

# **Protecting the Future**

**A guide to incorporating HIV prevention and  
care interventions in refugee settings**

**International Rescue Committee**

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## **Acknowledgements**

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## Contents

### Introduction

|  |    |
|--|----|
| Why relief agencies should concern themselves with HIV prevention and care | 5  |
| Challenges in incorporating HIV prevention and care in refugee settings    | 6  |
| How to use this manual   | 9  |
| How the manual is organized  | 10 |

### **Section One: Preparing yourselves** **11**

|  |    |
|--|----|
| Introduction   | 12 |
| Chapter 1. Exploring your own knowledge, attitudes and beliefs | 13 |
| Chapter 2. Basic facts about HIV infection                     | 22 |
| Chapter 3. Thinking about the community you work with          | 34 |
| Chapter 4. What role might IRC play in the response to HIV?    | 38 |

### **Section Two: Engaging the community** **41**

|  |    |
|--|----|
| Introduction   | 42 |
| Chapter 5. Gathering information – analysing the situation | 44 |
| Chapter 6. The strategic planning process                  | 65 |

### **Section Three: What can we do to contribute to HIV prevention and care?** **78**

|  |     |
|--|-----|
| Chapter 7. Counselling for HIV prevention and care                                 | 80  |
| Chapter 8. Strategies for prevention of sexual transmission                        | 101 |
| Chapter 9. Strategies for prevention of transmission through<br>injecting drug use | 150 |
| Chapter 10. Strategies to enable people to live positively with HIV                | 160 |

|  |            |
|--|------------|
| <b>Section Four: Issues for health care services</b>                               | <b>167</b> |
| Chapter 11. Parent-to-child transmission: prevention and care                      | 169        |
| Chapter 12. Strategies for prevention of transmission through<br>blood transfusion | 190        |
| Chapter 13. Strategies for prevention of transmission in<br>health care settings   | 198        |
| Chapter 14. Providing care   | 206        |
| <b>Appendices</b>  | <b>1</b>   |
| 1. List of Abbreviations   | 2          |
| 2. Questions to assist in planning a situation analysis                            | 4          |
| 3. HIV testing strategies  | 10         |
| 4. PLA exercises for gathering sensitive information – some examples               | 12         |
| 5. Flow charts for syndromic management of STIs                                    | 16         |
| 6. Resources and references  | 25         |



## Introduction

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### **Why relief agencies should concern themselves with HIV prevention and care**

We know that when populations move in large numbers because of a crisis they are vulnerable to rapid spread of infections: to cholera, other diarrheal diseases, measles and malaria. Sexually transmitted infections (STIs), including HIV, also spread quickly among displaced populations. In crisis situations women and men are often subjected to sexual assaults, and may have to exchange sex for money or food to survive. Blood may be transfused without screening. Normal patterns of sexual behaviour are often disrupted, and young people may have sex more often and with more partners than they would in their usual circumstances. Local or international military, and the host population, may be interacting sexually with the refugee population, and may have higher rates of STIs and HIV. The purpose of providing clean water, food, shelter, measles vaccination and malaria control is defeated if the lives saved are later lost to AIDS.

The HIV epidemic presents a challenge to relief agencies both in the acute emergency phase and afterwards. During the acute emergency phase it is essential to distribute condoms, screen blood for transfusion for HIV, and try to protect refugees from rape. Once the situation is more stable relief agencies can work with the refugees to develop community-based strategies to minimize further spread of HIV and provide care and support to those affected.

Relief agencies that have been present during a crisis will be in a useful position to undertake such work. They may have gained the trust of the refugees and local population. They may have established good communication with the host government and therefore be able to advocate for effective and appropriate strategies to prevent HIV and modify the impact of the epidemic. They will be establishing a range of health, education and social activities that provide opportunities to raise awareness of HIV and reduce vulnerability. To do this their staff need to be well informed about HIV and aware of its importance.

Most conflicts are now complex and long lasting. Refugees may be in camps for many years; displaced people may return home only to be forced to move again. The IRC is now most likely to remain in a country for several years. After the period of crisis there is a need for a more community-based development-oriented approach. For this changed role staff need to have different skills and experience to those needed during a crisis, when water, sanitation, food and shelter are the priorities. Development activities are also influenced by the uncertain, artificial and temporary nature of refugees' lives, especially in camps.

In recent years there has been a new emphasis on the reproductive health needs and concerns of refugees, and on the problem of sexual and gender-based violence. A great deal has already been learnt and documented about how to tackle these sensitive issues. This experience is of great relevance to HIV prevention and care.

In some countries the impact of the HIV epidemic has been disastrous. IRC has a role in helping communities to prepare for disasters associated with large movements of refugees and internally displaced persons. It is also appropriate to assist people to prepare for and prevent the slow disaster of the HIV epidemic.

## **Challenges in incorporating HIV prevention and care in refugee settings**

### ***1. Addressing HIV in different contexts***

Successful interventions in relation to HIV prevention and care are built on an understanding of the sensitive issues of sexual behaviour, gender relations, drug use, health care and dying, as well as on technical knowledge. What is appropriate will vary with the setting. IRC works with displaced people in different contexts: reception centres; refugee camps, both new and well established; communities that host displaced people; refugee-impacted areas; and in re-settled communities. IRC works in different countries with different cultures, histories and languages, and both high and low HIV prevalence. In this manual we present up to date information, explain options for interventions, describe processes, suggest ideas, describe experiences and point the way to additional resources. We hope that this will assist IRC staff to gather information, prioritize interventions, and implement activities that will be appropriate for their context. The manual is designed primarily for the late-emergency and post-emergency phases of complex emergencies. The UNAIDS document ‘Guidelines for HIV interventions in emergency settings’ is a useful resource for the acute emergency phase.

The manual should also be a useful resource for those working towards the reconstruction of health care service systems in the aftermath of conflict; it is important to build in HIV prevention and care efforts from the start.

### ***2. Integrating HIV prevention and care with existing activities***

It is important that a manual on HIV prevention and care guidelines does not lead to the development of separate HIV projects in refugee camps or affected communities. Awareness of the risk of spread of HIV among refugees and in refugee affected areas is growing. Donors may call for proposals that address this issue. But when preparing a proposal for HIV prevention and care activities it is important to think about how these will be integrated with existing activities.

Even for refugees who are aware of HIV, the threat of a disease that may kill them in years to come is not likely to be a priority when they are struggling to survive or fatalistic about the future. However unwanted pregnancy, STIs and resulting infertility are often of great concern to them. There is no need to focus on HIV because activities that promote sexual health and prevent STIs and unwanted pregnancy will also reduce the risk of spread of HIV.

Often a great deal is already being done that contributes to the prevention of spread of HIV. This needs to be recognised. For example:

- projects that aim to increase the skills and confidence of young people can assist youth to better protect themselves from unsafe sex;
- promotion of exclusive breastfeeding helps to reduce the risk of spread of HIV from mother to child;
- income generating activities for women may help them to avoid hazardous sex work; and
- efforts to protect women from sexual violence also protect them from HIV.

The manual includes stories of relevant activities carried out in different IRC settings.

A HIV prevention and care component can often be added to existing activities.

- HIV and STI information can be a theme within projects for young people – as the topic for a play or a poster competition.
- Booklets on aspects of HIV infection can be used within literacy programs.
- There may be scope for community health workers undertaking home visits to provide one-to-one education about HIV, identify and arrange treatment for STIs, and distribute condoms.

‘Primary health care’, ‘reproductive health’, ‘maternal health’, ‘sexual and gender-based violence’, ‘family planning’ and ‘HIV/AIDS’ are overlapping categories. It is important not to develop separate programs in these areas, but to integrate activities, including the training of counsellors.

It is also important that focusing on reproductive health and HIV prevention does not divert resources away from other necessary life-saving measures.

### ***3) Coordinating and collaborating with other sectors***

At government level HIV prevention and care efforts are usually coordinated and funded through the Ministry of Health. However it is widely recognised that the factors that increase the spread of HIV concern many sectors of society and the impact of the epidemic is broad. The response to HIV needs to be intersectoral. It is important that this manual is not used only by IRC health coordinators, but also by staff working in education, welfare, children and youth programs, and with sexual and gender-based violence issues.

### ***4) Addressing controversial issues***

Planning HIV prevention and care interventions raises many controversial issues. Some behaviours and practices that increase the risk of spread of HIV may be illegal and/or stigmatized, such as sex work; injecting drug use; sex before or outside marriage; and homosexuality. Strategies to promote modifications of these behaviours in order to reduce the risk of spread of HIV may be seen by some to condone the behaviours.

Within the manual we present a number of boxes containing “Discussion points” to help to guide discussions. IRC health staff may have their own concerns about exposure to the virus; some staff may be infected. The manual emphasizes the importance of initial awareness raising and training for the IRC team, and suggests ways to explore attitudes and promote a non-judgmental and non-discriminatory approach.

### **5) *Developing an ethical and human rights framework***

Much progress has been made in recent years in linking the fields of public health and human rights. Too often strategies to prevent the spread of HIV aim to alter the behaviour of individuals, and fail to take into account sufficiently the societal factors that determine vulnerability. A human rights framework can help to generate new creative approaches to address the spread and impact of HIV.

When planning and implementing HIV prevention and care work there are ethical issues to consider in relation to:

- gathering quantitative and qualitative information,
- surveillance,
- blood screening,
- establishing voluntary counselling and testing services, and
- preventing mother to child transmission of HIV.

These ethical issues are explored in the relevant sections of the manual, with suggestions for ways to avoid causing unintended harm.

### **6) *Gender analysis***

In planning to address the problem of HIV it is important to understand the roles, responsibilities and rights of men and women, and the relationships between them. Men and women are different and play different roles in all societies, but should share equal rights and status. We need to recognise that gender roles and relationships are often changed as a result of crises, especially when refugees live for a long time in camp settings. Gender analysis involves thinking about the impact of activities on gender roles and on gender equity.

### **7) *Involving men***

Because women more often suffer the consequences of poor reproductive health they are often the focus of attention in reproductive health programs. However the reproductive health status of men has a direct effect on that of women. Many HIV interventions have failed because they have not engaged men. It is essential to consider the knowledge, attitudes and behaviours of men as well as women, and to engage men in HIV prevention and care.



## **8) Resources**

A great deal has already been learned about effective ways to respond to the HIV epidemic. It is important to learn from the experiences of others. There are many existing sources of information, resources and training materials. Indeed there are so many materials available on HIV, in journals, books and on the Internet, that it is easy to become confused. We have identified a small range of particularly useful resources to form a mini-library on HIV/AIDS for IRC staff. There are lists of additional resources at the end of chapters, and an annotated list of resources and addresses in Appendix 1. If you cannot access the Internet ask IRC staff at headquarters to obtain the information you need. The manual also includes a range of sample checklists and guidelines for different situations.

This manual aims to supplement the 1999 Inter-agency Working Group on Reproductive Health in Refugee Situations Field Manual, which has been widely used.

## **9) Coping with constraints and frustrations**

IRC staff live and work in difficult conditions. There is always too much to do, too little time, and too few resources. With competing demands it is difficult to address the spread of HIV. Interventions often concern numerous stakeholders with different points of view, and the technical issues can be difficult to understand. It is not easy to persuade people to change their behaviour. In this manual we try to acknowledge the limitations workers face and the frustrations that occur. We try to avoid telling you what you should do and instead make suggestions and give ideas.

We hope that this manual will assist you to achieve the IRC mission of improving the social, economic and health status of refugees and victims of oppression or violent conflict.

### **How to use this manual**

The manual may be used in a number of ways:

- to find suggestions for ways to integrate HIV prevention and care activities with the work that you and your team are already doing;
- to assist in planning and proposal writing for new HIV prevention and care activities;
- as a reference to check information or to point the way to other relevant resources. HIV is a rapidly changing area – the resources mentioned can help in staying up to date;
- as a source of ideas for training exercises. Although this is not a training manual there are examples of games, exercises and discussion points that can be useful in teaching, raising awareness and planning;
- to help in orientation for new staff;
- to find and photocopy checklists and guidelines that you can use or adapt for your own programs and settings.

## How the manual is organized

### 1) *Section one: Preparing yourselves*

The manual begins with a section about preparing yourself and your team. It includes ideas to stimulate discussion and explore attitudes. It provides some basic up to date information about HIV infection and answers some of the questions most frequently asked by IRC staff in the field. Then there are some suggestions for how to identify ways to integrate HIV prevention and care activities with existing activities.

### 2) *Section two: Engaging the community*

The next section deals with how to engage the local community. Different settings require different strategies. There will always be a need to gather information in a participatory way to inform local strategic planning, to consult closely with local stakeholders, and to engage community members in the response to the epidemic.

### 3) *Section three: What can we do to contribute to HIV prevention and care?*

The third section presents information about strategies and interventions that contribute to HIV prevention and care. Each has an *introduction* to describe the strategy; a *rationale* which presents the arguments and evidence for adopting the approach; a description of some possible *strategies*; some examples of appropriate evaluation *indicators* and some suggested *additional resources*. This manual does not include instructions for proposal writing or project design\*, but we hope that this structure will be useful when preparing funding proposals.

### 4) *Section four: Issues for health care services*

Although the response to the epidemic needs to be intersectoral there are some issues that are inevitably the concern of health care services, so we have placed these within one section. They include prevention of spread of the virus from mother to child, through blood transfusions, and within clinics and hospitals. The continuum of care needs to extend to home-based care within the community, but since this is most likely to be coordinated by health care services we have also included the issue of providing care, and looking after the carers, within this section.

### 5) *Appendices*

The appendices contain lists of resources and useful addresses, question guides and ideas for participatory exercises useful for information gathering, and reference material in relation to HIV testing strategies and management protocols for STIs.

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\* For this see “The Training Guide to IRC’s Program Design, Monitoring and Evaluation Framework, International Rescue Committee and Columbia University, Joseph L Mailman, School of Public Health, New York, 2000” and “IRC’s Proposal Guidelines based on the Causal Pathway.”

## **Section One: Preparing yourselves**

|   |           |
|---|-----------|
| <b>Introduction</b>   | <b>12</b> |
| <b>Chapter 1. Exploring your own knowledge, attitudes and beliefs</b> | <b>13</b> |
| <b>Chapter 2. Basic facts about HIV infection</b>                     | <b>22</b> |
| The virus   | 22        |
| Stages of infection   | 23        |
| Case definition of AIDS   | 24        |
| Prognosis   | 25        |
| Tests for HIV infection   | 25        |
| Transmission of HIV   | 26        |
| Epidemiology and surveillance   | 29        |
| Treatment for HIV infection   | 29        |
| Ten commonly asked questions  | 30        |
| Additional resources  | 33        |
| <b>Chapter 3. Thinking about the community you work with</b>          | <b>34</b> |
| Understanding vulnerability and resilience                            | 34        |
| Impact of the epidemic  | 36        |
| <b>Chapter 4. What role might IRC play in the response to HIV?</b>    | <b>38</b> |

### Introduction

The first step in planning how to incorporate HIV prevention and care is to raise awareness within your own team. Think about whether you need to include others that you work closely with, such as other NGOs or local government counterparts, at this early stage. Of course consultation with all stakeholders is essential, but it is important to prepare for this first.

You may already be undertaking HIV-related activities – but you may still like to hold one or more sessions with all the staff to make sure that all are aware and have up to date knowledge.

In these sessions you might aim to:

- Check understanding and increase people’s knowledge of HIV infection
- Answer any questions and correct common misconceptions
- Provide an opportunity for staff to explore their own attitudes and beliefs
- Think about the characteristics of the population that you work with in order to identify:
  - factors that make them vulnerable to HIV
  - strengths that may help them to protect themselves and to care for those infected, and
  - the likely impact of the epidemic
- Gather ideas for incorporating HIV prevention and care activities into your existing activities

In this section we present some ideas on how to do this, the basic facts about HIV/AIDS, and answers to some commonly asked questions.

If you will be the facilitator for these sessions we suggest that you read through the section on “basic facts” and the answers to the “commonly asked questions” before the session.

# 1

## Exploring your own knowledge, attitudes and behaviour

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IRC staff come from a variety of backgrounds, cultures and religions, and have different beliefs and attitudes. Staff often work under stressful conditions. It is important to acknowledge this and to think about possible implications for HIV prevention and care work.

Some staff may be worried about their own risk of HIV infection, and some may know that they are infected but not wish to disclose this. Take care to avoid an “us and them” tone in the discussions.

In some societies there will be an expectation that unmarried staff have no sexual experience. These staff may then feel uncomfortable discussing sexual health and sexual practices. Staff with certain religious beliefs may not be willing to promote or discuss safer sexual practices such as mutual masturbation, inter-femoral sex (sex between the thighs), or condom use because they believe the practices are immoral.

In most societies it is not culturally acceptable to talk openly about sex, especially with members of the opposite sex. It is important to begin by pointing this out and explaining that because of the spread of HIV and STIs it is important for our work that we know about and feel comfortable to discuss a wide variety of sexual behaviours, attitudes and practices. But sex is an interesting subject, and it is often surprising how willing people are to talk about sex when they are given ‘permission’.

Take into account that staff may have different cultural expectations of the roles of men and women and of what behaviour is appropriate by the different sexes and between sexes. In this environment it is easy for misunderstandings and problems to occur. With discussion such problems can often be prevented, but arrangements need to be available to manage problems in the workplace, including sexual harassment, if they do occur. It is helpful to nominate a male and a female person that staff know that they can talk to in confidence if they experience a problem with another staff member.

How many information and discussion sessions to have will depend on the experience and knowledge of the team, but it is sensible to have at least two because the first session may raise questions or issues that can be addressed at the second session. A good way to begin a session is with a game or exercise such as one of the ones below, which allow participants to check their knowledge and to start to talk about sensitive topics.



## Transmission picture card game

### *Materials:*

Two sets of 5 cards with “No risk, “Very low risk” “Low risk”, “Medium risk” and “High risk” written on them.

Two sets of picture cards. Page 15 and 16 have pictures that you can photocopy and adapt as necessary. Cut out the pictures and stick them on card. If you have time you can color the pictures and laminate them so that you have a long lasting resource for HIV training.

### *Instructions:*

On each of two tables, or on the floor, lay out the ‘risk’ cards.

Divide the participants into two teams, and give each team a set of the picture cards.

Ask the participants to discuss each behaviour or situation shown on the cards to decide in which risk category the card belongs.

When they have finished each team should look at the other’s table to see whether they agree.

Participants may argue about what the words “high risk” and low risk” mean. This is a useful discussion. Explain that in real life there are no clear-cut categories of risk – but rather a transition from low to high risk.

In discussing the picture that represents sexual intercourse they may say that they cannot decide about the level of risk because they do not know whether one of the sex partners is infected with HIV. You can point out that this is true in real life.

You might introduce the idea of ‘attributable risk’- how many of the total number of cases of HIV infection can be attributed to a particular risk factor? For example, a single act of vaginal sexual intercourse between a couple where one has HIV carries a low risk of transmission if both partners have healthy genitals. Yet heterosexual sex is undoubtedly the most common route of spread of HIV in the world. It is a common behaviour, frequently repeated. If a blood transfusion of HIV infected blood is given to a patient the risk of transmission is 100%, but this event happens less often.

Participants may also have a useful discussion about the picture of the whisky bottle. HIV does not spread through drinking alcohol or sharing glasses, but drinking may lead to unwise decisions in relation to unprotected sex or needle sharing.

Summarize the discussion at the end of the game, and have a break.









## **HIV epidemic exercise**

### *Materials:*

- One white cup for each participant
- Enough water to fill each cup one third full
- Enough starch solution to fill one or two cups one-third full
- 10 ml of polyvidone iodine 10%
- An ‘instruction’ card for each participant
- Pens to write on the cups

### *Preparation before the exercise*

Instruction cards: On one or two cards write: “Mix your water with 10 or more other people’s water”. If you have 20 participants or less, make one card with these instructions, if more than 20 make two.

On half of the remaining cards write: “Mix your water with four or five different people’s water”.

On half the remaining cards write: “Mix your water with one other person’s water. Do this with the same person four times”.

On the rest of the cards write: “Touch your glass with the glass of two or three other people. Do not mix your water with anyone.”

Starch solution: Make the starch solution by mixing half a teaspoon of clothes starch (or maize flour or cassava flour) in a cup that is one-third full of water (or water that has been used to cook rice). If you use flour instead of starch, or rice water instead of water, test that the exercise will work before the lesson.

Before the participants arrive fill one cup only one-third full with starch solution. If you have more than 20 participants, fill two cups one-third with starch solution. Fill all other cups one-third full with water.

### *Instructions:*

Introduce the exercise by explaining that the purpose is to show how rapidly HIV can spread. Explain that in this exercise mixing the water in your glass represents the sharing of body fluids that occurs during sex. Touching glasses together without mixing the water represents using a condom during sex. Explain that in the exercise, as in life, there will be some people who “have sex” with many people, and some who “have sex” with only one person. A few use condoms, but most don’t. The instruction cards will tell them which role to play. Do not mention that one of the cups is different from the others.

Adapted from “Wildfire” 1st Caribbean HIV and development workshop: Facilitators' Workbook, 1999 <http://www.undp.org/hiv/publications/>, and an idea in “Diagnosis and Treatment: a training manual for primary health care workers” Birrell K, Birrell G. 2000 MacMillan Education Ltd



Although this exercise usually leads to a lot of laughter, remember that some participants may feel awkward or embarrassed when they take part in this exercise. Also, bear in mind that one or more participants may in fact be infected with HIV. Explain that, although the exercise is fun, it has a serious purpose.

Hold the cards so that you cannot see the instructions, but make sure that you have one that says “Mix your water with 10 or more other people’s water” on the top. Give one participant the cup with the starch solution (which looks just the same as the other cups) and the top instruction card. Give all other participants cups with water and a card.

Next ask the participants to walk around the room and talk to at least four other participants. Tell them “If your card and the card of the person you are talking to tells you to mix water together, pour your water into the other cup and then pour half back into your own cup.”

After 10 to 15 minutes ask the participants to stop. Say, “Now it is three months later. You have all been counselled and decided that you would like to have an HIV test. In this exercise we represent the HIV blood test by adding drops of iodine to the water in your cup. If the water turns blue this represents a positive test result. If the water turns yellow or brown, this represents a negative result. To preserve confidentiality before you send your sample to the lab for testing please put a four letter or digit code, that you will remember, on the cup.”

Then ask the participants to put their card face down on the table with the cup on top. Put four drops of polyvidone iodine 10% into each cup. Tell everyone how many of the cups have turned blue (i.e. tested positive). Ask them to calculate what percentage this is. Read out some of the instruction cards for the positive cups and some for the negative cups. Next call out the code numbers and give each participant their cup so that they can see their ‘result’.

Tell the participants that at the beginning of the exercise only one person was ‘infected with HIV’. Ask if anyone knew who was “infected” before the exercise.

Finally ask all the participants what we can learn from this exercise. They may make some of the following points:

- Most people with HIV do not know that they are infected. They may infect a large number of other people without knowing.
- It is not possible to know from looking at a person whether they are infected with HIV or not.
- Condoms protect against HIV infection.
- If a person only has one sexual partner, they may still become infected with HIV if their partner has other sexual partners.
- People who have many sexual partners and who do not use condoms are most likely to become infected with HIV.
- The time of waiting for the HIV test result is likely to be a worrying time for people, especially if they have to keep it secret.



### **Group discussion exercise – talking about gender expectations**

This is a useful and non-threatening session that works well with a mixed group of men and women from different backgrounds.

Ask members of the group to think of rhymes or proverbs that they were taught as children that carried messages about what boys and girls, or men and women, should be like. An example from British culture is:

“Sugar and spice and all things nice, that’s what little girls are made of  
Rats and snails and puppy dog tails, that’s what little boys are made of.”

This often leads to a discussion about what the ‘real’ innate differences are between the sexes, and what differences are the result of society’s expectations. Did society’s expectations come from observations of innate gender differences? It may also lead to a discussion about how those who do not fit into gender stereotypes feel – and what reactions they trigger from other people.

If you have time you can finish the discussion by asking what might be the implications for HIV prevention.



### **Group discussion exercise – talking about sexuality and sexual health**

First introduce the exercise. “This morning we are going to talk about sex. Sex is always an interesting topic. In most societies there are taboos and unwritten rules about discussing sex. We have to agree today that although it is not usual to discuss sex in detail we are professionals who want to prevent the spread of STIs and HIV and to promote sexual health, so we need to be able to talk about sexual matters.”

Ask the participants to break into smaller groups of three or four and discuss the following questions, in relation to their own society:

- Is it easy to talk about sex? Is this different for men and for women, for different age groups?
- Where and how do we usually talk about sex?
- What are socially acceptable ways to talk about sexual intercourse? For example in English people say “sleeping with...” when they mean “having sexual intercourse with...”. Point out that the problem with this euphemism is that it may mislead or confuse – because it is possible to sleep with someone without having sex and possible to have sex without sleeping with someone!
- What does “sexual health” mean to you?



After five minutes ask the groups for their suggestions about the meaning of sexual health and write them up on a large sheet of paper. Then show a transparency or large sheet with the WHO definition of sexual health: “the integration of the physical, emotional, intellectual and social aspects of sexual being, in ways that are enriching and that enhance personality, communication and love.”

Explain that if we want to promote sexual health we need to understand sex, sexuality, sexually transmitted infections, and the social factors that influence sexual behaviour.

If education about safer sex is to be effective it has to be based on what people really do, rather than on what society says people should do. “Sexuality” is about more than sexual practices and includes the relationships in which they occur.

Next ask the groups to discuss:

- What are some of the reasons why men have sex?
- What are some of the reasons why women have sex?

After five minutes put all the reasons up on paper. Point out that there is a spectrum of what is sometimes called ‘transactional sex’. Someone may exchange sex for love, protection, financial security, luxuries, essentials such as food or clothing, or money – and this may be a single incident or a long relationship. This understanding can help to change judgmental attitudes towards sex workers.

Then ask them to discuss:

- How do children / young people learn about sex?
- How did you learn about sex yourself? Did you learn about self-confidence, respect and relationships, as well as the facts about sex?
- What sexual practices are common and acceptable for men, for women?
- How common is homosexuality? Do homosexual men tend to live with other men or do they marry but continue to have sex with other men? What are attitudes towards male and female homosexuality?
- What happens to men and women who break society’s “rules” for acceptable sexual behaviour?

After the discussion ask the participants to discuss for a moment how they felt about talking freely about sexual matters. Is it easier to talk about other people’s sexual behaviour than your own?

### ***Checking knowledge – basic facts about HIV***

To prevent the spread of HIV we have to have a good understanding of the way that the virus behaves, how it spreads, and the way that it affects the body.

“Basic facts” provides information about the virus, stages of infection, definition of AIDS, tests for HIV, transmission routes, surveillance, and treatment. More detailed information is included elsewhere in the manual. For example, “Basic facts” describes the different tests for HIV, but testing strategies are described in Appendix 3, facts about the way that the virus passes from an infected mother to her baby are described, but the interventions to prevent parent to child transmission are described in Chapter 11.

Depending on the level of knowledge of the staff you might want to go through “Basic facts”, have a question and answer session, or simply distribute the section as a hand-out. Scientists’ understanding of HIV is increasing all the time. It is important to stay up to date with these advances in knowledge. Some useful newsletters are mentioned under “Additional resources” and the websites and mailing lists are a good source of information if you have access to the Internet.

# 2

## Basic facts about HIV infection

Acquired Immune Deficiency Syndrome (AIDS) is a new and fatal disease caused by a virus called the Human Immunodeficiency Virus, or HIV. Since the early 1980s it has spread rapidly and is having a serious impact on the social and economic structure of many countries. In some areas AIDS has become a major threat to child survival. Productive young adults are becoming ill and dying, which leaves children and the elderly without support.

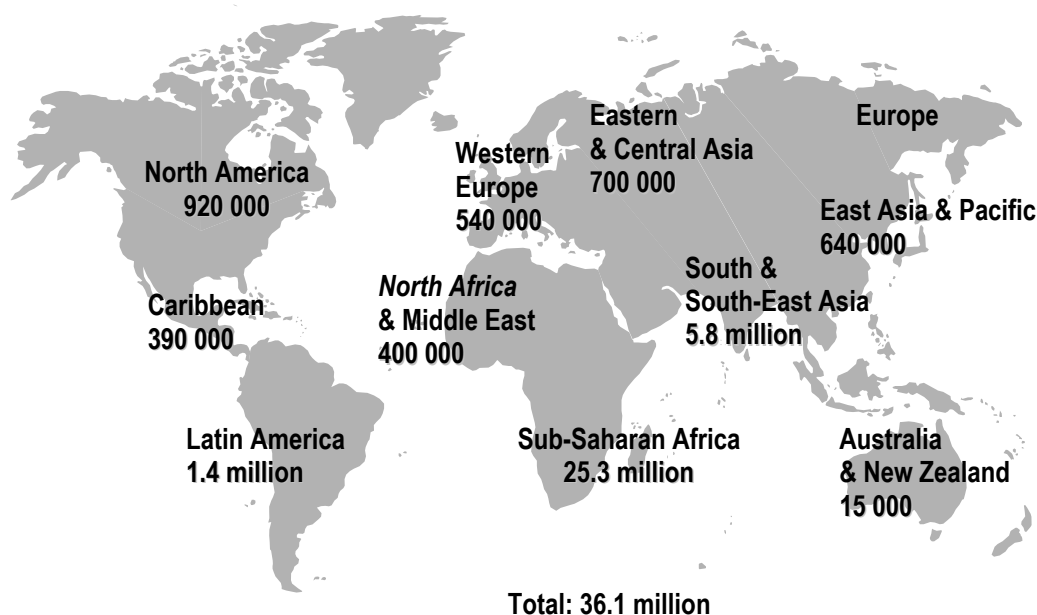


Figure 1. Adults and children estimated to be living with HIV/AIDS as of end 2000  
Source: UNAIDS, 2001

### The virus

AIDS was first described in the United States in 1981, but the virus that causes the immune deficiency was not discovered until 1983. HIV infects and damages or destroys the white blood cells of the body which make up the immune system.

Like other viruses, HIV is only able to reproduce inside the cells of the infected person. Viruses contain genetic instructions (the genome), but they lack the machinery to make new viruses. In most groups of viruses the genome remains separate from the host cell genome, and the body is able to eliminate the infection. However the genome of HIV integrates with the genome of the host cell. When the infected host cells multiply each new cell contains the HIV genome. In this way, HIV remains permanently in the infected person. When infected cells are stimulated they produce new viruses.

There are two viruses that cause immune deficiency: HIV-1 and HIV-2. In this manual we use HIV to refer to the more common virus, HIV-1. HIV-2 is transmitted in the same ways as HIV-1, but it is less infectious and infected people remain well for longer. HIV-2 was first identified in West Africa where it remains common, but it has also since been identified in many parts of the world, including Asia.

The virus is sensitive to heat and is killed at 56°C. It is only able to survive outside the body for a brief period that depends on the temperature and fluid around the virus.

## **Stages of infection**

### ***Seroconversion***

During the first few weeks after exposure to the virus, HIV multiplies rapidly. Next, usually within three months, the person starts to produce antibodies to HIV. This process is called sero-conversion. Antibodies are formed to several parts of the virus. However most of these antibodies are not neutralising antibodies; they cannot overcome the infection. The virus mutates frequently, especially the gene for the virus envelope (or coat) which is the part of the virus that the host's immune system recognises first. This makes it difficult for the antibodies to recognize and destroy the virus.

Many people experience an acute illness at the time of seroconversion, with fever and enlarged lymph glands. Some have neurological symptoms. The illness lasts about 14 days, and may be mistaken for infectious mononucleosis (glandular fever) or 'flu.

### ***Latency***

After this, most people infected with HIV have no symptoms for months or years. During this 'latency' period the virus is reproducing slowly and there are low levels of virus in the blood. The HIV antibody test is positive. Later, the number of white cells decreases, the amount of virus in the blood increases and infected people develop clinical disease. They may suffer a wide range of symptoms including loss of weight, tiredness, fever, cough and diarrhoea. The latency period is long and variable, and may range from four months to greater than 10 years. A period of three years without symptoms is typical.

### ***AIDS***

Acquired Immune Deficiency Syndrome, or AIDS, is what we call the final stage of HIV infection when the immune system is very weak. Micro-organisms are then able to take the opportunity to infect the person so these infections are called 'opportunistic'. The weak immune system may also allow cancers to develop. Tuberculosis, *Pneumocystis carinii* pneumonia, fungal infections and cryptococcal meningitis are common opportunistic infections in AIDS patients. Kaposi's sarcoma, lymphoma and cervical carcinoma are common cancers. Neurological disease, due to direct infection of brain cells by the virus, may occur early or late in the course of HIV infection. HIV infected women may also suffer from severe vaginal herpes, candidiasis (thrush), and pelvic inflammatory disease. The spread of tuberculosis is increased in the crowded conditions in which refugees often live.

After infection with HIV about one third will develop AIDS within five years; and about two thirds will develop AIDS within 12 years. A small number of HIV infected people have not developed symptoms or immune deficiency even after many years. Shorter times between HIV infection and the first signs of illness, and shorter survival times with AIDS, have been reported in poor countries in comparison with richer countries. Access to new combination anti-viral therapies and to antibiotics that prevent and treat opportunistic infections are increasing these differences.

Where laboratory resources are available doctors can measure the white cell count and the viral load to monitor the progress of the disease.

#### Discussion point

There is strong evidence that HIV is the cause of AIDS. However some people have suggested that it is not HIV that causes AIDS but poverty and abuse of drugs. HIV causes immune deficiency so people with AIDS may have very different patterns of illness because they have different opportunistic infections. This makes it easy for people to believe that AIDS is not a new and distinct disease. The way this virus behaves is not familiar to most people. But there are other viruses like HIV, that have a long incubation period before they cause illness, and that set up a permanent infection, such as hepatitis B, or herpes simplex.

In fact, of course, there are many studies from all parts of the world that prove that people with AIDS test positive for HIV antibodies and for the virus itself. The virus has been isolated from the blood and tissues of people with HIV. We can see photographs of HIV taken through a very powerful microscope. The US Centers for Disease Control and Prevention have produced a paper providing the evidence to counter some of the many myths that people believe about HIV, available at: [www.niaid.nih.gov/factsheets/evidhiv.htm](http://www.niaid.nih.gov/factsheets/evidhiv.htm)

Why do you think people believe these myths? What are the effects when policy makers hold and promote these false beliefs?

### Case definition of AIDS

The US Centers for Disease Control and Prevention (CDC) definition of AIDS is complicated and has changed several times. It depends on the diagnosis of at least one of a list of diseases that indicate immune deficiency, and includes laboratory evidence of HIV infection and a low T4 white cell count.

Where there are no facilities for the diagnosis of indicator diseases or the detection of HIV antibodies, the World Health Organization clinical definition may be used. However, this definition is not very accurate in diagnosing persons with HIV infection because it includes symptoms and signs that may be common in uninfected individuals in developing countries, such as chronic cough, weight loss and recurrent fever. Some countries use their own modification of the clinical definition.



**Table 1: WHO Guidelines for clinical diagnosis of AIDS in adults**

|   |  |
|---|--|
| <b>Major signs</b>  | <ul style="list-style-type: none"> <li>• Weight loss of over 10% of body weight</li> <li>• Fever for longer than one month</li> <li>• Diarrhoea for longer than one month</li> </ul>   |
| <b>Minor signs</b>  | <ul style="list-style-type: none"> <li>• Persistent cough for more than one month</li> <li>• General itchy skin rash</li> <li>• Recurring shingles (herpes zoster)</li> <li>• Thrush in the mouth and throat</li> <li>• Long-lasting, spreading and severe cold sores (herpes simplex)</li> <li>• Long-lasting and symmetrical swelling of the lymph glands (general lymphadenopathy)</li> <li>• Loss of memory</li> <li>• Loss of intellectual capacity</li> <li>• Peripheral nerve damage</li> </ul> |
| At least two major and at least one minor sign in an adult, in the absence of any other clear explanation for the signs (such as cancer or malnutrition), defines AIDS. |  |

## Prognosis

Where anti-viral treatment and prophylaxis for opportunistic infections are not available, people usually die within a year of diagnosis of AIDS. Where intensive monitoring and treatment are available, people with AIDS may live for many years. The main causes of death in developing countries are chronic diarrhoea, chest infection, tuberculosis, cryptococcal meningitis, and disseminated Kaposi's sarcoma.

## Tests for HIV infection

The first blood test for HIV was developed in 1985. It was a test for the antibodies to HIV, not for the virus itself. Therefore in the early stage of infection, before antibodies have been produced, it is possible for infected persons to test negative. Infected people usually test positive for HIV antibodies within one month after infection, however, in a small number of people this may take three months or more (the "window period"). When people become very ill with AIDS they may stop making antibodies to the virus so the antibody test may be negative. However they are still able to transmit the virus to other people.

### *Purposes of HIV antibody testing*

- \$ diagnosis, when a patient has signs and symptoms suggestive of HIV;
- \$ when an individual wants to know their HIV status, as part of voluntary counselling and testing services;

- \$ ante-natal screening, when interventions are available to reduce the risk of mother to child transmission;
- \$ screening of donated blood for transfusion;
- \$ surveillance, to provide data about the extent of spread of the epidemic; and
- \$ research.

The different types of HIV tests are described in Chapter 8.

## **Transmission of HIV**

HIV spreads in three ways: 1) through sexual intercourse, 2) through blood, and 3) from mother to child.

The virus is not transmitted by coughing or sneezing, shaking hands, sharing a cup or plate, hugging or kissing, insect bites, spitting, or by living or working with someone who has HIV infection or AIDS.

People are more infectious shortly after they become infected and again when they later develop the signs of damage to their immune system. This is because there is a greater viral load, or concentration of virus in the bloodstream and other bodily fluids, at these times.

The pattern of transmission depends on behaviour patterns and varies from place to place, and in different groups within a population.

### ***1) Transmission through sex***

Vaginal sexual intercourse is the most common route of transmission of HIV. Anal sex (whether male-male, or male-female) carries a higher risk of transmission than vaginal sex.

Sexually transmitted infections (STIs), especially those that cause genital sores or ulcers, increase the risk of getting and of passing on HIV for both men and women. Chlamydia and gonorrhoea, which cause a discharge, are more common than ulcerative STIs such as syphilis or chancroid. They may cause no symptoms and so remain untreated for long periods. For these reasons they may be relatively more important than ulcerative STIs in adding to the risk of transmission. Other infections of the reproductive tract, that are not necessarily sexually transmitted, including thrush (candidiasis) and bacterial infections (bacterial vaginosis) also increase vulnerability to HIV. These are common and easily treatable conditions. The probability of infection from a single act of vaginal intercourse when both partners have healthy genitals is very small – about one in 1,000. So preventing STIs and providing effective treatment are important strategies to prevent the spread of HIV.

Young women are especially vulnerable to HIV. HIV is more likely to spread when sexual activity is rough or repeated frequently. Anything that increases the risk of damage to the skin of the vagina such as the common practice of using herbs and other substances to dry and heat the vagina, or use of sex ‘toys’, is likely to increase the risk of transmission. There is evidence that uncircumcised men are at greater risk

of becoming infected with HIV than circumcised men. Both male and female condoms reduce the risk of transmission through sexual intercourse (see page 114).

## 2) *Transmission through blood*

### a) *Blood transfusion*

A transfusion of blood from a donor infected with HIV will infect the patient who receives it. Whole blood, red blood cells, platelets, and plasma may contain HIV. HIV can also be transmitted from one person to another through transplantation of any organ or tissue. Routine testing of all blood for transfusion greatly reduces the chances of transmitting HIV this way, but there always remains a small risk because of the “window period” (see page 25). Strict criteria for blood transfusion can reduce the frequency of transfusions greatly without increase in deaths. The viruses hepatitis B and C can also spread through blood transfusions.

### b) *Needle-stick injury*

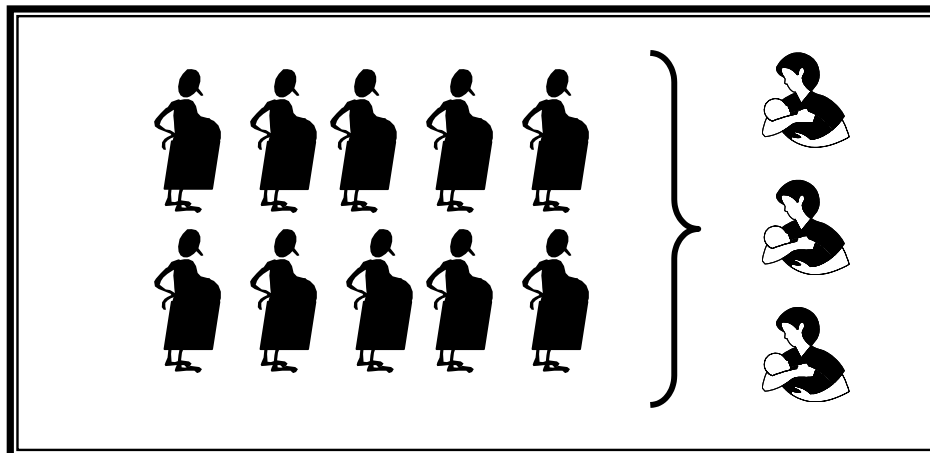
Needle-stick accidents and blood splashes to the mouth or eyes in the health-care setting may lead to the infection of health-care workers. The risk is very low, and can be reduced further by strict attention to universal infection control precautions (see page 200).

### c) *Injecting drug use*

Injecting drug use is becoming increasingly common in many countries, especially in Asia and eastern Europe. HIV, and hepatitis B and C, spread very easily between people who inject drugs together and share needles, syringes and other injecting equipment. Blood drawn back into the syringe can pass directly into the bloodstream of the next person to use the syringe, so infection is almost certain. HIV may then spread from infected drug users to others in the population through sexual intercourse.

## 3) *Transmission from mother to child*

HIV can pass from an infected woman to her baby during pregnancy, at the time of delivery or afterwards through breastfeeding. Not all babies born to a mother with HIV become infected with HIV. Of 10 infected pregnant women on average three of their babies will become infected with HIV.



In breastfeeding populations if we take 10 HIV infected babies on average two became infected during the pregnancy, five at the time of delivery and three through breastfeeding.

HIV antibodies from the mother cross the placenta to the baby so the HIV antibody test is positive at birth whether the baby is infected or not. These maternal antibodies stay in the baby for as long as 18 months, although most babies lose maternal HIV antibodies by nine months of age.

The virus is more likely to pass to the baby if the woman is newly infected. This is because the level of HIV in the blood is very high a few weeks after infection with the virus. After this the body starts to fight the virus and the level in the blood becomes very low. It usually stays low for several years. The risk of transmission to the baby is also high when the mother develops symptoms and signs of AIDS when the amount of HIV in the blood rises again.

The risk also depends on the health of the woman: it is higher when she has other infections, especially infection of the placenta and amniotic fluid, and STIs; and when there is poor maternal weight gain and micronutrient deficiencies.

The risk is increased by invasive procedures such as amniocentesis and artificial rupture of membranes. It is possible, but not yet proved, that episiotomy and certain practices of traditional midwives, such as firm abdominal massage, may increase the risk. Caesarean section performed before labor begins reduces the risk of HIV to the baby.

The baby of an HIV infected woman may remain uninfected during pregnancy and delivery but become infected through breastfeeding. Other babies become infected when their mothers become infected after the birth during the period of lactation. The only randomized controlled trial of breastfeeding versus formula was conducted in Kenya and found an increased risk of transmission in breastfed babies of 16%. The risk is higher when a woman becomes infected with HIV during the period of lactation, because of the post-infection rise in viral load. Most breast milk HIV transmission occurs early during breastfeeding, although some risk continues throughout the period of breastfeeding. Most babies born to HIV infected mothers who are breastfed do not become infected with HIV and may benefit from the general and HIV-specific antibodies in breast-milk.

The risk of infection through breastfeeding is increased by inflammation of the breast, such as mastitis or an abscess. There is evidence that exclusive breastfeeding, when the baby receives nothing but breastmilk, may be safer than mixed feeding (breast and other fluids).

There is a range of strategies to reduce the number of babies with HIV. These are described in Chapter 11.

Our knowledge about the factors that influence the risk of transmission of HIV is changing rapidly. It is important to keep up to date with changes through newsletters, journal articles and, if you are able to access it, the Internet.

## Epidemiology and surveillance

UNAIDS/WHO use the following classification to describe the HIV epidemic:

- a ‘generalized’ epidemic is one where HIV prevalence has reached at least 1% among the general population;
- a ‘concentrated’ epidemic is one where HIV prevalence has exceeded 5% among certain sub-populations; and
- a ‘low prevalence’ epidemic is one in which infection remains below 5% in any given sub-population.

Most sub-Saharan African countries suffer generalised epidemics. In many countries of the former Soviet Union and eastern Europe there are rapidly increasing epidemics concentrated among people who inject drugs. Many countries in South-East Asia currently have ‘low prevalence’ epidemics. However this may change rapidly, and there is evidence that incidence of HIV is rising rapidly in certain population groups such as sex workers and their clients, those who inject drugs and men who have sex with men. Several southern and central states of India have generalised epidemics.

Surveillance means collecting data on HIV infection rates in a systematic way so that it is possible to follow trends in the prevalence of HIV infection in different groups within a population. Surveillance data is valuable for deciding which interventions and groups to prioritise.

The pattern of HIV transmission in populations that have been forced to migrate is likely to differ from that in stable settings. Sentinel surveillance is likely to be difficult in most refugee settings because it relies on a functioning and accessible health care system and some stability in composition of the groups that are sampled over time. Suggestions for gaining information about the extent of spread of HIV in forced migrant populations are described in Section 2.

## Treatment for HIV infection

At present, there is no cure for AIDS. However there are treatments for the relief of symptoms, treatments for opportunistic infections, and an increasing range of antiretroviral drugs that attack HIV itself.

Unfortunately the countries that have the largest numbers of people infected with HIV are unable to afford the high cost of the new antiretroviral drug combinations; many cannot afford to provide treatment for opportunistic infections; and many people affected by HIV are unable to afford even medicines to relieve symptoms.

Good nursing care can do much to relieve the symptoms of HIV related disease such as fever, sweating, itching, diarrhoea, pain, headache, and cough. Local home-made remedies and traditional healers can be very helpful. Paracetamol, aspirin, oral rehydration solution, gentian violet and antiseptic cream are useful and morphine, if it is available, helps to relieve pain in dying patients at low cost (see page 210). Nutrition and food preparation advice is also important.

Treatment for opportunistic infections such as tuberculosis, diarrhoea, fungal infections and *Pneumocystis carinii* pneumonia can extend and improve the life of

people living with HIV and their family. Effective low-cost generic drugs for opportunistic infections should be on “essential drugs lists” and available to those who need them. It is important to treat tuberculosis both for the individual and the community. Thrush (candidiasis), toxoplasmosis and pneumonia can be treated at low cost, which may enable a person with HIV to live for several more years.

A person with HIV can take isoniazid to prevent tuberculosis and co-trimoxazole to prevent other bacterial infections. These are called prophylactic medicines.

Antiretroviral drugs kill HIV and so reduce the level of virus in the blood. A combination of these drugs need to be taken for life and they often have side-effects. People living with HIV/AIDS (PLWH) who are able to access these drugs can remain well for many years, although the virus remains in the body. However, despite recent price reductions these drugs remain out of reach for most PLWH (see page 218).

## **Ten commonly asked questions**

Answering these questions often provides an opportunity to explore attitudes and to correct common misunderstandings.

### ***1. Where did HIV come from?***

We are still not certain about the origin of HIV. It is likely that HIV evolved from similar viruses, called simian immuno-deficiency viruses (SIVs) found to infect monkeys. It is possible that an SIV transferred to humans in central Africa as a result of hunting and handling of chimpanzee meat. The first documented case of HIV-1 infection occurred in 1959 in a man living in what is now the Democratic Republic of Congo.

The suggestion that humans may have been infected with SIV through vaccination with a contaminated oral polio vaccine has been discounted. There is no scientific evidence that HIV came from space or from a germ warfare laboratory.

### ***2. Why didn't public health doctors isolate people with HIV from the beginning to prevent it spreading, as they do for other diseases?***

By the time that the virus that causes AIDS was identified there were already many people infected with HIV. Most people with HIV do not know that they are infected. If those known to be infected were isolated the rest of the population might feel that they are not at risk so there is no need to change high-risk behaviour or to protect themselves against infection. People would not come forward for testing if they knew that they would be isolated. Even if it were possible to screen everyone in the population at once, there would still be some infected people who test negative because of the window period. People infected with HIV usually remain well for many years. Isolating people for life is a violation of their human rights.

### ***3. Mosquitoes spread malaria and dengue fever. How do we know that they don't spread HIV?***

This subject has been carefully researched. There are several reasons why we can be sure that HIV does not spread through mosquito bites:

- Studies show that, even in places where there are lots of mosquitoes and HIV infection is common, elderly people and children often get bitten by mosquitoes but do not become infected with HIV.
- When an insect bites a person, it does not inject any blood, only saliva.
- Researchers have studied mosquitoes in the laboratory, allowing them to suck up HIV infected blood and then killing and examining them. They find that HIV cannot survive or reproduce inside the mosquito's stomach (unlike the malaria parasite). So the mosquito cannot transmit HIV to the next person it bites.
- Mosquitoes do not bite one person straight after another – they rest after they have sucked blood from one person.

#### ***4. When will we have a vaccine for HIV? Why is it taking researchers so long?***

Although research laboratories around the world are trying to develop vaccines against HIV a safe, reliable vaccine is unlikely to become available for many years. Researchers are trying to develop two types of vaccine: one to prevent infection with HIV and the other to prevent progression to AIDS once someone is already infected with the virus.

Vaccines usually work by making the body produce antibodies which attack the virus or bacteria. The envelope pattern of HIV mutates (changes) frequently. Antibodies are unable to recognize the virus, so they cannot attack it.

Once a vaccine is developed there are many problems to overcome, including testing of the vaccine and effective distribution. These involve many complex ethical, legal and socio-political issues. The International AIDS Vaccine Initiative is working to evaluate trial vaccines and to provide up to date information on the progress of vaccine development. (Web-site: <http://www.iavi.org>)

#### ***5. How is it possible that there are couples where the husband is infected and the wife is not, or where the wife is infected and the husband is not?***

There are many cases of couples where one has the virus and the other has not, even though they have had sex many times. The risk of transmission through sex is very low when there are no STIs and when sexual practices do not damage the skin of the genital organs. Some people have a lower risk than others of becoming infected after being exposed to HIV. This may be related to the strain of the virus, the level of the person's immune system, and genetic factors that are not yet well understood. When a couple is tested and one is found to be infected with HIV, it is important to recommend condom use during sex and to explain that although the partner has not yet become infected this does not mean that it could not happen.

**6. *Is it true that an infected man is more likely to pass on HIV than an infected woman?***

Studies from Europe suggested that HIV passes from an infected man to a woman during sex more easily than it passes from an infected woman to a man. However a large study from Uganda found the opposite<sup>1</sup>.

**7. *How can it be that some babies born to HIV infected women are not infected with HIV?***

Many people assume that all babies born to a mother infected with HIV will also be infected with HIV because they think that the baby shares the same blood supply as the mother in the womb. In fact the blood circulation of the growing baby and of the mother are separated in the placenta by a layer of cells. Oxygen, food, antibodies and some medicines can pass across this cell barrier, but usually HIV does not. If the placenta is inflamed or damaged it is easier for the virus to cross the cell barrier and the risk that the baby will be infected increases. There is often some mixing of the baby's and mother's blood at the time of delivery so this is the time when HIV transmission is most likely to occur. But most babies of HIV positive women do not become infected with HIV.

Factors that increase the risk of transmission of HIV from mother to baby are described in "Basic facts".

**8. *Once a person has tested positive for HIV, can they become negative again – even without treatment?***

HIV, unlike most viruses, sets up a permanent infection in the body. The genetic material of the virus merges with the genetic material of the host cells. A positive test for HIV means that the person has antibodies to HIV. It is possible, although rare, to have a false positive result. If this happens another test in the future might test negative.

But if a person is infected then the HIV test will usually stay positive. Sometimes the immune system can be so damaged by HIV that the person stops making antibodies to HIV and the test may become negative, even though the person is still infected and able to infect others.

A few people infected with HIV continue to have a positive antibody test, but remain well for much longer than the average. It may be that some people are able to keep HIV at such low levels in their body that they never develop signs and symptoms of HIV-related immune deficiency.

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<sup>1</sup> Gray RH, Wawer MJ, Brookmeyer R, Sewankambo NK, Serwadda D, Wabwire-Mangen F, Lutalo T, Xianbin Li, Thomas vanCott T, Quinn TC, and the Rakai Project Team. Probability of HIV-1 transmission per coital act in monogamous, heterosexual, HIV-1-discordant couples in Rakai, Uganda Lancet 2001; 357: 1149-53.



**9. How reliable is the HIV antibody test? I heard that it can be positive if you've had measles.**

The first antibody tests used mashed up HIV. They cross-reacted with many other antibodies which resulted in a high rate of false positives. People who had had multiple infections in the past were more likely to test positive, so there were more false positive results in African than in European populations. Newer tests use genetically engineered components of HIV and have fewer false positives.

The first objective of developing a test for HIV was to screen blood for transfusions. The cut off point for the test was therefore designed to decrease the chance that an infected sample would falsely test negative, that is, the test needed to be very sensitive. Tests that are very sensitive tend to be less specific and result in higher rates of false positives. Modern antibody tests are very sensitive and very specific.

**10. Why won't a complete transfusion of blood, like an exchange transfusion for a jaundiced baby, cure someone with HIV?**

HIV infects white cells in the blood, but the virus does not stay only in the blood. The virus spreads to other parts of the immune system, including the lymph nodes, the spleen and the liver. The virus can also infect cells in the brain and in the gut. So even if you could completely change the blood in the body this would not cure the person and HIV in the person's body would soon enter the blood stream again.

**Additional resources**

UNAIDS. HIV/AIDS: the global epidemic. UNAIDS, Geneva. 1996. (and 'update December 1998') Summarizes the status and trends of the epidemic. Includes global/regional estimates and selected examples on the epidemic in specific countries/regions. [www.unaids.org/publications/documents/epidemiology/index.html](http://www.unaids.org/publications/documents/epidemiology/index.html)

UNAIDS. Trends in HIV incidence and prevalence: natural course of the epidemic or results of behavioral change? UNAIDS in collaboration with Wellcome Trust Centre for the Epidemiology of Infectious Disease. UNAIDS, Geneva. June 1999.

WHO. WHO Fact sheets on HIV/AIDS for nurses and midwives  
[http://www.who.int/HIV\\_AIDS/Nursesmidwivesfs/index.html](http://www.who.int/HIV_AIDS/Nursesmidwivesfs/index.html).

**Useful web-sites:**

WHO. Sexually Transmitted Infections  
(<http://www.who.int/emc/diseases/hiv/index.html>) This WHO Communicable Disease Surveillance and Response site includes information on HIV/AIDS and sexually transmitted infections as well as links to many other AIDS-related sites.

AEGIS. AIDS Education Global Information System (AEGIS):  
<http://www.aegis.com/aegis/aidslines/>

CDC. Division of HIV/AIDS Prevention (DHAP)  
[www.cdc.gov/nchstp/hiv\\_aids/dhap.htm](http://www.cdc.gov/nchstp/hiv_aids/dhap.htm)

# 3

## Thinking about the communities you work with

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### Understanding vulnerability and resilience

HIV spreads through the behaviors of individuals, but these behaviors are influenced by the social and cultural context. To plan for prevention and care we need to understand this context and how the community is affected by displacement due to armed conflict. The impact of displacement may lead to behaviors that increase vulnerability to HIV, and affects the way that the community responds to the epidemic.

IRC staff work in a wide range of contexts. The effects of displacement will depend on the refugee population's culture, and their current situation and composition, experiences during the conflict, length of time since they were displaced, the status of the conflict that led to their displacement, and their prospects for returning home. In resettled communities the morale and outlook of the population will depend on whether they feel defeated, or victors.

Ask the team to think about the consequences of displacement for the people that they work with (including the host population). Make a list of these down the left-hand side of a large sheet of paper. Then ask what effects these may have on refugees. Write these characteristics to the right of the list of consequences. Page 34 shows the outcome of one team of staff's discussion.

In such environments behaviours that facilitate the spread of HIV and STIs are likely to be common. Social life is disrupted, along with the usual patterns of sexual behaviour. There is likely to be a lack of opportunities for social activities that enable men and women to meet in culturally acceptable ways. There may be an increase in casual sex, sex in exchange for food, goods or protection, coerced sex, commercial sex, and high rates of sexual assault and rape. Local or international military, and the host population, may be interacting sexually with refugees, and may have higher rates of sexually-transmitted infections and HIV. Blood may be transfused without screening, and access to health care is limited. There may be excessive use of drugs and alcohol, and anti-social behaviour such as stealing, vandalism and violence.

The roles and responsibilities of men and women, and the relationships between them, are often dramatically altered when populations are displaced as a result of conflict. Nevertheless both men and women continue to be influenced by the gender roles and relations that prevailed in their own communities. It is important to think about the differences in impact of displacement for men and for women.

Women's reproductive health and vulnerability to STIs and HIV are greatly affected by men, whose behaviour is influenced by their experiences during and after armed conflict. Men may be traumatized by torture or rape, feel guilty because they failed to protect their family, or perhaps committed atrocities themselves. They may be depressed, lonely and bored. Men generally have few emotional outlets, and lose their role in refugee camps while women's work of caring for children, cleaning,



## Understanding vulnerability to HIV

| <i>Consequences of displacement due to armed conflict</i>  | <i>Characteristics</i>   |
|--|--|
| <p><i>Multiple losses</i></p> <ul style="list-style-type: none"> <li>- <i>deaths of family/friends</i></li> <li>- <i>home</i></li> <li>- <i>land</i></li> <li>- <i>job/school</i></li> </ul>   | <p><i>sadness</i><br/><i>bereavement</i><br/><i>depression</i></p>             |
| <p><i>Uncertain future</i></p>   | <p><i>fatalism</i><br/><i>desire to go home</i><br/><i>short-term view</i></p> |
| <p><i>Loss of legal status; rights; autonomy</i></p>   | <p><i>apathy</i><br/><i>fear</i></p>   |
| <p><i>Dependence on camp routines and regulations</i></p>  | <p><i>insecurity</i><br/><i>anxiety</i><br/><i>loneliness</i></p>              |
| <p><i>Breakdown of family and social structures</i></p> <ul style="list-style-type: none"> <li>- <i>increase in proportions of single men, and women-headed households</i></li> </ul>  | <p><i>suspicion</i><br/><i>lack of trust</i><br/><i>lack of respect</i></p>    |
| <p><i>Impoverishment</i></p>   | <p><i>hunger</i></p>   |
| <p><i>Loss of services</i></p>   | <p><i>poor health</i></p>  |
| <p><i>Suffered traumatic events:</i></p> <ul style="list-style-type: none"> <li>- <i>captivity</i></li> <li>- <i>rape</i></li> <li>- <i>torture</i></li> <li>- <i>witnessed deaths</i></li> <li>- <i>committed atrocities</i></li> </ul> | <p><i>stress</i><br/><i>numbness</i></p>                                       |
| <p><i>Lack of meaningful activity</i></p>  | <p><i>guilt</i></p>  |
| <p><i>New influences</i></p>   | <p><i>boredom</i><br/><i>aggression</i><br/><i>frustration</i></p>             |
|  | <p><i>risk-taking</i></p>  |

cooking and collecting fuel continues. One man in a camp in Tanzania said “UNHCR is now my wife’s husband”.

Similarly the impact will be different for different age groups. Encourage the group to discuss differences between how children, young people, adults, and the elderly, experience the changes forced on them by displacement.

Consider whether there are any strengths or positive outcomes from the community’s experiences. These might include:

- feelings of belonging and solidarity within the group – shared sense of identity
- awareness of resilience and ability to endure
- strong women – women’s role maintained
- increased opportunities for women to be independent
- time to be involved with communication and behaviour change activities, and with care for those infected and affected.

Finally ask the team to think about the attitudes and behaviour of the host population in relation to the refugees. Are they sympathetic and supportive, or resentful of the resources and services provided for the refugees?

Although it is important to have an understanding of the culture and characteristics of the community we should be careful not to stereotype people. Ask the staff to think about how well they fit within their own culture. Few people think of themselves as typical.

Once you have built up a picture of the impact of displacement on the community, invite the staff to get into smaller groups. Ask them to discuss the implications of these characteristics for the community’s vulnerability to HIV and for their capacity to respond.

### ***Impact of the epidemic***

The impacts of the epidemic depend on the prevalence and pattern of HIV infection among the refugees, and in the host population.

For political reasons it is often difficult to obtain information about rates of HIV amongst refugees. If information exists it may be difficult to access. Surveillance studies may not have been carried out for logistical reasons, or out of fear that the host government or resettlement countries might not accept refugees if they fear that they may have HIV.

Some assessment of the likely prevalence of HIV may be made by considering:

- the rate in the population that the refugees have come from,
- the rate, if known, in the host population, and
- other markers of risk such as high rates of sexually transmitted infections, or injecting drug use.

Ask the staff to think about likely impacts in the setting in which you work. These might include:

- Increased burden of illness
- Decreased ability to work – whether subsistence farming or paid jobs
- Possibility of spread of tuberculosis if many people have HIV-related immune deficiency
- Increased need for health care services and medicines
- Strain on already stretched health care workers and counsellors
- Increased burden on women caring for sick relatives or children
- Increased numbers of orphans needing care
- Increased vulnerability of young people left without parents
- Emotional and mental health problems caused by discrimination and stigma
- Fear of rejection by host country, home country, or resettlement country

# 4

## What role might IRC play in the response to HIV?

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Take some time to discuss what role the IRC team might play in response to the needs for HIV prevention and care. This will vary greatly from one setting to another and will depend on:

- the prevalence of HIV in the population from which the refugees have come
- the prevalence of HIV in the host population
- the level of risk factors
- the type of setting: refugee camp; refugee-impacted area; or resettlement area
- the degree of stability and security
- whether the refugee's current circumstances are anticipated to be short or long-term
- the types of programs that IRC is already implementing
- existing responses that may have been initiated by the host government, UN agencies, international NGOs, local NGOs and the community

### *What aspects of your work already contribute to reducing vulnerability to HIV?*

Examples might include:

- social activities that promote equality and respect, provide some relief from stress and anxiety, and enable men and women to meet in culturally acceptable ways;
- efforts to protect women from rape and coerced sex;
- sports activities for young people that give them confidence and hope for the future;
- ante-natal, delivery and post-natal care that improves the health of pregnant women, minimizes interventions at delivery, and increases the likelihood of optimal exclusive breastfeeding – all measures that will reduce the risk of mother to child transmission of HIV (see Chapter 11).

Often an increased awareness that their work contributes to HIV prevention and care raises the morale and commitment of staff.

### *How might HIV prevention and care be incorporated into existing programs?*

There may be ways to build in responses straight away without the need for additional resources:

- within a program for young people a poster competition could have the theme “reducing stigma associated with HIV infection”;
- inviting a panel of community leaders to be the judges may also engage them in the issue;
- a women's literacy program might use material with HIV related topics. The AIDS Action newsletters (see Appendix 6) are a useful source of material to stimulate discussions

- community health workers that undertake home visits could be trained to provide one-to-one education about HIV and STIs, and distribute condoms.
- during supervisory visits to clinics staff can ensure that appropriate measures are in place to prevent transmission of HIV within the health care setting, and that simple opportunities to contribute to HIV prevention and care are not being missed.

Encourage the team to think of ideas for your setting.

***What HIV-related issues should IRC address because of particular designated responsibilities?***

For example, if IRC has responsibility for health care services, the organisation also has a responsibility to ensure that measures are in place to minimize the risk of transmission within health care settings, and to provide non-discriminatory counselling, care and support to people infected and affected by HIV.

***Which organisation in your setting is responsible for coordinating the implementation of MISP?***

The components of the evidence-based Minimum Initial Service Package for reproductive health form a minimum requirement of actions in the emergency phase (see page 42). In your setting, which organisation is responsible for coordinating the implementation of MISP? To what extent has the package been implemented and monitored?

***Next steps***

In addition to strengthening what is already being done, the team may feel that there is a need for a greater or more comprehensive response to the threat of HIV. Coordination, collaboration and communication are as important in relation to HIV interventions as to other interventions in refugee situations. Before new responses are implemented there will need to be an analysis of the situation with review of existing responses. This should include all those with an interest. The findings provide the basis for strategic planning.

HIV prevention and care efforts need to fit within the policy framework of the host government. It is important to become familiar with national AIDS control plans, policies and programs.

In any setting consultation is important, but in refugee settings it assumes an even greater significance. HIV is a sensitive issue - a stigmatised condition surrounded by misconceptions. It is associated with illegal and stigmatised behaviours such as injecting drug use, sexual assault, and sex work. Gathering information about these issues can put people at risk and needs to be done cautiously, with full consultation and using participatory methods. But gathering information can be difficult in often chaotic refugee settings, where there may be high mobility and security concerns. In particular confidentiality can be difficult to maintain, but is essential.

There is a need to plan consultation carefully. There are inevitably delicate political tensions to take into account, and a range of stakeholders. These might include:

- officials of the host government,
- refugee leaders (of different factions),
- representatives of people living with HIV,
- military officials,
- religious leaders,
- representatives of UNHCR and other UN agencies, and
- other local or international relief agencies and NGOs.

Consultation may be at several levels. For some stakeholders it may be appropriate to simply inform them of what is planned through a meeting. Others might be invited to comment on plans, while some will need the opportunity to participate fully in the cycle of gathering information, strategic planning, implementation and evaluation.

Brainstorm with the team a list of people who need to be consulted. Go through the list deciding what level of consultation is appropriate for each stakeholder. Decide what will be the best approach and who will make contact. For example, you might invite people to an initial large open meeting to determine the level of interest and support, or organize a number of smaller consultations.

The next section describes how to undertake a situation analysis, response review and strategic planning process.



## **Section Three: What can we do to contribute to HIV prevention and care?**

|   |            |
|---|------------|
| <b>Chapter 7. Counseling for HIV prevention and care</b>                | <b>80</b>  |
| Introduction  | 80         |
| Rationale   | 82         |
| Strategies  | 83         |
| Training of counselors  | 84         |
| Pre-test counseling   | 85         |
| Post-test counseling  | 89         |
| Supportive and problem-solving counseling                               | 91         |
| Crisis counseling   | 93         |
| Prevention counseling   | 94         |
| Counseling for children   | 94         |
| Role-play exercise  | 94         |
| Preparation of checklists   | 97         |
| Support for counselors  | 98         |
| Suggested indicators  | 99         |
| Additional resources  | 100        |
| <b>Chapter 8. Strategies for prevention of sexual transmission</b>      | <b>101</b> |
| Introduction  | 101        |
| Interventions that relate to provision of services:                     | 108        |
| Establish and promote VCT services                                      | 108        |
| Promote and distribute condoms  | 113        |
| Strengthen management and control of STIs                               | 120        |
| Interventions that relate to changing individual behaviors:             | 124        |
| Develop and disseminate communication materials for behavior change     | 124        |
| Peer education  | 133        |
| Sex education for young people  | 134        |
| Role of HIV positive people in prevention                               | 136        |
| Prevention counseling for STI patients                                  | 137        |
| Interventions that relate to the societal context:                      | 137        |
| Prevent and manage the consequences of sexual and gender-based violence | 137        |
| Provide opportunities for social activities                             | 140        |
| Social activities for youth   | 141        |
| Community communication activities to change attitudes                  | 142        |
| Support micro-finance schemes and income generating activities          | 143        |
| Suggested indicators  | 144        |
| Additional resources  | 146        |

|  |            |
|--|------------|
| <b>Chapter 9. Strategies for prevention of transmission through injecting drug use</b> | <b>150</b> |
| Introduction   | 150        |
| Rationale  | 151        |
| Strategies   | 152        |
| Education and communication  | 154        |
| Advocacy and stigma reduction  | 155        |
| Needle-syringe programs  | 155        |
| Drug treatment programs  | 156        |
| Suggested indicators   | 158        |
| Additional resources   | 159        |
| <br>   |            |
| <b>Chapter 10. Strategies to enable people to live positively with HIV</b>             | <b>160</b> |
| Introduction   | 160        |
| Rationale  | 160        |
| Strategies   | 162        |
| Protect the human rights of people living with HIV                                     | 162        |
| Establish peer support groups  | 163        |
| Build capacity and enhance skills of PLWH  | 163        |
| Train counselors to give psychological support to PLWH                                 | 164        |
| Suggested indicators   | 165        |
| Additional resources   | 165        |

## Introduction

### *What is counseling?*

Counseling is a process that helps a person to cope with problems and to make their own decisions. The counselor listens and encourages them to talk about their situation and their feelings, and empathizes, that is, they show that they understand how the person is feeling. The counselor gives them accurate clear information to help them to make decisions; and tries to give them support and confidence to do what they decide.

UNAIDS define counseling as “a confidential dialogue between a client and a counselor aimed at enabling the client to cope with stress and take personal decisions related to HIV/AIDS.”

Counseling is different from advising. When you advise someone you tell them what you think they should do. When you counsel you do not impose your own ideas and values.

In many societies counseling may be a new and unfamiliar idea. When people have problems they traditionally take them to an older family member who is likely to tell them what to do. However people from any culture are usually glad to have the opportunity to talk about their worries with someone who will listen, is well informed, will not judge them, and will not tell anyone else.

### *When can counseling be useful?*

Some of the situations in which counseling can be helpful include:

- When someone is considering having an HIV test or has signs and symptoms of HIV infection they need **pre-test counseling**
- When someone receives an HIV test result they need **post-test counseling**
- Post-abortion care, ante-natal care, family planning care, treatment for sexually transmitted infections and pre-marital counseling all provide opportunities for **prevention or behavior change counseling**
- When someone has problems they may benefit from **supportive and decision-making counseling**
- When someone has suffered a serious loss they may benefit from **grief counseling**
- When someone is distressed they need **crisis counseling**

The needs of people confronted with HIV change over time; counseling sessions need to reflect these changes. Families or couples may attend counseling sessions together, as long as they all agree to “share confidentiality”. Specific counseling may be needed for:

- parents and siblings of an HIV infected child
- women, men or children who have been sexually assaulted or abused

- HIV positive pregnant women
- people who are dying, and their families

Training in counseling skills is an important component of several strategies and interventions, including voluntary counseling and testing (VCT) services (page 108), strengthening reproductive health services (page 120), behavior change for young people (page 135), establishing a continuum of care for those infected and affected (page 195), VCT during pregnancy (page 170), and counseling in relation to HIV and infant feeding (page 172).

### ***What qualities does a counselor need to have?***

Counselors need to be:

- good listeners
- warm and caring
- respected
- well informed
- motivated
- resilient, and
- familiar with the cultural context and the history of displacement of the people they will counsel.

Different categories of workers can be trained in counseling skills. In refugee settings these might include:

- primary health care workers,
- social welfare workers,
- workers in sexual and gender-based violence programs,
- traditional birth attendants,
- family planning workers,
- teachers,
- people living with HIV,
- community volunteers, and
- ministers.

These skills are useful for communicating with and caring for all their clients, not only those with HIV infection. Some of these workers may already have counseling skills and experience but need to become well informed about HIV related issues. They may be able to train others.

### ***What sort of place is suitable for counseling?***

Counseling can take place in many settings in clinics, hospitals or within the community. It is important to provide a setting that is private, comfortable, quiet, accessible and able to protect confidentiality. In busy clinics it may not be possible for a room to be set aside for counseling, but with thought it may be possible to create a private space using curtains or screens. If a room or space is set aside it is important

not to label it as an HIV counseling room. If this room is within an MCH clinic men may feel awkward to attend.

It is also important to ask whether different ethnic groups will be able to access the counseling site, especially marginalized groups who may be particularly vulnerable. All clinic staff need to understand the importance of a friendly and non-discriminatory manner and the need for confidentiality.



Consider other possible sites for counseling in the camps or community. Consult with women, men, young people, elderly people and different ethnic groups. They may each have different reasons for finding access difficult. It may be embarrassing or stigmatizing to visit a site that is only used for counseling, while a room within a youth center or administrative building may be noisy but more anonymous. Will the host population be able to access the site? If not, do they have access to alternative counseling services?

### **Rationale**

Studies show that counseling can help people infected with HIV, and their families, to cope. Counseling can also help people to change behavior to avoid infection with HIV. But counseling cannot be effective unless it is properly supported, coordinated and funded. Training too few counselors and expecting them to work on their own can be harmful for the clients and the counselors. Service managers and policy makers need to be convinced that counseling is valuable, and they need to understand that counselors require training and supervision. It may be important for IRC staff to play an advocacy role. Be able to explain simply what counseling is and the role it can play.

A number of studies and evaluations have been documented. Try to identify studies that are locally relevant to use for advocacy with local officials.

A randomized controlled study of voluntary counseling and testing compared to basic health information in sites in Tanzania, Kenya and Trinidad found that the proportion of individuals reporting unprotected intercourse reduced more in the group who

received voluntary counseling and testing, than in the group who received health information alone<sup>1</sup>.

In Uganda, TASO conducted a study on 730 HIV-positive clients to whom it had given long-term counseling. Counseling appeared to help these clients cope with their infection. Of the clients sampled, 90% had revealed the fact of their infection to another person, with 85.3% telling relations. TASO clients who had received regular counseling also reported a high level of acceptance of HIV-positive people within families and in communities<sup>2</sup>.

Community-based counseling for behavioral change has been successfully provided in a rural Medical Research Council project in western Uganda where condom use increased from 2000 to 7000 per month<sup>3</sup>.

In 1992, a study in Rwanda examined the impact of preventive counseling. It was shown that for the women whose partners were also counseled and tested the annual incidence of new HIV infections decreased from 4.1% to 1.8%. Among women who were HIV-positive, the prevalence of gonorrhoea decreased from 13% to 6%, with the greatest reduction in those using condoms<sup>4</sup>.

It is difficult to measure the effects of counseling interventions. If you are able to it is valuable to document the process of implementing counseling strategies and evaluate the impact. Be sure to publish your experiences through journal or newsletter articles.

### **Strategies**

- Train counselors
- Prepare checklists
- Support counselors
- Publicize availability of counseling (see page 124)

### ***Training of counselors***

It is not necessary to train as a psychologist to be a counselor. However it is not enough simply to have a caring personality. Counseling requires training in specific skills which include:

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<sup>1</sup> The Voluntary HIV-1 Counseling and Testing Efficacy Study Group. Efficacy of voluntary HIV-1 counseling and testing in individuals and couples in Kenya, Tanzania, and Trinidad: a randomized trial. *Lancet* 2000; 356: 103-12.

<sup>2</sup> TASO Uganda—the inside story: Participatory evaluation of HIV/AIDS counseling, medical and social services, 1993–1994. Kampala: TASO, 1995. WHO/GPA/TCO/HCS/95.1.

<sup>3</sup> Mugula F, et al. A community-based counseling service as a potential outlet for condom distribution. 9th International Conference on AIDS and STD in Africa, Kampala, Dec. 1995 [paper WeD834].

<sup>4</sup> Allen S, Serufilira A, Bogaerts J, Van de Perre P, Nsengumuremyi F, Lindan C, Caradl M, Wolf W, Coates T, Hullely S. Confidential HIV testing and condom promotion in Africa: impact on HIV and gonorrhoea rates. *Journal of the American Medical Association*, 1992; 268 (23): 3338-3343.

- listening in an open and non-judgmental way,
- asking supportive questions,
- discussing options,
- encouraging the client to make his or her own informed decisions,
- giving accurate information and
- arranging follow-up.

A short period of training in counseling can improve the skills and confidence of health care and social workers. After the initial training the counselor should receive support and supervision in their work and participate in a further training workshop several months later.

It is important to select trainee counselors carefully – they should be people who will be in a position to counsel others as part of their job. The AIDS Support Organisation (Uganda) suggests a useful approach to trainee selection. They conduct a one-day AIDS counseling awareness workshop for a large group of people being considered for training. During the workshop they raise controversial issues such as compulsory partner notification. The trainers observe the attitudes, reactions and interpersonal interaction skills of the prospective trainees, and based on this, select people for the counseling skills training.

During the training it is most important to include a session discussing the meaning and practice of confidentiality. Refugees and displaced people may have reasons to feel very insecure and to fear serious consequences if other people learn their status. Counselors need to have a clear understanding of why confidentiality is so important, and that it is important not just to practice it, but to tell the client that everything that is said will remain confidential, and that you will not tell anyone their HIV status unless they give consent. Confidentiality may be difficult to maintain in overcrowded clinics. When chatting with friends after work it can be very tempting to mention something about a client that the counselor has learnt within a counseling session. How to safeguard confidentiality when documenting counseling sessions, or referring clients to other services, are challenges that also need to be resolved through discussion. Trainees should be encouraged to discuss solutions for their particular setting. In some circumstances it may be best not to record any personal information about clients. If the counselor writes on a client-held health card it is important to be sure that the client knows what has been written.

It is also important for the trainees to understand denial. Denial may be a powerful and unconscious influence on behavior. Denial can prevent people from seeking treatment, accepting an HIV test, and coming back for results of a test if they have one. Denial can prevent someone telling their sexual partner about their infection, or practicing safe sex to protect others, and may result in aggressive reactions towards counselors and partners who raise these issues.

### Discussion point

Some people worry that the principles of confidentiality and informed consent lead to more spread of HIV. They worry particularly that the wives of infected men are exposed to risk when their husbands do not know their status, or will not tell their wives and use condoms. Experience from many countries shows that these principles do not increase the spread of HIV, but can increase the likelihood that people will come forward for counseling and testing. Denial, stigma and discrimination result in secrecy and are obstacles to an effective response to HIV. What are the best ways to reduce denial, stigma and discrimination, and to open up the epidemic?

UNAIDS and WHO offer suggestions in the document:

"Opening up the HIV epidemic: Guidance on encouraging beneficial disclosure, ethical partner counseling, and appropriate use of HIV case reporting." November 2000. Available from UNAIDS or at

[www.unaids.org/publications/documents/epidemiology/surveillance/](http://www.unaids.org/publications/documents/epidemiology/surveillance/)

Questions and Answers on Reporting, Partner Notification and Disclosure of HIV Serostatus and/or AIDS, Public Health and Human Rights Implications. Geneva, WHO/UNAIDS, June 1999 (UNAIDS/00.26E).

### ***Information for trainees about counseling in different situations***

This information is aimed at the trainee counselors, and could be adapted or translated and used as hand-outs.

#### **Pre-test counseling**

*Why is it necessary to counsel before doing an HIV antibody test?*

Pre-test counseling is necessary to enable the person to reach an informed decision about whether to have the test or not: and, if they decide to have it, to prepare them for the result.

*Why is it necessary for the client to make an informed decision?*

There is no cure for HIV infection as there is for syphilis or gonorrhoea. There may be disadvantages to having the test, and it is important for the client to consider the disadvantages and advantages before deciding.

A client who has been prepared may be less disturbed by a positive result. When someone receives a positive test result they are often too shocked or upset to take in what they need to know about HIV, so it is important to give information before the test.

In pre-test counseling the counselor explores with the person behavior that may have placed him or her at risk. Testing for HIV, when accompanied by pre-test counseling, is a very important component of prevention of spread of HIV. The person realizes that the possibility that they may be infected with HIV is real, and that they need to change their behavior whether the test result is positive or negative.



In refugee or refugee-impacted settings it is important to bear in mind what may have happened to the client during the conflict or emergency that led to their displacement, and the changed social context in which they now live. Many displaced women will have experienced rape, coercive sex, or have been obliged to have sex in exchange for food for their family. They may have lost their partner and other family members. They may have special reason to fear having an HIV test, and may become upset when asked about whether they have been at risk. They may still be experiencing risk that they are not able to control. Men and children may also have experienced sexual assault. In the context of pre-test counseling it needs to be clear to both counselor and client what the agenda of the session is – ‘We are here to discuss the possibility of an HIV test’. If difficult issues do come up the counselor can listen and empathize, but should not feel that they must address the issue themselves. They may decide that an HIV test would not be appropriate at that time and if possible refer the client.

Many women find it easier to discuss the possibility of HIV infection with their partner than to tell him that they have had a positive test. Ask the woman if she would prefer to talk to her partner or bring him for counseling before you test her blood. Then, if both agree, you can test their blood at the same time. When both partners are infected sometimes one blames the other. It can be helpful to discuss this possibility with the couple, and explain why such blaming is inappropriate, before the tests.

During pre-test counseling it is important to discuss who the client might tell if the result is positive. In refugee settings there is often a very high level of concern about confidentiality.

Explain clearly how the results will be handled and how confidentiality will be maintained. When people are open about their HIV infection it is easier for them to receive help and support, others may decide to protect themselves against infection, and stigma may become less in a community where many are open about their infection. Keeping the diagnosis secret is stressful. For these reasons it is reasonable to encourage (but not to force) disclosure. There are different levels of disclosure – someone might want to tell only their partner, they might be comfortable to tell their closest family members or friends, or they might be willing to be publicly open about their HIV status. At the pre-test counseling session you might discuss the first two levels of disclosure – but it is more appropriate to delay discussion about being publicly open until later.



## Checklists

It is helpful to prepare a checklist of points that you want to cover. Keep it with you when you counsel until you become experienced. Do not be embarrassed to look at the checklist when you are counseling. You can say, “There is a lot to explain – I want to make sure that I do not miss anything”.

The following checklists provide a guide, but they may need to be adapted to make them appropriate to the local context.

### Checklist for pre-test counseling

- Introduce yourself
- Explain that the interview is completely confidential
- Explain why the doctor or nurse has suggested an HIV antibody test, or explore why the client is requesting the test
- Assess with the client behaviors that may have exposed them to infection with the virus.
- Ask what the client already knows about HIV transmission and prevention
- Correct any false beliefs and explain the basic facts about HIV infection and how it is spread:
  - how HIV affects the immune system
  - how HIV differs from AIDS
  - that there is a long incubation period
  - the routes of transmission
  - how HIV does not spread
  - that there is no cure at present
  - that treatment for opportunistic infections is available
  - that treatment for symptoms is available
  - give hope that there may be a cure in future
- Explain that the HIV antibody test is not a test for AIDS
- Explain the “window period”, that is, the time between infection and the development of antibodies (seroconversion), when the test is negative but the person is infected and infectious
- Explain how long it takes for the test results to be available and discuss how the client will cope during the waiting time.
- Explain policies for confirmatory tests and for follow up
- Ask about family circumstances and identify what support they have from family and friends
- Discuss the personal implications of a positive result: Whom would they tell? How might they cope with a positive result? Explore the advantages of disclosure.
- Discuss some of the practical issues, e.g. how to use and where to get condoms and family planning advice
- If clients keep their own health care record, tell them what you write on it so that they can protect their confidentiality
- Check the client’s understanding
- Arrange a follow up appointment

What are the possible advantages and disadvantages of having an HIV test that you should be prepared to discuss with a client? Remember that the advantages and disadvantages vary with the individual, and their circumstances. Helping clients to see which is important for them is a counseling skill.

Possible **advantages** include:

- Having the test may reduce the anxiety of not knowing whether they are infected
- They will be in a better position to make decisions about the future (such as whether to become pregnant or not)
- If they are infected opportunistic infections can be treated more quickly, and unnecessary tests avoided
- If they are infected they may be motivated to take up a healthier lifestyle
- There may be benefits that they become entitled to if they are known to be HIV positive

Possible **disadvantages** include:

- The dangers of stigmatization if others learn that they are HIV positive
- Possible rejection by partner or family
- Women may lose financial support if their husband learns that they had a positive test result
- Limitation of travel to other countries
- Being unable to obtain life insurance or a mortgage

*Why do people find AIDS a difficult disease to understand?*

Many people do not know about the immune system. People often find it difficult to understand why different AIDS patients suffer from such different symptoms. It can be helpful to describe the immune system as the “defense army” of the body. HIV attacks the “soldiers” (white cells). It is easy to understand that disease of the sex organs can be spread sexually. But many find it hard to believe that HIV, which causes symptoms in other parts of the body, can be transmitted sexually. The fact that someone who is well can be infectious also causes confusion.

The following tips can help clients to remember information:

- Be brief. Try not to give too much information. Emphasize the important points.
- Organize the information. Explain to the client how you organize the information.
- Give the most important information first.
- Be simple. Use short sentences and simple words. Avoid technical terms.
- Repeat the most important information.
- Be specific: say “You can get condoms free from the Family Planning Clinic near the market” not “condoms are easy to get”.
- Give information slowly.
- Ask the client to repeat back to you in his own words what you have said.

## Post-test counseling

When someone arrives to obtain their result try not to keep them waiting for a long time. Once they are sitting down tell them the result in a straightforward way. Give them time to respond before giving them any information. Only give someone their test result when there is enough time to counsel them.

Common reaction stages that many people pass through when they learn that they are HIV antibody positive include shock, fear, anxiety, denial, anger, blame, resignation



or depression, and acceptance. One of the aims of post-test counseling is to help the person to pass through these stages to reach an acceptance of their condition. This is likely to take more than one session, and some people may need several further sessions.

People may express their initial distress in different ways.

- Some cry. This is a natural response. Give them time to cry.
- Someone who is shocked may appear to listen to you, but does not take in anything that you say. They may fall quiet for a long time. You need to ask questions which may engage them.
- Some express anger – it is important that you do not take offence.
- Some become agitated. You must remain calm yourself.

The content of a post-test counseling session will vary with different individuals. It depends on the emotional state of the client, their level of understanding, their cultural beliefs, and whether they already have HIV-related illness. It can be helpful to talk about the idea of living positively with HIV. Emphasize that being infected with HIV is not the same as having AIDS, and that they may have many years of healthy life ahead.

In refugee settings people who test positive for HIV are likely to be very concerned about the consequences if people find out. Reassure them that you will not tell anyone.

The need for a “crisis counseling” approach can arise during post-test counseling. When someone feels overwhelmed by a problem, they become distressed or agitated. They feel that they have lost control and do not know what to do. The aim of “crisis counseling” is to restore a sense of control. (see page 93)

Many people find it difficult to tell their spouse or sex partner about a positive result. Ask them how they think that their partner will react. If appropriate, ask them how they have coped when their partner has reacted like this in the past. The client may find it helpful to role-play with the counselor how they will tell their partner. The counselor might offer to be present when the client tells their partner.

You may be tempted to falsely reassure a client – for example, to say that they will not become ill. This is not helpful, because when they do become ill, they will lose confidence in you. Also, it encourages both client and counselor to avoid facing difficult issues such as dying.

Clients often forget what was said after they receive a positive result. Give literate clients a leaflet with the most important facts simply explained, for them to read later. Many clients will benefit from a second counseling session one week later when they have had a chance to think about the implications of their diagnosis and have more questions. A few clients will need several sessions. In refugee settings there are likely to be few counselors. If there is a local support group refer the client. But if you assess that the client has little social support offer a follow-up visit.

Post-test counseling is also necessary when the test result is negative. A negative result can make a person feel free to continue high risk behavior, so you need to repeat advice about preventing the spread of HIV. If the person was infected recently and has not yet made antibodies the result may be a false negative (the window period). If the patient has been at risk, suggest another test in three months.

The following checklist is a guide that you may adapt to your own context by adding relevant referral or resource options.

- Check-list for post-test counseling when the test is negative**
- Greet the client and tell them the result of the test
  - Check what they understand by the result
  - Explore whether the client has been at risk in the past three months. If so, explain that they may be infected and should have another test in three months time
  - Explain the importance of maintaining safe behavior. Ask them what difficulties they might have in avoiding risky behaviors.
    - If relevant, show them a condom and explain how to use condoms properly.
    - Let them know that if they have difficulties they can return for further counseling
  - Ask them to tell their peers about the risk of HIV infection and how to protect themselves

### **Checklist for post test counseling when the test is positive**

- Greet the client and tell them the result of the test
- Give them time to react
- Check that they understand what the test result means, and the difference between HIV infection and AIDS
- Ask them what worries them most about the result - discuss alternatives for dealing with this worry
- Check their knowledge of HIV and its transmission
- Explain any facts that they have forgotten or misunderstood
- Ask if they will find it difficult to tell their sex partner/s
  - Help them to plan how to do this
  - Invite them to bring their partner for counseling
- Ask them who else they plan to tell - identify what emotional support they have from family and friends
- Discuss the responsibility to protect others - ask about risk behavior, and discuss how they might change
- Repeat information about "safer sex". If relevant, show them a condom and explain how to use condoms properly.
- Explain the practical precautions the client needs to take in the home
- Give them time to ask questions
- Put the client in touch with any local support groups
- Explain the medical follow up procedure. Stress that, although there is no cure, symptoms that might develop can be treated. Advise them to come early for treatment.
- Arrange a further appointment
- Give written information (if literate)

### **Supportive and problem-solving counseling**

After the shock of learning that they have HIV has passed, people with HIV face many problems. They may find it helpful to be able to talk to a counselor about these – it does not have to be the same counselor. The aim of problem-solving counseling is to help them to reach and carry out decisions to enable them to cope with their problems. These might include:

- decisions to change high risk behavior, or to talk to their partner about high risk behavior
- decisions about who to tell about the diagnosis; and when and how to tell them
- decisions about how to care for children or other dependents
- decisions about whether to have more children.

Problem-solving counseling includes the following steps:

1. **Listen** carefully. Allow the client to describe their problems in their own way. Encourage them to express their feelings and fears: “What frightens you most when you think about telling your wife / husband?”
2. **Show empathy**, which means showing that you know how they feel, and support: for example: “That must worry you a lot”, “Did you find that frustrating?” “It is not surprising that you feel anxious/angry/depressed. I am here and can help you with this problem”.
3. **Summarize** what the client has said. This clarifies exactly what the problem is and lets the client know that you have heard them. Ask whether you have understood the problem correctly.
4. Help the client to **prioritize** their problems. They may feel overwhelmed: “It’s so awful, I can’t begin to think what to do”. It can help to identify which problems they feel are most important, “What is your greatest worry?” (“That I will be dependent on others”) “What worries you most about being dependent?” and so on.
5. **Clarify the possible alternative courses of action**. Make suggestions (without telling the client what to do): “Have you thought of.....” or “What might happen if...”. If you explore the consequences of taking different courses of action you can help the client to reach a decision. Summarize the options.
6. **Provide any factual information** that they need on which to base decisions.
7. **Help the client to put their decisions into practice**. Discuss their strengths and skills to increase their confidence. Ask them how they have coped with problems in the past.
8. Help the client to **establish a plan of action**. Discuss other resources that might be available to help solve the problem, for example, legal advice or welfare services, if available.
9. Discuss which **family and friends** might be able to give support. Ask about the client’s religious or spiritual beliefs.
10. Put them in touch with any **local support** groups.

Some clients may deny their HIV status. Sometimes what may seem like denial is a genuine lack of understanding. For others denial is a way to cope with an unacceptable truth. Do not force these patients to face reality because they may react with explosive emotions, becoming very anxious or aggressive. The counselor needs to adopt a gradual and sensitive approach.

Refugees may have so many other problems to cope with that the idea that in years to come they will become sick and die of AIDS may not seem like a priority. They may be more worried about their short term survival.

The counselor cannot take responsibility for providing for all the client’s needs, but should be able to refer them to other services that might be available. It can be tempting to try to solve the clients’ problems for them. This can lead to dependence. If you arrange counseling sessions too frequently, the client may begin to feel that they cannot do without you.

Counselors need to be aware that neurological and psychiatric complications of HIV infection may affect a client's behavior.

Fears of dying, of serious illness, or of a partner leaving, may be difficult to talk about. But they are easier to talk about before a patient becomes seriously ill. Do not avoid talking about these fears, although people may fear that talking about death will bring bad luck. People who have accepted that they have AIDS will be able to prepare for dying. They may have family problems that they would like to resolve; they may need to arrange for care of their children, and prepare a will. They need to be able to choose whether to die at home or in hospital; they need acceptance from staff, family and friends, so that they can die with dignity. They also need relief from pain and discomfort (see page 210).

The counselor can help a client to prepare instructions in the form of a will. This can:

- bring peace of mind to people who know they are dying
- prevent the deceased's assets being lost by their spouse or children
- ensure that they are able to choose a suitable guardian for their children
- reduce the chance of legal fights after the death, and
- lessen worries about insecurity.
- state how and where the client wishes to be buried or cremated.

### **Crisis counseling**

A crisis may be precipitated by a variety of problems: perhaps someone has been told that they have HIV, or finds that their spouse or child is infected; perhaps someone fears that they have been exposed, for example, through a needle-stick injury. In a crisis, a person feels helpless and anxious. They may feel suddenly intensely threatened and appear to react irrationally. A counselor who remains calm can help an agitated client to calm themselves.

1. First ensure the safety of the client and others, including yourself.
2. Take steps to help the client calm down: ask them to sit down, get them a sweet warm drink.
3. Do not offer false reassurance, or give advice, or take offence.
4. Offer acceptance and support: "You are very anxious. You need to talk about this. I have time to listen to you".
5. When the client is calmer, ask questions to find out more about the problem and the patient's circumstances.
6. Ask about the client's present feelings and fears. (This is not an appropriate time to ask about the client's past). Summarize your understanding of the problem.
7. Find out what the client thinks is the worst aspect of the crisis.
8. Discuss what needs to be done most urgently to contain the crisis now.
9. Agree on a small task that the client can carry out, with support. For example, the client feels that they can never return to work because they think fellow workers have discovered that they have HIV. An appropriate small task might be for them



to visit a fellow worker for a chat. Performing such a task can help to ease the crisis and restore a sense of control.

10. Arrange a further session to discuss longer term solutions to the problem.

### **Prevention counseling**

Prevention counseling is similar to one-to-one health education. However counseling is a deeper, more personal and detailed process. The counselor provides information and encourages the patient to discuss their feelings and attitudes, and together they explore obstacles to behavior change. If a health care worker simply tells a patient what they should do, it may increase their resistance to changing their behavior.

The principles of counseling for prevention have been described already. The key is engaging the client to think about the ways that they may be vulnerable to infection with HIV. Remember that some people have little control over the factors that put them at risk of infection with HIV. Be wary of suggesting simple solutions.

### **Counseling for children**

The HIV epidemic often places great responsibilities and stresses on children. Counseling may help them to cope when their parents are ill or dying, or with worries about their own infection. They may face discrimination because of HIV in the family. The siblings of infected children also often need attention and support. Older children may need counseling related to sexual issues. Children may have been sexually abused and need supportive counseling in relation to this.

#### *Role-play training exercise*

Role-play is especially helpful in counseling training, as participants have the opportunity to practice skills and gain confidence in a safe situation. Below there are some scenarios that may arise in relation to HIV infection. The names may be changed to locally familiar ones, and the scenarios copied on to cards. More scenarios appropriate to the context may need to be prepared.

The participants work in groups of three or four. Each group takes a card. One participant plays the client, and another plays the counselor. The others observe what is helpful and what is not. After the role-play has finished they are asked to give positive comments first, then make some suggestions for improvements. Then the group takes another card and they change roles. All the small groups may perform the same role-play situation and discuss all the observations together afterwards.

In real life, a counseling session may last from 15 minutes to one hour. In this exercise it will be necessary to limit the time for each role play to about 15 minutes. Participants should be reassured that they are not expected to “complete” the counseling “sessions” in that time. It can be helpful to identify a specific task for some scenarios for the trainees to practice, for example, for Ned’s scenario the task could be to find out what he knows about HIV and correct misconceptions, in Angela’s role-play the task could be to discuss home-based care options.

To be sure that the exercise is successful it needs to be led by someone with experience of counseling. If participants try the exercise without enough help, they may find that they do not know what to do, which may reduce their confidence in their ability to counsel clients in real life. Ideally, the facilitator should give a demonstration of role-playing counseling with another leader or with a participant, before participants attempt it themselves. Then, while the groups work, the facilitator circulates to comment and to sort out any problems that arise. It may be helpful to have the checklists available to the participants.

The facilitator needs to pay attention to the information and suggestions that the “counselor” gives to the “client”. Information must be accurate and appropriate for the situation, and corrected if necessary. The facilitator also needs to pay attention to the way in which the “counselor” handles the “client”. They should listen, empathize, explore possible solutions to problems, help with decisions and give support. They must communicate well. They should not impose their own ideas and values. Many health workers find this difficult at first, because in their training they have often learnt to give patients clear advice.

Role-play can be a powerful training tool. Participants temporarily adopt the character of the role they are playing and may experience the corresponding emotions. At the end it is important to have an informal discussion in order to debrief and restore the participants to their own roles.

### *Pre-test counseling scenarios*

Ned is a young man in the camp hospital with florid pulmonary tuberculosis. His doctor has referred him to you for pre-test counseling.

Mary, aged 25, was displaced from her home with all her neighbors, two years ago. She was raped repeatedly by soldiers at that time. She has heard about AIDS and has come to talk about having a test for HIV. Mary is single.

Rose is an 18 year old girl who has been in the camp for 6 months. She has been referred for pre-test counseling because she presented with an STI. On the long walk to the camp she was raped by two soldiers. She has to fetch wood each day and has been raped several times since she arrived at the camp.

*Post-test counseling scenarios*

Angela is a 35 year old nurse-aide, married with five children. She had been losing weight and feeling weak. She now comes to you to hear the result of her HIV antibody test, which is positive.

Jenny is 20, single, with no children. She works in a bar in the refugee camp. She had herpes zoster, but is now well. She has come to the clinic for the result of her HIV antibody test, which is positive.

Peter, aged 18, was referred for counseling and testing because he had an STI. The HIV test result is negative.

*Problem solving counseling scenarios*

Charles is a 22 year-old student. He has known that he is infected with HIV for 10 months. His health is good and he has accepted his condition. He comes to you now because he has a new girlfriend and he wants to find out where he can get condoms.

Anna and her husband Bernard have one child aged 18 months, who has HIV infection and who gets ill frequently. They have been thinking recently about having another child.

Stella, aged 24 years, is ill with HIV infection. She knows that she is infected and she has been counseled. She is now well enough to go home, but asks to see the counselor again because she cannot decide whether to tell her husband. Stella was divorced before she met her present husband, who has a second older wife.

Marie is 30 years old and has 3 small children. In recent months she has lost a lot of weight and has had recurrent illnesses. She feels sure that she has AIDS. She is troubled because although she is fond of her husband, and he has cared for her during her illnesses, she feels very angry with him for infecting her with this fatal virus, which he will not admit.

### *Crisis counseling scenarios*

Joseph, a teacher aged 25, has come to you in an extremely agitated state. At a pre-migration medical examination a doctor found some enlarged glands, and has suggested that he have an HIV antibody test. He is referred to you for counseling.

Mathias is 42, married with seven children. He arrives at the outpatient clinic in a very aggressive and angry mood. His wife has just come home and told him that she is infected with HIV. He blames the health worker for testing his wife without his consent.

### *Prevention counseling scenarios*

Simon, aged 18, has attended the clinic for treatment of a severe chancroid ulcer. He needs prevention counseling as well as antibiotics.

Anne, aged 23 years, was admitted with bleeding following an abortion. All women who have had an abortion are offered a chance to talk with the counselor. What will you say to her?

### *Bereavement counseling scenarios*

John's wife died two weeks ago of an AIDS-related illness. Their baby girl died six months ago aged two years. John has been left with a four year old boy. John's brother has brought him to the counselor because he has been sitting in his hut, and not looking after his son. John has not had an HIV test.

Sarah is an elderly widow. Her youngest son died of AIDS, aged 20, one month ago. Her second son died in the recent armed conflict, and two of her daughters died of AIDS in the past 5 years. A neighbor suggested she come for counseling because she is not sleeping or eating well and cries frequently.

### *Preparation of checklists*

It is helpful to inexperienced counselors to have printed checklists to consult when counseling. The checklists we provide in this manual will need to be modified to make them locally appropriate. Participants could undertake this task and then use the checklists in role-play practice. After this the checklists should be tested by both experienced and inexperienced counselors and modified before printing. The checklists will last longer if they are laminated or put in a clear plastic envelope.

### *Support for counselors*

Although there can be a great deal of satisfaction in providing support to people through counseling it can also be very stressful. Counselors can become emotionally exhausted or 'burnt out'. They feel tired and become irritable or depressed. It is essential to provide counselors with an opportunity to talk in confidence about the challenges their clients present, preferably at regular meetings with a familiar supervisor. They may also wish to meet in a group informally to share their experiences.

Counselors often have a position as a nurse or a social worker - their supervisor may expect them to give priority to tasks other than counseling. Counselors may then visit their clients as a voluntary activity and become exhausted. Administrative support can reduce stress by providing appropriate timetables, with rotation of tasks, clear job descriptions, and reasonable working facilities. It is important for managers and supervisors of counselors to identify mechanisms to reward commitment and maintain motivation. These might include awards, opportunities to attend conferences, and the chance to assist in training new counselors.

Counselors often feel frustrated because they have few ways to help their client, for example, when they counsel women who are exposed to the risk of HIV but are unable to do anything about it. The supervisor might arrange for them to talk in confidence (with the woman's permission) with appropriate officials, social welfare workers, or sexual and gender-based violence program workers to determine an appropriate plan to protect the woman. The counselor needs to be able to work closely with others to lessen feelings of isolation and powerlessness. The supervisor may need to help the counselor to see that there are inevitably limits to the help that they can give, and prevent them feeling responsible for factors that are beyond their control.

The resources needed to provide these supports for counselors should be considered a necessary part of the counseling program budget and an investment, since if it is ignored the turnover of counselors will be high.

## Suggested indicators

| <i>Indicator</i>   | <i>Method of measurement</i>   |
|--|--|
| Check-lists available in counseling settings   | Observation  |
| Number of counselors trained   | Review of training course reports  |
| Proportion of counselors assessed as competent after training  | Assessment of competence of trainee through performance during role-play of counseling situations using a checklist  |
| Proportion of women seen for post-abortion care who receive HIV counseling   | Review of clinic records   |
| Proportion of STI patients who receive counseling (by age and sex)   | Review of clinic records   |
| Level of community awareness of counseling services (both refugee and host)<br>Ability of community to access counseling services<br>Level of trust in confidentiality | Participatory appraisal and FGDs with community  |
| Attendance at VCT services* (by age and sex)   | Review of VCT service records  |
| Satisfaction of clients with quality of counseling   | Interviews with a sample of (consenting) clients – use checklist to see whether points have been covered. Ask about level of satisfaction with the counseling. |
| Satisfaction of counselors with level of support   | Regular discussions with 1) counselors and 2) supervisors using a checklist  |

\*Although it is interesting to follow trends over time in acceptance of HIV testing, it is not a good idea to use “Number of HIV tests” as an indicator of effective counseling. The purpose of pre-test counseling is to assist the person to reach their own decision about whether to have a test or not. Counselors should not feel that they are being evaluated by the number of clients that they ‘persuade’ to have an HIV test.

## **Additional resources**

UNAIDS Technical update: Counseling and HIV/AIDS. November 1997. Available at: <http://www.unaids.org/publications/documents/health/index.html#counseling>

Meursing K, Sibindi F. HIV Counseling – a luxury or a necessity? *Health Policy and Planning* 2000; 15 (1): 17-23.

Tijuana A. Tames-Traore, Valerie Flax. *Counselor Training: a manual for counseling adolescents with a special emphasis on reproductive health*. IRC. Guinea. March 1998.

WHO/GPA. *Source Book for HIV/AIDS Counseling Training*, WHO, 1994. WHO/GPA/TCO/HCS/94.9. Intended for use in training counselors. Deals with initial training and refresher courses.

WHO/GPA. *Counseling for HIV/AIDS: a key to caring*, WHO, 1995. For policy-makers, planners and implementers of counseling activities. Geneva: WHO, 1995. WHO/GPA/TCO/HCS/95.15. Explores programmatic and policy issues with regard to planning and setting up counseling services.

WHO/UNAIDS. *Questions and Answers on Reporting, Partner Notification and Disclosure of HIV Serostatus and/or AIDS, Public Health and Human Rights Implications*. Geneva, WHO/UNAIDS, June 1999.

*HIV/AIDS Counseling: the TASO experience (1998)* – a 30 minute video illustrating TASO's approach to counseling. Available in French, English and Swahili. Available from TALC (free for organizations in sub-Saharan Africa).

# 8

## Preventing transmission through sex

### Introduction

Sex is the most common route of transmission of HIV. Sexual activity, illness and death are often taboo subjects, so promoting change to safer sexual practices is difficult. Safer sexual practices include:

- Consistent use of condoms
- Non-penetrative sex (e.g. mutual masturbation, sex between the thighs)
- Sex with a single uninfected faithful partner
- Abstinence

### *Impact of displacement on sexual practices and attitudes*

Patterns of sexual behavior are likely to be altered by displacement. It is essential to analyse the changes and their probable impact. In a refugee camp with many single women and possibly poorly disciplined military groups in charge there are likely to be increased levels of violent or coercive sex. There may be mixing of groups with different rates of HIV. For example a study in two Mozambican refugee camps in different parts of Swaziland found a much higher rate of HIV in the camp where there had been interaction between refugees and the local population who had a high rate of HIV<sup>5</sup>. There may be soldiers from countries with a high prevalence of HIV deployed as international peacekeepers to an area with low rates of HIV. Single soldiers away from their wives and girlfriends are likely to pay for sex or start relationships with local women. This may be the starting point for a new epidemic of HIV in a vulnerable population. The usual restraints on young people may be lacking, and lack of activities and structure result in boredom and a search for excitement. They may be more likely to have sex at an earlier age and with more partners. Where displaced people are living with host families changes in sexual practices may be less significant, but overcrowding, enforced intimacy, and lack of privacy may affect sexual relationships. In countries where law and order no longer operate, women, young people and children are often sexually exploited and may be trafficked by organized criminals from one country to another, and forced into prostitution.

Whatever the changes in sexual practices it is likely that the former societal attitudes and expectations will persist. This may prevent individuals from talking about their problems, and communities from recognizing and responding to the problems associated with changed sexual practices.

Attitudes towards pregnancy are also likely to be affected by displacement. Women may be fearful of becoming pregnant because of their uncertain future, their poverty and the lack of services. If they have been raped they may be distressed at the thought of becoming pregnant. On the other hand populations displaced as a result of

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<sup>5</sup> Van Rensburg EJ, Lemmer HR, Joubert JJ. Prevalence of viral infections in Mozambican refugees in Swaziland. *East African Medical Journal* 1995; 72 (9): 588-90.



armed conflict may want to see more babies being born and view promotion of family planning and condoms as attempts to prevent them reproducing. This is an especially sensitive matter when ethnic groups have been targeted and expelled from their homes or killed in an attempt at genocide. These sensitivities need to be taken into account in planning condom promotion efforts.

The desire to see more babies born may mean that there is a general concern about infertility. Since the complications of STIs are the most common cause of infertility the community's concern may be a powerful motivation towards adopting safer sexual practices. This might be used as a strong appeal in communication materials.

Although the most vulnerable groups for transmission through sex are generally the young, and women, it is men who play the dominant role in deciding whether and under what circumstances sex will take place. It is therefore important to consider how to reach them with sexual behavior change programs.

Many HIV and STI programs have taken an approach that targets interventions narrowly to "high risk groups", on the basis that if HIV can be prevented in these groups it will not reach the rest of the population. While it is important to identify and work with groups that are more vulnerable than others because they have a greater likelihood of unsafe sex encounters and lack access to services and information, there is need to be cautious. The groups most often targeted are sex workers, men who have sex with men, and truck drivers. When these groups are singled out for messages about reducing the numbers of their sexual partners and using condoms they feel that they are being further marginalised and stigmatised. They suspect that the attention they receive is motivated by concern for the rest of the community rather than for themselves which leads to resentment and rejection of messages. There is also a danger that HIV becomes associated with these groups and others in the community then feel that they are not at risk. The targeted interventions fail to reach people with the same behaviours as those in the "high risk" groups who do not identify as 'sex workers', or 'men who have sex with men'. In refugee settings a wide range of transactional sex may occur for different reasons and soldiers may have sex with men but not identify as homosexual or 'gay'. It is wise to explore appropriate ways to reach all the different groups in the community with relevant messages. Outreach and peer strategies tend to be the most effective with marginalised groups.

### ***Behavior change strategies can succeed***

Much has been learned in the past twenty years about preventing transmission of HIV through sex. Uganda and Thailand are countries that have been able to achieve large scale changes in behavior that have resulted in decreased transmission of HIV; Senegal provides a valuable example of a poor country where HIV has not spread rapidly. It is difficult to be sure of the contribution of different factors to these successes. There are some features of the population that have been protective, but also evidence that actions carried out by communities, governments and non-government organizations have been effective. Some key features that seem to contribute to prevention of spread of HIV are:

- Political leadership and openness about the threat of the epidemic

- Religious leadership
- Community leadership
- Sex education for young people and school children
- Outreach and peer programs for sex workers, their clients and other vulnerable groups
- STI control programs
- Promotion of condoms
- Access to testing for HIV in combination with counseling

For example Thailand's 100 Percent Condom Program, which aimed to make condom use universal among sex workers, has been one of the world's most successful condom promotion campaigns.

In Uganda among men aged 15 to 19, the percentage who had ever used condoms rose from 20% in 1989 to about 60% in 1995 following a multi-sectoral program including condom distribution and promotion involving popular songs and drama groups, counseling, and support services. There is evidence that the reduction in prevalence of HIV in Uganda is also related to people having fewer numbers of sexual partners. Other factors that have been shown to have slowed the spread of HIV were knowing somebody who had died of AIDS, and talking with family and friends about the epidemic. Despite limited resources, Ugandans have developed personal and culturally appropriate behavioral strategies, which have dramatically reduced HIV prevalence.

Experience from Rwandan camps in Tanzania shows that such multi-sectoral approaches can be achieved in refugee settings<sup>6</sup>. A large-scale collaborative program was implemented in camps of more than 250,000 refugees. An initial community health survey of knowledge, attitudes, and practices provided baseline data. The program included distribution of free condoms and dissemination of HIV/AIDS information by community educators, treatment and counseling for STIs, mass education campaigns targeting adolescents and women as well as the general population, and creation of culturally-specific videos in the local language to promote safer sexual behavior.

### ***Some ideas about behavior change***

To prevent the spread of HIV we need to change individual behaviors, such as having unprotected sex or sharing needles to inject drugs, although we recognise that individual behavior is part of a complex web of factors that influence risk of HIV in a community.

A talkback radio program asked their listeners how they were getting on with their New Year's resolutions\*. Some callers had tried to exercise more, some to give up

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<sup>6</sup> Benjamin JA, Engel D, DeBuysscher R. AIDS prevention amid chaos: the case of Rwandan refugees in Tanzania. International Conference on AIDS. July 1996 11(1): 255 (abstract no. Tu.D.241).

\* There is a custom in Western countries to make resolutions to change bad habits on New Year's day.

fatty foods, or smoking. Some had succeeded by stopping suddenly, others by cutting down gradually. Some had been helped by regular counseling, others by non-smoking friends, and others by chewing nicotine gum. All had changed their behavior and they had done so using different strategies. But some useful lessons about effective behavior change strategies have been learned in recent years.

To make a resolution to change your behavior you need to have some sense that you can control your life. The examples of behavior change given above are likely to be meaningless to refugees, who may have lost a sense of control, as well as their loved ones, and their possessions. When refugees have to rely on donations to survive for long periods, and have no opportunity to work or determine their future, they suffer feelings of powerlessness and dependency. In these settings community level strategies are likely to be more effective at reducing vulnerability to HIV, and can create an environment that increases people's belief in their ability to take effective action.

Studies show that strategies that try to change individual behavior only succeed when people believe:

- they are susceptible to the problem
- the problem is serious
- their health will benefit if they change their behavior
- the new behavior is socially desirable
- the benefits will outweigh potential costs and barriers, and
- they have the ability to take effective action<sup>7</sup>.

People are more likely to change their behavior because of short-term consequences rather than more distant consequences. For example, a young man is more likely to use condoms to prevent a short-term consequence such as an STI or pregnancy, than a longer-term consequence such as AIDS. What a person views as socially desirable depends on what their peers think is socially desirable. A young man is more likely to use a condom if he feels that his friends think it's a normal and smart thing to do. In relation to sexual violence this theory suggests that we need to try to modify social norms to make sexual assault unacceptable and that it is important that penalties are strictly enforced so that there are short-term consequences to be feared from such behavior.

The Stages of Change Model<sup>8</sup> describes behavior change as a process not an event.

- **Pre-contemplation:** The person has not begun to think about the need to change.
- **Contemplation:** Something happens to prompt them to start thinking about change.

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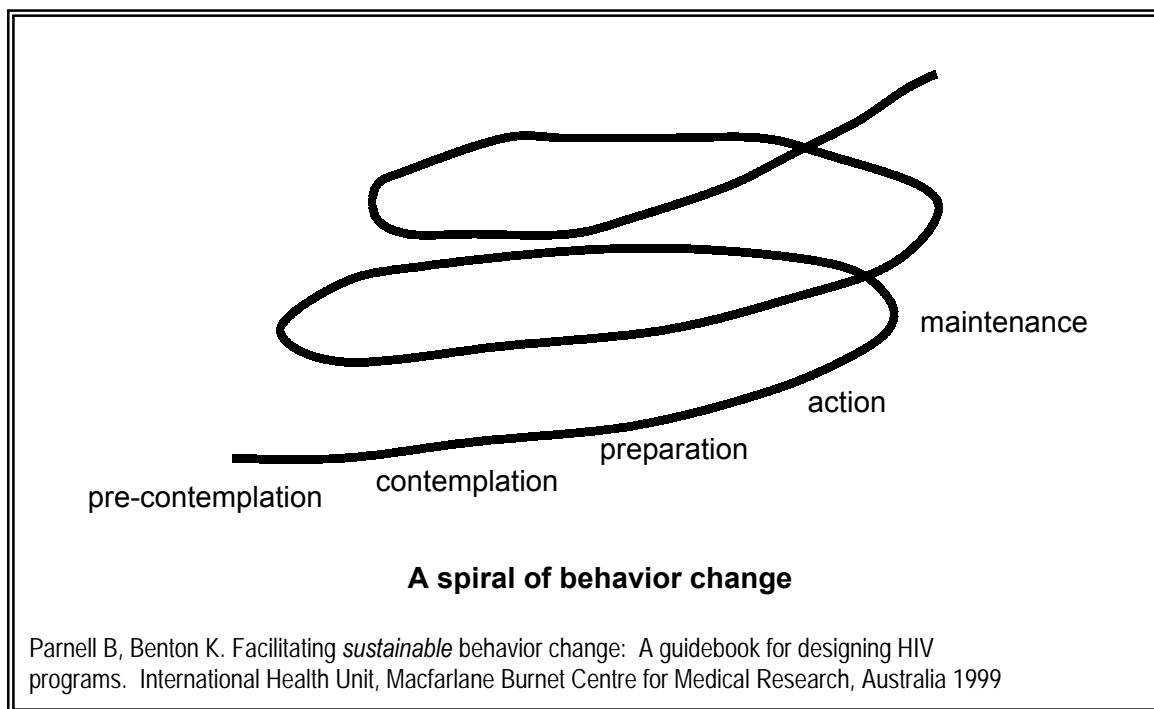
<sup>7</sup> Strecher VJ, Rosenstock IM. The health belief model. In: Glanz K, et al. Health Behavior and Health Education: Theory, Research and Practice. San Francisco, CA: Jossey-Bass, 1997.

<sup>8</sup> Prochaska JO, DiClemente CC, Norcross JC. In search of how people change: applications to addictive behaviors. American Psychologist 1992; 47 (9): 1102-1114.

- **Preparation:** The person makes a commitment to change. They might look for information, and decide when they will change.
- **Action:** The person begins to change their behavior
- **Maintenance:** The person sustains their behavior change and starts to benefit. With practice the behavior becomes familiar and habitual.

The pace of progress through these stages is variable; people may become ‘stuck’ at any stage. It can be helpful to counselors to have these stages in mind when they try to help someone to achieve a change in behavior.

Although a person may intend to maintain a new behavior they might find it difficult. The resources they need, such as condoms, might cease to be available. People who supported the change might move away. For a range of reasons, people might move back to the earlier stages. But they never return to the precontemplation stage<sup>9</sup>. Because someone reverts to an earlier pattern of behavior this does not mean that they have ‘failed to change’. Many people who eventually adopt a new habit make several attempts before the behavior is maintained long-term.



<sup>9</sup> Parnell B, Benton K. Facilitating *sustainable* behavior change: A guidebook for designing HIV programs. International Health Unit, Macfarlane Burnet Centre for Medical Research, Australia 1999.

### *The enabling environment*

Behavior does not occur in isolation; people respond to what is happening around them. The factors that influence positive change have been described as making up an *enabling environment*<sup>10</sup>.

#### *Social factors*

An example of how the social and cultural context influences the prospects of behavior change relates to male homosexual behavior. In societies in which male homosexuality is taboo men who want to have sex with men are more likely to marry, but continue secretly to have sex with men. They may not admit even to themselves that they have sex with men. This makes it very difficult to reach this group with messages about safer sex behaviors. In this way social attitudes present a barrier to achieving behavior change, and these men and their wives remain vulnerable to infection with a fatal virus.

#### *Religious factors*

Religious beliefs are powerful influences on behavior. In some cultures religious prohibitions affect what can be discussed. If sex outside marriage is viewed as a sin, then it becomes difficult to discuss the issue, even though everyone may know that it is a common practice. Women may not feel that they can discuss their husband's infidelity, or strategies to reduce the risk that results, even with other women.

Actions by leaders from many religions have contributed to HIV prevention and care. For this political and religious leadership to occur the leaders need information about the epidemic. As with other groups, peer education is effective. In many parts of the world religious groups have got together to form "faith-based networks" to share experiences about how best to contribute to both prevention and care. This can be important in shifting attitudes away from a judgmental and prohibitive approach. In Senegal for example, conferences for senior Islamic leaders and Christian bishops led to an increase in support for people living with HIV, including acceptance of the use of condoms.

#### *The legal framework*

Laws that prohibit certain behaviors can work against behavior change. For example, because it is illegal people may inject heroin rather than risk detection through the smell of smoking.

The extent to which laws are enforced is also important – in refugee settings there may be little chance that sexual assault or rape will be punished, even when evidence is available. There may be more than one system of law operating – and different groups enforcing their own rules to varying extents. The unpredictable nature of the enforcement of laws may make it a difficult environment in which to encourage

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<sup>10</sup> Klouda T. Responding to AIDS: are there *any* appropriate development and health policies? Journal of International Development 1995; 7 (3): 467-487.

behavior change. An unstable political environment may affect who can gain access to information and services necessary for behavior change. It is easier to obtain the cooperation of those responsible for law enforcement if they are included in planning strategies for behavior change.

Laws relating to freedom of access to information, discrimination and advertising are also relevant.

### *Framework for planning interventions*

At the end of section two we showed a framework for planning prevention interventions. Behavior change to prevent HIV depends upon services and supplies, including treatment for STIs, distribution of condoms and access to voluntary counseling and testing for HIV. These are described under “Interventions that relate to provision of services”. Advice for developing effective IEC programs and other strategies to change individual behaviors are also presented. “Interventions that relate to the societal context” presents some ideas for increasing the community’s capacity to create an ‘enabling environment’.

In this chapter we describe:

1. *Interventions that relate to provision of services:*
  - 1.1 Establish and promote VCT services
  - 1.2 Promote and distribute condoms
  - 1.3 Strengthen management and control of STIs
2. *Interventions that relate to changing individual behaviors:*
  - 2.1 Develop and disseminate communication materials for behavior change
  - 2.2 Peer education
  - 2.2 Sex education for young people
  - 2.3 Role of HIV positive people in prevention
  - 2.5 Prevention counseling for STI patients
3. *Interventions that relate to the societal context:*
  - 3.1 Prevent and manage the consequences of sexual and gender-based violence
  - 3.1 Provide opportunities for social activities
  - 3.2 Social activities for youth
  - 3.4 Community communication activities to change attitudes
  - 3.5 Support micro-finance schemes and income generating activities

The choice and design of these interventions will depend on the results of the local situation analysis.

## 1. Interventions that relate to provision of services

### 1.1 Establish and promote voluntary counseling and testing services

#### Rationale

Voluntary counseling and testing (VCT) services are part of a continuum of care and support for people with HIV. VCT can also be an effective prevention strategy, promoting behavior change among those who test negative as well as positive<sup>11</sup>.

#### *Should you introduce VCT?*

It is important to know whether refugees or displaced people had access to VCT in their home area, and whether VCT is available for the host population. In refugee settings VCT services should only be established where there are relatively stable conditions and confidentiality can be guaranteed.

When you discuss whether you should introduce VCT ask yourselves:

1. Is there the technical capacity?
  - a regular, reliable and sufficient supply of HIV test kits?
  - an appropriate testing strategy, including confirmatory testing of positive results as outlined in the UNAIDS Policy on HIV Testing and Counseling (see Appendix 3)?<sup>12</sup>
  - high quality testing and laboratory procedures in place to ensure accurate results?
  - systems in place to identify and correct technical and clerical errors?
2. Is there the staff capacity?
  - experienced health staff available who can take blood samples and who are trained to follow universal precautions?
  - trained counselors available to provide pre-test and post-test counseling?
  - support and supervision available for health workers and counselors?
  - laboratory staff trained in carrying out tests?
3. Is there the capacity for treatment and care?
  - medical treatment available for people diagnosed with HIV?
  - referral systems for people who are diagnosed with HIV? be referred for care and support?
  - family and community support for people with HIV?

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<sup>11</sup> Efficacy of voluntary HIV-1 counseling and testing in individuals and couples in Kenya, Tanzania and Trinidad: a randomized trial. *Lancet*; 2000;356:103-112.

<sup>12</sup> Voluntary Counseling and Testing Technical Update. UNAIDS, May 2000.

4. Is there the administrative capacity?
  - adequate space for confidential counseling and testing?
  - proper recording systems to ensure confidentiality, and to make sure that people are given the correct results?
  - monitoring system for quality of counseling and testing services?
  - secure arrangements for supplies, transport and storage?
5. Are there sufficient resources available - ?
  - to set up services, including training and improving laboratory infrastructure?
  - For recurrent costs such as purchases of tests and any additional staff salaries?
  - to run a comprehensive program that includes education, follow-up counseling, care and support?

### *Informed consent*

Informed consent requires an understanding of the implications of a positive test result and the voluntary decision to be tested. Pre-test counseling should include:

- the individual's personal history and possible exposure to HIV,
- their personal context, including whether they have been exposed to violence, and
- their understanding of the modes of HIV transmission (see page 85).

During post-test counseling, when the test result is positive, the person should be given emotional support and information about available care and social services (see page 89). If the HIV test is negative, then the person must be advised about the "window period" of three to six months when a negative result may be false. This counseling session is an important opportunity to discuss how HIV spreads and methods of protection.

Mandatory testing violates human rights and does not contribute to public health. It is sometimes suggested for:

- refugees prior to acceptance for resettlement to another country
- pre-employment screening
- prior to surgery or other medical treatment
- pre-marital screening

It is important to argue against mandatory testing in all these circumstances. Pre-marital testing for couples may be useful if the couple are counseled together and are tested voluntarily with informed consent.

If you establish VCT services they need to be widely publicized. Increased awareness of VCT increases awareness of the risk of HIV. In publicity make clear that people can go to a VCT center for counseling even though they may not want an HIV test. They may be seeking answers to questions, or advice about communicating with their partner about safe sex. It is also important that indicators for evaluating VCT centers



measure trends in the numbers of people attending the center, rather than the numbers tested.

### *Advantages and disadvantages of HIV testing*

Advantages of testing include:

- improved health care, such as early treatment for tuberculosis, and prevention of opportunistic infections with co-trimoxazole (see page 213)
- avoiding the expense of unnecessary screening tests and ineffective treatments
- more informed decision making about the future
- access to emotional and practical support
- increased motivation to prevent HIV transmission
- increased perception of vulnerability to HIV
- alleviates anxiety for those who test negative
- more open and positive attitudes towards living with HIV, and reduced stigma
- ability to make decisions about pregnancy and infant feeding

The availability of VCT can create an environment in which more people are willing to be tested, and helped to change their behavior, which in turn encourages beneficial disclosure. This is disclosure that is voluntary, respects the dignity of affected individuals, maintains confidentiality and leads to greater openness about HIV in the community.

The disadvantages of testing include problems with coping with the result, and problems as a result of stigma, rejection and discrimination. These were described in Chapter 7. Other problems are the cost of testing, and the possibility of inaccurate test results.

The planning team might conclude that while it is not feasible to implement a VCT service for all, it is possible to offer VCT to certain groups, such as pregnant women (see Chapter 11), injecting drug users, sex workers and their clients, or patients with tuberculosis.

### **Strategies**

The steps in establishment of a VCT service are:

- Train counselors and supervisors (see Chapter 7)
- Train laboratory staff in HIV testing
- Establish systems for procurement, and secure storage of test kits
- Establish system for confirmatory testing (see Appendix 3)
- Establish quality control for testing and laboratory procedures to ensure accurate and confidential results
- Establish systems to minimize clerical errors
- Identify and strengthen management, referral and support options for those who test positive and their families.
- Promote and publicize VCT, especially to couples and youth (see page 124)

- Establish a system for monitoring and evaluation

### *Interpreting results of HIV antibody tests*

A test result may be negative even though the person is infected if they are in the window period, that is, if they have not yet made enough antibodies for the test to detect. A test result may be positive even though the person is not infected. This is called a 'false positive' and it is the reason why confirmatory tests are necessary before someone is given a positive result. The chance that a positive test result is a false positive is greater in areas where HIV is rare. You can work through the example in the box to see why this is.

#### **False Positives**

Assume that the false positive rate of the HIV antibody test is 0.5%

**Low prevalence population** e.g. 0.004% HIV infection rate.

Of 100,000 tests done, there will be 4 true positives and 500 false positives. The chance of any positive result being a false positive is 500/504 or 99%.

**High prevalence population** e.g. 25% HIV infection rate.

Of 100,000 tests done, there will be 25,000 true positives and 500 false positives. The chance of any result being a false positive is 500/25,500, only 1.9%.

A real example is given by a study at the AIDS Reference Laboratory in Delhi in 1992. They found that when they tested blood donors, (prevalence low at 0.1%), 31.7% of the positive results were false positives. However when they tested thalassaemic children who had had many transfusions (prevalence high at 8.5%), 100% of the positive results were confirmed as true positives.

### *Types of HIV test*

#### 1) ELISA

The Enzyme Linked Immuno-Sorbent Assay (ELISA) HIV antibody test is most efficient for testing large numbers of samples each day. It is most commonly used for screening blood and for surveillance purposes. The testing kits require skilled technical staff, equipment and a constant power supply so they are not suitable for smaller or more isolated hospitals and clinics. The ELISA test is very sensitive, but a small percentage of false positive results do occur so it is necessary to confirm positive results.

#### 2) Rapid antibody tests

Several simple antibody tests (such as Serodia, Capillus, Multi-spot, HIV-CHEK, Determine) have been developed which are more suitable for use in small hospitals and laboratories. They are as sensitive and specific as ELISAs. Some take less than 10 minutes to perform and so are called 'rapid' tests. They do not need trained technical staff or expensive equipment and are usually provided in kit form. Some of these tests are able to detect HIV antibodies in specimens of saliva or dried blood.

There are four types: agglutination assays, comb/dipstick assays, flow-through membrane assays and lateral flow membrane assays. In most of these, a positive result is indicated by the appearance of a clearly visible dot or line. Many of these tests have an internal sample addition control that validates each test run. The cost of an individual ELISA test is usually less than that of a rapid test, but because the ELISA tests are carried out in batches, rapid tests are cost-effective when small numbers of tests are performed.

### 3) Confirming HIV

WHO has recommended strategies for confirming a positive HIV antibody test using combinations of ELISA and simple tests (Appendix 3). These strategies mean that it is not necessary to send blood specimens away for the expensive 'Western blot' confirmatory test. The strategy varies according to the purpose of the test and the prevalence of infection in the population. Because these tests are now very sensitive false positives are a possibility so the strategy for confirming test results is complicated.

### 4) Tests for the virus

There are several tests that detect the presence of the virus itself, which are expensive and require sophisticated laboratory support. These include the polymerase chain reaction test (PCR), virus culture, and the antigen test.

#### *The choice of test*

This will depend on the numbers of samples to be tested each day, the cost, storage characteristics and the sensitivity and specificity of the test<sup>13</sup>. A test that is very sensitive produces few false negatives. A test that is very specific produces few false positives. Today's standards require HIV tests to have a sensitivity of >99% and a specificity of >98% (the specificity of test kits may vary according to the geographical origin of the serum samples). Some simple/rapid tests do not require refrigeration and can be stored at temperatures between 2 °C and 30 °C. Detailed data about ELISA and simple/rapid tests evaluated by WHO are provided in the report 'Operational characteristics of commercially available assays to determine antibodies to HIV-1 and/or HIV-2 in human sera'. This is available from the Blood Safety Unit of WHO, or seek assistance from IRC headquarters.

Be sure that HIV antibody test kits are stored securely, because they have potential to be abused in the wrong hands.

Antibody tests for HIV are expensive. There are a number of strategies to reduce the costs of testing (see page 193). Options for recovering the cost of testing by charging clients are not likely to be feasible in refugee settings.

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<sup>13</sup> The importance of simple/rapid assays in HIV. Testing Weekly Epidemiological Record, 1998; 73 (42): 321-326.

### *Integrating VCT with existing activities*

In most refugee settings there will not be enough resources to have a dedicated VCT center staffed full-time. There are advantages to integrating VCT services with existing activities, both within and outside health care facilities. Chapter 8 discusses the range of potential counselors. A VCT service might be available intermittently at youth centers or general refugee information or advice centers. Members of an outreach team that visit clinics could be trained so that VCT is available at intervals to more remote communities.

#### **Discussion point**

Role-plays of counseling on radio or TV can be very helpful. It helps people to understand exactly what will happen when they go for VCT. It is important to have more than one role-play to show a variety of experiences. It is important to make clear that this is a role-play though, to emphasize the importance of confidentiality. In Botswana the Minister of Health was challenged on TV to have an HIV test, and she received her result on TV. This had a powerful effect with VCT centers reporting large increases in attendances. However it undermined the Minister's right to confidentiality. The lessons are that role-plays of the VCT process are helpful, and that personal experiences of well-known people or role models may stimulate people to accept VCT.

What do you think about this? If you cannot prepare a radio role-play perhaps you could prepare a drama or puppet role-play of a VCT session.

## **1.2 Promote and distribute condoms**

### **Rationale**

Promoting and distributing condoms is an important component of preventing sexual transmission of HIV. When people use condoms correctly and consistently they are extremely effective at preventing the spread of STIs including HIV and pregnancy.

Even if both partners are already infected with HIV there are benefits to using condoms. They prevent exposure to semen, to different strains of the virus, and to other STIs; all these may stimulate white cells to increase viral replication.

### *Attitudes towards condoms*

The group responsible for the condom program need to be aware of the situation analysis findings in relation to condoms. In order to be able to address people's fears and concerns it is important to understand their attitudes towards condoms.

Many young people have been willing to adopt the use of condoms to protect themselves against infections and pregnancy, and many couples around the world have successfully used condoms to space their families.

But in many settings condoms are still unfamiliar and many men are reluctant to use them. They may believe that condoms are uncomfortable or reduce pleasure. Young people are often too embarrassed or shy to ask for condoms. Some may not be able to afford condoms, or are unable to obtain them. People often associate condoms with infidelity and immoral behavior. Some do not believe that condoms prevent pregnancy and infections. Some women fear that a condom may get lost inside them. Men and women often find it difficult to talk about sex together. Condoms are used



more often during sex outside marriage than inside marriage, and with casual sex more often than with sex within a long-term or loving relationship. For many people, asking their partner to use a condom suggests a lack of trust. Wives may know that their husbands have sex outside marriage but cannot suggest condoms

for fear of abuse or rejection. Another barrier to use is the desire to achieve a pregnancy.

### *The male condom*

The male condom is a thin latex rubber tube that covers the penis during intercourse. Sometimes a condom slips or breaks. Breakage is more common when the condom is too small for the size of the penis. Condoms that are too tight or too short are uncomfortable and might put men off using condoms<sup>14</sup>. Condoms that are too big may slip off. It is therefore important to order a range of sizes of condoms. There is no evidence that uncircumcized men have more difficulty using condoms than uncircumcized men. If a condom is stored in a hot place, or is past its expiry date it may tear during use. Long fingernails may damage the thin rubber. Oil-based lubricants, such as Vaseline, body lotions, or cooking oil, will damage the latex of the condom within five minutes. It is important to use water-based lubricants such as glycerin, egg white, commercial condom lubricants (e.g. K-Y Jelly), or saliva. In some countries fancy condoms with beads or feathers attached are popular. It is important to communicate the message that these condoms will not protect against infection.

### *The female condom*

The female condom (manufactured by the Female Health Company with trade names: 'Reality', 'Femidom' and 'Care') is like a plastic bag with a flexible ring at each end.

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<sup>14</sup> Smith A, Jolley D, Hocking J, Benton K, Gerofi J. Factors affecting men's liking of condoms they have used. *International Journal of STD and AIDS* 1999; 10: 258-262.

A woman inserts the condom before sexual intercourse by squeezing one ring and placing it in position over the cervix. The other ring rests against the vulva outside the vagina.

The female condom is now widely available in many developing countries and is often popular. Unfortunately it is sometimes associated with sex work, but may be a useful option for married women and couples. It is possible to reuse the female condom, although this is not currently recommended by the manufacturer. A laboratory study of the effects of washing, drying, and relubricating female condoms 10 times found no significant deterioration in their structural integrity – but it is essential that they be carefully washed and dried to remove any infectious organisms. Advantages include:

- it can be put in place some hours before intercourse, so the woman has some control over her own protection
- the thin plastic transmits heat so that sex feels more natural than with a male condom
- oil-based lubricants can be used, and
- sex workers like them because they can continue to work during menstruation

The disadvantages are:

- can be difficult to manipulate and insert, especially for inexperienced users,
- often noisy during sex,
- the man is able to see and feel the condom, and
- the female condom is more expensive.

### *Microbicides*

A microbicide is a cream, foam, or gel that is suitable for use in the vagina which will kill HIV, and could also reduce the risk of STIs. If these substances cause vaginal inflammation they could increase risk. At present there is no effective microbicide available. Studies of the spermicide nonoxynol-9 suggest that it will not be a useful microbicide. There are a number of substances under investigation at present including a polymer-based "liquid condom" that forms a gel at body temperature. But there are many problems in setting up ethical clinical trials of the efficacy of potential microbicides.

## **Strategies**

### *Procure adequate numbers of good quality condoms*

Condom distribution is an important component of the Minimum Initial Service Package<sup>15</sup> for reproductive health in emergency settings. This is especially important where displaced people have been used to using condoms. However procurement of condoms does not always mean that they will be distributed and used correctly.

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<sup>15</sup> The SPHERE Project, Humanitarian Charter and Minimum Standards in Disaster Response, Geneva 2000.

### Unpopular condoms

In Eastern Zaire in 1996 the IRC procured condoms for refugees. It was noted that when clinics were looted during the conflict everything was taken: medicines, needles and syringes, equipment, even the windows. But the boxes of condoms remained untouched. This emphasises that ordering the condoms is only one component of an effective condom program and highlights the importance of publicity and distribution efforts.

It is possible to contact UNAIDS, UNHCR, UNFPA or WHO to assist with the purchase of bulk quantities of condoms at low cost\*. If possible procure a range of sizes. If men try condoms that are too small they may be put off forever.

Condoms usually come in boxes of 144, called a gross. Quantities may need to be adjusted depending on the situation. You might find that the proportion of the refugee population that are sexually active males differs from the assumptions in the formula below. The rate of use of condoms may also vary. To avoid shortages, make sure a three-month reserve supply is available.

### Formula for calculating condom requirements

Condom needs can be calculated if you can estimate the following:

- The size of the target population (i.e., refugee population and adjoining areas). Roughly 20 per cent of this number represents the size of the sexually active male population.
- The percentage of males using condoms. Results from previous knowledge, attitudes, behavior and practices (KAPB) studies can be used when they exist. If they do not exist, plan from data provided by the most reliable source and adapt according to needs.
- Plan for about 12 condoms per sexually active male per month.
- Add 20 per cent to the above figure for wastage and loss.

#### Example:

One month's supply of condoms for an estimated refugee and adjoining population of 10,000 people, with 20 per cent of sexually active males using condoms:

|  |                          |
|--|--------------------------|
| 2,000 sexually active males                        |                          |
| 20 per cent use condoms:                           | $2,000 \times 0.2 = 400$ |
| 12 condoms per month per sexually active male:     | $400 \times 12 = 4,800$  |
| Add 20% to allow for wastage or loss:              | $4,800 \times 0.2 = 960$ |
| Estimated total condom requirements for one month: | <b>5,760</b>             |

\* Contact addresses for condom supplies: IPPF: Dr H Mahler, Regent's College, Inner Circle, Regent's park, GB-London NW1 4NS, Fax: 44-71 487 7950; UNFPA: Dr Nafis Sadik, 220 East, 42<sup>nd</sup> Street, New York, NY 10017, USA, Fax: 1 212 297 4915; WHO: Chief, Supplies, CH-1211 Geneva 27, Fax: 41-22 791 41 96.

There are many brands of condoms on the market. Find out what types of condoms are already available, their quality and their cost. Is there already any social marketing of condoms in the area? (Social marketing is a process that applies marketing tactics to sell a product or promote a practice with the aim of improving health and well-being). Take care not to undermine existing programs.

*Increase accessibility*

Consider how to distribute condoms so that they will be accessible to everyone, including the host population. This can best be achieved when condoms are distributed through a variety of channels. Consider all the different groups who may need condoms and how best to reach them. It is especially important to consider how to encourage young sexually active people to use condoms. Free condoms and instructions for use should be available in health care facilities and food distribution centers. They might also be distributed free of charge in workplaces and youth centers, available at low cost through a social marketing program, and sold commercially in hotels, bars, pharmacies and shops. Consider locating condom outlets where people with high-risk behavior gather. This might be, for example, in military barracks, army shops, and canteens, school dormitories, transport centers, truck stops, injecting drug treatment clinics, bars, and in commercial sex districts or informal brothels. Peer educators (such as youth, women, sex workers) may also be recruited to distribute condoms in their communities. If feasible in your setting, condom vending machines provide anonymity as well as convenience and so can improve access.

Social marketing programs have greatly increased access to condoms in many countries. Condoms are heavily promoted through a targeted mass media advertising campaign and sold at a low price, subsidized by donor agencies, such as Population Services International. People sometimes think that free condoms are of lower quality. A high price will put condoms beyond the reach of most people, but a small cost makes them more valued and likely to be used than if they were free.

*Promote condoms*

Promoting condoms needs to include efforts to change community attitudes towards condom use and sexual risk-taking. Promotion needs to do more than warn about the



risks of AIDS and STIs. It should seek to engage people's interest and persuade them that using condoms is easy, worthwhile, and socially approved.

Communication materials can promote an association between condom use and demonstrating care and responsibility, providing



peace of mind, and pleasure. Condoms may be promoted for disease prevention, or family planning or both, depending on the audience. Women may feel more comfortable talking with their husbands about using condoms for family planning, though they may be more concerned themselves about protection from AIDS. For advice about preparing a community education campaign see page 124.

Catholicism is the religious denomination that has shown the greatest reluctance to promote the use of condoms to protect against the spread of HIV. However in April 2000 the Rev. Jacques Suaudeau, of the Pontifical Council for the Family published an article in the Vatican's official newspaper indicating that condoms might be permissible for containing the spread of the AIDS virus. The article does not endorse condoms, but tolerates their use as part of a comprehensive AIDS education program where the primary emphasis is on moral behavior. He wrote that condoms may be a "lesser evil" than the spread of HIV: "Until a real effort is made (to change their sexual behavior), the prophylactic is one of the best ways to contain the sexual transmission of HIV and AIDS". It is important that Catholics become aware of this shift in attitude from the Vatican.

### *Teaching condom skills*

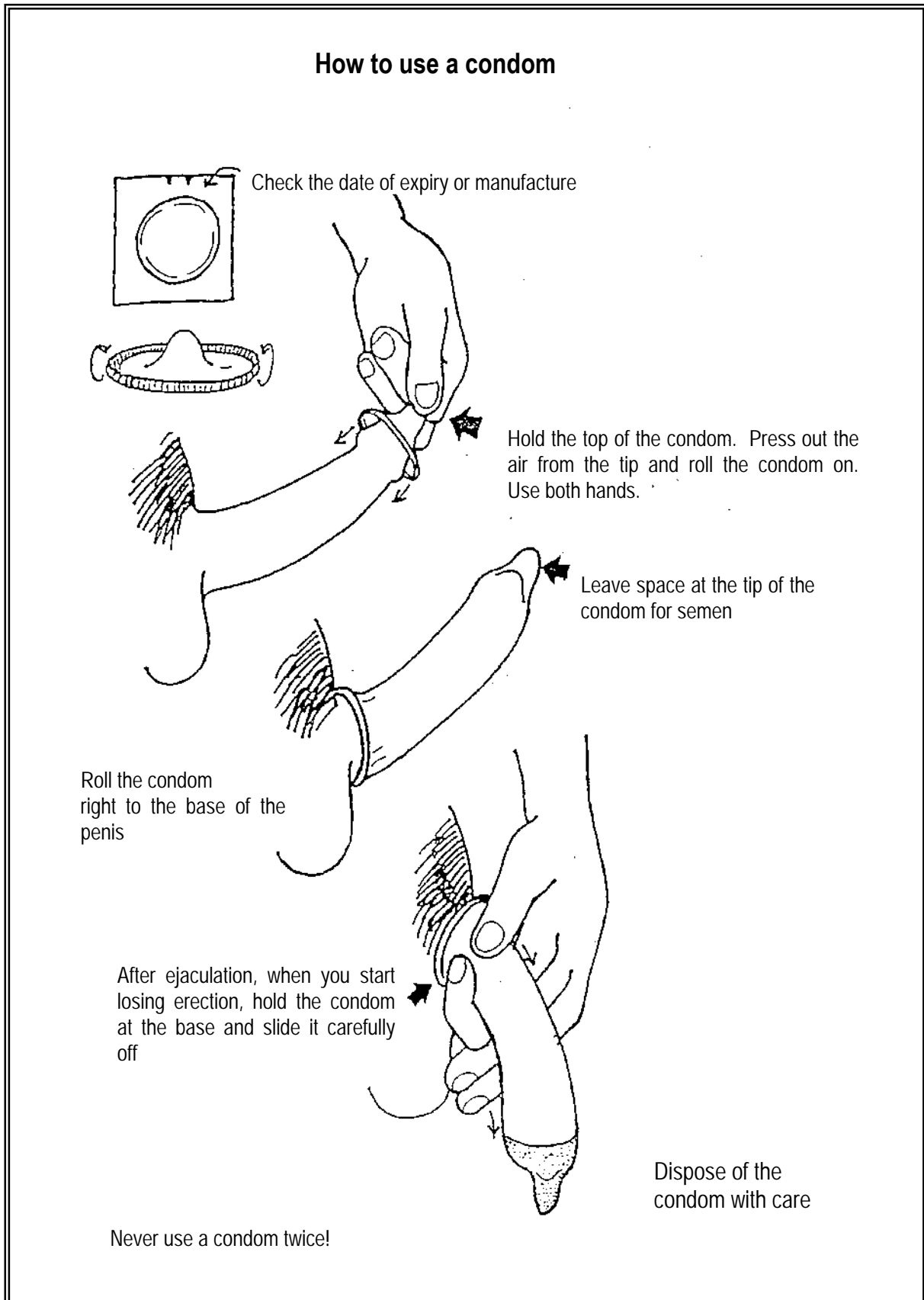
Many men feel embarrassed to try using condoms because they do not know what to do. They need to feel confident about their ability to use condoms before they need them. Make sure that instructions are available where condoms are distributed and that staff are trained in how to educate about their use. Counseling and sex education can inform young people and help them to be able to raise the subject of condoms with their partner. Women and girls, as well as men, need to be taught how to put condoms on the penis – this is usually best done one-to-one in a counseling session or in single-sex group education sessions.

The pictures below can be used in information materials for education sessions on condom use. They show the following important steps:

| <b>Instructions for use of condoms</b>   |
|--|
| <ul style="list-style-type: none"><li>• Do not try to put on the condom when the penis is soft. Put the condom on when the penis has become erect and hard, before the penis touches the partner's genital or anal area.</li><li>• Take the condom out of the packet</li><li>• Roll the condom onto the penis</li><li>• Never unroll the condom before use to test it</li><li>• Withdraw the penis soon after ejaculation</li><li>• Hold the condom onto the penis during withdrawal, so that no semen is spilt</li><li>• Tie a knot in the condom and throw it in a latrine or bury it</li><li>• Use a new condom for each act of intercourse</li></ul> |

When teaching people about condoms it can help to have condoms available. They can open the condom to feel how thin the rubber is. They can put a condom over their fingers and feel the eyebrow through the rubber. They can blow up the condom like a balloon to see how strong the rubber is. During post-test counseling or prevention

counseling for STI patients, the counselor can rehearse each step of condom use with the client, from buying the condom to disposing of it.



### ***1.3 Strengthen management and control of sexually transmitted infections***

#### **Rationale**

Control of STIs is one of the most effective interventions to reduce HIV transmission\*.

Some common STIs are gonorrhoea, chlamydia, trichomonas, syphilis, chancroid, herpes and HIV. It is easier for HIV to pass between sexual partners when another STI or other infection of the reproductive tract is present. The risk is much higher when there is an ulcer or sore.

STIs have the same underlying risk factors as HIV. So efforts to prevent the spread of STIs help to prevent the spread of HIV, and the treatment of STI patients presents an opportunity to reach a group at high risk of HIV.

The incidence of STIs varies greatly in different parts of the world, depending on patterns of sexual behavior, susceptibility to infection, and access to health care services. There have been few published studies of STIs among refugee populations. Studies from Mozambique and Tanzania have shown a high prevalence of STIs and bacterial vaginosis among refugees. The diagnosis and treatment of STIs is inadequate in many parts of the world, and has rarely been given much attention in refugee settings.

Women often have no symptoms when infected with gonorrhoea or chlamydia, which generally cause a discharge in men. If their sexual partner does not inform them that they may have an infection they will remain unaware. The infection may spread from the vagina or cervix up through the uterus (womb) to the fallopian tubes and the ovaries to cause acute or chronic pelvic inflammatory disease. The result may be blocked tubes causing infertility or tubal pregnancy. In sub-Saharan Africa 50% of cases of infertility are the result of STIs. STIs may also result in cervical cancer, and cause miscarriages, stillbirths, low birth weight, prematurity, congenital syphilis and gonococcal eye infection in the newborn.

The genital sore caused by syphilis will heal by itself if left untreated. The person may think that they are clear of the infection. But in fact the syphilis organisms continue to multiply and later cause signs and symptoms throughout the body. This is called secondary syphilis.

Many individuals with symptoms of STIs seek care outside formal health services. This may be because of shame, fear of discrimination, lack of availability of formal health services, cultural beliefs, unwelcoming attitudes of staff or because of inability to pay for the treatment. In many countries in Asia and sub-Saharan Africa, it is common to buy antibiotics from pharmacies. People with STIs may then take an inappropriate antibiotic, or take too short a course, resulting in resistant organisms.

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\* WHO and UNAIDS now tend to use the term “sexually transmitted infections (STIs)” rather than “sexually transmitted diseases (STDs)” because someone may have an STI without having symptoms or signs.

## Strategies

To prevent the spread of STIs we need to consider both primary prevention and secondary prevention. Primary prevention aims to change sexual behavior. It includes the encouragement of safer sexual choices, such as abstinence, monogamy, non-penetrative sex and consistent use of condoms, and the provision of condoms (see above). Secondary prevention aims to improve access to effective treatment for STIs, to encourage care-seeking behavior, and to detect and treat asymptomatic and symptomatic infections early.

### *Improving access to effective treatment*

A wide variety of services and individuals, both medically qualified and otherwise, provide care for people with STIs. These include STI clinics; hospital outpatient clinics; maternal and child health centers; family planning clinics; private medical practitioners; pharmacies; traditional healers; and street vendors. These can all be sources of information about trends in the rates of STIs and attitudes towards them. Workers in all these settings need training in appropriate management of STIs. The influence of traditional healers can be used to reinforce advice about condom use and reducing the number of sexual partners.

Acceptable and effective STI care needs to be available in a range of settings if it is to be accessible to different groups in the population, who have different needs and preferences. For example STI care integrated with maternal and child health, and family planning services, is important to enable women to have asymptomatic STIs detected, and to seek treatment for symptoms without fear of stigmatization. But men



also be available at primary health care and hospital out-patient clinics. Youth may benefit from health care sessions offered in the evenings in an informal youth center setting and may sometimes prefer to be able to see a doctor or nurse with one or more friends. Sex workers may be reached through outreach clinics.

Privacy and confidentiality are essential features for all population groups. The attitudes of staff may prevent people seeking treatment.

When someone presents to a clinic with an STI it is important that they receive comprehensive care. This means that:

- a correct diagnosis is made
- effective treatment is provided

- the patient is advised how to take the treatment and for how long
- future risk taking behavior by the patient is reduced or prevented
- condoms are promoted and provided
- sexual partners are told that they may have an STI and are appropriately treated

### *Correct diagnosis*

In some settings laboratory services may be available that allow blood tests for syphilis, and culture of swabs for gonorrhea and chlamydia. New DNA tests enable diagnosis of STIs from urine or tampon specimens. Where such services are not available there may be a microscope that allows for simple observation for gonorrhea (using a gram stain) or trichomonas. Simple serological testing for syphilis is recommended for case finding in pregnant women and screening of blood donors.

However often health care workers need to rely on syndromic management, where the choice of treatment depends on the particular pattern of signs and symptoms. For example, for the syndrome ‘vaginal discharge’ they treat for gonorrhea, trichomonas and chlamydia. Syndromic diagnosis avoids wrong diagnoses and ineffective treatment, can be learned by primary health workers and allows treatment of symptomatic patients in one visit. However it cannot assist in the management of asymptomatic infections and means that patients may take medicines for STIs that they do not have.

The flow charts for syndromic management of STIs appear in Appendix 5.

### *Effective treatment*

The specific choice of treatment will depend on local antibiotic sensitivity studies and availability of antibiotics. Whenever possible the choice of antibiotics should be consistent with national treatment protocols. For effective treatment to be possible health care workers need to be well trained in syndromic management, and antibiotics need to be appropriately ordered and stored. Patients need specific advice about how to take the treatment and for how long. As services and awareness improve expect a rapid increase in the amounts of antibiotics required.

In Uganda pre-packaged treatment kits have been introduced for male urethral discharge<sup>16</sup>. The kits contain the antibiotics ciprofloxacin and doxycycline, condoms, partner referral cards, and patient information. They have been socially marketed with success. The kits are popular with patients, but not with health workers who may feel that they lose their role when people can buy treatment without a consultation. But in places where well-informed counseling is not available and people are literate these kits may well be a valuable strategy in the management and control of STIs.

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<sup>16</sup> For more information contact The Futures Group International, <http://www.tfgi.com/>

### *Prevention counseling*

When patients attend with an STI this is an opportunity to counsel them about the risk of HIV infection. If HIV testing is available this should be offered to them. Condoms need to be available in all clinics to offer to patients with STIs.

### *Contact tracing (partner notification)*

Contact tracing means finding and telling the partner/s of a person with an STI that they might be infected and should be treated.

The aim is to:

- Treat all sexual partners (within the past three months, at least) of the STI patient
- Treat the partners for the same STI

This should be done in a way that maintains confidentiality and is not compulsory. Counseling and support should be available.

Contact tracing is always difficult – but is likely to be even more difficult to carry out in a refugee setting. Although in a camp setting it may be easier to contact partners it is unlikely that many patients will be willing to identify their sexual partners. However contact tracing is a very effective way to reduce the spread of STIs in a community so it is worth considering whether it would be feasible to introduce any of the following systems.

Because women often have no symptoms when they have an STI it is particularly important to try to contact and treat the female partners of male STI patients.

There are several ways to contact partners:

1. **Patient referral:** The health care worker asks patients to tell their partners to come for examination and treatment. They do not ask for information about the partners. Patients may receive contact cards or referral slips to give to their sexual partner/s.

In some places the health care workers give the patient medicines to give to their partners. If health care workers refuse to treat patients unless they bring their partners this might discourage people with STIs from attending the clinic for treatment.

2. **Health care worker referral:** The health care worker obtains names and contact details of sexual partners and tries to contact them by visiting, mail or by telephone.

3. **Patient and health care worker referral:** The health care worker asks for names and contact details of partners, but gives the patient time to ask them himself / herself. If they do not appear for treatment, health care workers try to contact them.

### *Encouraging care-seeking behavior*

The above measures to improve access to effective STI treatment will encourage care-seeking behavior. A community education campaign, targeted to those most vulnerable to STIs, such as young people, the military, and clients of sex workers, can

also encourage attendance. Such a campaign will be more effective if those targeted are involved in designing the materials, and if the messages and media are based on an understanding of the barriers to seeking care.

### *Detecting and treating asymptomatic and symptomatic infections early*

Detecting asymptomatic infections is not possible without laboratory diagnostic services. Where these are not available health workers need to be trained in syndromic management, and to treat women who have reason to fear that they have been exposed to an STI, even though they do not have symptoms. Community education and the chance to be seen in private by a female health worker who is non-judgmental will encourage women to attend for screening and treatment. The management of women who have been raped or sexually assaulted should include screening for STIs. Testing for syphilis, and treatment if required, should be a routine part of antenatal care whenever possible. If the prevalence of syphilis is known to be 10% or greater consider treating all pregnant women with a single injection of benzathine penicillin at the first antenatal visit.

An STI increases the risk of transmission from an HIV infected mother to her child so it is especially important to screen for and treat STIs promptly during pregnancy and to promote condom use. Sex workers also need access to non-judgmental health care services – an outreach service by a trusted health worker can increase the likelihood of early diagnosis and treatment.

### *Surveillance*

The situation analysis should reveal whether there are local, provincial or national STI surveillance systems in place. A service for refugees should become part of such a system if feasible. If possible try to obtain a baseline assessment of the prevalence of STIs through a population-based survey.

## **2. Interventions that relate to changing individual behaviors**

### ***2.1 Develop and disseminate communication materials for behavior change<sup>17</sup>***

‘Information, Education and Communication’ (IEC) is a jargon term, but can be a useful way to describe a necessary component of the overall response to HIV. We know that information alone is insufficient to achieve behavior change or reduce people’s vulnerability. Nevertheless information is necessary, and communication campaigns can certainly raise awareness and change attitudes. Commercial companies allocate a large part of their budget to advertising because they know that it is effective at persuading people to buy a particular product or service. A lot of this budget is spent on market research in order to understand the characteristics of the audience that they want to target, and their attitudes, beliefs and practices in relation

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<sup>17</sup> Much of this section is adapted from Starrs A. Rizzuto R. Getting the Message Out: Designing an information campaign on women’s health. 1995. Family Care International, Inc.

to the product or service. Their market research helps them to make decisions about the messages, the media and the types of appeal that they will use to reach particular groups. Advertisements are always pre-tested and modified before being displayed or broadcast.

It is challenging to carry out a communication campaign in a refugee setting. But in the post-emergency phase it may be possible and there may be additional benefits such as providing purposeful activity and much needed entertainment through the development of appropriate folk media. It may be possible to make use of materials already in use in the refugees' country of origin. But bear in mind that sensitivities may have changed with the population's changed circumstances, so that old messages may no longer be appropriate or effective. It will be difficult to engage people who are fatalistic with little optimism for the future.

There is a range of interventions that need the support of an IEC campaign. For example IEC is an important part of a condom promotion and distribution intervention, it can make people aware of the availability and benefits of a new service such as VCT, and help to alter discriminatory attitudes before ante-natal VCT testing is introduced. IEC materials can assist peer educators in their work.

Communication programs are most useful when they are interactive, or stimulate responses from the community. It is important when planning IEC campaigns to think about their timing in relation to other initiatives, especially activities that allow opportunities for community discussions. Look for opportunities to convey messages related to HIV prevention and care through existing activities. Perhaps a relevant video might be shown in a youth center, a singing group could perform songs that reinforce caring and non-judgmental attitudes, or a literacy group could prepare posters with simple messages.

All three components of IEC need to be taken into account in planning:

- Information (accurate facts about the topic)
- Education (understanding and making meaning of the information in a given context)
- Communication (interaction between people to enable understanding to occur)

Information must be accurate, clear, and at an appropriate language level. To increase understanding people need opportunities to talk with others about the information. One of the most powerful communication strategies is "word of mouth" or "friend to friend" conversations. The speed at which rumours spread is evidence of this. Unfortunately misinformation can also spread in this way. Understanding and using informal communication networks is valuable in promoting dialogue.

In planning an IEC campaign you first need to think about the interests and needs of the different kinds of people you want to reach – that is, the **target groups**. 'Target groups' might be those at higher risk, such as young people, sex workers, military personnel, drivers, or those who inject drugs. But take care not to stigmatize or offend these groups, for example by obviously targeting them in posters viewed by all. Communication campaigns are more likely to be effective if the target group themselves help to design and deliver them. Target groups may also be segments of the population divided by sex, age, occupations or beliefs. It is generally more cost-



effective to appeal separately to different groups than to try unsuccessfully to reach everyone in the same way.

You then need to think about the special information that each group needs, and how to present it to them in a meaningful way. So you have to think about the **messages**, and the **media**, or channels, that will be used to communicate the message.

Whatever the specific objective of the IEC campaign the working group, which should include members of the targeted groups, will need to review the relevant findings from the situation analysis.

### *Content of messages*

The content of the messages needs to include:

- Information that the different target groups need to have but don't have now
- Actions that the target groups need to take but are not yet taking
- Suggestions for overcoming obstacles that may stop them from taking an action that they have decided they want to take.

### *Media or channels of communication*

In order to choose appropriate channels of communication you need to know how to reach the target groups. The situation analysis report should provide information about the ways that the target groups get information. You also need to think about which media, and method of distribution, might be appropriate for the specific messages. It is always best to use a variety of media.

There are six main types of communication channels:

#### *1) Mass media*

Mass media (newspapers, magazines, radio and television) are able to reach large numbers. Mass media can help to raise awareness, but alone may not influence people to change their behavior. Mass campaigns can have a harmful effect if they are conducted before supportive services are available. For example, it is no use promoting condoms if they are not available; or alarming people about AIDS if there are no counselors. A mass campaign may result in mis-information if there are no sources of further information and explanation. Health workers need to be aware of programs on the radio and articles in newspapers about AIDS, so that they know what their patients may have heard or read.

In the settings in which IRC works radio may be the most widely available and popular form of mass communication. Radio programs are not expensive to produce, are convincing, and reach people that cannot read. When the programs are entertaining, relevant to people's lives and informative, they often stimulate discussion with friends and relatives. Radio can be a useful tool in raising awareness for behavior change, and in maintaining commitment. It is helpful to include in the situation analysis questions about how many people own radios, who listens, how often, and at what times of day. What programs do people of different ages and gender prefer? What different types of radio channel are there? Do people trust the

information they hear on the radio? Different styles of program appeal to different age groups and genders; they also listen at different times of day. Consider preparing a simple fact sheet on AIDS as background material for radio announcers.

Newsletters and magazines may include articles about health or sex. They sometimes have very useful articles about HIV. They can explain “safer sex” in more detail than is acceptable on TV or radio, or in newspapers. But magazines are expensive, and like TV, they may reach only a small proportion of the population. Young people might like to produce their own ‘magazine’, including articles that promote sexual health, which could be copied and passed around among young people.

Mass media can also be interactive - through letters or telephone if available. A simple quiz competition with a prize in a newspaper or newsletter can be an effective way to engage people and convey information.

## 2) *Print media*

- Publications for reading, such as pamphlets, leaflets, brochures, and booklets
- Materials for display, such as posters, calendars, and wall charts; and
- Materials for use with individuals or groups, such as flip charts, and picture cards.

Leaflets and brochures are useful for people who can read. They can contain information which might be embarrassing and the client can take it away to study privately. Leaflets can give detailed information and remind a client about important points from a counseling session. They can include pictures or diagrams and can be shared and discussed to spread the information and gain the support and understanding of others.

Flip-charts and brochures can help health workers and counselors to give accurate information without forgetting important points.

By themselves, posters have little value because they can only give brief information. They cannot explain details of safe sex practices for example. However, they can draw attention to a topic, and they can reinforce a message that the public receives through other media. They can provide a point for discussion.

A ‘picture code’ is a poster-sized illustration that can be used to present a familiar problem about which a community or group has strong feelings, in order to stimulate discussion and suggestions for solutions<sup>18</sup>.

Some tips for designing print media:

- Print media should be in the local language.
- Use large type that will be easy to read. Try to avoid CAPITALS and *italics* – studies show that these are more difficult to read. Use only one font or style.
- Use simple but precise words, and short sentences.

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<sup>18</sup> Laver S. “Let’s teach about AIDS” HealthLink.

- Make sure that colors used are acceptable and do not have inappropriate meanings for the refugee or local population.
- Try to make any pictures realistic and include familiar objects.
- Always include information about where to get more detailed information and advice.

It is important to think about how people who are not literate or do not understand the local language may interpret materials such as pamphlets and posters. For example, a pamphlet may use illustrations to show both how HIV is and is not transmitted - to someone who cannot read the explanation it may appear as though HIV spreads through mosquitoes and sharing plates and cups.



Similarly it is important to be careful that pictures used to illustrate routes of transmission are clear and not open to misinterpretation. For example a picture of a couple embracing might suggest that HIV spreads through hugging rather than through sexual intercourse. This adds to stigmatization.

Of course it is difficult to illustrate sexual intercourse in a way that is both unambiguous and acceptable. Think about whether there are symbols that might be appropriate to use and easily recognized by the population. For example, in China, the magpie is the Bird of Joy and two magpies represent 'marital bliss' or 'happy sex'; in some countries a picture of an empty double bed might be appropriate. But all such images need pre-testing to check how they are understood by a variety of audiences.

### 3) *Folk media*

These are traditional forms of communication and entertainment. They might include theatre, puppet shows, story-telling, songs, dance, poems and messages displayed on cloth or clothing. They have a useful place in refugee settings because they bring many people together in traditional and familiar ways.

Puppets can introduce sensitive topics, such as death and sex, and they can act what people think and do, without causing offence or embarrassment. Puppets can criticize, use humor, try out solutions, and show difficulties that people face.

A puppet show is most likely to be effective if the target group is involved in both development and performance. Follow it with a small group discussion that enables people to relate what they have heard about AIDS to their own lives. Puppets cost little to make, but to organize a puppet show takes time and enthusiasm. Puppet shows and drama can reach remote areas that mass media cannot. Use local references and familiar place names in your stories.

In some countries religious sermons might be an appropriate and effective means of communication. Imams broadcasting from the mosque, or ministers preaching in

church, can be influential. Involve them in discussions with community members to develop messages.

When preparing folk media make a clear outline of the story and messages that you want to present so that everyone is working towards the same goal. Perhaps there are traditional stories that can provide the base for the narrative. Try to include a mixture of emotions so that the event will be entertaining and engaging. Think about ways to get the audience to join in.

#### **Discussion point**

What do you think about mixing religious or moral messages with health messages?

When you facilitate this discussion make sure that several religions are discussed rather than focussing on a single religion. Encourage people to speak with respect for other's beliefs.

Some points to consider:

Changes in hygiene behavior are important to prevent the spread of many infectious diseases. Hygiene practices certainly have sensitive cultural aspects and there are strong attitudes and beliefs connected with them. Nevertheless religions do not generally mix moral messages with health messages in relation to the prevention of diarrhoea and trachoma. It is safer to wash your hands before you eat and to wash your children's faces – but you are not considered to be a sinner if you do not do these things. But in relation to sexual behavior it is common for the messages to be mixed. Religious leaders sometimes use health messages to reinforce their teaching of morals. They may say to young people: "If you remain abstinent and do not sin then you will not contract HIV or STIs." "If you are unfaithful to your wife you are sinning and you may get HIV". One unfortunate effect of this is that when someone has HIV others will think that they have sinned. The messages stigmatize the disease.

Sometimes people with strong religious beliefs will not promote certain methods to protect against spread of the virus, even though they may be effective, because they believe that they are morally wrong. For example Catholics may be unwilling to teach that using condoms will reduce the risk of HIV transmission during sex. They may also be unwilling to teach young people that masturbation, and non-penetrative sexual activity, are safe ways to enjoy their sexuality and express love without risking pregnancy, STIs and HIV infection.

On the other hand religious leaders might argue that it is very difficult to change behavior – and that love or fear of God may be a strong motivating factor that helps people to change. Appeals to people's sense of responsibility to care for each other may challenge stigma and increase care and support for people with AIDS.

Church groups or religious organisations are often important structures within the community. They often provide support and welfare services and are well placed to coordinate home-based care and orphan support services.

When preparing folk media make a clear outline of the story and messages that you want to present so that everyone is working towards the same goal. Perhaps there are traditional stories that can provide the base for the narrative. Try to include a mixture

of emotions so that the event will be entertaining and engaging. Think about ways to get the audience to join in.

4) *Visual electric media*

Films, videos and slide shows easily catch the interest of people who rarely have the chance to see such images. However these media can be very expensive to produce and require technical skills. Unless a portable generator is available they cannot be used where there is no electricity. It is best to use these media as a discussion starter, with a trained facilitator who has a discussion guide. There are several videos that tell a story, case studies, and documentaries related to AIDS (see Appendix 6). Try to find out whether there are any in appropriate languages.

Be careful when showing graphic images or slides of clinical manifestations of AIDS or very helpful for health care workers to see these so that they can recognize signs in their patients. But such pictures should not be used to 'scare' people into safer sex. They can be upsetting, may increase stigma, and can result in young people associating sex with disease.

5) *Special events*

Special events might include competitions, games, parades, rallies, and launches of new projects or activities. Social events, or awareness raising days, can provide an opportunity to use a range of media to get messages out. Make sure that you consult carefully before choosing the date. Allow plenty of time for consultation and planning. Allocate resources and time for publicity so that you get maximum coverage for your event. Ask local celebrities to become involved. Don't forget to arrange some activities that children can participate in.

6) *Personal or community counseling*

Direct contact with a health worker or counselor can make people decide to change their behavior. It can give them a sense of personal risk. This contact may be individual, during consultations for other purposes, or in groups at a community level. Health workers need to be trained in communication skills. They need to become confident at starting to talk with the community, showing respect, and in listening skills. Refer to Chapter 7 on counseling, and to guides on communication skills<sup>19</sup>.

Try to identify people in the community who have a lot of contact with people, such as hair-dressers or barbers, who could be trained to provide information about AIDS. They have an opportunity to talk with people privately, and may also be in a position to distribute or sell condoms. In Vietnam cyclo drivers were trained as peer educators because they often take men to sex workers. But the drivers often found it difficult to initiate a conversation about AIDS and condoms despite having good knowledge. Provide suggestions and role-play practice for how to start a conversation about AIDS.

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<sup>19</sup> Strengthening Communication Skills for Women's Health: A Training Guide Family Care International, Inc.

### *Choosing the appeal*

The appeal is the approach that the material uses to attract attention and influence people, such as fear, humor, or emotion.

Because of the fatal nature of AIDS, it is tempting to try to frighten people into changing their behavior. The skeleton must be one of the most common images used in AIDS information campaigns! Health educators can learn from studies by market researchers. These studies show that messages that are too frightening produce psychological barriers. Fear may cause people to notice only part of the message, or make people believe that the message does not apply to them. People may laugh off or deny a frightening message. Fear of AIDS together with ignorance can encourage misunderstandings about who is at risk and why. Fear may be one cause of the stigma attached to AIDS patients.

Humor can reduce the tension that may arise when people discuss serious and sensitive topics.

Educated people may respond to messages based on facts and figures, but you do not have to give details about the virus or the immune system to justify safer sex advice. Refer to ideas of disease and family values that people in the community already understand.

### *Pre-testing materials and ideas*

Understandings of disease and human behavior vary greatly. It is easy for messages to be misunderstood. HIV/AIDS is a particularly difficult disease for people to understand. Try out drafts of leaflets or other material with people from the target group to find out if they can understand and respond.

- Do they agree with the information?
- Do they find it easy to understand?
- Do they find it offensive?
- Do they think the advice applies to them?

You can use in-depth interviews and focus group discussions for pre-testing materials (see page 53). Try to talk with different people to those who were interviewed during the situation analysis. It is especially important to avoid leading questions because you want to know what people have understood from the materials. Often several rounds of pre-testing are necessary. Test early drafts, make modifications, and test again.

### *Production and distribution*

Once the messages and media have been pre-tested and finalized they need to be distributed. IEC materials cannot be effective sitting on a shelf.

If you have materials that need to be printed find out whether others in your setting have had things printed and find out where they did so. If you are in a position to choose obtain quotes from different printers. Make sure that copyright issues are clear. You might need to discuss this in the team if several organizations are

involved. Who has ownership of the materials? Remember to always get permission when you take and use photographs. If you are showing people with HIV they should either not be recognizable – or they should be identified by name with their permission. If you use pictures from other publications check whether you need to get permission from the publisher. Many books produced for developing countries give permission for pictures and text to be copied or adapted – but they appreciate receiving copies of such materials.

Think carefully and consult about the best places to put posters and brochures. Consider distribution points, markets, churches, sports venues, youth centers and clinics. Try to make sure that posters are protected from wind and rain – ask permission to place them inside buildings.

Train health workers or volunteers in the use of flip charts and brochures.

### *Post production*

It is important to monitor and evaluate responses to the IEC campaign, make appropriate revisions and seek new ideas.

### *Some hazards in choosing HIV/AIDS education messages*

Information about AIDS without discussion can increase stigma, especially when the messages are designed to frighten people, and the routes of transmission are presented in a way that associates them in people's minds with bad or immoral behavior.

Be wary of using terms that may have different meanings to different people. For example don't label people as "heterosexual" or "homosexual", or as "sex workers", but find out about people's own definitions and identities.

Don't forget that older people have sex too, and in refugee settings they may have lost their partners and seek new partners. Include some older people, both men and women, in pictures or songs.

The term "innocent victims" is often used when referring to children with HIV. Avoid this term because it implies that other people with HIV are 'guilty'. The word "victims" makes people with HIV sound passive. It is better to use the expression: 'People living with HIV'.

Messages such as "You get AIDS from having multiple partners" or "Don't be promiscuous" are misleading as well as resulting in stigma. In many countries the majority of women infected with HIV have only had one sexual partner – their husband. Women are unlikely to be willing to learn about HIV, or admit to knowing about HIV when it has been so closely associated with socially unacceptable sexual behavior. Women who may be infected will be reluctant to be tested or to disclose their infection because they will be thought by others to be promiscuous. The message contributes to stigma and discrimination and adds to the risk that people infected with HIV will be rejected by their families.

HIV/AIDS has several features that make it a difficult disease for people to understand. You might want to review the discussion about this on page 88 when preparing information materials.

## 2.2 Peer education

Peer educators can be effective at disseminating information and influencing behavior. It is a cost-effective strategy that is likely to be feasible in refugee settings and can be readily incorporated with existing activities. Groups from whom peers may be recruited and trained include married women, youth, and workplace colleagues. The peer education strategy can be especially useful with groups that may be difficult to reach such as sex workers, men who have sex with men and injecting drug users.

### *Advantages*

Peer educators may be able to incorporate their HIV awareness messages into their daily work and activities. They may have several roles – disseminating information, distributing condoms, or supervising ‘directly observed short course therapy’ for tuberculosis patients (DOTS). They may also play the role of facilitators in community group discussions. Peer educators may be given resources to develop their own ideas. They may be able to reach large numbers of people through extensive informal networks.

Being a peer educator can increase confidence and self-esteem, encourage a sense of ownership of the program, and provide useful skills to refugee volunteers. Peer educators can also play a useful role in advocacy work, since they become aware through their work of the needs of their peers.



### *Support*

Although a peer education strategy is relatively inexpensive it does need to be adequately resourced if it is to be effective. A system for coordination, supervision and support needs to be established. Peer educators need to be well trained in one-to-one health education and counseling so that they feel equipped to provide support if needed. They need to be able to refer people with problems or illness. For example, if women peer educators raise the awareness of other women about the need to get treatment for STIs, they need to have somewhere to refer them when they do



complain of symptoms. It is important not to exploit volunteer peer educators or treat them as though they were paid workers. Peer educators can keep logbooks to keep a record of their contacts with community members.

### *Constraints*

Peer educators often face difficulties which lead to frustration and high turnover:

- lack of time of community members who are struggling to survive;
- lack of space to meet;
- lack of interest of many who feel that AIDS is not a big problem for them;
- lack of community structures through which to work;
- mobility;
- diversity of cultures and language; and
- lack of literacy.

Community members who are out-going or have useful skills are often recruited for many roles and become overburdened.

Peer educators often gain status from their role, but in some settings adolescent girls trained as peer educators have been stigmatized by their families and communities. Knowledge about sex and reproduction is often hidden from girls until they marry. Some may believe that these young girls have acquired their knowledge through experience rather than through training and so they may be rejected. It is important that these peer educators remain associated with and supported by the program team. The subject matter of training should be broad so that public perception is not that peer educators have been trained only in sex. For example training in child health could usefully be included in the 'curriculum' for young peer educators. Youth peer educators might be linked with adult peer educators for support.

### *Encouragement*

Encouragement for peer educators might take the form of T-shirts, practical help, for example with sewing classes, or schoolwork, or small cash allowances. Motivation can be maintained by putting peer educators into contact with other peer educators – perhaps through an electronic mailing list. The opportunity to attend a conference and meet other peer educators can provide great encouragement and enable them to see the significance of their role in a wider context.

## **2.3 *Sex education for young people***

Young people learn about sex and sexuality in every society. They may learn from parents, aunts and uncles, or through sex education in schools. Some societies leave young people to find out about sexuality through trial and error on their own, from friends, or from films, magazines, books and advertisements.

### *Sexual health*

It is very important for girls and boys to have knowledge about how their bodies work and change during puberty. If they understand about sex and relationships they will

be in a better position to protect themselves from harm and to enjoy good sexual health throughout their lives. The World Health Organisation describes sexual health as “the integration of the physical, emotional, intellectual and social aspects of sexual being, in ways that are enriching and that enhance personality, communication and love.”

In some places sex education in schools is more than simply a lesson in biology. Children learn about self-confidence, respect and relationships as well as the facts about sex. Studies show that sex education for young people does not make them more likely to have sex at an early age. In fact it often helps girls to have the confidence and communication skills to say "no" to boys who pressure them to have sex against their wishes.<sup>20</sup>

It is best to emphasize the positive benefits of safer behavior, and suggest different and safer ways to express sexuality. Attempts to frighten young people into not having sex at all are not effective. They may react to fear by denying that there is a problem. It is natural for young people to enjoy taking risks. Also, linking sex with death and disease can have bad effects on young people’s future relationships and prevent them from fully enjoying sex. Help them to develop communication and assertion skills, and try to increase their self-esteem. Some youth are full of false confidence and believe that they are immune to disaster. On the other hand young people may believe that all their peers are having sex, so it may be important to emphasize that many young people prefer to choose to wait until they are older before they have sex. Adolescents are often very aware of their bodies. This may show itself by interest in grooming, or in sport. Stress their responsibility to protect their bodies.

There is a need to understand local attitudes towards what are thought of as desirable characteristics for sexual intercourse. For example, in some countries well lubricated sex is generally thought to be more desirable than dry sex. But in many countries girls are taught to use a variety of substances, such as leaves, herbs, and various powders, to dry and tighten their vaginas, because there is a perception that men prefer ‘dry’ sex. It is important to teach girls that it is healthy to wash the external genitals, but that there is no need to wash inside their vagina because it is a self-cleaning organ. They need to know that putting chemicals or herbs in the vagina may cause inflammation which predisposes to infections, including possibly infection with HIV. Boys also need to be taught about the importance of washing their genitals and that it is normal and natural for a woman to have slippery vaginal secretions if she is relaxed and sexually excited.

### *Sex education in school*

Research shows that AIDS education targeted at young people before they become sexually active is most successful in minimising future risk behavior. The school setting is the most obvious in which to reach young people, but class teachers may not be the most appropriate people to deliver AIDS education in a sensitive way. Some

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<sup>20</sup> Lessons from “Auntie Stella”: using PRA to promote reproductive health education in Zimbabwe’s secondary schools. PLA Notes No. 37, February 2000.

students prefer to discuss sexual behavior with an anonymous person rather than with their teacher. Some classroom teachers may feel uncomfortable, uncertain and embarrassed when they talk with their students about sexual practices.

Your strategic plan might include training teachers and providing them with resources to assist them to teach children about sex and HIV infection. It is important to be aware that there may be resistance to the idea of sex education in schools from parents and education officials.



If you can talk to them first about the risks of HIV infection, it may help you to obtain their approval. Consulting parents about what to teach their children about AIDS may also help.

### *Methods*

Learning methods which lead young people to make their own decisions are more effective than lectures. Small group discussions in privacy can lead young people to explore their own feelings and values. Teachers might use games, role-play, puppets, songs and drama. Talks by people living with HIV are very effective ways to personalize the risk for young people.

The popularity of “problem aunties” in magazines led to an idea for an effective method of sex education for young people in schools in Zimbabwe. “Auntie Stella” consists of cards with questions supposedly written by adolescents seeking advice about a range of sexual health related topics. There are corresponding cards with Auntie Stella’s replies. Young people discuss the ‘problem’ cards in small single-sex groups, guided by ‘talking points’ that follow the problem letter. Then they look at and discuss the ‘answer’ cards, which include ‘action points’. This has been found to be very effective because adolescents are most at ease when talking to peers of the same sex, but feel inhibited in full class discussion and in discussions with the opposite sex, especially if a teacher is present. The “Teacher’s Guide’ emphasizes that the teacher is a facilitator and emphasizes that the pupils’ discussions and writing are private.

Some young people who have never been to school may be geographically or socially isolated by poverty, or disability. These young people can be very difficult to reach, and yet may be vulnerable to exploitation and HIV infection.

In many societies there are traditional rules governing sexual behavior, which can prevent the spread of HIV. There may be traditional methods to encourage young people to practice safer sex. The elderly may have a beneficial influence on the behavior of young people so encourage activities that bring them together.

### **2.4 Role of HIV positive people in prevention**

PLWHs who are willing to tell their stories publicly are able to change attitudes, reduce discrimination, and encourage behavior change by personalizing vulnerability

to infection. Many people believe that it is possible to tell that a person has HIV by their appearance. PLWH who look healthy challenge this false belief. When people with HIV/AIDS speak out in public they challenge stereotypes about who becomes infected. It also increases tolerance and understanding towards PLWH. When people meet PLWH they feel able to talk more openly about AIDS and the social and sexual issues that increase its spread. But there can be adverse effects for those who speak out - PLWH should never be pressured to disclose their infection as a service to the general community (see Chapter 10.)

### ***2.5 Prevention counseling for STI patients***

When patients seek treatment for an STI there is an excellent opportunity to counsel them about behavior change and provide condoms. (see page 94).

## **3. Interventions that relate to the societal context**

Efforts to increase the community's capacity to create an enabling environment for behavior change and to reduce vulnerability to HIV presents a challenge in refugee settings.

Often the refugees gathered in a camp, living among a host community, or in re-settled villages, were originally members of several different communities, possibly on opposing sides in the conflict. They may have different values and beliefs. Even where all are from a single community the social fabric is likely to have been torn by displacement, with community leaders missing, the usual composition of the community disturbed, community structures damaged and social rituals interrupted.

Community development initiatives in these circumstances are not impossible, but there are likely to be frequent setbacks. The need to restore dignity and trust is great.

Where refugees have been living together for years, community structures and relationships will have evolved and the setting will have more similarity to a stable community. Nevertheless the nature of refugee life is temporary, and if there are changes in the refugees' place of origin that make returning home feasible, they will leave. Community development initiatives often imply a long-term commitment and permanence. For this reason such initiatives may be resented or opposed by both the refugees and the host government and population.

### ***3.1 Prevent and manage the consequences of sexual and gender-based violence***

This is a difficult issue to study, but wherever attempts have been made to document sexual and gender-based violence it has been found to be extremely common during armed conflicts and in displaced populations. In the early phases of a conflict rape is most likely by unknown men and soldiers, while in the post-emergency phase rape and coerced sex are more likely to be by men known to the woman. Domestic violence seems to be common in all settings, and there is evidence that it is also common in refugee settings, where men may have high levels of frustration, powerlessness and boredom. In a camp with Somali and Sudanese refugees in

northern Kenya, 12% of women surveyed said they had been hit by someone in their home in the past month<sup>21</sup>.

Apart from the risk of HIV sexual and gender-based violence has other serious impacts. Survivors often experience depression, terror, guilt, shame, and loss of self-esteem. Rejection by families can further increase their vulnerability to exploitation. They may also suffer from unwanted pregnancy, unsafe abortion, STIs, sexual dysfunction, trauma to the reproductive tract, and chronic infections leading to pelvic inflammatory disease and infertility<sup>30</sup>.

Rape and sexual assault violate the victims' rights to privacy and integrity of the person. The UN Commission on Human Rights passed the first resolution to identify rape as a war crime in 1993. The conviction for rape of three soldiers at the war-crimes tribunal in the Hague in March 2001 was an important step in undermining the culture of impunity. In local settings advocacy for publicizing and applying penalties for rape and domestic violence are also essential in order to raise awareness and shift community attitudes.



Men may also be subjected to rape and sexual assault, especially in captivity. It may be even more difficult for them to disclose this than for women. Children too may be vulnerable to sexual abuse.

#### Rape and economics

In a population of 106,000 refugees in Dadaab, Kenya, 106 cases of rape were reported in the first nine months of 1998, more than in all of 1997. Researchers discovered that the refugees attributed increased sexual violence to worsening security and to lack of economic opportunity for women. Economic security would allow women to buy firewood rather than collect it in unsafe areas outside the camp, where more than 90% of rapes were said to occur, and also would allow them to resist demands for sex from other refugees and authorities within the camp.

Olila S, Igras S, Monahan B. Assessment report: issues and responses to sexual violence, Dadaab refugee camps, Kenya, 16-23 Oct. 1998, Nairobi, Kenya, and Atlanta, GA, USA: CARE.

<sup>21</sup> Krause S, Jones R, Purdin S. Programmatic responses to refugees' reproductive health needs. *International Family Planning Perspectives*. 2000; 26 (4): 181-187.

But protecting against sexual and gender-based violence is a difficult challenge. There is much greater awareness now among relief agencies, and preventing and managing the consequences of sexual violence are key components of the Minimum Initial Service Package for reproductive health in refugee settings.

Measures for assisting refugees who have experienced sexual violence, including rape, must be established in the early phase of an emergency. The UNHCR Guidelines for Prevention and Response to Sexual Violence against Refugees (1995) should be followed. Women who have experienced sexual violence should be referred to the health services as soon as possible after the incident. Key actions to be taken during the emergency to reduce the risk of sexual violence and respond to survivors are:

- design and locate refugee camps, in consultation with refugees, to enhance physical security
- ensure the presence of female protection and health staff and interpreters
- include women in the distribution of shelter, food and other supplies
- include the issues of sexual violence in the health coordination meetings
- ensure refugees are informed of the availability of services for survivors of sexual violence
- provide a medical response to survivors of sexual violence, including emergency contraception, as appropriate
- identify individuals or groups who may be particularly at risk of sexual violence (single female heads-of-households, unaccompanied minors, etc.) and address their protection and assistance needs.

In the post-emergency setting protection involves both practical measures and assisting the community to develop their own responses and change attitudes. This requires exploration of gender relations. Planning practical measures for protection needs to involve community leaders, men and women, to avoid well intentioned mistakes. For example, toilets may be well lit to try to prevent attacks, but women may not be able to use them because modesty demands that they use toilets only when they will not be seen.

We recommend that you refer to the Inter-Agency Manual of Reproductive Health in Refugee Settings which has a useful chapter on preventing and managing sexual violence in the post-emergency setting. Here we present only the summary check-list for sexual violence programs.

### **Key Interventions – Preventing Sexual Violence**

- Ensure that women have proper personal documentation for collecting food rations or shelter material
- Increase availability of female protection officers and interpreters and ensure that all officers have knowledge of UNHCR Protection Guidelines and UN Security Guidelines for Women
- Facilitate the use of existing women's groups or promote the formation of women's groups to discuss and respond to issues of sexual violence
- Improve camp design for increased security for women
- Include women in camp decision-making processes, especially in the areas of health, sanitation, reproductive health, food distribution, camp design/location
- Distribute essential items such as food, water and fuel directly to women
- Train people at all levels (NGO, government, refugee, etc.), to prevent, identify and respond to acts of sexual violence.

### **Key Interventions – Responding to Sexual Violence**

- Adapt WHO protocols to limit further traumas to survivors of sexual violence
- Engage socially and culturally appropriate support personnel as a first contact with people who have been subjected to sexual violence
- Provide prompt and culturally appropriate psychosocial support for survivors and their families
- Provide medical follow-up immediately after an attack that also addresses STDs, HIV infection and unwanted pregnancy
- Establish closer links among protection officers, women's groups, TBAs and community leaders to discuss issues related to the attacks
- Document cases while respecting survivors' wishes and confidentiality.

### **3.2 *Provide opportunities for social activities***

In addition to protecting women from forced or coerced sex there is a need to create opportunities for men and women to meet in culturally acceptable ways. Social activities should not be viewed as a luxury, secondary to the essentials of shelter, water and food, but as necessary to restore refugees' rights to dignity. Such activities can restore morale, a sense of trust, hope for the future, promote equality and respect, and facilitate companionship, comfort, and consensual sex. Men's lack of meaningful activity is a danger to the mental and emotional health of both men and women. Organizing and contributing to social activities and events can provide work as well as entertainment.

Questions about talents and skills might be added to surveys to identify those who can sing, draw, sew, play sports, or have organizational skills. Activities such as choirs, drama or dance could be supported. Singing groups can involve both sexes, and provide an opportunity for pleasure and expression of emotions, while performances provide much needed entertainment. An enthusiastic sports trainer can help to

motivate youth and provide a safe place for them to meet. These types of activities depend on identifying motivated leaders, and the main constraint is likely to be space.

### **3.3 Social activities for youth**

Programs for youth are particularly important. Armed conflict often leaves a population with a disproportionate number of youth who are vulnerable to exploitation and have few skills or employment prospects. Often young people have to take on burdensome responsibilities for siblings or elderly relatives. Young people, especially girls, are at highest risk of HIV, other STIs, unwanted pregnancy, and the complications of abortion.

#### **Promoting Unity: A Youth Participatory Development Program**

In Rwanda the IRC team have developed a Youth Participatory Development Program, in partnership with the Ministry of Youth, Sports and Culture, to accomplish three primary objectives:

- To increase young people's capacity for participatory development by training democratically elected youth committees as a means of underscoring principles of coexistence and reconciliation.
- To ensure inclusion of all community youth in identifying problems and devising their own solutions by conducting participatory awareness campaigns in villages.
- To assist youth in planning and implementing viable, sustainable projects that promote their development through cooperative efforts that are inclusive of all community members.

During 1998, IRC conducted a youth-focused community planning exercise in Kibungo. Using PRA techniques, IRC was able to identify issues and needs of importance to youth. Using these findings as a framework, during 1999 IRC commenced a youth development program in two communes of Kibungo district, Birenga and Rutonde.

The expected outcomes include model programs to encourage youth participation, responsibility, and accountability; youth involved in their own development and civic society; increased productivity and cohesion through social, economic and cultural activities; marginalized and female youth promoted through targeted participation; and improved reproductive health through peer education and counseling.

Thousands of youth have participated in assessment and planning sessions, in sports competitions, and in poetry and theatre competitions with themes of peace, reconciliation and HIV/AIDS.

Involve young people in their own needs assessment, which include both the needs of unaccompanied young people and of youth-headed households. PLA methods are useful for this (see Appendix 4 for some ideas). Youth that are looking after young siblings may not be able to participate in school or youth center activities unless child care can be arranged. There are a wide range of potential activities in refugee settings that could provide a sense of purpose and self-esteem for young people. It is important for young people to gain experience and skills that provide feelings of competence, self-respect and hope that they will be able to make a living in the future. Meaningful activity and a sense of belonging to their community provide a counter to the factors that make young people likely to participate in high risk behaviors.



Young people are generally full of energy which can be channeled constructively. Try to identify leaders among them and give them recognition and acknowledgement. With a small amount of resources and some adult guidance young people might be encouraged to:

- Set up an open air ‘gymnasium’
- Look after and teach small children
- Learn traditional crafts from older people
- Organize sports tournaments
- Form music groups and plan entertainments
- Participate in protecting single women

### ***3.3 Community communication activities to change attitudes***

Structured community discussions provide opportunities for men and women to better understand each other’s perspectives and problems, and have been found to be effective in altering HIV risk behaviors.

In 1995 the British NGO, ActionAID, produced the Stepping Stones training package which helps communities to develop communication and relationship skills<sup>22</sup>. The package was designed for use in sub-Saharan Africa, but it has also been successfully adapted for use in Asia, North and Latin America and Europe. It includes a manual for trainers, and an accompanying workshop video. The package aims to enable individuals, their peers and their communities to change their behavior - individually and together - through the ‘stepping stones’ which the various sessions provide. Evaluations suggest that one of the most useful features of the Stepping Stones process is that the participants are divided into four small groups of 10-20, by age and gender: older men, older women, younger women, and younger men. All the groups are brought together for occasional sessions.

The aim of Stepping Stones is to enable women and men to describe and analyse their relationships and other experiences, and to develop solutions to the sexual health problems and risks that they face in the course of their daily lives. The materials enable people to explore issues that affect sexual health including gender roles, money, alcohol use, traditional practices, and attitudes to sex and death. The process can be used in existing HIV/AIDS projects, and in general development projects which plan to introduce an on-going AIDS component.

Stepping Stones is based on the following important principles:

- The best behavior change strategies are those developed by the members of a community themselves
- Peer groups need their own private time and space to identify and explore their own needs and concerns

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<sup>22</sup> Welbourn A. Stepping Stones: A training package on HIV/AIDS, gender issues, communication and relationship skills. Actionaid, London. 1995. <http://www.actionaid.org/stratshope/ssinfo.html>

- The process of self-analysis leads to greater self-awareness and self-respect, and this enables people to practice more assertive behavior
- The expression of our own needs leads to awareness of the needs of others, respect for others, better communication and care
- Behavior change will be more effective and sustained when the whole community is involved.

The sessions use a participatory approach of adult learning through shared discussions. The exercises are all based on people's own experiences. Role-play, drawing, and songs enable everyone to take part. Literacy is not needed. Participants discuss their experiences, act them out, analyse them, consider alternative outcomes, and then rehearse these together in a safe, supportive group. This approach may also be helpful in challenging cultural practices that increase risk of spread of HIV such as 'widow cleansing' when a dead man's brother has sex with his widow.

In some communities workshop sessions have been organized on a weekly basis, so four or five months are needed to complete the course. In other communities sessions have been held every afternoon five or six days a week, so that the course is completed in only three weeks. In some refugee settings it may be possible to conduct the sessions in this more intensive way. It may be difficult to get refugees or displaced people to engage with a process that they know is planned to take many months when they are hoping to go home as soon as possible, or when they are feeling fatalistic about the future.

It is important to bear in mind that in the safe environment created in the peer group sessions people may say more than they usually would. When these things are shared with the other groups the person may feel ashamed or embarrassed. Sometimes a woman may say something in a community meeting that gets her into trouble when she is alone with her husband. It is important that facilitators are well trained. In several different countries the Stepping Stones process has resulted in greater openness and reduced stigma and fear<sup>23</sup>.

### **3.4 Support micro-finance schemes and income generating activities**

Poverty is the major reason for vulnerability to HIV infection. Refugees are almost always poor, and have generally lost their means of earning an income. In camp settings all their needs may be provided for, but in many settings refugees try in a wide variety of ways to generate an income.

The United Nations Development Programme (UNDP) has recently become interested in the possibilities for linking NGOs that try to respond to the HIV epidemic with micro-finance institutions. They point out that these institutions work at the community level, with poor people, predominantly women, and often hold weekly meetings with small groups. Information could be shared at these meetings. Partnerships between these types of organisations could have obvious benefits.

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<sup>23</sup> Kaleeba N, Kadowe J, Kalinaki D, Williams G. Open Secret. People facing up to HIV and AIDS in Uganda. Strategies for Hope Series No. 15. [www.stratshope.org](http://www.stratshope.org)

It is difficult, but not impossible, for NGOs to implement income generating schemes supported by small revolving loans. There have been many failures and it is important to learn from these. Features that have been found to improve the chances of success include:

- consultation with local community structures
- guidelines for management of loan scheme with appropriate criteria for selection of beneficiaries and a clear policy for defaulters
- small standardized loans with increased loan size available if previous loan repaid
- realistic interest rates that cover management costs
- individuals responsible for loans, rather than groups
- training in budgeting, loan management and skills associated with provision of loans
- careful selection of appropriate activities for income generation, based on familiar and manageable activities such as selling vegetables or raising chickens, chosen by the beneficiary

It is important to avoid providing loans to the poorest indebted families who are too poor to repay a new debt. It is better to establish a savings scheme or provide animals or food directly to the poorest families, to avoid increasing their stress.

Income generation activities can be designed to encourage women to be involved in a support group and community activities.

IRC has implemented income generation schemes and has a Microfinance Technical Unit. Seek advice from IRC headquarters when you plan a microfinance program.

### **Suggested indicators**

Clinic reports are not a reliable way to measure a decrease in STIs or incidents of sexual violence in a population. This is because trends in these reports will depend on:

- quality of and access to services
- awareness of the population
- willingness to attend with an STI or after being raped
- the quality of recording of consultations

as well as

- the actual rate of incidents of sexual violence or STI in the community.

Since any program that addresses these issues would hope to increase the quality and accessibility of services, raise awareness in the community, and improve reporting, as well as prevent the problems, we would expect rates of reported cases of STIs and sexual violence to increase initially. It is important to document reported rates of STIs and sexual violence, but such statistics need to be interpreted cautiously, and in the light of other information from focus group discussions and community based surveys.

| <b>Indicator</b>  | <b>Method of measurement</b>   |
|---|--|
| <b>VCT services</b>   |  |
| Proportion of population aware of VCT service by age and sex  | Community survey   |
| Numbers attending VCT service by age and sex  | Review of records  |
| Quality control system established for HIV tests  | Observation and review of documents  |
| <b>Promotion and distribution of condoms</b>  |  |
| Number of outlets distributing condoms  | Observation, review of documents   |
| Knowledge of correct condom use   | Survey   |
| Number of condoms distributed per month per capita  | Distribution records   |
| Increase in use of condoms with last sexual intercourse (with regular partner / with non-regular partner), among specified groups | Survey among specified groups  |
| Change in attitudes towards condoms   | Focus group discussions  |
| <b>Prevention and management of STIs</b>  |  |
| Increase in knowledge of men and women in relation to STIs  | Survey   |
| Improved quality of documentation of consultations for STIs at the clinic   | Focus group discussions<br>Review of clinic records  |
| Proportion of patients with an STI appropriately managed according to the syndromic management protocol                           | Clinic observation checklist   |
| Proportion of STI patients who receive condoms by age and sex   | Review of clinic records   |
| Number of health workers trained in syndromic management of STIs  | Review of training reports   |
| Increased satisfaction of men and women with treatment for STIs   | Focus group discussions  |
| Reduction in prevalence of STIs among pregnant women  | Survey of antenatal clinic attenders (with genital examination and swabs or urine specimens for PCR testing if available.) |

### IEC materials

|   |   |
|---|---|
| Numbers and range of IEC materials produced as planned to support interventions | Review of materials                         |
| Numbers of IEC materials distributed appropriately                              | Observation<br>Community survey             |
| Target groups reached and messages understood                                   | Focus group discussions<br>Community survey |
| Changed attitudes, beliefs and knowledge  | Focus group discussions<br>Community survey |

### Prevent sexual violence and provide care for survivors

|   |   |
|---|---|
| Increased feeling of safety among women and young people  | Survey<br>Focus group discussion                            |
| Protocols available for psychosocial and medical care of survivors of sexual violence.  | Observation<br>Review of protocols                          |
| Proportion of survivors of sexual violence who receive appropriate psychosocial and medical care within a specified time period | Clinic records  |
| Number of health/social workers trained to manage survivors of sexual violence  | Review of training reports                                  |
| Increased awareness that care and counseling are available for survivors of sexual violence                                     | Survey<br>Focus group discussions                           |
| Proportion of reports of sexual violence that result in a penalty for the perpetrator   | Will depends on circumstances – definition of 'penalty' etc |

### Societal context

|  |                         |
|--|-------------------------|
| Changes in attitudes and practices as described by different groups within the community | Participatory processes |
|--|-------------------------|

### Additional resources

UNAIDS. Acting early to prevent AIDS: The case of Senegal. UNAIDS Best Practice Collection 1999.

The Reproductive Health of Refugees. Special supplement, edited by Laurel Shreck, International Family Planning Perspectives. 2000;26(4):161-192

### ***Behavior change***

Parnell B, Benton K. Facilitating *sustainable* behavior change: A guidebook for designing HIV programs. International Health Unit, Macfarlane Burnet Centre for Medical Research, Australia 1999.

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### ***Condoms***

Gardner R, Blackburn RD, and Upadhyay UD. Closing the Condom Gap. Population Reports, Series H, No. 9. Baltimore, Johns Hopkins University School of Public Health, Population Information Program, April 1999. Available at <http://www.jhuccp.org/pr/h9edsum.stm>.

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### ***Voluntary counseling and testing***

UNAIDS. The importance of simple rapid assays in HIV testing. HIV VCT Evaluation Guides [www.unaids.org](http://www.unaids.org)

UNAIDS/WHO. Guidelines for using HIV testing technologies in surveillance. UNAIDS/WHO Working group on global HIV/AIDS/STI Surveillance Geneva, 2001.

### ***STI management and control***

UNAIDS. The public health approach to STD control. UNAIDS Technical Update. May 1998.

WHO/UNAIDS. Sexually transmitted diseases: policies and principles for prevention and care. Geneva. WHO/UNAIDS. 1997.

WHO Initiative on HIV/AIDS and Sexually Transmitted Infections (HSI) STD case management course [http://www.who.int/HIV\\_AIDS/knowledge/stdcourse.htm](http://www.who.int/HIV_AIDS/knowledge/stdcourse.htm)

Adler M, Foster S, Richens J and Slavin H. (1996) Sexual Health and Care: Sexually Transmitted Infections – Guidelines for Prevention and Treatment. London: Overseas Development Administration. Overseas Development Administration, £6.95, pp 136. ISBN 0 902 500 902 Copies can be obtained, free of charge, by people working in developing countries from International Family Health, 13 Northburg St, London EC1V 0AH (tel 0171 336 6677; fax 0171 336 6688; email IFH-UK@dial.pipex.com)

WHO. Management of patients with sexually transmitted diseases, WHO Technical Series Report Series 810, 1991.

Dallabetta G, Laga M, Lamptey P. Control of Sexually Transmitted Diseases. A handbook for the design and management of programs. 1997. AIDSCAP / Family Health International.

### ***Communication***

You, Your Life, Your Dreams: A Book for Adolescents 2000. Developed by Family Care International, Inc and the Family Planning Association of Kenya in collaboration with Deutsche Stiftung Weltevölkerung US \$12.00/copy for recipients in Europe and North America and representatives of international organizations. 1 copy free, 2+ US \$6.00/copy for recipients in developing countries. An information handbook designed for young people, aged 14 to 19, to read themselves. It is an excellent resource for youth centers, schools, health facilities, libraries and programs that serve young people in Anglophone Africa

Starrs A, Rizzuto R. Getting the Message Out: Designing an Information Campaign on Women's Health. Family Care International, Inc. 1995. US \$6.00/copy for recipients in Europe and North America and representatives of international organizations. 1 copy Free, 2+ US \$3.00/copy for recipients in developing countries.

Strengthening Communication Skills for Women's Health: A Training Guide Family Care International, Inc.

The three books above can be ordered from: Family Care International, Inc. 588 Broadway, Suite 503. New York 10012, USA. .  
[http://www.familycareintl.org/pubs/pubs\\_aapw.htm](http://www.familycareintl.org/pubs/pubs_aapw.htm)

UNAIDS. Radio and HIV/AIDS: Making a difference. A guide for radio practitioners, health workers and donors by Gordon Adam and Nicola Harford. Media Action International UNAIDS Best Practice Collection Key material.

### ***Prevent and manage the consequences of sexual violence and coerced sex***

Security Guidelines for Women, United Nations Security Coordination Office, United Nations, New York, 1995.

Sexual Violence against Refugees: Guidelines on Prevention and Response, UNHCR, Geneva, 1995.

WHO. Emergency Contraception: A Guide for Service Delivery, WHO, Geneva, 1998.

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WHO/UNHCR. Mental Health for Refugees, WHO/UNHCR, Geneva, 1994.

***Microfinance and HIV/AIDS***

UNDP. Microfinance and HIV/AIDS: A consultation on joint involvement in effective responses to HIV and AIDS. 15 – 18 September 1999.



# 9

## Strategies for prevention of transmission through injecting drug use

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### Introduction

HIV spreads very easily between people who inject drugs together and share needles, syringes and other injecting equipment. Blood drawn back into the syringe can pass directly into the bloodstream of the next person to use the syringe.

Because it is illegal to inject drugs it is often difficult for governments and communities to admit openly that it occurs. Those who inject are often reluctant to admit their drug use, or to seek information and treatment. This means that it is difficult to ask about the extent and nature of injecting drug use.

There are now an estimated 5.5 million people who inject drugs in the world. Since it is a hidden problem there may be many more. There are people who inject in at least 128 countries<sup>24</sup>. Injecting drug use is spreading to new countries, including eastern Europe, Latin America and, more recently, to African countries. Epidemics of HIV follow the spread of injecting drug use. Injecting drug use is the most common cause of transmission of HIV in many Asian countries, including Malaysia, Vietnam, Yunnan province in China, and the north-eastern states of India, parts of eastern Europe and several of the Newly Independent States, a number of Latin American countries, and some western European countries such as Spain and Italy. In the Russian Federation, more than half of all reported HIV cases to date has been in injecting drug users.

The problem of injecting drug use does not occur in all refugee settings, but there are a number of reasons why it may be a major problem. Breakdown in law and order in chaotic situations allows organized criminals to traffick drugs as well as people. Armed conflicts are linked with arms sales, and arms sales are often linked with drug production and trafficking. Refugees in camp settings may be bored and fatalistic about the future. Drugs can provide excitement and an escape from the painful reality of life in a camp. Groups who inject together provide a ritual and a sense of belonging that is attractive to young people, especially to those who have lost their families. Taking drugs can relieve feelings of fear, anxiety and depression and provide a way of coping with painful memories.

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<sup>24</sup> Drug use and HIV/AIDS UNAIDS statement. United Nations General Assembly Special Session on Drugs UNAIDS Best Practice Collection Key Material, Geneva, UNAIDS, 1999.

Military personnel may introduce new drugs, or new ways of taking drugs, to a refugee population. As a result of mass displacements there may be a mixing of populations with different drug taking behaviors.

Drugs that are commonly injected include:

- **Opiates** produced from opium, collected from the sap of the seed pods of the poppy plant. Opium contains morphine, which can be converted to heroin by a simple chemical process. There are also synthetic or man-made opiates such as methadone and pethidine. These substances share the ability to relieve pain and produce a detached and pleasant mood. They induce physical dependence leading to distressing withdrawal symptoms when the drug is stopped.
- **Stimulants** including cocaine from the coca leaf. It produces a sense of exhilaration and decreases fatigue and hunger. There are also synthetic stimulants such as amphetamines. These substances have a high potential for dependence, and can lead to psychosis.
- **Depressants** including barbiturates and sleeping tablets. These substances cause drowsiness or pleasant relaxation. They also lead to physical and psychological dependence.

Of course drugs that are legal in many countries – alcohol and tobacco, also have serious health consequences, but they are not injected and do not lead directly to spread of HIV so we do not discuss them here.

## Rationale

It is usually difficult to get people to stop injecting drugs. However many people who inject drugs do eventually stop. The idea of harm reduction is to reduce the harmful effects of injecting drugs for the injecting drug user, their family and community, until they cease injecting. The harmful effects of injecting drug use include:

- death from overdose,
- infection with blood-borne viruses including HIV, hepatitis B and hepatitis C,
- spread of HIV or hepatitis B to sexual partners,
- abscesses and bacterial blood infections from dirty needles,
- embolism from impurities in the drug,
- family conflict,
- STIs and sexual violence associated with prostitution,
- crime and time in prison.

To prevent harm from drug use we need to work in three areas:

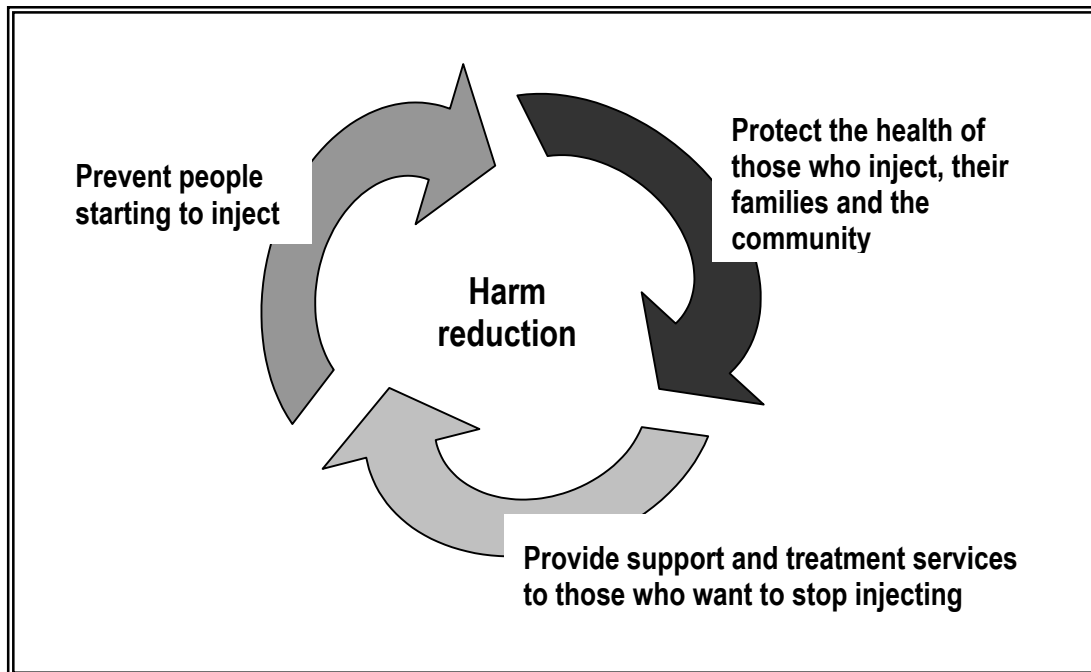
1. prevent people starting to inject
2. protect the health of those who inject and their families
3. provide support and treatment services to people who use and want to stop.

It can take a long time to prevent people starting to use drugs, or to provide treatment and rehabilitation services to help people to stop using. However it is possible to implement harm reduction strategies quickly, and it is important to do so because HIV spreads very rapidly among people who inject.

There is evidence that programs that supply sterile needles and injecting equipment are able to reduce the extent of spread of HIV among people who inject. A study in over 80 cities showed that the incidence of HIV decreased by 5.8% per year in the 29 cities with needle-syringe programs (NSPs) and increased by 5.9% per year in those without<sup>25</sup>. Countries that implemented harm reduction strategies early in the HIV epidemic, such as Australia, New Zealand, the United Kingdom, the Netherlands and Denmark, have had a much lower rate of infection among drug users than in other countries. There is a great deal of evidence that NSPs do not lead to increased drug use or the recruitment of new injecting drug users. NSPs also allow an opportunity to provide information and referral to treatment and rehabilitation services for those who want to stop injecting.

In settings where needles and syringes are difficult to obtain the drug dealer often provides the injection as well as the drug. This inevitably leads to spread of blood borne viruses as many people are injected with the same equipment. Sometimes drug users make and use their own substitutes for needles and syringes, including eye droppers and plastic pen parts.

### Strategies



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<sup>25</sup> Hurley S, Jolley DJ, Kaldor JM. Effectiveness of needle-exchange programmes for prevention of HIV infection. *Lancet* 1997; 349:1797-1800.

Strategies in each area need to be integrated. The detail of the interventions will depend on the situation analysis (see Chapter 5). The first priority is to provide access to sterile needles and syringes. Experience in many countries shows that it is essential to involve those who inject, their families, and the community in planning and implementation.

1) *Prevent people starting to inject – for example:*

- provide opportunities for a drug-free life-style (sport; skills-training; art; music; jobs)
- provide accurate information about drugs
- educate police, teachers, health and welfare professionals
- strengthen sense of community belonging and reconciliation
- strengthen mental health services
- strengthen opportunities for autonomy; foster sense of control
- provide informal counseling services for young people
- provide a place for young people to meet

2) *Protect the health of those who inject and their families:*

- improve access to sterile needles, syringes and injecting equipment. If it is necessary to re-use injecting equipment drug users need to know how to sterilize it through boiling or use of bleach between each use.
- inform those who inject and their families about blood-borne viruses
- provide information about safer injecting practices
- provide information about the danger of overdose and side-effects of drugs
- promote condom use
- train health workers to manage overdoses and drug side-effects
- encourage those who inject to dispose of needles and syringes with care
- improve access to health care services – reduce stigma and discrimination
- provide informal counseling and support services to families
- establish outreach education and peer education
- encourage voluntary counseling and testing for HIV for those who inject drugs
- advocate for policy and legislative support for harm reduction strategies

3) *Provide support and treatment services to people who use and want to stop:*

- provide opportunities for self-help groups / mutual support
- train health workers and doctors in counseling, withdrawal strategies, drug substitution, and referral services
- enable access to drug substitute programs
- establish referral mechanism for residential detoxification services

- provide support for home detoxification – including support and information for families.

### ***Education and communication***

The most effective way to reach those who inject is through outreach and peer education. Outreach workers are trained people from outside the community of injectors, although they may be former injectors. Peer educators are drug injectors who have been trained to work with their community. IEC materials that seek to communicate with drug users need to be prepared by drug users because they understand what drug injectors do and why they do it. They can express messages in ways that other drug users will understand, and they have more credibility with drug users than health or prison officials.

Peer educators may undertake a range of tasks including the provision of injecting equipment and bleach, the collection of used injecting equipment, disseminating information about how to use bleach and issues related to health care and counseling.

If it is feasible to assist in the establishment of injecting drug user groups they can be very effective at coordinating and supporting peer educators. However the existence of such groups requires the co-operation of the police or law enforcement officers.

#### **Discussion point**

Why do people inject drugs rather than smoke them or take them by mouth?

It can be difficult for people who do not inject drugs to understand why people inject. When someone injects a drug the effect is very rapid because the drug enters the blood stream straight away. Drug users sometimes call this the 'rush'. Injecting soon comes to be associated with feeling the 'rush'. Needles are associated in the injector's mind with pleasure rather than pain. This is why when someone is used to injecting a drug, if they cannot get their usual drug they will often inject some other drug, or even a substance that is not a drug.

When a drug becomes more expensive people are more likely to inject because they get more effect from the same amount of drug than if they smoke it or take it by mouth.

Injecting drug users often dissolve heroin in water and lemon juice in a spoon or bottle top over a candle; they may use cotton wool or cigarette filter tips as a filter when they draw up the drug. They use a tourniquet to enlarge their veins to make it easier to place the needle in the vein. Users often inject with others. The ritual of preparing a 'fix' of their drug becomes important to those who inject. When they stop injecting they will miss the ritual and the rush of injecting, as well as the effects of the drug itself. Sharing any of this drug injecting equipment, not just needles and syringes, carries a risk of transmission of HIV, and hepatitis C and B.

Heroin users may inject two or three times a day, but cocaine users inject much more frequently because it breaks down in the body more rapidly. It is almost impossible to supply sufficient needles and syringes to ensure that cocaine users inject safely.

### ***Advocacy and stigma reduction***

The harm reduction approach is often controversial because it may be interpreted as condoning drug use. Advocacy is necessary; presenting harm reduction in a broad way that incorporates strategies to prevent drug use can help. It is unfortunate that debates about how to prevent harm from drug use are sometimes presented as two extreme positions: an approach of “zero tolerance” towards drug use, in which drug use becomes a stigmatized, secret and hidden activity, and on the other hand, encouragement of drug use by giving users the equipment they need to inject. In fact there is evidence that a harm reduction approach does not lead to increased use of drugs.

Injecting drug use is a heavily stigmatized behavior in most societies. There may be disapproval of the pleasure drug users obtain from their drug use, and understandable resentment of the crimes that drug users commit and their neglect of their families and responsibilities. As a result drug users become marginalized.

One way to reduce stigma associated with injecting drug use is to ensure that needles and syringes are not discarded in public spaces. Needles and syringes left in public spaces are a source of danger to others, especially children who may play with them. They cause great concern and anger. Campaigns to clear away needles and syringes and to ensure that they are properly and carefully disposed of can do much to reduce anger against drug users and NSPs.

If being in possession of injecting equipment is a crime then those who inject are more likely to share needles and syringes. Education of police and advocacy with those who make and implement laws is necessary when planning a NSP. Local police may have a good understanding of the drug-using context and have often been willing to cooperate when they understand the benefits to the community as well as to the drug users.

Advocacy through peer education is likely to be most effective. Just as injecting drug users and others at risk of HIV are most likely to trust and believe their peers, so law making officials, political and military leaders and police officials are most likely to be persuaded by their peers.

### ***Needle-syringe programs***

If injecting drug use is a problem in your setting it is important to consider the establishment of a NSP. This may be situated in a health clinic, a welfare or youth center, or be run by outreach workers. The situation analysis should provide information about the most appropriate places to situate NSPs. Involve injecting drug users and the community in the planning. But be aware that this issue can be a source of much conflict in a community because people may worry that an NSP in their health center ‘normalizes’ the use of drugs. Also, those who inject drugs may be reluctant to visit health centers because they fear discrimination. Outreach workers need to be well trained, supervised and supported.

Consult with injecting drug users to estimate the numbers of needles and syringes that will need to be ordered. Monitor the use closely so that sufficient supplies are in stock.

### ***Drug treatment programs***

It is possible to stop heroin use abruptly ('cold turkey'), but it is painful and causes symptoms of diarrhea and muscle pains as well as severe cravings for the drug. Relapse is common. 'Drug substitution' means replacing the usual drug with another drug taken



by mouth. The aim is to enable the drug user to lead a more normal and productive life, avoiding crime and prostitution. The risk of overdose, of HIV, and of consequences of injecting contaminated drugs are all reduced. Methadone syrup taken by mouth is a long-acting substitute for heroin that prevents withdrawal symptoms. There is evidence that methadone maintenance is safe, improves the health of many users, prevents deaths, reduces crime and enables people to go back to work and provide for their families. A methadone service provides opportunities to provide other services to drug users. However some injectors do misuse the methadone they are prescribed – they may sell or even inject the methadone, while some continue to inject heroin. There is a need for counseling and support.

It will not be possible to establish drug substitution programs in unstable or temporary settings. An important principle of these programs is that the supply of methadone or other drug substitute needs to be consistent. If you are able to establish a methadone program for refugees, try to ensure that the local host population also has access to the service.

Experience shows that if drug users wait for weeks to get into a treatment and rehabilitation program by the time it is their turn they may have lost their motivation. Only voluntary detoxification is effective in the long term. When drug addictions are 'treated' in prison or prison-like rehabilitation centers relapse rates are high, especially when family members or the authorities arrange the detention.

Buprenorphine is a synthetic painkiller. When the price of heroin increases some drug users begin using buprenorphine as an alternative. In recent years it has been used successfully as a drug substitute for people who are dependent on opiates. In some

countries it is cheaper and more readily available than methadone. Buprenorphine is a good substitute drug for people with low to moderate opiate dependency because it has few side effects, only mild withdrawal symptoms, and does not need to be taken every day. A drop-in center can be established which clients visit twice a week and receive health care and counseling support as well as buprenorphine<sup>26</sup>.

### **Harm reduction among refugees in Hong Kong**

Pillar Point in Hong Kong was opened as a transit camp for Vietnamese people awaiting departure to a country of asylum. The camp is in an area well known for drug use and criminal activity. The difficult conditions, sense of helplessness and hopelessness about the future, the pleasure and social acceptance of drugs among the male refugees have led to much heroin use in the camp. It is estimated that up to 95 per cent of the men are dependent. They work mainly as day laborers and most now have criminal records, which block their chances of resettlement. In July 1996 Medecins Sans Frontiers began a harm reduction program among drug users. Their aims were to reduce the health risks of injecting drugs and to improve the overall quality of the lives of those who inject and their families. They planned to raise awareness of the health related risks, encourage safer injecting practices and safer sex, to encourage safer disposal of used needles and syringes, and to help injectors gain access to methadone programs.

The field team was composed of a Vietnamese drug counselor and a doctor: they worked in the evening and on the weekends as this was the best time to reach injecting drug users. The workers offered confidential individual counseling when alternatives of drug treatment and safer injecting practices would be discussed. They also gave out a pack containing three needles and syringes, three sterile water vials, three sterile swabs, one condom and a leaflet with appropriate information about STIs, HIV/AIDS and condoms. They discussed methods of safer using and listened to concerns. Individual needle and syringe boxes, closed by a tamper proof seal, were distributed and, when used, collected by the doctor. A three month survey of the program's clients found that:

- 70 per cent of injecting drug users had not shared needles and syringes
- 30 per cent of those who had shared had cleaned the needle and syringe before injecting
- 81 per cent always cleaned their skin with a swab before injecting
- 74 per cent used boiled or sterile water to mix up their drug

They also found that 75 per cent of their clients were concerned about disposal issues and understood the danger discarded needles and syringes could be to other people, especially to the children in the camp. The camp has now become free of discarded used needles and syringes.

Nemayechi, G. Taveaux, T. Medecin Sans Frontiers HARP (Harm Reduction Program) for the Vietnamese drug users in Pillar Point refugee camp, July 1996- April 1997. Evaluation Report.

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<sup>26</sup> Dorabjee J, Samson L, Dyalchand R. A Community Based Intervention for Injecting Drug Users (IDUs) in the New Delhi Slums, WHO Drug Substitution Project Meeting on Opioid Substitution Programs in Asia, Kathmandu, February, 1997.



## Suggested indicators

| <i>Indicator</i>   | <i>Method of measurement</i>                                   |
|--|--|
| Plan to address risk of spread of HIV through injecting drug use developed with injecting drug users   | Review of documented plan                                      |
| Numbers of teachers, police, health and welfare workers trained in harm reduction for injecting drug use issues                                    | Training reports   |
| Improved understanding of the harm reduction approach among key officials, teachers, police, health and welfare workers, and the general community | Focus group discussions and in-depth interviews                |
| Centers or activities available for youth  | Observation, camp documents                                    |
| Injecting drug users aware of and able to access sterile needles and syringes  | Interview survey   |
| Number of needles and syringes exchanged or distributed  | Needle-syringe exchange program records<br>Review of materials |
| Pre-tested information materials available about how to prevent spread of blood borne viruses through injecting drug use                           | Systematic observation   |
| Public spaces free of discarded needles and syringes   | Review of training reports                                     |
| Number of peer educators trained   | Review of logbooks of peer educators                           |
| Number of peer educator contacts   | Review of training reports                                     |
| Number of health workers trained   | Clinic records   |
| Proportion of clients in drug substitution program that have been followed up appropriately  | Follow up survey   |
| Proportion of clients that have relapsed and gone back to injecting drugs 6 months after completing the substitution program                       | Annual anonymous unlinked survey                               |
| Decreased HIV incidence among injecting drug users   | In-depth interviews and focus group discussions                |
| Improved quality of life of drug users and their families  |  |

### **Additional resources**

Manual for reducing drug related harm in Asia. The Centre for Harm Reduction, Macfarlane Burnet Centre for Medical Research and Asian Harm Reduction Network. Available at: <http://www.chr.asn.au>

Wodak A, Crofts N, and Fisher R. HIV infection among injecting drug users in Asia: an evolving public health crisis. *AIDS Care* 1993, **5**: 315 - 322.

Crofts N and Herkt D. A history of peer-based drug user groups in Australia. *The Journal of Drug Issues* 1995 25(3): 599-616.

Des Jarais DC. Harm Reduction: A Framework for Incorporating Science into Drug Policy. *American Journal of Public Health* 1995;85: 10-12.

UNAIDS. Drug use and HIV/AIDS. June 1998.

Drucker E. 1995. Harm Reduction: A Public Health Strategy. *Current Issues in Public Health* 1: 64-70. <http://www.lindesmith.org/library/tlcdruck.html>

Friedman S, De Jong W and Wodak A. Community development as a response to HIV among drug injectors. *AIDS* 1993. (Suppl 1):S263-S269.

# 10

## Enabling people to live positively with HIV

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### Introduction

HIV positive people are often seen as carriers or victims of a deadly virus. They are usually unable to discuss their status openly. But increasingly people living with HIV/AIDS (PLWH) are looking at life beyond diagnosis; HIV infection needs to be viewed as a chronic, long-term disease. With acceptance, good nutrition, care and support, people with HIV live long and productive lives.

PLWH have much to contribute to the design, implementation, monitoring and evaluation of HIV prevention and care activities. There is a strong link between the promotion of the rights of PLWH and prevention of spread of HIV. PLWH often have much to tell about local treatment, care and support services including ideas on how they can be improved. Supporting PLWH to speak about their own experiences is a valuable behaviour change communication strategy<sup>27</sup>.

### Rationale

*What do we mean by “people living with HIV”?*

Most people who are living with HIV do not know that they have it. But some who have never had a test may feel certain that they have become infected with the virus, for example a widow of a man who dies of AIDS who becomes sick with similar symptoms. Others who have the virus may suspect or fear that they are infected, while some are quite unaware of the possibility. Among those who have tested positive for HIV there are those who deny their HIV status, either consciously or sub-consciously, and continue to believe that they are not infected. Some of those who accept that they have HIV choose not to tell anyone. Some may tell their partner or closest friend; some tell most of their family and friends; others are willing to become publicly positive and to talk about living with HIV with people that they do not know. Some people are willing to become publicly positive soon after their diagnosis; some may take time to tell family and friends gradually before they start to talk in public. Others may be willing to talk to people that they do not know - but do not want to tell their family or their work colleagues for a variety of reasons. It is important not to make assumptions and to respect the right of PLWH to choose who they want to tell. We should also remember that there are PLWH

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<sup>27</sup> Much of this chapter has been adapted from the chapter ‘Positive Action: The Central Role of HIV+ People’ by Susan Paxton in “Community Action on HIV” edited by Kwarteng, Moodie, and Holmes. Second edition. December 2001. Macfarlane Burnet Centre for Medical Research.

who did not choose to publicise their HIV status but because of a lapse of confidentiality it became public knowledge. When working with PLWH it is vital to maintain confidentiality.

Any of the above groups of PLWH may contribute to the field of HIV prevention and care, not only those who are willing or able to be publicly positive. In addition, it is vital to hear and consider the views of those who are affected by HIV – the family, friends and lovers of those infected.

### ***Stigma***

PLWH have the same rights to privacy, freedom from violence, freedom of movement, housing, employment, care and support, and access to health care as those who are not infected. Yet positive people are often deprived of their rights because of the stigma surrounding AIDS. People are often afraid to talk about AIDS because it means talking about culturally taboo subjects such as sex and death. So they push it away and convince themselves that HIV only affects particular groups, 'other' people. They transfer their fears onto those already living with the virus.

We need to encourage people to talk openly about AIDS and listen to what HIV-positive people have to say about their experience. By creating an environment in which PLWH have a voice, people begin to identify with those living with the virus. The issue of HIV becomes more familiar and stigma and discrimination decrease. People begin to examine their own risk of infection in a responsible way.

The Paris AIDS Summit Declaration<sup>28</sup>, signed by 42 countries, states that the success of HIV prevention and care programs depends on the full participation of PLWH. The Declaration commits governments to consult with affected groups, eliminate discrimination against PLWH, and decrease women's vulnerability to HIV. In order to carry out this commitment to greater involvement of PLWH the Declaration acknowledges the need to strengthen the skills of HIV-positive people.

HIV often robs people of control over their life. A positive diagnosis is accompanied by loss, disempowerment and social ostracism. Rather than become victims many PLWH choose to respond in a positive way to their situation. Often they are passionately motivated to contribute to HIV prevention and care. If a strategy is in place to ensure adequate training and support, positive people can be involved at every level of the community response to AIDS. They might become involved in:

- \$ counseling, care and support;
- \$ disseminating information to others infected with HIV;
- \$ prevention programs, including raising awareness and educating the community;

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<sup>28</sup> Declaration of the Paris AIDS Summit (Section IV, Paragraph 1) available at <http://www.unaids.org/whatsnew/conferences/summit/index.html>

or in working groups designing models of health care and service delivery.

Because of stigma there are few who are willing to make their positive HIV status public, so those that do have a huge burden of work, with little opportunity to gain support from each other. PLWH meeting in Kenya described four areas of stigma that need to be addressed<sup>29</sup>:

**1) Self-stigmatisation** - avoidance of people, withdrawal, depression and self-hatred. This may be expressed as low self-esteem and playing the role of an ill person or “victim”. This has a negative impact on mental well-being and in turn on physical health.

**2) Stigma from the health care sector** - apathy in medical services, judgmental attitudes from counselors, nursing and medical staff, compulsory or involuntary disclosure, and denial of treatment or sterilization without informed consent.

**3) Representation and communication** - sources of stigma due to careless language and unclear terminology used by the media, social leaders and society in general. Stigma arises from misrepresentation of PLWH as people who are dying from, rather than living with, a virus. Misconceptions are also presented about the behaviour of PLWH, particularly sexual behaviour. Misinformation about routes of transmission of HIV generates discrimination and fear. Finally, tokenism was considered as an additional source of stigma for PLWH, when individuals are used for the needs of other people or organisations.

**4) Social and work environments** - hostility, violence, silence and denial about HIV/AIDS often lead to exclusion of PLWH. These environments include work, housing, and insurance systems. The children of PLWH may be ostracised at school and in the community.

## **Strategies**

### ***1) Protect the human rights of people living with HIV/AIDS***

Relief agencies can assist PLWH to document and describe the human rights issues they face and examine the impact of discrimination on their quality of life in order to achieve changes in attitudes, policy and legislation. If possible they should be helped to contact other PLWH groups in the region or in other countries (see addresses below). For example, APN+, the Asia Pacific Network of People Living with HIV/AIDS, has undertaken a peer-based project to document violations of human rights in a systematic way.

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<sup>29</sup> Report of the technical consultation on greater involvement of people living with HIV/AIDS (GIPA) March 2000 Nairobi, Kenya.

When IEC materials are produced in relation to any aspect of HIV care and prevention there is an opportunity to address stigma and ignorance. Materials can also be produced specifically to counter fear, stigma and discrimination. PLWH may be invited to speak at important occasions such as the opening of a building, the launch of a new program, judging a competition, or meeting a visiting dignitary. Encourage representation of PLWH on refugee committees, hospital boards and local government advisory committees.

Many health professionals did not learn about HIV during their original training, and may be ignorant about the transmission and management of HIV infection. Because doctors and nurses tend to be trusted opinion leaders health care consultations can be a potent generator of stigma, especially if other staff and patients observe the doctor taking unnecessary precautions. On the other hand consultations can provide an opportunity to reduce stigma and fear by demonstrating that physical contact does not transmit HIV, and providing an example of compassion and respect. Health professionals need clear information about transmission routes and universal precautions (see page 200), as well as their obligations to respect the rights of PLWH. Invite PLWH to assist in planning and teaching training courses for health workers to improve the care health workers provide to people with PLWH and to explain their information needs.

## ***2) Establish peer support groups***

Because positive people are marginalised and isolated it is important to create a supportive environment in which they can contribute effectively. The first step is to facilitate peer support. This means enabling HIV-positive people to meet each other in a safe, comfortable and confidential environment. Lack of space and fear of identification may make this difficult in refugee settings where there may be a lack of trust. In insecure environments, fear and discrimination flourish. The prime purpose of support groups is to empower PLWH to live satisfying and productive lives. Members of support groups know that there will be someone to care for them when they are ill, just as they have cared for others.

'Peer support' may be as simple as two people having an opportunity to meet with each other. Once a group is established, other people will join. It is a good idea for the group members to decide some rules early on. Some examples are: 'Listen to each other and respect what each other says'; 'Everything discussed in the group will stay in the group and will not be discussed with others outside the group'. Peer groups can help PLWH to understand their own health and treatment information through newsletters and workshops. Contact details for the group can be given to PLWH during post-test counseling. Resources should be set aside for publicity. There is a particular need to attract men as members. Men are often more reluctant than women to acknowledge their positive status to themselves or others.

## ***3) Build capacity and enhance skills of PLWH***

Talk to positive people who want to offer their time. Find out about their skills and experience and what they would like to learn. This might include:

- basic facts about HIV and AIDS
- advocacy, public speaking and media skills
- counseling
- group development and facilitation skills, and meeting procedures
- financial management
- strategic planning and organizational skills
- evaluation and monitoring
- proposal writing
- home-based care
- stress management

Acknowledge the skills and talents that refugees who are positive already have. Positive people who have become actively involved in AIDS work include writers, nurses, performers, doctors, teachers, and lawyers.

#### ***4) Train counselors to give psychological support to PLWH***

Because HIV positive counselors often have an immediate understanding of many of the issues their clients face and may be highly sought after. They can become overwhelmed by the many demands and need supportive counseling or spiritual guidance.

Many women living with HIV already care for partners and children who also have the virus; some PLWH involved are in home care programs. Those who carry this double load need additional care and support themselves. Being a home-based care volunteer can be satisfying but may also be emotionally overwhelming when it makes PLWH think about their own future. The death of a client can be a particularly difficult time for positive carers, and counseling should be available to them.

Make sure that positive volunteers involved with your organisation have basic health care, including adequate shelter, a good diet and access to treatments for opportunistic infections. Maintaining the confidentiality of HIV-positive clients and volunteers is vital.

At times professionals may be reluctant to involve positive people. Often workers are so preoccupied with responding to the immediate demands placed on them that it is difficult to step back and plan a strategy which recognises, accepts and supports the participation of PLWH. It is important to be flexible and to collaborate with positive people as equal partners.

PLWH should never be pressured to disclose their infection as a service to the community. It is important to emphasise here that while the involvement of infected and affected people in HIV prevention efforts is encouraged, this should only happen in an environment where disclosure of their HIV-positive status will not endanger their lives or lead to discrimination.

Taking an active part in HIV programs can be one way that PLWH can regain a sense of control. It has enriched the lives of many, giving them dignity and self-respect. PLWH visibility is also inspiring for other positive people and helps them to develop a more optimistic outlook. They realise that it is possible to live a healthy, useful and fulfilling life with HIV.

### Suggested Indicators

| <i>Indicator</i>   | <i>Method of measurement</i>       |
|--|------------------------------------|
| Proportion of health care workers (of all levels) trained in non-discriminatory care and their obligations towards human rights of PLWH. | Training reports                   |
| Written information materials for health professionals to reduce stigma  | Review of materials                |
| Number of counselors trained in psychological support for PLWH   |                                    |
| Number of members of peer support group/s for PLWH   |                                    |
| Details of support groups available at post-test counseling  | Observation                        |
| Awareness of PLWH of peer support groups   | Observation                        |
| Testing for HIV always voluntary and accompanied by counseling   | Review of VCT centre records       |
| PLWH not segregated in clinics or hospital   | Observation                        |
| Referral and follow-up mechanisms in place at VCT centers and peer support groups for other sources of care and support for PLWH         | Observation<br>Review of documents |

### Additional Resources

Enhancing the greater involvement of people living or affected by HIV/AIDS in sub-Saharan Africa. October 2000.

[www.unaids.org/publications/documents/persons/index.html](http://www.unaids.org/publications/documents/persons/index.html)



Paxton S. Lifting the burden of secrecy: a manual for HIV-positive people who want to speak out in public. Asia-Pacific Network of People Living with HIV/AIDS. Available at [www.undp.org](http://www.undp.org)

**Regional networks of people living with HIV/AIDS:**

Asia Pacific Network of People Living with HIV and AIDS

62B Race Course Road, Singapore, 218568

Tel: 65 295 1153; Fax: 65 295 5567 e-mail [apn@pacific.net.sg](mailto:apn@pacific.net.sg)

Network of African People Living with HIV and AIDS,

PO Box 32717, Lusaka, Zambia.

Tel: 260 1 223 191/151 Fax: 260 1 223 209 e-mail [napnzp@zamnet.zm](mailto:napnzp@zamnet.zm)

Caribbean Regional Network of People Living with HIV/AIDS

PO Bag 133, St James, Port of Spain, Trinidad, W1

Voice mail: 1 868-622-8045; Tel/Fax 1 868-622-0176 e-mail [crn@carib-link.net](mailto:crn@carib-link.net)

Latin American Network of People Living with HIV/AIDS

CC 117 Suc.2 'B' (1402), Buenos Aires, Argentina.

Tel/Fax: 5411 4807 2772 e-mail [jihb@pinos.com](mailto:jihb@pinos.com)

European Network of Positive People,

250 Kennington Lane, London SE11 5RD, England

Tel: 44 171 564 2180 Fax: 44 171 564 2140 e-mail [ikramer@ukcoalition.demon.co.uk](mailto:ikramer@ukcoalition.demon.co.uk)

GNP+North America

2-12 Seaman Ave, 3H, New York, NY, 10034, USA

Tel: 212 569 6023 Fax 212 942 8530 e-mail [babaluaye@aol.com](mailto:babaluaye@aol.com)

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## **Section Four: Issues for health care services**

### **Chapter 11. Parent-to-child transmission: prevention and care 169**

|   |     |
|---|-----|
| Introduction  | 169 |
| Rationale   | 170 |
| Strategies  | 179 |
| Gather information for parent to child transmission prevention and care   | 179 |
| Prevent new infections during pregnancy, post partum and during lactation | 180 |
| Strengthen reproductive health services                                   | 180 |
| Prepare for introduction of test-dependent interventions                  | 181 |
| Develop a communication campaign  | 182 |
| Checklist for counselling on HIV and infant feeding                       | 183 |
| Suggested indicators  | 188 |
| Additional resources  | 189 |

### **Chapter 12. Strategies for prevention of transmission through blood transfusion 190**

|  |     |
|--|-----|
| Introduction                               | 190 |
| Rationale                                  | 190 |
| Strategies                                 | 191 |
| Selection of donors                        | 191 |
| Routine screening of blood for transfusion | 192 |
| Strict transfusion criteria                | 193 |
| Use of autologous blood transfusion        | 195 |
| Suggested indicators                       | 196 |
| Additional resources                       | 197 |

**Chapter 13. Strategies for prevention of transmission in health care settings**

|                      |     |
|----------------------|-----|
| Introduction         | 198 |
| Rationale            | 198 |
| Strategies           | 203 |
| Suggested indicators | 205 |
| Additional resources | 205 |

**Chapter 14. Providing care 206**

|  |     |
|--|-----|
| Introduction                           | 206 |
| Rationale                              | 207 |
| The continuum of care                  | 207 |
| Home-based care and self-care          | 208 |
| Primary health care                    | 212 |
| Hospital care                          | 215 |
| Care and support for orphans           | 220 |
| Strategies                             | 221 |
| Prioritize care and support activities | 221 |
| Develop policies                       | 222 |
| Train health care staff                | 223 |
| Establish home-based care system       | 223 |
| Arrange support for carers             | 224 |
| Care and support for orphans           | 225 |
| Suggested indicators                   | 226 |
| Additional resources                   | 227 |

# 11

## Prevention and care in relation to parent to child transmission

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### Introduction

The number of children infected with HIV is increasing rapidly in countries where HIV has spread widely in adults. Most women who become infected with HIV are in the reproductive age group. Since the beginning of the AIDS pandemic, an estimated five million infants have been infected with HIV. In many countries the gains made in child survival have been lost because of AIDS. The problem has been greatest in sub-Saharan Africa, but the number of babies infected with HIV in India and South East Asia is also increasing rapidly. We use the term ‘parent to child transmission’ (PTCT) when talking of public health and policy aspects to acknowledge the role of the father in transmission of HIV from mother to child. We use the term ‘mother to child transmission’ (MTCT) when referring to the risk of transmission from an infected woman to her baby.

### *HIV infection in children*

The babies of HIV positive mothers have a higher risk of low birth weight, prematurity, stillbirth and perinatal mortality. The most common clinical features of HIV infection in children are:

- failure to thrive,
- recurrent bacterial infections, especially pneumonia,
- recurrent and persistent diarrhoea,
- oral thrush (candidiasis),
- generalized enlargement of the lymph glands,
- itchy rashes,
- chronic cough,
- enlarged liver and spleen,
- developmental delay, and
- neurological problems.

Diagnosis of HIV infection in children is difficult before 18 months of age because maternal HIV antibodies cross the placenta. Most of the signs and symptoms of HIV infection in children are common and non-specific which makes it difficult to be certain of a clinical diagnosis. Tuberculosis, malnutrition, persistent diarrhoea and congenital syphilis can all be confused with HIV. They can also all occur in HIV infected children.

The course of HIV disease in most HIV-infected infants is more rapid than in adults. Children who develop manifestations of HIV infection before one year of age have a poor prognosis. Their condition usually deteriorates until they die within three years. Some children develop symptoms for the first time in their second or third year. Many of these children continue to grow well, although they may have frequent minor

illnesses. These different patterns of progression may be explained by different viral strains, genetic factors in the host, the timing of infection, the immune status of the mother, and co-factors such as other infections.

### ***Impacts of PTCT***

Many women will first discover their HIV infection, and that of their husband, when their baby becomes ill. Women whose babies fail to thrive may be blamed by their husband or relatives. Most women do not know whether they are infected with HIV. As awareness of the possibility and consequences of PTCT increases, women may fear becoming pregnant. Pregnant women worried about HIV need supportive counseling and information about risks, including acknowledgement of areas of uncertainty, and about actions that couples or women themselves can take to reduce the risk of PTCT. Once the baby is born, parents have to cope with uncertainty until the baby is old enough for diagnosis. Parents, especially mothers, of infected babies have to cope with the burden of recurrent illness of their child without hope of recovery. This often leads to many trips to clinic, hospital or traditional healer which cost money, time and cause distress. The burden can be managed more successfully at home if families have support, information and access to simple medicines (see page 208). Responsibility for orphaned babies may mean that older girls cannot attend school, or that elderly people become exhausted, so respite care is needed. Forced migration with children is always difficult but when a child has a chronic illness the burden on families is even greater.

Nurses, midwives, and health care professionals have to cope with uncertainty, rapidly changing knowledge, their own fears, and not being able to cure the disease. Dealing with the fears of women and their families, and with sick and dying children, is very stressful. It is easy for them to feel overwhelmed.

The uninfected children of infected parents have higher risk of illness than children of uninfected parents in the same settings, and suffer the emotional and social effects of chronic illness and death of their parents. Around the world, over 11 million children have already lost their mothers – and often their fathers – before they were 15 years old. Some argue against efforts to prevent PTCT of HIV on the grounds that more children of HIV infected mothers will survive to become orphans that need care. Clearly this is not an ethically defensible argument. Even with effective interventions in place there will still be many orphans, and children infected with HIV will require more costly care than if they were uninfected.

### **Rationale**

By paying attention to the factors that increase the risk that HIV will pass from mother to child there is much that can be done to prevent PTCT. You might want to re-read the information about the risk and timing of transmission from mother to child and the influences on this risk presented on page 28.

The pace of change in our knowledge about interventions to prevent the spread of the virus to the baby from an infected mother has been rapid. It is difficult for policy makers to know what to recommend in poor but stable settings. It is even more difficult in refugee settings.

The interventions that can help prevent PTCT of HIV relate to areas of life that have great cultural and social significance – sexual behavior, the desire to have babies, pregnancy, childbirth, the postpartum period, and infant feeding. They are areas of intimate concern to women, yet often governed by men. They are also areas of life that are greatly affected when populations are displaced as a result of conflict.

### ***Primary prevention***

The best way to prevent babies becoming infected with HIV is primary prevention – that is, to prevent the spread of the virus between men and women, (see sections 3 and 4). Community education to raise awareness that babies can be infected with HIV can contribute to primary prevention by appealing to men’s sense of responsibility for their families.

To prevent PTCT it is particularly important to prevent women becoming infected with HIV during pregnancy, at delivery, or while lactating. This is because the peak in viral load that occurs in the weeks after infection means that the risk of transmission to the baby then is much higher than for a woman who has been infected for longer and has a low viral load. Husbands may become infected through unprotected sex outside marriage during pregnancy or the weeks after the birth. They will be particularly infectious due to a high viral load when marital sex is resumed. Increased vascularity of the woman’s genitals during pregnancy and post-partum may increase her vulnerability to infection. It is also important to minimize blood transfusions during childbirth through training midwives in active management of third stage of labor and strict transfusion criteria (see page 194).

### ***Secondary prevention***

Secondary prevention means preventing transmission of HIV to the baby when the mother is infected. In recent years most attention has been given to secondary prevention interventions that depend on testing women for HIV during pregnancy: antiretroviral prophylaxis, avoidance or modification of breastfeeding and elective caesarean section. But since the majority of infected pregnant women do not know their HIV status it is also important to allocate resources to the secondary prevention strategies that do not depend on testing during pregnancy. Few women have access to ante-natal VCT as yet, and those who do may prefer not to be tested for HIV, or may not be in a position to decide. The secondary prevention strategies that do not depend on testing also assist the health of women and men in general. These include:

- preventing unwanted pregnancies through increasing access to information and contraception;
- improving the health and nutrition of pregnant women and treating infections, especially STIs, promptly;
- promoting exclusive breastfeeding for all;
- breastfeeding training for health care workers to minimize breast problems.
- encouraging women with any chronic illness to postpone pregnancy;
- avoiding unnecessary obstetric interventions, especially artificial rupture of membranes; and

Many of these activities may be components of existing reproductive health, or maternal and child health programs, but the recognition that they make an important

contribution to the prevention of PTCT of HIV justifies investment of increased resources.

### *Test-dependent interventions*

#### *1. Antiretroviral prophylaxis*

A short course of zidovudine (AZT) during the last four weeks of pregnancy and three hourly during labor reduces the risk of MTCT by half when babies are not breastfed. In breastfed populations the efficacy of this regimen is reduced. This intervention has been implemented widely in Thailand saving many babies from HIV infection. However Thailand is a middle income country with good health infrastructure and stable and cohesive communities. These interventions have proved more difficult to implement in poorer and less stable settings in Africa and Asia<sup>1</sup>.

A study in Uganda showed that a single dose of a different antiretroviral drug, nevirapine, given at the time of delivery to the mother, and then to the newborn, also reduces the risk of HIV infection by half. This intervention costs only a few dollars and has long-term efficacy despite continued exposure to HIV during breastfeeding. WHO have approved nevirapine for widespread use. It is likely that this cheap and practical regimen will replace zidovudine in many settings. The efficacy of anti-retroviral prophylaxis (ARVP) given to the baby during the breastfeeding period is also being studied.

Common problems experienced in implementing ante-natal VCT and ARVP include:

- providing training for sufficient clinic staff,
- the added workload of providing VCT in already over-stretched clinics,
- lack of privacy for VCT,
- high rate of loss to follow up of HIV positive pregnant women, and
- low rates of take up of antiretroviral prophylaxis.

If done well, the introduction of VCT at ante-natal clinics can strengthen the quality of reproductive health services. If women who test negative and their husbands, receive post-test counseling, ante-natal VCT can contribute to primary prevention.

#### *2. Elective Caesarean section*

Caesarean section before the onset of labor allows the baby to avoid contact with the mother's blood and cervical secretions. Recent studies have shown that elective caesarean section for HIV-positive women can reduce the risk of PTCT by 50 to 66%. However there is evidence that HIV-positive mothers have a higher risk of post-operative complications than HIV-negative women. In refugee settings it is important to consider the safety of caesarean section, the cost, whether women can access caesarean section surgery, and whether they will be able to do so for future

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<sup>1</sup> UNICEF/UNAIDS/WHO/UNFPA African regional meeting on pilot projects for the prevention of mother-to-child transmission of HIV. Gaborone, Botswana. March 27-31, 2000.  
[www.unaids.org/publications/documents/mtct/index.html](http://www.unaids.org/publications/documents/mtct/index.html)

pregnancies, since there will be an increased risk of rupture of the uterus with subsequent deliveries.

### 3. *Modification of breastfeeding*

For many years it was difficult for researchers to determine the size of the risk of transmission of HIV through breastfeeding. There is now sufficient evidence to show that non-exclusive breastfeeding carries a substantial additional risk of MTCT of HIV of about 16%. The risk is greatest in the early weeks, but remains throughout the duration of breastfeeding.

Breastfeeding plays a vital role in protecting children's health and has important nutritional and immunological benefits. Babies who are not breastfed have a high risk of death from malnutrition, diarrhoea, and respiratory infections. Breastfeeding also has important child-spacing and psychological advantages. In refugee settings breastfeeding is even more important to child health because providing an adequate alternative requires supplies of milk, water and fuel which may be impossible, and displaced populations may move again at short notice. If breastfeeding mothers have to move they have a safe, low cost, sterile, convenient source of food for their baby.

The health benefits of breastfeeding are of most importance in the first six months of life so shorter duration of breast-feeding by infected women may reduce risk of HIV transmission while allowing the benefits of breast-feeding in the early vulnerable months.

'Exclusive breastfeeding' means that the baby receives nothing but breastmilk and is a rare practice in all societies. It is common for feeds of water or other fluids to be given before the milk 'comes in', and for cereals to be introduced in the first weeks of life. Breastmilk contains both protective antibodies and growth factors that promote maturity of the gut wall. Babies do not need to receive any food or fluids other than breastmilk for the first six months of life. Other fluids or foods result in inflammation of the gut wall that may increase the risk that HIV in the breastmilk can enter the baby through the gut wall. The suggestion that exclusive breastfeeding may carry a lower risk of MTCT and even inhibit HIV transmitted to the baby at the time of delivery has been strengthened by findings from two observational studies.

There is an urgent need for further research to determine the safest pattern and duration of breastfeeding, and the safety, feasibility and safety of alternatives to breastfeeding when they are needed.

The fact that breastfeeding carries a significant risk of transmitting a fatal infection presents policy makers with a genuine dilemma. The balance of risk will vary for different mothers in different settings.

In May 1998, WHO, UNICEF and the Joint UN Programme on HIV/AIDS (UNAIDS) published new guidelines on infant feeding and HIV<sup>2</sup>. The guidelines recommend that women known to be infected with HIV be counselled about the risks

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<sup>2</sup> WHO, UNICEF, UNAIDS. HIV and Infant Feeding: a guide for health care managers and supervisors. WHO/FRH/NT/CD/98.2. May 1998. [www.unaids.org/publications/documents/mtct/](http://www.unaids.org/publications/documents/mtct/)



and, if feasible, helped to provide an adequate replacement for breastfeeding, even in poor countries. The guidelines stress the importance of protecting, promoting and supporting breast-feeding as the best method of feeding for infants whose mothers are HIV-negative or who do not know their HIV status. These guidelines have recently been clarified:

**Current recommendations of the inter-agency task force on infant feeding and HIV-infected mothers:**

- When replacement feeding is acceptable, feasible, affordable, sustainable and safe, avoidance of all breastfeeding by HIV-infected mothers is recommended.
- Otherwise, exclusive breastfeeding is recommended during the first months of life.
- To minimize HIV transmission risk, breastfeeding should be discontinued as soon as feasible, taking into account local circumstances, the individual woman's situation and the risks of replacement feeding (including infections other than HIV and malnutrition).
- When HIV-infected mothers choose not to breastfeed from birth or stop breastfeeding later, they should be provided with specific guidance and support for at least the first 2 years of the child's life to ensure adequate replacement feeding. Programs should strive to improve conditions that will make replacement feeding safer for HIV-infected mothers and families.
- HIV-infected mothers who breastfeed should be provided with specific guidance and support when they cease breastfeeding to avoid harmful nutritional and psychological consequences and to maintain breast health.

*UNFPA/UNICEF/WHO/UNAIDS Inter-Agency Task Team on Mother-to-Child Transmission of HIV. January 15 2001. [www.unaids.org/publications/documents/mtct/index.html](http://www.unaids.org/publications/documents/mtct/index.html)*

## ***HIV and infant feeding counseling in refugee settings***

### *Balancing the risks*

HIV infected pregnant women need advice and counseling to help them to make an informed decision about whether to breastfeed or not.

Weighing the risks has been difficult in resource-poor settings because we know little about safe, feasible and affordable alternatives to breastfeeding. In refugee settings exclusive breastfeeding for four to six months followed by early weaning is likely to be a much safer option for the baby than avoidance of all breastfeeding. It is true to say, currently, that we do



not know which of these options carries a lower risk of HIV transmission to the baby, and avoidance of all breastfeeding is certainly hazardous.

*Promote exclusive breastfeeding for all*

Exclusive breastfeeding for six months should be strongly promoted and supported in refugee camps for all babies, both because it protects babies against diarrheal and other infectious diseases, and because it may reduce the risk of transmission of HIV from infected mothers. The ten steps to successful breastfeeding should be promoted in all hospitals or clinics where displaced mothers give birth.

**UNICEF/WHO Baby Friendly Hospital Initiative:  
Ten Steps to Successful Breastfeeding**

To become a Baby Friendly Hospital, every facility providing maternity services and care for new-born infants should:

- Have a written breastfeeding policy that is routinely communicated to all health care staff.
- Train all health care staff in skills necessary to implement this policy.
- Inform all pregnant women about the benefits and management of breastfeeding.
- Help mothers initiate breastfeeding within half an hour of birth.
- Show mothers how to breastfeed, and how to maintain lactation even if they should be separated from their infants.
- Give new-born infants no food or drink other than breastmilk, unless medically indicated.
- Practice rooming-in - allow mothers and infants to remain together 24 hours a day.
- Encourage breastfeeding on demand.
- Give no artificial teats or pacifiers (dummies or soothers) to breastfeeding infants.
- Foster the establishment of breastfeeding support groups and refer mothers to them on discharge from the hospital or clinic.

“Infant feeding in Emergencies” is a helpful book designed to give advice to refugee and displaced women about breastfeeding (see below). The information can be adapted for women in your setting. Individual counseling about the benefits and practice of exclusive breastfeeding has been found to be more effective than just providing information. Counseling by someone trained in breastfeeding skills can help to reduce breastfeeding problems that increase risk, such as engorgement, mastitis, and sore nipples.

*Replacement options*

If an HIV positive woman chooses not to breastfeed she will need support to provide an adequate replacement. Where few women are infected with HIV it may be possible for women who cannot afford infant formula to receive subsidized or free formula for six months. But where HIV prevalence is high it will not be possible to supply commercial infant formula for all babies who need it. Care must be taken to ensure that breastfeeding in general is not undermined by the availability of free or subsidized infant formula. Ideally, if women are provided with commercial infant formula this will be provided in a generic form rather than with a brand-name label.

It is possible to make home-made formulas from animal milks, such as cow, buffalo or goat milk. Unmodified animal milk has too great a proportion of protein and can damage the baby's kidneys and irritate the gut. It is necessary to dilute the milk with water, and add sugar, for energy.

**Recipe for cow's milk formula for a baby from birth to six months**

To make 150 mls of formula:

100 mls of cow's milk

50 mls of water

10 grams (2 teaspoons) of sugar

Boil the mixture. Such formulas lack micronutrients.

HIV is killed easily by heat – the virus dies above 56° C. A woman could express her breastmilk, boil it and feed by cup to her baby. Although some of the anti-infective properties are reduced, many important components are unaffected, and heated breast-milk is nutritionally superior to other milks. In practice it may be difficult for a woman to express her milk for months without the stimulation of the baby sucking at the breast. However this is an inexpensive and nutritionally appropriate option and women may want to try it. They will need support and advice about other alternatives in case they are unable to maintain their supply of breast-milk. They will also need practical advice about boiling milk (at the same time as other cooking) in a small pan with a lid to avoid small amounts rapidly boiling away.

Whatever replacement is used, it is important that the mother or carer is taught how to use a cup to feed the baby. A cup is simple to clean thoroughly and does not need to be sterilized. Bacteria grow easily in bottles and teats, which are difficult to clean and need to be boiled before use. Even a newborn baby can cup feed, and cup feeding ensures that the mother or caregiver holds the baby during feeding.

It is possible that a female relative could breast-feed a baby who has an infected mother. In many cultures even post-menopausal grandmothers have relactated in order to feed a baby. (In some countries this must be the paternal grandmother, in others, it is the mother's mother who should feed the baby). Such traditional solutions can be encouraged. It is important to be sure that the "wet-nurse" is not infected with HIV and they should be counselled about the possibility that if the baby is infected with HIV there is a small risk that it may be transmitted to the "wet-nurse".

*Mothers need support*

In many countries, especially in rural areas, breastfeeding is highly valued and is regarded as an important part of mothering by the whole community. Women may find it very difficult not to breastfeed. Girls grow up expecting and looking forward to breastfeeding, a source of pleasure for the mother as well as the baby. A woman who does not breastfeed may meet with frequent social disapproval for not breastfeeding her baby. She needs to be prepared for this and given support. She may also feel that she is not a good mother and take time to come to terms with choosing not to breastfeed, especially if the decision has been made by a health professional or by her husband or his mother. It will be helpful to emphasize that she is a good mother

because she has weighed up the risks and made a difficult choice in the best interests of her child. Remind her that there are many things that mothers do for their children;



feeding is only one of them. Women who do not breastfeed need to be counselled to expect a rapid return of menses and fertility. Women may also be stigmatized if they are assumed to have HIV because they do not breastfeed. Support is also important because in refugee settings there are so many mothers without the support of a husband or mother.

### *Limitations of the test-dependent interventions*

Access to these test-dependent interventions in combination has reduced the risk of MTCT for positive pregnant women in industrialized countries to less than four per cent. Several analyses suggest that ante-natal VCT and ARVP would be cost-effective in both high and low prevalence countries. However these test-dependent interventions can only avert a limited proportion of HIV infections in children, even when acceptance increases. This is because not all women are able to access ante-natal care, and because these interventions miss women who become infected late in pregnancy or in the post-partum period. These women have the highest risk of transmission to their babies because the post-infection peak in viral load inevitably occurs when they are pregnant or lactating.

The potential public health impact of the test-dependent interventions is greater in countries with a very low incidence of new infections. ARVP regimens (such as nevirapine) that can be given during labor and post-partum might also improve their potential, although many women do not deliver in hospital and testing for HIV during labor has significant ethical implications. It has been suggested that in high prevalence areas all mothers and babies could be given a single dose of nevirapine without ante-natal VCT. This might be a short-term option in refugee settings when the prevalence of HIV among pregnant women is known to be high, and it is not feasible or safe to introduce VCT during pregnancy.

### *Rights and ethical considerations*

There can be pressure to implement screening for HIV during pregnancy and provide ARVP. This seems like a straightforward and effective intervention. However there are adverse effects associated with offering HIV testing during pregnancy and these test-dependent interventions need to be introduced carefully.

### *Informed consent*

When a woman attends ante-natal care she is not thinking of having an HIV test, yet may accept when it is offered because she thinks it is expected. In many studies a

high proportion of those who agreed to be tested did not return for their results. Women may justifiably fear the consequences of disclosure of their status for themselves and their children, including family conflict, stigma, isolation, fear, secret-keeping, expulsion from the family or violence. This fear may be even greater in camp settings. Sometimes husbands prevent their wives returning for the results and the woman then misses out on ante-natal and delivery care. In a camp setting it may be more difficult for a pregnant woman to avoid learning the result of an HIV test carried out at the ante-natal clinic.

Several countries have introduced group ‘counseling’ before HIV testing in antenatal clinics because of resource constraints and the need to improve coverage. It is important to study the impact of group counseling on informed consent.

There are ethical implications to the introduction of rapid tests in antenatal clinics, which provide the results within hours instead of requiring a second visit. Rapid tests may assist those for whom transport is an obstacle but may make it more difficult for women to choose not to receive their result. They should only be introduced where there is confidential and individual (rather than group) pre-test counseling.

In many societies the meaning of ‘informed consent’ may be confusing or problematic. Women, especially young married women, may have little autonomy. They may have no experience of being asked to make important decisions and may feel uncomfortable. Issues of pregnancy, childbirth and care of babies may also concern the husband, mother-in-law, or extended family. Whether and how they should be included in counseling can best be resolved through consultation with the community.

In refugee settings pregnant women may be especially sensitive. The pregnancy may be unwelcome, the result of rape or coerced sex. Women who are pregnant may fear what the future holds for their baby, and worry about how they are going to be able to look after a baby in such uncertain times, when they have no home or land. These issues need to be discussed when training ante-natal care workers in VCT.

#### *The man’s right to information*

The majority of HIV-infected pregnant married women have been infected by their husbands, so a positive HIV test result is a ‘marker’ of HIV infection in the husband. When we test a woman we put her in a position where she has a responsibility to inform her husband if she has a positive result. But he has not had the opportunity to receive pre-test counseling and give informed consent to knowing his HIV status. A possible solution to this conflict of rights is to encourage, as a routine, the second ante-natal visit to be a “couple visit”. This could be promoted in relation to the need to diagnose and treat for infectious diseases generally, rather than a focus on HIV, and to plan for emergency transport for delivery. At this visit the couple could be counselled together and the issue of blame addressed with both present. The visit would also provide an opportunity to give the man information about the risk he presents to his wife and baby if he has unprotected sex outside the marriage while his wife is pregnant or breastfeeding. The woman could be asked at the first visit whether she is willing to be counselled about testing with her husband.

*Care for the mother*

The availability of the test-dependent interventions leave us in the awkward position of being able to offer a woman some hope for her child, while leaving her with the knowledge that she has a fatal disease. It is important to include follow-up care and support for the woman and her family when such a program is introduced. This may include counseling, support groups and providing prophylaxis and treatment for opportunistic infections (see page 213). The reductions in prices of life-long treatment with combination antiretroviral drugs sharpen ethical concerns about identifying women with HIV during pregnancy. Noerine Kaleeba, UNAIDS Community Mobilisation Officer, has declared that we should not forget that the most important way to support children is to keep their parents alive: “As long as I am still alive and healthy, I will be able to take care of my children”.

Even if it is possible to ensure confidentiality when a woman is tested for HIV, the interventions of ARVP, avoidance of breastfeeding, or caesarean section may reveal her HIV status to others. There is an obligation to allocate resources and effort to the reduction of stigma when plans are made to introduce these interventions.

Women often discover for the first time that they have HIV infection when their baby shows signs and symptoms suggestive of HIV and is tested. It is not ethical to tell her that she should not have any more children. She has a right to information about the risk. But if she is well herself and does not have signs of HIV-related illness the risk of MTCT is likely to be low. In many societies the desire to have a baby is very strong, and women may have no social role if they are not mothers. Women who have HIV-related signs and symptoms are much more likely to have an infected baby. These women need careful counseling to make sure that they understand the risks and have thought about how the baby would be cared for if they were to die.

**Strategies**

Resources for prevention and care in relation to PTCT of HIV need to be allocated to both:

- specific primary prevention strategies to prevent new infections during pregnancy and lactation, and
- secondary prevention interventions, including those that do not depend on antenatal VCT, as well as the test-dependent interventions.

These strategies need participation from both men and women in initial assessment of the situation and planning, as well as in implementing and evaluation. Integrate strategies with existing community-based programs, rather than establish separate structures and processes. Page 185 shows a framework to aid discussion. Key steps for an integrated PTCT response include:

***1) Gather information relevant to the successful implementation of PTCT prevention and care strategies***

This should include rapid qualitative studies using key informant interviews and focus group discussions of attitudes, knowledge and practice in relation to:

- VCT during pregnancy (meaning of ‘informed choice’, involvement of husband and family, confidentiality);
- consequences of a woman disclosing a positive HIV test result;
- contraception;
- termination of pregnancy;
- antenatal care;
- influences on exclusive breastfeeding;
- pre-emergency infant feeding knowledge and practice;
- feasible alternatives to breastfeeding;
- current weaning food practices; and
- care of sick babies and orphans.

If possible, an estimate of the number of pregnant women in the refugee population is useful for planning.

### ***2) Prevent new infections during pregnancy, post partum and during lactation***

- Promote the idea of planning for pregnancy;
- Improve access to VCT (outside pregnancy) for couples;
- Introduce a routine evening “couple” antenatal visit;
- Promote condoms;
- Strengthen management of STIs;
- Train midwives in active management of third stage of labor to reduce need for transfusions, and implement strict transfusion criteria
- Train health care workers to advise fathers after delivery that unprotected sex with others carries a high risk of infection of HIV to their baby, and provide condoms;
- Develop IEC campaign and materials to support these activities, especially addressing men
- Train health care workers to advise discordant couples *if they are keen to conceive* how to minimize the risk of transmission to woman and baby by teaching women how to recognize the timing of ovulation so they need have unprotected intercourse only once each month.

### ***3) Strengthen reproductive health services for secondary prevention interventions (not dependent on HIV testing)***

- Prevent unwanted pregnancies;
- Encourage planning of pregnancies;
- Train health workers to counsel women with any chronic illness to avoid pregnancy until well for six months;
- Promote quality ante-natal care with treatment of STIs and other infections and nutrition advice;
- Train midwives and traditional birth attendants to reduce unnecessary obstetric interventions;
- Establish strict criteria for transfusion;
- Promote exclusive breastfeeding; and
- Train health care workers in breastfeeding to minimize breast problems.

### **Integrating PTCT strategies with maternal and reproductive health work**

IRC support health centers near Bukavu in the Democratic Republic of the Congo. One of these is the well-managed Mugeru health center, which has in-patient beds, caring and motivated staff, clean rooms, protocols and posters on the walls, and is popular with patients. The nurse in charge, Mr Nyankwega, said he regretted that they could do nothing to prevent mother to child transmission (MTCT) of HIV. In fact he and his staff are doing a great deal to prevent MTCT: they are providing good ante-natal care and involving the husbands; they are distributing condoms and contraception; they are treating sexually transmitted infections (STIs); they only rupture membranes and perform episiotomies when strictly necessary; and they keep new mothers for five days so they have a chance to rest and establish exclusive breastfeeding.

A father was sitting in a post-natal room proudly holding his new baby. This would be a good time to explain to men that unprotected sex would put them at risk of HIV, and they would then have a very high risk of infecting their wife and baby. He agreed that new fathers had a right to the information and would be receptive because they feel responsible and loving at this time. They could introduce a routine evening "couple visit" as the second ante-natal visit, at which any infections could be diagnosed and treated, couples could be counseled and tested together, men could be informed of the risks they pose to their baby if they had unsafe sex during or after the pregnancy, and emergency transport plans for labor could be discussed. The center's staff could also be trained to advise any women who had a chronic illness to avoid pregnancy until they had been well for six months, since the risk that HIV will pass to the baby is high when an infected pregnant woman is ill.

These measures to reduce the number of HIV infected babies in this population are feasible. They address the factors that we know increase the risk of transmission; they do not depend on identification of women who are infected with HIV; and they improve the health of men and women generally.

#### ***4) Prepare for introduction of test-dependent interventions***

The test-dependent interventions (ante-natal VCT, ARVP, HIV and infant feeding counseling and, when feasible, elective caesarean section) should only be introduced in refugee settings if the following are in place:

- well-functioning maternal and child health services;
- accessible and acceptable VCT services;
- quality and confidential testing facilities;
- sustainable supply of antiretroviral drugs;
- community acceptance of those infected and affected by HIV; and
- the resources for low-cost follow up care and support of infected mothers, babies and their families. Although long-term ART may not yet be affordable, it is important to ensure access to prevention and treatment of opportunistic infections.

It will also be necessary to train health care workers, and midwives, in VCT and counseling for HIV and infant feeding (see counseling checklist below).

If refugees come from a setting with a high prevalence of HIV where testing was available there may be pregnant women who already know that they are HIV positive. In these situations it is helpful to have a supply of antiretroviral drugs available for prophylaxis, even though it may not be possible to implement a full ARVP program.



Where termination of pregnancy is legal and feasible health workers may need to be trained in discussing this option with HIV positive women. Health workers may feel that HIV positive women should be encouraged to terminate their pregnancy because 1) the baby may become infected with HIV and 2) the baby will one day be an orphan. It is important to point out to these workers that when the mother is well the risk to the baby may be quite small and that their concern that the child may be orphaned is not an ethical reason to encourage a woman to terminate a wanted pregnancy.

### 5) *Develop an IEC community campaign*

Men's role in protection of their family and their desire for healthy children suggests that appeals to their sense of responsibility may be a powerful trigger to behavior change. An IEC campaign needs to disseminate the following messages:

- Plan for pregnancy – first seek VCT, treat any infections, improve nutrition
- Prevent unwanted pregnancies – use contraception
- Seek information about PTCT of HIV
- Mothers caring for sick babies need support and sympathy, not blame, from family and community
- Children with HIV do not spread the virus to others and need love and attention
- Ante-natal care can help you have a healthy pregnancy and avoid complications
- Couples attend the second ante-natal visit together
- Give the best food to the woman when pregnant, and make sure that she does not work too hard



- Use condoms (appeal to men's sense of responsibility and desire to protect family)
- Men can harm their baby by having unprotected sex during or after the pregnancy
- Couples should consider attending VCT
- Exclusive breastfeeding for six months is best for all babies
- It is best to postpone pregnancy if you are ill – wait until well for six months before becoming pregnant.

Awareness that HIV also affects babies may act as a stimulus for young people to protect themselves, and encourage communities to mobilize to care for orphans and sick children.

In this rapidly changing field it is important to keep up to date. The Inter-agency Task Force publishes frequent updates available on the UNAIDS web site ([www.unaids.org](http://www.unaids.org)).

## Checklist for counseling on HIV and infant feeding

[It is best if counseling for HIV and infant feeding does not take place at the same time as post-test counseling when the result has been positive. It will be difficult for the woman to take in information about the different risks and make a decision when she has just heard that she is HIV positive. Refer to the checklist for post-test counseling on page 91. Tell her that there are actions that she can take to lessen the risk to the baby and arrange a suitable time to discuss them with her.]

- Introduce yourself.
- Explain that the interview is completely confidential.
- Explain that the purpose of the interview is to provide information about HIV and infant feeding and to help the woman to reach a decision about the safest way for her to feed her baby.
- Ask whether she knows her HIV status. She may have had a test and so knows her status. If she has not had a test ask her how likely she thinks it is that she may be infected. She may have no reason to think that she is infected. On the other hand she may have good reason to believe that she is infected, for example, her husband may have AIDS, she may have HIV-related symptoms and signs, or her previous child may have died. In areas of high prevalence this situation is likely to be common. What the woman thinks about her likely risk of infection will influence her decisions about how to feed her baby. This discussion may lead her to think again about having an HIV test and it may be helpful to explore her reasons for not wanting to be tested. In particular, ask her whether it might be possible for her husband to come for counseling so that they could be tested together.
- Check her understanding about HIV infection and mother to child transmission.
- Correct any false beliefs and provide information about HIV and infant feeding.

Key points: \*

- Breastfeeding is very important to child health, particularly for the first six months. It provides all the nutrients the baby needs, and protects against infections, especially diarrhoea. Breastfeeding helps mothers and babies to feel close and warm.
- Breastfeeding protects a woman from becoming pregnant again quickly. Women who do not breastfeed have monthly periods again soon after the birth.
- Breastfeeding is the most convenient and cheapest way to feed a baby. It is difficult to provide an alternative to breastfeeding if you have to travel with a baby.
- Breastfeeding carries a risk of transmission of HIV. If 100 HIV infected positive pregnant women have a baby, we can expect that on average 5 of the babies will become infected in the womb, 15 of them at the time of delivery, and 10 of them through breastfeeding. But we cannot tell at birth which babies are already infected with HIV.
- The risk of transmission through breastfeeding is greatest in the early weeks, but remains throughout the duration of breastfeeding – even into the second year of life.
- Exclusive breastfeeding carries a lower risk than mixed feeding and may provide some protection against transmission of HIV that occurs at the time of delivery. Exclusive breastfeeding means that the baby receives nothing but breastmilk.
- Most babies born to HIV infected mothers who are breastfed do not become infected with HIV and may benefit from antibodies in the breastmilk

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\* It can be helpful to make a set of cards to assist in counseling. Each card has one of these key points (written in the local language) and illustrated with an appropriate picture. The counsellor then explains each card in turn to the woman, and asks questions to find out about the woman's own situation.

### Checklist for counseling on HIV and infant feeding (cont.)

- The risk is greater if the mother has signs and symptoms of HIV infection, especially if she is already ill with AIDS. The risk is lower if the mother is well.
- The risk is higher if there are any breast problems such as cracked nipples, engorgement, mastitis, or breast abscess, or if the baby has thrush in the mouth.
- If the woman is HIV negative or does not know her HIV status recommend that she breastfeed exclusively for six months, and then continue to breastfeed while introducing appropriate weaning foods. If she has not been tested discuss with her the possibility of an HIV test, and discuss whether she might like to ask her husband to come for counseling and testing.
- If the woman knows that she is HIV positive recommend that she avoid breastfeeding if it is possible for her to give an adequate replacement, or breastfeed exclusively for four to six months and then stop breastfeeding if safe weaning foods are available\*
- Help her to weigh up the risks relevant to her own situation\*\*. You can ask her the following questions to help her to decide.
  - What will be the most difficult problems if you decide not to breastfeed?
    - Do you have an affordable and accessible supply of cow's milk and sugar, or infant formula, that will continue to be available for at least six months?
    - Will you be able to boil water or milk?
    - Will you be able to prepare feeds in a clean way in your present circumstances?
    - Will you have time to feed the baby?
    - Is there anyone who will be able to help you to feed the baby?
    - What do you think your family/your friends/your neighbors will say if you don't breastfeed?
    - How will you feel yourself if you don't breastfeed?
    - What will you do if you have to travel with your baby and he/she is not breastfeeding?
    - What will you do about feeding the baby during the night?
    - What will you do if your husband, or other children, are hungry and ask for the baby's milk?

\* Point out to the woman that she does not need to decide everything about how she will feed the baby at this stage. Before the birth she needs to decide whether she will breastfeed at all, or not. After the baby is born it will be both difficult and unwise to reverse a decision not to breastfeed at all. If she decides to breastfeed she should breastfeed exclusively. She may later decide to stop breastfeeding and give a replacement, for example if her circumstances become more stable and she is confident that she will have an adequate alternative. On the other hand she may have planned to stop breastfeeding at six months – but if the baby is showing signs of HIV infection she may decide the best course of action is to continue to breastfeed. Then her baby can have the benefits of breastmilk for as long as possible to minimize the recurrent infections, and provide comfort when the baby is ill.

\*\* The idea of weighing up risks can be difficult for a woman to understand. Her choice is not a simple one of deciding whether the risk of death for her baby is greater if she breastfeeds than if she does not. Her decision will be influenced by many factors. Some she may tell you; some she may keep private. This is why it is important that the woman makes the decision and not the counsellor.

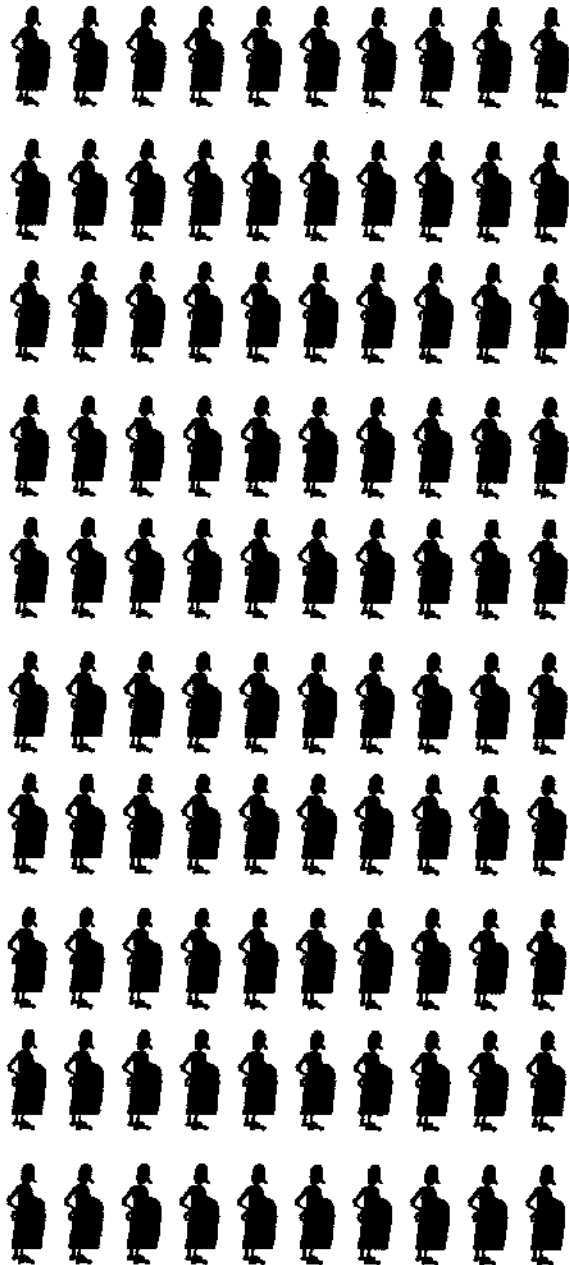
### Checklist for counseling on HIV and infant feeding (cont.)

- What will make it difficult to exclusively breastfeed (nothing but breastmilk, including no water)?
  - Is there a belief that colostrum is harmful?
  - Are newborn babies routinely given water?
  - Is there a belief that it is important to give herbs or medicines or any other fluid before the breastmilk 'comes in'?
  - Who makes the decision about when to give the baby foods in addition to breastmilk?
  - Are there times when you have to leave the baby and some other milk or foods are usually given?
- Give advice about storing, preparing and feeding weaning foods, since babies that are not breastfeeding have a higher risk of diarrhoeal disease.\*
- Whatever the woman decides, reassure her that she has thought carefully about the best decision for her baby. Check her understanding. Tell her that she can return if she has any questions or difficulties. If she is literate give her appropriate written information.
- Ask about family circumstances and identify what support she has from family and friends
- If the woman decides not to breastfeed arrange a follow-up appointment before the birth so that you can show her how to prepare a feed, and she can practice this.

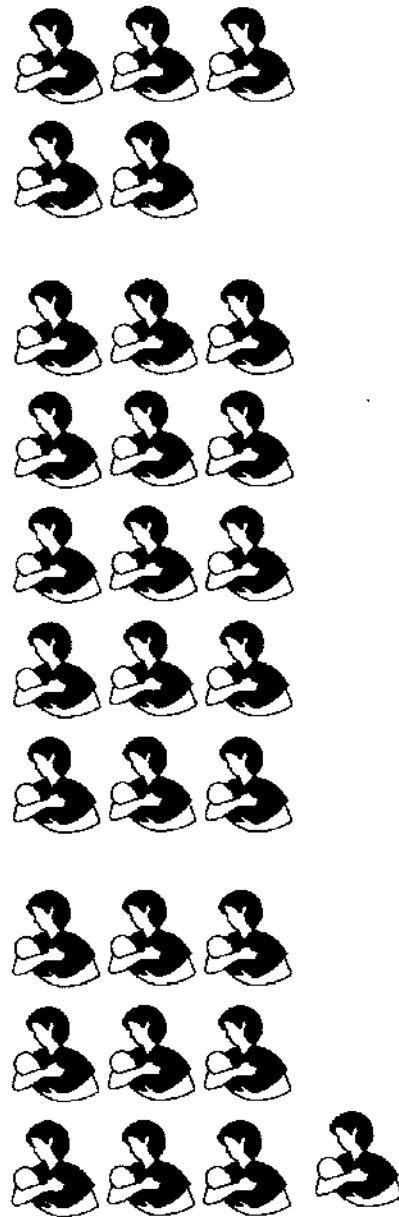
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\* Breastfed babies need no other food or drink until they are six months old. Babies fed on formula can start to have other foods from five or six months of age. Cereal porridge is fine as the first food for babies. At first they will still be getting most of their energy and growth needs from the milk they are drinking. When cereal porridge is cooked a lot of water needs to be added to make sure that the porridge is not too sticky or thick for the baby to eat. This means that the porridge is energy dilute – or not very concentrated in energy. Babies and small children have small stomachs, so they need to be fed very often. There are several ways to add energy to porridge: 1) add milk, sugar, peanut butter, oil, margarine, ground fish, or eggs, 2) ferment the porridge 3) use germinated flour. Fermentation also reduces bacterial growth in porridge. It is also important to provide vitamins and minerals – give mashed bananas, and other fruit or vegetables. Mothers also need advice about the importance of hand-washing before they prepare food for their baby, before they feed the baby, and after they clean the baby's bottom, and to dispose carefully of the baby's stools. Children's stools are more dangerous than adult stools. It is best not to store cooked porridge or other foods for the baby. Instead mothers should give left-over food straight away to other children or eat it themselves, rather than waste it. If possible prepare a pamphlet on safe weaning foods using information and pictures from the manual : Nutrition in developing countries. Savage-King F, Burgess A. MacMillan / TALC.

One hundred pregnant HIV positive women



On average 30 babies will be infected with HIV

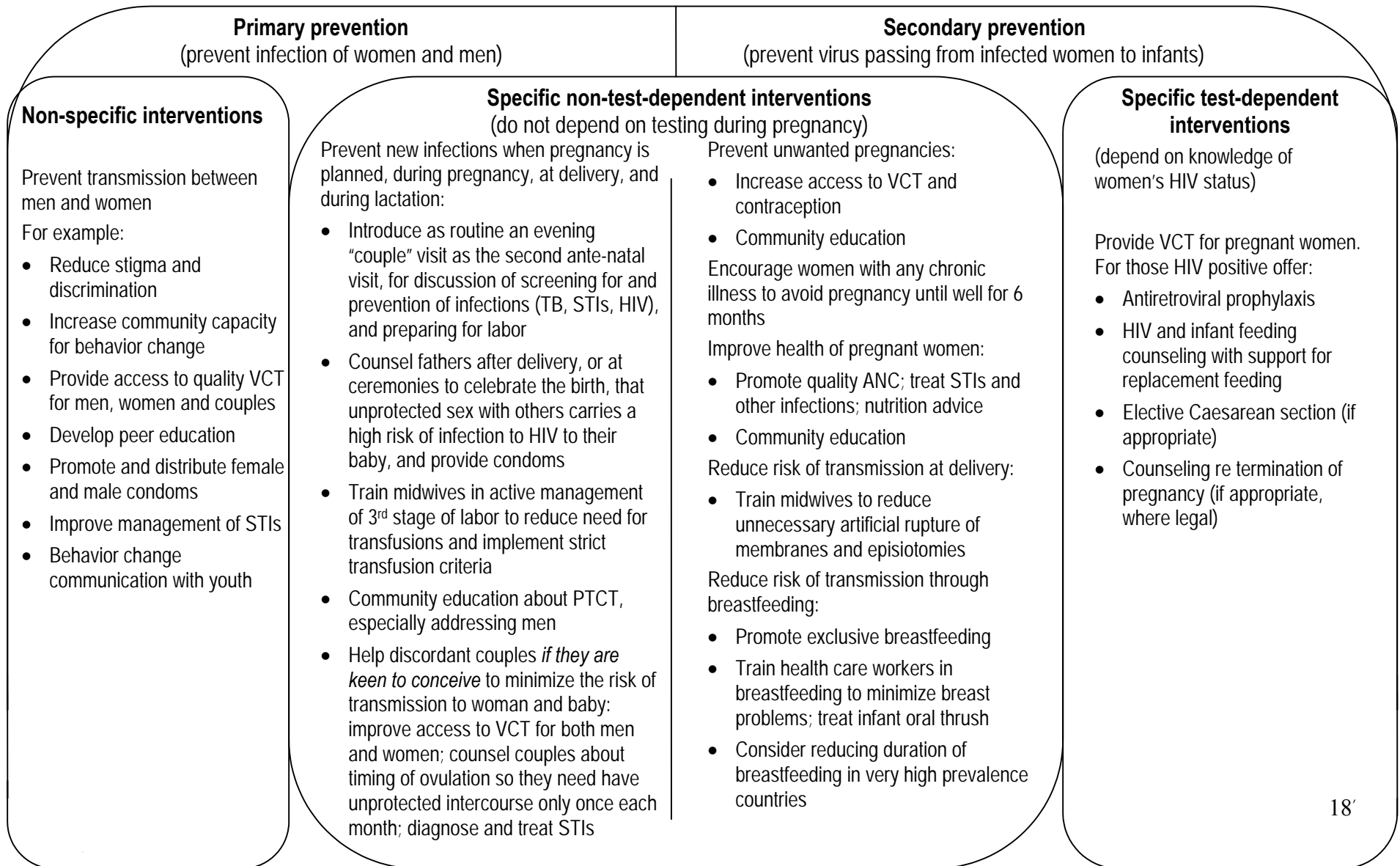


Five become infected during the pregnancy

Fifteen become infected at the time of delivery

Ten become infected through breastfeeding - most in the early weeks

## Conceptualizing prevention of parent to child transmission of HIV



**Plus – care and follow up support for infected mothers, sick babies and carers of orphaned babies**

## Suggested indicators

| <i>Indicator</i>  | <i>Method of measurement</i>   |
|---|--|
| PTCT interventions informed by an understanding of relevant attitudes, knowledge and practices              | Qualitative study report   |
| Proportion of pregnant women attending for ante-natal care  | Survey   |
| Proportion of husbands attending at least one ante-natal clinic visit                                       | Survey / review of clinic attendance records                         |
| Proportion of pregnant women using condoms  | Survey   |
| Midwives trained and competent in active management of third stage of labor and criteria for transfusion    | Review of training reports/supervision checklists                    |
| Proportion of births in clinic/hospital where the father has been counselled about risks of unprotected sex | Review of clinic/hospital records                                    |
| IEC materials developed and disseminated  | Review of materials and records                                      |
| Decrease in artificial rupture of membranes, and transfusions at delivery                                   | Review of hospital/clinic records                                    |
| Proportion of mothers of babies over four months who exclusively breastfed for at least four months         | Survey   |
| Increase in community knowledge about PTCT  | Survey results compared to baseline/ focus group discussion findings |
| Number of health care workers trained in HIV and infant feeding counseling                                  | Review of training records   |
| HIV and infant feeding counseling checklist developed and available   | Observation  |

## **Additional resources**

WHO, UNICEF, UNAIDS. HIV and Infant Feeding: a guide for health care managers and supervisors. May 1998. Available from Programme of Nutrition, WHO, Geneva, Switzerland, at the UNAIDS website: [www.unaids.org](http://www.unaids.org) (WHO/FRH/NT/CD/98.2)

UN Inter-Agency Task Team on Mother-to-Child Transmission of HIV. Geneva, 11-13 October 2000. New Data on the Prevention of Mother-to-Child Transmission of HIV and their Policy Implications. Conclusions and recommendations. Published 15 January 2001. Available at: [www.unaids.org/publications/documents/mtct/index.html](http://www.unaids.org/publications/documents/mtct/index.html)

WHO Infant feeding in emergencies. [For mothers] Prepared for the Programme for Nutrition Policy, Infant Feeding and Food Security Lifestyles and Health Unit World Health Organization Regional Office for Europe, Copenhagen World Health Organization, Regional Office for Europe EU/ICP/LVNG 01 02 08 Revised September 1997. Available at: <http://www.who.dk/nutrition/doc.htm>

Emergency Nutrition Network. Infant Feeding in Emergencies: Policy, Strategy & Practice. [For policy makers] Report of the Ad Hoc Group on Infant Feeding in Emergencies: May 1999 (compiled and produced by the Emergency Nutrition Network) Also - Infant Feeding in Emergencies: Module 1. [For emergency relief staff] March 2001. <http://www.tcd.ie/enn/InfantFeedingReport/>

Holmes W, Kwarteng T. Parent to child transmission of HIV: policy considerations in the Asia-Pacific region. *J Clin Virol* 2001;22:315-324



# 12

## Prevention of transmission through blood transfusion

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### Introduction

Blood transfusions can save lives, but in areas where HIV is prevalent and the rate of new infections is high, they may result in transmission of HIV or other blood borne infections. Armed conflict often gives rise to the need for blood transfusions. In the post-emergency phase childbirth, trauma, and severe anemia due to malaria may necessitate transfusion.

### Rationale

Transmission through transfusion of blood or blood products is preventable. Since 1985 it has been possible to test donated blood for HIV antibodies. Routine testing of all blood for transfusion greatly reduces the chances of transmitting HIV but a small risk remains. This is because a donor can give blood after infection, but before they develop antibodies, and before the test has become positive - the “window period”. The risk is greatest in areas where many people are becoming infected with HIV.

To reduce the risk of infection through transfusion:

1. reduce the risk that blood donors are infected with HIV through careful selection of donors
2. establish routine screening for HIV, syphilis, hepatitis B, and, if funds permit, hepatitis C
3. reduce unnecessary use of blood transfusion by introducing and monitoring strict transfusion criteria
4. encourage the use of autologous blood transfusions\* whenever possible.

In refugee settings there should be someone nominated to organise a safe blood supply. They will need to consult with the local health authorities, for example, the District or Provincial Medical Officer, and, if there is one, the local Blood Transfusion Service Officer. Is there a National Blood Transfusion Service blood policy and plan? How well does the Blood Transfusion Service function locally? Are blood donors paid or volunteers? Is there a system for selecting donors and excluding those who may be at risk of HIV infection? What infections, if any, is the blood screened for? Are there criteria for transfusion? Is there a campaign to recruit volunteer blood donors? The local service may need upgrading; in rural or remote settings a new system may need to be established. Donated blood can be stored for up to 35 days at a constant temperature between 2 and 8 degrees centigrade. Often it is not possible to set up a blood bank in refugee settings, but procedures for safe transfusion and training of health staff are essential. Efforts should be made to ensure that the local host population also have access to a safe blood supply.

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\* Autologous blood transfusion is the collection and subsequent reinfusion of the patient’s own blood or blood components.

## Strategies

### *Reduce the risk that blood donors are infected with HIV through careful selection of donors*

In some countries volunteers or family members donate most blood for transfusion. In others people are paid to donate their blood. These professional blood donors may be at higher risk for HIV. For example, injecting drug users may sell their blood to get money for drugs. Paid donors may donate blood frequently, which is a risk to their health.

A system of registered voluntary donors is the safest, but is likely to be difficult to achieve if the population have not experienced voluntary donation in their own country. When family members donate blood there can be problems with confidentiality in relation to testing – and family members may be less likely than anonymous volunteers to provide information about possible exposures to HIV. Nevertheless they may be the only option. Where there is no blood banking, donors may need to be selected case by case.

Community education about the value and responsibility of blood donation can encourage those who may be at risk of HIV or other blood borne viruses to exclude themselves from donation. This education should include the message that blood



donation should not be used as a way to find out your HIV status.

A questionnaire needs to be developed for potential donors. Experience suggests that it is helpful if a trained health care worker can go through the interview with each potential donor. The questionnaire should include questions about:

- sexual activities
- ear and skin piercing
- tattoos or traditional skin incisions

- injecting drug use and sharing of injecting equipment
- recent illnesses, including sexually transmitted infections
- family history of illness
- whether the potential donor has received a transfusion of blood or a blood product
- previous blood donations (including if paid)
- general health and nutrition

This information must be kept strictly confidential and the potential donor must be told this. The person should be asked not to give blood if they may have been at risk of HIV.

When feasible it is important to develop a system for registering donors and to make efforts to motivate and retain low-risk donors.

### ***Establish routine screening of blood for transfusion***

All blood for transfusion must always be screened for HIV, syphilis, hepatitis B, and, if funds permit, hepatitis C. Rhesus testing and simple ABO compatibility testing before transfusion should also be carried out.

#### *Linked or unlinked screening?*

In refugee settings confidentiality assumes even greater significance than in stable settings. Unless confidential pre- and post-test counseling by well-trained counsellors and confirmatory tests are available then screening of blood for transfusion should be anonymous and unlinked – that is, the test specimen and the donated blood are labelled with a common identity code – but not with the donor’s name – and the donor does not receive the result.

However, if it is feasible to provide counseling and confirmatory testing, then potential donors should receive information explaining the procedure for blood donation, including the need for screening for HIV. At the same time as the trained health worker conducts the risk history assessment described above, they can:

- check the donor’s understanding of how HIV spreads,
- correct any misconceptions,
- describe how to protect against the spread of HIV,
- explain about the length of time before they receive the result, the window period and confidentiality, and
- obtain informed consent.

#### *Tests*

The ELISA test is most commonly used for screening blood for transfusion. (See page 111 for a discussion of HIV antibody tests). Dual infection with HIV-1 and HIV-2 may occur so test kits that can detect both are necessary for screening of blood.

*Reducing the costs of screening*

Several strategies can help to reduce the cost of HIV antibody testing. The strategy used for screening blood for transfusion depends on whether or not the donors will be informed of the results.

**If the screening is anonymous and unlinked**, that is, the donors will not be told the results, then only one test is needed. All serum is tested with one ELISA or simple/rapid assay. Serum that is reactive (gives a positive result) is considered HIV antibody positive, and the blood is destroyed. Serum that is non-reactive is considered HIV antibody negative, and the blood can be transfused.

It is possible to pool several specimens of sera and test them together. If the pooled samples test positive each sample is then tested to find out which was positive. To maintain a high sensitivity the recommended pool size is five samples.

Some countries have developed their own local production facilities for low cost HIV antibody tests to reduce transport costs and need for foreign exchange. WHO and UNAIDS help national governments and agencies to obtain high-quality kits at low cost through international tendering for bulk purchases. The list of evaluated test kits and program criteria are available from the blood safety unit at WHO<sup>3</sup>.

**If the donors will be told their result** then it is necessary to confirm an initial positive result with another different test to be sure that the first result was not a false positive. If the initial test result was negative this can be reported to the donor who should receive post-test counseling. If both test results are positive the donor can be told they are infected with HIV and receive post-test counseling (see page 89).

However if the first test result was positive and the second test result was negative, further testing is necessary before the donor can be given a result. Of course any donated blood should not be transfused and should be destroyed, whatever the results of confirmatory tests.

Studies have shown that combinations of ELISA and/or simple/rapid assays for confirmation can provide results as or more reliable than using the more expensive Western Blot confirmatory test. UNAIDS and WHO recommend three testing strategies according to test objective and prevalence of infection in the population, to maximize accuracy while minimizing cost<sup>4</sup> (see Appendix 3).

***Reduce unnecessary use of blood transfusion by introducing and monitoring strict transfusion criteria***

Even when blood is screened it is important to transfuse blood only when absolutely necessary. Fresh whole blood or red blood cells are usually transfused because of

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<sup>3</sup> WHO. Comparative evaluation of the operational characteristics of commercially available assays to detect antibodies to HIV-1 and/or HIV-2 in human sera. 1991–1999. [http://www.who.int/pht/blood\\_safety/hivkits.html](http://www.who.int/pht/blood_safety/hivkits.html)

<sup>4</sup> Weekly Epidemiological Record 21 March 1997;72(12) [http://www.who.int/wer/72\\_1\\_26.html](http://www.who.int/wer/72_1_26.html)

blood loss, for example, during surgery, trauma, childbirth, gastrointestinal bleeding, or ruptured ectopic pregnancy, or for severe anemia, most commonly due to malaria. Anaemia due to malaria is the most common reason for children to receive a transfusion in sub-Saharan Africa. Studies show that many transfusions were not needed. Several studies have found that strict criteria for blood transfusion can greatly reduce the number of transfusions without any increase in mortality or morbidity<sup>5</sup>. Many patients can tolerate low levels of hemoglobin without transfusion. Effective treatment and control of malaria, and training midwives in active management of the third stage of labor, are also important ways to reduce the need for transfusions.

#### **Criteria for transfusion because of blood loss**

In previously healthy patients with acute blood loss of less than 1000 mls:

- Control the bleeding
- Give a non-blood plasma volume expander such as dextran 70, or polygeline. If not available infuse normal saline (0.9%) or Ringer's Lactate solution.

Restoring volume is more important than replacing oxygen carrying capacity so a transfusion is not necessary unless active bleeding continues with loss in excess of 1000 mls and signs of shock (low blood pressure and rapid pulse rate). Loss of over 40 per cent of blood volume is life threatening and requires transfusion of blood, if available.

#### **Criteria for transfusion because of anemia**

- Haemoglobin less than 7 g/dl and symptoms – oedema, dizziness, shortness of breath, tiredness, rapid heart rate
- Haemoglobin less than 6 g/dl, even without symptoms
- Angina pectoris with haemoglobin of less than 10 g/dl
- Before an operation if the haemoglobin is less than 7 g/dl and the surgical blood loss is likely to be greater than 500 mls.
- Find and treat the cause of the anaemia. Give iron and folate.

Children under 12 years with severe anemia due to malaria: The benefit from transfusion depends on the timing of the transfusion, haemoglobin concentration, and clinical status. Transfusions have been found to be beneficial only if given within the first two days of admission. In those with severe anaemia, transfusion may be harmful because of volume overload in those who are already haemodynamically compromised.

Transfusion is indicated if:

- Hb < 5.0 g/dl and symptoms and signs of congestive heart failure (breathlessness, rapid pulse, oedema)
- Hb < 3.0 g/dl without symptoms and signs

WHO. The Clinical Use of Blood Handbook, 2001. Geneva.

<sup>5</sup> NHMRC. Clinical Practice Guidelines on the Appropriate Use of Red Blood Cells. 12 December 2000 National Health and Medical Research Council and the Australasian Society of Blood Transfusion [www.health.gov.au/nhmrc/publicat/pdf/cp77.pdf](http://www.health.gov.au/nhmrc/publicat/pdf/cp77.pdf)

If these criteria are followed, transfusions could be reduced by over 50% without increasing mortality. Doctors in Kinshasa found that by following strict criteria they reduced transfusions by 75% without any increase in deaths<sup>6</sup>.

Training health professionals to minimize transfusions is essential; monitoring is also needed. The reason for a transfusion should always be documented. Doctors often believe what they were originally taught, and may resist adopting new criteria. In eastern block countries some children became infected with HIV because of the common practice of giving 'micro' transfusions to children to strengthen them.

***Encourage the use of autologous blood transfusions whenever possible***

Autologous blood transfusion is the collection and subsequent reinfusion of the patient's own blood or blood components. Such transfusions also avoid the problem of allergic reactions to blood transfusions, and minimize the use of limited supplies of donated blood.

*Before elective operations* in which substantial blood loss may occur it is possible to take and store the patient's own blood for use at the time of the operation if adequate blood storage facilities are available. It is safe to take 500 mls at three, two and one week before surgery in citrate-phosphate-dextrose-adenine to prevent clotting. (Take only 400 mls if the adult is less than 50 kgs). The patient should have a hemoglobin level greater than 10 g/dl (or haematocrit >30%) before their blood is taken. Give oral iron. Label carefully and store the blood in a separate section of the refrigerator to donated blood.

*Blood can be removed from a patient immediately prior to surgery* with simultaneous replacement by infusion of normal saline solution (3 mls for each ml of blood collected) to maintain the circulating volume. This technique is especially useful where there are no facilities for storage of blood. It does not require specialized equipment other than standard blood bags and transfusion sets. During surgery the patient will lose fewer red blood cells for a given blood loss. The collected blood can be reinfused, after bleeding ceases, which replenishes the patient's hemoglobin, clotting factors and platelets. The total volume of blood collected should not exceed 40% of the patient's estimated blood volume. The blood should be collected into standard plastic blood packs containing citrate-phosphate-dextrose, numbered and labeled, and remain with the patient until reinfused. Amounts should be carefully documented, and blood pressure and pulse monitored during the procedure. A blood administration set with a standard filter should be used.

*Intraoperative blood salvage* is the collection of shed blood from a wound or body cavity during surgery and its subsequent reinfusion into the same patient. This can be useful during surgery for ruptured ectopic pregnancy, ruptured spleen, some orthopedic procedures and traumatic penetrating injuries. Blood should not be salvaged if there has been perforation of the gut. At operation the surgeon collects

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<sup>6</sup> Davachi F, Nseka M, N'Galy B, et al. Effects of an educational campaign to reduce blood transfusions in children in Kinshasa, Zaire. Fifth International Conference on AIDS, Montreal, 1989.

blood from the body cavity using a ladle or small bowl and transfers it into a larger bowl or kidney dish containing acid-citrate-dextrose anti-coagulant. Tilting the head of the patient down can assist this process. The blood is then filtered into a sterile bottle through four to six layers of sterile gauze placed in a funnel. The bottle is sealed with the stopper and reinfused through a blood infusion set with a standard filter. Adverse effects are rare.

### Suggested indicators

| <i>Indicator</i>  | <i>Method of measurement</i>  |
|---|---|
| Blood safety officer designated   | Document review   |
| Blood safety system established and procedures documented   | Document review<br>Observation with checklist                         |
| Donor education campaign conducted  | Community FGDs<br>Donor interviews                                    |
| Register of volunteer donors established or case by case selection of donors documented                   | Document review   |
| Self-exclusion questionnaire developed  | Review of questionnaire   |
| Proportion of health workers trained to interview, counsel and exclude donors at risk of HIV              | Review of training reports<br>Observation with performance checklists |
| All blood for transfusion screened for HIV antibodies, syphilis and other relevant infections             | Review of records   |
| Procedures to ensure confidentiality established and monitored – or – unlinked anonymous testing in place | Observation checklist<br>Interviews with staff                        |
| HIV test kits stored securely   | Observation   |
| Transfusion criteria documented and disseminated to relevant health personnel                             | Review of documents   |
| Proportion of relevant health professionals trained in use of strict transfusion criteria                 | Review of training report   |
| System in place to monitor number of transfusions and their indications                                   | Review of documents   |

## **Additional resources**

UNAIDS. Blood safety and HIV UNAIDS technical update October 1997.  
<http://unaids.org/publications/documents/health/index.html#blood>

Wake DJ, Cutting WA. Blood transfusion in developing countries: problems, priorities and practicalities. *Trop Doct* 1998; Jan. 28 (1): 4-8.

HIV testing: a practical approach. Healthlink Worldwide. 1999.

WHO/GPA. WHO Health Laboratory Technology and Blood Safety Unit. Autologous blood transfusion in developing countries. WHO/GPA/INF/91.1, December 1990. WHO Web-site: Blood Safety and Clinical Technology  
<http://www.who.int/bct/>



# 13

## Prevention of transmission in health care settings

### Introduction

If proper precautions are not taken HIV may spread from one patient to another, from a patient to a health care worker, or from a health care worker to a patient.

Fortunately HIV does not spread casually. This means that there is no need for isolation practices or “barrier nursing” of HIV infected patients, unless they have a contagious opportunistic infection such as infectious diarrhea.

It is natural for health care workers to worry that they may become infected with HIV from their patients. Health staff need clear information about findings from studies of the risk of transmission in health care settings and the factors that increase risk.

### Rationale

#### *What is the risk of occupational transmission?*

The risk of occupational transmission of HIV depends on the prevalence of HIV in the patient population, the chance of becoming infected after a single exposure, and the type and number of exposures.

HIV can be found in blood, semen, vaginal and cervical secretions, urine and faeces, wound secretions, saliva, tears, breastmilk and other fluids inside the body. But blood is the only fluid that has been associated with transmission in the health care setting.

Health care workers worry about needlestick injuries, cuts, getting blood on sores or broken skin, and blood splashes in the eye or mouth. We can reassure them that their risk of infection with HIV through their work is extremely small. Analysis of results from 21 studies in developed countries and Brazil showed a 0.25% risk of infection (1 in 400) after a needlestick injury from an infected patient<sup>7</sup>. The average risk after a mucous membrane exposure (e.g. eye splashes) was only 0.09%. When researchers analysed 200 incident reports from hospital workers in Thailand who had occupational exposure to HIV-infected blood and body fluids during 1991-1997, none of the workers had become infected with HIV<sup>8</sup>. It is also reassuring to note that in places where HIV is common, such as Zaire, studies have found that HIV infection is no more common in health care workers than in the general population<sup>9</sup>.

<sup>7</sup> Ippolito G, et al. The risk of occupational HIV infection in health care workers. Archives of International Medicine 1993; 153: 1451-1458.

<sup>8</sup> Phanuphak P, Pungpapong K, Ruxrungtham K. The risk of occupational HIV exposure among Thai healthcare workers. Southeast Asian J Trop Med Public Health 1999; 30 (3): 496-503.

<sup>9</sup> Mann JM, Francis H, Quinn TC, Bila K, Asila PK, Bosenge N, Nzilambi N, Jansegers L, Piot P, Ruti K, et al. HIV seroprevalence among hospital workers in Kinshasa, Zaire. Lack of association with occupational exposure. JAMA 1986; 256 (22): 3099-102.

Although the risk is very small, needlestick injuries from an HIV infected person are more likely to lead to HIV infection, than splashes or skin contamination. The risk is higher when the needle or cannula has been in the patient's artery or vein, rather than used for an intramuscular injection, when the needle is visibly contaminated with the patient's blood, when the patient is ill with AIDS, and when the injury is deep<sup>10, 11</sup>.

#### Discussion point

How do health care workers behave when they are not well informed about the routes of transmission of HIV and the level of risk of transmission in the health care setting? What effects does this have?

Fear might make health care workers sit at a distance from the patient and not touch them. They might arrange for the patient to be isolated from others. They might take unnecessary measures such as wearing a mask or gloves during a consultation or fumigating the room afterwards. They might insist on testing patients for HIV before surgery, or test for HIV without obtaining informed consent. They might refuse to care for an HIV infected patient, or to undertake surgery or deliver a baby.

The impact of the behavior of uninformed health care workers can be considerable. Everyone has the same right to non-discriminatory care and to health care services. People living with HIV are likely to feel hurt and rejected. They may feel angry, or frightened and helpless. If they are refused treatment or surgery their health will be affected. The behavior of the health worker will be observed by others and contribute to fear and stigma associated with people living with HIV in the community. People will be less willing to be tested for HIV if they know that they will be discriminated against and less willing to be open about it if they have been tested already. When patients known to be infected with HIV are treated differently to others, health care workers may be less aware of the need to adopt appropriate infection control precautions with all patients.

A study of the frequency of needlestick injuries and blood splashes in Mwanza, Tanzania, found that they were quite common when universal precautions were not in place, with the average health worker being pricked five times and being splashed nine times per year<sup>12</sup>. The annual occupational risk of HIV transmission was estimated at 0.27%. This highlights the need for guidelines, training, sharps containers and supplies of gloves.

Midwives and surgeons are most often at risk so it is reasonable to train them first. Hospital and clinic workers who look after children are frequently exposed to blood

<sup>10</sup> Ippolito G, Puro V, Heptonstall J, Jagger J, De Carli G, Petrosillo N. Occupational human immunodeficiency virus infection in health care workers: worldwide cases through September 1997. *Clin Infect Dis* 1999; 28 (2): 365-83.

<sup>11</sup> Cardo DM, Culver DH, Ciesielski CA, Srivastava PU, Marcus R, Abiteboul D, Heptonstall J, Ippolito G, Lot F, McKibben PS, Bell DM. A case-control study of HIV seroconversion in health care workers after percutaneous exposure. Centers for Disease Control and Prevention Needlestick Surveillance Group. *N Engl J Med* 1997; 337 (21): 1485-90.

<sup>12</sup> Gumodoka B, Favot I, Berege ZA, Dolmans WM. Occupational exposure to the risk of HIV infection among health care workers in Mwanza Region, United Republic of Tanzania. *Bull World Health Organ* 1997; 75 (2): 133-40.

when they insert intravenous drips or take blood samples. Learning to perform these procedures with gloves on takes practice; the gloves need not be sterile and can be washed and reused many times.

Health care workers may also be at risk from other blood borne viruses, such as hepatitis C and hepatitis B. Practicing universal precautions will protect health care workers from these viruses too.

### ***Why are they called “Universal precautions”?***

Many health workers do not understand the term “Universal precautions”. We call the infection control precautions “universal” because they must be followed with everyone, not just patients known to be infected with HIV. It is not possible to know which patients may be infected with HIV or other blood borne viruses, so it is essential to adopt the same precautions with all patients. Sometimes the term ‘Standard precautions’ is used in place of ‘Universal precautions’.

#### **Universal precautions to prevent transmission of HIV and other blood borne viruses**

These infection control practices should be followed when caring for *all* patients, at *all* times

- Only give injections when absolutely necessary
- Have a puncture-resistant sharps container close to you when you carry out a procedure using a needle or blade
- Dispose of used needles immediately in a sharps container. Do not walk around carrying a used needle or blade.
- Never put needles in with general waste.
- Do not re-cap needles, or remove them from the syringe after use.
- Wash hands before and after procedures. Cover any sores with a waterproof dressing.
- Do not undertake procedures if you have a weeping rash.
- Limit skin contact with blood by wearing gloves when putting up intravenous lines, or taking blood. Keep sterile gloves for internal examinations and surgical procedures. Change gloves after contact with each patient. Wash hands after removing gloves.
- Use ‘non-touch’ technique for dressings by using forceps.
- Wear a gown or apron for procedures when there might be splashes of blood or body fluids.
- Limit the risk of splashes of blood to mouth or eyes by wearing a mask and goggles for procedures where blood may spurt e.g. dentistry, surgical operations and deliveries.
- Use new or sterilized needles, syringes and instruments for every procedure.
- Mop up spills of blood or other body fluids promptly. Wear gloves while you do this. Then wipe the area with disinfectant.
- Put blood stained sheets or cloths soiled with blood or body fluids in a plastic bag that will not leak, at the place where they were used. They should be laundered in the usual way.
- Report any needle-stick accident, blood splashes to eyes or mouth, or prolonged exposure to blood to the nurse in charge.

***Is there a risk from mouth-to-mouth resuscitation?***

Emergency mouth-to-mouth resuscitation does not carry a risk of transmission of HIV or blood borne viruses unless there is bleeding from the mouth or face. Where injecting drug use is a problem it is important to remember that when a drug user collapses from an overdose there may be a used needle on them or nearby.

***Can you become infected with HIV from a dead body?***

HIV will survive for some hours after the death of an infected patient. However there is no risk from handling a dead body unless there has been bleeding, when gloves should be worn to clean the body. In addition to the universal precautions already described, anyone performing or assisting in postmortem procedures should wear gloves, masks, protective eyewear, gowns, and waterproof aprons. Instruments and surfaces contaminated during postmortem procedures should be decontaminated with a chemical disinfectant.

***How should instruments and surfaces be sterilized to prevent transmission of HIV?***

HIV does not survive for long outside the human body. It is sensitive to drying and to heat. Studies show that commonly used chemical disinfectants kill HIV. So the usual methods of sterilizing instruments, equipment and surfaces will kill HIV, as well as other microorganisms.

Cleaning instruments with soap and water before they are sterilized is essential because viruses can survive chemical disinfection if they are protected within organic matter. Dismantle equipment before cleaning.

Selecting the method for decontamination:

| <b>Level of Risk</b> | <b>Items</b>  | <b>Decontamination Method</b>                    |
|----------------------|---|--|
| High risk            | Instruments which penetrate the skin/body                                 | Sterilization, or single use of disposables      |
| Moderate risk        | Instruments which come in contact with non-intact skin or mucous membrane | Sterilization, boiling, or chemical disinfection |
| Low risk             | Equipment which comes in contact with intact skin                         | Thorough washing with soap and hot water         |

Neonatal laryngoscope blades and endotracheal tubes in theatres and delivery rooms are often forgotten. They should be cleaned with surgical spirit, alcohol, or polyvidone iodine after every use.

A solution of sodium hypochlorite (household bleach) in a dilution of 1:10 is an inexpensive and effective disinfectant. However, it must be freshly prepared because it soon becomes inactive. Bleach at 1:10 dilution will corrode metals and plastic so it is best to use a different disinfectant for long-term use for soaking instruments.

Environmental surfaces such as walls, floors, and other surfaces are not associated with transmission of infections to patients or health care workers. Only ordinary cleaning is necessary and there is no need for fumigation.

### ***How should contaminated waste be handled?***

Careful thought should be given to the disposal of sharps containers. They should not be disposed of with general waste because they may end up being a hazard to rag-pickers at waste dumps. If they are buried care should be taken to ensure that they cannot be dug up easily by children playing or by people who may want to 'recycle' the needles, such as those who inject drugs. Incineration may be an option.

Place solid waste that is contaminated with blood, or body fluids, and body tissue in leak-proof containers and incinerate, or bury in a deep pit, at least 30 feet away from a water source. Pour liquid waste containing blood or body fluid into a pit latrine or drain connected to an adequately treated sewer.

The De Montfort incinerator is designed to be a relatively cheap unit for disposing of hospital waste. If used correctly it can ensure that waste is exposed to temperatures above 800°C for a period of over 1 second. It reduces waste such as dressings, wet or dry, plastics, and organic matter to ash and flue gases. Because needles may not all be reduced to ash care should be taken when removing ashes. Small glass sharps will normally be part melted and rendered safe. The flue gases emitted will have been held at a high temperature for at least one second and should be harmless. There are several designs of different sizes. The Mark 4 is a version specifically designed for use in emergency situations where low cost and a minimum of expensive materials and techniques are priorities. It contains only two metal components, and uses firebricks only where these are absolutely necessary. It will burn up to 12 kgs of waste per hour. For further information about these incinerator designs and details of manufacturing the various models apply to Professor DJ Picken, De Montfort University, Leicester, UK. [djpicken@iee.org.uk](mailto:djpicken@iee.org.uk)

### ***Infection control for home-based carers***

Family members and volunteers who help to care for people with AIDS at home can be reassured that there is very little risk of transmission of HIV. Explain to them how to mop up spills of blood or other body fluids. Ideally they should have plastic or rubber gloves, disinfectant, and soap. If gloves are not available plastic bags can be worn over the hands to avoid contact with blood and body fluids.

### ***What can be done if a health care worker is accidentally exposed to HIV infected blood?***

Immediately following an exposure to blood the health care worker should:

- Wash needlesticks and cuts with soap and water
- Flush splashes to the nose, mouth, or skin with water
- Irrigate eyes with clean water, or saline. This should be done gently to avoid harming the eyes.

Using antiseptics, squeezing the wound or using a caustic agent such as bleach will not reduce the risk of transmission of a bloodborne pathogen and are not recommended.

## ***Should HIV infected health care workers continue to be employed in health care settings?***

There is no reason why a health care worker with HIV should have to leave their job, whether or not they became infected through their work, as long as they remain well. Health care workers should be encouraged to reveal their status to a supervisor, who should be obliged to respect their confidentiality. The supervisor should counsel the health care worker about the need to follow universal infection control precautions. The supervisor may be able to protect the health care worker from infectious patients, such as those with tuberculosis or chicken-pox. HIV infected health care workers are in a strong position to provide HIV-related counseling and education, if they are willing. Supervisors should encourage a supportive and non-discriminatory work environment.

### **Strategies**

Interventions to minimize the risk of transmission of HIV and other blood borne viruses in health care settings include:

#### ***1) Develop and display guidelines for universal infection control precautions***



Detailed local guidelines for precautions, such as the example on page 198, should be prepared and displayed in the treatment room of every clinic, and in every ward and theatre of the hospital. Most emphasis should be placed on the avoidance of needle-stick injuries, since these are the greatest risk to staff and patients.

#### ***2) Train health care workers in the use of the guidelines***

Traditional healers and traditional birth attendants may be exposed to blood and other body fluids, and may use sharps such as blades or needles in their work. They should be included in infection control education.

#### ***3) Supply protective equipment***

This includes puncture resistant “sharps” containers, gloves, plastic aprons, gowns and goggles, and disinfectants.

If gloves are difficult to obtain make sure that they are used for procedures with a greater risk of exposure to blood such as surgery, attending deliveries, suturing, and placing intravenous cannulae in children. Plastic bags can be used instead of gloves for handling spoiled linen and clearing up spills of blood.

If protective goggles are not available spectacles with clear glass are an inexpensive alternative. Goggles can be made from an old pair of sunglasses or spectacle frames (pop out the lenses). Cut a square of plastic film (‘cling film’) and stretch over one

side of the frame. Hold it taut while someone else applies sticky tape around the rim. Trim the loose edges of plastic film. Repeat on the other side. These will protect the eyes from splashes during deliveries. But remember that the risk of HIV from eye splashes is very small.

#### **4) Introduce measures to reduce health worker's stress and fatigue**

These make accidents more likely. Try to ensure appropriate work hours and rosters.

#### **5) Develop a system for reporting and management of occupational exposures**

Those responsible for providing health care services need to document a system to provide adequate assessment, counseling, and follow-up for exposed health care workers. Guidelines and training should include advice to report accidental exposures to blood, and supervisors need to be aware of how to manage such incidents. Refer to the IRC staff health policies on post-exposure prophylaxis.

#### **Guidelines for management of accidental exposure to HIV infected blood**

- Assess the risk of HIV transmission:
  1. Assess whether the exposure was serious, that is:
    - needlestick or cut (parenteral)
    - splash to the eye or mouth (mucous-membrane exposure)
    - prolonged skin exposure to large amounts of blood, especially if the skin is broken or inflamed
 If there have only been splashes of blood on the skin then the staff member can be reassured that they are not at risk.
  2. Assess likelihood that the source patient is infected with HIV. Consider:
    - patient's HIV antibody test result if they have had one
    - prevalence of HIV in the population
    - patient's condition
    - possible risk factors of patient
- Inform source patient of the incident, counsel them and request consent to an HIV test.
- If the exposure was serious, and the source patient has AIDS, is positive for HIV antibody, or refuses the test, counsel the health care worker about the risk of infection. They should have an HIV test (if they consent) as soon as possible after the exposure. (This will show whether they were already infected with HIV.)
- If after the above assessment there are reasons to think that there may be a risk of transmission of HIV then the health care worker should be offered the option of post-exposure prophylaxis with a combination of antiretroviral drugs, if they are available. This should start within 24 hours of the exposure and continue for four weeks. Monitoring of side-effects will be necessary.
- Advise the health care worker to report and seek medical care if they develop a 'flu-like' illness with fever and muscle aches and pains within 12 weeks after the exposure.
- Arrange further HIV tests for the worker six weeks, 12 weeks and six months after the exposure to determine whether transmission has occurred, and follow-up counseling.
- If a health care worker has a needle-stick injury during a surgical operation there is a small theoretical risk to the patient. The patient should be informed of the incident, and the same procedure outlined above for management of exposures should be followed for both the source health care worker and the exposed patient.

**6) Monitor the implementation of these interventions**

**Suggested indicators**

| <b>Indicator</b>   | <b>Method of measurement</b>                                |
|--|---|
| Universal precautions guidelines displayed in health care settings and available to home-based care staff and volunteers | Observation   |
| Safe sharps container available and in use in health care settings   | Observation   |
| Gloves available and in use for procedures involving exposure to blood   | Observation   |
| Proportion of health care staff trained in use of Universal precautions guidelines                                       | Training records  |
| Proportion of procedures undertaken according to the guidelines  | Observation of a sample of procedures using a checklist     |
| System for reporting needlestick incidents in place  | Up to date register of needlestick incidents                |
| Management protocol for needlestick incidents available  | Observation   |
| Proportion of supervisors/ senior staff aware of management protocol for needlestick incidents                           | Interview survey of supervisors / senior staff              |
| Proportion of reported needlestick injuries adequately followed up   | Review of records / anonymous survey of health-care workers |
| Satisfaction of HIV infected patients that they are being treated in a non-discriminatory way                            | Focus group discussions with PLWH group.                    |

**Additional Resources:**

CDC Public Health Service guidelines for the management of health care worker exposures to HIV and recommendations for post-exposure prophylaxis. MMWR 1998;47(RR-7): 1-33. [www.cdc.gov/hiv/treatment.htm](http://www.cdc.gov/hiv/treatment.htm).

WHO. HIV and the Workplace and Universal Precautions. Fact sheets for nurses and midwives.2000 [www.who.int/HIV/AIDS/Nursesmidwivesfs/fact-sheet-11](http://www.who.int/HIV/AIDS/Nursesmidwivesfs/fact-sheet-11)

CDC. Exposure to Blood - What Health care Workers Need to Know 1999. CDC, National Center for Infectious Diseases [http://www.cdc.gov/ncidod/hip/blood/exp\\_blood.htm](http://www.cdc.gov/ncidod/hip/blood/exp_blood.htm)



## Introduction

Billy Mosedame of Botswana, a man living with HIV, declared at an international conference on home-based care: “We all need and deserve care, support and compassion.” Non-discriminatory health care is a human right.

The following story was told during an evaluation of an HIV prevention project:

*“The mother of a young man who was ill with HIV had spent a lot of money on medicines that had not worked – but when she discovered that her son had AIDS the family lifted the ill boy on his bedding and left him by the side of the road. No one would touch him. Project staff came and helped the boy, and took him to hospital, where he was treated and made a good recovery. Meanwhile the project staff talked with his family and gave them information about how HIV does and does not spread, and encouraged the family to accept their son back into the family. Because the family saw the staff were not afraid to touch and care for their son they felt ashamed, changed their attitude, and welcomed him back. The family were grateful to the project staff for their intervention. The neighbors also asked questions about how HIV spreads.”*

This is a very important story. It demonstrates how successfully attitudes can be changed, and shows the connection between care and prevention. When families are reassured about how HIV does not spread, and see others touching people with HIV, then they are willing to accept HIV positive family members – others are also then less likely to discriminate against positive people. When people see that they will not be discriminated against they are more likely to be willing to come forward for testing, counseling and treatment, and to make efforts to ensure that they do not transmit the infection to others. It becomes possible for them to lead productive positive lives. Also when local families see that neighbors are affected by HIV they believe that it is possible for them to be affected too, and they are then interested to learn how the virus spreads so that they can protect themselves.

Prevention efforts that begin with care and support are more likely to be effective and less likely to increase stigmatization than attempts to change behavior through information and education approaches alone.

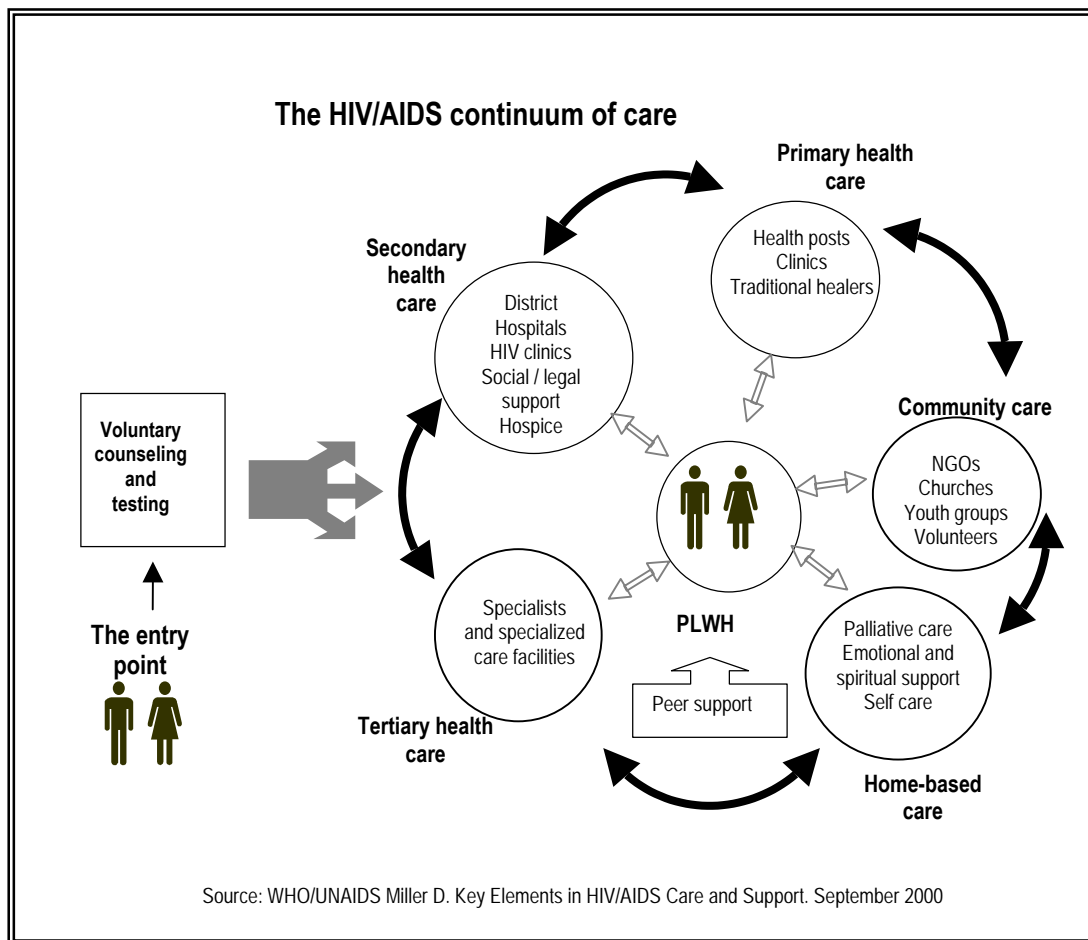
At present, there is no cure for AIDS. However there are treatments for the relief of symptoms, medicines to treat and prevent opportunistic infections, and an increasing range of antiretroviral drugs that attack HIV itself.

To meet the physical, emotional, social and economic needs of PLWH, care and support should be governed by the same principles as those described on page 65. In particular ethical issues need to be considered, including the importance of informed consent to treatment, respect for dignity, privacy and confidentiality, quality of care, equality of access, affordability, effectiveness and efficiency.

Appropriate care and support for people living with HIV will enable them to live longer, healthier and more productive lives, which benefits the individuals, their families and the whole society.

## Rationale

### *The continuum of care*



Voluntary counseling and testing should be an entry point to a continuum of care. Sometimes people will be well for years after they learn their HIV status. Others may only learn that they have HIV when they present with a serious opportunistic infection or malignancy. Ideally, even in refugee settings, people with HIV related illness will be able to be cared for in their own home or shelter, with support from their family, friends and community. Their symptoms and signs should be able to be assessed by health

workers at the local clinic, or by outreach health workers, and if they need to be hospitalized, there should be trained nurses and doctors, appropriate standard treatment protocols, and essential drugs available to treat the most common opportunistic infections. The idea of a continuum of care is that there will be links between hospital, clinics, community and home-based care, so that people do not get discharged from hospital without any support, and are able to be referred to specialist services from a primary health care clinic.

The ideal of a continuum of care can only be achieved with much consultation, communication and coordination between a range of stakeholders who provide care in these different settings. Even in refugee settings it is important to develop links between the levels of care that may be available.

### ***Home-based care and self-care***

When PLWH are able to accept their diagnosis they often start to live in a more healthy way. They may give up smoking cigarettes, drinking, or injecting drugs. They may try to improve their diet, take regular exercise and reduce their levels of stress. All this will help to prevent infections that may further damage their immune system, and may restore a sense of control.

Once a PLWH becomes sick experience in many countries shows that home-based care is often appropriate and acceptable. Most patients prefer to be looked after at home. Even in refugee settings people may prefer to be cared for in their own shelter by family members rather than in hospital. Where HIV is common home-based care may be the only way to care for the large numbers of patients when hospital services are overwhelmed.

Home-based care requires training, support, supervision and equipment. A hospital may deploy an outreach team that undertakes home visits. More commonly a team of volunteers are trained to provide care and support. It is important that carers know that they can refer patients to the clinic or hospital when necessary. Discharge policies need to be in place to ensure that arrangements are co-ordinated for home-based care before the patient is discharged from hospital. Caring for patients with AIDS is stressful. Volunteers must be treated with the same respect as health professionals. We also need to recognize that the burden of home-based care generally falls disproportionately on women. Child care, and preparing for the future care of orphaned children, are important components of home-based care programs.

When a PLWH receives care visits, the family and neighbors know that the patient has AIDS. The visits raise awareness of AIDS in the community. This leads to useful community discussion about the need for behavior change. Experience has shown that there is a strong link between home care and community action to prevent spread of HIV.

### *Nutritional support*

IEC materials about nutrition should be prepared in consultation with PLWH and their carers to ensure that the advice given is feasible, with appropriate foods and methods of preparation.

People with HIV who are asymptomatic should try to eat a variety of foods with sufficient calories and micronutrients. It is especially important that pregnant women infected with HIV have a good diet, with sufficient calories and plenty of fruit or vegetables, to maintain their health and reduce the risk that HIV will pass to the baby.

PLWH often have a poor appetite. They may have frequent diarrhoea and vomiting. PLWH who are ill may feel better if they can eat small frequent meals. Soft foods, such as soups and mashed bananas, are easier to eat for those who have an inflamed throat. Many societies have fermented foods or drinks, either dairy-based (such as yogurt) or cereal-based (such as mahewu). Fermentation increases the digestibility of foods, increases the absorption of micronutrients, and decreases bacterial contamination. If a person is too ill to eat they may need to be fed via a naso-gastric tube. It would be unusual to manage this at home in refugee settings but may be possible with support, depending on the context.

### *Relaxation exercises*

There is evidence that stress is harmful to the immune system, and may make HIV disease progress more quickly. Relaxation exercises, including progressive muscle relaxation, meditation, and massage, can help people with HIV to cope and lessen feelings of anxiety and depression.

### *Exercise*

Exercise, including walking and running, can also be beneficial to people living with HIV. Certain exercises can strengthen leg muscles, which may become weak in patients with HIV related symptoms.

### *Home nursing care*

Weight loss, fever, night sweats, diarrhoea and itchy skin disorders are common early symptoms and signs of HIV infection. Good nursing care such as washing, frequent mouth washes and massage can be a great help to patients. Nursing care needs to include sympathetic psychological support for patients who may often feel frightened. There are a number of simple medicines that can relieve symptoms:

- Chlorpheniramine for itching and drug reactions
- Calamine lotion for itchy rashes
- Prochlorperazine for vomiting
- Oral rehydration fluids for diarrhoea
- Analgesics, such as aspirin or acetaminophen (paracetamol) for pain

- Aspirin or acetaminophen (paracetamol) for fever
- Loperamide for diarrhoea

There may be traditional remedies that will also relieve symptoms.

### *Palliative care*

Palliative care is the care of someone who cannot be cured and who is too sick for carers to be able to prolong their life. Palliative care enables people to die with dignity. Palliative care does not hasten or try to postpone death. It aims to provide relief from pain and distressing symptoms and provides spiritual and psychological support to the patient and their family as they prepare for death.

Carers often find it difficult to talk with people who are dying, and to express the love and compassion that they feel. For carers who are HIV positive themselves dealing with death can be especially difficult because of their own fears.

Even in cultures where it is not traditional to talk about death people who are dying are usually grateful for the opportunity to talk about it. It is important to help PLWH to arrange for the care of their children after their death, and to prepare their children for their death. Often stigma associated with AIDS prevents parents from telling their children what is going on and this contributes to the confusion and grief that children feel when their parents die. PLWH may also need help to prepare a will, or legal advice to prevent problems when their assets are distributed after their death.

Common physical symptoms in the final stages of AIDS are

- cough
- diarrhea
- loss of appetite and wasting
- itching
- weakness and fatigue
- fever
- difficulty swallowing
- psychiatric symptoms – anxiety, depression, agitation
- pain

Effective management of pain is one of the most important components of palliative care. It is likely to be difficult to achieve in many refugee settings because export / import controls may make it difficult to obtain supplies of controlled drugs. Drug control authorities in the receiving country may not be functioning or may not have authority for the refugee affected areas. This is why humanitarian aid agencies do not provide narcotics in their emergency medical supplies. This difficulty has been recognised and is being addressed by WHO and the International Narcotics Control Board (INCB). The INCB and the 49<sup>th</sup> World Health Assembly have recommended that control obligations be limited to the authorities of exporting countries in emergency situations. Model

guidelines have been prepared to assist national authorities with simplified regulatory procedures. The guidelines and a model shipment request form are provided in the New Emergency Health Kit (WHO)<sup>13</sup>. This may help you to negotiate with the appropriate national drug control authorities to be able to obtain the opiate drugs needed for palliative care.

Pain may result from local tissue damage to skin or organs, or may result from pressure on or destruction of nerves. Pain also has an emotional component – when someone is feeling low they may experience pain as more severe than when they are feeling happier, or perhaps distracted by a visiting friend.

The person feeling the pain needs to make the decisions about pain relief. This is because they alone experience their symptoms, and also because a sense of control is very important at this stage of an illness.

The first step is simple analgesics such as aspirin and acetaminophen (paracetamol), and good nursing care to ensure that the patient is as comfortable as possible – for example a simple soothing cream may be applied to inflamed rashes or the anal area.

When these measures become ineffective, weak opioid drugs such as acetaminophen (paracetamol) or aspirin combined with codeine will be required, although they may be difficult to obtain in some refugee settings. These tablets may cause constipation.

The third step requires stronger painkillers in the form of strong opioid drugs. WHO's New Emergency Health Kit (1998) includes morphine injection, whereas the previous UNHCR essential drug list included pentacozine injection, which is inferior but may be a practical alternative when opioids are not available\*. Morphine, taken by mouth as a syrup or tablets, is the most effective drug for palliative care. It needs to be given every four hours, and regularly, in order to prevent the pain returning, rather than waiting until pain returns. Injections of morphine (under the skin) should only be used when the patient cannot swallow. Intra-muscular injections are painful, especially when the patient has reduced muscle mass.

The side-effects of morphine are:

- constipation (which may be useful when the patient has diarrhea),
- nausea and vomiting (anti-nausea treatment can be given),
- drowsiness, which wears off over time, and
- dry mouth (the patient will need frequent sips of water)

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<sup>13</sup> The New Emergency Health Kit, 1998. WHO, Geneva.

\* WHO New Emergency Kit: "Pentazocine and tramadol, diazepam and phenobarbitol are now controlled drugs in some countries and come under control measures additional to the UN Convention on Psychotropic Substances, resulting in the requirement for an import permit before authorization of an export permit."

There is no need to worry that the patient may become addicted to the drug, the important aim is pain relief. However it is not always legal to give morphine to these patients, even when it is available. We should advocate strongly for morphine to be available to patients dying from AIDS-related illnesses.

Other medicines that may be helpful include tricyclic antidepressants for nerve pain, steroids, anti-convulsants and anti-spasmodics.

Restlessness that sometimes accompanies dying may be relieved by diazepam given via the rectum. Check first for possible treatable causes of the restlessness such as urinary retention or pain.

### *Respite care*

Respite care is temporary care that enables the usual carer to have a rest from the stress and work of caring for an ill person. When respite care is available family and friends are more willing to care for PLWH and are able to have a better relationship with the person. The morale of both the patient and the carer will be improved. Respite care might be provided through a day-care center, a residential center, a drop-in center – or as respite for carers in their own home. Provision of regular and reliable respite care should be a priority for home-based care programs. There should be a clear time limit.

### *Primary health care*

The skills, knowledge and supplies to support home and community based care need to be available at primary health care level. The primary health care clinic should be the contact point for referral to hospital care and other relevant services.

### *Management of opportunistic infections*

There are a wide range of clinical manifestations associated with HIV infection. We do not know the cause of all of them. Some are due to a direct effect of the virus on certain body cells, such as those of the central nervous system and gastrointestinal tract. But many clinical manifestations are the result of damage to the immune system, which leaves the body open to infection by a variety of opportunistic organisms. Infections that are latent in the body, such as tuberculosis or herpes zoster, re-activate when immunity weakens. The most common infections suffered by people living with HIV are tuberculosis, pneumonia, diarrhea, candida infection of the mouth and throat, STIs and fungal skin infections. These infections can often be diagnosed at primary health care clinics and generally respond to affordable antibiotics. Gynecological problems are common in women infected with HIV. Most women prefer to be seen by a female health worker and want to be examined in privacy. There is a need for resource materials about HIV-related illnesses in local languages.

### *Prophylaxis*

Prophylaxis means taking a medicine to prevent rather than treat an infection.

Studies show that the antibiotic co-trimoxazole can prevent many bacterial and parasitic opportunistic infections in adults and children living with HIV, including toxoplasmosis, salmonellosis, pneumococcal pneumonia, and bacteremia.. This is a cost-effective intervention for people living with HIV and governments because it reduces hospital admissions and mortality.

WHO recommend that all HIV infected adults with symptomatic disease and asymptomatic individuals with a CD4 count of less than 500 (see page 216 for definition of CD4 count) should take a daily double-strength dose of co-trimoxazole (trimethoprim 160 mg; sulfamethoxazole 800 mg). Pregnant women infected with HIV should only take co-trimoxazole after the first trimester. The infants of HIV positive mothers should also receive co-trimoxazole syrup from six weeks of age, as should any child identified as being infected with HIV during the first year of life, and children older than 15 months who have symptoms of HIV infection.

This prophylaxis should continue indefinitely unless there are side-effects. If severe skin rashes occur the co-trimoxazole should be stopped. Patients will need to be followed up every month initially and then every three months.

Isoniazid prophylaxis is recommended for people living with HIV at risk of tuberculosis, such as those with a positive TB skin test or who are living in areas where the disease is endemic. Isoniazid has been shown to increase the survival of HIV-infected persons at risk of tuberculosis. Since isoniazid is relatively inexpensive this is likely to be a cost-effective measure, especially in the high-risk setting of refugee camps where tuberculosis can spread easily.

### *Detection and management of tuberculosis*

In many countries where conflict leads to displacement, tuberculosis (TB) is the most common opportunistic infection in people living with HIV, and the most common cause of death. Tuberculosis may present at any stage in the course of immunodeficiency. TB control programs should be integrated with primary health care services for the refugee population.

WHO have prepared a field manual on tuberculosis control in refugee settings<sup>14</sup>. It is recommended that a TB control program should not begin until crude mortality rates have been reduced to less than 1 per 10,000 population per day, basic needs are provided, and essential clinical services and supplies are available.

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<sup>14</sup> WHO. Tuberculosis control in refugee situations: an inter-agency field manual. 1997.



Because tuberculosis requires a long duration of treatment and there is a risk of resistant organisms developing if the course of treatment is not followed, a TB control program should be implemented only if the security situation is stable and the camp population are expected to remain for at least six months. Funding should be available for at least 12 months, along with sufficient medical supplies and trained staff.

The national TB program of the host country should be involved in the implementation of a TB program for the displaced population.

The priority of a TB control program is to identify and treat infectious patients, and ensure that they become non-infectious as soon as possible. Successful cure of infectious patients will reduce transmission. If drugs are taken regularly patients become non-infectious within two weeks of beginning the treatment.

In addition to the infectious smear-positive pulmonary TB patients, severely ill patients with non-pulmonary TB (who are not generally infectious) should be treated in the TB program. People with non-infectious TB who are not severely ill need not be included in the TB program until it has been demonstrated that cure rates are satisfactory.

People living with HIV who have tuberculosis respond well to standard TB treatment. The recommended strategy for curing infectious TB patients is the WHO TB control strategy: Directly Observed Therapy Short course or DOTS. This is implemented by providing the correct combination of TB drugs for 6 or 8 months, and observing patients swallowing their medicines. This is especially important during the first two months of treatment.

TB is a wasting disease. Many refugees may also be suffering from malnutrition. TB treatment will usually lead to an increased need for calories, therefore attention to nutrition will be an important component of a TB control program in refugee situations.

### *Supportive counseling*

The availability of well-informed, non-judgmental and objective supportive counseling can assist people infected with and affected by HIV to live useful and productive lives (see Chapter 7).

Health care consultations provide an opportunity to give information, and to talk about prevention. People living with HIV may also need good advice and access to methods of contraception.

Those who inject drugs need well informed advice and support. They may need referral to drug substitution and rehabilitation services if these are available. If they continue to inject it is essential to provide supplies of needles and syringes in order to protect others, and to counsel them about the need for safe sex.

### *The role of traditional healers*

In many of the countries severely affected by HIV people often attend traditional healers when ill and respect their knowledge and power to heal. There are many examples of traditional or spiritual healers and modern health practitioners working together in HIV prevention and care. Traditional healers have been trained to recognize and counsel HIV infected patients. When the traditional healer gives the same prevention advice as hospital or clinic staff, the message is likely to be very effective. Traditional healers may also be able to provide important relief for HIV-related symptoms.

### *Referral system*

It is important that staff at primary health care level know when and how to refer patients for further investigation or treatment. Standard treatment protocols for common problems in people living with HIV need to include indications for referral. It is helpful for PHC level staff to receive feedback from the hospital about the appropriateness of their referral and the outcome. But even where referral systems are in place, they are often not used. It is necessary to monitor whether systems are followed at hospital level. Problems with communications and transport are often obstacles to effective referral. Inter-sectoral and community consultation are necessary to identify solutions to these problems.

### *Hospital care*

The opportunistic infections suffered by PLWH generally respond well to treatment, but tend to recur frequently. This means that adults and children with HIV may require frequent admission to hospital. It is helpful to keep their notes on the ward and to try to make their admissions as brief and as comfortable as possible. Studies have found that lack of information about the patient's condition and progress adds to the stress of family members. Patients with HIV do not need to be isolated unless there are patients in the ward with infections that PLWH may be susceptible to, such as chickenpox or hepatitis. The need for guidelines on universal infection control precautions is described in Chapter 13.

### *Diagnosis and staging of HIV disease*

The combination of symptoms and signs of advanced HIV disease mean that it is generally not difficult to diagnose clinically – however HIV-negative tuberculosis may have a similar clinical presentation. It is desirable to be able to test patients who are suspected on clinical grounds to have HIV infection. Patients should always be counseled before and after testing. There is no need to test patients who are unconscious or otherwise unable to give informed consent. Policies on testing patients and arrangements to keep results confidential need to be discussed and documented. An alphabetical code system can be used to avoid labeling specimens and results with patient's names. The strategy for confirmation of HIV tests for diagnosis is outlined in Appendix 3.

WHO categorize clinical status into four stages which indicate the level of immune suppression and the prognosis of people living with HIV:

- Stage 1: asymptomatic infection.
- Stage 2: early (mild) disease.
- Stage 3: intermediate (moderate) disease.
- Stage 4: late (severe) disease.

The 'CD4 count' refers to the number of CD4 white cells in the blood. These are the white cells most affected by HIV and which control the immune system. This laboratory test is not widely available. The total white cell count also drops in immune deficiency – but is a less useful marker. Manifestations of HIV disease are rare at CD4 counts above  $500 \times 10^6$  cells/l and severe illness and death are rare in patients with counts above  $200 \times 10^6$ /l.

Bacterial infection of the blood can require admission to hospital. Gram negative organisms are the most common cause, especially non-typhoid Salmonella species. Pneumococcal pneumonia, meningitis and septicaemia are also frequent and may occur earlier than Gram negative infections. Many people with AIDS suffer severe wasting, with chronic diarrhoea and fever. Poor appetite and reduced food intake contribute to the wasting. A variety of protozoal and bacterial infections may cause diarrhea but often no specific cause can be found.

AIDS can present with florid pulmonary tuberculosis. The x-ray appearances are often atypical with the middle or lower lobes more commonly affected, and the upper lobes often clear. Enlargement of hilar lymph nodes, and effusions, are common. Mycobacteria may disseminate through the body, causing military tuberculosis or meningitis. Tuberculous lymphadenopathy is common.

Skin manifestations may be due to neoplastic disease, especially Kaposi sarcoma, or they may be of an inflammatory nature. These include drug reactions, infections such as secondary syphilis, seborrhoeic dermatitis and psoriasis. Generalized dry skin is a common problem in HIV infection. It is often very itchy.

Neurological disease is also a common need for admission. HIV can infect cells in the central nervous system (CNS) and cause neurological problems. The CNS may also be affected by opportunistic infections and tumors. Cerebral toxoplasmosis (presenting as a space occupying lesion of the brain) and cryptococcal meningitis (presenting as chronic meningitis) are the most common infections. Neurological manifestations usually occur late in the course of HIV infection. Dementia is the commonest problem, but almost any neurological symptoms may occur. Psychiatric disorders may be confused with neurological disease. Organic and psychiatric disease often occur together.

In resource-poor settings it can be difficult to identify different opportunistic infections without access to specific laboratory tests. There are a number of manuals and slide sets that can be helpful in training health care staff to recognize the signs of common HIV-

related opportunistic infections and cancers. Standard treatment protocols need to be developed for cost-effective management of the common problems that affect people infected with HIV.

### *Antiretroviral treatment*

Antiretroviral drugs (ARVs) kill HIV and so reduce the level of virus in the blood. A combination of these drugs need to be taken for life and they often have side-effects. PLWH who are able to access these drugs can remain well for many years, although the virus remains in the body. However, despite recent price reductions these drugs remain out of reach for most PLWH.

There are three classes of drugs that prevent HIV from multiplying by blocking the action of viral enzymes, but they do not remove the virus from the body. They are the nucleoside reverse transcriptase inhibitors (NRTIs), non-nucleoside reverse transcriptase inhibitors (NNRTIs) and the protease inhibitors (PIs). Zidovudine (or AZT) is an NRTI which improves clinical signs and delays death from AIDS for a time. However, it has severe side-effects and is expensive. Because HIV mutates rapidly within the body it becomes resistant to drugs so ARVs need to be used in expensive combinations. Guidelines for treatment of HIV recommend life long triple therapy, commonly two NRTIs, combined with a PI or NNRTI. These combinations are called 'highly active antiretroviral therapy' (HAART). Specialists have to monitor the patient's viral load, blood cells, and liver and renal function because of side effects. For the drugs to be effective the person has to take them correctly at least 95% of the time, and they have to be taken for life. Some are not able to tolerate the side effects.

Experts disagree about how early to start treatment. Some believe that it is best to wait until the patient's white cell count falls below  $500 \times 10^6/L$ , or the patient develops symptoms. Others think that treatment should begin even when the patient is asymptomatic. However the long-term side-effects of these drugs are not known; early use might limit later use of the drugs; use by people without symptoms turns them into patients; long-term compliance is likely to be poor; and treatment is costly.

| <b>Antiretroviral drugs (Brand names in brackets)</b>  |  |  |
|--|--|--|
| <b>Nucleoside reverse transcriptase inhibitors</b>   | <b>Non-nucleoside reverse transcriptase inhibitors</b>                     | <b>Protease inhibitors</b>   |
| Zidovudine (AZT)<br>Zalcitabine (ddC)<br>Didanosine (ddl)<br>Stavudine (D4T or Zerit)<br>Lamivudine (3TC or Epir)<br>Abacavir (Ziagen) | Nevirapine (Viramune),<br>Delavirdine (Rescriptor),<br>Efavirenz (Sustiva) | Indinavir (Crixivan)<br>Nelfinavir (Viracept)<br>Ritonavir (Norvir)<br>Saquinavir (Invirase) |

### Discussion Point

Until recently the cost of life long treatment with a combination of ARVs put them out of reach for all but a small elite in developing countries. We could describe these drugs simply as "not available". However persistent advocacy efforts, and pressures created by generic drug companies in some developing countries, have led to dramatic reductions in prices. A year's supply of medication may now cost only a few hundred dollars. Where HIV infection is not yet common it should be possible even in developing countries to encourage identification of those infected with the assurance that they will receive treatment. However where prevalence is high it will not be possible to treat everyone.

The cheaper price of ARVs, and the development of simpler regimens with three drugs combined in a single tablet, raises questions for those responsible for health care services in refugee settings.

- Refugee settings are unpredictable. What will happen if refugees start a course of life-long treatment, requiring monitoring, but then travel home or are transferred to another camp at short notice?
- Incorrect use of the drugs can lead to resistance. How could we increase the likelihood that drugs are taken in correct dosage and long-term?
- Because of the controlled environment it may be easier to implement an ARV program in a refugee camp than in the local host population. How could this inequality be avoided?
- What are some of the barriers to providing treatment in refugee settings? How can we best prepare for reductions in prices of drugs?

The drugs are not the only cost of providing effective treatment. There are also the costs of follow up, laboratory monitoring tests, and training of doctors and nurses. Trials will be needed to determine cost-effective regimens that minimize the risk of development of drug resistance and maximize continuity of treatment, monitoring systems, and protocols for treatment failures. Where treatment programs for tuberculosis are in place these offer an opportunity to integrate treatment of HIV with antiretrovirals.

The provision of ARVs in refugee settings needs to be considered in the light of national policy.



### *Drugs and medical supplies*

There may be a need to add new items to essential drugs lists such as nevirapine for prevention of mother to child transmission of HIV and drugs to treat specific opportunistic infections, taking into account national drug policies and costs. In addition it is important to ensure adequate supplies of the antibiotics and anti-fungal drugs needed to treat common HIV-related conditions, and analgesics and other medicines essential for palliative care. Adequate quantities of condoms, gloves, needles and syringes and surgical equipment also need to be obtained.

### *Discharge policy*

It is important that mechanisms are established to ensure continuity of care when patients are discharged. Home-based care has rarely been implemented in refugee settings so this will be a challenge. Family members need good information about the patient's needs and the likely outcome, with the consent of the patient. Local primary health care staff and a home-based care service if available, should be informed of the discharge and given details of necessary follow-up care. Efficient discharge and referral policies are cost-effective because well-informed and motivated carers can reduce the need for re-admission.

The following aspects of patient's needs should be assessed before discharge:

- psychological and neurological problems such as agitation, difficulty in concentrating, and disturbances in sleeping and eating patterns
- degree of disability and potential future disabilities
- psychosocial problems: social isolation, anxiety, anger, blame, guilt
- physical care needs
- need for pain management
- the greatest concerns expressed by the client or patient.

#### **Discussion Point**

What information should be recorded on outpatient cards? These cards are essential for communication between health care workers who may see a patient on different occasions. It is necessary to communicate the fact that the patient has been tested for HIV, and whether or not they have been counseled. However, if information on HIV status is recorded on patient held records the patient is at risk of exposure of his or her HIV status. Could symbols or codes be used to record: "blood taken for HIV antibody test", "HIV antibody positive" and "counseled about HIV infection"? Could a separate card be used for information about HIV? Would any of these methods succeed for long, or would the public soon learn about them?

### *Care and support for orphans*

The effects on children in a family affected by AIDS begin long before the parents die. Decreased income or productivity when the bread-winner becomes ill, and spending on medicines and health care services, result in the family's assets being depleted. Children suffer the emotional effects of seeing their parents die slowly from an often painful illness. They may be the only ones who care for their parents and may miss school. They may be stigmatized by neighbors, teachers and schoolchildren.

Because of stigma, parents may be reluctant to tell their children about their diagnosis. The Memory Books Programme in Uganda aims to support HIV-positive mothers to tell their children of their serostatus<sup>15</sup>. Mother and children write the memory book together and record important family history. Parents are encouraged to take time preparing the memory books because they include the sensitive issues of loss and changes ahead.

After the death of one or both parents children may suffer many changes in care-givers, and repeated bereavements. Orphaned children often undertake tasks that are beyond the level of responsibility usual at their age – for example, a twelve year old girl may be left to care for siblings. Their education is often compromised because they need to stay at home to care for others or to work, or because of lack of school fees. This reduces their opportunities for future employment. Poverty is an almost inevitable result of being orphaned. This adds to stigmatization and increases vulnerability to exploitation. Orphans may undertake hazardous activities to support themselves, including sex work.

The health status of orphaned children is often poor. Mothers are the most important providers of primary health care; they recognize when their child is ill and provide comfort and extra attention that may avert more serious illness. They are often the recipients of health promotion information such as oral rehydration for diarrhoea, and the benefits of vaccination. Grandparents and siblings may be less able to provide such care.

The loss of parents has an inter-generational impact. Children who lack parental love and support, and a sense of belonging to family and community, often grow up with psychological problems and may experience difficulties in their adult relationships and in parenting their own children.

There is therefore an urgent need to arrange for appropriate care and support for orphaned children, no matter what the cause of their orphan status. Support for orphans and other children in need should be integrated with the community's response to the need for home-based care.

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<sup>15</sup> The dilemma of HIV positive parents revealing serostatus to their children, Nyamayarwo, 2000, MoOrD250.

The primary aim is to try to keep orphaned children within their own extended family. Families may need assistance to enable them to care for orphans. If this is not possible then children should be cared for in a foster family, preferably within their own community. Studies have shown that orphanages are not an ideal environment for children, and are expensive. Institutional care often harms the emotional health of children, and means that they lose links with their own communities and their sense of belonging. They leave the orphanage when they are still very young adults and have to make their way in the world without any support from relatives or friends.

In refugee settings the conflict that led to displacement may have led to large numbers of orphaned or unaccompanied children requiring care within their extended families or with foster parents. In places where HIV is common there will also be large numbers of orphaned children. This can result in the coping mechanisms of the community becoming overwhelmed. There will be increasing numbers of households headed by children or by elderly grandparents. Financial and practical support will need to be provided to affected households to enable them to care for increased numbers of children.

## **Strategies**

### ***Prioritize care and support activities***

Care and support activities can be described at three levels of complexity and cost<sup>16</sup>.

#### 1. Essential activities

- HIV voluntary counseling and testing
- Psychosocial support for PLWH and their families
- Palliative care
- Treatment for common opportunistic infections
- Nutritional care
- STI care and family planning services
- Co-trimoxazole prophylaxis
- Reduction of stigma and discrimination

#### 2. Activities of intermediate complexity and cost. In addition to the above:

- Active case finding and treatment for TB; prophylaxis for TB
- Systemic anti-fungal agents for severe fungal infections
- Treatment for HIV-associated malignancies: Kaposi's sarcoma, lymphoma and cervical cancer
- Treatment for herpes simplex and herpes zoster infections
- Antiretroviral prophylaxis to prevent mother-to-child transmission of HIV

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<sup>16</sup> WHO/UNAIDS. Key elements in HIV/AIDS care and support – September 2000. <http://www.unaids.org/publications/documents/care/index.html#general>



- Post exposure prophylaxis following rape, and occupational exposure
  - Funding of community efforts that reduce the impact of HIV
3. Activities of high complexity and cost. In addition to the above:
- Highly active antiretroviral therapy
  - Diagnosis and treatment of opportunistic infections that are difficult to diagnose and/or expensive to treat, such as atypical mycobacterial infections, cytomegalovirus infection, multiresistant TB and toxoplasmosis
  - Specific public welfare services that reduce the economic and social impacts

In the post-emergency phase in refugee settings it should be possible to provide at least the essential care and support activities. The choice of strategies will depend on the prevalence of HIV in the refugee or displaced population, and the stage of the epidemic. If there are very few people ill with HIV they represent little additional burden to health care services and it is relatively easy to provide support to those who care for the PLWH at home and in the community. However when HIV is common and many people are sick and dying the capacity of the community to respond with home-based care and support for orphans is reduced. Good coordination of care and support is essential.

### ***Develop policies***

A number of policies and protocols need to be developed appropriate for each level of health care service delivery. It will be helpful to establish a small committee with representatives of people living with HIV, refugees, health staff, administration, appropriate NGOs, and host health officials to formulate these policies. Policies should be consistent with national guidelines.

Policies will need to be developed to address:

- HIV testing for diagnosis (ensuring confidentiality);
- Prevention of discrimination and stigma against PLWH in health settings;
- Treatment or management protocols for common HIV-related conditions;
- Referral protocols and discharge co-ordination;
- Universal precautions for infection control.

#### **PLWH-friendly hospitals**

The idea of accrediting hospitals that are 'friendly' to PLWH is being studied in India, based on the model of 'baby-friendly hospitals' that fulfill criteria supportive of breastfeeding. A set of indicators has been developed that include: 1) HIV testing voluntary, confidential and accompanied by pre-and post test counseling; universal precautions practiced with all patients; information about HIV status kept confidential; people with HIV not segregated; 2) staff trained in the basics of HIV/AIDS and transmission; clinical staff trained in case management; staff trained on rights and needs of HIV positive people; 3) trained counsellors available for additional counseling; systems for referral and follow-up in place for other sources of care and support.

Gilborn, Population Council, study currently underway in India, 2001

### ***Train health care staff***

Health care staff at all levels require training in the management and nursing care of adults and children infected with HIV, and in referral and discharge processes.

The need for confidentiality, and mechanisms to ensure this, need to be discussed with mortuary attendants, clerks, porters, general hands and drivers as well as doctors, nurses, and health workers.

All categories of staff will also need information and reassurance about the risk of occupational exposure to HIV (see page 198).

### ***Establish home-based care system***

The way that home-based care is organized will vary from one setting to another. It is important that communities identify their own needs and participate fully in the development of a system. Populations that have been displaced, whether they are living in camps or in re-settled areas, have usually experienced a breakdown in their community structures and networks. In this context a home-based care system may rely on care from family members, with support from health care workers at the nearest health care facility. However community structures that may be able to coordinate teams of home-care volunteers, such as church or faith-based organizations, traditional chiefs, and elected representatives, may still be in place. These community groups may have different agendas and constituencies; the relationships between community structures need to be taken into account to avoid tensions. Before planning it is important to find out whether there is already any organized support for home-based care – for example, by church groups.

The following are important components of a home-based care system:

- Recruitment, training and on-going support for volunteers
- Identification of households in need of support and assessment of their care needs
- Distribution of home-based care kits (see below for kit contents)
- Guidelines for home-based care volunteers or carers for nursing care, infection control and waste management
- Distribution system for supplies for home-based care
- Supportive visits, including spiritual support
- Access to legal advice in relation to writing wills
- Coordination with nearest health care facility and respite care

People living with HIV may play an important role as volunteer carers for others with HIV-related illness. People with HIV-related disease are often young and may prefer to be cared for by their peers. Young people are often willing to become involved in home-based care work.

Family carers are often women who are already looking after children or elderly dependents; some family carers may be elderly or very young; often family carers may themselves be living with HIV.

Caring for people with chronic illness at home is very stressful. It is very important that carers are able to access respite care and counseling. Home-based care is cost-effective and saves the health care system money. It is often appropriate to provide an incentive or small allowance to home-based care volunteers. This should be discussed with the community and thought should be given to sustainability.

Home-based care kits help volunteers to look after the sick person well and safely. Such kits might contain:

- analgesics, antibiotics, and anti-fungals medicines,
- antiseptics,
- emollient cream,
- vitamin and mineral supplements,
- disposable nappies, bandages, aprons and gloves.

### ***Arrange care and support for carers***

Health care professionals are used to being able to cure their patients, especially children. However, when the illness is caused by HIV, patients relapse frequently and health care workers often come to know the patient and their parents well by the time the patient dies. Health care workers are likely to be working hard and have little time to grieve with the family. This inability to cure their patients, and the sadness that they witness and share, are stressful and upsetting for health care workers at all levels.

Health care work in refugee settings is always stressful with scarce resources, poor facilities and high rates of infectious disease caused by overcrowding and poor nutritional status. Where HIV is common the workload in clinics and hospitals is further increased.

Caregivers, whether health care professionals, home-based care volunteers or relatives, may experience stigma and discrimination because they look after PLWH. The caregivers themselves may be infected with HIV, or at risk of infection with HIV, and may have to cope with their own fears of becoming ill, dependent and dying. They are members of the community and may be coping with multiple bereavement following the loss of friends and family members.

For all these reasons managers need to provide opportunities for health care staff and volunteers to meet and discuss their fears and concerns, and to receive confidential counseling if needed. Care needs to be taken to minimize stress in the workplace and to try to avoid excessive workload being placed on too few staff.

### *Co-ordinate care and support for orphans and other dependents*

It is likely to be more straightforward to support community efforts to respond to the needs raised by the HIV epidemic in stable communities than in refugee settings. Where people have been displaced it may be especially difficult to arrange appropriate care for children who have been orphaned, whether because of HIV infection, other illnesses or violence. Nevertheless the aim of placing children within their own extended family, or if not, with foster parents from the same community, is the same.

Community support programs should not discriminate between children whose parents died of AIDS and those whose parents died of other causes.

Mechanisms for the accountable distribution of small amounts of material support for households caring for orphans need to be established, and the community encouraged to respond to the needs of orphans in a variety of ways. It is important to first identify local community structures and leaders, such as women's groups, church groups, elected refugee representatives, and traditional leaders, and to understand how these structures relate to each other. Consultation with these groups and leaders can then help to identify a team who can be trained to train volunteers in mapping, enumeration, needs assessment and support skills. Traditional and local political leadership may be invited to participate in the initial training sessions with the aim of enlisting their support. They may not train others but could help to create an environment in which all refugees participate, drawing on traditional values and customs.

Those trained in the preliminary workshops could then facilitate at community gatherings where selected volunteers work in local area groups to produce community maps and lists of households with orphans and children in need in their camp area or villages. They would discuss how to assess the needs of households with orphans or affected children, including the following aspects:

- material needs – for shelter, food, clothes;
- emotional needs - for love, a sense of belonging, a sense of hope for the future, and comfort for bereavement;
- support needs – school fees, respite care, skills training, farming help;
- health care needs;
- recreational opportunities; and
- need for protection against exploitation<sup>17</sup>.

An information system needs to be coordinated to collate and analyse trends in numbers of orphans and children in need, and the size and types of households in which orphans live.

These needs might be met through volunteers undertaking to visit households regularly to provide support and through the establishment of day-care services which might provide

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<sup>17</sup> Convention on the rights of the child. 1990. <http://www.unicef.org/crc/crc.htm>

recreation and meals. Respite baby care may enable older siblings to resume attending school, and volunteers with skills might be recruited to train young people. Micro-finance schemes can assist foster families. Collaboration with other sectors is vital and a long term view is essential.

### Suggested indicators

| <i>Indicator</i>   | <i>Method of measurement</i>                               |
|--|--|
| <b>Home-based care</b>   |  |
| Volunteers recruited and trained   | Review of training records                                 |
| Rate of turnover of home-based care volunteers   | Review of register of volunteers                           |
| Proportion of PLWH who need home-based care receiving care   | Door-to-door survey / local mapping with community members |
| Numbers of home-based care kits distributed  | Review of records  |
| Proportion of home-based carers aware of 1) availability of respite care<br>2) referral procedures     | Survey of home-based carers                                |
| Awareness of hospital doctors that home-based care is available  | Review of discharge documents                              |
| Satisfaction of home-based care volunteers with level of support                                       | In-depth interviews  |
| Satisfaction of PLWH with home-based care system with PLWH receiving care at home                      | FGDs with PLWH; in-depth interviews                        |
| <b>Clinic care</b>   |  |
| Standard treatment protocols developed for common HIV-related conditions                               | Review of protocols  |
| Proportion of PHC health care staff trained in management of HIV-related conditions                    | Review of training records                                 |
| Proportion of health care staff who have received sensitization training, including the rights of PLWH | Review of training records                                 |
| <b>Hospital care</b>   |  |
| Patients with HIV not segregated   | Observation  |
| Ethical hospital policies developed and disseminated   | Review of policy documents<br>Observation                  |
| Number of health professionals trained in diagnosis and management of HIV-related conditions           | Review of records  |

## Suggested Indicators (cont.)

| <i>Indicator</i>  | <i>Method of measurement</i>                  |
|---|---|
| <b>Caring for carers</b>  |   |
| Satisfaction of health care staff with support available  | FGDs with staff; interviews with supervisors. |
| Regular meetings held with health care staff  | Recorded attendance at staff meetings         |
| <b>Orphan support</b>   |   |
| Number of volunteers in each district / camp area trained in mapping, enumeration, and needs assessment   | Review of records                             |
| Proportion of villages / areas with a register of orphan households   | Review of registers                           |
| Number of home visits per month by volunteers   | Review of volunteer logbooks                  |
| Number of orphan households provided with material assistance; type and quantity of material assistance provided                                      | Review of accounts                            |
| Proportion of registered orphans malnourished (by gender); and ratio malnourished orphans to malnourished non-orphan children in specified age groups | Household survey                              |
| Proportion of orphans attending primary school  | Household survey                              |
| Proportion of orphans participating in skills learning and recreational events  | Household survey                              |
| Well-being of orphan households as assessed by members of the household including children  | In-depth interviews                           |

## Additional Resources

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## Appendices

|    |   |    |
|----|---|----|
| 1. | List of Abbreviations   | 2  |
| 2. | Questions to assist in planning a situation analysis              | 4  |
| 3. | HIV testing strategies  | 10 |
| 4. | PLA exercises for gathering sensitive information – some examples | 12 |
| 5. | Flow charts for syndromic management of STIs                      | 19 |
| 6. | Resources and references  | 25 |

## Appendix 1. List of abbreviations

|        |   |
|--------|---|
| AIDS   | Acquired Immune Deficiency Syndrome                                   |
| ARVP   | Antiretroviral prophylaxis  |
| ARVs   | Antiretroviral (anti-HIV) drugs                                       |
| AZT    | Zidovudine (an antiretroviral drug)                                   |
| CDC    | US Centers for Disease Control and Prevention (in Atlanta)            |
| DNA    | Deoxyribo Nucleic Acid (genetic instructions in a cell)               |
| ELISA  | Enzyme-Linked Immunosorbent Assay (HIV antibody test)                 |
| FGD    | Focus Group Discussion  |
| HIV    | Human Immunodeficiency Virus  |
| IEC    | Information, Education, Communication                                 |
| IRC    | International Rescue Committee  |
| MCH    | Maternal and Child Health   |
| MISP   | Minimum Initial Service Package                                       |
| MTCT   | Mother to Child Transmission  |
| NGOs   | Non-Government Organisations  |
| NNRTIs | Non-nucleoside reverse transcriptase inhibitors (antiretroviral drug) |
| NRTIs  | Nucleoside reverse transcriptase inhibitors (antiretroviral drug)     |
| PCR    | Polymerase Chain Reaction (test for HIV)                              |
| PEP    | Post-exposure prophylaxis   |
| PIs    | Protease inhibitors (antiretroviral drug)                             |
| PLA    | Participatory Learning and Action                                     |
| PLWH   | People/person living with HIV/AIDS                                    |
| PTCT   | Parent to child transmission  |
| SGBV   | Sexual and gender-based violence                                      |
| SIV    | Simian (monkey) Immuno-deficiency Virus                               |

|        |   |
|--------|---|
| STI    | Sexually Transmitted Infection                |
| TASO   | The AIDS Support Organisation (in Uganda)     |
| TB     | Tuberculosis                                  |
| UNAIDS | Joint United Nations Programme on HIV/AIDS    |
| UNDP   | United Nations Development Programme          |
| UNFPA  | United Nations Population Fund                |
| UNHCR  | United Nations High Commissioner for Refugees |
| UNICEF | United Nations Children's Fund                |
| VCT    | Voluntary Counselling and Testing             |
| WB     | Western blot (confirmatory HIV antibody test) |
| WHO    | World Health Organization                     |

## Appendix 2. Questions to assist in planning a situation analysis\*

These are general questions from which you can prepare questions for a questionnaire survey or question guides for focus group discussions. It is important for the situation analysis team to think about the topics and questions that will be most relevant and appropriate in their particular setting.

### *Demographic and socio-economic data*

- How large is the displaced population? – the host population?
- Over what geographic area is the population distributed?
- What is the composition of the population in terms of age, sex, ethnic, language, religious, educational and socio-economic characteristics?
- What are the characteristics of the local population?
- What is the range of household structures and the average household size?
- What are the sources and levels of income? Is there much inequality in household income and living standards?
- What is the level of mobility into and out of the population, and what are the reasons for these movements?

### *Local decision-making structures and processes, gender relations, networks, interest groups, and elites*

- How is the refugee population living? - in camps, with host families, in informal settlements?
- How is the displaced population organised and what is their status? Who has responsibility for supplies, services and protecting their rights?
- Who has power in this population and how do they exercise it? Who are the formal and informal leaders of the community? How are they appointed or chosen? What role do religious groups and traditional structures play? What are relationships like between the various community structures?
- Are there military groups present? What are the relationships between different military groups?
- Does the refugee population have access to land, employment and to services such as education, health, and transport? Are some groups within the refugee population marginalised?
- How do the roles, status and power of men and women differ? How have they changed as a result of displacement? How do cultural expectations of men's and women's roles affect the lives of men and women?
- How common is domestic violence? (A useful question is to ask whether the respondent has been hit by someone in their home in the past month.)

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\* Adapted from Aboagye-Kwarteng T, Moodie R and Holmes W. Community Action on HIV 2<sup>nd</sup> edition. Macfarlane Burnet Centre. 2000.

- How much mixing is there between the refugee and the local population, and what form does this take?
- How and where do people gather to talk about issues of importance to the community?
- What is the influence of the seasons on the lives of the refugees?

### ***Opportunities for communication***

- Where do refugees or the displaced population obtain their information? – through newspapers, radio, word-of-mouth?
- What sources of information do people trust?
- What methods of communicating information are available?
- What proportion of the population can read (by age and gender) ?
- Are there different language groups among the refugees?
- How many people own or can listen to a radio? Who listens to the radio, how often, and at what times of day? What programs do people of different ages and gender prefer? What different types of radio channel are there?

### ***The health status of the community***

- What are the main causes of death? Are there any estimates on how this varies according to age, gender, and setting?
- What are the main causes of illness (by age, gender and setting)?
- What are the levels of disability in the community?

### ***Distribution and frequency of HIV infection, and other sexually transmitted infections***

- What types of STIs are common? Enquire about ulcerative STIs such as syphilis chancroid, herpes and granuloma inguinale, and STIs that cause discharge such as gonorrhoea and chlamydia.
- How are STIs treated and reported? Is laboratory diagnosis available or are health care workers trained in syndromic management of STIs? Is there any system for contact tracing? Is HIV testing provided? Is it confidential? Is pre and post-test counselling available?
- What are the incidence and the prevalence of STIs, and what are the trends? (Incidence is the number of new cases in the population over a given period of time, and prevalence is the number of cases in the population at any given time.)
- Is there any survey or sentinel surveillance data about prevalence of HIV?

### ***Access to and use of health care and welfare services***

- What types of health services are provided for women, men and children?
- Who provides the services, - government, religious or secular NGOs, private doctors, pharmacies, traditional healers, street vendors?
- Who is using health services? Are there any statistics available, by age, sex, location, type of service? How accessible, acceptable and affordable are these services? What are the barriers to their use?

- What are the most important cultural beliefs, including religious, social, family and political beliefs, that influence health behaviours?
- What support is available for single pregnant women?
- How are orphans and children without families cared for?

#### ***Young people\****

- What are the cultural norms related to sexual relationships and rites of passage into adulthood (including harmful traditional practices, such as female genital mutilation)?
- What are the typical patterns of adult authority over adolescents?
- What services are there for young people? What are the barriers to their access?
- What are the perceptions of camp staff/service providers related to providing health services to young people?
- How do young people perceive their reproductive health needs?

#### ***Care and support for people with HIV infection***

- What health and support services are available for people with chronic illness?
- Are any counselling services available? What are the training needs for counsellors?
- What are the traditional patterns of care for people with chronic illness?
- How open is the community about HIV? Are there PLWH who are open about their status? How are they treated?
- What are the most urgent needs of PLWH?
- What treatments are available for HIV-related symptoms and for opportunistic infections? Is any kind of palliative care available for the dying?
- Do people have to pay for health care, including medicines?
- Where are people with HIV related disease being cared for? How far do they have to travel, and at what cost?
- Are there any support groups for people living with HIV infection or AIDS?
- Are PLWH involved in planning and implementing HIV prevention and care activities?
- Is support available for family members, volunteers and health care workers who care for people with HIV related illness?

#### ***Patterns of sexual behaviour***

- What are the traditional societal and cultural attitudes and rules about sex? How do these differ for men and for women? Is there a difference between attitudes towards sexual behaviour expressed publicly and what people do in private?
- What social opportunities are available for the displaced population that enable people of opposite sexes to meet?

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\* Reproductive Health in Refugee Situations: An Inter-agency Field Manual, 1999.

- Has the gender and age structure of the displaced population changed greatly leaving an excess of single men or single women? What impact is this having on patterns of sexual behaviour?
- At what age do young people start to have sex and what are their patterns of sexual behaviour– has this changed as a result of being displaced?
- Who do young people learn about sex from?
- How common is transactional sex, that is when sex is exchanged for money, goods or protection?
- How is sex work organised? Who controls sex work? Do sex workers have access to health care services and to condoms? Do they have their own organisations?
- How common is coerced sex?
- How common is sexual violence and sexual abuse? - for women, for men, for young women, for young men? for children? When and where does it occur? How can the vulnerable be protected against sexual violence?
- What support is available for refugees who have been raped or sexually assaulted?
- What are the common attitudes towards homosexuality? Where and when do men have sex with men?
- Is there sexual contact between the displaced and the local populations, between the military and the displaced population?
- What is the level of knowledge about STIs and HIV? What are the common misconceptions?
- What is the level of concern and beliefs about the consequences of sex – STIs, infertility, and unwanted pregnancies?
- What is the level of knowledge, use of and access to contraception and family planning?
- What are the major influences on sexual behaviour and attitudes for men, women and young people?
- How common are sexual activities which increase risk? These include anal sex, dry sex, beating or traumatic sex, sex during menstruation, and sex during pregnancy.
- How common are sexual activities which decrease risk? These include non-penetrative sex, such as sex between the thighs, massage, mutual masturbation, and oral sex.
- What are knowledge, attitudes and practice in relation to condoms? What is the availability, cost, accessibility and quality of condoms? Can women access condoms? Can young unmarried people access condoms? Are female condoms available and acceptable?
- Do couples have sex during pregnancy? After childbirth?
- Has concern about HIV influenced sexual behaviour and practices? Management of blood safety and infection control
- How frequent are blood transfusions, who gives them and for what reasons? Are criteria to minimise the use of transfusions available?
- Is there a blood bank system in operation?
- Are blood donor volunteers, paid, or family members of the patient?

- Is blood for transfusion screened for antibodies to HIV, hepatitis and syphilis?
- What are the training needs in relation to blood safety?
- Are appropriate universal infection control practices followed in health care settings?
- What are the training needs of health care workers and traditional healers and birth attendants in relation to infection control?

### ***Exploring risk from injecting drug use***

- Is injecting drug use known to occur among the displaced population? Was it a problem in the country of origin? Is it a problem among the local population?
- Are drugs grown or produced in the area eg opium poppies or amphetamines? Are injectable drugs transported through the area?
- What is the estimated number of people who inject drugs? Is this increasing?
- Do people take drugs by other routes – such as smoking or by mouth?
- Who injects drugs, and in what circumstances? What are their reasons?
- Are there estimates of HIV infection and other blood borne viruses, hepatitis B and hepatitis C, among those who inject?
- Are the sexual partners of people who inject becoming infected with HIV and other blood borne viruses?
- What are the common attitudes towards those who inject drugs? Are they stigmatised and rejected?
- Is there a strong link between injecting drug use and commercial sex work?
- How do people inject? With what equipment? How many people do they share with? Where do they do it?
- Do injecting drug users make efforts to avoid HIV, for example, avoiding sharing, rinsing needles and syringes, boiling needles and syringes or using bleach to clean their needles and syringes? Is bleach available?
- How easy is it to get needles and syringes?
- Are there any treatment or rehabilitation services available for those addicted to drugs? If so, what type of services are they, and where are they situated?
- What are the attitudes of the police towards those who inject?

### ***Knowledge, beliefs and practice in relation to pregnancy, childbirth and infant feeding***

- What are the cultural beliefs in relation to pregnancy, childbirth, the post-partum period and infant feeding? How have these been affected by the displacement?
- Who makes decisions in relation to pregnancy, attendance at ante-natal care, delivery care and infant feeding? Is it the woman, her husband, her mother-in-law or other family members?
- What are the likely consequences if a pregnant woman discloses a positive HIV test result to her family?
- What are the influences on breastfeeding practices? How common is exclusive breastfeeding?



- Are there any practical, safe, affordable and acceptable alternatives to breastfeeding in this setting?
- What were weaning food practices before the emergency, and what are the current infant feeding practices?
- How are sick babies cared for?

***Laws that relate to HIV and other STIs***

- What laws are the refugee population subject to that relate to prevention and care of HIV? How are these laws interpreted and enforced?
- Are there legal requirements to notify government officials about individuals with HIV infection or AIDS? Are they reported with their full name and address or with a code? Is it a confidential system?
- Is mandatory testing for HIV antibodies forbidden?
- Is disclosure of information about people with HIV or STIs forbidden? Is there a law that requires a person infected with HIV to tell their sexual partner that they have HIV?
- Are there laws against discrimination on the basis of health status (including HIV infection), gender, sexual preference, political views and religion?
- Do women have the legal right to inherit or own property, particularly after the death of a spouse?
- Are there broadcasting, censorship or obscenity laws that prevent the dissemination of frank messages about HIV, STIs and sexual and drug injecting behaviour?
- How is rape defined in law, and what are the penalties?
- Is termination of pregnancy legal? Under what circumstances?
- Is prostitution illegal? Are there laws against living on the earnings of prostitution, or running a brothel?
- Is homosexuality an offence? Is this law enforced?
- What are the laws relating to production, to trafficking and to possession of drugs, and to equipment used for injecting, such as needles and syringes, swabs, and spoons?

### Appendix 3. HIV Testing Strategies

The use of a combination of rapid and/or simple tests can avoid the use of expensive tests such as the Western blot for confirmation. WHO and UNAIDS have recommended the following HIV testing strategies according to test objective and prevalence of infection in the population<sup>1</sup>:

| Reason for HIV antibody test                       | HIV prevalence  | Testing Strategy* |
|--|-----------------|-------------------|
| Identification of asymptomatic HIV infected people | < 10 %          | 3                 |
|  | > 10 %          | 2                 |
| Diagnosis of HIV-related disease                   | < 30%           | 3                 |
|  | > 30%           | 2                 |
| Epidemiological Surveillance                       | < 10 %          | 2                 |
|  | > 10 %          | 1                 |
| Screening blood for transfusion                    | All prevalences | 1                 |

#### Strategy One

A sample which tests positive can be counted as positive for the purpose of surveillance, or rejected as positive for the purpose of screening for transfusion. However if the donor is to be informed of the result then proceed as for “Identification of asymptomatic HIV infected people” with strategy two or three depending on the prevalence of HIV.

If the sample tests negative then the result can be reported as negative to the donor (with post-test counselling).

#### Strategy Two

If the sample tests negative then the result can be reported as negative to the client/patient (with post-test counselling).

If the sample tests positive on the first test repeat the test with a different type of test based on a different antigen preparation or different testing principle.

If the second test is also positive the result can be reported to the client/patient, with counselling.

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<sup>1</sup> UNAIDS and WHO recommendations for HIV testing strategies. Weekly Epidemiological record, No 12, 21 March 1997.

For samples which have tested positive on the first test and negative on the second test:

- Re-test the sample with the same two tests.
- If both tests are positive the second time, then confirm that a second sample is positive before telling the client/patient that they have a positive test result and counsel them.
- If both tests are negative the second time, tell the client/patient that they have a negative test result and counsel them.
- If the two test results still differ then consider the result uncertain or “indeterminate”. Repeat this testing strategy on a different sample taken 14 days later.

### **Strategy Three**

If the sample tests negative then the result can be reported as negative to the client/patient, with counselling.

If the sample tests positive on the first test repeat the test with a different type of test based on a different antigen preparation or different testing principle.

If the second test is also positive the result can be reported to the client/patient, with counselling.

For samples which have tested positive on the first test and negative on the second test:

- Re-test the sample with the same two tests.
- If both tests are positive the second time, then test the sample with a third different test.
- If the third test gives a positive result, then confirm that a second sample is positive before telling the client/patient that they have a positive test result and counsel them.
- If the third test is negative then consider the result uncertain or “indeterminate”. Repeat this testing strategy on a different sample taken 14 days later.
- If one test is positive and one test is negative, then test the sample with a third different test.
- If the third test gives a positive result, then consider the result uncertain or “indeterminate”. Repeat this testing strategy on a different sample taken 14 days later.

If the third test gives a negative result and the client/patient has been at risk of HIV infection in the previous three months, then consider the result uncertain or “indeterminate”. Repeat this testing strategy on a different sample taken 14 days later.

- If the third test gives a negative result and the client/patient has not been at risk of HIV infection in the previous three months tell the client/patient that they have a negative test result and counsel them (but do not use their blood for transfusion).

## Appendix 4. PLA exercises for gathering sensitive information – some examples

### What qualities do we like in the opposite sex – and why?

This exercise is designed to generate discussion about gender roles and relations and increase understanding about the choices that young people make.

Identify someone in the team who is good at drawing. You can use or adapt the pictures here as a guide to make two sets of picture cards that illustrate a range of characteristics for each sex. For example:

| <b>Boys</b>           | <b>Girls</b>          |
|-----------------------|-----------------------|
| Good-looking          | Pretty                |
| Brave                 | Brave                 |
| Cheeky                | Sexy                  |
| Bold                  | Shy                   |
| Arrogant              | Vain                  |
| Clever                | Clever                |
| Jealous               | Jealous               |
| Responsible           | Responsible           |
| Kind                  | Kind                  |
| Rich                  | Rich                  |
| Poor                  | Poor                  |
| Respectful            | Respectful            |
| Aggressive            | Quarrelsome           |
| Generous              | Good cook             |
| Angry                 | Angry                 |
| Strong                | Smart (fashionable)   |
| Likes children        | Likes children        |
| Affectionate / Caring | Caring / affectionate |
| Funny                 | Funny                 |
| Popular               | Popular               |
| Sporty                | Modern                |
| Smart (fashionable)   | Sporty                |
| Funny                 | Funny                 |
| Daring                | Daring                |





You can use these cards in a number of participatory exercises.

You might ask the boys and girls to get into separate sex groups. Ask each group to rank the cards in answer to the following questions:

What characteristics does a boy look for in a girlfriend? - and why?

What characteristics does a girl look for in a boyfriend? – and why?

What characteristics does a boy look for in a potential wife? – and why?

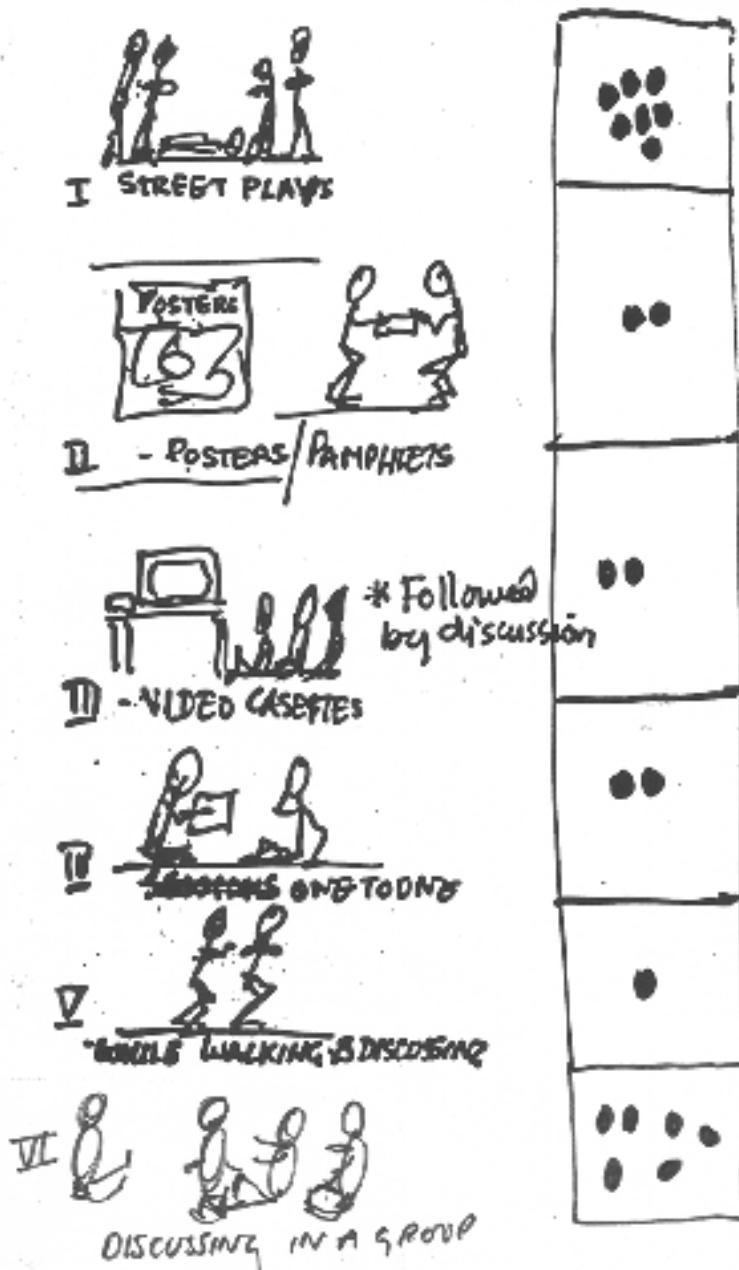
What characteristics does a girl look for in a potential husband? – and why?

After each ‘round’ you could encourage each group to ‘visit’ the work of the other group. This will generate a lot of discussion and increase understanding of how boys and girls view each other.

This is a useful exercise to have before a discussion or information gathering exercise about sexual behaviour.

### The ten-seed technique

The “ten-seed technique” is useful for asking about the relative importance of different sources of information about sex and sexual health, including HIV. For example a group of young people in Mumbai, India first described various different ways that they obtained information – and then distributed twenty seeds to show how they rated the importance of each<sup>2</sup>.

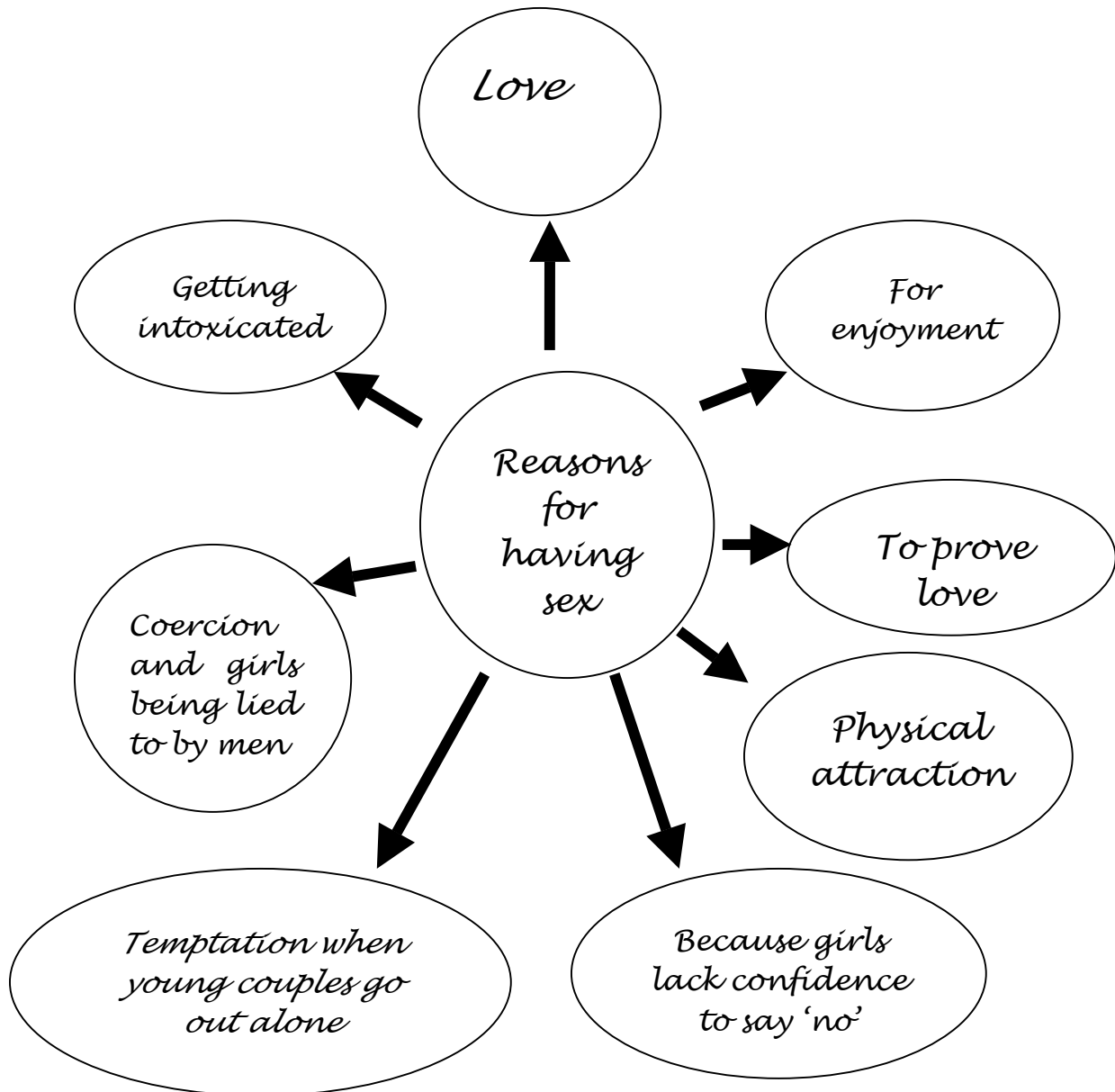


<sup>2</sup> From an evaluation exercise conducted by Ravi Jayakaran, WorldVision India.



## Causal diagrams

A causal diagram is a useful way to explore the different reasons why girls and boys have sex. For example, a group of young people in Laos came up with the following diagram:

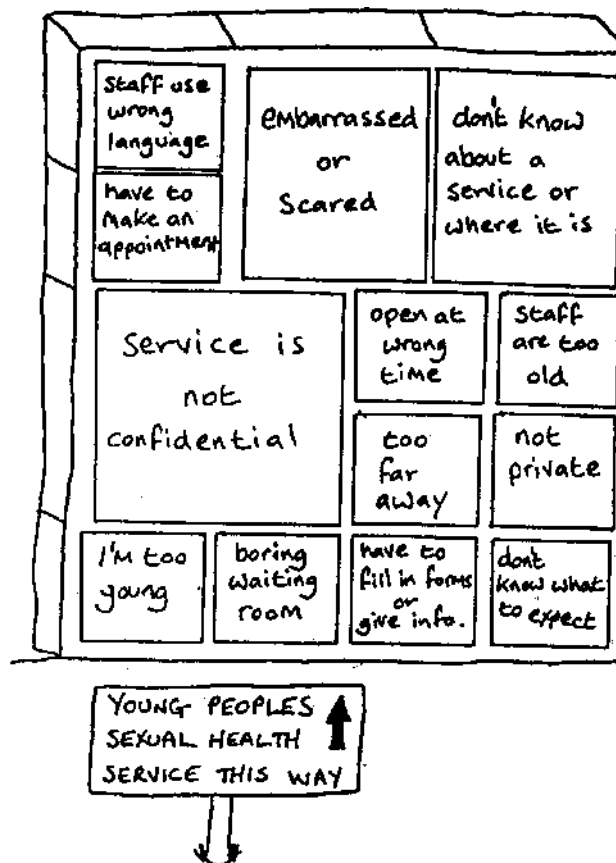


## The “barriers wall”

A group of young people from the South Humber region of the UK came up with an idea to highlight the barriers they feel when they try to access sexual health services\*.

They made a ‘wall’, using a large sheet of paper and differently sized sticky cards for ‘bricks’. The cards could be moved or replaced several times during the discussion. Each brick represented a barrier to using a local service, in this case a government clinic which they felt was difficult to access.

The young people suggested that separate walls could be created for different services – the higher the wall the more barriers. They also showed how the bricks can be taken out of the wall as solutions are found. For example they suggested that when young people are embarrassed or afraid to use a service, service providers should encourage them to bring their friends with them for moral support.



This tool could also be used to monitor how young people feel about a particular sexual health service as changes are made in response to the evaluation.

\* Evaluating sexual health services in the UK: adapting participatory appraisal tools with young people and service providers. Westerby M, Sellers T. PLA Notes 37. February 2000.

## **Appendix 5.      Syndromic management of sexually transmitted infections**

### ***Cervicitis (Gonorrhoea and chlamydia)***

Cervicitis means inflammation of the cervix of the uterus. It can be caused by gonorrhoea or chlamydia.

Both men and women can have gonorrhoea or chlamydia without any signs. Gonorrhoea and chlamydia can have the same signs, though gonorrhoea usually starts sooner and is more painful. A woman can have gonorrhoea and chlamydia at the same time so it is best to treat for both.

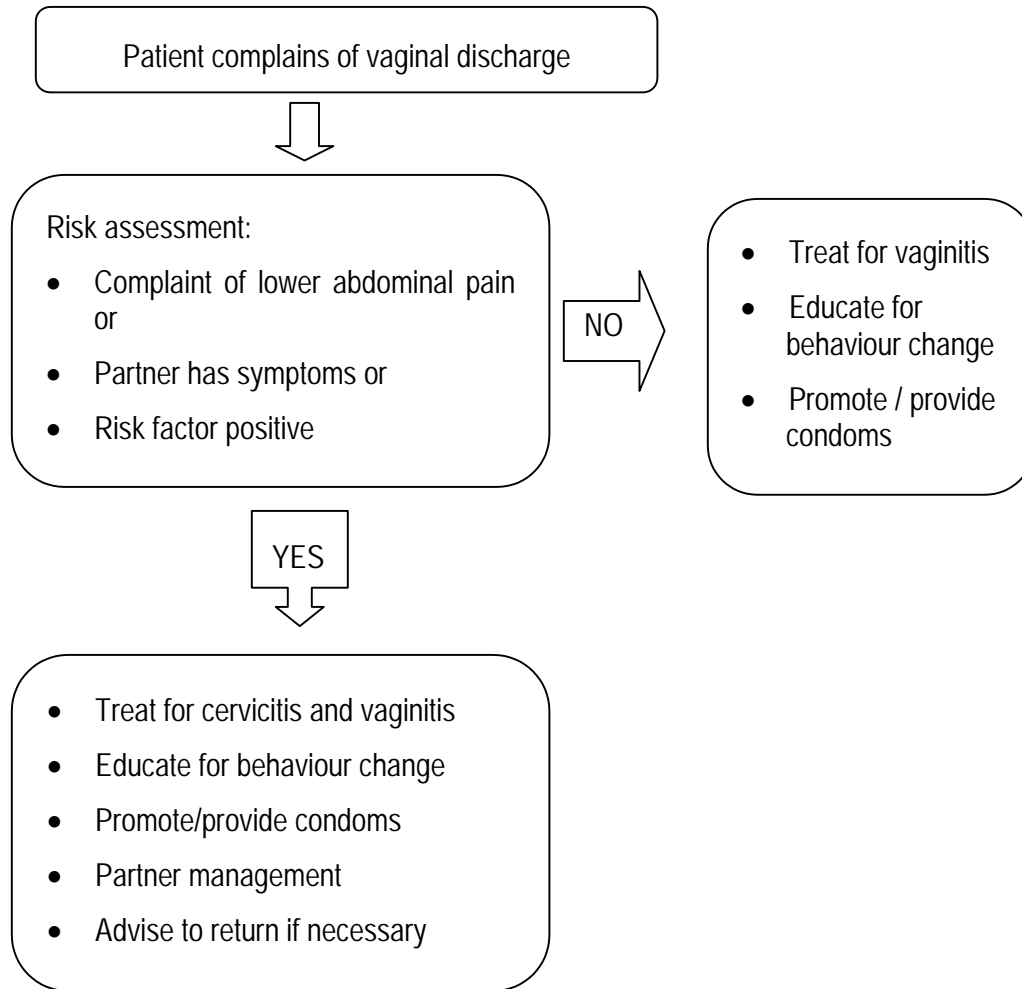
In a man the signs can begin as early as two to five days after he has sex with an infected person. But in a woman the signs may not begin for weeks or even months.

Signs:

- Yellow or green discharge from the vagina or anus
- Pain or burning during urination
- Pain in the lower abdomen
- Fever
- Pain during sex

Management: See flow chart for syndromic management of vaginal discharge below.

### Flow chart for vaginal discharge syndrome



**Treatment for vaginitis:** Metronidazole 2 x 2 x 7 orally

**Treatment for cervicitis:**

Ciprofloxacin\* 500 mgs in a single oral dose

or

Cotrimoxazole 10 tablets orally, once a day for 3 days

or

Ceftriaxone 250 mgs single dose im

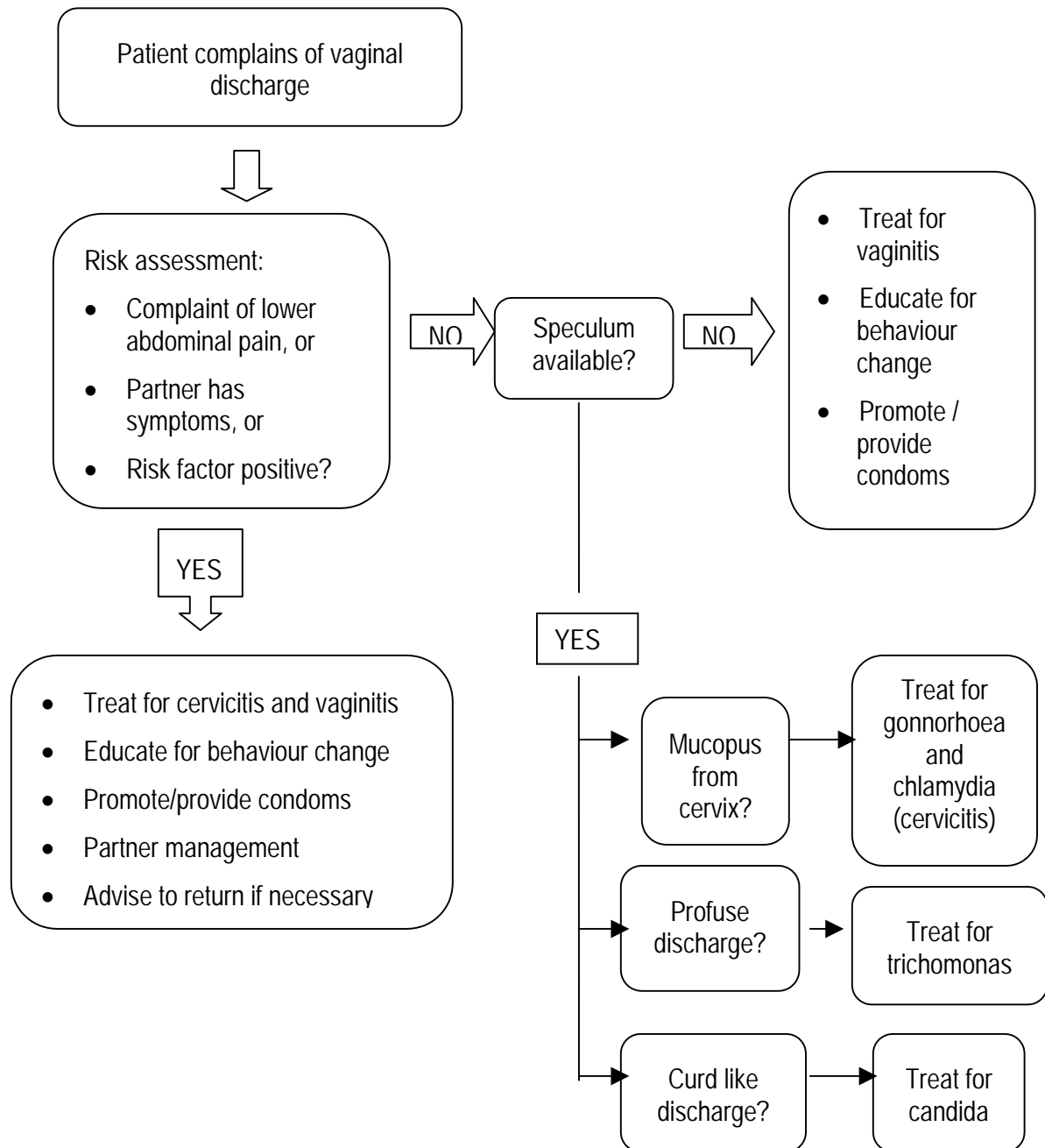
plus

Doxycycline\* 100 mgs orally twice daily for 7 days

or

Erythromycin 500 mgs orally 4 times daily for 7 days

### Flow chart for vaginal discharge with speculum



### ***Sores (ulcers) on the genitals (Syphilis, herpes, chancroid)***

Most sores or ulcers on the genitals are caused by having sex with an infected person. A single painless sore is a sign of syphilis. But if there is more than one sore, and they are painful, it is likely to be another STI such as chancroid or genital herpes. It is important to keep any genital sores clean until they are healed, and to avoid sex.

#### ***Syphilis***

Syphilis is a common and dangerous disease. A pregnant woman with syphilis can pass the infection to her unborn child.

Signs:

The first sign is a sore called a chancre. It appears two to five weeks after sexual contact with a person with syphilis. The chancre may look like a pimple, a blister, or an open sore. It usually appears on the genital area of a man or a woman but it might appear on the lips, fingers, anus or mouth. This sore is full of organisms which are easily passed on to another person. The sore is usually painless, and if it is inside the vagina a woman may not know that she has it, but she can still infect others.

The sore only lasts a few days or weeks. It then goes away by itself without treatment. But the disease continues spreading through the body. Weeks or months later there may be a sore throat, mild fever, mouth sores, swollen joints or skin rashes. During this stage the disease can be spread by simple physical contact, such as kissing or touching, because the organisms are on the skin.

All of these signs usually go away by themselves and then the person often thinks they are well. But the disease continues. Without proper treatment syphilis can invade any part of the body causing heart disease, paralysis, insanity, and sometimes death.

Management: See flow chart for syndromic management of genital ulcers below.

#### ***Chancroid***

These sores appear three to five days after sexual relations with an infected person. Each sore begins as a soft painful pimple, that quickly opens up to become a shallow ulcer with ragged edges. The ulcer is usually red around the outside edges.

Signs:

- Soft painful sores on the genitals or anus
- Enlarged lymph nodes in the groin

Management: See flow chart for syndromic management of genital ulcers below. Remember to suggest that the woman's partner be treated at the same time. Enlarged nodes in the groin may need to be incised.

## ***Genital herpes***

Genital herpes is a painful skin infection caused by a virus and spread from person to person during sex. Small blisters appear on the genitals and sometimes on the mouth. You can also get herpes sores on the mouth that are not spread by sex (cold sores).

Signs:

- A tingling, itching or painful feeling of the skin in the genital area or thighs.
- One or more small very painful blisters, appear on the genitals, anus, buttocks or thighs.
- The blisters burst and form small, red open sores that are very painful.
- The sores dry up and become scabs.

The first time someone gets herpes sores it can last for two weeks or more – with fever, headache, body ache, chills and swollen lymph nodes in the groin. There may be pain on urination.

The virus stays in the body after all the signs have gone away. New blisters can appear at any time, from weeks to years later. Usually the new sores appear in the same place. But there are not as many, they are less painful and they usually heal faster.

People with AIDS can get herpes anywhere on their body and it may take longer to get better.

Management:

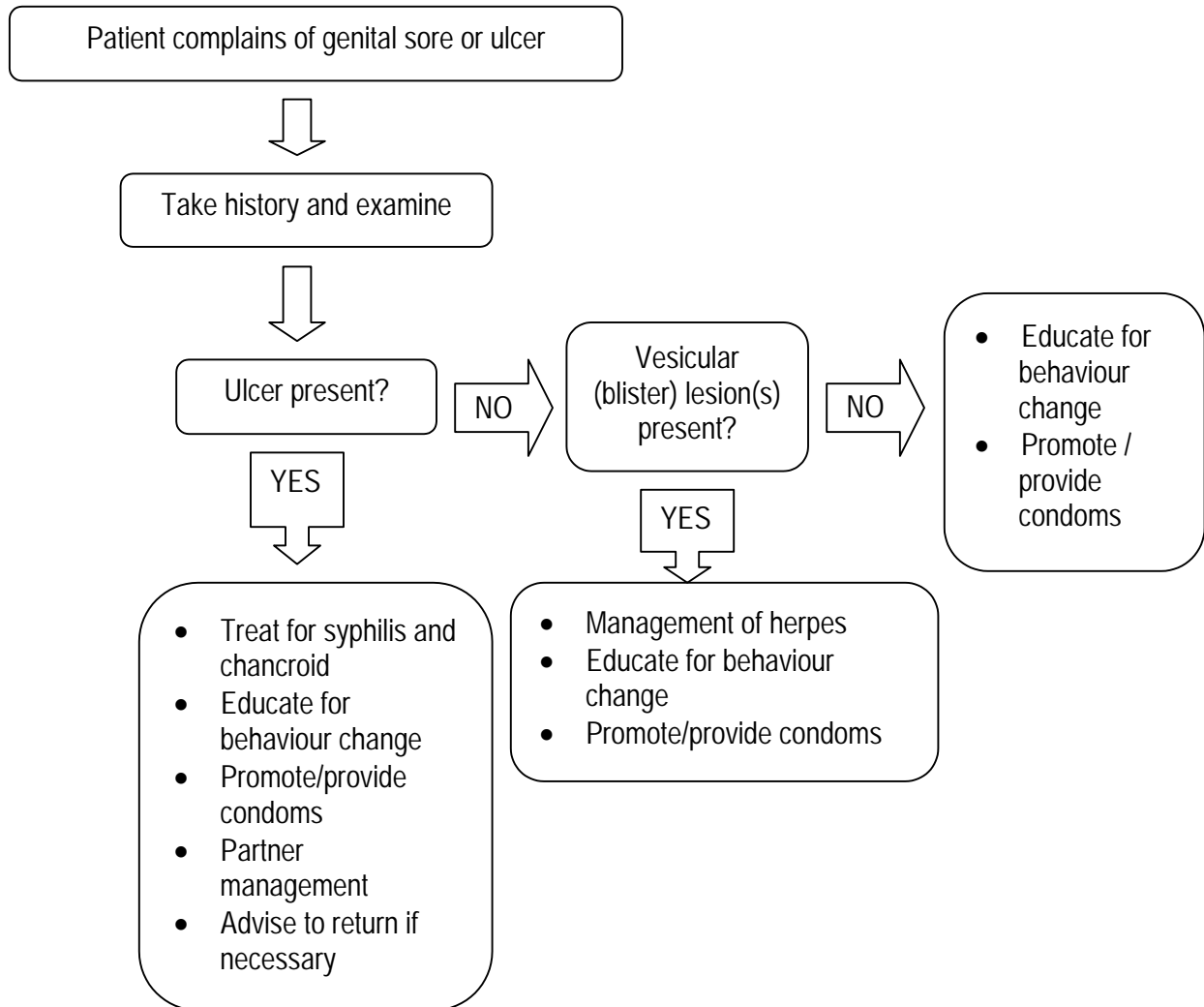
There is no cure for herpes. But there are some things a person can do to feel better.

Pour cool clean water over the genitals when passing urine. This helps to stop the burning. Soak some cloths in cool black tea and put on the sore. Sit in a pan or bath of clean, cool water. Give paracetamol 500 mgs every four hours for pain or aspirin 600 mgs four hourly.

Advise the woman to wash her hands frequently and not touch her eyes because the infection can spread to the eyes.

A pregnant woman with herpes sores can pass the virus to the baby during childbirth. The virus is very dangerous to the baby. It is best for her to have a caesarean section.

### Flow chart for genital ulcer syndrome



#### **Treatment for syphilis and chancroid:**

Benzathine penicillin G 2.4 Mus – single dose, i.m.

or

Procaine penicillin G 1.2 Mus daily for 10 days, i.m.

or

Doxycycline\* 100 mgs orally twice daily for 15 days

or

Erythromycin 500 mgs orally four times a day for 15 days (if allergy to penicillin)

Plus

Cotrimoxazole two tablets orally, twice daily for 7 days

or

Ciprofloxacin\* 500 mgs in a single oral dose

or

Spectinomycin 2 gms single dose, i.m.



## Appendix 6. Resources and references

### Manuals and Guidelines

**Resource Package for HIV/AIDS in Refugee Situations.** Geneva, UNHCR, January 1999. This resource pack contains: the UNHCR policy statement on HIV/AIDS in refugee situations; the UNHCR/UNAIDS Cooperation Framework; an HIV/AIDS programming checklist; the UNAIDS document request form; UNAIDS, Technical Updates and Points of View; Guidelines on HIV/AIDS Interventions in Refugee Settings; and an HIV/AIDS epidemic up-date. <http://www.unhcr.org>

**Reproductive health in refugee situations: Inter-agency field manual.** Reproductive Health for Refugees Consortium website at <http://www.rhrc.org/fieldtools/index.htm> lists Field Tools available on the site including this Inter-Agency Field Manual. Other field tools available on the site are:

- Training
- Needs Assessment Field Tools
- Inter-agency Field Manual
- Reproductive Health During Conflict and Displacement, WHO
- UNFPA Reproductive Health Kit for Emergency Situations: Information on ordering the supplies and equipment
- Sexual Violence in Refugee Crises: a synopsis of the UNHCR Guidelines for prevention and response

**Guidelines for HIV interventions in emergency settings.** UNAIDS 1998  
[www.unaids.org](http://www.unaids.org)

**Refugee health: an approach to emergency situations.** Médecins Sans Frontières. London: Macmillan/TALC/Médecins Sans Frontières; 1997. An invaluable guide to many aspects of refugee health. Has a brief chapter on STIs and HIV.

**Reproductive health issues in refugee settings.** CARE International, Atlanta, GA, 1996 This 5-day training module for health personnel focuses on skills learning and includes information on family planning, HIV/AIDS/STD, sexual and gender violence, maternal care, safe motherhood and obstetric emergencies.

**Refugee Reproductive Health.** Reproductive Health Outlook. Program for Appropriate Technology in Health. [www.rho.org/html/refugee-keyissues.htm](http://www.rho.org/html/refugee-keyissues.htm). Provides a useful overview with links to useful publications.

**Migrant Populations and HIV/AIDS: The development and implementation of programmes: theory, methodology and practice.** Geneva: UNAIDS; 2000. <http://www.unaids.org/publications/documents/specific/rufugees/jc397migrantpope.pdf>

**HIV Prevention and AIDS in Africa.** Royal Tropical Institute (KIT). Amsterdam: Royal Tropical Institute (KIT): 1997. US\$ 25.00 from Mr. Max Mink [kitpress@mail.support.nl](mailto:kitpress@mail.support.nl)

**Stepping Stones: A training package on HIV/AIDS, communication and relationship skills.** Alice Welbourn. Strategies for Hope, London: Action Aid; 1995 ([mail@actionaid.org.uk](mailto:mail@actionaid.org.uk)). Available from TALC (address below).

**Facilitating sustainable behaviour change.** Bruce Parnell and Kim Benton. A guidebook for designing HIV programs. Melbourne: Macfarlane Burnet Centre for Medical Research; 1999 ([community@burnet.edu.au](mailto:community@burnet.edu.au)).

**The Reproductive Health of Refugees.** Special supplement, edited by Laurel Shreck, International Family Planning Perspectives. 2000;26(4):161-192

**Community action on HIV: A resource manual for HIV prevention and care.** Macfarlane Burnet Centre for Medical Research. Melbourne. 2001 ([community@burnet.edu.au](mailto:community@burnet.edu.au)).

**Health and Population Occasional Paper, 'Sexual Health and Health Care: Care and Support for People With HIV/AIDS in Resource-Poor Settings'** 1998. Gilks C. A 192-page guidance book for planners and policy makers on how best to utilise scarce financial and human resources for health and disease, specifically HIV/AIDS care and prevention, promoting positive attitudes for care and support for people living with HIV/AIDS; examples from developing countries are provided. DFID fax+44(0)171-336 6688 ([info@ifh.org.uk](mailto:info@ifh.org.uk))

**Mental health of refugees.** Geneva, WHO and the UNHCR, 134 pp. This manual focuses on specific learning objectives for relief workers. It gives practical advice on how to help refugees and displaced people through counselling, self-help groups, modern drugs, and traditional medicine. A special section on refugee children is included.

**Sexual violence against refugees: guidelines on prevention and response.** Geneva, UNHCR, 1995, 99 pp. (English and French). This booklet describes when and how sexual violence can occur in the refugee context, its effects, and basic practical advice in areas of medical treatment, psychological support and legal intervention.

**Surveillance in emergency situations.** Médecins Sans Frontières. Brussels, Médecins Sans Frontières, 1993, 46 pp. This practical guide describes how to set up a surveillance system in the early stages of an emergency situation, especially in refugee or displaced person camps.

**UNAIDS best practice reports** <http://www.unaids.org/bestpractice/index.html>

**Fact Sheets on HIV/AIDS for nurses and midwives.** WHO  
[http://www.who.int/HIV\\_AIDS/Nursesmidwivesfs/index.html](http://www.who.int/HIV_AIDS/Nursesmidwivesfs/index.html)

**Expanding the global response to HIV/AIDS through focused action reducing risk and vulnerability: definitions, rationale and pathways.** UNAIDS.

**Women and AIDS** - an international resource book by Marge Berer with Sunanda Ray Available from TALC (address below).

**Clinical tuberculosis** by John Crofton, Norman Horne and Fred Miller Available from TALC (address below).

**Preventing a crisis** by Gill Gordon and Tony Klouda. Available from TALC (address below).

**Second generation surveillance for HIV. Compilation of basic materials on CD ROM.** UNAIDS / WHO Working group on Global HIV/AIDS and STI Surveillance. January 2001. WHO/CDS/CSR/EDC/2000.8. Available from WHO/UNAIDS.

## **Newsletters**

**Healthlink Worldwide** (used to be called AHRTAG- Appropriate Health Resources and Technology Action Group) produces excellent newsletters:

- AIDS Action - published four times a year.
- Child Health Dialogue - published four times a year, concentrates on international paediatric health promotion and disease prevention in relation to acute respiratory infections, diarrhoea, malaria, malnutrition, and measles.
- Health Action - published three times a year, emphasises international implementation of primary health care.

The newsletters include practical information, case studies and training ideas and provide a forum for questions and exchange of ideas. They are available as:

- hard copies by subscription
- PDF format at <http://www.healthlink.org.uk/PDFnotes.html>
- email text (recent editions only).

*How to order Healthlink Newsletters (hard copy)*

Single copies of most of Healthlink Worldwide's publications are FREE to individuals and indigenous organisations in developing countries. For others, payment is required with order: students £6/US\$12; individuals £12/US\$24; organisations £24/US\$48. See postal address below. E-mail: [publications@healthlink.org.uk](mailto:publications@healthlink.org.uk)

*How to get email text versions of the newsletters*

The text without illustrations is available by email from HealthNet, a communications network administered by SatelLife linking health workers in developing countries and other parts of the world. This service is particularly useful in situations where it is hard to receive attachments or download documents from the web. To subscribe to the email text version of AIDS Action write to: [robin@usa.healthnet.org](mailto:robin@usa.healthnet.org) and in the body of your message, type: 'subscribe aids-action' for AIDS Action; 'subscribe chd' for Child health Dialogue; 'subscribe health action' for Health Action.

## Population reports

These are very useful, comprehensive and well referenced reports available on the internet or free of charge (single or multiple copies) from:

John Hopkins University, Population Reports, 111 Market Place, Suite 310, Baltimore, MD 21202-4024, USA

Examples:

- Closing the Condom Gap (Vol XXVII, Number 1 April, 1999) Series H, Number 9.
- GATHER Guide To Counseling (Vol XXVI, Number 4 December, 1998) Series J, Number 48.
- Reproductive Health New Perspectives on Men's Participation (Vol XXVI, Number 2 October, 1998) Series J, Number 46.
- Ending Violence Against Women (Vol XXVII, Number 4 December, 1999) Series L, Number 11.
- Meeting the Needs Of Young Adults (Vol XXIII, Number 3 October, 1995).

Controlling Sexually Transmitted Diseases Volume XXI, Number 1 June, 1993

Phone: (410) 659.6300/Fax: (410) 659.6266 E-mail: [Poprepts@jhucpp.org](mailto:Poprepts@jhucpp.org)  
[www.jhucpp.org/pr/index.stm](http://www.jhucpp.org/pr/index.stm)

**The Clearinghouse on Infant Feeding and Maternal Nutrition** produces a regular free newsletter of abstracts on infant feeding relevant to developing countries. For more information contact: American Public Health Association Clearinghouse, 1015 15th St. NW, Washington DC 20005, USA. Phone: 202-789-5600, Fax: 202-789-5686. Email: [apha@permanet.org](mailto:apha@permanet.org) [aphach@igc.apc.org](mailto:aphach@igc.apc.org)

## Useful websites

UNAIDS: [www.unaids.org](http://www.unaids.org)

**Sexually Transmitted Infections** (<http://www.who.int/emc/diseases/hiv/index.html>) This WHO Communicable Disease Surveillance and Response site includes information on HIV/AIDS and sexually transmitted infections as well as links to many other AIDS-related sites.

**AIDS Education Global Information System (AEGIS):**

<http://www.aegis.com/aegis/aidslite/>

**The Body website** <http://www.thebody.com/learning.html>

This page is written for people who have just found out that they are HIV-positive, and provides much information that is both useful and comforting. The Body is a U.S. website, so much of the practical information on where to find help is aimed North

Americans. The site also has Spanish information  
at <http://www.thebody.com/whatis/espanol.html>

**The ProCAARE email discussion forum** on all aspects of HIV/AIDS, established as a partnership between SATELLIFE and the Harvard AIDS Institute/Harvard School of Public Health (HAI), has been operating since 1996. To participate in discussions on procaare, send a message to [procaare@usa.healthnet.org](mailto:procaare@usa.healthnet.org). You must always give your full name, affiliation and physical address when you submit a message. Procaare discussions are archived and the archives can be searched at:  
<http://www.healthnet.org/programs/procaare-hma/>

**Inventory of applied health research in emergency settings.** International Health Unit, Macfarlane Burnet Centre for Medical Research. Melbourne: MBC/WHO/EHA; 2000 ([community@burnet.edu.au](mailto:community@burnet.edu.au))

**Straight Talk Foundation** (useful for IEC materials), PO Box 22366, Kampala, Uganda. [Strtalk@swiftuganda.com](mailto:Strtalk@swiftuganda.com)

**Strategies for Hope Series [www.stratshope.org](http://www.stratshope.org)** - Strategies for Hope is a series of books and videos which focus mainly on sub-Saharan Africa, and also includes the training package 'Stepping Stones'. Issues covered include counselling, home-based care, workplace-based prevention, orphans, young people and gender issues.

**The Global Network of people living with HIV/AIDS (GNP+)** (<http://www.hivnet.ch/gnp/>) is a global network for and by people with HIV/AIDS. The central secretariat of the network is based in Amsterdam, Netherlands and has a board of 12 members representing the following regions.

**ACT UP (<http://www.actup.org>)** ACT UP is a diverse, non-partisan group of individuals united in anger and committed to direct action to end the AIDS crisis.

**Drum Beat (<http://www.comminit.com>)** This is an email and web network from THE COMMUNICATION INITIATIVE partnership with The Rockefeller Foundation, UNICEF, USAID, WHO, BBC World Service, CIDA, Johns Hopkins Center for Communication Programs, Soul City, The Panos Institute, and UNFPA. It offers information, ideas, and dialogue on communication, development and change, including sexual health and HIV/AIDS issues.

**ELDIS (<http://www.ids.ac.uk/eldis>)** ELDIS, a Gateway to Information Sources on Development and the Environment, offers an easy route to the latest information on development and environmental issues as both a directory and an entry point to electronic information resources. It is available free via the Internet. Recent new entries related to HIV/AIDS include materials on World Bank Health Sector Reforms and on gender and health.

**CDC - Division of HIV/AIDS Prevention (DHAP)**  
[http://www.cdc.gov/nchstp/hiv\\_aids/dhap.htm](http://www.cdc.gov/nchstp/hiv_aids/dhap.htm)) CDC's HIV mission is to prevent HIV infection and reduce the incidence of HIV-related illness and death, in collaboration with community, state, national, and international partners.

**The International AIDS Vaccine Initiative's (IAVI)** mission is to ensure the development of safe, effective, accessible, preventive HIV vaccines for use throughout the world. IAVI's web site provides information about IAVI's activities and background information and news about AIDS vaccine development.

### **Reference Addresses**

Centers for Disease Control and Prevention  
International Emergency and Refugee  
Health Branch, Mailstop F-48, 4770 Buford Highway  
Atlanta, Georgia 30341 USA  
Fax: 770 488 7829; E-mail: [baw4@cdc.gov](mailto:baw4@cdc.gov); Website: [www.cdc.gov](http://www.cdc.gov)

HealthLink Worldwide  
Cityside, 40 Adler Street, London E1 1EE, UK  
Fax + 44 20 7539 1580; [Publications@healthlink.org.uk](mailto:Publications@healthlink.org.uk); [www.healthlink.org.uk](http://www.healthlink.org.uk)

International Federation of the Red Cross and Red Crescent Societies  
17, Chemin des Crets, Case postale 372  
1211 Geneva, Switzerland  
Fax: 41 22 730 0395 Website: [www.ifrc.org](http://www.ifrc.org)

International Rescue Committee  
Health Unit, 122 East 42nd Street, New York, NY, 10168  
Ph: (212) 551-3019; Fax: (212) 551-3185

International Planned Parenthood Federation  
Regent's College Inner Circle, London NW1 4NS UK  
Fax: 44 171 487 7950; Website: [www.ippf.org](http://www.ippf.org)

Médecins sans Frontières International  
39, rue de la Tourelle, B-1040 Brussels, Belgium  
Fax: 32 2 280 1881; Website: [www.msf.org](http://www.msf.org)

Population Information Program  
The Johns Hopkins School of Public Health  
111 Market Street, Suite 310, Baltimore, Maryland 21202 USA  
Fax: 410 659 6266; E-mail: [poprepts@welchlink.welch.jhu.edu](mailto:poprepts@welchlink.welch.jhu.edu)

Reproductive Health for Refugees Consortium (RHR Consortium)  
Contact: The Women's Commission for Refugee Women and Children  
122 East 42nd Street - 12th Floor, New York, NY 10168 USA  
Fax: 212 551 3186; E-mail: [wcrwc@intrescom.org](mailto:wcrwc@intrescom.org)

Save the Children Fund UK  
17 Grove Lane, London SE5 8RD UK  
Fax: 44 171 703 2278

Teaching Aids at Low Cost - TALC  
PO Box 49 St Albans, Herts AL1 5TX UK  
Fax: 44 1727 846 852; [talcuk@btinternet.com](mailto:talcuk@btinternet.com); [www.talcuk.org](http://www.talcuk.org)

UNAIDS, Information Centre  
1211 Geneva 27, Switzerland  
Fax: 41 22 791 4187; E-mail: [unaids@unaids.org](mailto:unaids@unaids.org); [www.unaids.org](http://www.unaids.org)

UNFPA - Contact local country offices or  
220 East 42nd Street, New York, NY 10017 USA  
Fax: 212 297 4915; or

UNFPA Emergency Relief Office  
9 Chemin des Anemones, 1219 Geneva, Switzerland  
Fax: 41 22 979 9049; E-mail: [unfpaero@undp.org](mailto:unfpaero@undp.org); Website: [www.unfpa.org](http://www.unfpa.org)

UNHCR - Centre for Documentation for Refugees  
Case postale 2500, 1211 Geneva 2 Switzerland  
Fax: 41 22 739 73 67; E-mail: [cdr@unhcr.org](mailto:cdr@unhcr.org); Website: [www.unhcr.org](http://www.unhcr.org)

UNICEF  
Three United Nations Plaza, New York, NY 10017 USA  
Fax: 212 824 6464; Website: [www.unicef.org](http://www.unicef.org)

World Health Organization  
Distribution and Sales  
1211 Geneva 27 Switzerland  
E-mail: [publications@who.ch](mailto:publications@who.ch)

World Health Organization  
Department of Reproductive Health and Research  
1211 Geneva 27 Switzerland  
Fax: 41 22 791 41 89; E-mail: [lamberts@who.ch](mailto:lamberts@who.ch); Website: [www.who.org](http://www.who.org)

World Bank  
1818 H Street N.W. Washington, DC 20433 USA  
Fax: 202 477 6391; Website: [www.worldbank.org](http://www.worldbank.org)

