

Inter-Agency Task Team (IATT) on Education



Treatment Education

A Critical Component of Efforts
to Ensure Universal Access to Prevention,
Treatment and Care



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HIV and AIDS Treatment Education:

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to Ensure Universal Access
to Prevention, Treatment and Care**

UNAIDS Inter-Agency Task Team (IATT) on Education

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Preface

HIV and AIDS Treatment Education: A Critical Component of Efforts to Ensure Universal Access to Prevention, Treatment and Care explores some of the main issues contained within the definition of treatment education, signalling ways that the education sector can play a role along with others engaged in efforts to achieve universal access to prevention, treatment, and care. The paper considers some key strategies, including how to effectively engage and prepare communities and how to involve key constituencies and in particular people with HIV and those on treatment. The paper elaborates on the link between prevention and treatment, re-examines the harmful effects of stigma and discrimination and explores how these factors impede progress in prevention and expanding treatment access. In addition, the paper suggests some possible future directions, underscoring areas of particular priority, which include the need for dissemination of effective approaches to treatment education, the development of practical guidelines and materials that can be used by programme implementers to support the integration of treatment education within ongoing HIV and AIDS education efforts, and ongoing close communication with authorities and

organizations responsible for expanding treatment access to ensure coherent and well-coordinated programming.

The paper was developed for the UNAIDS Inter-Agency Task Team (IATT) on Education, for initial presentation at a meeting in Cape Town, South Africa 17 to 19 January 2005. The IATT is convened by UNESCO and includes as members the UNAIDS Co-sponsoring agencies, bi-lateral agencies, private donors, and civil society. The IATT aims to accelerate and improve the education sector response to HIV and AIDS. It has as specific objectives to promote and support good practices in the education sector in relation to HIV and AIDS and to encourage alignment and harmonisation within and across agencies to support global and country-level actions. The IATT seeks to achieve these objectives by: strengthening the evidence base and disseminating findings to inform decision-making and strategy development, encouraging information and materials exchange, and working jointly to bridge the education and AIDS communities and ensure a stronger education sector response to HIV and AIDS.

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Acronyms

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
ARV	Antiretroviral
CBO	Community Based Organization
CDC	Centers for Disease Control and Prevention
COCEPWA	Coping Centre for and by People Living with HIV/AIDS
DOTS	Directly Observed Treatment Short-course
FBO	Faith Based Organization
GFATM	Global Fund for AIDS, TB and Malaria
GIPA	Greater Involvement of People Living with HIV and AIDS
GNP+	Global Network of People Living with HIV and AIDS
HAART	Highly Active Antiretroviral Therapy
HEARD	Health Economics and HIV/AIDS Research Division
HIPC	Heavily Indebted Poor Countries
HIS	Health Information System
HIV	Human Immunodeficiency Virus
IATT	Inter-Agency Task Team
IAVI	International AIDS Vaccine Initiative
ICT	Information and Communication Technologies
ICW	International Community of Women Living with HIV/AIDS
IEC	Information, Education and Communication
IFPRI	International Food Policy Research Institute
IRD	Institut de Recherche pour le Développement
ITPC	International Treatment Preparedness Coalition
MAP	Multi-country AIDS Programme
MoE	Ministry of Education
MSF	Médecins Sans Frontières

MTCT	Mother to Child Transmission
NGEN+	The National Guidance & Empowerment Network of People with HIV/AIDS
NGO	Non-governmental Organization
NZP+	Network of Zambian People Living with ` HIV/AIDS
PEPFAR	President's Emergency Plan for AIDS Relief
PHATAM	Pan-African HIV/AIDS Treatment Access Movement
PMTCT	Prevention of Mother to Child Transmission
PTCT	Parent to Child Transmission
STI	Sexually Transmitted Infection
TAC	Treatment Action Campaign
TAP	Treatment Acceleration Project
TB	Tuberculosis
THETA	Traditional and Modern Health Practitioners against AIDS
TRIPS	Trade Related Intellectual Property Rights
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNESCO	United Nations Educational Scientific and Cultural Organization
UNGASS	United Nations General Assembly Special Session
UNICEF	United Nations International Children's Fund
US	United States
USAID	United States Agency for International Development
VCT	Voluntary Counselling and Testing
WFP	World Food Programme
WHO	World Health Organization
WTO	World Trade Organization

Executive Summary

What is treatment education?

Treatment education is a critical part of overall efforts to prepare people for treatment and to engage communities and individuals to learn about antiretroviral therapy so they understand the full range of issues involved with treatment. These include understanding the benefits of treatment, the importance of maintaining protective behaviours, knowing one's HIV status, getting access to treatment, adhering and supporting others to adhere to treatment and understanding the negative role of stigma and discrimination and gender inequality. Treatment education complements the provision of drugs and medical care by preparing and involving people in comprehensive responses to HIV and AIDS, and places people on treatment at the centre of their own care.

The “3 by 5” initiative led by the World Health Organization (WHO) and the Joint United Nations Programme on HIV/AIDS (UNAIDS), the US President’s Emergency Relief Plan for HIV/AIDS (PEPFAR), other global and national initiatives, as well as expanded funding mechanisms and significant reductions in costs, have increased access to antiretroviral therapy (ART). ART is now recognised to be an essential component of comprehensive responses to the epidemic, which include HIV prevention, treatment, care, and impact mitigation. The recent endorsement of universal access to ART by 2010 by the Group of 8 leading industrialised

countries at the Gleneagle’s Summit in July 2005 is a major boost to these efforts. With the recent adoption of the UNAIDS policy position paper “Intensifying HIV Prevention”, expanded treatment access is also increasingly viewed as an integral part of efforts to strengthen prevention and care.

Alongside efforts to increase treatment access, there is a growing realisation of the critical need to develop ways of preparing and educating communities and individuals about issues relating to ART. Experts working on expanded treatment access acknowledge that the success of these programmes will require much more than the reliable provision of antiretrovirals (ARVs) and related monitoring and laboratory tests by qualified clinical staff.

There must also be effective community and individual preparation and education to appropriately manage health care and social services to support good health outcomes.

Treatment education informs and engages individuals and communities about ART, including how the drugs must be taken and adhered to, treatment benefits and side effects, criteria for enrolment into ART programmes, and issues relating to equity of access. Equally, the need exists for redoubled efforts to educate about the harmful effects of stigma and discrimination and how this impedes people from accessing programmes and services. The value of HIV counselling and testing is more important than ever so people learn their HIV status, a key entry point for care and treatment, and to sustain behaviour changes, particularly among those who already have HIV. Without effective treatment education including treatment preparedness, the full potential of ART is not likely to be realised.

Activists and health professionals involved in efforts to expand treatment access have coined the expression “treatment preparedness” as broadly consisting of three areas: treatment literacy, treatment advocacy, and the mobilisation of the treatment activist community. This paper primarily focuses on the first of these, although “treatment education” as defined here would also comprise advocacy and community mobilisation, and is therefore loosely interchangeable with “treatment preparedness”. The term “treatment education” is utilised throughout this paper because it is believed to resonate more widely within the education sector, the main audience for this publication.

Treatment education provides an opportunity for community members, educators, health workers and others

to become active partners in addressing HIV prevention, care and treatment needs. It strives to ensure that people on treatment are at the forefront of such efforts, and it supports key players in the education sector to become active and engaged participants. Treatment education aims to bring together stakeholders to identify and link needs and resources in a way that helps people to help themselves.

It is well established that individual and community education contribute to the reduction of stigma and can enhance positive living. Reducing stigma can, in turn, encourage people to come forward for testing, which is essential for accessing treatment.

Treatment education can also emphasise that to achieve the full benefits of ART, adequate dietary intake is essential. Good nutrition helps to maintain a person's immune system, sustain healthy levels of physical activity, and ensure an optimal quality of life. Treatment education can also dispel the myth that good nutrition is an *alternative* to ART or that unproven diets and dietary therapies can cure HIV infection.

Evidence from a number of disease areas, such as malaria and tuberculosis (TB), indicates that education involving and focusing on families, peers and communities is critical for large-scale implementation and increased coverage of programmes. Lessons from efforts to treat TB, for example, show that systematic and coordinated engagement of community groups can improve treatment and prevention outcomes as well as generate more effective local responses. Evidence also indicates that community structures or institutions can be effectively mobilised to reach the general public with HIV and AIDS education.

The full and effective involvement of people with HIV and those on treat-

ment is a critical factor in successful responses to the epidemic. This notion is widely accepted in HIV prevention and care programmes, but is equally true with regard to HIV and AIDS treatment education. Good chronic care practice is equally important. In this instance, it means putting people on treatment at the centre of their care so that they can appropriately manage health care and social services themselves to support good health outcomes. People on treatment need accurate and appropriate education and skills in problem-solving around their social and health situations in order to adhere to treatment and to access support when needed.

This paper explores some of the issues contained within the definition of treatment education, signalling ways that the education sector can play a role along with others engaged in treatment access and education. It considers some key strategies, including how to effectively engage and prepare communities and how to involve key constituencies, particularly people with HIV and those on treatment. Moreover, the paper re-examines the harmful effects of stigma and discrimination and how these impede progress in prevention as well as expanded treatment access. The paper also suggests some possible future directions, underscoring areas of particular priority. These include the need for:

- Identification, documentation and wide dissemination of effective approaches to treatment education that are feasible, sustainable and that can be scaled up.
- Development of practical guidelines and materials that can be used by programme implementers to support the integration of treatment education within ongoing HIV and AIDS education efforts.
- Ongoing and close communication with authorities and organizations responsible for expanding treatment access to ensure coherent and well-coordinated programming.

To recognise the full potential of treatment education, education ministries, civil society organizations, and development partners need to:

Ensure that the education sector is fully engaged in treatment education efforts and in supporting people on treatment to take a leading role

– addressing treatment education within all modalities of education—formal, nonformal, and informal, at all levels from early childhood through to higher and adult education, and in all aspects of the sector such as policy and legislation, as well as curriculum and materials. The development of policy and practice will be greatly strengthened through the involvement of people with HIV, including those on treatment.

Support inter-sectoral collaboration

– engaging treatment educators and providers, ministries (health, education and others), non-governmental, community-based, and faith-based organizations, local and international authorities, the private sector and local groups of people with HIV and treatment activists.

Focus on gender-responsive strategies

– promoting the shared responsibility of men and women in safer sexual behaviours and other risk-reduction strategies, addressing barriers often

faced by women and girls in accessing and adhering to ART, and supporting women's advancement and the full enjoyment of human rights—including equitable access to prevention and treatment services.

Maintain and expand prevention efforts

– building on the potential synergy between treatment and prevention, and guarding against the erosion of preventive behaviours and prevention efforts, in line with conclusions and recommendations from the UNAIDS policy position paper “Intensifying HIV Prevention,” and in support of efforts toward universal access.

Address the needs of multiple groups with targeted messages

– employing communication strategies to identify key audiences, develop appropriate messages, identify particular formats and pedagogies for delivery and establish means of monitoring and evaluating effectiveness and impact.

Use different approaches for different settings and groups

– exploring a range of creative means to reach into communities with interactive and participatory approaches, and making sure that all approaches are age-appropriate, gender-responsive and culturally sensitive.

Introduction

In 2005, an estimated 38.6 million people worldwide were living with HIV, the virus that causes AIDS, including 4.1 million newly infected in 2005 alone. In the same year, nearly 3 million people died from AIDS-related causes, contributing to the more than 20 million deaths since the first AIDS diagnosis in 1981 (UNAIDS 2006). Many of these deaths could have been significantly delayed if the appropriate treatment, including ART, and the expertise to monitor its impact had been more widely available.

Although there is no cure for HIV, ART has demonstrated effectiveness and positive long-term outcomes for people with HIV, including reduced HIV-related morbidity and mortality and improved quality of life. ART helps keep families intact and communities economically productive. It reduces absenteeism and treatment costs for ill employees in the private and public sectors and reduces the burden on health systems of HIV-related admissions and morbidity. For example, as a result of increased treatment access, between 250,000 and 300,000 deaths were averted worldwide in 2005 (UNAIDS 2005a). In Brazil, ART is estimated to have averted more than 60,000 AIDS cases, 90,000 deaths and 358,000 hospital admissions from 1996 to 2002 while the savings in outpatient and hospital costs outran the cost of programme implementation by more than US\$ 200 million (Teixiera 2003).

Treatment is a critical component of a comprehensive response to the HIV and AIDS pandemic, which include prevention, voluntary counselling and testing (VCT), the treatment of opportunistic infections including TB, and psychosocial support for people living with HIV. The 2001 United Nations General Assembly Special Session (UNGASS) on HIV/AIDS' Declaration of Commitment highlighted that *"prevention, care, support and treatment for those infected and affected by HIV and AIDS are mutually reinforcing elements of an effective response and must be integrated in a comprehensive*

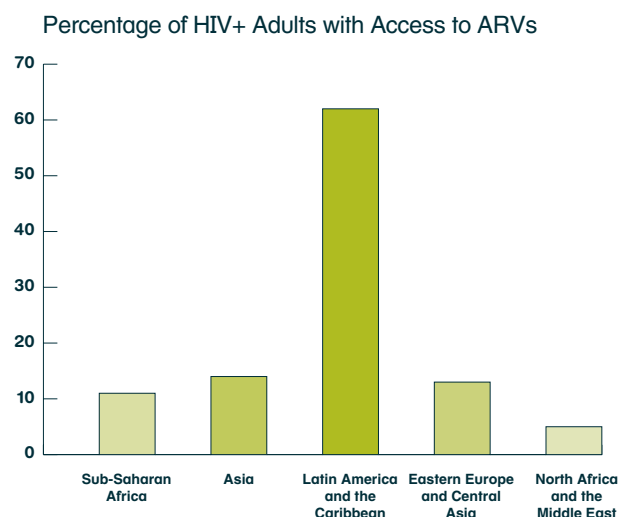


approach to combat the epidemic" (paragraph 7). This was reaffirmed by Member States in 2005. Access to ART is a basic human right in accordance with the Universal Declaration of Human Rights, which recognises the right to health care and the right to share in the advances of science (Mukherjee 2004).

At the 2005 World Summit, UN Member States committed to developing and implementing a package for HIV prevention, treatment and care with the aim of coming as close as possible to the goal of universal access to treatment by 2010 for all those who need it. Based on the World Summit outcomes, efforts are underway to establish a global initiative on "Scaling Up Towards Universal Access" driven by rapid, inclusive and country-owned processes for setting country-specific targets to be achieved by 2010 (UNAIDS 2005b). The endorsement of universal access to ART by 2010 by the Group of 8 leading industrialised countries at the Gleneagle Summit in July 2005 has been a major boost to these efforts.

Scaling up access to ART requires significant financial, technical, social and political support to be sustainable over time. Significant progress has been made since UNGASS in expanding access to ART, due to the "3 by 5" initiative led by WHO and UNAIDS, PEPFAR, other global and national initiatives, as well as expanded funding mechanisms and significant reductions in costs. According to a recent survey of 73 low- and

Figure 1: Access to Antiretrovirals by Region, June 2005



Source: UNAIDS, WHO 2005

middle-income countries that represent almost 90 percent of the global burden of HIV, the number of people receiving ART has increased by 56 percent since 2001 (USAID *et al.* 2004:v). Despite these improvements, access to ARVs and other HIV-related treatment remains profoundly low (see *Figure 1*).

The success of programmes to scale up access to treatment will require not only the reliable provision of ARVs and related monitoring and laboratory tests by clinical staff. It will also require community, institutional, and individual preparation and education to appropriately manage health care and social services to sup-

port good health outcomes. Equally, the need exists for redoubled efforts to educate about the harmful effects of stigma and discrimination and how this impedes people from accessing programmes and services. The value of HIV counselling and testing is more important than ever so that people learn their HIV status, as well as to sustain risk-reducing behaviours, particularly among those with HIV.

Scaling up the provision of ARVs in countries with severely under-resourced health systems challenges how we think of provision in new and progressive ways, reaching beyond health facilities and into other institutions and communities. Treatment education must engage community members, educators, health workers, traditional healers and other stakeholders to become partners in addressing HIV prevention, care and treatment needs, thus essentially enabling a wider group of people to become involved as care providers. With active community engagement, treatment education will reduce the burden on care providers and support health and social systems already under pressure to provide HIV testing and counselling, as well as treatment and prevention services. Comprehensive treatment education will generate effective local and national responses to a global epidemic that remains one of the greatest challenges facing our generation and represents a key contribution to treatment access efforts.

Treatment Education

As initiatives to scale up treatment access gain momentum, there is a critical need to develop ways of educating and preparing communities and individuals about issues related to ART. The concept of “treatment preparedness” grew out of the 2002 International AIDS Conference in Barcelona, when a group of over two dozen advocates gathered to discuss how to boost treatment advocacy and education efforts. Treatment preparedness is an overarching term that includes the components of treatment literacy, treatment advocacy, and the mobilisation of the treatment activist community (FCAA 2003).

The term treatment preparedness was initially outlined at the International HIV Treatment Preparedness Summit held in Cape Town, South Africa, in March 2003 and was based originally on examples of activists preparing for their own treatment. At the Summit, 125 community-based AIDS treatment advocates and educators from 67 countries emphasised that *“information is as important as medicine,”* and that *“without good treatment education, we cannot effectively manage side effects or expect good adherence to therapy”* (FCAA 2003:5). The Summit was organised to address multiple issues in the realm of treatment education but the primary goals included general information and advocacy as well as efforts to develop a global framework for treatment preparedness activities. The Summit concluded that treatment education is essential not only for people with HIV, but for health care providers, educators, advocates, government officials, families, communities and the greater public.

Many of these principles have been adopted by WHO and UNAIDS as fundamental for the effective mobilisation of affected communities in scaling up and preparing for access to treatment. The International Treatment Preparedness Coalition (ITPC) has actively promoted the acceptance and promotion of such principles. WHO initiated a Preparing for Treatment Programme in 2004 to support community-based organizations (CBOs) working on HIV and AIDS treatment preparedness at the country level. Following an interna-

tional tendering process, the Tides Foundation was awarded US\$ 1 million for community-based HIV treatment preparedness activities, including the distribution of grants to CBOs, support for regional networks, information distribution and technical assistance (WHO 2004b). WHO funding has been put into the “Collaborative Fund,” a community grants-making mechanism managed by the Tides Foundation. This Fund, now totaling over US\$ 3.5 million, provides small grants that fully integrate people living with HIV not only as recipients but as donors, and that ensure ownership by networks of people living with HIV at each level of the grant making and implementing process (Quan 2004, Tides Foundation 2004, UNESCO and WHO 2006).

Treatment education engages communities and individuals to learn about ART in order to:

- Encourage the wider use of VCT services to know one’s HIV status, a prerequisite for enrolment in treatment programmes;
- Improve understanding of ART and drug regimens (where to access treatment, how the drugs must be taken, its benefits and potential side effects, possible interactions with other drugs, and options for alternative treatments) and how treatment may affect men, women and children differently;
- Prepare for treatment-related costs (drugs, laboratory tests for monitoring, provider fees, and indirect costs such as transport to the clinic, lost wages, etc.), and how to access related social and public health services;
- Advocate for greater and more equitable access to treatment, including the consideration of gender equity;
- Support people on treatment to adhere to ARV regimens as instructed by health professionals;
- Encourage continued protective behaviours and healthy living;
- Reduce stigma and discrimination against people with HIV; and
- Link prevention, care and treatment initiatives to ensure a comprehensive response to HIV and AIDS.

I. Knowing One's Status

Scaling up ART will require more people knowing their HIV status as the majority of people living with HIV are unaware of their infection. In 2003, less than one percent of adults aged 15-49 years in the 73 low- and middle-income countries most affected by AIDS were accessing VCT services (USAID *et al.* 2004a). In a recent survey in a rural district in Malawi, only 11 percent of men and 7 percent of women had received HIV testing, but 76 percent of untested men and 61 percent of untested women expressed a desire to learn their HIV status (Degraft-Johnson *et al.* 2005).

Multimedia communication campaigns are a method for promoting VCT services. Launched in 2003, Brazil's US\$ 13 million Fique Sabendo (Be in the Know) Campaign resulted in a 30 percent increase in VCT in just one year (Ministry of Health Brazil 2004). Brazilian television and newspapers carried images of national celebrities and officials testing publicly for HIV in T-shirts with the now familiar campaign logo (*see Figure 2*), a winking face with a plus and a minus sign symbolising the two possible results of an HIV test (Ballve 2003, Ministry of Health Brazil 2004). These messages helped to destigmatise HIV, facilitated widespread public awareness about VCT, encouraged people to seek services and were delivered synergistically with Brazil's free and universal ART programme (Galvão 2002).

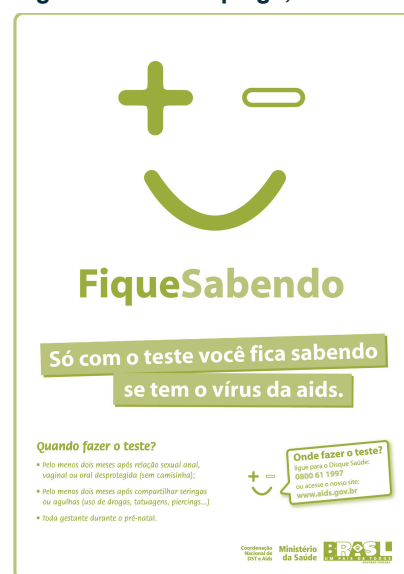
There is some evidence that ART availability may provide an incentive for people to know their HIV status (Global HIV Prevention Working Group 2004). For example, VCT increased in the township of Khayelitsha in South Africa's Western Cape Province following the introduction of ARVs, rising from less than 1,000 HIV tests in 1998 to more than 12,000 in 2002 (WHO 2003c). The Partners in Health/Zamni Lasante clinic in rural Haiti reported a 300 percent increase in the use of VCT services two years after the introduction of ARVs (Farmer *et al.* 2001a, WHO 2003b). Dr. Nathan Kenya-Mugisha, Medical Superintendent at Masaka Regional Hospital in Uganda, explained that until the centre opened, people felt that there was little they could do if they were infected. *"Now that antiretroviral therapy is available, people have a reason to*

know their status" (Mpiima 2003).

Treatment education links testing with pre- and post-test counselling (including information on HIV and AIDS and treatment options and referrals to services) and psychosocial support. Namirembe Diocese in Uganda, a Christian Aid partner, invites people with HIV to post-test clubs where they can speak with a trained counsellor, meet with other people with HIV and access other support, including micro-credit programmes (Christian Aid 2004:14). Pre- and post-test clubs and other support groups can also help people disclose their HIV status to their partners and family members, can encourage VCT for family members who may be at risk and can provide information on protective behaviours to reduce the risk of further transmission (*see p. 21 Continued Protective Behaviours*) (International HIV/AIDS Alliance 2002c).

For the education sector, more can be done to step up messages in ongoing HIV and AIDS education efforts about the importance of knowing one's HIV status and to encourage VCT. In Lebanon, for example, the national AIDS programme and NGOs have been working with the education authorities to raise awareness inside schools and universities to promote learning one's HIV status, as part of overall educational efforts on treatment, the importance of maintaining protective behaviour, the negative role of stigma and discrimination, and gender inequalities.¹ Increasing treatment access provides hope to those infected with HIV, as well as to communities heavily affected by the epidemic. This in turn can provide a powerful incentive for communities and individuals to overcome the hopelessness that has often run parallel to the epidemic, and to start to take control of their lives.

Figure 2: VCT campaign, Brazil



Source: Ministry of Health/Brazil, 2003

2. Enrolment Criteria and Equity of Access

“It’s a troubling decision to make about who will get the drugs and who won’t. We base it on a combination of factors—who needs it most, good compliance to the ART and who came first.”

-Dr. Annop Lekhakul, a physician working at a government hospital in Non Jok, Thailand (Macan-Makar 2003)

Treatment education must make it clear that not all people living with HIV will benefit immediately from ART. Eligibility criteria for treatment are usually based on the amount of HIV in the blood (known as the viral load), level of immune suppression (based on CD4 cell counts), evidence of HIV-related disease (based on WHO disease stage criteria), or some combination of these factors (US DHHS *et al.* 2004). A person’s readiness to begin treatment must also be taken into consideration, as ART is a life-long commitment (Ammassarri *et al.* 2002). Although not all people who test positive for HIV need treatment immediately, people can be registered with the programme and be followed regularly so that they access ART at the appropriate time. UNAIDS has suggested that the process of decision making regarding eligibility criteria should be guided by the following principles: be inclusive, impartial, transparent, public, relevant, revisable and accountable (UNAIDS 2004b).

To improve equity of access to treatment, WHO, UNAIDS and numerous civil society organizations have called for the introduction of appropriate eligibility criteria, both socio-economic and medical, that ensures equitable and fair access to ART. Expanding treatment eligibility criteria to include socioeconomic and cultural factors, rather than simply relying on clinical indicators, would increase access to treatment to groups which, due to social, economic and cultural discrimination, gender inequality, and limited access to health care, already face a disproportionately high risk of infection. The groups that could benefit from this type of revision include women and girls who are discriminated against on the basis of their sex, and those whose behaviour is widely stigmatised, including sex workers, injecting drug users and men who have sex with men (WHO/UNAIDS 2004b, WHO/UNAIDS 2003, CHANGE 2004, Oxfam 2002). Special efforts may also need to be undertaken for young people who often report having

difficulty accessing VCT and ARVs due to costs, social barriers, legal barriers (e.g., age of consent laws), attitudes of health personnel and distance to services (UNICEF 2004b, CHANGE 2004).

Additional steps may be needed to ensure equity of access to ART, such as the establishment of targets based on local epidemiology. On World AIDS Day 2004, WHO Director-General Dr. Jong-Wook Lee said that to “*ensure equitable access to prevention and treatment services for women and girls, it is important for countries to set their own national targets*” adding, “*the target must match the proportion of men, women and children who are living with HIV and in need of treatment*” (WHO 2004b). A recent framework demonstrated how data could be used at local, district and national levels to measure progress toward such targets in Malawi (Kalanda *et al.* 2004). This included the use of graphical representations such as maps with the sex ratios of people accessing ART by district per year and bar charts presenting the use of ART by distance to the nearest health facility. Though designed for use by health programmes, one could imagine that these graphics could also be used as part of treatment education programmes to advocate for more equitable access to treatment among concerned populations.

Approaches that promote treatment access for those unable to afford it should also be supported to guarantee access to care for the most poor and vulnerable citizens (Panos 2000, Mukherjee 2004). Poverty is a factor contributing to HIV prevalence, and the cycle is a vicious one because as prevalence increases, so does the likelihood that people will fall into poverty. WHO has encouraged that every country and community should “*ensure that the lowest socioeconomic classes and the poorest individuals are given high priority for access to ART, consistent with other eligibility criteria for treatment*” (Macklin 2004:2) (*see p. 18 Treatment Costs*). The

Namibian AIDS Law Unit (ALU) initiated a treatment literacy campaign in 2003 to raise awareness and understanding

Figure 3: Namibian ALU Treatment Literacy Campaign



Source: Namibian ALU 2003

about HIV and AIDS treatment as a human right. This included the production and distribution of T-shirts, posters (see Figure 3) and booklets on access to treatment as well as the production of a series of radio programmes broadcasted on national radio.

Treatment education can assist in making decisions about which categories or groups should receive prioritised access to ART and the rationales for these decisions publicly available and transparent (Macklin 2004, McCoy 2003). A number of local and national programmes are including communities affected and infected by HIV in the decision-making processes for the development of eligibility criteria and the selection of people for treatment (see p. 18 *Selection for ART Programmes*).

This has proven to be beneficial in numerous countries in terms of building confidence in and acceptability of ART programmes, reducing corruption and mismanagement of drug supplies and improving transparency of decision-making regarding treatment.

Zambia's Ministry of Education (MoE) has recently announced a new scheme to enrol teachers and their families in the government ART programme. The MoE intends to provide referral and to cover the participation costs of teachers and family members in the treatment programme. Ministry officials have pointed to a number of factors that motivated the new scheme, including a desire to provide tangible support for teachers and their families with HIV. This support includes recognition that treatment can reduce absenteeism due to illness and time required to care for ill family members and can enable teachers to remain active and teaching longer, thus reducing pressures on new recruitment and training. There is also some speculation that teachers who benefit from ART may become more visible and effective in teaching about HIV and AIDS.²



3. Information on Drug Regimens

Treatment education can de-medicalise the terminology surrounding ART and make information on drug regimens more accessible by developing messages that are gender-responsive, culturally-appropriate, age-specific and available in local languages (UNAIDS, Kaiser Family Foundation 2004). In 2002, South Africa's TAC created the Resource Project that aims to pull together the wealth of information on ARVs from scientific journals and academic institutions and translate it into a form that is accessible to the general public. The Resource Project, like other treatment education programmes, provides information on how to access treatment, how the drugs must be taken, possible side and adverse effects, interactions with other drugs, and alternative treatments in cases of treatment failure or toxicity.

“Most people are illiterate as far as drugs are concerned, and it’s not enough for us to tell them ‘you have a right to treatment.’ We have to explain why, what’s available and how it works.”

Rukia Cornelius, Director of the Resource Project, South Africa Treatment Action Campaign (TAC) (UNAIDS 2003a:38)

Where to Access Treatment

“When we hear about these drugs we feel like they are somewhere near, but hiding—we just hear about them like a story.”

Person living with HIV, Zambia (International HIV/AIDS Alliance 2002c:18)

How the Drugs Must be Taken

“People are ready for the ARVs but they will not take the medicine if they are not given the appropriate information.”

Person living with HIV, Zambia (International HIV/AIDS Alliance 2002c:16)

Economic and equity barriers restricting access to ARVs has fuelled “black market” sales in the private and often unregulated sector (Katzenstein *et al.* 2003, International HIV/AIDS Alliance 2002a:23). In Kenya, researchers found that part of the reason for the illegal trade in drugs is that people didn't know where to go to get treatment for their infection while others preferred private purchases because of the stigma attached to HIV and AIDS (Siringi 2004). Treatment education programmes can work with traditional and local media (interactive community theatre, exhibitions, radio, print and television) to help communities identify legitimate drugs and ARV programmes, as well as to link communities to these services. Treatment education can also facilitate overcoming obstacles to treatment access.

In the last decade, the pharmaceutical industry has greatly contributed to the simplification of ARV regimens through the development of fixed-dosed combinations. Fixed dose combinations permit all three individual molecules to be taken in one table or capsule. For example, people taking the most widely prescribed fixed dose combination, Stavudine (d4T)/Lamivudine (3TC)/Nevirapine (NVP), are able to take one pill twice a day instead of six pills a day (Ballard 2004).

While fixed-dosed combinations have simplified ARV regimens, people still require detailed information on how the drugs must be taken. This information includes what time they should take which medication, diet restrictions (food and drink), whether the drugs should be taken on a full

or empty stomach, possible side effects, potential interactions with other medications and drugs, and other information to support positive living. Treatment education can reinforce this information and provide support to people upon initiation of ART.

A number of treatment education materials including booklets, fact sheets and posters have been developed to support ARV programmes. For example, Absolute Return for Kids in South Africa has developed a treatment information form that shows visual images of each of the medications (identifying shapes and colours of the different pills), a warning label for storage and dietary restrictions, and information on side effects and adverse events. This form is distributed to people along with a medication diary that enables them to record what time they take their medication and to report any side effects, problems or other constraints (ARK 2003).

“After ARVs, good nutrition is the first line of defence in warding off the detrimental effects of HIV.”

**James Morris,
Executive Director, WFP
World AIDS Day 2005
(Morris 2005)**

The International Food Policy Research Institute (IFPRI), the World Food Programme (WFP), WHO and others have emphasised moving beyond the provision of information about how the drugs must be taken to include the importance of food and good nutrition for people with HIV (WHO 2005a Gillespie 2005, Morris 2005). Treatment education can encompass practical information about healthy foods and hygienic food preparation, an important part of supporting the overall health and well-being of people with HIV.

Potential Side Effects

Treatment education can help people on treatment anticipate and manage side effects and adverse experiences of ART. These adverse events can be temporary such as nausea, vomiting, diarrhoea, and fatigue, or longer-lasting such as physical changes in body appearance including

fat redistribution (also called lipoatrophy or lipodystrophy), metabolic complications (lipid abnormalities, abnormal blood sugar) and nerve problems (also called neuropathy) (Population Council/Horizons *et al.* 2004). If side effects are intolerable or unexpected, they can undermine people's faith in treatment and lead to unscheduled treatment interruptions. Not taking the correct dose in the correct way at the times prescribed by a health practitioner, also called non-adherence, can compromise the health of a person living with HIV by enabling a rapid increase in viral load and the development of drug resistant strains of the virus (*see p. 19 Adherence to Drug Regimens*). A review of 20 studies investigating the issue of barriers to optimal Highly Active Antiretroviral Therapy (HAART)³ adherence found that symptoms and adverse drug effects were among those factors most consistently associated with non-adherence (Ammassari *et al.* 2002).

The Chris Hani Baragwanath Hospital in Soweto, South Africa has created a “patient passport” that enables people on treatment to keep a record of their health and treatment history (*see Box 1, opposite*). This passport includes results from blood tests including CD4 count, viral load and resistance tests, drug history and reasons for changing medications. It also includes information on what the results from CD4 and viral load tests mean, reminders regarding continued protective behaviours, nutrition and adherence, information on side effects and when to see medical help and other social services including conditions for child care and disability grants. Also in South Africa, MSF has developed treatment diaries and tick sheets (*see Figure 5, p. 20*) that encourage people on treatment to consider problems encountered with adherence and potential side effects. These records enable them to recall information on side effects and other problems during subsequent health visits to health facilities.

Support groups of people with HIV can provide opportunities to develop strategies to reduce the impact of side effects. They can be effective “adherence partners” or buddies to support adherence

to treatment. For example, in Beira, Mozambique, “activistas” assist people on treatment with the supervision of antiretroviral therapy, outreach and home visits through the mother-to-child-transmission (MTCT)-plus sites (Meldrum 2004, *see p. 19 Adherence to Drug Regimens*). Support groups of people with HIV can also assist health workers, educators and NGOs develop appropriate treatment education materials. In Kenya, local illustrators joined with support groups for people with HIV and health care providers to develop treatment education materials for illiterate audiences and low literacy populations. This counselling guide for health workers, “Healthy Living,” assists health workers in providing information on opportunistic infections, ARVs and management of side effects related to treatment (FHI *et al.* 2003).

Box 1: Excerpt from “Patient Passport”

Important side effects and allergies to ARVs

- Nausea
- Dizziness
- Loose Stools/Mild Diarrhoea
- Mild Muscle Pains
- Headaches
- Heartburn

Seek Medical Help if:

- You develop a severe rash
- You develop sores in the mouth
- You start feeling confused
- You experience severe stomach pain
- You lose a lot of weight
- You feel very ill

Source: University of Cape Town, Western Cape ART Rollout Resource Site

Possible Interactions

Many drugs that are used to treat HIV can interact with other medications or drugs, increasing the toxicity of some drugs and reducing the effects of others. For example, drugs used in ARV regimens can interfere with certain drugs taken for TB treatment. Drug interactions may also occur between drugs in ARV regimens and injecting and recreational drugs (Farragon and Piliero 2003). Treatment education should reinforce consultation between people on ART and health service providers so that drug users can make informed decisions regarding potentially dangerous interactions and access substance abuse programmes, where available. Treatment

education should describe common drug interactions with the aim of supporting people on treatment to identify and avoid potentially dangerous drug interactions (*see Figure 4*).

Second Line Therapy

Second line therapy may need to be considered in cases of drug failure or drug toxicity. Drug failure occurs when ART is unable to decrease viral load significantly, when viral rebound occurs (e.g., viral loads decline significantly and rise again), when immune suppression continues (as demonstrated by declining CD4 counts), or when people develop resistance to treatment. People with unusual or severe side effects should also be monitored for drug toxicity, and treatment should be discontinued if toxicity is confirmed.

In such cases, the WHO recommends that the entire drug combination be changed from a first to a second line regimen. The new second line regimen will ideally include at least three new drugs, with one from at least one new class, in order to increase the likelihood of treatment success and to minimise the risk of cross resistance. In developing countries, monitoring treatment effectiveness remains very difficult due to limited access to laboratory facilities. Moreover, in many countries there are few therapeutic choices beyond the first-line regimens and—when available—the cost of second-line regimens is beyond their reach. Second-line treatments can be more than 20 times more expensive than first-line therapies (Calmy 2004). Wherever available, people should be provided with the full range of information on treatment options and their impact on long-term prognosis.

Figure 4: TAC Treatment Literacy



Source: TAC, no date

4. Treatment Costs

Individuals and communities need to understand the full range of costs related to treatment in order to make informed decisions about their readiness to begin ART. This includes costs for HIV testing, medical consultations (user fees), biological tests (for viral loads and CD4 counts), and pharmaceutical expenses including ARV treatment, treatment for sexually transmitted infections (STIs) or opportunistic infections (Kombe *et al.* 2003). Costs associated with ensuring food security and maintaining adequate nutrition during treatment must also be factored into treatment costs. Other significant costs include those for transportation to get to the clinic and lost wages.

The prices of ART have fallen dramatically in the past decade. In the 1990s, costs ranged from US\$ 10,000 to US\$ 15,000 to treat one patient for one year (UNAIDS 2004b, Chirac 2002). These costs have fallen rapidly in recent years to as low as US\$ 200 to US\$ 300 per person per year in some countries, due largely to competition from generic drug companies. A handful of countries are providing free ART including Brazil, Senegal, Thailand, Uganda, and Venezuela (Berry 2004, University of KwaZulu-Natal *et al.* 2004, Desclaux *et al.* 2004). In Brazil, the national AIDS programme supports the full coverage of medical needs, including free and universal access to ART and drugs for opportunistic infections (Galvão 2002, Levi 2002, Teixeira 2004). Senegal's Antiretroviral Drug Access Initiative (ISAARV) provides free ART and laboratory exams, including CD4 counts and viral load tests, although laboratory exams and drugs for opportunistic infections must be covered by the patient (Desclaux *et al.* 2004).

One of the pillars of the WHO/UNAIDS "3 by 5" strategy was to favour access to ART among the poor through the creation of sustainable financing mechanisms that ensured that poor people were exempt from user fees and co-payments (WHO/UNAIDS 2003). Numerous studies have demonstrated that these fees affect the uptake of and the adherence to drug regimens, particularly among the poor who may need to make trade-offs in payments for food and shelter as opposed to medicines (Attawell and Mundy 2003, Lanièce *et al.*



2004, WHO 2003f). Where subsidies are in place for those most in need, it must be clear which groups will receive free treatment, which groups will receive treatment at subsidised prices, and which will self-pay (CHANGE 2004). Established measures should also be in place to ensure that people pay the listed prices at the source of drug disbursement.

Treatment education can provide information on services that can help people afford ARVs on a regular, long-term basis. In Senegal, the Alliance nationale contre le SIDA has helped to develop multi-sectoral "cellules" to facilitate access for people with HIV to a comprehensive range of services at regional and local levels. While some facilitate access to subsidised drugs from pharmacies or hospitals, others have developed local insurance schemes whereby they buy drugs from the government's essential drug list and resell them to members at a reduced, subsidised cost (International HIV/AIDS Alliance 2002a, International HIV/AIDS Alliance 2003b). In Burkina Faso, AMMIE, an NGO based in Ouahigouya, provides free drugs to families who can no longer afford treatment (International HIV/AIDS Alliance 2000).

Treatment education can also play a role in mobilising political will and commitment to improve access to and reduce the costs of ART. In Brazil, religious groups, networks of people living with HIV, feminist, gay and lesbian groups, and NGOs and CBOs contributed greatly to the continuity of the government's response to the epidemic (Galvão 2002). In South Africa, activists have been vocal in demanding greater involvement

by the government in the response to HIV and AIDS. South Africa's national AIDS care plan is now largely based on government financing (UNAIDS 2004a) and aims to cover all medical needs for people living with HIV (University of KwaZulu-Natal *et al.* 2004).

5. Adherence to Drug Regimens

“Patients also need to understand that they have to take pills for the rest of their lives, even when they don’t feel ill—a concept that is not always easy to absorb in a setting where most diseases are either cured or (they) kill.”

Cory Kik, MSF Project Coordinator, Bukavu, Democratic Republic of the Congo (MSF 2003)

Adherence is defined as a person's ability to follow a treatment plan, take medications at prescribed times and frequencies, and follow restrictions regarding food and other medications (Population Council/Horizons *et al.* 2004). Strict adherence to ARV drug regimens is essential—successful HIV therapy requires adherence of 90 to 95 percent (Chesney 2003, Paterson *et al.* 2000). Inadequate adherence to treatment is associated with high levels of HIV in the blood (viral loads), continued destruction of the immune system (declining CD4 counts), disease progression, episodes of opportunistic infections, and poorer health outcomes (Chesney 2003).

Good nutrition slows progression of the disease and helps people living with HIV to manage symptoms and effectively respond to drug therapy. Energy needs are greater among HIV-infected adults and children, increasing by 10 percent in asymptomatic HIV-infected adults and children, and by 20 to 30 percent in adults with more advanced disease. Loss of appetite and poor dietary intake are important causes of weight loss associated with HIV infection; children living with HIV experiencing weight loss have energy needs which increase between 50 and 100 percent (WHO 2005b). Treatment education can include nutritional advice and

link individuals to services to monitor and improve dietary and nutritional intake for successful treatment outcomes.

Taking inappropriate combinations or frequently missing doses can also have serious public health consequences, as the virus can mutate and develop resistant strains. Recent evidence is beginning to support, however, that concerns about the possibility of resistance may be exaggerated with regard to expanded access to antiretroviral treatment in developing countries. In Brazil, observed rates of HIV-1 drug resistance are very low compared with other countries with extended access to HAART with only 6.6 percent of total resistance. This compares to 10.9 percent reported by Canada in 2001, and 11 percent in Europe from data collected from 1996-2002 (Soares *et al.* 2004).

Education for people before the initiation of therapy is vital for successful adherence to medication. They need information on HIV, the potential side effects of ART, information on how the medications should be taken (when, with or without food and /or water, etc.) and the importance of not missing doses (Macklin 2004, WHO 2004d) (*see p. 15 Information on Drug Regimens*). Possible obstacles to successful adherence should be discussed and addressed, including issues concerning food security and good nutrition. In Botswana, Kenya and Zambia, women reported returning drugs provided to them for treatment due to opposition to their use from partners, or, in the case of pregnant women, misconceptions that drugs can harm or kill the foetus (Attawell and Mundy 2003, International HIV/AIDS Alliance 2002c). Culturally appropriate and gender-responsive adherence support systems should be developed to address these concerns and misconceptions.

Treatment education can reinforce messages delivered by health professionals and support individuals and families to develop good treatment-taking behaviours. In South Africa, MSF has developed treatment diaries and tick sheets (*see Figure 5, next page*) that encourage people to consider problems encountered with adherence and potential side effects (UNAIDS 2003c:40). In Thailand, MSF/Belgium is working with the Prachomklao Hospital for children on ART through the use of drug diaries and calendars with stickers for reminders (Bachman 2004).

Treatment education can provide information for people with HIV regarding ongoing support, including peer support groups and networks of people

with HIV. In the Sekgoma Memorial Hospital in Serowe, Botswana, people are encouraged to have an “adherence partner” who helps them to take the drugs on time, encourages them when they are feeling too sick or demoralised to continue with the treatment, collects their repeat prescriptions when necessary and alerts the health system in an emergency (UNAIDS 2003a). In Botswana, the Coping Centre for and by People Living with HIV/AIDS (COCEPWA) teams people on treatment with “buddies” who are specially trained to support them (COCEPWA no date). In Malawi, people are asked to identify someone close to them to support their adherence (*see Box 2, opposite*).

Treatment education on the importance of adherence to HIV treatments should not only be directed to people on treatment but to the families and communities

that support them. In 2002, the Population Council interviewed 38 clients currently using HIV and AIDS care services in Mombasa, Kenya. Almost half of the clients surveyed reported taking prophylactic therapies for opportunistic infection and regularly adhering to treatment schedules. When asked to elaborate on the reasons for regular adherence, respondents most frequently cited help from family members, followed by calendars or reminder cues, clear instructions, personal determination to take medicines correctly, and the incentive of feeling better as a result of the medication (Hutchinson *et al.* 2004). The AIDS Healthcare Foundation, working in South Africa and Uganda, stresses three factors that enhance ARV adherence including on-site support by NGOs, ongoing education by peers also enrolled in ART, and involvement of family members before and during treatment (WHO 2003a:6).

Figure 5: MSF Adherence and Side Effect Daily Ticksheet

	1	2	3	4	5	6	7	8	9	10	11	12	13	14
Morning														
Evening														
How have my ARVs made me feel?														

Source: University of Cape Town, Western Cape ART Rollout Resource Site

Box 2: Improving Adherence: Guardian Supported Treatment

In Malawi, The Lighthouse Trust was established in 2001 to provide a continuum of quality care and counselling, as well as to improve the quality of life of people infected and affected by HIV, including the terminally ill. The overall aim of the programme is to inform, encourage and empower people infected and affected by HIV to cope with the disease and related problems and to live positively. Acknowledging the importance of long-term adherence for the success of an ART programme, the Lighthouse emphasises the importance of peoples' own understanding of treatment implications.

The Lighthouse developed its education programme based on experience with other chronic diseases that require people's self-management such as diabetes, and with regard for their personal dignity and responsibility. Strategies used include daily group discussion, individual counselling, leaflets and a suggestion box.

With respect to ART, the Lighthouse uses the principles of empowerment and the reinforcement of key messages. Clients are asked to identify a guardian or relative to support them in following treatment, termed "guardian supported treatment" or "empowered reinforced therapy". Prior to the initiation of treatment, all clients and guardians are required to attend an education session on ART. This session touches on the natural history of HIV and AIDS, including opportunistic infections, the treatment process at the Lighthouse, messages on healthy, positive living, including partner notification/disclosure, and finally ARVs, their mode of action and potential toxic and adverse effects. The group session is well accepted, and there are clear indications that this contributes to decreased stigma and increased understanding. In a recent survey among 122 people taking ART, over 92 percent reported greater than 95 percent adherence to the medications, after an average of seven months on treatment.

Source: WHO 2004

6. Continued Protective Behaviours

Studies in industrialised countries suggest that optimism about the effectiveness of HAART, often called "HIV optimism" or "treatment optimism," has contributed to increased risk-taking by some people with HIV (Remien *et al.* 1998, Scheer *et al.* 2001, Stall *et al.* 2000, Kelly *et al.* 1998a, Kelly *et al.* 1998b, Dravcik *et al.* 1998, Dilley *et al.* 1997, Van der Ven 1999, International Collaboration on HIV Optimism 2003). As the lives of people with HIV are extended due to treatment and HIV-related illness and deaths decline, the disease may seem to be less life threatening, potentially leading to increased risk-taking behaviours. Therefore, prevention services must provide ongoing risk-reduction counselling for people with HIV and emphasise that ART does not provide a cure for HIV or AIDS (Lamprey 2002, Mills 2002, King-Spooner 1999).

Tailoring prevention and treatment education efforts to meet the needs of people with HIV reflects an emerging area of interest for HIV prevention, and forms part of a comprehensive HIV prevention strategy (UNAIDS 2005c). This recognises that since the beginning of the epidemic, prevention strategies have been more effective when people with HIV have been meaningfully involved in the design, implementation and evaluation of efforts. It also acknowledges that for HIV transmission to occur, a person with HIV (whether they are aware of their HIV status or not) by definition must be a part of the equation, underscoring the importance of involving everyone, including people with HIV, in prevention efforts.

"Positive prevention" programmes support people with HIV to:

- Protect their sexual and overall health;
- Avoid practices that put them at risk of contracting new STIs, other opportunistic infections, such as TB, or super-infection with other strains of HIV;
- Delay the weakening of the immune system and the onset of AIDS-related illnesses; and
- Prevent further transmission of HIV.

Prevention focusing on people with HIV has recently emerged as a programmatic strategy by the US Centers for Disease Control and Prevention (CDC). In 2003, the CDC acknowledged that there had been missed opportunities in directing prevention messages towards people with HIV (CDC 2003). In its document "Advancing HIV Prevention: New Strategies for a Changing Epidemic

Initiative”, the CDC recognises the importance of prevention with, by and for people with HIV across the continuum of strategies, from helping people find out their HIV status by increasing access to VCT to enabling people who know they have HIV to reduce the risk of onward HIV transmission.

Local and international networks of people with HIV can also assist other people with HIV to focus on their individual health needs and to advocate for their rights to make informed decisions regarding their health and healthcare. For example, the NGO *Soins Infirmiers et Développement Communautaire* (SIDC) in Lebanon created the first support group for people with HIV in the country, and during the group’s weekly meetings, the importance of maintaining protective behaviours is included in discussions along with how to access treatment, the benefits of treatment, and support for adherence.¹⁴ In British Columbia, Canada, the British Columbia Persons with AIDS Society (BCPWA) developed a prevention campaign targeting HIV-positive men who have sex with men (MSM). The campaign includes four posters and postcards that deal with particular situations where MSM may face challenges in maintaining safer behaviours. The campaign is meant to encourage discussion about HIV between positive people and in the community at large. At the bottom of each poster is the phrase

“I have HIV. It’s complicated. We need to talk about it” (BCPWA no date). The information and graphics contained in these materials can be adapted both clinically and culturally for use in various settings. The International Community of Women living with HIV/AIDS (ICW) and the Global Network for People living with HIV/AIDS (GNP+) are other important sources of information and networking opportunities for these types of prevention programmes (ICW 1999, GNP+ 1998).

Special efforts may need to be taken to assist women living with HIV who often need particular support with issues such as getting their partners to practice safer sex and disclosing their HIV status to their partners and children (International HIV/AIDS Alliance 2003a). Counselling on protective behaviours should address potential difficulties in sharing test results, negotiating condom use, using safe injection equipment, and adopting and maintaining other risk reduction behaviours (see Figure 6). Programmes that encourage people with HIV to disclose their status to their partners must be sensitive to women’s concerns related to partner violence, abandonment or violence from other members of the community. Information should also be carefully tailored and given to women on risk reduction strategies during pregnancy, childbirth and breastfeeding (Synergy Project 2004, USAID/Synergy Project 2003).

Figure 6: ABIA Treatment Education Poster



Source: ABIA 2004

Strategies for Treatment Education

UNESCO's Division for the Promotion of Quality Education, in close collaboration with partners including WHO and the UNAIDS Inter-Agency Task Team (IATT) on Education, is working to identify and develop practical treatment education strategies that can be widely disseminated and implemented to assist developing countries in achieving the maximum benefit of expanded ART programmes, while also strengthening HIV prevention efforts.⁵ Such treatment education strategies may use the following approaches:

- Support individual, small group and large group activities using traditional and adult educational techniques that are context specific, gender responsive, and culturally appropriate with a range of stakeholders to conduct community education on HIV and AIDS, increase awareness about the existence of the government ART programme and criteria for enrolment, improve health seeking behaviour including HIV counselling and testing, and ART and prevention for people with HIV. This includes improving knowledge and understanding about ARVs, clarifying misconceptions and implications about ARVs as they relate to adherence and prevention for people with HIV, and developing practical strategies to overcome barriers to adherence and risk behaviour.
- Facilitate two-way referral between health outlets and clinics providing ART and community-based services, in part through the placement of trained people with HIV within health outlets and educational settings and through training of implementing partner staff to expand learning opportunities for people with HIV about all facets of HIV infection and disease and treatment options and issues.
- Strengthen groups of people with HIV, including the provision of support to establish such groups for education personnel with HIV, by addressing issues such as group solidarity, mutual social support, developing practical strategies for overcoming barriers to treatment access, adherence and risk behaviour, and supporting people with HIV to play a full and active role in HIV and AIDS education activities rooted in culturally appropriate contexts and that are gender sensitive.
- Strengthen community structures by building bridges between the educational institutions and the community through the provision of education and expanded learning opportunities to promote awareness about HIV and AIDS, VCT, STI and TB diagnosis and treatment, ARVs, treatment adherence and prevention for people with HIV. This will include integrating information and activities on HIV and AIDS, VCT, ARVs, adherence and prevention for people with HIV into existing community-based structures and services, including at schools and health clinics, and will likely be done through small group activities.
- Encourage inter-sectoral engagement, particularly the development of productive relationships between ministries of education and health, and with ministries responsible for social services, for training and capacity building of ministry personnel to ensure that treatment education complements and achieves synergy with treatment programmes, and for supporting effective educational strategies on treatment education within the health care system.
- Develop or adapt curriculum, teaching methodologies and materials development at various levels in the education sector to include treatment education issues, with inputs from health professionals regarding content and accuracy and to ensure that these are consistent with national policies.
- Consider opportunities for developing or strengthening public education and media communication on treatment education, and in formal and non-formal education settings.
- Review and, where necessary, revise education policy, including sound workplace policies throughout the education sector, with policies that protect and support HIV infected and affected education personnel and their families, and where possible, seek to facilitate and support their access to treatment programmes.
- Advocate for the right of education personnel and their families to equitable access to treatment programmes, and broadly mobilise teachers unions and professional associations as part of this effort.
- Utilise the infrastructure of schools and education institutions as a community resource, for example, as delivery sites for treatment education, and where possible and appropriate, for access to prevention and treatment services, linked to social services such as support for children, families, carers and others affected by HIV and AIDS.

Methods to support the ongoing monitoring and evaluation of these activities will be a critical component of all programme structures. Systematic monitoring and evaluating of treatment education activities will enable an assessment of what works well and what needs to be strengthened to help refine and improve the strategies employed and share lessons.

The specific treatment education strategies should be further defined as part of participatory intervention design processes responding to local cultural, contextual and gender factors. In all activities, specific efforts must be made to encourage those exposed to treatment education activities to become key actors in other related, similar interventions.⁶ This should be done on an on-going basis to help to increase the intensity, the reach and the quality of treatment education. Examples of activities that may be included are:

- Conducting educational health fairs and other informational events about ART, HIV prevention and the promotion of health-seeking behaviour where health information on HIV and AIDS, ART and HIV prevention is provided, utilising existing community structures including schools.
- Organising educational street theatre, songs and exhibitions to dispel myths surrounding HIV and those with HIV, and promote ARV treatment, HIV prevention and health seeking behaviour.
- Working through community radio and other media to promulgate treatment education messages.
- Building linkages between formal educational structures, such as schools, and the community to expand opportunities for treatment education, particularly in non-formal educational structures such as youth groups,

unions, neighbourhood associations and others.

- Incorporating health education messages about HIV, ART and prevention, as well as information about how to access prevention and treatment services, in sermons and other congregational or religious activities.
- Mobilising faith-based groups, youth clubs and women's groups to share information about ART, HIV prevention, the importance of respecting confidentiality, and the promotion of health-seeking behaviour.
- Conducting support groups on ART and prevention.
- Providing health education on HIV and AIDS, ART, HIV prevention and health-seeking behaviour in clinics and other community settings where possible including schools.
- Implementing health education on HIV and AIDS, ART, HIV prevention and health-seeking behaviour in the community (e.g., TB-Directly Observed Treatment Short-course (DOTS) teams and home based care teams conducting HIV-TB, ART and HIV prevention education).
- Increasing the quality and quantity of services and mobilising uptake of services through support for collective action.

The selection of treatment education strategies will depend on the specific needs in the programme area, the local social and cultural context including sensitivity to gender issues, and the availability of financial, material and human resources. All strategies should include a combination of efforts to prepare communities, involve people with HIV and those on treatment, link prevention and treatment programmes, combat stigma and discrimination, and work with traditional leaders to support the strengthening of health and social systems.

I. Preparing Communities

While individuals need to be prepared with accurate and appropriate education and problem-solving skills to adhere to treatment and to access support when needed, treatment education will be ineffective without the engagement of a wide range of actors at the community level. Community preparedness is essential because: people seek support and information about HIV and ART from a wide range of sources; fear and stigma and lack of understanding inhibit people from accessing VCT and treatment; and increased knowledge and understanding of HIV and ART can increase support for people on treatment, reduce stigma and support protective behaviours (UNESCO and WHO 2006).

WHO and UNAIDS have emphasised the need for community preparedness for the availability of antiretroviral treatment as this will determine how people understand and accept treatment, as well as influence their health-seeking behaviour. The International HIV/AIDS Alliance has reiterated this need, and has encouraged donors, policymakers, NGOs and others involved in treatment education to place HIV-affected communities at the centre of ARV provision as both implementers and users of ART services (McClean *et al.* 2004). Communities can play a key role in advocating for treatment, selecting people for ART programmes, and providing care and support services to people with HIV.

Advocacy for Treatment

Treatment education engages community members, educators, health workers and other stakeholders to become active partners in addressing HIV prevention, care and treatment needs. Communities have a critical role in mobilising political will and commitment to improve access to ART and reductions in cost of treatment. Brazil has recognised the important role of civil society. From 1994 to 2002, more than US\$ 40 million was invested in 2,300 projects implemented by civil society or-

“Community preparedness for ARVs will help to reduce the burden on the public health care system, improve the morale of health care workers, reduce stigma and potentially have a positive impact on HIV/AIDS prevention.”

Dr. Mandeep Dhaliwal, International HIV/AIDS Alliance (International HIV/AIDS Alliance 2002c:39)

ganizations, including communities and NGO networks of people with HIV and AIDS (Texeira *et al.* 2003:84). In South Africa, TAC has played a key role in raising public awareness and understanding about issues surrounding the availability, affordability and use of HIV and AIDS treatment (*see p. 18 Treatment Costs*).

Advocacy at the individual level is also a critical component for promoting change within healthcare systems and gaining access to treatment. Individuals who are able to lobby on their own behalf for free and equitable access to treatment, when coupled with community efforts, have the ability to make a significant impact on institutional reform. Information, education, and communication (IEC) campaigns and other multi-media can also be used to create informed clients, stimulate demand for services, and encourage communities to expect quality care. For example, “Beat It! Your Guide to Better Living with HIV/AIDS”, a weekly television series in South Africa, aims to combat fear and denial of HIV and AIDS by promoting accurate knowledge and information on a variety of HIV-related subjects, in turn empowering people to “take charge of their own health.” In a recent Treatment Education Consultation co-sponsored by UNESCO and WHO, the representative of Siyayinqoba Beat It! explained that the series “*is about making good decisions and creating environments in which those decisions can be made in a safe space*” (UNESCO and WHO 2006). Concerted efforts are required to ensure that IEC and multi-media strategies and messages are culturally and linguistically appropriate for target communities.

Selection for ART Programmes

“People with HIV should be involved in deciding who gets treatment and in implementation of the programme. It validates and gives power to messages of community preparedness.”

Network of Zambian People Living with HIV/AIDS (NZP+) member (International HIV/AIDS Alliance 2002c:35)

Because the availability of ART in most developing countries does not meet the demand, ARV programmes are required to establish selection criteria. A number of programmes are involving community members, such as people with HIV, community leaders, and home-based care workers in the selection of beneficiaries for ART. The rationale for their inclusion is based on a number of factors including that these members may have good local knowledge of who would benefit from and adhere to ART, that their involvement can enhance equity of access to services, and ensure community ownership of the programme (International HIV/AIDS Alliance 2002c, Loewenson *et al.* 2004, Attawell and Mundy 2003, McLean *et al.* 2004).

Programmes in Senegal (UNAIDS 1998), Malawi (Namakira 2002) and South Africa (WHO 2003c) have demonstrated the benefits of involving community members in the selection process. In Khayelitsha, South Africa, MSF's ART programme offers treatment to individuals meeting the following set of criteria: biomedical (CD4 count less than 200 and a WHO disease stage of 3 or 4), adherence (having regularly attended the clinic for at least 3 months), and geographical (for people living within the catchment area of the project). A participative method has also been introduced that involved community representatives, typically people having experience of working with people with HIV (and including those with HIV), meeting regularly to assess candidates and to determine who would receive ARV treatment. Deliberations are based on established criteria, as well as other social factors such as the health status of the individual, his/her income level, the level of social support available, his/her openness about HIV infection and whether other family members are already receiving ART (WHO 2003f, Kasper *et al.* 2003). Preliminary results of the Khayelitsha ART programme demonstrated that 89 percent of respondents indicated adherence exceeding 95 percent at three months on treatment (WHO 2003c:7).

Care and Support

Community-based care and support programmes, including faith based organizations (FBOs), are increasingly involved in the delivery and support of ART, moving beyond earlier roles that focused on prevention, care and support, and incorporating treatment education as part of their work. The Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM) recently funded a two-year programme for community-based HIV and AIDS management, care and counselling in three provinces in Viet Nam. The model employs a home- and community-based approach to care to enhance social and health services and to enable a favourable environment for people with HIV that includes many of the elements of treatment education (GFATM website). Many CBOs, such as Project Orange in Burkina Faso (Dhaliwal 2003), are delivering ART, although such programmes are confronted with numerous challenges including procuring affordable ART and treatment for opportunistic infections, improving access to treatment, building capacity of programme managers and staff, and scaling-up programmes. Bristol-Myers Squibb is currently testing how HIV treatment can best be combined with community-based care in its US\$ 115 million Secure the Future® Initiative. Initiated in 1999 in five countries in southern Africa (Botswana, Lesotho, Namibia, South Africa and Swaziland), the pro-



gramme was expanded in 2001 to four countries in West Africa (Burkina Faso, Cote d'Ivoire, Mali and Senegal) (BMS 2004). Many such care and support programmes are already offering treatment education as part of the package of services provided and represent an opportunity for strengthening work in this area in future.

The International HIV/AIDS Alliance has also supported capacity-building programmes for community members to expand HIV-related counselling services. Supervision, support and ongoing training is provided to lay counsellors by professional counsellors, who are then able to rely on a wider group of people within the community to refer clients to support (International HIV/AIDS Alliance 2002c).

ing acknowledgment that the needs and concerns of teachers themselves with regard to HIV and AIDS must be addressed, and that they must not be viewed as merely a channel for delivering HIV and AIDS education.



2. Involving People with HIV, including those on Treatment

At the 1994 Paris AIDS Summit, 42 governments declared that the principle of greater involvement of people living with or affected by HIV and AIDS (GIPA) is critical to ethical and effective national responses to the epidemic. This principle was reinforced at the UNGASS in 2001 and was further upheld in the Guiding Principles for WHO/UNAIDS' "3 by 5" Initiative. GIPA recognises that people with HIV can make important contributions at multiple levels, from the individual to the organisational, and in multiple sectors, from the social and cultural to the economic and political. Consistent with the GIPA principle, people on treatment need to be part of policy making and educational efforts at all levels and must be involved in the implementation of services (WHO 2004b).

As individuals or as members of support groups, people with HIV have a crucial role to play at every level of treatment education, as active and informed participants in treatment, as treatment service providers, as treatment educators and counsellors, as programme managers, planners and evaluators, and as treatment advocates. The involvement of people with HIV enables important links to be built between communities and services. It can also lead to increased health and well-being of those involved and can reduce HIV-related stigma and discrimination.

The Ministry of Education in Malawi is considering how it can support the establishment of support groups for teachers with HIV, recognising the difficulty and strong sense of isolation these teachers often experience.⁷ There is an increas-

Builds Links between Communities and Services

Although treatment education involves everyone, regardless of HIV status, people with HIV can build important links between affected communities and treatment services. Many are involved in key elements of treatment education, including treatment adherence support programmes as adherence partners or "buddies" and as ART counsellors (see p. 19 *Adherence to ARV Regimens*). In India, HIV-positive service providers take people to the hospital, where they mediate with health professionals and facilitate access to care. Some also refer HIV-positive service users to social services and assist with administrative paperwork (Population Council *et al.* 2003:83). Treatment uptake and adherence have been found to be higher in settings, such as in Brazil and Khayelishta, South Africa, where people with HIV have been involved in counselling and in community mobilisation, key facets of treatment education (Attawell and Mundy 2003, WHO 2003c, Reuter *et al.* 2004).

Provides Personal Benefits to those Involved

The involvement of people with HIV in treatment education provides important opportunities for those involved to focus on their individual health needs and to advocate for their rights to make in-

formed decisions regarding their health and healthcare. Reported benefits include increased peer support, decreased isolation and self-stigma, better access to information, care and treatment and improved knowledge of HIV and AIDS, increased confidence and self-esteem, and greater acceptance by families and communities. In Zambia, involvement in the Care and Prevention Teams at the Salvation Army's Chikankata Health Services helped people with HIV to gain the education necessary to identify opportunistic infections at an early stage and promptly seek medical attention. One member explained, *"My health has really improved because I have now learnt how to look after myself properly"* (Population Council *et al.* 2003:105). In Ecuador, a person with HIV working with the Fundación Simpre Vida voiced a similar experience, *"Since I joined the organization...I have learned more about the disease, how to live with it and how to accept my positive status...I know where to go and what to do and who to get help from when I need it"* (Population Council *et al.* 2003:103-104).

Reduces Stigma

Stories of personal experiences can also help to reduce the stigma surrounding HIV and treatment. MSF and grassroots treatment advocates from the South Africa's TAC have established community-based education programmes, such as Ulwazi—the Xhosa word for "knowledge"—in Khayelitsha. Ulwazi conducts workshops about HIV and AIDS and treatment in schools, workplaces, churches

and community gatherings. Many of the Ulwazi volunteers are themselves HIV-positive and have confronted barriers of disclosure. Their openness has helped others come forward and face their fears about being infected (Reuter *et al.* 2004, WHO 2003c).

Important Considerations

The involvement of people with HIV in treatment education programmes must be carried out in a planned, sensitive and responsible manner to avoid being tokenistic, or to expose them to further stigma or discrimination. It is also critical to remember that there are many people who do not know their HIV status, and that not all people with HIV have the proper skills or knowledge to advocate on their own behalf. This may require the provision of:

- Training and other educational opportunities to develop HIV and AIDS knowledge, communication, organisation and management skills.
- Psychosocial and material support to people with HIV with few resources (through, for example, peer counselling, financial compensation, food, drugs, medical care, travel reimbursement, child care and education programmes).
- Links to referral services for medical care, counselling, training, support groups and positive living skills (*see p. 21 Continued Protective Behaviours*). (International HIV/AIDS Alliance 2002a, UNAIDS 1999a, GNP+ 2004, Population Council *et al.* 2003)

3. Linking Prevention and Treatment

More widespread access to ART has the potential to attract millions of people into health-care settings, thus increasing opportunities to promote HIV and STI diagnosis and treatment, and providing an environment in which HIV prevention messages can be delivered and reinforced. This is recognised in the recently adopted UNAIDS policy position paper “Intensifying HIV Prevention” (UNAIDS 2005b). The availability of HIV treatment provides new incentives for HIV testing (see p. 12 *Knowing One’s Status*), which can, in turn, increase counselling opportunities for prevention (see p. 21 *Continued Protective Behaviours*). Increased knowledge of HIV status has the potential to enable prevention programmes to develop interventions that are specifically targeted to the different needs of HIV-positive, HIV-negative, and untested individuals (Gayle and Lange 2004). ART also has the potential to lower the infectivity of HIV-positive individuals who are on ART, making transmission less likely (Porco 2004, Mukherjee *et al.* 2003). Improved diagnosis and treatment of STIs are also an important part of HIV prevention as evidence has demonstrated that an untreated STI can increase both the acquisition and transmission of HIV by up to tenfold (CDC 2005). Clinical services offering STI care are also an important access point for people at high risk for HIV, not only for diagnosis and treatment but also for information and education.

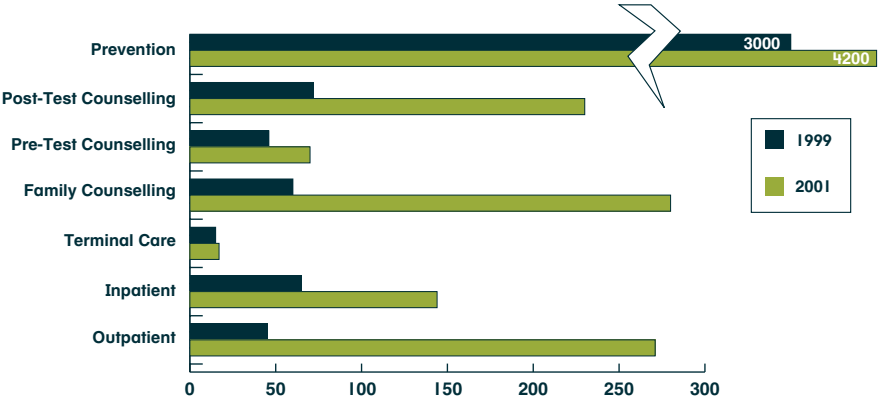
Linking prevention and treatment services maximises the use of resources, increases the potential to reach more people, and enhances the sustainability and impact of the response. In Khayelitsha, the availability of comprehensive HIV and AIDS services that include ART has had effects on use of prevention services. The number of pregnant

“ARV therapy is not only an ethical imperative, it will also strengthen prevention efforts, increase uptake of voluntary counselling and testing, reduce the incidence of opportunistic infections, and reduce the burden of HIV/AIDS—including the number of orphans—on families, communities and economies.”

Pan-African HIV/AIDS Treatment Access Movement (PHATAM)’s Declaration of Action (PHATAM 2002)

women attending VCT has tripled between 1999 and 2002 (Reuter *et al.* 2004, WHO 2003c). In Brazil, prevention and treatment strategies have contributed to a ten-fold increase in the consistent use of condoms from 4 percent in 1986 to 48 percent in 1999 (Teixeira *et al.* 2003). In India, increased availability of care and support services led to an increased demand for all services, including prevention (see Figure 7), suggesting that attention to care and support need not detract from prevention, and in fact may help strengthen prevention efforts. Improved care will also strengthen prevention by promoting greater openness in discussions of HIV and AIDS in the community, reducing stigma and discrimination, and potentially slowing the growth of populations at risk such as orphans and sex workers (Ciccio 2004, Farmer 2001a, Farmer 2001b, International Treatment Access Coalition, WHO, 2002).

Figure 7: Service Utilisation Before and After Scale-Up of HIV Care and Support Services in Chirala, India



Source: Castle *et al.* 2002

4. Tackling Stigma and Discrimination

“AIDS is becoming a chronic treatable disease like diabetes and hypertension. There is no need to stigmatise people anymore.”

Community leader, Uganda (Kagimu 2003)



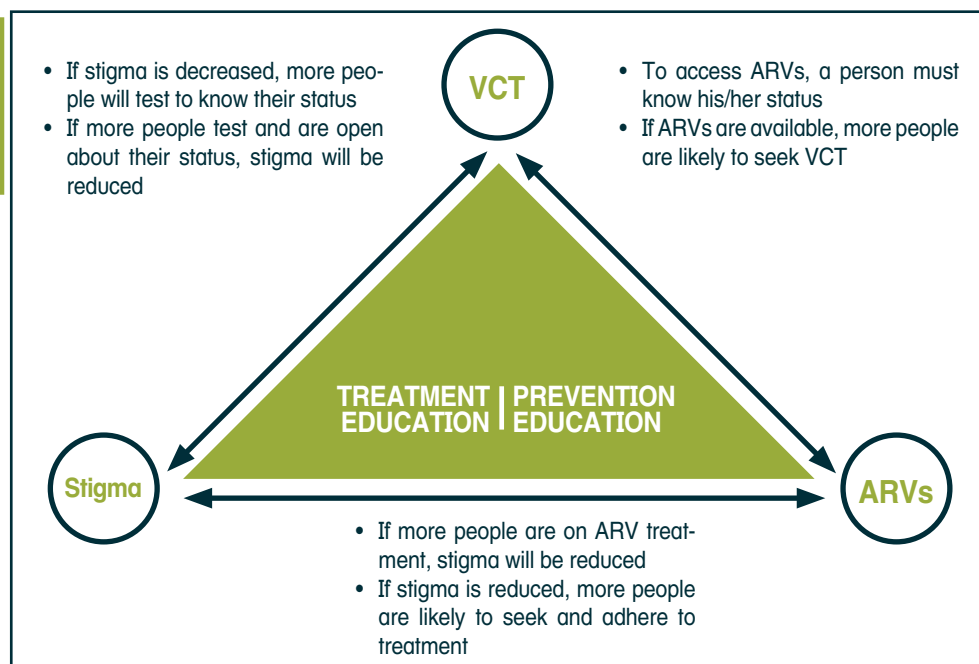
HIV-related stigma and its associated discrimination are known to negatively affect all aspects of HIV prevention, diagnosis, treatment and care (Brown *et al.* 2001). Stigma prevents many people with HIV from receiving the support that they need due to rejection by their partners, families or communities, or because fear of rejection prevents them from being tested for HIV, adopting preventive behaviours, or otherwise addressing precarious situations (Panos 2000, UNAIDS 2003b).

WHO and UNAIDS assert that access to ART will rapidly reduce stigma by making it a chronic, but treatable condition (WHO, UNAIDS 2003). Decreased stigma is reflected in an increased willingness of people with HIV to discuss their diagnosis openly, an increased

demand for HIV testing, and a reduced number of complaints of stigma and discrimination by people with HIV, family members, colleagues, and communities. One person in MSF's pilot programme in Malawi described ART at the International AIDS Conference in Barcelona in 2002 as *“the best tool against stigma”* because *“people do not reject you when you feel better”* (Minandi 2002).

In a community consultation on ART in Zambia, participants depicted the relationship between stigma, VCT, and ARV as a triangle with mutual reinforcements (see Figure 8, opposite). Treatment education, placed in the centre of this diagram, can be considered as the foundation that strengthens and reinforces these relationships. It revitalises prevention education. It improves the quality of life of people with HIV and AIDS and promotes a safer environment where people will feel more comfortable being tested for HIV and aware of their status. It improves health-seeking behaviour, including VCT, diagnosis and treatment of STIs, treatment of opportunistic infections, and other elements of HIV prevention and care. In addition, programme experience indicates that treatment education can promote dialogue and partnerships between treatment providers, NGOs, local and national governments, international agencies, private sector and local groups of people living with HIV in order to improve equity of access to ART and bolster efforts to reduce stigma and discrimination (Mills 2002).

Figure 8: Relationship between Stigma, VCT, ARVs and Treatment Education



Source: Adapted from International HIV/AIDS Alliance 2002c:34

5. Working with Traditional Healers

Involving traditional health practitioners as part of treatment education can be key to scaling up comprehensive care in many locations. For example, in Africa, traditional health practitioners and traditional birth attendants represent the first line of care for 70 percent of the population (WHO 2002b). They often have a wide audience as well as an in-depth knowledge of the culture and the community, and are thus ideally placed to promote behaviour change and to care for, support and refer people with HIV and AIDS to services (UNAIDS 2002). To be effective, traditional practitioners must be provided with the right information and skills to combat misconceptions, rumours and incorrect information and linked to facilities that can provide appropriate care.

Over the past decade, Traditional and Modern Health Practitioners against

AIDS (THETA) have involved thousands of African traditional health practitioners in STI and HIV prevention and care (Homsy *et al.* 2004). Equipped with adequate skills, knowledge and support, these providers have played numerous roles including complementary care providers, treatment adherence counsellors, and referral advisors. They have assisted in educating communities, promoting and distributing condoms, treating and referring the sick, directing clients to VCT services, referring those in need of diagnosis and treatment of STIs and opportunistic infections, or to PMCT programmes, and conducting pre- and post-test counselling (Homsy *et al.* 2004, UNAIDS 2002).



6. Supporting and Strengthening Health and Social Systems

Treatment education cannot replace the need for functioning health and social systems that ensure adequate diagnosis and treatment of STIs and opportunistic infections, procurement and stock management support for essential drugs, ensure the skills and expertise to manage all aspects of HIV-positive diagnoses, and the correct use of and adherence to ARVs to avoid the emergence and transmission of drug-resistant strains (WHO 1998). Education on these elements is important, particularly at the tertiary level.

The Declaration of Commitment issued by UNGASS calls for the strengthening of health systems for implementing comprehensive strategies in the expanded global response to HIV and AIDS (UNGASS, paragraph 55). The WHO's 2003 World Health Report reiterated this need. ART programmes should be reinforced by:

- Drug and commodity procurement policies;
- Logistics management, storage and supply systems;
- Regulatory and distribution mechanisms;
- Infrastructure development and maintenance, including laboratory facilities;
- Functioning health information systems (HIS);
- Long-term financing mechanisms to ensure that availability, accessibility, cost-effectiveness, sustainability of programmes; and
- Capacity building of counsellors, lab technicians, medical practitioners (doctors, nurses and relevant health staff) in the use of standard ARV

guidelines (*see p. 15 Information on Drug Regimens*), confidentiality, informed consent and other ethical issues (WHO 2003e). Capacity building should focus not only on clinical issues but also personal attitudes, biases and values of service providers towards those affected by AIDS or living with HIV (WHO 2004b).

Advocacy for these critical elements of ART programmes can be supported through good treatment education programmes, working to help raise awareness of the full range of things that need to be in place in order for treatment programmes to function effectively.

In Uganda, the Ministry of Health developed accreditation criteria for clinical centres that would be authorised to prescribe ART. The minimum criteria for accreditation include setting and achieving targets for the comprehensive basic health care services as outlined in the minimum health care package, the presence of basic physical infrastructure (space for HIV counselling and testing, clinical assessment, drug storage and laboratory facilities), minimum numbers of qualified personnel with experience in HIV and AIDS management and the ability to ensure the provision of follow-up care and support for families and communities with people with HIV (WHO 2003f). The last point, concerning follow-up care and support, represents a key area where treatment education can help to mobilise individuals and communities to play an important complementary role in treatment programmes.

Conclusions and Recommendations



Treatment education complements the provision of drugs and medical care by involving community members, educators, health workers and other stakeholders to become active partners in addressing HIV prevention, care and treatment needs. It recognises that HIV and AIDS is not only a health issue, but also a social, economic, cultural and development issue and that, as such, treatment education needs to reach beyond health facilities into other institutions and into communities.

It has been argued in this publication that the education sector has—in collaboration with other sec-

tors including health, communication, culture and science—a vital role to play in the delivery of treatment education. For example, the media can be sensitised and engaged to include treatment education messages, and treatment education can be more fully incorporated into ongoing VCT efforts. Treatment education can be included as part of culturally-sensitive and gender responsive efforts, for example integrated in community drama forums, practices of traditional healers and religious leaders. Bioethics committees can be consulted and involved to support thinking around the ethical issues related to equity of access to treatment.

To recognise the full potential of treatment education, education ministries, civil society organizations, and development partners need to:

I. Ensure That the Education Sector is Fully Engaged in Treatment Education

The Education Sector, defined broadly, has an important role to play in relation to treatment education as educational institutions reach further into communities around the world than many others. It is important to understand that treatment education can be addressed within all modalities of education—formal, nonformal, and informal, at all levels from early childhood through to higher and adult education, and in all aspects of the sector such as policy and legislation, as well as curriculum and materials.

Consideration of treatment education, as a key element of education, is best conceptualised from a sector-wide approach. Thus, it should be considered in relation to the entire sector including ministries, universities, teacher education institutions, research and evaluation centres, schools, and community and literacy centres.

A key area for the Sector to address as quickly as possible is the development of a coherent policy and workable practice on treatment education that is consistent with national and legal frameworks that address issues of HIV and AIDS, such as workplace policies and insurance frameworks. Obviously, this links to the need for inter-sectoral

collaboration, particularly with the Health Sector. The development of policy and practice will be greatly strengthened through the involvement of persons living with or affected by HIV, including those on treatment.

Within curricula and learning materials, there is the need to ensure that correct information is available to learners at different levels. In addition to age-appropriate accurate information, the rights and responsibilities of all regarding ART will need to be clear. This is a major role for the Sector—again through all modalities. Another area for further development by the Sector relates to the teaching and learning of problem-solving skills around symptom and side-effect management by people with HIV in order to effectively liaise with community- and facility-based services and to ensure good adherence to their regimens.

In some circumstances educational meeting places may, in collaboration with other sectors, also serve as locations for care and treatment, including the availability of drugs and access to counselling. These responsibilities should not, however, in any way impinge on or take resources from already stretched educational resources.

2. Support Inter-Sectoral Collaborations

Scaling up the provision of ART and related services is placing enormous demands on the health sector and on health systems. The health sector should not additionally be expected to be solely responsible for refining and improving knowledge, skills and attitudes regarding HIV-related treatment. Instead, inter-sectoral collaborations should be encouraged between treatment educators and providers, NGOs, CBOs and FBOs, ministries (including the ministry of health, ministry of education, and other relevant ministries) and local au-

thorities, international agencies, the private sector and local groups of people with HIV. Coordinating such an effort is a considerable task that will require the cooperation of many stakeholders, as well as a strategic plan for moving forward. It is also essential that experiences and knowledge on inter-sectoral collaborations to promote treatment education be shared within and across regions, reflecting the role and contribution of the education sector, to promote cooperation and adaptation of good practices.

3. Focus on Gender-Responsive Strategies

The theme of World AIDS Day 2004, “Women, HIV and AIDS”, reflected the international community’s growing concern regarding the increasing “feminisation” of the epidemic, the importance of advancing the basic human rights of women and girls, and increasingly recognising and demanding accountability with regard to the roles and responsibilities of boys and men (UNAIDS 2004c). In response to these concerns, the Global Coalition on Women and AIDS is working with partners to bring attention to the issues

that women face, including higher burdens of disease, poverty, and violence. Treatment education programmes must develop gender-responsive strategies that address barriers that women and girls often encounter in accessing and adhering to ART, that promote shared responsibility of men and women for safer sexual behaviours and other risk-reduction strategies, and that support women’s advancement and their full enjoyment of their human rights, including equitable access to prevention and treatment services.

4. Maintain and Expand Prevention Education

Antiretroviral drugs do not cure HIV, they only suppress viral replication and improve the quality of life of persons living with HIV. As such, continued prevention education is needed to equip people with the knowledge, skills and tools required to prevent new infections. With the expansion of ARV availability, there is the concern that prevention efforts may wane or lose valuable progress made over the last two decades. It is essential that this loss not occur and that advancements in prevention education are coupled with treatment education, so as to mutually reinforce one another. There is an increased understanding that ART and prevention for people with HIV have a symbiotic relationship, and that efforts to

scale up access to ART must go hand in hand with specific prevention efforts targeting those with HIV (UNAIDS 2005c). Furthermore, ART offers important opportunities for the delivery of secondary prevention interventions and ongoing health management.

Strengthened programmes at the tertiary level, including teacher training, is an area where the education sector can particularly help to improve prevention education efforts. This contribution extends to the training of health workers, ensuring that they receive a quality education that includes a good understanding of treatment education issues and opportunities.



5. Address Multiple Groups with Targeted Messages

Treatment education is needed not only for people with HIV and those on treatment, but also for health care providers, community members, educators, advocates, government officials and the wider public. Treatment education programmes will need to develop communication strategies to identify key audiences, develop appropriate messages, identify particular formats and pedagogies and channels for delivery (e.g., radio spots, professional meetings, leaflets and posters, traditional theatre), and establish means of monitoring and evaluating the effectiveness and efficacy

of different approaches. As discussions about HIV often include issues of human sexuality and sexual orientation, it is critical that these dialogues be developed in context with the cultural situation.

Different treatment education messages will be more or less effective depending upon the group that they are targeting and the method in which they are delivered. See *Appendix 1* for an example of key audiences and messages identified by the Ministry of Health in Botswana for their behaviour change and communication strategy for ARV treatment.

6. Employ a Range of Approaches for Different Settings and Groups

Specially tailored materials and programmes must be developed employing a range of approaches for different settings and groups, and be age-appropriate, gender-responsive and culturally sensitive. Materials must be kept updated regularly to include the latest and most relevant information and wherever possible, developed through participatory approaches with relevant groups.

Educational approaches should be appropriate to the objectives at hand, need not be didactic, and could include traditional media such as theatre, drama or

other means. Interactive theatre (such as participatory forum theatre or popular theatre) has proven to be a culturally appropriate, participatory and effective means of achieving behaviour change and may be effective for treatment education. Community radio programmes reach a wide population in many settings; radio programmers must be properly trained to provide accurate and appropriate information. Treatment education should explore other creative means to reach into communities such as educational street theatre, song and other exhibitions about ART, HIV prevention and health seeking behaviour.

Endnotes

- 1) Personal communication from Dr. Mostafa El Nakib to Ms. Noha Bawazir, 31 August 2005.
- 2) Information provided by the officials from the Zambian Ministry of Education during a Sub-regional colloquium “Teaching in A World with AIDS” organised by the UNESCO Harare Cluster Office, 29 November – 1 December 2004.
- 3) Highly Active Antiretroviral Therapy (HAART) is the ‘cocktail’ of individual HIV treatment medications that compose the treatment therapy regime.
- 4) Personal communication from Dr. Mostafa El Nakib to Ms. Noha Bawazir, 31 August 2005.
- 5) As part of the effort to develop work in this area, UNESCO co-hosted a technical consultation on treatment education with WHO in 22-23 November 2005. For the outcomes of the consultation, see UNESCO and WHO 2006.
- 6) This is based on the model used by MSF and Treatment Action Campaign in the Khayelitsha treatment project in South Africa.
- 7) Information provided during a Sub-regional colloquium “Teaching in A World with AIDS” organized by the UNESCO Harare Cluster Office, 29 November – 1 December 2004.

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Appendix:

Examples of Target Audiences and Sample Messages for Treatment Education

Target Audiences	Sample Messages
Service Providers	<ul style="list-style-type: none"> • Counselling plays a crucial role in ART. HIV is not a death sentence, it is worthwhile to test • ART improves peoples' health and allows them to remain productive • ART is not a cure, it is a disease management tool • ART is a lifelong commitment • Adherence is crucial if the therapy is to work effectively • People with HIV must understand how the drugs work and why they must be taken exactly as prescribed
NGOs	<ul style="list-style-type: none"> • Your organization is pivotal to the success of the ART programme • You can make an impact by promoting positive living
Private Sector, Employers and Trade Unions	<ul style="list-style-type: none"> • A healthy workforce supports healthy profits • A caring company will be supported by employees, government and customers
Religious Leaders	<ul style="list-style-type: none"> • ART improves your congregation's quality of life • Your commitment to ART initiatives illustrates your support to your country • ART and faith can benefit the patient and reinforce the management of AIDS
Traditional Health Practitioners	<ul style="list-style-type: none"> • You play a vital role in the success of the ART programme • Traditional and modern medicine can work together to combat HIV/AIDS • Health authorities respect and acknowledge you as health practitioners
Family Care Givers	<ul style="list-style-type: none"> • Make sure that your family member on ART takes the right medication at the right time • Protect your loved ones and yourself • Strong family values safeguard the future • Love and accept family members with HIV/AIDS
General Public	<ul style="list-style-type: none"> • HIV is not a death sentence • Get tested for HIV to see whether you have the virus and are eligible to start ART • Not everyone with HIV needs to start ART right away • People on ART are still HIV positive and can still infect others • You must have protected sex while on ART • ART is not a cure for HIV/AIDS • PLHA, on ART or not, must live a positive lifestyle, which includes eating a balanced diet, resting properly and being physically active • ART is a lifelong commitment • ART will improve your health and allow you to be more productive • Some people on ART will develop side effects, these people must consult their healthcare team • For ART to work, you must take your pills at the right time, in the right way, every day
Persons on ART	<ul style="list-style-type: none"> • Understand the patient selection criteria for ART • Ask your medical team what to expect from ART to avoid having unrealistic expectations • ART is a lifelong commitment—once you start, you can never stop taking the medicines

Source: Ministry of Health Botswana 2002. Modified by AED 2002:19.

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This report signals ways that the education sector can play a role along with others engaged in efforts to achieve universal access to prevention, treatment, and care. It considers some key strategies, including how to effectively engage and prepare communities and how to involve key constituencies including people with HIV and those on treatment.

The paper addresses the link between prevention and treatment, examines the harmful effects of stigma and discrimination and explores how these factors impede progress in prevention and treatment access. In addition, the paper suggests priority future directions, including the development of practical guidelines and materials that can be used to support the integration of treatment education within ongoing HIV and AIDS education efforts, ongoing close communication with authorities and organizations responsible for expanding treatment access to ensure coherent and well-coordinated programming, and the dissemination of effective approaches to treatment education.

The paper was developed for the UNAIDS Inter-Agency Task Team (IATT) on Education. The IATT on Education is convened by UNESCO and includes as members the UNAIDS Co-sponsoring agencies, bilateral agencies, private donors, and civil society. The IATT on Education aims to accelerate and improve the education sector response to HIV and AIDS.

For more information about the IATT on Education, visit <http://www.unesco.org/aids/iatt>