV/AIDS tree: Branches of tree: layer above symptoms and signs = emotions;
next layer = impacts on families; top layer = impacts on society.

5.4 Addressing the needs of PLWA

5.4a PRESENTATION: *A holistic approach to care of PLWA*

Presentation - 45 minutes. (break for tea part of the way through)
Materials: Posters: Holistic approach; AIDS is not a death sentence
(PowerPoint: Teaching aids Day 5)
Audio CD: Tracks 09 and 10
PowerPoint 5.4a&c Medical care of PLWA

(Refer to AIDS tree).

So far we have seen that PLWA have medical needs - we identified symptoms and signs on Day 1 - but PLWA also have emotional needs and practical needs.

At present there is no cure for HIV/AIDS. However, much can be done to prolong and improve the quality of life of PLWA, and to support those who are caring for them. PLWA have different needs, depending on the stage of the infection and their individual circumstances. It is important to address the needs of the whole person, rather than focusing only on medical care.

We can summarize the components of care required by PLWA as follows:

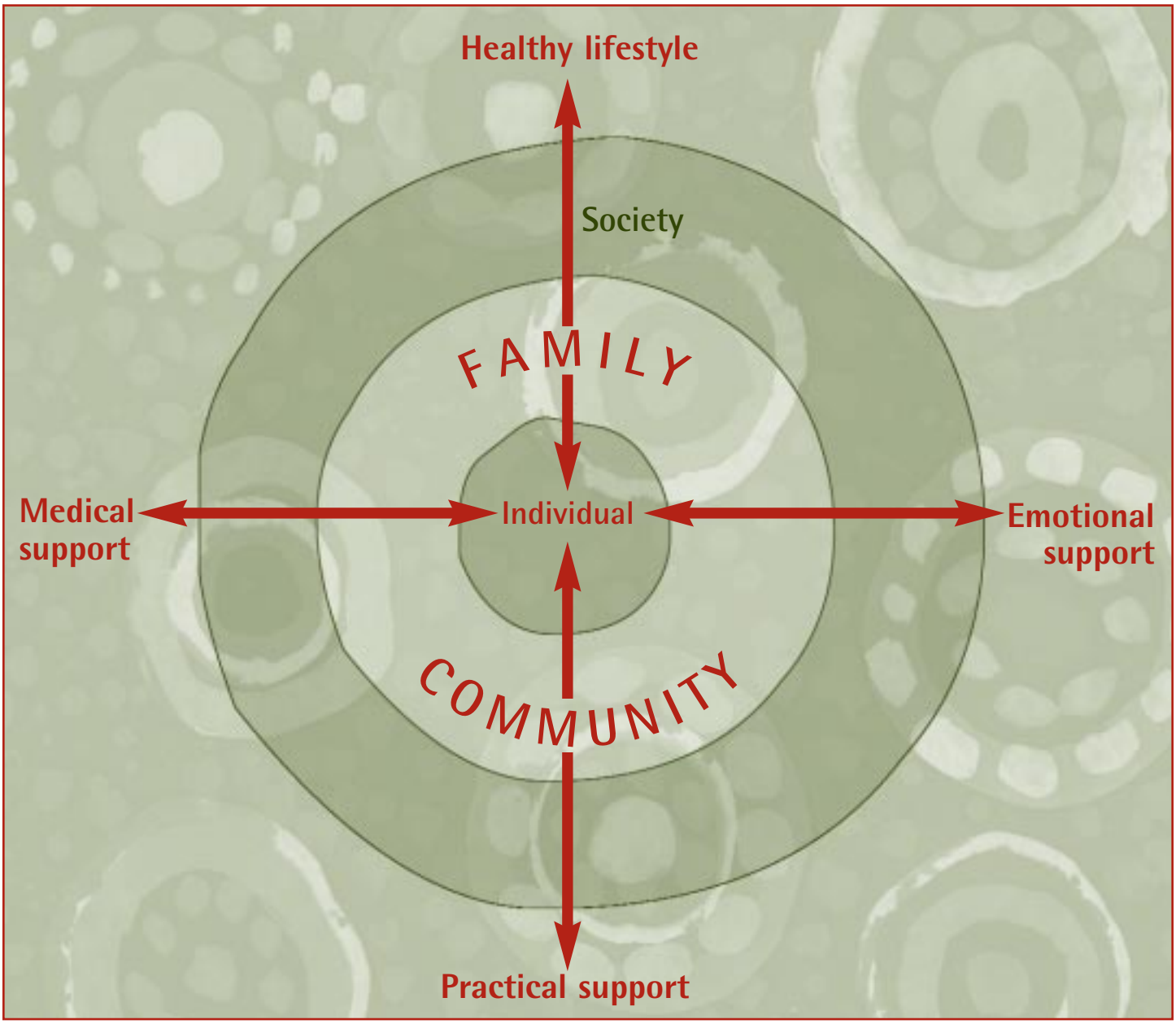
- A healthy lifestyle, including good food
- Emotional support
- Practical support
- Medical care

These components of care are necessary not only for PLWA, but for all people living with chronic illness or disability. Interventions should therefore focus on holistic care for all these groups. This reduces the possibility of stigma and also ensures care for all those in need.

On Day 1, we said that a person does not exist in isolation: a person exists within a community and within a broader society. *(Refer to levels of influence in vulnerability areas poster.)* When looking at care of people living with chronic illness, we need to look at the person themselves, their family, their community and the broader society. As before, the different levels of influence will interact with and support each other.

Make poster of diagram; add details during presentation:

COMPREHENSIVE CARE – A HOLISTIC APPROACH



We do not have the time to examine all the components of care in detail, but a range of materials is suggested for further reading. In order to achieve comprehensive care (or a "continuum of care"), various sectors of a community must be involved: health care providers, social services, community members, families and PLWA themselves. In various parts of the world, communities have worked in different ways to provide comprehensive care. A number of examples are described in the document: "UNAIDS (2001) Best practice collection. Reaching out, scaling up: Eight case studies of home and community care for and by people with HIV/AIDS." (*Refer to additional resources.*)

In some conflict-affected settings, NGOs are coordinating comprehensive care for chronically ill people, including PLWA. For example, in Lukole refugee camp in Tanzania, chronically ill patients were responsible for 30% of bed occupancy in the camp hospital. Norwegian People's AID (NPA) then introduced a home-based care program, utilizing a multidisciplinary team. Elements of the home-based care program include clinical care, nutrition care and counseling (including spiritual care), as well as education of service providers, family members and neighbors. Referrals for care come from community-based volunteers, community health workers, and clinic and hospital.

As we work through the different components of comprehensive care, consider how each component is applied or could be applied in your work situation.

1. Healthy lifestyle and environment

Although health services play an important role in the care of people who have chronic illnesses, most of the time they are cared for at home by family members, sometimes assisted by community workers. People need to know how to take care of themselves and their caregivers need to know how to assist them. *(Refer to additional resources.)*

a) Nutrition

A healthy diet can help people maintain their strength and live longer. This does not necessarily mean buying special food. People need to know how to make the best use of locally available foods.

b) Exercise

Moderate exercise helps to keep the body strong.

c) Hygiene

PLWA are very vulnerable to infection. They need to keep their bodies, clothes and houses clean to help prevent infections. Well-ventilated houses help prevent respiratory tract infections. Ensuring that drinking water is clean and that food is hygienically prepared can help prevent diarrhea. Keeping clothes and bodies clean can help to prevent skin infections and good dental hygiene can help prevent mouth infections.

d) A positive attitude *(CD: UWC Interviews Tracks 09 and 10.; Poster: "AIDS is not a death sentence")*

The students interviewed exude optimism and a zest for life that is remarkable.

These are simple measures that can make a big difference. Paying attention to these issues can also give people living with chronic illness and their families a sense of control: they are actively working to stay healthy. Families of sick people, as well as communities in general, must be educated on these simple care measures. This should be included in BCC activities, including school curricula, and should emphasize that men also have a responsibility as caregivers.
(Ask participants if any community education on care of the chronically ill is taking place in their settings.)

2. Emotional support

We saw from the case studies that living with HIV is associated with a great deal of stress, e.g., the knowledge that you are going to die; the fear of rejection; problems of poverty, etc.

Emotional support and reduction of stress have been shown to improve the physical as well as emotional well-being of PLWA and are extremely important components of care. Where can people get this emotional support?
(Ask participants for examples from their settings.)

Examples:

- Family, friends, colleagues
- Trained counselors
- Health workers
- Peer support groups
- Religious groups. It should be remembered that many people take comfort and strength from their religious beliefs and many counselors encourage this. For example, Edna is a Kenyan woman living with HIV. She was asked how she dealt with rejection from other people when they found out she was HIV positive. "…She says that it was her faith in God that has helped her, because she knows that she is never alone and always loved. She laughs when she says that she does not care what people think of her anymore – she knows that she is following the path that God intends for her…"
  (From: Orr NM / Metropolitan. (undated) Positive Life. Empowerment Concepts. Nelspruit, South Africa. p8.)

Support for caregivers:

Caregivers are often under a great deal of stress. Taking care of a person with AIDS, especially in the terminal stage, is not easy. (Ask participants to suggest sources of stress.) Caregivers are mostly women, who may have to go out to work, do house-work and take care of children as well as care for a sick person. A person with AIDS may be difficult to nurse; s/he may be bedridden, have chronic diarrhea and may be confused. Caregivers may be HIV positive themselves and also in poor health. It is very stressful to care for a dying person, and even more stressful when you know that you may die in the same way.

Interventions to assist people living with chronic illness must therefore also consider the needs of caregivers and seek ways to support them. This could include training on care of the sick person, practical support in the home, respite care and counseling.

Caring for PLWA is also stressful for health workers who may feel overwhelmed and powerless. They must be trained in the care of PLWA and provided consistent support. For example, the Mildmay Center for Palliative HIV/AIDS Care near Kampala, Uganda, holds weekly interdisciplinary meetings to discuss patients. This is helpful in allowing staff to plan together on how best to address the patients' needs. It also provides an opportunity for staff to share their emotions about the situations they face. This has been found to be a useful technique in countering burnout. (Ask participants what is done to support health workers and other caregivers in their settings.)

3. Practical support

Measures should be established to identify and assist vulnerable families.
(Ask participants for examples of what is being done in their settings.)

Examples:

- Food and shelter
- Transport
- Assistance with basic household activities such as cooking, cleaning and childcare
- Financial support and access to income generation opportunities
- Parents may need assistance in planning for the future of their children
- People may need legal assistance, for example, in drawing up a will, or protecting a widow from losing her property
- Children orphaned or made vulnerable by HIV/AIDS (OVC) must be identified and assisted

4. Medical care *(Start PowerPoint 5.4a)*

In this section we are going to look at care of PLWA using medicines. It is important to remember that medical treatment is only one aspect of care for PLWA. Treatment must always be linked to and supported by other forms of care, such as emotional support, practical support and nutrition.

When we talk about treatment for HIV, ART is often the first option that comes to mind. However, there are other forms of treatment that can prolong life and improve the quality of life, in addition to or even without ARVs. It is particularly important to emphasize other forms of treatment in settings where ARVs are not yet available.

General aims of treatment using medicines:

Curative - curing or controlling disease either temporarily or permanently
Preventive - preventing disease from occurring or becoming worse
Palliative - treating symptoms to reduce discomfort and distress

Aims of treatment using medicines in people with HIV/AIDS:

1. Alleviating symptoms, e.g., pain, loss of appetite, nausea, diarrhea, dementia
2. Curing or preventing opportunistic infections
3. Curing or controlling cancers
4. Controlling the HIV virus

a) Relief of symptoms:

It is very important that a person who is severely ill be kept as comfortable as possible, as this helps him/her to maintain his/her dignity and reduces stress. Many symptoms can be relieved using simple and inexpensive medicines like lotion for itchy skin and loperamide for chronic diarrhea. Traditional remedies may also be helpful. *(Note example of traditional healer from "A Broken Landscape")* Mental problems like confusion and depression are common among people with HIV. Alleviating these conditions greatly improves the quality of life of PLWA and their families. About 50% of AIDS patients suffer from chronic pain, often as a result of peripheral neuropathies, but also from other causes such as pressure sores and infections. In a terminally ill patient, pain should be treated aggressively with strong painkillers. (Management of symptoms is described in detail in "AIDS Palliative Care – UNAIDS.")

b) Treatment and prevention of opportunistic infections:

This is a crucial part of the care of PLWA. As HIV/AIDS progresses and the immune system becomes increasingly weakened, the person becomes increasingly susceptible to infections. *(Refer to "timeline" poster.)* Many infections, for example pneumonia and candidiasis, can easily be treated with drugs that are widely available and relatively inexpensive. It is important to help PLWA and health workers understand that these options are available.

PLWA can also take medication to protect themselves against getting infections. A daily dose of the antibiotic cotrimoxazole has been shown to prevent many infections in PLWA, including PCP, bacterial pneumonia, toxoplasmosis and a variety of gastro-intestinal infections including shigella, nocardia, isospora and salmonella. Before the introduction of ARVs in developed countries, no single medial intervention had a greater impact on the health and survival of PLWA than the use of cotrimoxazole in people with CD4 counts below 200.

WHO recommends cotrimoxazole 800mg daily for HIV-positive adults in the following circumstances:

- CD4 count below 500
- Total lymphocyte count below 2000
- No CD4 count available: treat all PLWA who have TB or who have symptomatic disease (stages 2 to 4); also treat HIV-positive pregnant women in the third trimester.

Cotrimoxazole should be taken indefinitely, as long as there are no serious side effects.

In many developing countries, TB is the most common cause of death among PLWA. It is important for the patient and the community that TB is treated properly and promptly. People with HIV can also take an inexpensive anti-TB drug called isoniazid (INH) to prevent TB, if this is part of the national TB policy.

Activity

5.4b *Assessing the availability of treatment options other than ARVs*

Plenary – 10 minutes.
Materials: Flipchart
Research on local drug availability

Facilitator...

...introduces:

On Day 1, we identified some common medical problems associated with HIV/AIDS. Now we are going to look at what we have available to treat these problems or at least alleviate the suffering they cause. One of the facilitators/course participants has done some research on drug availability in her/his community. She/he went to some drug outlets and asked whether certain drugs were available, and what they cost.

The following are some common problems, and examples of drugs that can be used to treat them. Facilitator describes availability, form and price:

Skin problems: Itchy skin: aqueous cream; calamine lotion
Fungal skin infections: miconazole cream
Bacterial skin infections: erythromycin, penicillin, cloxacillin

Respiratory tract infections: cotrimoxazole; amoxycillin; doxycycline; ciprofloxacin; anti-TB treatment
Gastrointestinal system: oral candida: nystatin; chronic diarrhea: loperamide, codeine
Central nervous system: pain, e.g., shingles: paracetamol, NSAID, codeine
STIs: ciprofloxacin, doxycycline, metronidazole, benzathine penicillin, erythromycin

What was the point of this exercise? *(Ask participants.)*

...concludes:

With this exercise, we are emphasizing that many of the common problems experienced by PLWA can be treated with locally available and relatively inexpensive medications. Just because ARVs or other expensive medications are not available, does not mean that we cannot do anything to help PLWA. It is important that health workers and PLWA understand these components of care.

5.4c PRESENTATION: *Antiretroviral therapy*

Presentation – 15 minutes.
Materials: PowerPoint 5.4c

HIV is a retrovirus. Antiretroviral drugs (ARVs) are used to treat HIV/AIDS. They cannot completely remove the virus from the body, but they can reduce the levels of the virus in the blood by preventing the virus from multiplying. This gives the immune system an opportunity to recover to some extent. People on these drugs can remain well for many years and their life can be considerably prolonged.

There are three classes of antiretroviral drugs:
1) Nucleotide reverse transcriptase inhibitors (NRTIs)
2) Non-nucleotide reverse transcriptase inhibitors (NNRTIs)
3) Protease inhibitors (PIs)

The different classes of ARVs inhibit different parts of the lifecycle of the HIV virus. Guidelines for treatment of HIV recommend lifelong triple therapy, commonly two NRTIs with a PI or NNRTI. These combinations are called "highly active antiretroviral therapy" (HAART). WHO has recently included a number of ARVs in the WHO model list of essential medicines. These medicines are considered safe and effective and appropriate for use in developing countries. However, there are many more on the market and new medicines are constantly being developed.

Further details about ARVs may be found in: *(Refer to additional resources.)*

- WHO (2004) Scaling up ART in resource-limited settings: treatment guidelines for a public health approach.
- Family Health International (2003) HIV/AIDS Care and Treatment: A Clinical Course for People Caring for Persons Living with HIV/AIDS.

Challenges related to anti-retrovirals:

- They are expensive and although prices are coming down, they are not yet affordable for most developing countries. At present the cost of antiretroviral therapy in developing countries is between $300 and $1,200 per patient per year.
- In order to be effective, the drugs have to be taken correctly 95% of the time and they must be taken for life. Compliance may be difficult.
- Unpleasant side effects may impact compliance. Side effects of ARVs include: tiredness, anemia, headache, nausea and vomiting, diarrhea, weight loss, dry mouth, rash, peripheral neuropathy, hair loss, menstrual problems, allergic reactions, liver and kidney problems.
- As some of the side effects can be potentially serious, the patient's blood counts and liver and kidney functions should be monitored regularly.
- CD4 counts and/or viral loads should be measured at intervals to see if people are responding to treatment.
- Drug resistance is a significant issue. *(What is resistance? Ask participants.)*

Resistance:

Drug resistance (also called antimicrobial resistance) means that the organism is no longer sensitive to the drug and therefore continues to multiply in the patient. Drug resistance is a very important issue in relation to HIV/AIDS. It impacts antiretrovirals, anti-TB drugs and also some of the drugs used to treat STIs.

Resistance is influenced by two factors:

1. The characteristics of the organism: some organisms become resistant more easily than others.
2. When the drug is not taken in adequate doses, is not taken at the correct time intervals and/or is not taken for a long enough time period.

If a person is only partially treated, an opportunity is created for resistance to develop. The result of this is that drugs that were commonly used are no longer effective and that different, often more expensive, drugs are needed. This has already happened with gonorrhea. In some cases, multidrug resistance develops, so that a patient does not respond to a variety of drugs, as has happened with TB and other infections such as malaria in some parts of the world. Because the HIV virus mutates rapidly in the body, it becomes resistant rapidly. (This is also the reason why it has been difficult to develop a vaccine against HIV.) Using combinations of drugs (triple therapy in the case of HIV/AIDS) reduces the risk of resistance developing, but increases costs and the potential for side effects and toxicity.

VERY IMPORTANT :

When thinking about starting an HIV, TB or STI treatment program, it is essential to consider the possible factors that would influence whether or not people are going to be able to take the drugs appropriately and ways to address these factors. *(Ask participants what the factors could be.)* Where drug resistance is a concern, at population level, no treatment is better than incorrect or inadequate treatment.

Activity

5.4d *Debating the introduction of ART*

Two groups.
Preparation – 15 minutes. Debate – 15 minutes. Facilitator's conclusion – 5 minutes.
Materials: Introduce with PowerPoint 5.4d(i): Introduction to debate; Conclude with PowerPoint 5.4d(ii): ARVs in resource-poor settings

Facilitator...

...introduces:

In September 2003, WHO declared lack of access to ARVs a global health emergency. On World AIDS Day in 2003, WHO and UNAIDS released a global initiative aiming to provide ART to 3 million people with HIV/AIDS in developing countries by the end of 2005. The costs involved in introducing ARVs are high and some have argued that these funds may be better used in other ways, for example, on prevention efforts. But, if people do not receive treatment, the ultimate costs to society could outweigh the costs of treatment.

Debate:

- Should the government provide ARVs free of charge to all PLWA?
  Alternately question, if most participants are working in refugee settings:
- Should NGOs/UNHCR provide ARVs to refugees?

...notes:

Are the following in place to allow safe and effective use of ARVs?

- VCT services
- Health workers trained in clinical management of HIV/AIDS and opportunistic infections
- Laboratory services to monitor CD4 counts and side effects of drugs
- Reliable supply system for providing drugs and laboratory supplies
- Strong social structures to help people maintain the treatment

Further points to raise:

- Feasibility issues: health system infrastructure; costs; equitable access
- Conflicting priorities: ARVs versus preventive interventions, e.g., improved STI treatment; intensive public awareness campaigns; HIV versus other health or development needs, e.g., education
- Consequences of not providing ARVs
- Refugee issues: equal treatment of refugees and host population; inclusion of refugees in host country plans to address HIV/AIDS; access to ARVs when refugees return home

...concludes: (Start PowerPoint 5.4d(ii))

There are significant challenges to providing ARVs in resource-poor settings. However, it can be done.

In Haiti, a community-based ARV program started in 1998 has been very successful. Community health workers visit patients in their villages on a daily basis to provide support and ensure that ARVs are being taken. This project has resulted in decreased mortality among PLWA as well as decreased stigma.

In Khayelitsha, an urban slum area of Cape Town, South Africa, a combined MSF/government initiative has provided ARVs since 2001. ARVs are provided through primary health care facilities and peer educators provide support to patients in their homes. The project has been very successful, with significant increases in CD4 counts, weight gain and reduction of opportunistic infections. Of an initial group of 288 patients, the median CD4 count before starting ARVs was 43. After six months on ARVs, the average increase in the CD4 count was 143. The average weight gain after 6 months was 6 kg. The incidence of TB and oral or esophageal candida decreased by two-thirds for the same group of patients when the period of treatment was compared to the same length of time before starting treatment.

5.5 Support group case studies

One of the most important aspects of care for PLWA, is involvement of PLWA themselves. PLWA have been very effective in raising awareness, in advocating for rights of PLWA, in organizing services for PLWA and in providing care and support for each other. Examples of successful PLWA organizations include the TAC (Treatment Action Campaign) in South Africa, TASO (The AIDS Support Group) in Uganda and the post-test club in Kakuma refugee camp, Kenya.

We are going to listen to perspectives from a group of people belonging to a support group at the University of the Western Cape (UWC) in Cape Town, South Africa.

Activities 5.5a to 5.5c are linked. Pauses are needed between activities for thought, questions and discussion. Participants may by now have developed an emotional involvement with the UWC group. This culminates in the writing of messages to the students. (Messages from pilot courses have been very well received by the UWC group. They feel that they are making a positive contribution to the fight against HIV/AIDS in a different part of the world.)

Activity

5.5a *UWC student group on support group*

Audio – 15 minutes; Feedback – 10 minutes.
Materials: Audio CD: Tracks 11 to 15
Flipchart

The UWC group discusses the benefits of the support group.

Participants are asked to note the most striking benefits.

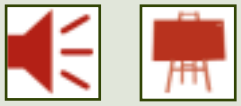
Facilitator...

...notes:

The members of the group have formed strong bonds, supporting each other through problems and celebrations. They find acceptance and understanding in the group. Many of the members say that it is the group that has given them the strength to live positively.

Activity

5.5b *UWC counselor on support group*



Audio – 6 minutes; Feedback – 10 minutes.
Materials: Audio CD Track 16
Flipchart

A counselor for the UWC group discusses issues in managing a support group.
Participants are asked to note important issues impacting the functioning of the group.

Facilitator...

...notes:

Issues include:

- Confidentiality
- Group members taking responsibility for leadership themselves
- Limiting the size of the group
- Sharing a meal
- Some members of the group take on the burdens of others – they need additional support outside of the group.
- There is a need to monitor the emotional well-being of the group – someone with counseling expertise should be available to work with them.

Activity

5.5c *Messages to PLWA group*

Individual – 10 minutes.

Participants are given the opportunity to write messages of encouragement to the UWC group. The messages can be emailed to the Cape Town group at: tvergnani@uwc.ac.za

5.5d PRESENTATION: *How can we control the HIV/AIDS tree?*

Presentation – 5 minutes.
Materials: HIV/AIDS tree
Poster: Mandela's speech (In PowerPoint: Teaching aids Day 5)

We used the HIV/AIDS tree throughout this course as a model for describing and understanding the epidemic.
The tree illustrates the many dimensions of HIV/AIDS. In order to control the growth of this tree and ultimately kill it, we need to attack it in a number of ways:

- Cut the tree down (lifestyle, support, treatment).
- Kill the roots (transmission routes).
- Take away the fertilizers (biological risk factors).
- Change the soil that nourishes it (vulnerability factors).
- Block the water supply (stigma).

Activity

5.5e *Video - A red ribbon around my house.*

Video - 30 minutes.

This video of a dynamic woman living with HIV/AIDS provides a very positive ending to the course.

5.6 Conclusion

- Post-test and daily evaluation
- Overview of course
- Course evaluation: evaluation forms and plenary discussion
- Finalize participant objectives
- Closing ceremony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