KNOWING MUTAPOLA

A Resource and Action Guide
for Women's Rights
and HIV & AIDS in Africa

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Foreword

Knowing Mutapola: A Resource and Action Guide for Women's Rights and HIV and AIDS in Africa was born out of a series of meetings in several African countries where participants realised that, in the absence of specific women-centred rights-based approaches, marginalisation of vulnerable women in HIV and AIDS programming would continue. This would in effect mean the overall impact of the AIDS response will be seriously undermined. HIV and AIDS threaten strategies and efforts that were almost coming to fruition after decades of sustained efforts to achieve equality for women.

Despite campaigns to reduce the spread of HIV and its impact on society, it is indisputable that HIV and AIDS have assumed the face of a woman in sub-Saharan Africa and beyond. Lack of autonomy for women has resulted in the continued spread of the pandemic. This human catastrophe has resulted in the impoverishment of women and a subsequent increase in gender violence. Together, these factors threaten the livelihoods of women, devastate their health and impose the burden of caring for the sick without getting the same care in the event of their own illness.

In light of this dilemma, the Mutapola Framework was developed as a direct response to increasingly visible gaps. These gaps include the laws and cultural practices that continue to disadvantage women by denying them the enjoyment of fundamental and globally accepted rights.

The dynamic Mutapola Framework proffers appropriate interventions for women in the context of HIV and AIDS. It touches on all facets of the pandemic from a women's rights perspective through its four pillars which include rights to comprehensive prevention, treatment, care and support; sustainable livelihoods; freedom of association and voice and an enabling policy environment.

It is our hope and conviction that this resource and action guide will meet the challenges it addresses and will take programming in women and HIV and AIDS to levels unattained before. While it is Africa-specific, the publication can be adapted for use in other regional contexts across the world.

We look forward to working with all of our partners in implementing the ideas in the resource and action guide to bring an end to HIV&AIDS.

Sincerely

Noreen Kaleeba
Chair Board of Trustees

WHO IS MUTAPOLA?

Mutapola is the campaign voice of a woman living with or affected by HIV and AIDS in Africa. She has many faces: young and old; urban and rural; married and single. The many Mutapolas have different experiences and face different realties. But while they might all appear different, one thing unites them – they are all women. The single name 'Mutapola' signifies that, at the end of the day, the major marker of all Mutapolas is their femaleness, which is then used to describe, define and circumscribe their lives. Gender-based notions further define, describe and deny or violate Mutapola's rights.

Mutapola carries a triple burden; she is poor, black, and female. In some cases, she has a fourth burden, a disability. All of these shape and affect how she lives, her power to make decisions over her life, her ability to reach her potential as a human being and the ways in which the world responds to or treats her.

But Mutapola is not a victim. She is strong, proud, loving and caring. She knows her own joy and spirit. She knows what she wants and needs, but very often she is deliberately silenced or ignored. Mutapola holds families and communities together. She is an organiser, a teacher and a thinker. Generations have been raised by grandmother Mutapolas, but she is kept in the background, only brought out when others feel it convenient to do so.

Mutapola carries the heavy burden of HIV and AIDS in Africa. She has agency and is a survivor!

The story below exemplifies the plight of women in sub-Saharan Africa today. The question is how many Mutapolas do we come across every day in our day-to-day work and lives? Is there anything that can be done to reduce pain, suffering and HIV vulnerability?

Box 1: A Mutapola story

Mutapola left school at an early age, as soon as she could read and write, in order to help with the chores and work in the fields so that her two older brothers could go to school. Her father, like other fathers in the community, saw education as an investment. His view was that sending girls to school was a waste of resources as they ended up getting married, so the investment would be lost to the family. The father believed that investing in a boy child was the logical thing to do.

Although her father worked in town, he could only afford to buy her a dress once a year at Christmas, as the rest of the money paid school fees for her brothers. Mutapola learned to do all the cooking and to wash everyone's clothes at an early age as part of her training process for motherhood. At the age of 14 Mutapola, like any woman in her village, could do any chore.

Not long after she turned 14, her 'aunt', who lived several kilometres away, arrived at her home to take Mutapola away. Her mother told Mutapola that she was to go and live with this 'aunt' but could come home if she wished. When she arrived at their home, her 'uncle', the husband of her aunt, welcomed her heartily and started calling her his wife as he usually did. That night her 'uncle' and her 'aunt' came to her room to tell her formally that she was now his wife. She did not know that many years earlier her father had met with difficulties and had to borrow money and some food from this rich uncle in exchange for her. The day had come for the 'uncle' – who already had five wives – to claim his payment. Her aunt physically held her down while her uncle raped her. Mutapola cried all night. This incident was repeated several times over the next few weeks. Although Mutapola's aunt had daughters the same age, Mutapola was not allowed to play with them as they were regarded as her children. Mutapola soon fell pregnant and before she saw her 15th birthday she was a mother of a beautiful baby girl.

By the age of 19, she had three children. In that year, Mutapola's father died. After his burial, her husband started regularly ill-treating her and took another wife, his seventh. He told Mutapola that she couldn't go anywhere as her father was dead and her elder brothers were now married and lived with their own wives.

When Mutapola was pregnant with her seventh child, her husband fell sick and died with AIDS. By that time, he had nine wives and 42 children. All his property was inherited by his younger brother who made an offer to his brother's wives, giving them the option to stay as his wives or go back to their parents.

Mutapola had no option but to stay. Her oldest daughter had barely turned 15 and was still going to school. Mutapola vowed not to let her daughter repeat her own experience if she could help it.

Today, Mutapola is a grown woman of 33 struggling on with life in the firm belief that she is better off with her brother-in-law as husband than without a husband.

Mutapola Framework rationale

Research the world over shows that women are more at risk of HIV infection and bear the brunt of the AIDS epidemic – and that both vulnerability and burden are increasing. The declaration by heads of states and governments at the United Nations General Assembly Special Session on AIDS (UNGASS) in 2001 stated very clearly that unless the issues of women are made central to the HIV and AIDS response the epidemic will continue unabated. Unfortunately, infection rates in women continue to rise and very few HIV and AIDS programmes address the specific needs of women. While contextual analyses around Africa depict a situation of HIV and AIDS with women more infected and affected, national strategic frameworks do not have women-focused interventions to address their countries' needs.

The full impact of AIDS on people's lives is simply difficult to quantify. How does one begin to 'measure' the loss of both parents or the impact on a mother of losing her six adult children? One in five children in Southern Africa is now orphaned – but such statistics do not even begin to convey what the lives of these orphans are like. Even before the discovery of HIV, women and girls experienced discrimination and oppression based on now well-documented gender-related factors. HIV and AIDS merely exacerbated the inequality and injustice that already prevailed in all African countries.

- The traditional payment of bride price – customary in almost all African countries – curtails a woman's ability to make reproductive and sexual choices.
- The incidence of all forms of violence against women is an indicator of the status of women. Rape and sexual violence are quite common.
- Women still do not have access and control over land and other productive assets in their own right as citizens, leaving them dependent and vulnerable to abuse by male partners.
- Women are less educated and by extension less economically independent than men.
- Women and girls are disproportionately saddled with household work.
- In most African countries, women still face discrimination by law or through the biased implementation and interpretation of the few good laws that may exist.

In summary, even before HIV and AIDS, a great deal of 'unfinished business' remained as regards to the promotion and protection of women's rights. It is this unfinished business, as well as longstanding socio-cultural factors, that make women and girls in Africa more likely to become infected with HIV and less able to protect themselves or fight for their rights. In addition, biological factors predispose them to infection. Statistics tell the story of gender inequality and injustice very starkly.

In the age group 15-24, females are two and half times more likely to be infected more than males.

In most African countries, infection rates are higher for women of all ages than for men.

Using the region as a pilot, ActionAid International's Southern Africa Partnership Programme (SAPP) together with partners called a forum of women vulnerable to, living with and affected by HIV and AIDS, to seek knowledge on women's specific and peculiar needs. The women identified the key issues of concern to them:

- Lack of access to information,
- Poor access to education for their young daughters,
- Lack of freedom of association and voice,
- Lack of safe and satisfying sex,
- Poor access to comprehensive treatment, care and support,
- Dependence on a male spouse and lack of access to a sustainable livelihood,
- Customary norms and practices that increase vulnerability,
- Ignorance of available laws and policies.

The consultative forum led to the development of a women-centred conceptual framework for interventions in HIV and AIDS from a rights perspective. In line with the campaign voice, the framework is called the Mutapola Framework.

THIS GUIDE

Knowing Mutapola: A Resource and Action Guide for Women's Rights and HIV and AIDS in Africa is a handy resource on issues that have an impact on the lives of women and girls in the face of the HIV and AIDS pandemic. Intended for HIV and AIDS programme frontline managers, the guide has been written from a programming point of view and from a women's rights perspective, to serve as a:

- Primary resource and action guide for ActionAid staff and partners who deal with HIV and AIDS issues,
- Tool for identifying policy issues with impact on women and girls in HIV and AIDS programming,
- Quick reference for basic facts and statistics on the impact of HIV and AIDS on women and girls in sub-Saharan countries.

Objectives

Primarily, the guide aims to assist programme managers in developing rights-based women-specific HIV and AIDS interventions. Specific users include ActionAid International (AAI) staff and partners, community-level workers, policy makers, women's rights activists working on HIV and AIDS issues, women activists living with HIV/AIDS, media workers and service providers.

This guide also serves as a useful tool for identifying key policy issues on women and HIV and AIDS. A number of real-life experiences were gathered as case stories for this specific purpose. Each case story can be used to stimulate debate and thought about various issues affecting Mutapola.

The resource and action guide is designed to be interactive. Discussion and action points follow case stories not only to generate interest, but also to arouse curiosity and stimulate debate on critical issues. Women, the communities in which they live

and even policy makers will find debates emanating from this guide critical in redressing certain injustices.

The resource guide is also intended as a reference tool for those interested in knowing about women in the context of HIV and AIDS. It is made up of six modules that all contribute to an understanding of the plight of women and girls in the face of the HIV and AIDS pandemic.

Illustrations, case stories and tables present information in a variety of ways in order to facilitate individual as well as group learning.

Knowing Mutapola: A Resource and Action Guide is the basis for a training curriculum for cascaded training up to community level.

Structure

To achieve these objectives, the guide is made up of six modules that can be used either individually or as a complete package. Each module is a complete unit with its own objectives, case stories and discussion and action points. The final section in each module explores one particularly significant focus for action related to the module's theme. The issues covered are current and emerging, and will be reviewed periodically.

Module 1. Women's rights and HIV and AIDS: an overview
The theoretical background of the Mutapola framework explains how HIV and AIDS intersect with gender issues, women and women's rights, in view of women's vulnerability to the pandemic. This module also provides basic information on the situation of women as regards HIV and AIDS.

Module 2. Women's rights dimensions of HIV prevention
Women's lack of rights makes prevention difficult for women. This module identifies major HIV and AIDS prevention strategies and the challenges women face, proposes a link between violation of women's and girl's rights and the spread of HIV, and offers alternative prevention methodologies for women.

Module 3. Treatment of HIV and AIDS
A range of treatment options (such as antiretroviral therapy, medications and treatment for opportunistic infections and cancers) can be made available to women living with HIV and AIDS. This module discusses some of these options, highlights the global campaign for universal access to treatment and goes on to identify the challenges to attaining access to treatment for Mutapola.

Module 4. Care and support
There has been a fundamental shift in the way that care is offered, from public health systems to families and communities. The burden of caring for the sick as a result of the HIV and AIDS epidemic is borne largely by women, including grandmothers and young girls, at both family and community levels. This module describes the different types of care and levels of support, highlighting the importance of instituting the continuum of care while emphasising the role of women in both clinical and

community-based care. It also gives alternative community and home-based care models.

Module 5. HIV and AIDS and sustainable livelihoods
While the need to mitigate the effects of HIV and AIDS is increasingly acknowledged, it is equally important to recognise that food and livelihood security is a key element of prevention. This module reviews sustainable livelihood issues for women and girls living with and affected by HIV and AIDS. It establishes the links between food security, nutrition, livelihoods and HIV and AIDS.

Module 6. Policy and advocacy
Women in Africa have limited voice and lack access to the mechanisms and political platforms from which to speak on issues that concern them in the context of HIV and AIDS. Advocacy plays a major role in bringing about change by drawing attention to policy issues pertaining to women in the context of HIV and AIDS. Women must play an active role in advocating for their issues themselves, so that they can be heard, adequately listened to and responded to by policy makers. This module goes on to emphasise the need for associations or coalitions of women and women's rights organisations on HIV and AIDS.

MODULE 1

WOMEN'S RIGHTS AND HIV AND AIDS: AN OVERVIEW

"If women's sexuality in Africa wasn't under assault, if women were able to say no, if women weren't subject to predatory attacks by men, or predatory behaviour generally, then you would have a disease in Africa called AIDS. But you wouldn't have a pandemic."
Stephen Lewis, UN Special Envoy for AIDS in Africa

Introduction

Although HIV and AIDS affect both men and women, recent trends show an increase in the number of women becoming infected at a very young age. Thus age and gender implications are key variables in the incidence of HIV. In Africa, as in most developing countries, the degree of response lags far behind what is required for effective prevention, care and support, treatment and long-term mitigation of the impact of HIV and AIDS.

In the current world of HIV and AIDS it has been necessary to assess the epidemic in the context of women's human rights. Safeguarding these rights – civil, political, economic, social and cultural – can enable women to avoid infection or, if already infected, to cope more successfully with the effects of this epidemic. Denial of women's rights limits Mutapola's capacity to protect and defend her autonomy, develop viable livelihoods and cope with the consequences of the epidemic.

Most of the rights protecting women's autonomy are present in international human rights instruments. However, the gendered dimensions of rights are not sufficiently explicit in mainstream human rights discourse. The same applies to HIV and AIDS. If the rights of women in respect of HIV and AIDS lie in the development of sexual rights and/or civil and political rights, this must be faced directly and within a broader context than health alone. Women should be able to assert clear and general rights to have autonomous control over their person and sexuality, so that decisions about sex do not endanger their life and health. Here, it is necessary, but insufficient, to cross-refer to the current conceptualisation of reproductive or sexual rights. These rights remain contested and do not necessarily capture the full meaning of the absence of women's autonomy as highlighted by HIV and AIDS.

ActionAid promotes the rights-based Mutapola Framework to fight HIV and AIDS amongst women and girls. This approach addresses the deep and specific roots of the inequality that exists between men and women in Africa, an inequality apparent in laws that treat women as second-class citizens; in social norms and customs that deprive them of knowledge about their own bodies and strip them of the power to make independent decisions; in endemic patterns of violence and abuse; in inadequate access to health care; in the disproportionate burden women bear in caring for the sick and in holding ravaged families together. The organisation holds

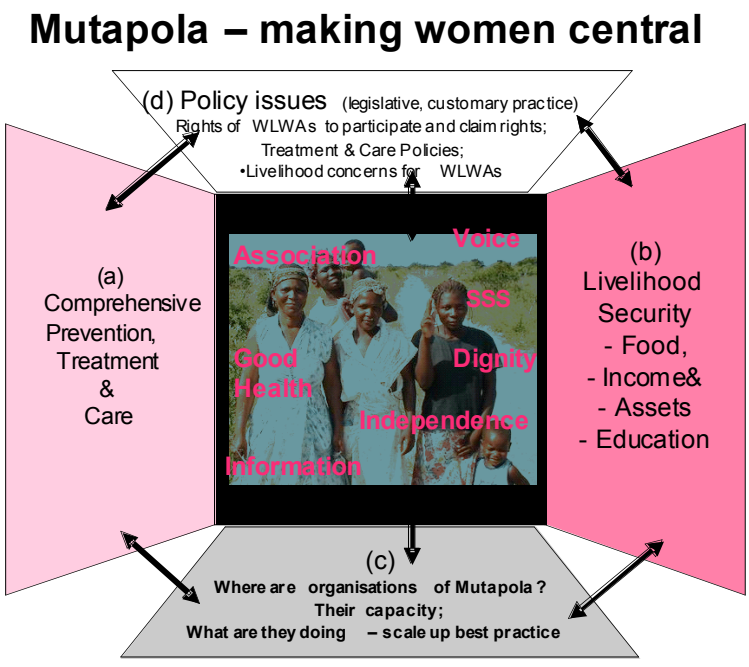
the view that failure to transform the status of women and girls means that the catastrophe of HIV and AIDS will deepen and that women's ability to cope may totally disintegrate.

Objectives

The purpose of this module is to provide the theoretical background to the Mutapola Framework along with basic information on the situation of women in the HIV and AIDS environment. It focuses on HIV and AIDS in relation to gender issues and on women's rights in view of their vulnerability to the pandemic. Its specific objectives are to:

- Explain the Mutapola Framework and its relevance,
- Explain basic concepts as they relate to gender and HIV and AIDS,
- Propose ways to operationalise the Mutapola Framework,
- Relate women's human rights to HIV and AIDS issues with the aim of addressing the factors that fuel the pandemic among women and girls,
- Give an overview of HIV and AIDS, from infection, mode of transmission and progression, in a women-focused manner,
- Show sex-disaggregated data on the prevalence of HIV and AIDS globally and more particularly in sub-Saharan Africa.

The Mutapola Framework



The Mutapola Framework consists of four pillars, labelled a, b, c, d, and grouped around the woman vulnerable to, infected with and affected by HIV and AIDS – her name is Mutapola.

Pillars

a. Comprehensive prevention, treatment and care

This pillar deals with Mutapola's rights to comprehensive HIV and AIDS services. Mutapola needs to be given options for HIV prevention. She needs to be equipped to say No or to engage in safer sexual practices; to have clinical care as a right if infected; and to be well informed, protected and assisted while she is providing care.

b. Livelihood security: food, income, assets, and education

For the young Mutapola, access to education is a right. Mutapola needs to be economically independent so that if she loses a spouse, she can fall back on her own resources. She also has the right to inherit assets. For the HIV-infected Mutapola, access to food and food security is a right.

c. Amplification of women's voices

Women living with and affected by HIV and AIDS face double stigma and discrimination. On the one hand, she is HIV-infected and, on the other, she is a woman – perceived as a second-rate citizen who should only be seen but not heard. While women's movements have made strides in protecting women's rights, there has been a disconnect between the movements and female HIV and AIDS activists. As a result, women's issues in HIV and AIDS, particularly rights violations, have not received the priority they warrant. Supporting the establishment of Mutapola organisations and integrating HIV and AIDS into women's rights organisations will amplify women's voices.

d. Policy issues: customary practices, legislation

Because they subjugate women, certain cultural norms and practices increase their vulnerability to HIV. In some instances, policies and legislation are available, but either women do not know about them or the environment does not enable them to demand access to their rights using these instruments.

Relevance

The Mutapola Framework addresses violations of women's human rights across the spectrum of HIV and AIDS, from prevention to treatment, care, support and impact mitigation. It enables more systematic planning for interventions to address women's specific needs. At the same time, the framework also highlights key policy concerns and allows for opportunities to influence policy and decision-makers for change. The framework makes women central to the AIDS response.

Rights-based implementation

A rights-based prevention approach recognises societal vulnerability to HIV and AIDS and not just individual risk behaviour. It also recognises vulnerability in different contexts of stigmatisation of disempowered populations such as women, girls and sex workers. Women's rights norms provide a coherent normative framework for analysis of the HIV and AIDS problem amongst women. Using the women's rights approach will also provide a legally binding foundation with procedural, institutional and other accountability mechanisms to address the societal basis of vulnerability and to implement change.

Programming

Questions at various levels[1] guide the first steps to programming the Mutapola Framework effectively.

Level 1: Vision

Guiding questions for action with respect to developing the vision for the Mutapola Framework:

- What is the vision of the Mutapola Framework?
- For whom is it important that this vision be achieved?
- What is happening that makes it imperative to achieve this vision?
- As indicators that the vision has been achieved, what knowledge, attitudes and skills must the people/women and girls have?
- What is the policy and cultural environment that can support or hinder the vision?

Level 2: Policy

Guiding questions for action with respect to the policy environment conducive to implementing the Mutapola Framework:

- Are there laws and policies in place that incorporate women's human rights?
- Are women's rights protected in the constitution?
- What is the extent of the implementation of these laws at the highest levels of government?
- Has the government in question ratified international and regional conventions that protect the rights of women such as CEDAW[2] and the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa (the Protocol)?
- To what extent do judicial decisions reflect application of CEDAW and the Protocol?

[1] Adapted from Thelma Awori: *Monitoring and Evaluation Framework for Africa: UNIFEM M&E Framework*, 2003

[2] United Nations Convention on the Elimination of All Forms of Discrimination against Women.

Level 3: Social and economic rights

Guiding questions for action with respect to Mutapola's enjoyment of social and economic rights:

- What is the experience of women, in contrast with men, with regard to access to economic assets, exposure to HIV and AIDS, violence and physical abuse?
- In what ways do women enjoy their social and economic rights?
- With what innovative approaches are women experimenting in order to enjoy economic and social rights?
- What support is available for women's initiatives to protect themselves against and prevent violence?

Level 4: Social context

Guiding questions for action with respect to the social context in which Mutapola exercises her rights:

- Are women aware of their livelihood, protection and public participation as rights issues?
- What are the key constraints to women's capabilities to enjoy social and economic rights? What are the key opportunities?
- Is there information on social and economic rights that is accessible to women and that enables them to demand these rights?
- Are women organised and reflecting on the institutional and social causes of their situation? Does such reflection lead to action that brings change?

Gender issues and HIV and AIDS

The subject of HIV and AIDS is a gender issue because, while the disease affects both men and women, women are more vulnerable for biological, epidemiological and social reasons.

Box 2: Critical gender concepts linked to HIV and AIDS

Gender
Gender refers to the socially construction of roles and responsibilities assigned to women and to men in a given culture or location. In most African societies, socially constructed gender relationships keep women subordinate to men, reducing the status of women's identity and access to rights. The same constructs accord a husband the status of primary decision maker even on matters affecting his wife's sexuality.

Sex
These are characteristics that are biologically determined or, some would say, divinely ordained.

Gender gap
This is a measure of inequality, indicating the disparities between men and women, and between boys and girls, in terms of accessing opportunities, resources, services and information.

Gender stereotypes
These are a common set of beliefs and attitudes that define the society's perception of the attributes and abilities of women/girls compared to men/boys. Stereotyping has serious repercussions for gender and HIV prevention. For example, boys are expected to be more knowledgeable about issues of sexuality, while for girls such discussions are taboo.

Reproductive rights
All couples and individuals have the basic right to decide freely and responsibly on the number, spacing and timing of their children; the right to have the information and means to make these decisions; and the right to attain the highest standard of sexual and reproductive health.

Sexual rights
Everyone has the right to have safe and satisfying sex, free of discrimination, coercion and violence.

Risk and vulnerability

The risk of HIV infection from unprotected sexual contact is two to four times higher for women than it is for men. This is partly because a larger surface area is exposed to body fluids in women. Girls and younger women are even more vulnerable because their reproductive systems are physiologically immature and so provide less of a barrier to HIV transmission.

In many African countries, the feminine ideal is characterised by passivity while control over sexual interactions defines masculinity. These factors contribute to the risk of infection for both men and women. It is regarded as inappropriate in some African societies for women to seek or have extensive knowledge about sexuality or reproductive health. This limits women's ability to accurately determine their level of risk and to acquire accurate information and means of protection against HIV infection.

Women's and girls' vulnerability to HIV is compounded by a host of cultural, legal and economic factors that put them at risk. Their low economic status makes women socially vulnerable to HIV infection. They are expected to tolerate male infidelity even in the event of exposure to HIV. Tolerance and silence may cost them their lives.

Intergenerational sex – young girls having sexual relationships with older men – also places women at risk. Discriminatory forces, including the culture of paying bride price, limit the opportunities for women and girls to gain information about the functioning of their bodies, their sexuality and health. This cripples women's autonomy and power to seek protection from infection.

Box 3: Women's human rights to reduce vulnerability to HIV and AIDS[3]

The right to a life of dignity
Freedom from inhuman, degrading treatment or punishment, e.g. prohibiting automatic isolation of HIV positive women.
The right to work
Equal opportunity for employment and job security, e.g. prohibiting dismissal of staff or refusal of employment on the basis of their HIV status.
The right to education
Equal access to quality education for all, e.g. preventing dismissal or lack of access to education for girls orphaned by AIDS.
The right to social security services
Women have a right to enjoy social and economic rights, e.g. promoting property inheritance especially for women, and acceptance of life insurance irrespective of HIV status
The right to equality
Non-discrimination and equality before the law, e.g. eliminating discrimination against women living with HIV and AIDS in all areas of health care.
The right to marriage and family life
The right to decide on whom to marry, when to marry and the number and spacing of children, e.g. stopping early or forced marriage and preventing girl-child pledging.
The right to health
Equal access to prevention, treatment and care, e.g. access to ARV.
The right to privacy
Both informational and physical, e.g. ensuring voluntary and confidential testing.
The right to freedom of association
Women have the right to form and belong to groups of their choice, e.g. prohibiting discrimination by churches and other places of worship against women living with HIV and AIDS.
Right to information
Equal access to factual information on sexual and reproductive health and HIV and AIDS, e.g. exclusive targeting of women with HIV and AIDS information.

Reproductive rights

Systematic discrimination in all facets of life – but particularly sexual and reproductive rights, education, health care and employment – disproportionately increase the risk of women becoming infected. Lack of education stands in the way of prevention programmes, as women may lack the skills to understand and/or the capacity to act upon the information contained in these programmes. Few women can negotiate safer sex or leave their partners because of social and legal norms and economic dependency. Lack of empowerment to decide whether or not to have children, how many and when puts a woman at increased risk of infection especially

[3] Contained in the United Nations Universal Declaration of Human Rights of 1948

where culture places a high premium on the male child. The woman risks her health and life in the quest for a male child even when her husband is HIV infected.

Some countries do not legally prohibit sexual and other forms of violence directed at women (including within marriages), for example rape, or traditional practices such as female genital mutilation. Such acts of violation of women's rights cause increased risk of HIV infection as well as physical and emotional harm to women.

Scope and prevalence of the pandemic

In recent years, the overall proportion of HIV positive women has increased steadily. In 1987, women made up 41% of people living with HIV and AIDS; by 2000 this figure rose to almost 50%. This trend is most marked in places where heterosexual sex is the dominant mode of transmission, particularly in the Caribbean and sub-Saharan Africa. Women also figure significantly in many countries whose epidemics are concentrated in key populations such as injecting drug users, mobile populations and prisoners.

Nowhere is the 'feminisation' of HIV and AIDS more apparent than in sub-Saharan Africa, where 59% of the adults infected are women.[4] Several social factors are driving this trend. Pervasive gender inequality and the violation of the rights of women are among the most important forces propelling the spread of HIV amongst women. Gender inequalities in the region make it much more difficult for women to negotiate condom use. Furthermore, sexual violence, which damages tissues and increases the risk of HIV transmission, is widespread, particularly in areas of violent conflict.

Box 4: Women and HIV and AIDS[5]

- Worldwide, 17.3 million women aged 15 years and older are living with HIV. This is 48% of the global total.
- In Asia 30% (39% Thailand, 46% in Cambodia), Eastern Europe (Ukraine, 46%) and Latin America, an increasing proportion of people living with HIV are women and girls.
- In the Caribbean, an average of 57% of the adults living with HIV are female.
- Three quarters (76%) of the world's HIV positive women live in sub-Saharan Africa, where women comprise 59% of adults living with HIV.
- In sub-Saharan Africa, nearly three out of four (74%) young people aged 15 to 24 years living with HIV are female.

The high prevalence of HIV and AIDS amongst Mutapolas in Africa is caused by a combination of factors, mainly poverty and the power imbalances that subordinate her to men. These gender aspects of the epidemic can only be removed by investigating existing inequalities and discrimination, making these the guiding principles in addressing the epidemic. While most countries sign international and

[4] Report on the Global AIDS Epidemic, UNAIDS/WHO, 2006
[5] *Keeping the Promise, An Agenda for Action on Women and AIDS*, UNAIDS, The Global Coalition on Women and AIDS, June 2006: http://womenandaids.unaids.org

local instruments to protect Mutapola from deprivation and neglect, they fail to review their own legislation and do not put in place policies and gender frameworks consistent with those instruments. Instead of positive change, the result is to reinforce negative stereotypes and to limit opportunities for women and girls to enjoy the full benefits of equal citizenship in their own countries.

Essential strategies to reduce infection rates must ensure that Mutapola has equal access to education; rights to own property and land; access to and control of financial credit on an equal basis with men; equality in employment and equal pay for work of equal value; adequate information, especially if she lives in a rural situation; and the capacity and opportunity for full and equal participation in rural economies and national development. Achieving these goals is only possible if all stakeholders in the development process receive relevant education and information.

A strong relationship exists between women's low status and HIV prevalence. In countries where women's social status is low, the general population's prevalence is high and so is the risk of HIV infection through sexual violence. A survey of 1,366 women attending antenatal clinics in Soweto, South Africa, found significantly higher rates of HIV infection in women who were physically abused, sexually assaulted or dominated by their male partners.[6]

[6] Dunkel et al., 2004

Table 1: Regional distribution of women living with HIV in 2003 and 2005 (estimated numbers)[7]

2003				2005		
Region	**Total adults & children**	**Women (15–49)**	**% of women to total**	**Total adults 15+**	**Women 15 +**	**% of women to total**
Sub-Saharan Africa	25,000,000	12,200,000	48.8	22,400,000	13,200,000	58.9
East Asia	900,000	200,000	22.2	680,000	35,000	27.9
Oceania	32,000	6, 100	19.1	75,000	35,025	46.7
South & South-East Asia	6,500,000	1,800,000	27.7	7,400,000	2,200,000	29.7
Eastern Europe & Central Asia	1,300,000	440,000	33.8	1,500,000	420,000	28
Western Europe	580,000	150,000	25.9	710,000	200,000	28.2
North Africa & Middle East	480,000	220,000	45.8	400,000	190,000	47.5
North America	1,000,000	250, 000	25.0	1,200,000	310,000	25.8
Caribbean	430,000	200,000	46.5	300,000	160,000	53.3
Latin America	1,600,000	560,000	35.0	430,000	430,000	26.9

What are HIV and AIDS?

Human Immunodeficiency Virus (HIV)
HIV is the infectious agent that causes AIDS. There are two types of this virus, HIV-1 and HIV-2. HIV-1 is the primary cause of AIDS worldwide. HIV-2 is found mostly in West Africa. HIV replicates only in human beings and has been found in most organs and fluids of the human body.

Acquired Immunodeficiency Syndrome (AIDS)
AIDS is a human viral disease that destroys the immune system and undermines the body's ability to defend itself from infection and disease. AIDS is the final stage of a chronic infection with HIV.

[7] Calculated from: UNAIDS Reports on the Global AIDS Epidemic 2004 and 2006

HIV and AIDS transmission

There are three primary modes of transmission of the virus:

- Unprotected sexual relations with an infected person;
- Blood and blood products, e.g. blood transfusion with infected blood, sharing hypodermic needles or accidental pricking by a needle contaminated with infected blood;
- Transfer of the virus from an infected mother to her baby during pregnancy, childbirth or breast-feeding.

Most HIV-positive women were infected through unprotected heterosexual intercourse. Women, being the most frequent recipients of blood transfusions, particularly during childbirth, are also at increased risk of HIV infection from donated blood.

Disease progression

When HIV enters the body, it attacks the white blood cells of the immune system, known as T cells, that provide the defence mechanisms for the body. Particularly vulnerable to this attack are certain T cells known as CD4 cells. When HIV infects a CD4 cell, it commandeers the genetic tools within the cell to manufacture a new HIV virus. The newly formed HIV virus then leaves the cell, destroying it in the process. This loss of CD4 cells endangers health because these immune cells help other types of cells respond to invading organisms.

An average healthy person has over 1,000 CD4 cells per micro-litre of blood. In a person infected with HIV, the virus steadily destroys CD4 cells. When the density of CD4 cells drops to 200 cells per micro-litre of blood, the infected person becomes vulnerable to opportunistic infections and rare cancers.

The last phase of the infection is the AIDS phase, which is characterised by a series of opportunistic infections that can cause death if not treated on time. Common ones include:

- Lung infections such as pneumocystis pneumonia, *Histoplasmosis, and Tuberculosis;*
- Fungal infections such as Cryptococcal meningitis;
- Viral infections, especially members of the herpes virus such as cytomegalovirus (CMV), Epstein-Barr virus (EBV), herpes simplex virus (HSV) types 1 or 2;
- Cancers such as Kaposi's sarcoma, B cell lymphoma and cervical cancer, whose prevalence has gone up as a result of the pandemic
- A variety of neurological disorders such as HIV-associated memory loss or dementia.

Voluntary counselling and testing (VCT)

Some women infected with HIV discover their status during antenatal care. Others discover after childbirth when their children show symptoms of the disease. Most women, because of their health-seeking behaviour, usually go to hospitals earlier than men, and thus are usually the first to be tested for HIV. VCT centres also offer an opportunity for testing.

The question of VCT highlights the connection between HIV and AIDS and women's rights. Women's access to HIV and AIDS-specific services is largely reliant on voluntary counselling and testing. The gap between the desire to test and actual testing is inversely related to a woman's social status, self-confidence, location, knowledge about HIV and financial status. It is surprising to note that even among women with 'higher education', there is a significant unmet need to access VCT.

Box 5: Advantages of VCT

- Well designed HIV prevention activities can lead to increased voluntary counselling and testing (VCT), which in turn can lead to broader and quicker access to treatment for people with HIV and AIDS.
- VCT can reduce fear and stigma, which in turn improves the quality of life of people living with HIV and AIDS as they become more accepted and understood in their families and communities.
- Through VCT, people can learn about HIV prevention and, if they are HIV positive, be given information about how to live safely with the virus and plan for the future.
- It helps people to get assistance early on and to learn about possible treatment for health problems that may occur. For example, VCT can be helpful in preventing tuberculosis and sexually transmitted infections.
- VCT thus promotes acceptance and facilitates enhancement of positive attitudes towards people living with HIV and AIDS.

Box 6: Pregnant at last

Marie struggled with sub-fertility for 10 years of her marriage. Her husband, the sole breadwinner, was unfaithful and very aggressive, and denied her sexual pleasure. When Marie discovered, to her delight, that she was pregnant she thought her marital problems were over. Her friends Fatu and Isatu were happy when they heard the news and insisted that she go for an early HIV test. Without giving it too much thought, Marie visited an antenatal clinic where a doctor examined her and ordered a blood test including HIV, as part of the routine for pregnant women. When she told her husband that she had been tested for HIV, he was furious. He told Marie that if she ever went to collect the results, she must not return to the house.

Discussion points

- What is your reaction to mandatory antenatal testing for HIV?
- In your community, what are the typical health-seeking behaviours towards VCT?
- From your experience, what is the normal reaction of friends and relatives towards VCT for pregnant women?
- What do laws in your country say about marital rape?
- Which women's rights were violated in Marie's case?
- Identify the issues in this case that you think could be addressed by policy.

Action points

- Marie, who is economically dependant on her husband, is being threatened with eviction. What options would you offer her?
- In view of women's rights and HIV and AIDS, how would you, as a programme officer/manager, assist people like Marie?

MODULE 2

WOMEN'S RIGHTS DIMENSION OF HIV PREVENTION

"Prevention is key to curbing spread of AIDS in Africa and containing its ultimate impact."
Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa

Introduction

HIV and AIDS are preventable and manageable, a disease that has been turned into a pandemic by the ignorance, neglect and violation of women's rights. The disease most deeply affects those least able to enjoy their rights: the poor, the weak, the least educated and the most stigmatised in society. These include, among others, Mutapola, children and the disabled.

Global efforts to slow down or stop the spread of HIV and AIDS have changed over the history of the pandemic. Because most HIV infection (80%) is via sexual intercourse, it is logical that the strongest efforts be focused on preventing sexual transmission of the virus (UNAIDS 2002). The promotion of behavioural change among women, men, girls and boys is important for the prevention of the spread of the epidemic as well as for minimising its impact. Some consensus has emerged among experts that the subordination of women and girls in Africa, caused by strong patriarchal social systems and related women's rights abuses, constitute a major driving force of the AIDS epidemic.

Objectives

This module aims to:

- Identify major HIV and AIDS prevention strategies and the challenges women and girls face;
- Establish the link between violation of women's and girls' rights and the spread of HIV and AIDS;
- Identify actions to be taken to make HIV prevention strategies applicable to women and girls.

Critical factors in prevention

Relevant messages

HIV awareness messages are usually generic and do not speak to issues of Mutapola. The most common awareness campaign strategy, the ABC message, is too general. (**A** stands for abstinence, **B** means to be mutually faithful to one's partner and **C** means correct and consistent use of condoms.)

Box 7: Inadequacies of the ABC prevention message

Abstinence

Abstinence – not engaging in sexual intercourse – can be total or periodic. To prevent HIV infection, total abstinence is required. Whether a girl or woman delays sexual debut or abstains from sex at a later stage, she will need access to information and education about alternative, safer sexual practices if she is to avoid HIV infection when she begins or resumes sexual activity. Yet, many campaigns advocate abstinence without giving this critical information.

In addition, abstinence messages are usually given out of social context in most African countries. Conflict situations, schools, mosques and churches, for example, require differently packaged messages that recognise diverse cultural, traditional and religious beliefs and practices.

Overall, abstinence can not be an effective strategy in many situations. Where a girl can only survive by exchanging sexual favours from men,or where a 10-year-old girl is betrothed to an older man, or where incidences of teenage pregnancies are on the increase abstinence is simply not a workable strategy. Instead, the abstinence message here reflects a lack of understanding of young girls' needs and realities.

Be mutually faithful

Having fewer sexual partners and being faithful to one's partner reduces the risk of HIV exposure. However, strategies to promote faithfulness among couples will not necessarily lead to lower incidence of HIV unless neither partner has HIV infection and both are consistently faithful. The 'be mutually faithful' message has also failed to reduce transmission in women, as about 60% of women living with HIV the world over declare that they were faithful, yet contracted the virus in their marriages. Mutual fidelity has to speak to both men and women, and in the absence of preventive options and lack of empowerment for Mutapola, she continues to place herself at risk even when she knows that her partner is unfaithful. In the African context, where sexual prowess in men is celebrated, Mutapola finds herself a victim of serial monogamy and of polygamy, which render this strategy unreliable or totally ineffective.

Correct and consistent condom use

Condoms reduce the risk of HIV transmission for sexually active people. Research has found that if people do not have access to condoms, other prevention strategies lose much of their potential effectiveness. Nevertheless, this approach is greatly undermined by women's lack of power to negotiate condom use. The condoms message is completely unrealistic for Mutapola and even, to some extent, for men. It is sometimes difficult for a man to negotiate condom use with a steady partner and almost impossible for Mutapola. Discussions about condom use touch on issues of mistrust and usually elicit violence.

For those women who may be able to negotiate condom use, for example single women, access to the female-controlled condom (sometimes called a femidom) is limited or impossible because of its cost, design and non-availability, particularly in rural areas where the majority of Mutapolas live.

Religion, culture and tradition

In sub-Saharan Africa, as elsewhere, women's and girls' rights are violated in the name of religion, culture and tradition. Indeed, many religions and traditions condone, if not promote, the subordination of women by men. Persistent, harmful

cultural practices in Africa increase the vulnerability of women to HIV and other sexually transmitted infections (STI). Cultural practices that prevent open discussions of sex and sexuality mystify sex, and this is reinforced by the taboo against talking about sex. 'Son preference' places a higher premium on the boy than the girl, granting him more access to information, while women and girls tend to be excluded from education. Where the practice is for the boy but not the girl to retain the family name, this contributes to preventing the education of girls. Some societal, cultural and religious practices teach women not to refuse sexual overtures from their husbands and forbid divorce even in the event of unfaithfulness and possible HIV infection.

Practices such as early marriage, forced marriage, girl-child pledging, widow inheritance, widow cleansing, female genital mutilation and the denial of property rights seriously undermine women's control over their own lives, leaving them dependent on male partners for economic support.

Box 8: Happily married

Sokari and Kaine Okon were married and had a very happy family of three boys and a girl. They were both educated and belonged to many professional and village clubs. After several years of work that took them all over the world, they retired home to the village but maintained many social activities. Their children were also educated and left home after a while, but always returned periodically with the grandchildren to visit their parents in the village.

After a brief illness, Mr Okon died at the age of 63. It was a very painful experience for his wife, Kaine, and the children, who insisted on giving their father a formal burial. According to the culture of the village, Kaine should sleep alone in the same room with her dead husband on the night before burial. Despite protests from her children, tradition prevailed and she did. The night after her husband was buried, four old women in the community visited to sympathise with the family. They announced that the burial rites were not yet over. Kaine was informed that to cleanse her of the spirit of her husband she must sleep with her husband's brother, whom she could also marry if she wanted to. Shocked, Kaine vehemently refused to comply.

Her children dispersed to their various homes two weeks after the burial ceremony. The tradition is for widows to be assisted with shopping and other household chores, but Kaine was denied this help. Instead, she was ostracised by her late husband's family members and other women in the community.

Discussion points

- What women's human rights were violated in this case?
- What are the root causes of the rights violations?

Action Points

- As a programme officer/manager, how would you assist this community to recognise and take action on issues of HIV and AIDS?
- Identify the issues in the case that you think could be addressed by policy.

Violence against women

'Violence against women' (VAW) refers to any act of gender-based violence that results in, or is likely to result in, physical, sexual or psychological harm to or suffering by women, including threats of such acts, coercion or arbitrary deprivation of liberty, whether occurring in public or in private life.[8]

Women's vulnerability to HIV is further perpetuated by VAW. Common forms include verbal abuse that results in emotional scarring especially in marital relationships. Physical violence occurs in marriages and schools as well as on the streets, while sexual violence increasingly targets younger girls. Manifestations of VAW include harmful traditional practices such as female genital mutilation, rape, abduction and trafficking, early marriage and impediments to girls' access to education. Violence is an unacceptable fact of life for many women in all countries, whether in peacetime or during conflict and post-conflict periods. The true extent of violence against women is unknown, but current research indicates that intimate-partner violence ranges from 10 to 69%, with one in four women experiencing sexual violence by an intimate partner in her lifetime.[9] In many cases, other forms of violence, such as abandonment or eviction from the home hold even greater terror for economically dependent women, who, confronted by a hostile social environment, ignore husbands´ adultery and acquiesce to their demands for unprotected sex. Economic disruption, war and conflicts exacerbate gender-based violence and HIV vulnerability in numerous ways. Rape, for example, is a common weapon of war in Africa, and at the same time, forced penetration and tears increase a woman's likelihood of HIV infection.

Box 9: Civil strife and VAW

During the Rwandan genocide of 1994 and the war in Sierra Leone, and conflict in the Democratic Republic of Congo (among other instances), peacekeepers, regular armies and guerrilla forces used rape of mostly young women and girls to terrorise, humiliate, punish, and ultimately force the civilian population into submission. This resulted in devastating injuries and health consequences in addition to disrupting communities dependent on the labour and household leadership of women. In many instances, escape was extremely difficult for violated women and girls. In northern Uganda, thousands of children who were abducted by the Lord's Resistance Army suffered sexual abuse and sexual slavery as part of that group's campaign of terror and violence. In all these cases, HIV transmission is only one of the traumas of horrific sexual abuse suffered by women, girls and sometimes boys. HIV infection amplifies the stigma of rape and adds to the medical and psychological injuries of these violations.

Discussion points

- What forms of VAW can you identify in this case story?
- What factors contribute to VAW in the case story?

Action points

- As a programme officer/manager, how would you assist this community to recognise and take action on issues of VAW?
- Identify the issues in the case story that can be addressed by policy.

[8] UN Declaration on the Elimination of Violence Against Women (DEVAW), 1993.

[9] ''WHO country study on Women's Health and Domestic Violence Against Women. Summary report of the initial findings on prevalence, health outcomes and women's responses,'' WHO, Geneva, 2005.

Box 10: Traditional birth attendants and transmission through blood

Dodo and Balele, his 13-year-old pregnant wife, live in Zaki Village, 50 kilometres from the local government headquarters. In the village, traditional healers are the primary source of medication for ailments and are patronised primarily by low income earners and women. Other sources of health care are the patent medicine providers who employ unqualified personnel and the government primary health care centre situated in the capital city. Only big farmers and merchants can afford these services because of the high cost of treatment and of transportation to and from the city.

Dodo could not afford the cost of transportation to the government health centre in the city for prompt attention. So, when Balele went into labour, she had to wait for two days before she received attention. Like most women in Zaki, she had to depend on Uwale – the local traditional birth attendant – to attend her delivery. But Uwale was attending to Asma'u, the only surviving wife of a business magnate who was said to have died of AIDS on one of his numerous trips to the city. His three other wives had died one after the other of a strange and probably AIDS-related ailment.

Uwale attended to Balele as soon as she was done with Asma'u. Using the same instrument from the last delivery, she gave Balele the traditional salt cut ('yankan gishiri'), a deep cut in the vaginal wall believed to hurry the arrival of the baby. Balele did not object to 'yankan gishiri' because her mother, as part of her psychological preparation for birth, told her that most women went through it.

Discussion points

- What factors worsen Balele's vulnerability to HIV infection?
- What cultural practices in the case story make women more vulnerable to HIV?
- Are there programmes in place to upgrade the skills of traditional birth attendants?

Action points

- What can be done to make the services of traditional birth attendants safer?
- As a programme manager/officer, what can you do to increase access to health facilities for women?

Transmission through blood

Being the most frequent recipients of blood transfusions, especially through childbirth, women are at greater risk than men of HIV transmission through blood and blood products. Although accurate data about HIV transmission via blood transfusion are scarce, reports indicate that unscreened blood is still being used in certain parts of Africa. The 100% efficiency in HIV transmission through blood thus puts women at great risk.

Responses and gaps in prevention

A range of preventive measures are underway in response to HIV and AIDS in general, and to women's greater vulnerability to infection in particular, with differing potential to benefit Mutapola.

Education and information

Anecdotal evidence shows that education for girls delays the onset of sexual activity and early sexual debut. This means it also reduces the number of a girl's sexual relationships, another factor, according to research, in the transmission of HIV. According to UNICEF, education is the fundamental building block for women's empowerment and social transformation. Girls who are educated are more likely to delay marriage, postpone childbearing and plan families.

Education is thus key to an effective response to HIV and AIDS. Studies have shown that out-of-school youth were five times more likely to have sex than those in school. Research also reveals an association between higher education levels and increased awareness and knowledge of HIV and AIDS; greater knowledge of HIV testing facilities; higher rates of condom use among both males and females; and better communication on HIV prevention between partners.[10] As the saying goes, 'Information is power', while ignorance of the modes of HIV transmission increases vulnerability to infection.

Girls' opportunities for education are on the increase as many African countries are now offering free primary education and establishing schools for girls. Life skills in particular has the potential to guide young women and girls to make informed decisions, communicate effectively, assert themselves, manage anger, resolve conflict without resorting to violence and build their self-esteem. Many women and girls who engage in unprotected sexual intercourse are blind to the consequences of their actions.

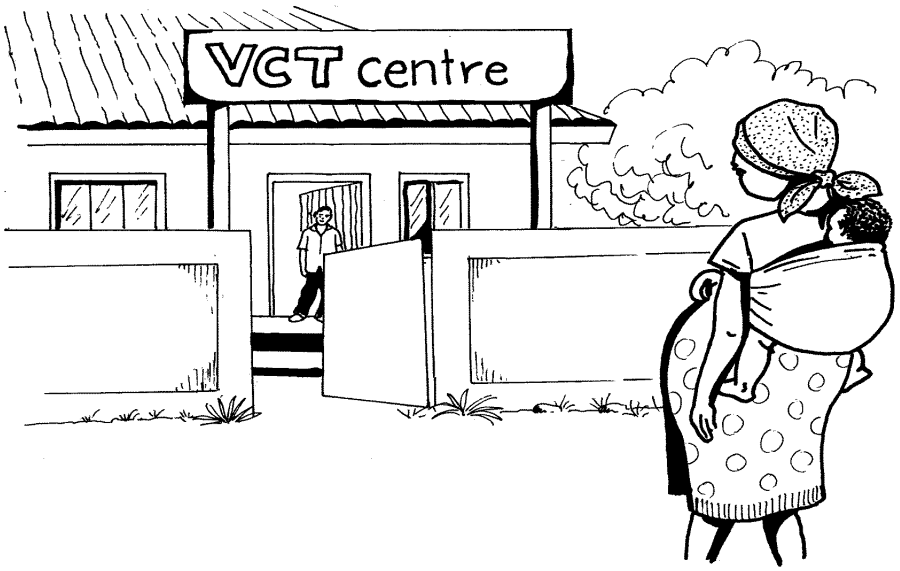
[10] Facing the Future Together: Report of the United Nations Secretary-General's Task Force on Women, Girls and HIV/AIDS in Southern Africa, 2004.

By contrast, the ABC message has been adopted worldwide, despite its limitations and much to the detriment of women's well being. Women-focused interventions are needed in its place, including context-specific messages and emphasising assertiveness for young girls.

Technologies

At a global level, the Universal Access initiative provides an opportunity to address issues of prevention methodologies in the context of failing health systems and inadequate access for women.

Prevention of mother to child transmission (PMTCT) marked a historic breakthrough in the control of HIV and AIDS and the strategy in many African countries, is an attempt to ensure an AIDS-free younger generation. Recent advances prescribe a combination of drugs that is still out of reach for many Mutapolas in Africa. In parts of Africa that have scaled up PMTCT, some programmes rank the life of the child over that of the mother, forgetting that a child thrives better with maternal care, not to mention the mother's right to survival in her own right. Women are given ARVs during pregnancy only, a practice that overlooks the dangers to the mother of taking and then stopping treatment. Evidence abounds of facilities that offer both ARV and PMTCT programmes but that fail to register women for ARV after they give birth increasing the risk of rapid progression towards AIDS.



Many PMTCT programmes fail to consider the social and cultural context for breast-feeding from a woman's perspective. A woman who follows advice not to breastfeed, as an option to reduce transmission to the baby, faces stigmatisation and discrimination, in addition to bearing the cost of baby formula as an alternative. As a result, many mothers choose to breastfeed regardless of the transmission risk.

Microbicides are different products that can be applied to prevent the sexual transmission of HIV and other sexually transmitted infections (STIs). The

development of microbicides represents a welcome intervention, particularly for women, but funding for the research is still limited and advocates are few. Political will remains insignificant, while ethical queries arise around the risks for the women who participate in trials.

The female condom provides an alternative woman-controlled prevention method, but its cost, design and availability limit its use by Mutapola.

Access to early diagnosis and treatment of STIs is important for prevention. The transmission of HIV from an infected person is greater in the presence of an STI, because STIs inflame membranes and cause them to tear, giving easier passage to the virus. Also, STIs may be asymptomatic in women while many are unable to distinguish infection-related discharge from a normal vaginal discharge.

Prompt and effective management of STIs poses a challenge in resource-poor settings that lack adequate equipment, supplies and trained personnel. Syndromic management – where a diagnosis is based on symptoms rather than on an expensive laboratory test – does not reduce the added risk of HIV transmission in a woman with an STI, nor can it help with the asymptomatic infections that are common for women.

Ultimately, it is hoped that an HIV vaccine will help to eradicate the virus. Meanwhile, in the search for such a vaccine, the risk of transmission increases for women who participate in clinical trials without being given adequate information or, in the event of sero-conversion, quality medical care.

Addressing tradition

Cultural practices that prevent HIV transmission, such as male circumcision, are being promoted at policy level as a prevention strategy. However, it is important to bear in mind the rebound effect of newly circumcised men erroneously believing that their new status replaces the condom.

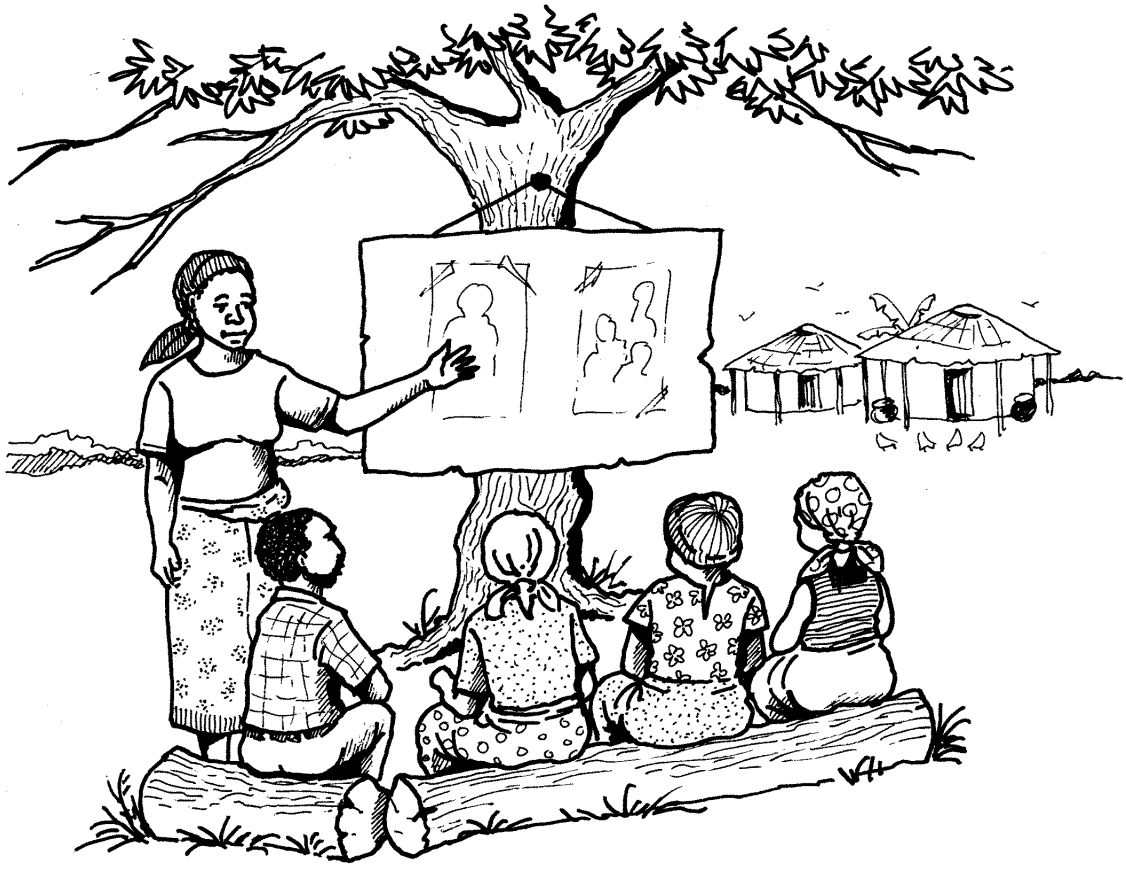
At the same time, traditional practices that increase the risk of HIV transmission are being addressed through international and regional instruments such as The Protocol to the African Charter on Human and People's Rights of Women in Africa. Some African countries, for example, have passed laws against female genital mutilation.

Individuals and communities have begun to interrogate the meaning of practices such as the payment of bride price or exchange of gifts. For example, in Uganda, instead of giving the girl grinding stones or mortars and pestles (denoting the expectation that the bride will labour in the home), some families have given the bride a laptop (which may be interpreted to mean recognition of a professional wife).

Women's rights

Legal instruments that protect women's rights are being adopted by increasing numbers of African countries, although implementation and enforcement still leave a great deal to be desired.

At programme level, ActionAid and others have developed effective participatory methodologies such as Stepping Stones, Reflect and STAR. Stepping Stones helps community members to discuss HIV and AIDS, sex and sexuality issues more openly. This methodology deals particularly with the empowerment of women, seeking to reduce gender-based violence through effective communication between partners. Reflect enables communities to deal with local development issues using adult learning and communication techniques, while STAR combines Stepping Stones and Reflect methodologies to empower communities in the face of HIV and AIDS. These methodologies which have been widely used in Africa to help communities decide on how to respond to HIV and determine their greatest needs. They also focus on behaviour change and allow community members to reflect on attitudes and actions that may have contributed to the spread of HIV. They aim to empower women and girls and stimulate the community to demand their rights.



End Violence Against Women

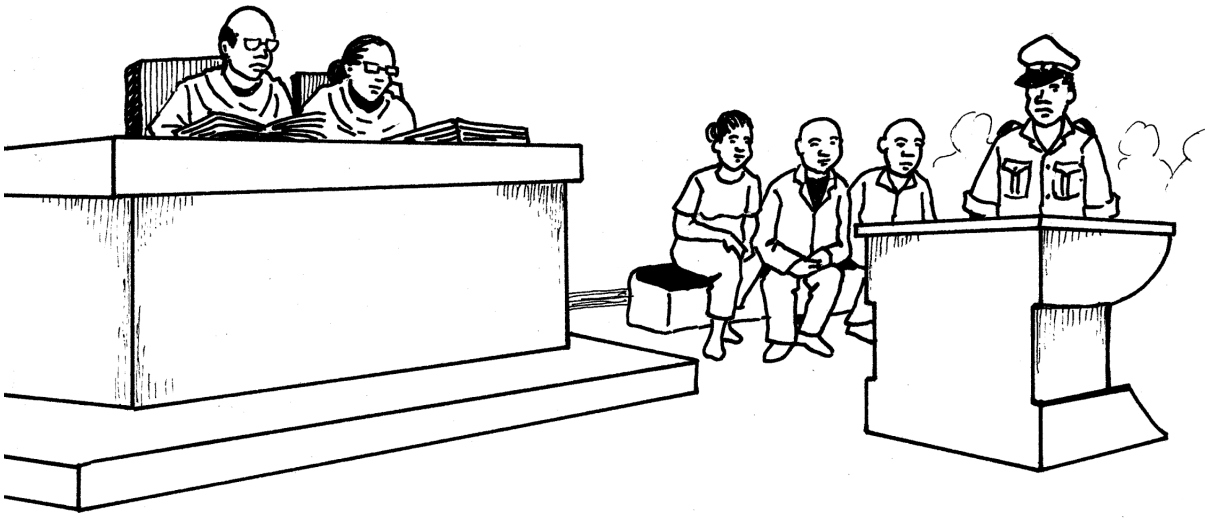
Campaigns and activism to eliminate violence against women (VAW) have assumed a new urgency as a strategy to reduce the incidence of HIV. As women's rights organisations have begun to tackle HIV and AIDS from a women's rights perspective, increased policy advocacy for VAW in HIV and AIDS has resulted.

A range of strategies are suggested at programme level:

- Raise public awareness on the human rights of women.
- Support the enactment of legislation to address domestic violence, sexual abuse and rape.
- Design research and advocacy programmes to address legal and policy gaps, such as gender audits of the administration of justice, the impact of violence on women and the provision of related psychosocial support.
- Provide assertiveness and life-skills training for girls.
- Train and sensitise law-enforcement officers.
- Disseminate and popularise international and national women's rights instruments.
- Involve traditional leaders and custodians of culture in mobilising both men and women in communities to address harmful traditional practices, gender-based violence, sexual abuse and rape.
- Challenge wedding-gifts practices that imply women's subservience, and encourage those that can be interpreted to mean women's empowerment.
- Organise women and girls into associations or coalitions to address VAW.
- Provide access for women and girls who have been sexually abused to post-exposure prophylaxis (PEP) – short-term antiretroviral treatment to reduce the likelihood of HIV infection after potential exposure. In some countries (such as Zimbabwe) programmes provide PEP to women who have been raped.

At national level, ActionAid could assist governments to protect women's rights in various ways:

- Support parliament to ratify various international and regional human rights instruments.
- Promote free and compulsory basic education for girls in school.
- Take action to prevent violation of women's rights. Examples might be advocating for equitable access to education, sexual and reproductive health care services and information, or for legislation to address gender-based violence.
- Initiate and support legal support services to educate women affected by HIV and AIDS about their rights, to enforce those rights, to develop expertise on HIV-related legal issues and to take advantage additional available means, such as offices of Ministries of Justice, public complaints mechanisms, health complaint units and women's rights organisations.
- Promote consequences for law-enforcement officers who ignore regulations that protect women's rights.
- Take necessary measures – including the allocation of sufficient resources – to ensure that women and girls can realise their rights and be assertive in decision-making about their reproductive and sexual lives.
- Monitor the implementation of international human rights instruments, for instance through shadow reports to parliament and the mobilisation of civil society watchdogs.



Box 11: Married at 12

Kadiatu is 19 years old and HIV positive. She was infected with the virus five years ago. In her culture, girls are expected to marry early, usually as they begin their periods. She was one of the lucky girls in the village to have gone to school before her parents forced her to marry an old man with ten wives. In her parents' view, he was a rich man who could give them a cow in return for giving him a wife. So, at the age of 12, she was married. She didn't know what to do with the man who was the age of her grandfather. Her aunt briefed her on how to please a man during sex. It was her first time to learn about sex because in her village the subject was taboo. After a few weeks of marriage, she felt great pain, especially in her vagina. She complained to her stepmother (her mother had died long before). Her stepmother and her father did not want her to divorce the man, despite her unhappiness.

Finally, late one night, Kadiatu ran away. She went directly to the home of an aunt, who had not supported Kadiatu's forced marriage to the old man. The aunt and her husband sympathised with Kadiatu, took her in and agreed to put her back in school since she was a bright student.

However, when she turned 14, her aunt's husband demanded sex. Kadiatu told him that she was not interested. He raped her. For fear of being driven out of the house, Kadiatu kept her ordeal secret. A few months later, her aunt fell sick with all the symptoms of AIDS and tested HIV positive. When her aunt died, Kadiatu also took the test and the results were positive. With the help of an NGO, Kadiatu reported her aunt's husband's actions, but he was rich and simply bribed court officials. She was denied justice.

Discussion Points

- Which of Kadiatu's rights were violated in the above case story?
- If this had taken place in your country and community, do you think that education and knowledge could have helped to address Kadiatu's challenges? Why?
- What are the issues that contributed to Kadiatu's vulnerability to HIV in the case story?

Action points

- As a programme officer/manager, what measures would you take to deal with the rapist and rape survivor in your community?
- Identify the issues in the case that you think could be addressed by policy.
- What programmes would you initiate to address the issues that arise in this story?
- What support would you provide to enable women's groups to lobby on their own around the issues raised here?

Box 12: I will marry when I want

Fantu, a 14 year old girl in seventh grade, lives with her aunt in the city, as there is no school near her parents' rural village . Several times, Fantu has fought her way out of marriages her parents have arranged with someone they consider to be of ´high status´. Seeing the sufferings of her older sister Bogalech, who married at the age of 13, Fantu is determined to finish her education and find employment so that she can live as she wishes. She always feels sorry for Bogalech, who suspects that her husband is having an affair but suffers in silence since her husband has paid bride price for her and so she can't leave the marriage.

Unfortunately, Fantu faces a challenge of her own. The headmaster makes sexual advances, threatening that she will not survive in the school if she does not comply. Fantu has visited the school counsellor who, to Fantu's dismay, only said that the headmaster is a powerful person.

Discussion Points

- What rights violations have Fantu and Bogalech experienced?
- What programmes are available to reduce violence against girls in schools?
- What do you think will happen to Fantu?
- How does the legislation in your country address the issue of sex with minors?
- Can women's groups and communities play any role in challenging violence against girls in schools?

Action Points

- What mechanisms would you recommend to schools in order to address sexual harassment of girls?
- What steps would you take to assist the government to act on sexual harassment in schools?
- Identify the issues in this case that could be addressed by policy.

MODULE 3

TREATMENT OF HIV AND AIDS

"People no longer accept that the sick and dying, simply because they are poor, should be denied drugs which have transformed the lives of others who are better off,"
Kofi Annan, United Nations Secretary General

Introduction

Antiretroviral therapy (ART) can not cure HIV and AIDS but it can stop people from becoming ill for many years. ART has the potential to dramatically improve the health and extend the lives of people with HIV and AIDS.

For Mutapolas living with HIV and AIDS, possible treatment includes that of opportunistic infections, ART, complimentary and alternative medicines, and good nutrition. Access to treatment remains a major challenge, especially for women in Africa, but there have been efforts to address this issue. The high cost and demanding clinical requirements of these drugs put them out of Mutapola's reach. Globally, the number of people living with HIV is about 38.6 million, of whom 47.7% are women.[11] This number continues to rise steadily each year. Worldwide, less than 8% of the people who need antiretroviral treatment receive it and the majority of women and girls remain untreated. There has been some political will in some countries and commitment to fund treatment. However, much remains to be done to persuade global and national communities to expand financial support.

Objectives

This module provides information on treatment that should be made available to women living with HIV and AIDS, such as ART, medications and treatment for opportunistic infections and cancers. The module aims to:

- Highlight available treatment options for HIV and AIDS and the benefits each one offers;
- Outline the global initiative for Universal Access to Treatment;
- Identify the gaps and challenges to attaining access to treatment for Mutapola;
- Identify gender and women's rights issues in the treatment of HIV and AIDS;
- Explain recent advances and initiatives for treatment of HIV and AIDS;
- Propose actions to make universal access to treatment a reality for Mutapola.

[11] Report on the Global AIDS Epidemic, UNAIDS, 2006

Treatment options available to Mutapola

While no medical treatment cures AIDS, new methods to treat the disease have developed rapidly. Three types of therapy exist for people living with HIV infection or AIDS: antiretroviral therapy (ART) using drugs that suppress HIV replication; medications and other treatments that fight the opportunistic infections (OIs) and cancers that commonly accompany HIV infection; and support mechanisms that help people deal with the emotional repercussions as well as the practical considerations of living with a disabling, potentially fatal disease.

Antiretroviral treatment (ART)

Antiretroviral drugs (ARVs), which directly deal with the replication of the virus, remain the major intervention in the history of the pandemic. Governments worldwide have wished to roll out ART for everyone who needs it. This has resulted in the UN's initiative for Universal Access for HIV Prevention, Treatment, Care and Support by 2010, among other international efforts. However, one needs to be critical as to what this means for women. ART is just one component of the treatment continuum. Others include laboratory monitoring and diagnostic tests, VCT, palliative care, management of opportunistic infections and prophylaxis.

Complementary and alternative therapy[12]

This describes treatment using medicines, substances or methods other than those of orthodox or modern medicine. In different ways, these therapies supplement the body's natural systems for fighting disease. Some can cure OIs that follow HIV infection, including fungal infections manifesting on the skin. By easing pains and aches, some compliment orthodox medicines. As traditional healers tend to be near the community and are relatively inexpensive, these alternative medicines are preferred for long-term therapy. Some alternative therapies have succeeded in alleviating suffering. Others have been used to exploit poor women whose only choice is this method of therapy, and fake claims of cure have reduced the span of some women's lives.

Beneficial traditional practices that provide readily accessible, effective and low-cost remedies should be identified and promoted. Traditional treatments differ greatly from region to region and tend to be highly location-specific. It is important to identify locally known and available treatments and to discuss their advantages and disadvantages.

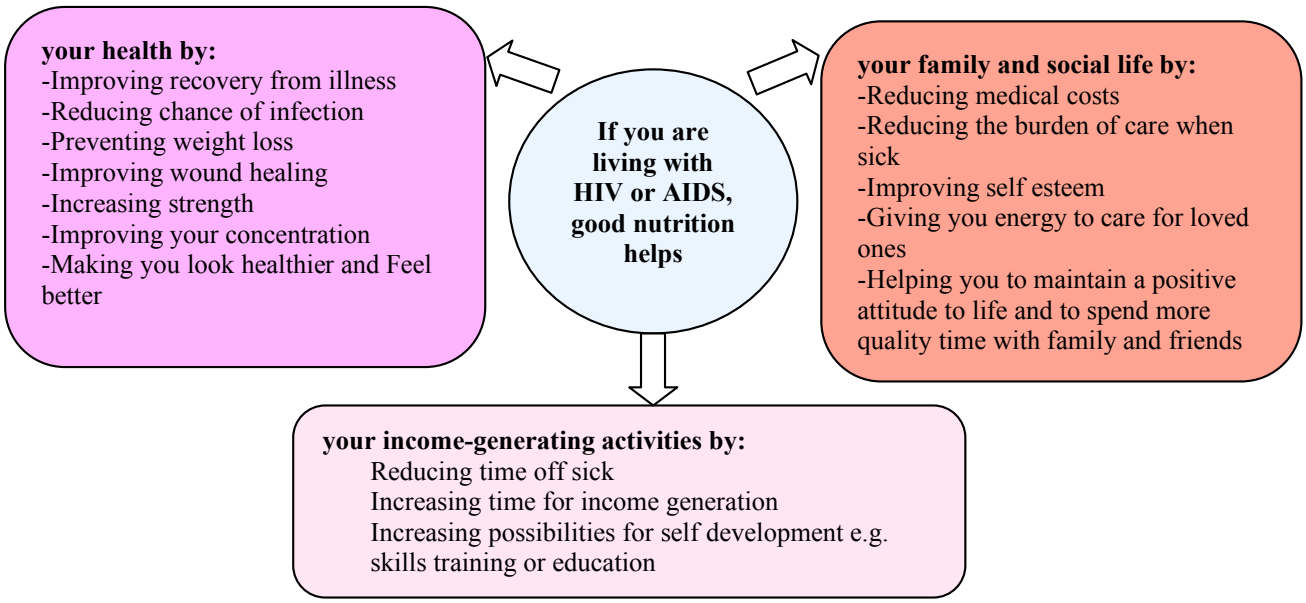
Herbs and spices can improve digestion, stimulate appetite and preserve food, although effects may not be the same for everyone. Useful examples for people living with HIV and AIDS include aloe (helps to relieve constipation), basil (has antiseptic effect for mouth sores, relieves nausea and aids digestion), calendula (healing and anti-inflammatory function), cloves (stimulate appetite) and coriander (controls bacteria and fungi, reduces flatulence).

[12] *Living well with HIV and AIDS: A manual on nutritional care and support for people living with HIV and AIDS*, WHO and FAO, 2002

Nutrition

HIV and AIDS treatment is closely linked with nutrition. Eating a balanced diet is one of the first steps in taking care of oneself in HIV infection, as it helps the immune system fight diseases. Malnutrition and mal-absorption are major problems for people living with HIV. In HIV-positive persons, the body uses up vitamins and minerals faster than normal and it becomes more difficult for the body to break food down into a form the body can absorb. Multiple nutritional deficiencies are shown to occur early in the course of HIV infection. Deficiencies of certain nutrients weaken the immune system, including T-cell function and count.

Many HIV-infected people are unable to meet their nutritional needs and become weak and malnourished. Given the lack of medical care and drug treatment in most AIDS-affected developing countries, it is imperative to undertake vigorous efforts to achieve and maintain good nutrition among HIV infected people as a matter of priority.



Challenges in accessing ART

There is no doubt that strides have been made in the development and administration of ARVs for HIV and AIDS. These drugs have been proven to improve the duration and quality of life, and have changed the status of AIDS from a deadly to a chronic disease. However, access to ART and treatment for other HIV–related diseases remains a problem for women. Overall, the numbers of those who access the drugs remain abysmally low. Five to six million people in low and middle-income countries need ART treatment immediately. However, the World Health Organisation (WHO) estimated that only 400,000 of these people had access by the end of 2003. In other words, 9 out of 10 people who urgently need treatment for HIV are not being reached.[13] As is usually the case, the gender-based inequalities that affect women's ability to access other services also limit their access to HIV treatment. It is crucial to

[13] UNAIDS Report, 2004.

consider the constraints that women and girls face when accessing such services and then to design interventions accordingly.

In southern Africa, Mutapola's access is affected by limited mobility, her responsibility for childcare and her lack of treatment literacy. In addition, Mutapola has specific reproductive health concerns, which must be addressed with patience, respect and confidentiality by HIV treatment and care providers.

At household level, Mutapola's access to health care is largely determined by her husband. For example, 76% of married women in Malawi report that their husbands make all the decisions related to the wives' health care. Only 20% of married women report making independent decisions about their health care. The fact that Mutapola is usually the first to be diagnosed with HIV in the home results in stigma and discrimination that may inhibit her health-seeking behaviour and further reduce her access to treatment.

In Africa, Mutapola is usually economically dependent on men. However far the cost of treatment has been lowered, it is still too expensive for the average Mutapola. Only economically empowered women can access treatment, and vulnerability assessments reveal that there are few such women in Africa.

Affordability

The cost of ART is a major barrier for Mutapola, as it is for most low-income groups. While most sub-Saharan African governments have declared that ARV drugs are to be offered for free through public health systems, there are hidden costs in accessing them. Mutapola must find money to travel to the hospitals where services are available and to cover food expenses there, as well as pay fees for complementary support services such as blood tests, chest x-rays and counselling.

While ART is critical, it is only one of several components in a continuum of treatment and care. Other essential components needed to complement ARVs include laboratory and diagnostic tests, palliative care, VCT, food supplements, management of OIs and prophylaxis. In most cases, these come at a cost. Meanwhile, time to seek treatment results in cumulative disability life-years[14] that affect GDP[15].

[14] DALY.
[15] Gross Domestic Product.

Box 13: There is life after infection

I am 24 years old, a school teacher and still single. I share fellowship within the Deeper Life Bible Church.

When I first got to know about my HIV-positive status, I wanted to kill myself. I felt disgraced and feared that I would not get married and that meant not having children of my own. I termed myself useless and not worthy to live and therefore preferred death. But I thank God for this workshop, which He used to convince me that ***"there is life after infection."*** I am now courageous. Praise God. My problem now is the far distance between my place of work (Taraba) and where I am receiving ARVs (Maiduguri). My salary is N7000 and I spend almost N8000 monthly on transport alone to collect ARVs.
Ekklesiyar Yan'uwa A Nigeria (Church of the Brethren in Nigeria)

Availability

ARV availability, like access, continues to be a problem in resource-poor settings, despite cost reductions in some countries in the region. ARV therapy requires viral load monitoring and CD4 T-cell counts, both services that are expensive and available only at certain centres. Most facilities for ARV therapy in southern Africa are currently concentrated in urban health institutions that have suitable infrastructure in place. Conversely, health care centres in rural areas, where most Mutapolas live, are ill-equipped as well as inadequate in number.

Characterised by long waiting lists, corruption and nepotism, access to ARVs remains a major obstacle to health care delivery. Rural women, those with no medical aid or insurance, and the unemployed are the ones most affected by the urban location and paucity of health care centres.

Adherence

The administration of ARVs is only a small component of treatment. Monitoring of the person on the drugs is crucial. For example, drug reactions, resistance or adverse effects, all potentially life threatening, can be averted if they are identified in time.

According to current evidence, once a person begins to take protease inhibitors, treatment must continue uninterrupted for life. Interruptions in treatment allow the virus to resume rapid replication and to generate resistant mutant strains that do not respond to available antiretroviral drugs. This kind of resistance can develop if, for example, a woman saddled with multiple chores in the home forgets to take her ARVs at the prescribed time. The development of drug-resistant HIV strains can negate the benefits of a prescribed treatment protocol.

Gender issues in ART provision

ARVs affect men differently from women and this needs to be taken into account in the design and administration of treatment programmes. Also, in the development of ARVs, specific needs for women have not been taken into consideration. Guidelines are not clear for the continuous use of ARVs for a woman who is pregnant or who decides to have a child, or for a woman who has chosen to breastfeed. Guidelines are also needed for the use of ARVs alongside hormonal changes in a woman during her menstrual cycle, when taking contraception and at menopause.

Service providers, for example in PMTCT programmes have been known to display discriminatory attitudes towards women taking ARV drugs. In some instances, women have been chastised for continuing to have sex and becoming pregnant in the presence of HIV infection.

Box 14: Treatment challenges for rural women

Jacinta, a 38-year-old widow, lives 120 miles from the nearest referral hospital at Lira in Northern Uganda. The only means of transport to Lira are by bicycle or in an old truck that provides a once-weekly service.

When Jacinta's daughter had a protracted illness, she had to delay taking her to hospital because she had no money. When she eventually sought treatment for her daughter, she was made to wait in the reception area while her daughter was taken into an examination room. After some time, the nurses came out of the room screaming at Jacinta and asking why she had infected her daughter with HIV.

Her daughter had developed a cancer and the hospital at Lira did not deal with such serious conditions. Jacinta was then referred to Mulago Hospital in Kampala for further treatment. This meant that she had to travel another 400 miles. Her daughter is currently being managed for HIV and cancer. While the HIV drugs are free, a fee is charged for the cancer medication. The ARVs are supplied on a monthly basis, so Jacinta must travel to Kampala every month to access her daughter's medication.

Discussion point:

- Identify the difficulties that Jacinta faces in accessing treatment.

Action points:

- As a programme officer what would you do to address the barriers?
- What is the HIV/AIDS treatment policy in your community/country?
- How would you deal with the attitude of health care workers?

Cultural practices and beliefs

Cultural and social barriers can also affect women's access to care and treatment, especially in the African context. Where culture defines women as second-class citizens, and where choices must be made about who should receive treatment, Mutapola may, willingly or unwillingly, decide that her husband should seek treatment first. Mutapola must then wait until the husband recovers and returns to work before her turn comes to seek treatment.

ART literacy

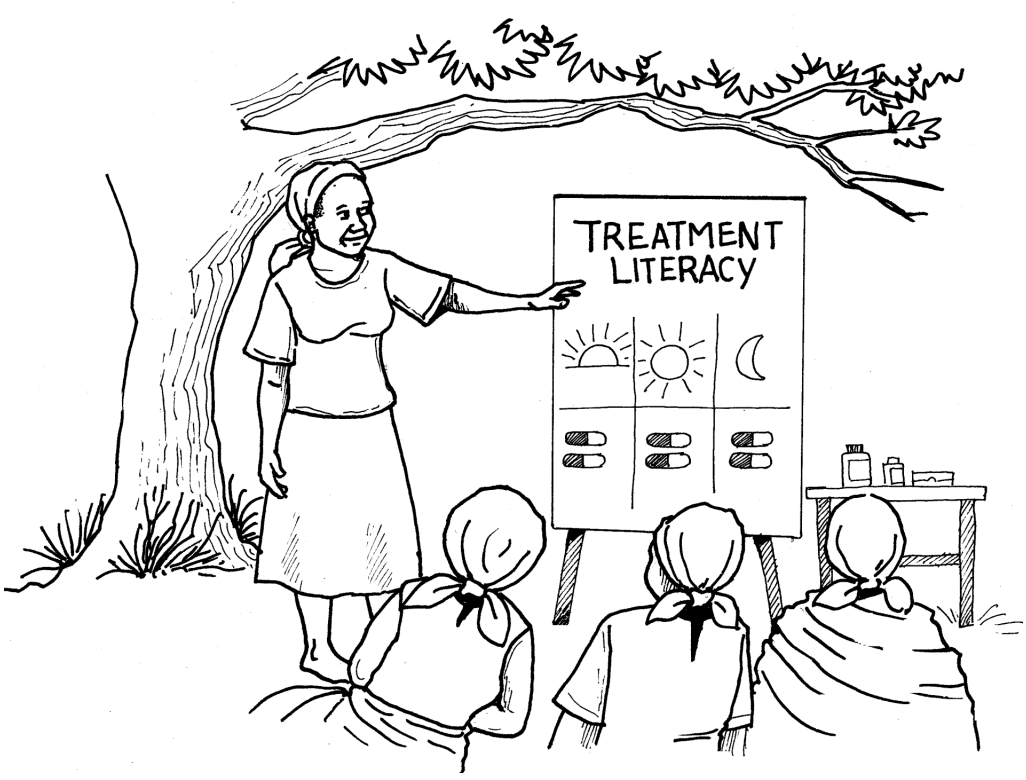
While many people clamour for ARVs, community-level preparedness – including treatment literacy – has not been adequate. For example, women are taking the drugs without knowing about their toxicity, about the importance of taking the correct dosage and at particular times, or about the consequences of stopping the therapy or not adhering to the regimen. The fact that ARVs should be taken with food poses another challenge.

Organised ART literacy programmes are urgently needed, to spell out misconceptions, benefits, accessibility and utilisation of the therapy, along with information and education on treatment of opportunistic infections. Such treatment literacy information must be designed with a view to convincing women living with HIV and AIDS (and communities at large) to avail themselves of this treatment.[16]

Fear, stigma and misinformation affect adherence to ART. Providing treatment for women and girls requires focusing on all the constraints that make it difficult for them to adhere to drug regimes. They will often require counselling to help them stay on treatment in the face of opposition and stigma. The misconception that drugs can harm the foetus may prevent Mutapola from enjoying her reproductive right to have an HIV-free baby.

Box 15: Side effects and treatment challenges

When my husband died, I did not know that he had succumbed to AIDS. It was from my little children that I learned this, after their playmates told them that their father had died of AIDS. When I heard the sad news, I was devastated. I went for an HIV test in 2004 and started treatment immediately but then stopped because of the side effects. I made up my mind to wait for death instead of taking the HIV treatment. It was when I met this organisation through the help of my pastor that I resumed treatment. Since then, I have been able to concern myself with taking care of my eight children.



[16] *Women's Treatment Literacy Toolkit*, SAFAIDS, American Jewish World Service, ActionAid International, 2005.

Responses and gaps in treatment

At international level, the Global Fund to Fight AIDS, Tuberculosis and Malaria and other multi- and bilateral donor agencies have made significant contributions to treatment needs. At regional and national levels also, there has been increasing commitment to treatment for HIV and AIDS. However, the issue of access to treatment from a women's rights perspective has not been addressed by these agencies and governments.

International context

While the Global Fund to Fight AIDS, Tuberculosis and Malaria has helped to initiate roll-out programmes, it is also suffering from donor fatigue. The aid conditionalities attached to the Fund limit its effectiveness. Other bilateral donor agencies have also contributed through various initiatives to improving access to ARVs. However, these funds may have detrimental long-term consequences for Africa because of the principles that underlie them. For example, the Presidential Emergency Programme for the AIDS Response (PEPFAR) preaches abstinence-only prevention that is not practical for women; covers the use of American-produced generic and branded drugs that are out of reach of poor Africans especially women; and has established parallel systems for patient management and drug procurement which will not be sustainable after the remaining four years support.

The World Trade Organisation (WTO) trade regimes under the Trade Related Intellectual Property Rights (TRIPS) agreement on drug patenting present a barrier to accessibility. Conditionalities including compulsory licensing and data exclusivity of intellectual property rights will continue to increase the cost of drugs and thus inhibit Mutapola's access. The breakthrough in the availability of generic drugs for HIV and AIDS treatment in Africa has been compromised by these trade barriers, and so it has become imperative that Africa produces generic drugs to improve access and ensure a sustainable supply for Mutapola.

Vaccine trials are on-going in some countries in Africa. Currently, 21 types of HIV vaccines are undergoing trials worldwide, with research biased in favour of the global North as African governments have not prioritised HIV research for funding.

African governments have, however, agreed to ambitious targets to achieve universal treatment access, as reflected in the African Common Position Paper to the UNGASS, 2006.[17] Unfortunately, this common position has not been reflected in the global political outcomes document from UNGASS 2006 that, instead, focuses on countries' national targets.

Following the controversial 3 x 5 initiative,[18] the global community has initiated another plan, this time aiming to ensure universal access to treatment for all who need it by 2010.[19] Despite global consensus on supporting and committing resources to this initiative, the road map to achieving success is still unclear. Health systems are still underdeveloped and a critical capacity and skills gap within the region limits

[17] African Common Position to the UNGASS, AU, 2006.
[18] "Treat 3 million people living with HIV/AIDS by 2005", launched by UNAIDS and WHO, 2003.
[19] Universal Access to HIV Prevention, Treatment, Care and Support by 2010.

the potential to achieve universal access. African governments are yet to explore workable alternatives for addressing obstacles that have hindered access to health care for decades. Within the Universal Access debate, women's needs are not central.

Some rich countries divert attention and focus from public health and pressure African governments to sign free trade agreements (FTAs) and economic partnership agreements, (EPAs) that are detrimental to the provision of cheap quality generic drugs for Mutapola. Unfavourable trade agreements may be the conditions for receiving resources to implement universal-access programming.

As is well documented, African health systems are failing as a result of debt-related conditionalities imposed by the International Finance Institutions – the World Bank, and the International Monetary Fund (IMF). The IMF in particular insists on restrictive social sector budgets in the name of maintaining stable macro-economic frameworks and lowering inflation rates. Among many other consequences, this translates into a lack of funding for the training and retraining of health personnel and an unrealistically low ceiling on health staff recruitment. With the current 'brain drain' from Africa, governments seek to retain their locally trained health staff but IFI conditionalities prevent the necessary salary increases. This leaves only a limited number of health care providers on the continent who are trained in HIV and AIDS drug management.

Roll-out

Many governments have instituted highly subsidised ARV roll-out programmes. Access to these programmes for women is not assured as gender equity is seldom given consideration. Nonetheless, some women, especially those living in urban centres close to the sites of ARV provision, are beneficiaries of the roll-out.

Factors limiting the reach and efficacy of roll-out programmes affect women disproportionately. Many African countries have included drugs for the management of HIV and AIDS on their national essential-drugs lists. The challenge of stock outs however still remains to be overcome. With these limits on the supply of drugs, many programmes prefer to maintain patients currently on the medication rather than register new patients.

Indicators for monitoring activities within roll-out programmes tend to be gender-blind. In most African countries, roll-out monitoring systems are not adequate to ensure compliance, retention and survival of those on treatment.

It is mainly first-line drugs that are made available at no cost; second-line alternatives are only available at prohibitive costs. As resistance continues to develop to first-line drugs, there is need to fast track second- and third-line drugs into accessible, mainstream treatment. In women particularly, the use of certain contraceptives increases resistance to some first-line ARVs. Most countries have developed strategic plans but these unfortunately do not adequately address the issue of access to treatment from a women's rights point of view. Generally ARV programmes lack sustainability components due to inadequate funding.

Some countries have established dedicated clinics to manage opportunistic infections. Access to these clinics and drugs remains a problem, particularly for Mutapola.

In 2001, African governments committed to allocating 15% of their annual budgets to health. By 2005, only two African countries had done so. Meeting this commitment will go a long to providing ARVs for Mutapolas who need it.

Some African countries, for example Zimbabwe, have established an AIDS fund, supported through a contribution of 3% of tax payers' salaries. Unfortunately, there is no gender equity in the administration of this fund and certain instances of misuse of funding have been reported.

Ministries of health in collaboration with developmental partners have developed guidelines for managing HIV and AIDS. These guidelines however, are not defined in the context of specific communities (a prerequisite if they are to be effective), nor do they address women's particular needs. The decision to have a baby while on ARVs, for example, is still a challenge for Mutapola as the guidelines are unclear about stopping or continuing with the drugs during pregnancy.

Adherence to ARVs has emerged as a significant issue in Africa. Some of the reasons for poor adherence have to do with side effects for which Mutapola is not prepared or given counselling. The drugs must be taken with food, so when Mutapola has no food, the effects of the drug are grave and she may decide to skip taking the drugs. Myths surrounding ARV therapy limit Mutapola's access, as does the belief in certain quarters that HIV can be cured by prayer.

Box 16: Child refuses ARVs

Sophie is 38 years old, a single mother of four children living in the suburbs of Kampala and HIV positive. After a long illness, her third child tested HIV positive and needed immediate ARVs as his viral load was extremely high. Although there were no free ARVs at the time, Sophie could afford to begin the child on the drugs because she had a job.

Despite the treatment, Sophie was worried because the six-year-old child continued to be ill. After psychological counselling, she discovered that the child had not been taking the drugs and had been throwing them under the bed. He complained that there were too many pills and that they were unpleasant. He said it was better to lie at the side of the road and be crushed by a passing vehicle than to take ARVs. Being a single working mother, Sophie had no time to closely monitor her child to ensure compliance with the regimen.

Discussion point
What treatment challenges are faced by Sophie as a single parent?

Action point
As a programme manager, what advice would you give to mothers of children on treatment?

Integrating traditional medicine with orthodox medicine is being seen as a priority and has enriched HIV and AIDS management in Africa where traditional health systems are well established. Inadequate research into these remedies currently poses a challenge, however, as the ideal dose and exact constituents of herbal

remedies are seldom known. Mutapola utilises these services for herself and for her family and she can be subject to exploitation.

Swaziland is one country that has recognised the importance of combating the epidemic, declaring HIV and AIDS a national emergency. The implication, ideally, is that HIV and AIDS treatment is to be prioritised in terms of budget and skills building. However, this declaration is yet to be put into practice, given the women's rights abuses that continue to be reported from that country.

Box 17: Discrimination

Hawa is a 45-year-old, disabled mother to twin boys who are still in high school. She was diagnosed HIV positive a year ago. She works in a cloth factory. Six months after getting a job in a cloth factory, she became ill. When it got worse, she visited the medical clinic at her workplace. In the course of being managed, she disclosed her HIV status to the health worker and was subsequently fired from her job.

As a follow-up to her therapy, she had to see a gynaecologist for a specific ailment. During the consultation at a hospital, Hawa disclosed her HIV status to the nurse in charge. This nurse told her that she could not be examined using the medical instruments there and shouted at Hawa because she had vaginal thrush. She asked Hawa why she was still having sex. Hawa was distressed and broke down.

Discussion points

- Which of Hawa's rights were violated in the case story?
- Do you think Hawa's disability increased her vulnerability to HIV?

Action points

- What measures would you put in place in Hawa's community to reduce stigma and discrimination in health care systems?
- What advice could you give Hawa to address her loss of a job due to her HIV status?
- What steps would you take to raise awareness in communities and the nation at large about the rights of people living with HIV and AIDS, especially those who are disabled?
- What issues could be addressed by policy in this particular case?
- What interventions does your programme have that target disabled people?

Make universal access to treatment a reality for Mutapola

To ensure universal access to treatment for Mutapolas, the following programme actions are suggested:

- Generate new knowledge about the accessibility of treatment for women and use this information to influence treatment policies.
- Improve health care services at community level by providing qualified staff and equipment.
- Train health care providers on pertinent issues, such as stigma and discrimination suffered by women living with HIV and AIDS, and recent advances in treatment.
- Support the design and implementation of effective monitoring and evaluation systems for tracking access to treatment for Mutapola.

- Generate new knowledge about the allocation of resources for women and use it to advocate for increased resources for women-focused treatment programmes such as treatment literacy.
- Generate new knowledge about use of locally available foods as nutrition supplements.
- Support treatment literacy programmes.
- Support the review or development of treatment guidelines that cover women-specific issues, for example combining ARV treatment with hormones.
- Support women's organisations, networks and coalitions to advocate for universal access to treatment for women.
- Review policies addressing the age of consent to enable young Mutapolas to access treatment services.

MODULE 4

CARE AND SUPPORT

Everyone has the right to a standard of living adequate for their health and well-being and that of their family including food, clothing, housing and medical care.
Universal Declaration of Human Rights, 1948.

Introduction

There has been a fundamental shift in the way that health is offered since the advent of HIV and AIDS. Although governments continue to bear the primary responsibility of providing their citizens' health care, donors and international financial institutions ask or insist that they scale back their public-health budgets. Communities usually bear the brunt of this shift. The burden of caring for the sick as a result of the HIV and AIDS epidemic is borne largely by women, including grandmothers and young girls, in both families and communities. Mutapola does this with none or very little support from her government or from other institutions. "We as women now carry hospitals on our heads," lamented one community caregiver.

Care in HIV and AIDS includes clinical care (such as bed bathing), psychological care (such as counselling both the ill and the bereaved), organising wills, offering spiritual solace, compassion and love.

Community-based care is undertaken largely by female volunteers who receive limited or no external support or resources. National AIDS plans seldom take women's care-giving into account, and thus it remains unpaid and therefore

undervalued in economic terms, despite the direct and hidden costs associated with this care, both in hospitals and in communities. The burden of care threatens to impoverish women and girls as they are left with little time for education, employment or other productive or income-generating activities. Nor do they have time for leisure, social activities or rest. In Zimbabwe, for instance, 61% of households taking care of orphans are headed by women, with female-headed households tending to take in more orphans per household than male-headed households.[20]

Women's subordinate status in many countries limits their access to information about HIV and AIDS. As well as making women more vulnerable to infection, this impairs their ability to deal with possible consequences of infection that require care and support such as violence and abandonment by family. In Africa, when women themselves fall sick, men usually look for female members of the extended family or older daughters to provide care for them.

The impact on Mutapola's life is immeasurable; she will give up other work outside the home, with further loss of income and independence. She may give up schooling, leading to fewer choices and independence in later life. Even more disconcerting is the fact that nobody really cares for Mutapola herself. If she is married and falls ill, she is likely to be sent back to her own people.

Objectives

The purpose of this module is to describe the different types of care that HIV and AIDS necessitate, and the types of support given at different levels. The specific objectives of the module are to:

- Highlight the importance of instituting a continuum of care;
- Acknowledge the role of women in both clinical and community-based care;
- Appreciate the issues of home-based care and its impact on women and girls, and identify sources of support;
- Spotlight and compare different models in home-based-care programming.

[20] Facing the Future Together: Zimbabwe Country Report of United Nations Secretary - General's Task Force on Women and Girls and HIV and AIDS in Southern Africa, UNAIDS 2004

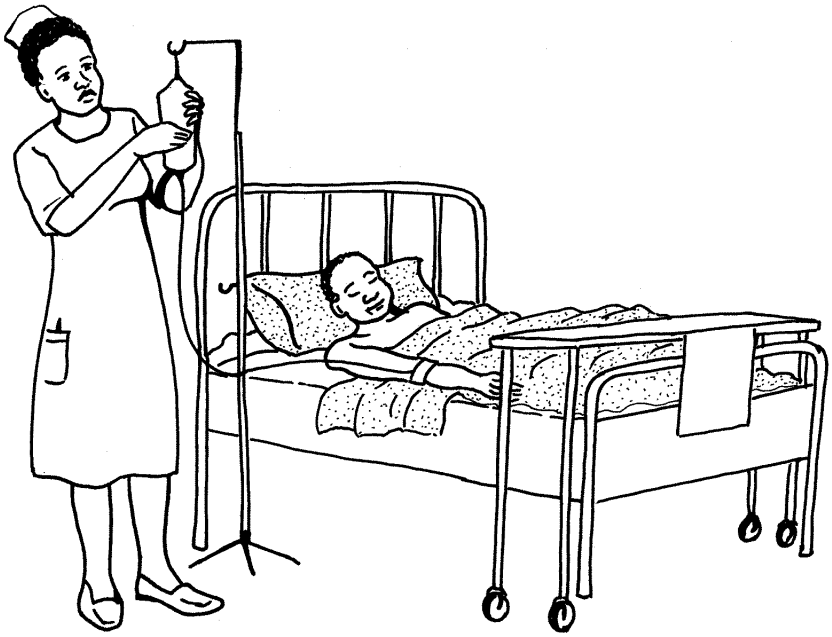
Types of care

People living with HIV and AIDS (PLWHAs) may receive care from hospitals and clinics (public or private), from community members and organisations, or from their own families. Each model has a particular impact on Mutapola's access to care for herself and the burden on her of care for others.

Model:	*Characteristics:*	*Examples:*
Community-driven	Usually, heavily dependent on volunteers who visit patients at home to provide basic nursing care and other services.	
Formal government sector	Generally operated as a collaboration between departments of health and social welfare, run at district level by a multidisciplinary team (doctors, nurses and a social worker) within the hospital structure.	South Africa
Home-based palliative care	Usually carried out by hospices, registered as non-profit organisations (NPOs). Palliative care is given to the terminally ill, to provide succour and death with dignity. Patients are admitted for a short period and, once discharged, may then link up with a home-based caregiver trained by the hospice or with private nurses.	Kenya and South Africa
Step-down palliative care	Provides strictly institutionalised care, filling the gap between hospital and community care by serving as a half-way house.	Not very common in Africa
Semi-comprehensive care	A wide variety of services for PLWHAs and their families, including medical care, counselling, health education, material and financial support. These programmes may operate as a direct extension of a hospital or with only indirect links to a hospital.	South Africa and Nigeria
Integrated community and home-based care (ICHC)	A continuum of quality care from diagnosis to death and bereavement, offered within a palliative care philosophy, with support from PLWHAs and their families, community caregivers and hospices as well as clinics and hospitals.	Not common in Africa
Comprehensive care	A full range of medical, psychological and spiritual care, provided by specific organisations, including home-based care and referrals to their own clinics for treatment of opportunistic infections, and also addressing the socio-economic conditions of affected families by providing food parcels.	Few in Africa

Clinical care

For HIV and AIDS, clinical care is provided in a hospital setting by a care management team consisting of doctors, nurses, laboratory workers, pharmacists, social workers and counsellors. Each member of the health team plays a crucial role in providing appropriate care for the client.



Clinical care may be provided in public or in private health facilities. Because health is a fundamental human right, African governments are duty bound to provide these services. While each country has a different way of managing its health care system, it is generally the case across Africa that public health facilities have limited capacity to cope with the demands made by HIV and AIDS. Donor conditionalities – in particular the privatisation of health care – have played a major part in crippling public health services on the continent. Access to public health facilities, especially for women, remains a challenge (as extensively discussed in previous modules). While some private health facilities exist to bridge the gap in provision of care, their cost limits women's access.

Problems arise in the hospital context when the attitudes of health workers undermine the dignity of PLWHAs. Since women attend health facilities more frequently than men, often for children's illnesses, they are the ones whose rights to dignity are more often violated in the clinic setting. Sometimes, they are refused medical attention outright because of their HIV status.

Care-giving takes a toll on providers too. Because of social stereotyping of roles, most nurses are women and most doctors are men. The fact that nurses are expected to provide tender loving care may also have contributed to the perception of that profession as 'womanly'. Similarly, most counsellors and social workers are women too. Managing HIV and AIDS routinely, particularly in high prevalence communities, can be extremely traumatising for these caregivers. Many get 'burnt out' from providing care but there is seldom provision for support for these categories of health staff.

HIV and AIDS services provided in the clinic are seldom linked with those provided in the community. The client is usually accompanied to the health facility by the primary care provider, in many cases a woman. The doctor then attends to the client alone.

While this is consistent with the patient's right to confidentiality about their HIV status (for disclosure, the patient's consent is necessary)it also means a lost opportunity to inform and educate the care provider about the infection. Women care providers risk HIV transmission if they do not take the requisite precautions.

Community-based care

Many home-care programmes were established by community- or faith-based organisations. Mission hospitals employ this model too, with community members as volunteers. In these programmes, Mutapola usually has no option but to take care of the sick. From a women's rights perspective, dependence on volunteerism has affected a woman's right to livelihood. Nonetheless, this remains the most widely used model in communities.

Home-based care

Home-based care (HBC) is defined by the World Health Organisation as the provision of health services by formal and informal caregivers in the home in order to promote, restore and maintain a person's maximum level of comfort, function and health, including care towards a dignified death.[21] While HBC applies to all diseases, in sub-Saharan Africa it has become almost synonymous with PLWHAs. HBC services are mainly provided by women.

HBC has many advantages. It has enabled a scaled-up HIV and AIDS response and provides patients with care in familiar environments and the opportunity to die with loved ones by their side. In addition, HBC reduces the burden on public health facilities and lowers costs such as those related to transporting the sick to and from hospitals. In the absence of adequate state resources for hospitals and medical professionals, HBC has become the primary mode of caring for the large numbers of PLWHAs.

Most PLWHAs spend the better part of their illness at home, and research suggests an increase in the number of PLWHAs being cared for at home. Public hospitals cannot cope with the burden of care and so they discharge infected patients to receive HBC instead. In some countries, for example Zimbabwe and South Africa, it is part of the government's health policy to do so.

Despite its benefits, a growing body of evidence confirms that HBC is demanding and exacts an insidious toll, particularly on Mutapola. Yet, many governments in sub-Saharan Africa continue to promote HBC, to the detriment of the livelihoods and well-being of women and girls. The advantages have been so magnified that inadequate attention is paid to the costs of such care provision to women and girls and of the burden it imposes.

Unpaid work versus the Alma Ata Declaration

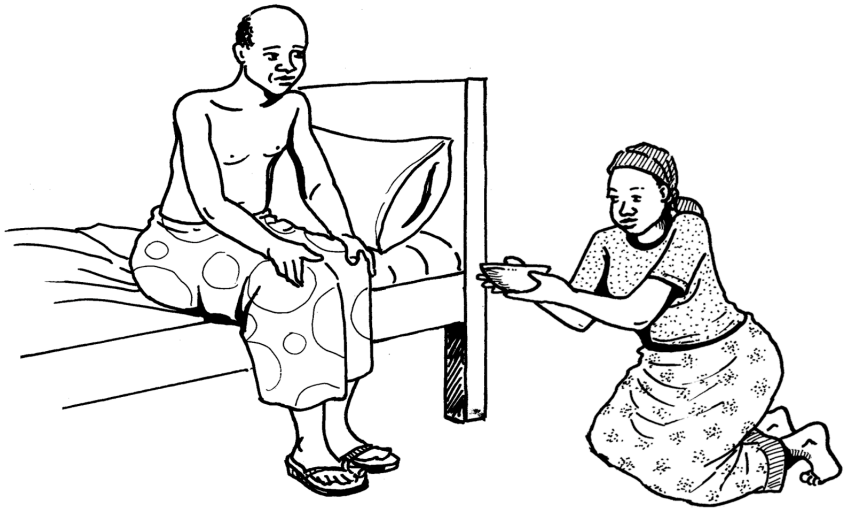
At a meeting in Alma-Ata In 1978, most countries in the world agreed to implement programmes to spread access to primary health care to communities. According to the Alma Ata Declaration, governments would train volunteers as village health workers and pay them stipends for their services. In most countries, these

[21] WHO, 2003.

programmes were functional before the advent of HIV and AIDS, but the extent of the pandemic, has necessitated increased numbers of community-level workers and volunteers.

In African societies, responsibility for the care of others lies in Mutapola's heart. She tends to put her children and husband first, eating after them or, if food is inadequate as it is in most sub-Saharan countries, she often goes without altogether. Generally, Mutapola is less educated, has less access to jobs and earns a lower income than her male counterpart.

In this context, as the AIDS pandemic has swelled, women have taken the place of the community health extension workers and village health workers as the Alma-Ata conference conceived of them, but with little or no remuneration.



Cost of HBC

Families incur increased costs as a result of caring for PLWHAs, paying directly for food, medication, water, electricity and housing, as well as the hidden costs of emotional and psychological investment in the care of the terminally ill. These are difficult to quantify.

Given Mutapolas' other household duties and their role as nurturers, the pressure on women and girls is enormous, in addition to the cost of missed opportunities for their personal development. Mutapola's involvement in home-based care needs to be meaningfully compensated.

The table shows some of the costs of HBC that is connected to institutions in Rwanda.[22] It is evident that, even within HBC programmes, the costs for actual caring (volunteers, orphans) rank lower than the costs of staff and training.

[22] Adapted from Chandler et al: *Estimating the cost of providing HBC for HIV/AIDS in Rwanda,* 2004

Table 3: Cost of institutionalised home-based care

Ranking	Score*	Rank**
Staff costs	70	1
Transport	58	2
Training	57	3
Medical supplies	55	4
Food	52	5
Capital costs	46	6
Volunteer incentives	43	7
Other family support	43	8
Orphan support	38	9
Other non capital costs	30	10

* The score index is the total addition of the cost rankings in different programmes so as to show what appears the most. **The rank depicts the hierarchy of the unit in terms of cost

Care giving is very time-consuming and in many instances caregivers have to forego other commitments. Additional costs arise in seeking traditional remedies, transport and funerals. Mutapola plays a key role in funerals, feeding the people who attend and entertaining guests for prolonged mourning periods. The loss of productive time is one of the most subtle and unacknowledged economic costs of care giving.

Box 18: Cost of care

One Tanzanian woman remarked: "This is a full-time job that keeps one busy day and night." (HelpAge International)

One primary caregiver had to scale down on the number of days that she was paid as a temporary domestic worker in order to have time to care for her ill mother. Other volunteers reported losing income from their self-employment because of care-giving activities. (Akintola 2004)

In Botswana, the majority of caregivers spent between six and more than twelve hours every day providing care. However, the cost of this time was not estimated. (Lindsey et al 2003)

A woman volunteer in a community-supported programme that feeds 33 children in Swaziland had this to say: "I don't have time to look after my home because looking after children takes all my time."

A dressmaker and mother of three volunteers for Swaziland Positive Living (SWAPOL) is a caregiver and also looks after a number of relatives with AIDS-related illnesses. She commented: "We have to give up our own work to be able to care for them (the ill people). I am a dressmaker, but I can't do my own work. I sit down to work and I'm told there is someone sick who needs care. I end up not working and losing my income."

Discussion question

- Which women's rights were violated in these cases?

Action points

- What steps would you take to restore these rights?
- Identify the issues in these cases that you think could be addressed by policy.

Risk of exposure to HIV and TB

Most volunteers receive training on precautionary measures and infection control. However, a handful report that they were at risk of being infected with HIV as a result of occasional exposure to the patient's fluids during emergencies when they do not have gloves or time to put them on. The Mutapola who takes care of her loved ones at home – especially a young Mutapola – is often ignorant of the modes of HIV and TB transmission and not trained. She is at risk of exposure and infection.

HBC training and activities

An analysis of the full extent of training required to deliver home-based care reveals an obvious lack of skill in most caregivers. Women usually practice HBC on an ad hoc basis, treating care as a traditional role. In fact, to deliver a comprehensive HBC programme requires basic information on HIV, AIDS and STIs along with skills and training in basic nursing, universal precautions, control of pain and other symptoms, palliative care, basic nutrition, bereavement counselling, stress management and writing wills.Few Mutapolas especially those in rural areas, have such knowledge but must deliver nonetheless.

The burden of care

Caring for PLWHAs can increase the workload of Mutapola significantly. A burden in any family, this is particularly onerous for the poor and not formally employed Mutapola, who already spends much of her day in subsistence activities. Women's role in the care economy intensifies their poverty and insecurity since a large proportion of an already meagre income is used to meet the costs of care. The increased workload, loss of family income and deepening poverty make women more dependent on others and exacerbate gender inequalities.

Box 19: Burden of care

In Swaziland, school enrolment is estimated to have fallen by 36% due to AIDS, with girls the most affected.

A rural woman interviewed in Lesotho estimated that it took 24 buckets of water a day, fetched by hand, to care for a family member who was dying of AIDS – water to wash the clothes, the sheets and the patient after regular bouts of diarrhoea.

In Kenya, a health-care trainer described a woman who was raising the 10 children of her late brother and sister along with six of her own. She worked as a home health-care provider, in charge of 13 patients, four of whom depended on her for their daily provisions.

Discussion point
In your community, what challenges are faced by caregivers?

Action point
As programme manager what issues in these cases do you think can be addressed by policy?

As the crisis deepens in Africa, girls are being taken out of school to provide HBC. At the same time, older women are pushed into the labour force to support their grandchildren and adult children living with AIDS. Grandmothers, aunts and cousins may be caring for orphaned children from several families. The burden is enormous on these women, who have nowhere to turn when the workload becomes overwhelming.

Conditions are most difficult for Mutapola who lives in rural areas. Many people who migrated to cities in search of work return home to their villages when they develop AIDS, to be taken care of and to die. Because most health-care facilities in the developing world are located in or near urban centres, the women in rural villages caring for AIDS patients have little moral or material support. Lacking skills, information and resources, the mother or girl child risks compassion fatigue or burn-out, which may result in depression.

The burden on volunteer caregivers may differ in some ways from that carried by family members, but volunteers too lack incentives and protective clothing, such as gloves, and experience physical stress, walking several kilometres daily to reach clients. High morbidity levels increase the emotional burden.

Box 20: My husband infected me

My late husband was infected with HIV by his third wife. He in turn infected his first wife and me. The third wife died of AIDS and was later followed by my husband and the first wife. I am the only one left with my two children - a boy and a girl - who were forcefully taken away from me by my late husband's relatives. I am now staying with my parents who are farmers. Since God has allowed me to live, I have hope that he will continue to help me even to the point that I will be gainfully employed to raise my children and also to assist others.
Ruth Calvin, Nigeria.

Sources of support

People living with and affected by HIV and AIDS benefit from emotional, spiritual, psychological, physical and material support given by the family, community, institutions and peer organisations. Sources of support can be located at different levels.

Family-level support – provided at household level by family members.

Community support – received from neighbours and other community members, especially offering care and providing compassion during funerals. Faith-based groups and community-based organisations provide emotional, psychological and spiritual support, as do other support structures in the community such as the church, schools, women's groups and the workforce.

Institutional support – mainly to provide financial and material resources to families and communities. Sources include civil society organisations, community- and faith-based organisations, support groups for PLWHA and AIDS service organisations.

National-level support – including PLWHA advocacy platforms and moral and technical assistance from national networks of PLWHA. As well as supplying material support, funding and technical assistance directly to PLWHA, government structures train for village health workers who in turn provide support through the primary health-care system.

International level support – through private-sector donations and bilateral and multilateral institutions such as the Global Fund for AIDS, TB and Malaria, and the World Bank's Multi-Country HIV/AIDS Programme (MAP). International support has also taken the form of technical assistance and of setting standards for reduction in discrimination and respect for the human rights of PLWHA.

Responses and gaps in care and support

Many African governments have embarked on training in clinical management of HIV and AIDS for doctors, nurses and laboratory workers. However, the training does not emphasise on ensuring the individual's right to a life of dignity, nor are women's issues properly addressed. The attitudes of health-care providers are a great source of concern for many PLWHA, making some health facilities unfriendly and inaccessible.

With the advent of HIV and AIDS, sensitisation of health-care providers on universal safety precautions has been taken very seriously. However, the challenge still remains to follow up such sensitisation by procuring appropriate supplies and equipment for health facilities. For example, cases have been reported of health-care providers – most of them women – having to deliver babies with their bare hands. In some instances, patients are required to provide preventive supplies, and this further increases the costs of hospital attendance. This cost is particularly noticeable for the Mutapola who needs obstetric care, as she must buy gloves, blades, rubber sheets, and bleach. Such stipulations make it impossible for many women to get health care

in hospitals and/or put hospital workers at even greater risk of exposure and infection.

As a means of standardising practice, guidelines for clinical management of HIV and AIDS emphasising the continuum of care are being developed across Africa. Gaps in implementation of the guidelines that need to be addressed include the linkage between the health facility and the home. PLWHA may not need prolonged hospital admission and so they need training and sensitisation on drug compliance, adherence and good nutritional supplementation. The home care provider must also understand the medication, while information about modes of transmission will help her protect herself from HIV infection during the course of her duties.

Recognising its importance to the infected person, HBC guidelines and manuals have been developed. However, some of these materials do not address the importance of using locally available food for nutrition. Governments have given only limited support for implementation of the guidelines. While HBC training, particularly targeting women, has been provided, more people, both men and women, need to be trained.

Some African governments have recognised the important role that community- and home-based care plays in the management of HIV and AIDS, by establishing HBC departments in their ministries of health. The terms of reference for such departments are unclear and the methods of supporting heroic HBC providers are questionable. For example, in some countries, the identified care providers are trained for one day, given buckets and gloves and then directed to rows of houses to perform some household duties. These care providers are mainly women, many of whom have to walk long distances to perform these chores as volunteers, and may or may not be given a stipend.

Many African countries have supported training for counsellors. However, to deal with the psychological and mental consequences of HIV and AIDS, psychologists must be included to provide psychological counselling in the management of HIV and AIDS at community level.

Due to several reasons ranging from discrimination to stigma and economic difficulties, the traditional African support structure is now being eroded. Many families are unable to provide support for PLWHA and children orphaned by AIDS.

Palliative care is an important part of care in HIV and AIDS. While NGOs and private hospitals have begun to provide this type of care for the terminally ill, few governments have so far.

In some countries, organisations working on HBC initiatives meet regularly to deliberate on the services provided. These meetings however do not involve the primary care provider, Mutapola, who also needs care and counselling. Most HBC initiatives are implemented by NGOs and FBOs; governments need to play a coordinating role and ensure minimum standards, including the provision of care and support for Mutapola.

Support in the form of income generation activities (IGA) and microcredit may actually add to Mutapola's burden, rather than relieving it, if she has no time to invest in the IGA to repay the loan, because most of her time is spent providing care. There is a need to develop effective economic empowerment strategies that are informed by women's burden in providing care.

Governments need to adopt a holistic and coordinated approach to care and support involving linkages of relevant service providers and sectors. For example, ministries of agriculture, health, local government, education, water and sanitation, social welfare and finance can all have roles in home based care.

Reduce the burden of care

- To reduce the burdens of care global institutions, national governments and NGOs dealing with HIV and AIDS should mount vigorous campaigns: Research and document the impact of home-based/women-based care on the lives and rights of women.
- Design care programmes for women in their own right, offering a continuum of care that takes into account the burden of care that women bear.
- Provide training for all carers in the community, with proper career paths for young girls so they can use these skills and experiences as the basis for earning a living later in life.
- Provide stipends and some form of remuneration for many women who volunteer as caregivers, so that their livelihoods are not affected. Initiate programmes to remunerate Mutapola for participation in advocacy and pilot programmes and to relieve her of HBC. Scale up good practices.
- Review HBC programmes run by institutions like NGOs, to ensure that they recognise and work to reduce the burden that women bear.
- Advocate for policies that promote girls' education and retention in schools, as well as sharing care responsibilities between boys and girls.
- Advocate for governments to take back their responsibility to provide health care for their citizens, including a continuum of care when someone is discharged.
- Participate in and support campaigns and advocacy for international financial institutions to stop putting pressure on African governments to reduce public health expenditure (for example, pressure to privatise public goods such as health care, education and water).
- Conduct research into alternative, women-friendly models of HBC.
- Advocate for provision of psychosocial support for Mutapolas who provide care.
- Implement training to increase caregivers' knowledge about HIV, to reduce their risk of exposure and help them better execute their duties.
- Advocate for and promote male involvement in HBC provision.
- Advocate for increased funding by national governments for HBC initiatives, to cover, for example, remuneration for Mutapola and labour-saving technologies.
- Conduct research into innovative economic empowerment models that would address limitations of traditional income-generating activities.

MODULE 5

HIV AND AIDS AND SUSTAINABLE LIVELIHOODS

"Throughout the region, people are walking a thin tightrope between life and death. The combination of widespread hunger, chronic poverty and the HIV/ AIDS pandemic is devastating and may soon lead to a catastrophe. Policy failures and mismanagement have only exacerbated an already serious situation."
James Morris, World Food Programme's Executive Director, July 2002

Introduction

While the need to mitigate the effects of HIV and AIDS is increasingly acknowledged, it is equally important to recognise that food and livelihood security are key elements of prevention. Livelihood insecurity often pushes people into behaviours and strategies that increase their risk of infection, such as migration and sex work. To make matters worse for Mutapola, various systems deny her the right to own and control productive resources such as land and limit her access to food – especially troubling when she is on TB or antiretroviral treatment. Everyone involved in responses to HIV and AIDS needs to take a fresh look at sustainable livelihood issues.

Access to and control over productive resources including land are critical if Mutapola is to sustain her life and that of her family through non-risky means. With HIV infection, it is the lack of a sustainable means of income to meet basic needs that becomes the immediate issue of concern.

The burden for HIV-positive women is doubled since they have to take care of themselves at the same time serving as the primary care providers for other members in the household. Care of children orphaned by HIV disproportionately rests on the shoulders of female relatives, including widows, grandmothers, and paternal and maternal aunties, according to a study by UN-HABITAT[23] on the situation of orphans and other vulnerable children in selected slums in Kenya, Tanzania, Uganda and Swaziland. Improving livelihoods, especially of the most vulnerable groups in society, can provide a concrete way to tackle one of the most fundamental issues behind the spread of HIV.

Objectives

The purpose of this module is to provide information on sustainable livelihoods for women and girls living with and affected by HIV and AIDS. Specific objectives of the module are to:

- Establish how food security, nutrition and livelihoods are linked wjth HIV and AIDS;
- Highlight livelihood challenges presented by the burden of care for orphans;

[23] 2004, unpublished

- Bring to the fore property issues such as land and inheritance for women and girls living with and affected by HIV and AIDS;
- Stimulate discussion and recommend actions on a variety of ways, including skills development, to empower women and girls economically.

Food security

HIV and AIDS threaten food security, which relies on women as major contributors to the agricultural workforce. With women's decreasing agricultural productivity, food security at the household and community levels is seriously threatened. Additionally, inter-generational knowledge, specialised skills, practices and customs of indigenous farming are lost, but few governments are making any effort to give women appropriate technologies in their place. HIV and AIDS undermine the sustainability of the agricultural sector, and leave a bleak future to HIV positive women that can no longer survive as they used to. For example, the Food and Agricultural Organisation (FAO) reports that over the past five years, the agricultural output of women in Zimbabwe's communal areas has halved, largely due to AIDS.

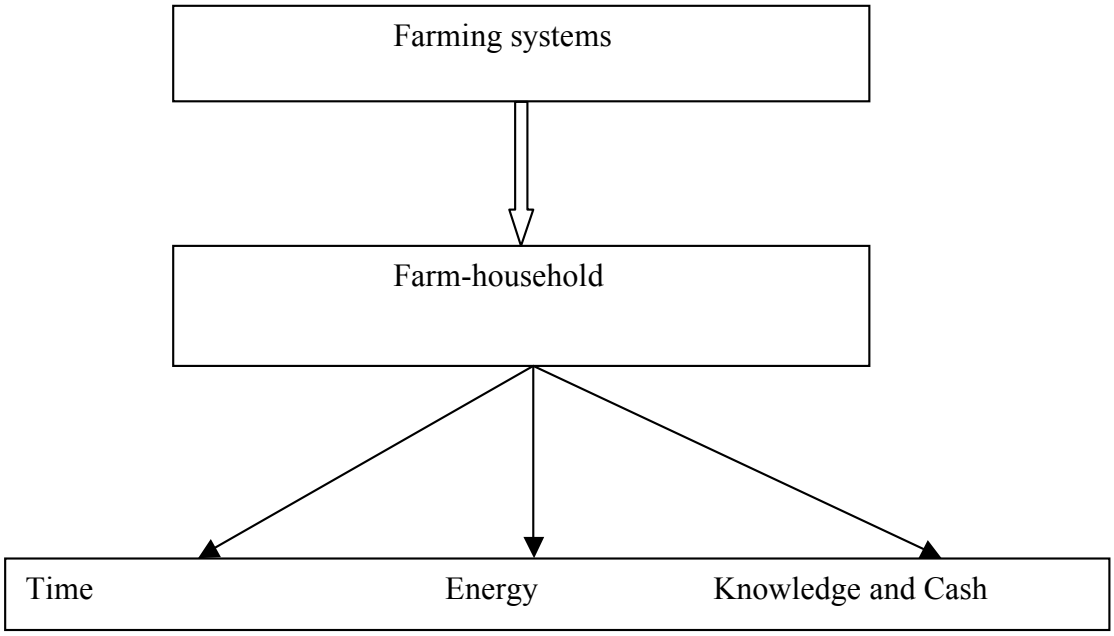
The aspect that is most devastating to agricultural production is the diversion of available labour to caring for people who stay ill for long periods of time. As a result, many farmers switch to less labour-intensive crops. In many cases, this means switching from export to food crops.

A woman living with HIV needs nutritious food, particularly when she is on ART, as do family members. While HIV infection and disease increase the urgent need for

proper nutrition, Mutapola lacks information about the nutrition necessary for PLWHA, and about the types of food that provide them. Then, too, certain cultures have eating taboos against, for example, eggs, chicken or pork, which deprive Mutapola of nutrients. As women in sub-Saharan Africa are generally less educated and have less access to jobs and lower incomes than men, they are unable to buy food items to meet their nutrition needs. This, coupled with systems that deny them the right to own and control productive resources such as land, means that women's access to food is limited and their right to food is compromised. Mutapola is entitled to increased availability, accessibility and proper utilisation of food.

Agricultural practices and systems should also take into account the special needs of women and children in the face of HIV and AIDS. For Mutapola living with HIV and for those who are primary care providers, it is important to promote less labour-intensive technologies and more women-sensitive extension services. In crisis situations of food shortages, women living with HIV should be involved in planning food aid as well as being properly targeted to receive supplies.

Among the loan conditions imposed by international financial institutions is the privatisation of institutions that provide food to rural Mutapolas. As a result, prices of previously cheap foodstuff have become inflated and out of reach for Mutapola.



Suggested areas of intervention for labour saving in food production

Here, the importance of the farm household cannot be over-emphasised. When its members can no longer cope with the impact of HIV and AIDS, they do not have the required time or energy to do the tasks necessary for the continuation of the unit or to ensure minimum food security.

Livelihood challenges in orphan care

Throughout Africa, as more people die from the effects of AIDS, the socioeconomic role of women and girls changes. Those who are already poor fall even further down the economic ladder and tend to lose hope. Much of the increased poverty in these households is directly related to care giving responsibilities. Some AIDS orphans become heads of households and are forced to make choices in order to sustain their siblings. The burden generally falls on girls, many of whom drop out of school to provide care. In Zambia for example, a study revealed that there were twice as many female- as male-headed households caring for children who had lost both parents. In addition, female heads of household had taken on the responsibility for more orphans than male heads.

Anecdotal evidence confirms the drop in family income as a result of HIV and AIDS. In traditional African society, families taking over and care for orphans. As the numbers of orphans have risen in the face of HIV and AIDS, meaning more mouths to feed, there is a drop of income per capita at household level. Unfortunately, the interlinkages between the increase of HIV and AIDS-related mortality, farm labour shortages, and the breakdown of the household economy lead to a collapse of traditional structures and coping mechanisms. For example, in most affected countries, elderly women are compelled to assume the responsibility of caring for grandchildren when the parents died with AIDS. Deprived of economic resources and support, impaired by poor health, and unprepared to assume such a role in the family, the elderly women experience tremendous difficulty in carrying out these new obligations.

Box 21: A girl-orphan-headed household

Monica Kyalo, aged 17, lives in the Soweto slums, in Kenya. Her mother, Jeniffer Kyalo, a single parent, succumbed to AIDS-related complications and died in 2002. Monica takes care of six younger siblings aged between three and fifteen.

Monica and the three-year-old sleep on the small bed while the others sleep on the floor of their tiny one-roomed mud-walled house. Monica starts her day at 6.00 am when she goes in search of water, often about 2kms from home. She asks the other children to sleep on the bed while she cleans the room.

Since toilets are far away and the children are afraid in the increasingly violent Soweto slums, the family relieve themselves using 'flying toilets' – plastic containers and bags. In the morning, Monica empties the containers, sweeps the room, washes utensils and then prepares all children for school.

When the others leave for school, Monica ties the three-year old baby onto her back in her old 'lesso' for the journey to the nearest rich estates of Komarock, Buruburu and Umoja to look for casual jobs. Monica carries a plastic bottle of white porridge to feed the baby but she does not know, when she leaves home, what she and the other children will eat in the evening.

At every door she knocks on, Monica asks the same question: "Do you need somebody to wash your clothes?" When lucky, she gets a heap of dirty clothes that takes her almost the whole day to wash. She looks for a place for the baby to sit, with a big smile on her face, as this heap of clothes assures her of a meal for the rest of the family on the particular day. She takes a few minutes' break to feed the baby on porridge. After all this work, Monica is paid Kshs 100.00, the equivalent of 1.3 USD. On her way back to Soweto, she buys a kilogram of maize flour, cooking fat, onions, paraffin, and soap. This is how life goes on, and when she doesn't get any washing work, they go without food.

Discussion point
What livelihood challenges does Monica face?

Action point
As programme manager, what assistance would you recommend be given to Monica?

Property issues

The realisation of her rights to inheritance and to equitable access to land is empowering for Mutapola because it enables her to meet her material, emotional and psychological needs. Land in Africa continues to be a crucial source of livelihood for women. However, a complex mix of cultural, legal and social factors violates women's property rights. In many countries, customary laws – largely unwritten but influential local norms that coexist with formal laws – were based on patriarchal traditions in which only men were entitled to inherit and to control land and other property. Women were 'protected' but had fewer rights to property.

A common excuse given by men in defence of their role in property inheritance is that, women needed male protection, were untrustworthy and incapable of handling property. The guise of male 'protection' does not obscure the fact that stripping women of their property is a way of asserting control over their autonomy, bodies and labour – and enriches their 'protectors' at the same time.

Traditional customs permeate contemporary practices that deprive women of property rights and silence them when those rights are infringed. Constitutional provisions in most African countries prohibit discrimination on the basis of sex but undermine this protection by condoning discrimination under customary laws. The few statutes that could advance women's property rights defer to religious and customary property laws that privilege men over women. Similarly, most African countries have laws that prescribe non-discrimination in land use transfer, administration and control. Nevertheless, mechanisms to address social and cultural constraints have not been put in place. Instead, culture and tradition sometimes influences the design and implementation of statutory laws. For example, few countries provide for co-registration of land in the event of an allocation or redistribution. Instead, land is usually registered in the husband's name, as he is always assumed to be the head of the household.

Box 22: Land to cultivate

When [a particular woman] became ill from AIDS-related diseases in 1998, she was chased away by her husband who refused to give her support. All the land was in his name. "I was shattered. My hopes and dreams had come to an end," she says. "I thought I was going to die and leave my children alone."

With the help of the Network, however, she learned about laws and practices governing women's rights to own land, as well as how to work around them. With newfound confidence she approached her village chief who gave her a plot of land to cultivate. She was able to purchase seed through the Network's revolving fund and her new life began. She later took on the role of advising women in similar predicaments.

"I would not want to see other women go through the difficulties I experienced because of ignorance," she says. "If I had known that I had my own rights, even though I was married, I would not have ended up HIV-positive. What women need is peace of mind and a piece of land to cultivate and to be equal to men."
Nyaradzo Makambanga , Network of Zimbabwean Positive Women

Economic empowerment

Poverty and gender discrimination have turned a devastating disease into a social and economic crisis. For many disadvantaged women and girls, transactional sex is one of the few options available to them for survival. Mainstreaming HIV and AIDS education into skills development programmes for women could help Mutapola to access wage-earning opportunities, thus reducing economic dependence. Support for livelihood activities for Mutapola, including micro-financing, can increase Mutapola's income. Unfortunately, many Mutapolas do not have access to micro-finance services. There have been incidents where women with HIV were expelled from credit schemes for fear they would not pay their debts. Increasing economic empowerment of women and girls affected and infected by HIV is vital for their survival and attainment of quality life. Mutapola should have all possible options and information on opportunities and support services.

For instance, a clinic in South Africa offers HIV-positive people income-generation training and marketing assistance in bead craft. The clinic also supports a choir, which raises funds for drugs through the sale of music CDs. A Nigeria non-governmental organisation that offers care and support to people living with HIV and AIDS also conducts training for women in income-generating ventures such as soap making, cooking and fabric production. In Zambia, a drop-in centre and Care Club for commercial sex workers has established links to the Department of Social Welfare, which offers support for education – an ideal mechanism for helping women move out of sex work.

Responses and gaps in linking HIV and AIDS with livelihood security

The adoption and implementation of the Protocol to the African Charter on Women's Rights is a milestone for the protection of property rights for women. The protocol explicitly emphasises property rights of women in many of its articles. However, the process of ratification and domestication needs to be accelerated. By 2006, only 17 African countries had ratified it and none of these had taken any visible action to ensure its implementation.

Women's rights organisations are working to enhance access to justice for women. Their awareness-raising programmes equip victimised women to claim their rights and seek justice for violations. Nevertheless, the magnitude of injustice around these issues is overwhelming, and few such organisations receive any support from governments.

Some countries have provided legal prescriptions that deal with the rights of people living with HIV from a women's rights perspective. However, such laws are not popularised and so awareness is limited at all levels. The local government level in particular seems immune from such provisions. It is time that local government officials are held accountable as regards women's rights.

Many African countries have designed strategies for food security and agricultural sector reform. However, these steps have not benefited landless women. Those women who are land holders commonly lack oxen and other farm implements to fully utilise the land.

Legal reforms pertaining to land administration and use in some African countries have resulted in the recognition of property and land inheritance rights for women. However, the laws have not yet been translated into practice.

Responses to HIV and AIDS food insecurity are being addressed at international level with food aid. However, food distribution protocols do not consider the needs of women living with HIV and AIDS.

Development, relief and rehabilitation initiatives for people living with HIV and AIDS do exist in some African countries. However, policies should encourage and be influenced by local implementation.

Labour management through labour-saving technologies, for example drip irrigation in Zimbabwe, has reduced the demand for intensive labour. Some NGOs, for example in Zambia, support nutrition gardens cultivated by those Mutapolas who are still strong, for the benefit of all including those who are too ill to work. This approach should also be scaled up, shared and adopted as best practice.

Box 23: Left with no parents

Purdina is the elder daughter of Rosa and Rodolfo. She is 12 years old and lives with her two younger brothers in Mocuba District, Zambesia Province, Mozambique. Her father, a primary school teacher, left the family home for a year to attend a teacher training course in Quelimane. During his absence, Purdina and her mother worked in the field, after which Purdina would go to school. Her dream was to do a professional course that would land her a job. When her father came back he was HIV positive and ill with tuberculosis. He died shortly afterwards.

Although Purdina and her mother put all their effort into their plot of land, they produced very little because of drought. Rosa also became sick and was soon too ill to continue working on the plot. Purdina had to plough the fields on her own and take care of her mother as well. As a result she could not attend school. Purdina asked a former colleague of her father's for help, as she still hoped to further her education and classes were only available away from the home. The father's colleague took advantage of her vulnerability and promised to help as long as she agreed to become his second wife. This was the only way to help her mother and to take care of her younger brothers.

Discussion points

- Which of Purdina's rights were violated in this case?
- What are the gender issues in the case study?
- What specific sustainable livelihood options are available for the Purdina in your areas of operation?
- In your community, what policies and strategies address sustainable livelihood issues related to women heads of households and orphans?

Action points

- How best could you help a Purdina in your community, to enable her to enjoy her rights and make her less vulnerable to HIV?

Box 24: Traditional customs and official laws

"Ugandan women have almost the same rights as men according to the law books but in reality, tradition rules," says Winnie Sekaddie of Legal Aid Organisation for Women in Uganda. "It means, for example, they have no right to property and income." The HIV and AIDS epidemic has presented Legal Aid Organisation with a growing number of cases regarding property and succession rights, although maintenance money remains the biggest issue. "Women get into trouble when their husbands die because of the gap between traditional customs and the official laws. Women in rural areas are not aware of written laws. Even if they are, the pressure to comply with tradition is enormous." In short, women do not even know their rights.

According to traditional custom, when a woman marries, her father receives a bride price from her husband. She then belongs to her husband's clan. She must take care of his household and work his land; any earnings go to the husband. "Women are economically and socially completely dependent on their husbands. If a man dies, she loses everything to the clan, even the custody of her children."

According to written laws in Uganda, women have a right to their own income and small inheritance. In practice, women almost never get this. The amount is divided if the man has more than one wife, which is common in Uganda. Other family members can also claim possessions. In case of doubt, judges may also fall back on customary laws, often to the detriment of the woman's claim.

Discussion points

- Identify the gender issues in the case story.
- Identify the human rights violations in this case.
- What are the conflicts between culture and women's human rights in this case? How do these compare with the situation in your communities?

Action points

- If you were the legal practitioner working with Ugandan women, being sensitive to women's rights, how would you assist the women so that they are not victims of circumstances surrounding them?
- Reflect on the case story and identify from your own society or experience some of the cultural practices that fuel the spread of HIV and AIDS. Discuss what is good or bad about the practices.

Which issues in this case can be addressed through policy?

Source: Facing the Challenges of HIV and AIDS, STDs and Gender-Based Responses, KIT, SAFAIDS and WHO, 1995.

Ensure a sustainable livelihood for Mutapola

For Mutapola to be empowered to claim her rights to a sustainable livelihood – such as the right to own property including land – a wide range of actions need to be taken:

- Train Mutapola in intensified farming or improved farming technologies to maximise yield and profits from her effort and land.
- Promote the provision of appropriate seeds and labour-saving technologies to reduce Mutapola's burden.
- Promote customary systems that are beneficial to Mutapola.
- Encourage and protect common-property arrangements between spouses that benefit the wife.

- Address constraints to women's access to and control over land under both customary and statutory tenure.
- Increase Mutapola's awareness of issues related to her rights to ownership of property including land.
- Encourage broad-based participation, especially that of Mutapola, in land tenure reform moves, in order to enhance equitable and sustainable livelihood.
- Take action to empower women and girls economically, including providing skills development and micro-financing.
- Advocate for the development and implementation of women-responsive sustainable livelihood policies within, for example, the agriculture, health, education and labour sectors.
- Promote the integration of services at community level with Mutapola's meaningful involvement.
- Increase Mutapola's awareness and knowledge of the production and utilisation of nutritious foods to meet dietary requirements in the face of HIV and AIDS.
- Support programmes that enhance girls' rights to and in education as well as skills development.
- Conduct and analyse research to determine appropriate livelihood support for Mutapola, especially where she is providing care, to reduce the burden she carries.

MODULE 6

POLICY AND ADVOCACY

"We must have HIV and AIDS programmes, but not only that. There must be programmes in all other development areas which address equality, autonomy, encouraging girls and women to be independent and that must be extended to the political arena and every aspect of life."
Nafis Sadik, UN Special Envoy to the Secretary General on HIV/AIDS for Asia and the Pacific.

"It is critically important to be an advocate for your own health and health care. If you feel that you might be receiving less than optimal care, you should take the initiative to speak up and ask for what you believe you need."
Valerie Stone: "Women, Access and Adherence to HAART: A Vital Connection"
http://www.sfaf.org/treatment/beta/b43women_access 2006

Introduction

Advocacy work – targeting policy- and decision-makers (formal or informal) with the aim of changing policy, norms, customs and practices – can be a process of mobilising people and adding women's voice. In its widest definition, policy can be understood as a set of written or unwritten norms and guidelines that shape behaviour, attitudes and actions within a particular entity or social system.

The increasing demand for the enjoyment and exercise of rights for African women requires new leadership, governance and decision-making approaches. Advocacy plays a major role in bringing about change for Mutapola. Strong and progressive advocacy skills are required to change policies, programmes and resource management for the well-being of Mutapola. Customary and traditional norms that seek to deprive women and girls of their rights can also be the target for advocacy. Women in Africa have neither decision-making voice nor access to mechanisms and political platforms to speak on issues that concern them. In the context of HIV and AIDS, the voices of women are heard inadequately or not at all, and policy-makers do not respond. Others speak *for* women on HIV and AIDS issues and often they are misrepresented and wrongly quoted. In many forums, the few women at decision-making level are mere window-dressing appointments and do not represent the concerns of Mutapola. Organisations of and by Mutapola still do not adequately address fundamental rights issues. Many organisations simply do not have the technical capacity or the political orientation.

Women comprise half the global population, yet their voices – particularly those of women living with HIV – are too seldom heard.[24] Critical to turning the tide is the governmental acknowledgement and political commitment at the highest levels to national and international action. Many governments remain slow to acknowledge

[24] "Mores seats at the table for women" in *Keeping the promise: An agenda for action on women and AIDS*, the Global Coalition and UNAIDS, 2006.

and respond with appropriate measures. To combat the AIDS pandemic takes strong leadership, working with international institutions, NGOs and civil society to share specialised skills. These are some of the key directions for advocates for Mutapola.

Objectives

This module underlines the policy and advocacy issues pertaining to women in the context of HIV and AIDS. Specific objectives of the module are to:

- Highlight the advocacy issues around HIV and AIDS from a women's rights perspective;
- Provide information on various strategies including people-centred advocacy;
- Outline the steps involved in carrying out advocacy work;
- Identify responses at national and international level that address policy and legislative gaps;
- Identify action points to support local-level people-centred advocacy

The right to justice

The state is governed by three arms: the executive, the legislature and the judiciary. The judiciary is primarily responsible for the enforcement of rights. However, in most circumstances in Africa this arm is marginalised, under-financed and closely tied to the executive. Judges may be ill trained, estranged from progressive human rights instruments, insensitive to women's rights issues or corrupt. Law enforcement officers suffer from similar limitations.

Justice systems in most African countries are unfriendly to Mutapola, especially to the rural, poor, uneducated and vulnerable Mutapola. Cases brought to the judicial system may take a long time to be heard and decided, which is problematic for a woman with limited resources, knowledge and capacity. Discouraged by the justice system, Mutapola is likely to resort to traditional mediation systems of justice. These systems are generally patriarchal and settle a case by compromising Mutapola's interests and rights. Other women turn for mediation to religious institutions, which are equally embedded in patriarchy and likely to offer impractical solutions or favour men. This leaves the many Mutapolas who seek no remedy and suffer in silence, often ignorant of their rights.

Women's representation in decision making

Women constitute 50% or more of the population. As they comprise most of the voters, they choose who will represent them in the legislative or law-making arm of the government. However, women seldom use their voting power meaningfully by electing other women and those men who are likely to take up issues of concern to women. The few women that are elected into power are generally not well equipped to push women's rights issues onto the agenda, let alone HIV issues.

In the executive arm of government, representation across Africa remains abysmally low. At times, women are given positions in the ministries of gender or women just because they are female. In the private sector, executive leadership positions are traditionally taken by men, who seldom represent women's workplace issues in the context of HIV and AIDS. Even in organisations that purport to represent Mutapola, such as networks of PLWHA, leadership positions are usually taken by men while

the membership draws heavily on women. As a result, resource allocation is usually skewed against women's interests.

In traditional systems, including religious institutions, leadership roles are usually reserved for men. This further marginalises women's voices in decision-making. Influencing such systems positively to involve women in the leadership arena is critical.

Violence against women

The law can be a powerful tool for protecting women and girls and reducing their risk of HIV infection. But the law is just one step. It is equally important to challenge the social norms that undermine women's rights and to expand legal services for women. Greater efforts to make laws work for women, particularly in the areas of gender-based violence and property and inheritance rights, could dramatically strengthen the AIDS response.[25]

Violence against women (VAW) is widespread in all regions and includes verbal violence that results in emotional scarring, common in marital relationships. Physical violence can be found in marriages and schools and on the streets, while sexual violence increasingly targets younger girls. Manifestations of violence include any form of violation of women's rights such as harmful traditional practices, rape, abduction, trafficking and lack of education for girls.

Due to gender biases in the justice system, the Mutapola victimised by violence rarely claims her rights. Psychosocial support systems for victims of violence do not exist or are irrelevant to the needs of the abused Mutapola. There is also a lack of coordination between the different institutions that need to address consequences of abuse in a holistic manner.

Box 25: Women's rights consistently violated

A 14-year-old girl was repeatedly raped by her father in Ethiopia. The case went to court and the father was sentenced to 10 years in prison. However, on appeal the lower court's judgment was reversed and the perpetrator was acquitted. In pursuance of justice, the prosecutor appealed to the Supreme Court which passed 17 years of imprisonment, to no avail as the man had already disappeared.

A 34-year-old woman who had been HIV infected for five years was dismissed from work because of her status. She took the case to court. When the judge realised that the woman was HIV positive, he threw her out of the court room, for fear that she would infect others including himself.

[25] "Secure women's rights" in *Keeping the promise*.

Women's rights in conflict situations

The rule of law is virtually nonexistent in situations of conflict, while violence is used as a weapon of war, often against women.

Box 26: Stigma and fear

In one survey of 1,125 women who had survived rape during the Rwanda genocide, 70% tested HIV positive. Now, an NGO devotes a substantial amount of time and resources to helping women get medical support for opportunistic diseases and provides counselling to prepare families for the ravages of HIV.

"They have such courage," said an officer of the NGO. "The women have challenged everybody and everything. It is the challenge of life over death."

In Uganda, despite the openness around HIV and AIDS, the stigma of AIDS remains. The fear of violence prevents many women from seeking and gaining access to HIV testing, information and other services. Some women attend HIV and AIDS clinics in secret, and are afraid to discuss HIV and AIDS with their husbands, even when they suspect that the men are HIV-positive and the source of their own infection.

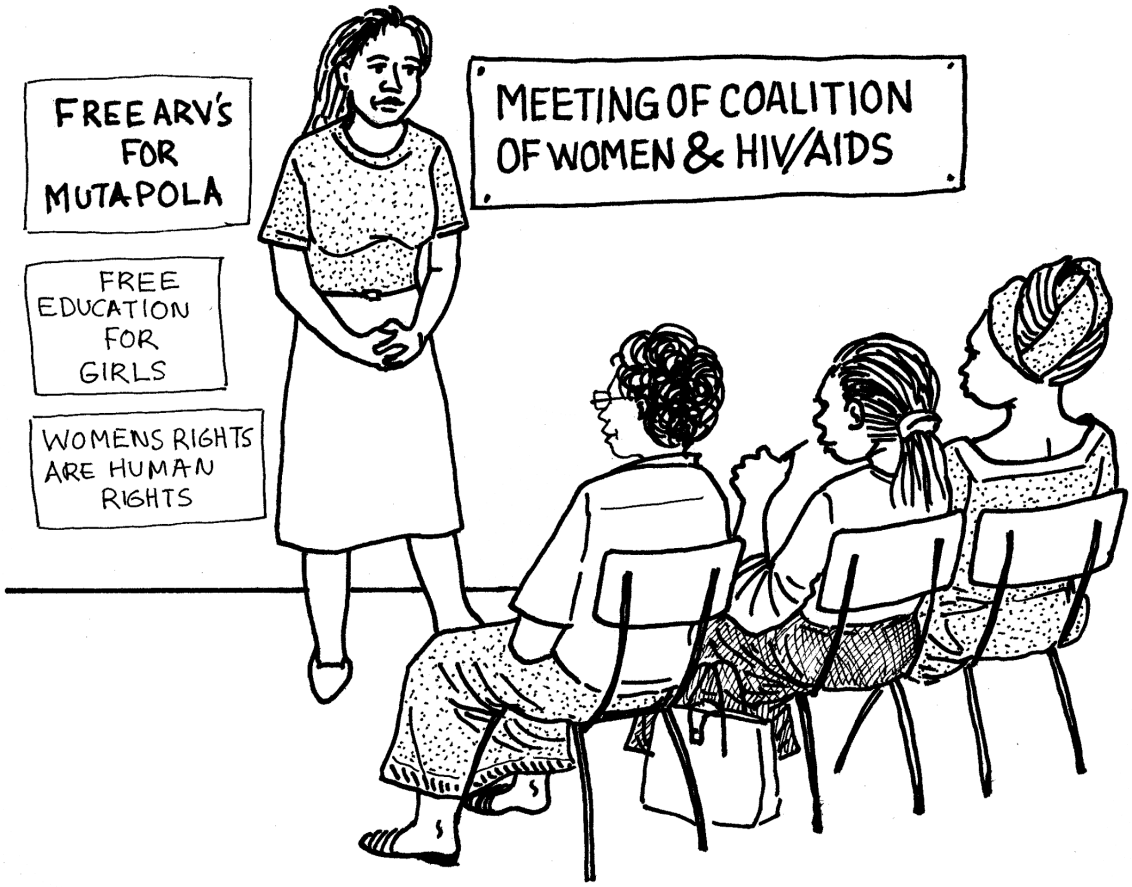
Advocacy platforms and capacity for Mutapola

Women with HIV can be their own best advocates. In cases where Mutapola knows the issues that she should advocate for, she may not know how to push for them. Identifying platforms for advocacy, for example, may be a problem. Media may be a tool limited to a few, especially if a country has repressive media laws. With limited resources, going for meetings is a mammoth task. In some countries, one has to start from scratch to create these platforms.

Most Mutapolas lack the capacity for advocacy and need to gain knowledge about advocacy issues as well as the skills to conduct advocacy work.

Organisations, networks, alliances

Advocacy relies for its power on the people who support the goal for change. Especially where democracy and advocacy are new, a phenomenon involving large numbers of people representing diverse interests can provide safety for advocacy as well as build political support. It is important for members to know who to invite to join the cause and who could be an ally.



Across Africa, very few Mutapola organisations exist. They are non-existent in many countries. While organisations of PLWHA are proliferating, with women members the majority, issues pertinent to Mutapola are not brought to the fore by male office-bearers. Because Mutapolas are best placed to advocate for themselves, Mutapola organisations are urgently needed.

In accordance with the principles of Greater Involvement of People Living with HIV and AIDS (GIPA), many PLWHA have been involved in advocacy initiatives. But it is usually executives of PLWHA organisations, who are mostly men, who select participants for leadership training. Thus, few Mutapolas have been able to benefit from such training. The formation of Mutapola organisations will greatly enhance the opportunities for women living with HIV and AIDS to be trained.

The alliances and networks of PLWHA formed in many parts of Africa often advocate for generic HIV issues, ignoring women-specific issues. They tend to be challenged by 'founder syndrome' and by selfish agendas to meet short-term gains, and work in isolation from other networks and alliances. In some countries, women living with HIV and AIDS are beginning to organise into networks. While this is desirable in many ways, challenges in human capacity and financial resources are emerging.

Organisations that try to support women's programmes are still marginal, small and seriously lacking in various capacities and resources. In some instances, PLWHAs, HIV and AIDS activists and practitioners come together to form loose coalitions to advocate for an issue of concern. These initiatives are, unfortunately, not sustainable as they are short lived and lack a proper institutional structure and financial resources. As a result, they are not taken seriously; policy-makers dismiss them.

Mainstream women's rights organisations have made giant strides in advocating for the protection of rights for women. They have, however, shied away from involving women living with HIV or HIV issues for women in their agendas. In order to amplify women's voices it is important for a coalition of mainstream women's rights organisations and women HIV and AIDS activists to work together for more effective results. Working through alliances or coalitions of women living with and affected by HIV and AIDS helps reduce stigma.

Box 25: Tilla – a Mutapola organisation

Tilla, the Ethiopian association of women living with HIV and AIDS, started with a small group struggling to raise funding from reluctant donors. Tilla emerged, was nurtured with support from AAI, has grown in capacity and ability and is now a recognised and respected civil society organisation supported by several donors. 'Tilla' is an Amharic word literally meaning 'umbrella' and figuratively denotes something that provides protection.

A founding member tells how it began: "We started with five women living with the virus and no donor was interested in supporting us. With AAI support, we started educating the public, mainly women and girls, on HIV and AIDS and provided home-based care for bed ridden people living with AIDS." The founding member and executive director of Tilla ran for parliament in the 2005 national elections. While she didn't secure a seat, she did demonstrate that being infected with HIV should not be an obstacle to aspiring for political office. She succeeded in placing the issues of women and HIV and AIDS on the national agenda.

Advocacy strategies

Prior to engaging in actual advocacy work, it is necessary to have evidence-based information on issues related to women in the context of HIV and AIDS. The art of packaging and communicating this new knowledge – information dissemination, documentation and sharing of good practice – is also important in advocacy. The following strategies are useful.

Use of media

Widely employed in advocacy, the media can assist in popularising the issues through messages in print, or by electronic or popular means. However, this industry is also the domain of men, is highly commercialised and often has political interests attached to it. In some countries, extreme regulatory measures inhibit the media from being accessible to and effective for women. Stereotyping and the limited capacity of media professionals mean that women are often portrayed in negative ways. To advocate through the media, it is necessary to define the advocacy message clearly

and contextually to address the audience. A media plan must be developed, and should include fostering the participation of diversified experts including women living with HIV. Messages should be short, concise and persuasive.

Mobilisation

Mobilisation is the art and practice of bringing people and organisations together for a specific cause. Numbers count in advocacy, therefore mobilisation and alliance-building strategies should be strengthened. In order to mobilise effectively for Mutapola, it is important to identify targets for change, and also like-minded interest groups and allies. Clear information should be accessible to all involved in the advocacy campaign. Effective mobilisation requires developing an implementation strategy with a budget, concrete action plans and clear timeframes. To keep momentum and ensure continuity, plans for feedback and follow through after specific mobilisation and advocacy events are important.

Lobbying

Lobbying entails communication, often on a one–to-one basis, with a policy- or decision maker, and is particularly critical as a strategy to address hidden power. Mutapolas and their interests can be put on the political agenda through effective lobbying.

Box 27: What does advocacy involve?

In principle, advocacy includes the following stages:

- Identifying the problem;
- Consultation and consensus building;
- Identifying policy issues;
- Generating knowledge and gathering data;
- Identifying the target group and allies;
- Developing an action plan, which should include specific and time-bound activities;
- Implementing the plan;
- Evaluating the advocacy action or campaign;
- Assessing the impact.

Responses and gaps in advocacy

Many African countries have signed and adopted or ratified the legal instruments below. However, domestication and implementation are yet to be fully achieved.

International policy instruments

The Protocol to the African Charter on Human Rights on the Rights of Women (2003)
The Beijing Declaration and Platform for Action (1995)
The International Conference on Population and Development (1994)
The Declaration on the Elimination of All Forms of Violence Against Women (1993)
The Convention on the Elimination of All Forms of Discrimination Against Women (1979)

National legal reforms in some countries have resulted in the criminalisation of some harmful traditional practices such as female genital mutilation (FGM) in Ethiopia and of violations such as marital rape in Zimbabwe. The issue of domestic violence is also now becoming a point of discussion in some African countries, to the extent that laws are being revised to address it, for example in Mozambique.

The implementation and enforcement of laws from a women's rights perspective is slowly becoming visible, as government and non-government actors engage in capacity building and gender sensitisation of law enforcement officials including the police force. However, more work needs to be done to change their attitudes and behaviours.

In many countries that have enacted laws against gender-based violence, there is an increase in the reporting of rape and sexual assault. Many countries have specialised police units dealing with domestic violence and sexual abuse of women and children. Increasingly, these units offer counselling and either access or referrals to emergency health services.

Women's rights organisations who advocate for Mutapola are gaining ground. Due to these organisations' advocacy in various countries, increasing numbers of rapists are tried and convicted. Health professionals have been obligated to report violence and the police have begun to take it seriously.

Women's rights organisations and HIV and AIDS activists are beginning to come together to address the issue of HIV and AIDS from a women's rights perspective.

More work needs to be done to integrate HIV and AIDS into mainstream women's rights agendas.

The Rome Statute of 1998 that established the International Criminal Court, which came into effect in 2002, recognises "rape, sexual slavery, enforced prostitution, forced pregnancy, enforced sterilisation or any other form of sexual violence of comparable gravity" as war crimes within the jurisdiction of the court. These same crimes, when "committed as part of a widespread or systematic attack directed against any civilian population" are recognised as crimes against humanity by the court. These provisions allow for prosecution of the specified sexual crimes by the International Criminal Court if they occur in a country where the court has jurisdiction.

International entities and NGOs are attempting to distribute emergency health kits to women in conflict zones. The kits contain post-exposure prophylaxis (PEP), condoms and other medications – a small but critical part of women's health-care needs. The need to protect women from the risk of HIV transmission in situations of conflict is imperative.

Some countries are now adopting positive measures to improve the representation of women in decision-making, for example by enforcing a quota system. Women who reach decision-making positions as a result should be supported and their capacities built for effective representation of women's issues.

National strategic frameworks on HIV and AIDS are beginning to position women's issues. All HIV national strategic frameworks in Africa must be encouraged to prioritise issues of women in the face of HIV and AIDS according to their situational analysis.

VAW campaigns have been designed for implementation in several countries in Africa.

Refugee camps and centres for the internally displaced are also becoming sites for education and services relating to HIV, which have been sorely lacking up to now. As more women take on leadership roles in camps, they are able to bring about changes that make the camps safer for women. Peacekeepers are also providing education and raising awareness.

Some African governments, for example that in South Africa, are working with NGOs and women's groups to establish 'one-stop' facilities for survivors of domestic violence and sexual assault. These centres offer access at a single site to police, social workers, counselling services and health workers dispensing PEP. This intervention needs to be scaled up.

Regional economic communities are beginning to prioritise HIV and AIDS as a key development issue. Examples are the Southern African Development Community (SADC), the Economic Community of West African States (ECOWAS) and the African Union (AU). At least up until 2006, such strategic plans are devoid of women's rights dimensions of the epidemic.

There is increasing political will and commitment to women's rights issues in HIV and AIDS, as world leaders begin to recognise publicly the feminisation of the AIDS epidemic. This needs to be encouraged further, and to involve commensurate resource allocation.

Take strategic action

- Establish critical shelters or safe havens where abused women and girls can access round-the-clock support including legal services and health care.
- Advocate for government and civil society to provide free legal aid and psychosocial support services for survivors of violence and abuse, to ensure that Mutapola realises her right to justice.
- Support the establishment and strengthening of organisations, networks and coalitions for policy advocacy by women living with and affected by HIV and AIDS.
- Raise awareness and increase the knowledge base on policy issues at international, national, and local community levels on issues of women's and girls' rights in the context of HIV and AIDS, especially in relation to the vulnerability of women and girls to HIV and AIDS, access to health care, prevention methodologies, inheritance and property rights and access to education.
- Invest more in training women, especially those living with HIV, to be effective advocates and leaders in the AIDS response.
- Review and adapt existing AIDS strategies to ensure they all work for women.
- Ensure that laws, whether statutory or customary, protect women against violence and uphold their rights, including their right to own, inherit and control property.
- Invest in strategies to educate the police, the judiciary, social service providers, civil servants and community leaders about laws and their legal responsibilities to enable women to enjoy their rights.
- Develop and fund programmes to improve legal aid and other forms of support so that Mutapola can claim her rights.
- Enhance the capacity of Mutapola organisations and women-led PLWHA organizations.
- Promote the meaningful involvement of Mutapolas in policy dialogue and decision-making on HIV and AIDS issues at all levels.
- Advocate and campaign for changes in societal attitudes and behaviour, with an emphasis on the role and use of mass media.

Box 28: What can parliamentarians do?[26]

Parliamentarians can advance women's rights within HIV and AIDS at local, national and regional levels in several of their roles:

- As political leaders, they can influence public opinion and can increase public knowledge of relevant issues.
- As legislators, they vote on acts of parliament and can ensure that legislation protects women's rights and advances effective prevention and care programmes for women and girls.
- As advocates, they mobilise the involvement of government, private sector and civil society to discharge their societal responsibilities in responding appropriately to the epidemic.
- As resource mobilisers, they can allocate financial resources to support and enhance effective HIV and AIDS programmes that are consistent with the principles of human and women's rights.

Specifically, parliamentarians can assist with implementation of women's rights and HIV and AIDS guidelines through:

- Educating their peers about the guidelines at national and local levels to encourage acceptance and endorsement;
- Devising a strategy for disseminating the guidelines to key actors;
- Developing action plans for monitoring and implementing priority issues;
- Participating in consultative review and reform of the laws by drafting appropriate bills;
- Adopting, ratifying and domesticating regional and international women's rights instruments.

[26] Handbook for legislators on HIV and AIDS, Law and Human Rights, UNAIDS 1999 pp20

ANNEXES

ANNEX A. Managing Mutapola Programme

Programme components

Programme inputs

Refer to a set of resources which include personnel, facilities, space, equipment and supplies

Programme process

Set of activities in which programme inputs are utilised in pursuit of the results expected from implementing Women's Rights and HIV programmes. Programme process include all of the service delivery operations (management, training, commodities and logistics, information-education communication and research and evaluation

Programme outputs

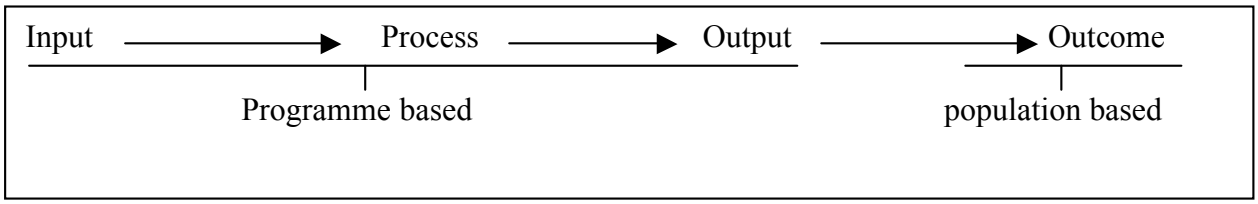
Results obtained at programme level through execution of activities using programme resources.

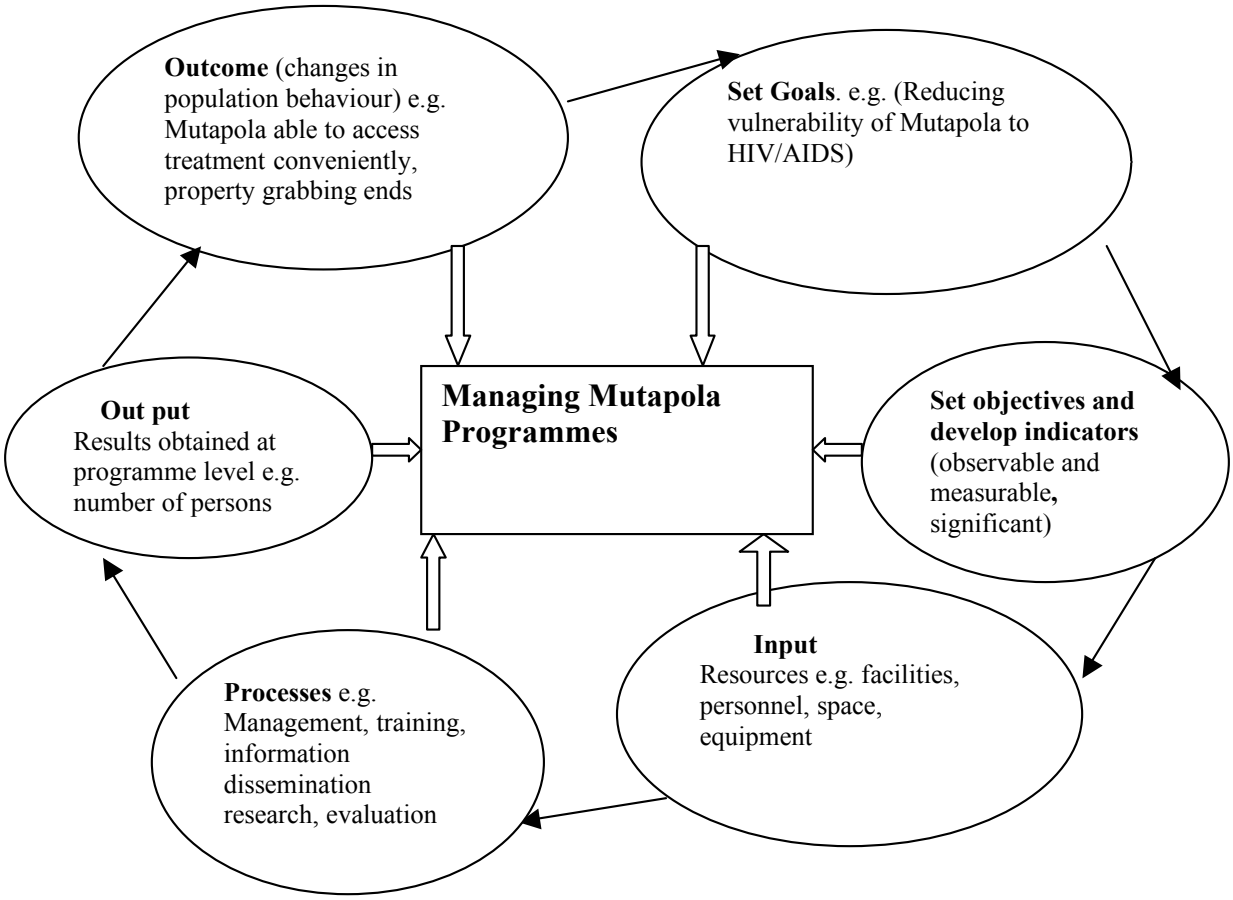
Programme outcomes

These are the set of results expected to occur at the population levels due to programme activities and generation of programme outputs.

Relationship between Program components

Relationship between programme components




Outcome (changes in population behaviour) e.g. Mutapola able to access treatment conveniently, property grabbing ends
Set Goals. e.g. (Reducing vulnerability of Mutapola to HIV/AIDS)
Out put Results obtained at programme level e.g. number of persons
Managing Mutapola Programmes
Set objectives and develop indicators (observable and measurable**,** significant)
Processes e.g. Management, training, information dissemination research, evaluation
Input Resources e.g. facilities, personnel, space, equipment

ANNEX B: HIV Laws, Policy and Human rights- International Guidelines

- Human Rights instruments containing guidelines on HIV and AIDS
- The United Nations Charter
- The Universal Declaration of Human Rights
- The International Covenant on Economic, Social and cultural Rights
- The International Covenant on Civil and political Rights
- The Convention on the Elimination of all forms of Discrimination against Women
- The Convention on the Rights of the Child
- The Convention against Torture, and other Cruel, Inhuman or Degrading Treatment or Punishment
- The African Charter on People and Human Rights

ABBREVIATIONS

AAI	ActionAid International
ABC	**A** stands for abstinence, **B** stands for be mutually faithful and **C** means correct and consistent use of condoms
AIDS	Acquired Immunodeficiency Syndrome
ART	Antiretroviral therapy or treatment
ARVs	Antiretrovirals
AU	African Union
CMV	Cytomegalovirus
DEVAW	Declaration on the Elimination of Violence Against Women,
EBV	Epstein-Barr virus
SADC	Southern African Development Community
ECOWAS	Economic Community of West African States
EFA	Education For All
FAO	Food and Agricultural Organisation
FBOs	Faith Based Organisations
FGM	Female Genital Mutilation
GDP	Gross Domestic Product
HAART	Highly Active Antiretroviral Therapy,
HBC	Home based care
HIV	Human Immunodeficiency Virus
HSV	Herpes simplex virus
ICHC	Integrated community and home-based care model
IP	Integrated Programme
NGO	Non-governmental organisations
VCT	Voluntary Counselling and Testing
VAW	Violence against women
PMTCT	Prevention of mother to child transmission
MAP	World Bank Multi country AIDS Programme
MDGs	Millennium Development Goals
NPOs	Non-profit organisations
OIs	Opportunistic infections
PEP	Post Exposure Prophylaxis
PEPFAR	Presidential Emergency Programme for the AIDS Response
PLWHAs	People living with HIV and AIDS
SAFAIDS	Southern African Aids Information Dissemination Service
SEAGA	Socio-economic and Gender Analysis
STIs	Sexually Transmitted Infections
SWAPOL	Swaziland Positive Living
TB	Tuberculosis
UNDP	United Nations Development Programme
UNIFEM	United Nations Fund for Women
WHO	World Health Organisation
WLWA	Women living with AIDS

REFERENCES

A Test of Equality: Discrimination Against Women Living with HIV in the Dominican Republic.

Facing the Future Together: Zimbabwe Country Report of United Nations Secretary-General's Task Force on Women and Girls and HIV and AIDS in Southern Africa, UNAIDS 2004.

Keeping the Promise: An Agenda for Action on Women and AIDS, UNAIDS, 2006.

Eating health, staying positive: Manual for HIV positive people, SAFAIDS, 2005.

Living well with HIV and AIDS: A manual on nutritional care and support for people living with HIV and AIDS, FAO/WHO, 2002.

Meeting the HIV and AIDS Challenge to Food Security: the role of labour saving technologies in farm-households, FAO and UNDP, December 2002.

HIV and AIDS and Agriculture: Impacts and Responses: Case studies from Zambia, Uganda and Zambia, FAO, 2003.

Incorporating HIV and AIDS considerations into food security and livelihood projects, FAO Nutrition Programmes, Rome 2003.

Handbook for Legislators on HIV and AIDS, Law and Human Rights, UN, 1999.

Addressing HIV and AIDS through Agriculture and Natural Resources Sectors, SEAGA IP FAO, 2004.

Gender and reproductive rights, WHO, accessed on http://www.who.int/reproductive-health/gender/glossary

Evaluating Family Planning Programmes, B. M. Ruternberg/ USAID, 1996.

ActionAid International HIV and AIDS Strategic Plan 2005-2010.

Monitoring and evaluation framework for Africa: UNIFEM M &E Framework, Thelma Awori, 2003.

Violation of Women's Human Rights in Health Care Systems in Dominican Republic: Human Rights.

Websites visited

Research and Training Institutions

AIDS and Society Research Unit
http://www.cssr.uct.ac.za/asru.html
Description: This is the new website for the ASRU that conducts research into the psycho-social, economic and political impact of HIV/AIDS in Southern Africa.

The Centre for Young Women's Health
http://www.youngwomenshealth.org/hiv-aids.html
Description: This site provides information for young women on HIV/AIDS.

Demographic and Health Surveys
http://www.measuredhs.com/
Description: This site contains HIV/AIDS Surveys Indicators Database, demographic and health information and data on gender indicators from the developing world.

Gender and Health Group at Liverpool School of Tropical Medicine
http://www.liv.ac.uk/lstm/research/GenderHealthGroup.htm
Description: This site provides Gender and Health Guidelines.

Human Rights Watch's web page on Women and HIV/AIDS
http://www.hrw.org/women/aids.html
Description: This site provides information on the work of Human Rights Watch on women and AIDS.

The International Centre for Research on Women (ICRW)
http://www.icrw.org/html/issues/hivaids.htm
Description: This site provides information and toolkits on gender and HIV/AIDS-related projects undertaken by ICRW.

Regional AIDS Training Network (Africa)
http://www.ratn.org/
Description: This site provides training material on STIs/HIV/AIDS for the Eastern and Southern Africa region.

ReproLearn: Care of Women with HIV Living in Limited Resource Settings
http://www.reproline.jhu.edu/video/hiv/tutorials/English/index.htm
Description: This site contains a series of multimedia tutorials to provide physicians, faculty and healthcare trainers with technical knowledge, enabling them to provide high quality healthcare services and to train other healthcare providers about the needs of women with HIV/AIDS.

Stepping Stones: A Training Package on HIV/AIDS, Gender Issues, Communication and Relationship Skills
http://www.steppingstonesfeedback.org/
Description: This site contains the Stepping Stones training package on gender and HIV/AIDS, which is also a life-skills training package.

Virtual Libraries and Clearinghouses

16 Days of Activism Against Gender Violence
http://www.cwgl.rutgers.edu/16days/home.html
Description: This is the site for the 2004 16 Days of Activism Against Gender Violence. The theme for this year is: "For the Health of Women, For the Health of the World: No More Violence." The 2004 16 Days of Activism theme is also intended to highlight the intersection of violence against women and the HIV/AIDS pandemic.

A Broken Landscape: HIV & AIDS in Africa
http://www.networkphotographers.com/aidsinafrica/
Description: This site provides a description of the tragic realities of AIDS, both in images and in voices of the people featured in images.

AIDS Education Global Information System (AEGiS)
http://www.aegis.org/
Description: This site is a knowledge base for HIV/AIDS on the web and provides abstracts and files that are fully-indexed, cross-referenced, and keyword searchable.

AIDSmap
http://www.aidsmap.com/
Description: This site contains original, daily news on developments in the world of HIV/AIDS. The site also includes completely searchable databases of HIV treatment and care, worldwide HIV organisation listings, and a comprehensive range of patient information.

The Body
http://www.thebody.com/whatis/women.shtml
Description: This site is the Women and HIV/AIDS page of The Body, which is an HIV and AIDS Information Resource.

Canadian HIV/AIDS Information Centre
http://www.aidssida.cpha.ca/
Description: This site provides up-to-date information and communication services on HIV prevention, care, treatment and support; it is also Canada's largest library collection of HIV/AIDS resources. All resources are available in both English and French.

Education International - Education and HIV/AIDS
http://www.ei-ie.org/aids/en/index.htm
Description: This site lists press articles on education and HIV/AIDS and on major international events along with a range of publications on HIV/AIDS-related topics. The site also contains EL-Newsletters and training tools on HIV/AIDS prevention in schools.

Eldis Gateway Resource Guide to HIV/AIDS
http://www.eldis.org/hivaids/index.htm
Description: This site provides comprehensive thematic and regional resources on HIV/AIDS.

Eldis Gender and HIV/AIDS Dossier
http://www.eldis.org/gender/dossiers/index.htm
Description: This site is an online, dynamic guide that provides narrative and up-to-date resources to guide the user through the key issues and debates on Gender and HIV/AIDS.

Engender Health
http://www.engenderhealth.org/
Description: This site provides comprehensive resources on reproductive health, sexuality, gender and HIV/AIDS.

Family Health International's Focus on Gender
http://www.fhi.org/en/Topics/gender.htm
Description: This site focuses on the gender aspects of health and provides resources including training manuals on STIs/HIV/AIDS.

GenSalud - Virtual Library on Gender and Health
http://www.paho.org/english/hdp/hdw/library.htm
Description: This site is a virtual library on gender and health for the Central American region. It brings together disparate information resources and services from across the region including training tools, fact-sheets, and gender and health indicators.

Global Campaign for Microbicides
http://www.global-campaign.org/
Description: This site provides information about the campaign that is working to accelerate access to HIV prevention options like microbicides. It also includes information about related events and regional activities.

Health Link
http://www.asksource.info/databases.html
Description: This site is a searchable database of materials on international health, gender and HIV/AIDS.

The HIV, Women and Youth website
http://www.ppfc.ca/ppfc/HIV/
Description: This site provides resources and information focused on women and youth.

The HIV/AIDS Impact on Education Clearinghouse
http://hivaidsclearinghouse.unesco.org/ev_en.php
Description: This site provides resources on HIV/AIDS and education, with a specific topic on gender.

HIVInsite
http://hivinsite.ucsf.edu/
Description: This site provides comprehensive, up to date information on HIV prevention, treatment, and policy, including information on gender and HIV/AIDS.

KIT Royal Tropical Institute - Gender and AIDS Overview
http://www.kit.nl/frameset.asp?/specials/html/ga_gender_and_aids.asp&frnr=1&
Description: This site is the Gender and AIDS resources page at KIT and provides links to within KIT's website that contain information on gender and HIV/AIDS.

MDGenderNet
http://www.mdgender.net/
Description: This site is an online resource on gender equality and the Millennium Development Goals.

Siyanda - mainstreaming gender equality website
http://www.siyanda.org/
Description: This site is an online database of gender information and materials that are organized in broad categories and types of material. It also includes useful resources on gender and HIV/AIDS.

Synergy HIV/AIDS Online Library
http://www.synergyaids.com/resources.asp
Description: This site provides an online library containing over 2800 technical HIV/AIDS documents, many produced by USAID-funded organisations. The database is searchable by keyword and country and includes resources on the issue of gender and HIV/AIDS.

UNESCO - IBE HIV/AIDS Clearinghouse
http://www.ibe.unesco.org/hivaids/1-about/ab3_mandate.htm
Description: This site provides information on identifying good practices, curriculum development, implementation and evaluation for the prevention of HIV/AIDS at national, regional and international levels.

UNIFEM Gender and HIV/AIDS Web Portal
http://www.genderandaids.org/
Description: This comprehensive site provides up-to-date information on the gender dimensions of the HIV/AIDS epidemic. The wide-ranging resources on gender and HIV/AIDS include training materials, fact-sheets and reports sorted according to regions and topics.

WHRnet special on women and AIDS
http://www.whrnet.org/docs/issue-AIDS.html
Description: This site contains WHRnet's special issue on women and HIV/AIDS and lists other useful sources on the topic.

The Women and International Development Programme of Michigan State
http://www.isp.msu.edu/wid/biblios/AIDS_bib.htm
Description: This site contains an annotated Bibliography on Gender and HIV/AIDS.

Women's Net HIV/AIDS Page (South Africa)
http://womensnet.org.za/hivaids/aids.htm
Description: Women's Net HIV/AIDS Page (South Africa)

Women, Children and HIV
http://womenchildrenhiv.org/
Description: This site contains a library of practically applicable materials on prevention and treatment particularly for mother-to-child transmission.

You and AIDS
http://www.youandaids.org/Cosponsors/unifem.asp

Description: This site is UNIFEM's HIV/AIDS Portal for South and North East Asia

Description: This site is UNIFEM's HIV/AIDS Portal for South and North East Asia and provides thematic and regional information on HIV/AIDS.

UN and Other Multilateral Organisations

Canadian International Development Agency
http://www.acdi-cida.gc.ca/cida_ind.nsf/vall/c5f1dc10bb131992852568fc0054df2c?OpenDocument
Description: This site contains resources on different aspects of HIV/AIDS including women's special vulnerability to HIV.

Commonwealth Secretariat
http://www.thecommonwealth.org/Templates/Colour.asp?NodeID=34021
Description: This site is the Gender and HIV/AIDS page of the Commonwealth Secretariat and provides useful links to resources on gender and HIV/AIDS.

Global Coalition on Women and AIDS
http://womenandaids.unaids.org/default.html
Description: This site provides information on tools, resources on women and HIV/AIDS along with information on regional initiatives of the coalition.

HIV/AIDS and armed conflict
http://www.unicef.org/aids/index_armedconflict.html
Description: This site provides resources on HIV/AIDS and armed conflict.

How does HIV/AIDS affect girls and women?
http://www.unicef.org/aids/index_hivaids_girls_women.html
Description: This site focuses on how HIV/AIDS affects girls and women.

ILO
http://www.ilo.org/public/english/protection/trav/aids/
Description: This site provides resources on ILO programme on HIV/AIDS.

ILO Gender Equality Tool
http://www.ilo.org/dyn/gender/gender.home
Description: This site contains resources on gender equality and also contains a search function for resources on gender and HIV/AIDS.

Prevention of parent-to-child transmission of HIV/AID
http://www.unicef.org/aids/index_preventionMTCT.html
Description: This UNICEF site talks about HIV positive pregnant women, and the risks to their children. It gives advice to seropositive women.

UNAIDS
http://www.unaids.org/en/default.asp
Description: This site provides gender and HIV/AIDS resources.

UNESCO
http://portal.unesco.org/en/ev.php-URL_ID=1134&URL_DO=DO_TOPIC&URL_SECTION=201.html
Description: This site provides resources on HIV/AIDS.

UNESCO's HIV/AIDS Training Materials (Asia and the Pacific)
http://www.unescobkk.org/ips/arh-web/resources/repackaids.cfm
Description: This site contains an inventory of educational materials focused on Adolescent Reproductive and Sexual health - including HIV/AIDS/STDs mainly produced in Asia/Pacific region by UNESCO.

UNFPA
http://www.unfpa.org/gender/hiv.htm
Description: This site provides gender and HIV/AIDS resources.

UNICEF
http://www.unicef.org/lifeskills/index.html
Description: This site provides gender and HIV/AIDS Resources.

UNIFEM
http://www.unifem.org/
http://www.unifem.org/index.php?f_page_pid=27
Description: These sites are UNIFEM's website and gender and HIV/AIDS pages.

United Nations General Assembly Special Session on HIV/AIDS
http://www.un.org/ga/aids/coverage/
Description: This site provides summaries of the United Nations General Assembly Special Session on HIV/AIDS and links to different statements and press releases.

WHO
http://www.who.int/gender/hiv_aids/en/.
http://www.who.int/reproductive-health/gender/glossary
Description: This site is World Health Organisation's gender and HIV/AIDS page

NGOs, Foundations and Other Organisations

AIDSQuest: The HIV/AIDS Survey Library
http://www.popcouncil.org/horizons/AIDSQuest/index.html
Description: This site contains surveys and scales from a number of international and local organisations, and from the published literature. Information on how each survey was developed and used is also provided. Also featured in AIDSQuest are methodological tips on designing AIDS-related questions.

CADRE - Centre for AIDS Development, Research and Evaluation
http://www.cadre.org.za/
Description: This site contains resources on HIV/AIDS.

The Female Health Company
http://www.femalehealth.com/
Description: This site provides comprehensive information and training resources on the female condom.

Human Rights Watch, HIV and Women
http://hrw.org/women/aids.html
Description: This site contains resources on women and HIV/AIDS.

International Community of Women Living with HIV/AIDS
http://www.icw.org/tiki-view_articles.php
Description: This site contains resources for and about women living with HIV/AIDS.

The International Women's Health Coalition
http://www.iwhc.org/
Description: This site provides resources on reproductive health, women and HIV/AIDS, concentrating on Africa, Asia, Latin America, and countries in post socialist transition.

National Paediatric AIDS Network
http://www.npan.org/
Description: This site provides information on pregnant women, children and adolescents with HIV/AIDS.

Positive Women!
http://www.positivewomen.org/
Description: This site contains a newsletter written by and for HIV-positive women. It also includes links to helpful web sites, announcements of events of interest to HIV+ Women.

Sisters for Life International
http://www.sistersforlife.com/
Description: This site provides information and training resources on women and HIV/AIDS.

Society for Women and AIDS in Africa
http://www.swaainternational.org/
Description: This site provides information and training resources on women and HIV/AIDS in Africa.

Women and AIDS Coalition Group http://womenandaids.unaids.org
http://www.sfaf.org/treatment/beta/b43women_access

WASN Women and AIDS Support Network
http://www.wasn.org.zw/
Description: This site provides resources on women and HIV/AIDS.

The Well Project
http://www.thewellproject.org/
Description: This site provides the latest information on living with and managing HIV disease for HIV positive women, health care providers and advocates. Interactive features include Discussion Groups, where HIV-positive women and those that care for them have the ability to communicate with one another online.

Women, HIV/AIDS and Microbicides
http://www.ipm-microbicides.org/women_aids.cfm
Description: This site talks about the vulnerability of women to HIV/AIDS infection, and the option of microbicides as a method of prevention.

World Volunteer Web
http://www.worldvolunteerweb.org/events/UN_days/IWD04/index.htm

Description: This site is the special page created for the occasion of International Women's Day, with a focus on volunteering, women and AIDS.

Zimbabwe Women's Resource Centre and Network
http://www.zwrcn.org.zw/
Description: This site provides information on gender and HIV/AIDS.

Media Sites

All Africa
http://allafrica.com/
Description: This site provides comprehensive information about Africa and includes information on HIV/AIDS.

Health Action AIDS
http://www.phrusa.org/campaigns/aids/bgrd_women.html
Description: This site provides resources on women and HIV/AIDS.

IPS - Gender, HIV/AIDS, and Rights
http://www.ipsnews.net/aids_2002/index.shtml
Description: This site provides a comprehensive list of resources on HIV/AIDS from around the World.

IRIN PlusNews
http://www.irinnews.org/AIDSFP.ASP
Description: This site provides comprehensive information on HIV/AIDS and advocacy in Africa.

Journ-AIDS
http://www.journ-aids.org/
Description: This site provides support to media professionals to ensure in-depth, accurate and critical reporting on HIV/AIDS.

SHAAN UNIFEM/IPS e-zine on Gender, Human Rights and HIV/AIDS
http://www.ipsnews.net/hivaids/index.shtml
Description: This site is an electronic magazine on Gender, Human Rights and HIV/AIDS.