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**H**  **rizons**

**Current Research and Good Practice  
in HIV and AIDS Treatment Education**

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## Preface

The paper on 'Current Research and Good Practice in HIV and AIDS Treatment Education' was written for the United Nations Educational, Scientific, and Cultural Organization (UNESCO) and the World Health Organization (WHO) for presentation at a Technical Consultation in Paris, France 22-23 November 2005. The Consultation was co-organised by UNESCO and WHO, and aimed to review the current status of treatment education at the global, country and community levels and 'take stock' of experiences, lessons learned, and good practices in treatment education; and to identify needs in the realm of treatment education, with a focus on treatment literacy and community preparedness. The meeting was designed to develop an action framework with key priorities for work in the near future for the various partners, including UN agencies, national authorities and civil society, taking into consideration the added value of each and encouraging joint programming; and to identify how the UNESCO-led EDUCAIDS Initiative and the UNAIDS-led campaign on "Universal Access to Prevention, Treatment and Care" can contribute to treatment education.

**A copy of the "HIV and AIDS Treatment Education Technical Consultation Report, 22-23 November 2005" (UNESCO and WHO, 2006) can be downloaded at:**  
<http://unesdoc.unesco.org/images/0014/001461/146120e.pdf>

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## Acronyms

<b>AIDS</b>	Acquired Immune Deficiency Syndrome
<b>ART</b>	Antiretroviral therapy
<b>ARV</b>	Antiretroviral
<b>CBO</b>	Community based organization
<b>CDC</b>	US Centres for Disease Control and Prevention
<b>CHW</b>	Community health workers
<b>DAART</b>	Directly administered antiretroviral therapy
<b>DOT</b>	Directly observed therapy
<b>DOTS</b>	Directly observed therapy short-course
<b>FBO</b>	Faith based organization
<b>FHI</b>	Family Health International
<b>FHO</b>	Field health officer
<b>GFATM</b>	Global Fund to fight AIDS, Tuberculosis and Malaria
<b>HAART</b>	Highly active antiretroviral therapy
<b>HCW</b>	Health care worker
<b>IDU</b>	Injecting drug user
<b>MHS</b>	Mental health scores (Medical Outcomes Study (MOS) HIV Quality of Life)
<b>MSM</b>	Men who have sex with men
<b>NGO</b>	Non-governmental organization
<b>OI</b>	Opportunistic infection
<b>PEPFAR</b>	(US) President's Emergency Plan for AIDS Relief
<b>PHS</b>	Physical health scores (MOS HIV Quality of Life)
<b>PLHIV</b>	People living with HIV
<b>PMTCT</b>	Prevention of mother-to-child transmission
<b>REALM</b>	Rapid Estimate of Adult Literacy in Medicine
<b>QOL</b>	Quality of life
<b>TAC</b>	Treatment Action Campaign
<b>TASO</b>	The AIDS Support Organization
<b>TB</b>	Tuberculosis
<b>UNAIDS</b>	Joint United Nations Programme on HIV/ AIDS
<b>UNESCO</b>	United Nations Educational, Scientific and Cultural Organization
<b>VCT</b>	Voluntary counselling and testing
<b>WHO</b>	World Health Organization

## Executive Summary

As ART is scaled up, there is a growing realisation among programme managers and donors that merely providing ART and training health providers is not sufficient and that unless efforts are made to engage communities and individuals to improve their knowledge and understanding of HIV, AIDS, and ART, programmes will not be able to meet the targets set by these initiatives, and will fall far short of contributing to the goal of attaining universal access to treatment. Treatment education has thus become a critical link between service provision and actual uptake of services.

This paper describes current research and field experiences related to HIV and AIDS treatment education undertaken with individuals and communities and focuses on a select number of treatment education programmes that are currently underway in Kenya, South Africa, Thailand, Uganda, and Zambia. The paper also discusses a treatment literacy intervention evaluated in the United States. These programmes in Africa and Asia were selected because they represent a range of treatment education and adherence support interventions that target individuals and/or communities in developing countries, where documentation has been more limited. The paper highlights some of the successes of these programmes and identifies the gaps and problems experienced while conducting treatment education.

### **The Importance of Treatment Education**

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With the success of ART in reducing morbidity and mortality, HIV infection has become a chronic, manageable disease. However, to achieve successful treatment outcomes (undetectable viral loads and increasing CD4 counts) and prevent viral resistance, patients on ART require high levels of adherence – greater than 95 percent. The management of adherence is made more complicated and influenced by multiple, often overlapping factors. Preparing patients through treatment education and providing ongoing need-based education helps persons with HIV manage their treatment and HIV-related diseases. At the community level, treatment education encourages people to learn their HIV status and seek care, thereby increasing uptake of VCT and care services, and reducing stigma in the community.

The need for treatment education is evident in the findings from the field. The ACER (Community Education and Referral) project in Zambia aims to improve health-seeking behaviour, equity of access to care, adherence to ART, and adoption of safe

sexual behaviours among people with HIV through a community preparedness strategy. Baseline findings from a community survey highlight the need for raising HIV and AIDS awareness and providing treatment education in the community to increase understanding of ART and to reduce stigma. For example, just over half of respondents had heard of ART and less than a third had undergone HIV testing and counselling. More than a third did not know that condoms could reduce the risk of contracting HIV. The survey also revealed stigmatising views among community members. In a similar vein, baseline data from people living with HIV initiating ART in Mombasa, Kenya, revealed high levels of internalised or perceived stigma.

A situation analysis of the newly introduced national Thai ART programme in 2002, conducted in 15 hospitals in five Northern provinces of Thailand, documented a high drop-out rate (30 percent) among patients in the first six months of the programme mainly due to the severity of side effects experienced by clients. Varying patterns of non-adherence to ART, which included missed doses, not taking medications on time, and not following instructions, were also reported.

## **Existing Individual and Community Treatment Education Interventions**

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### **Individual Approaches**

As new ART programmes are rolled out and existing programmes scaled up in many countries, a variety of treatment education initiatives are being undertaken. While basic information on ART is generally provided to persons with HIV initiating treatment, many programmes have also introduced specific treatment education interventions at the individual level to support treatment adherence, such as peer support, treatment “buddies,” visits by community health workers, and formal adherence counselling. In general, the programmes examined for this paper included comprehensive counselling and adherence support for patients receiving ART.

### **Community Education and Preparedness**

The report documents community education and preparedness interventions in several countries. In South Africa, the Treatment Action Campaign (TAC) has a very active community mobilisation and treatment literacy programme, “Project *Ulwazi*” (meaning knowledge). Through a cadre of volunteers, the programme reaches the community with information via high schools, public sector health clinics, shopping centres, workplaces, churches, the media, and other fora. The programme also uses HIV-positive “treatment supporters” to assist persons with HIV receiving ART.

TASO in Uganda uses HIV-positive peers, several of whom are on ART, and community health workers, known as ‘Field Health Officers’ (FHOs), to conduct

community outreach and education. In Zambia, the ACER project uses a variety of community resources to conduct treatment education such as traditional healers, church groups, networks of people living with HIV and community health workers (CHWs).

A review of the literature shows that ART community education initiatives are taking place in other countries as well: in Cambodia through monks and networks of people living with HIV, in Haiti through community health workers, in Tanzania through traditional healers and traditional birth attendants, in Thailand through peer educators and in Poland through NGO activists.

### **Use of Community Resources for Treatment Education**

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Health staffing is crucial to increasing access to ART. Unfortunately, health workforces are shrinking in many low-income countries, mainly due to migration of staff seeking better working conditions, and uneven distribution of workers between urban and rural areas.

Overburdened health workers can rarely extend their reach beyond the limits of the health facilities in which they work. ART programmes are finding that CHWs and people living with HIV are useful resources to help mitigate the shortage of health workers by providing outreach support near patients' homes, and in the case of peers, serving as role models for others infected with HIV.

Haiti's Equity Initiative is well known for using CHWs, also called *Accompagnateurs*, in its tuberculosis (TB) and HIV directly observed treatment (DOT) programme. The Mombasa ART pilot project also uses CHWs as "tracers" to verify addresses of patients initiating ART, trace defaulters who miss clinic appointments, and carry medications for sick patients who are unable to visit the clinic. In Thailand, the national ART programme is using peer educators to support people living with HIV on ART in the northern provinces of the country. Using peer educators not only benefits clients in the programme but also benefits the peers themselves by improving their self-confidence and self-esteem, and gaining a source of income.

### **Gaps and Challenges of Treatment Education**

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Although treatment education initiatives in the community cover a wide range of activities, as illustrated by the examples discussed in this report, as the programmes mature, a number of challenges and gaps have emerged.



- **Reaching marginalized groups and key populations** such as men who have sex with men (MSM) and injecting drug users (IDUs) that are largely invisible and therefore do not benefit from standard community education initiatives.
- **Offering treatment education in educational institutions.** A large number of community initiatives provide HIV and treatment education in schools. But managers felt that programmes were limited in their reach and confined to a limited number of schools within small geographical areas. The need for a standard curriculum on HIV and treatment education in schools across a country, including universities and vocational institutions, was mentioned.
- **Expanding treatment education in the private sector.** Although the private sector provides services to a significant portion of the population, private sector health facilities, employer-based health programmes, and workplace interventions are often left out of HIV education and awareness programmes due to problems of access.
- **Improving coordination among agencies that provide HIV and treatment education in the community** was listed as a major challenge. There are often several agencies operating within a given community and programme managers stressed that there is frequently very little coordination among them, giving rise to inconsistent and conflicting education messages being sent out to the field.
- **Developing and disseminating treatment literacy materials.** Programme managers of the three community-based programmes interviewed for this paper (TAC, TASO, and ACER) noted shortages of literacy materials and funds to reprint materials. Programmes also lack resources to translate literacy materials into local languages. Non-availability of age-appropriate materials was also mentioned as a gap by programme managers.
- **Maintaining ongoing services while expanding into new areas.** Treatment education is an ongoing process that requires a repetition of education sessions. The need for repetition and reinforcement of messages within the same community raises the issue of resources. All programme managers highlighted the challenge of conducting ongoing services in the face of resource constraints. Shortages of literacy materials, education tools for health workers, and materials in local languages, and the need to update literacy materials to reflect recent developments were mentioned.
- **Extending ARV treatment literacy and education to existing HIV prevention settings.** An important priority is for other HIV prevention services, such as those for voluntary counselling and testing (VCT) and prevention of mother-to-child transmission (PMTCT) of HIV, to include treatment education.
- **Addressing gender gaps in HIV knowledge and service utilisation.** Research data from many African countries show that women tend to have less HIV prevention knowledge than men. In some communities, women may be more likely to seek treatment or take advantage of support services, such as post-test clubs or peer support, therefore programmes may need to reach out more to

men. Thus treatment education efforts need to be responsive to gender differences in access to and utilisation of information and services

- **Meeting other needs.** As programmes mature and patients' health improves, programme managers encounter new challenges beyond providing information about HIV and treatment. These often relate to the need to provide a complete package of care that takes into account the economic and nutritional needs of HIV-positive persons on ART. Such challenges are coming up in Kenya, India, and Zambia and other developing countries.

### **Effectiveness of Treatment Education**

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Because most programmes being implemented in communities in resource-constrained settings have been in existence for a relatively short period of time, the focus has largely been on initiating and carrying out treatment education activities. Therefore, research to assess the effectiveness of AIDS-related treatment education in developing countries is limited. Evidence from ongoing studies or recent assessments of interventions profiled in this paper highlight positive associations between exposure to treatment education and various outcomes such as HIV- and treatment-related knowledge, self efficacy, adherence to treatment, immunological and virological outcomes, health related quality of life, internalised or perceived stigma and practice of preventive behaviours.

### **Conclusions and Recommendations**

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This paper documents the importance of treatment education as part of ART service delivery and the variety of approaches being used worldwide for treatment education in health care settings and in the community. These approaches often include the use of community resources, such as peer educators, community health workers, treatment buddies, and support groups for people living with HIV, to help people on ART take medications correctly and adhere to treatment and to increase awareness and knowledge about HIV and ART in the wider community. Several of the programmes profiled target a wide range of populations through schools, markets, workplaces, homes, health facilities, and the community, using a range of activities such as street plays, radio and television media, school education programmes, and home visits, among others.

However, documentation and availability of information on the effectiveness of programmes is limited. Monitoring and evaluation are necessary to provide evidence-based information to feed back to programmes. Evidence-based information is also necessary to identify successful interventions and good practices that can be disseminated widely for replication, adaptation and scale up in other

areas. Targeted evaluation is an important tool, as evident from the research presented, to identify problems in services delivery and test strategies to address these problems. More resources need to be committed for monitoring and evaluation research activities.

Despite limited research, the paper does document some successful outcomes associated with treatment education, such as accessing HIV services, adhering to treatment, achieving successful treatment outcomes, and reducing internalised stigma.

The paper highlights important gaps in and challenges to treatment education interventions. Innovative strategies to reach key yet neglected populations such as MSM, IDUs, sex workers, migrant workers, and persons displaced by conflict need to be piloted and evaluated. There is also the need to tailor treatment education efforts to meet women's and men's gender specific needs and concerns.

The private health sector, which provides health care to a significant proportion of the population in many countries, and private business enterprises that employ a large section of the working population, have been neglected. At a local programmatic level, a greater effort is needed to reach out to these two sectors. At the national level, ministries and departments of industry and labour need to be engaged to institute HIV-related policies to help expand treatment education to these sectors. 'Healthy Positives' is yet another population that needs focused treatment education interventions to keep people with HIV meaningfully engaged in the response to HIV and AIDS.

An important gap identified by programme managers and of relevance to UNESCO is the absence of treatment education in higher educational institutions such as universities, vocational training centres, and adult education institutions. While there are some treatment education efforts in primary and secondary schools, more could be done with these institutions as well. In most countries, the education system is the largest public sector employer and has the capacity to reach a significant part of the population. A uniform national HIV and treatment education programme run through the Department of Education that reaches students of many age groups and in different contexts warrants consideration.

Other important challenges faced by treatment education initiatives are shortages of educational materials, limited availability of materials in local languages, insufficient resources for translation of materials, lack of literacy materials targeted to different populations and insufficient resources to respond to the capacity building and training needs of those delivering treatment education. More resources need to be committed to these areas within programmes. UNESCO has a role to play

in helping to meet the growing need for treatment literacy materials that are relevant to local country contexts.

In conclusion, treatment education for individuals and communities is an important component of HIV and AIDS care programmes. Several successful strategies are being implemented across countries. There is a need to document and disseminate these experiences to maximise replication and scale up at other sites.

## Introduction

Global efforts, such as WHO/UNAIDS' "3 by 5" initiative; the US President's Emergency Plan for AIDS Relief (PEPFAR); and the Global Fund to fight AIDS, Tuberculosis and Malaria (GFATM), have dramatically increased access to ART for people living with HIV. As ART is scaled up, there is a growing realisation among programme managers and donors that merely providing ART and training health providers is not sufficient and that unless efforts are made to engage communities and individuals to improve their knowledge and understanding of HIV, AIDS, and ART, programmes will not be able to meet the targets set by these initiatives, and will fall far short of contributing to the larger goal of attaining universal access to treatment, prevention, care and support. Treatment education has thus become a critical link between service provision and actual uptake of services.

Treatment education targeted to individuals and communities encompasses a wide range of ART-related issues, including how the medication should be taken, the importance of adhering to prescribed medication regimens, treatment side effects and how to manage them, interpreting CD4 counts, and how to access local ART services. Treatment education aims to empower persons with HIV to navigate the health system, learn their serostatus, access care, effectively manage ART, and practice HIV transmission-related protective behaviours. In the community, treatment education raises awareness about HIV and AIDS and the effectiveness of ART; encourages people to know their HIV status; and provides information on the availability of VCT and ART, eligibility criteria for accessing ART, and the management of ART. Treatment education also mobilises action to combat AIDS-related stigma and discrimination, which act as barriers to accessing HIV counselling and testing—a key entry point for care and treatment, and as barriers to HIV prevention programmes (UNAIDS IATT on Education 2006).

The International HIV Preparedness Summit, held in South Africa in 2003, concluded that treatment education is needed not only for people with HIV, but also for health care providers, educators, advocates, government officials, and the larger public. Treatment education can mobilise political will and commitment to improve access to and reduce the costs of ART. Brazil is a good example where networks of people living with HIV, feminists, gay and lesbian groups, religious organizations, and NGOs and community based organizations (CBOs) have contributed greatly to increasing understanding of ART issues and the continuity of the government's response to the epidemic (Galvao 2002).

This paper describes current research and field experiences related to HIV and AIDS treatment education undertaken with individuals and communities. The paper first

describes the value of treatment education for individuals and communities. Second, it discusses how treatment education is being operationalised in the field and identifies existing gaps. Third, it presents data from studies primarily conducted in developing countries on the outcomes of different approaches to treatment education. Finally, it concludes with lessons learned and recommendations for improving treatment education.

The paper focuses on a select number of treatment education programmes that are currently underway in Kenya, South Africa, Thailand, Uganda, and Zambia. The paper also discusses a treatment literacy intervention evaluated in the United States. These programmes were selected because they represent a range of treatment education and adherence support interventions that target individuals and/or communities. The sample also reflects field experiences and research in developing countries, where documentation has been more limited. The paper highlights some of the successes of these programmes and identifies the gaps and problems experienced while conducting treatment education. Data for this paper were collected from available reports (gray literature), published journal articles, and from interviews with programme managers or principal investigators affiliated with the programmes. Findings on the value and effects of treatment education from other programmes documented in the literature supplement this information.

A brief overview of the six highlighted programmes is provided in Annex 1. Although findings from a convenience sample of programmes are not generalisable, this paper provides important insights into programmes and highlights accomplishments and gaps for conducting treatment education that have implications for policymakers and programme managers.

## The importance of Treatment Education

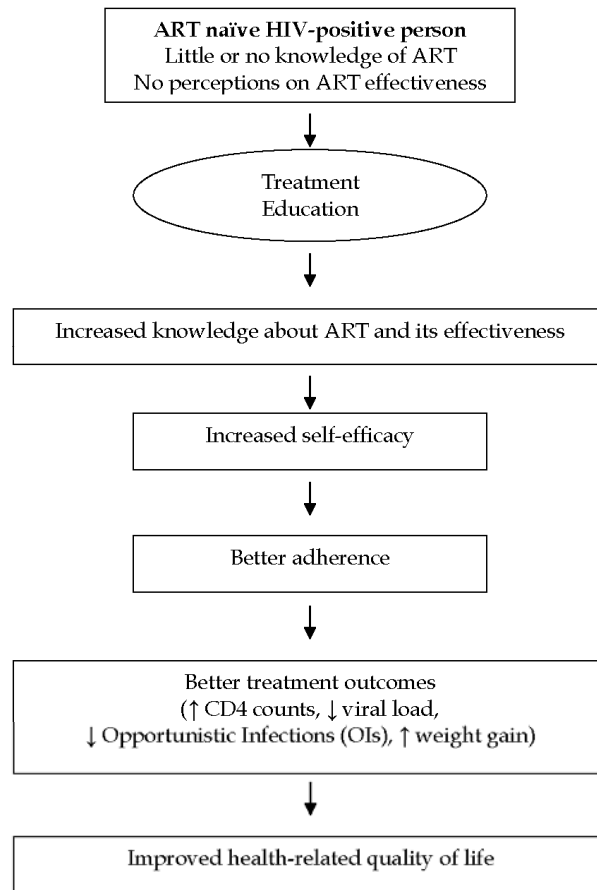
With the success of ART in reducing morbidity and mortality, HIV has become a chronic, manageable disease. Experiences with other chronic illnesses, such as diabetes and hypertension, reveal how challenging chronic disease management is, both for patients and health providers. Medication adherence for chronic diseases, on average, ranges from 50 to 80 percent (WHO 2003a). Unlike diabetes and hypertension, HIV is an infectious disease and carries the public health risk of transmission of resistant viral strains. To achieve successful treatment outcomes (undetectable viral loads and increasing CD4 counts) and prevent viral resistance, patients on ART require high levels of adherence – greater than 95 percent (Paterson et al. 2000). The management of adherence is made more complicated by the fact that multiple, often overlapping factors, such as patient belief in treatment effectiveness, self efficacy (confidence in managing their own illness), disease stage, medication regimen, patient-provider relationship and health system issues, can influence adherence (Ickovics et al. 2002; Fogarty et al. 2002).

Several studies highlight the importance of health literacy (i.e., understanding of basic health concepts), and its relationship to behaviour, including medication-taking and health-seeking behaviour, and health outcomes. The WHO Collaborative Fund for HIV Treatment Preparedness defines health or treatment literacy as the possession of scientifically sound knowledge, skills, and attitudes. Kalichman and colleagues report that poor health literacy creates barriers to fully understanding one's illness and treatment needs, and is associated with poor adherence outcomes in persons receiving combination ART (1999). They found that those with lower health literacy had lower CD4 counts, had higher viral loads, were less likely to adhere to treatment regimens, and reported more hospitalisations than those with higher levels of health literacy (2000).

Patients with chronic conditions make day-to-day decisions about managing their illness. Self-management education complements traditional patient education in supporting patients to live with and manage their chronic illness with the best possible quality of life outcomes (Bodenheimer et al. 2002), and is an integral part of treatment education at the level of the client.

Figure 1 illustrates the relationship between treatment education and ART outcomes for HIV-positive individuals. Preparing patients through treatment education and providing ongoing need-based education and support to empower them to manage their disease is necessary for patients to achieve high levels of adherence and good clinical, virological, and psychological outcomes. Specifically, patients need adequate information about HIV, potential side effects of ART, information on how

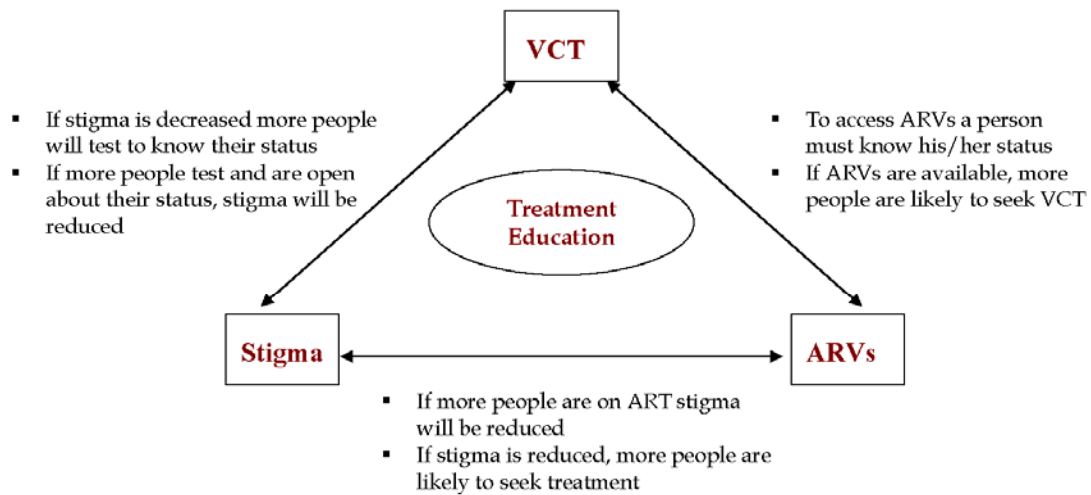
the medications should be taken (when, with or without food/water, etc.) and the importance of not missing doses (Horizons/Population Council 2004). Treatment education can foster the development of good treatment-taking behaviours among clients by reinforcing messages given by health professionals and by supporting individuals and their families.



**Figure 1:** Conceptual framework illustrating the link between treatment education and knowledge, self-efficacy, adherence, treatment outcomes, and perceived quality of life.

At the community level, treatment education encourages people to learn their HIV status and seek care, thereby increasing uptake of VCT and care services, and reducing stigma in the community. Figure 2 illustrates the relationship between treatment education and VCT uptake, access to ARVs, and stigma.





**Figure 2:** Relationship between treatment education and VCT, ARVs, and stigma

**Source:** UNAIDS IATT on Education 2006, adapted from the International HIV/AIDS Alliance 2004.

## The Need for Treatment Education

Baseline findings from research projects in Kenya, Thailand, and Zambia, provide evidence supporting the need for treatment education at the individual and community levels.

The ACER project in Zambia aims to improve health-seeking behaviour, equity of access to care, adherence to ART, and adoption of safer sexual behaviours among people with HIV through a community preparedness strategy that includes community education and referral, and significant involvement of people living with HIV and other stakeholders. Baseline findings from a community survey conducted at intervention and control sites (1,200 respondents) show that just over half of respondents had heard of ART and less than a third (30 percent) had undergone HIV testing and counselling. More than a third (38 percent) did not know that condoms could reduce the risk of contracting HIV. For almost all of the knowledge questions, slightly more males than females answered them correctly, although the differences were not statistically significant. The one exception was about HIV transmission and mosquitoes; 68 percent of men said that mosquitoes do not transmit HIV compared to 59 percent of women ( $p = .02$ ). The survey also revealed stigmatising views among community members. For example, only a third (33 percent) of the respondents reported they would buy meat from an HIV-positive butcher, 58 percent believed that an HIV-positive person could not prepare food for

others, and 62 percent felt that AIDS is a punishment for bad behaviour. In addition, many respondents also feared stigma; 43 percent believed families should keep information about a HIV-positive family member secret (Simbaya et al. 2005b). Baseline findings highlight the need for raising HIV and AIDS awareness and providing treatment education in the community to increase understanding of ART and to reduce stigma. According to Cynthia Bowa, Intervention Coordinator of the ACER Project, "We still have stigma in the community, although it is coming down gradually. This contributes to self-stigmatisation, which prevents a lot of people from accessing services."

Baseline data collected in 2003-04 from 234 people living with HIV initiating ART in Mombasa, Kenya, reveal high levels of internalised or perceived stigma. Internalised stigma was measured using items from the Berger scale (Berger et al. 2001). The median stigma score for respondents was 44.36 (possible range of 16-64; higher values indicate greater internalised stigma) and more than two-thirds of respondents (69 percent) reported moderate to high scores. Women reported significantly higher mean scores for internalised stigma compared to men ( $p = .014$ ). Interestingly, respondents reported low levels of experienced stigma. For example, 86 percent of respondents had disclosed their serostatus within the family, and of those, less than 10 percent reported any negative reaction. Non-disclosure within the family was due to fears of abandonment, rejection, emotional stress to the family, and verbal abuse (Kaai et al. 2005).

In the same study, serostatus disclosure to someone in the community was much less; only a quarter of the respondents had disclosed their status. Disclosure was most often made to a friend (70 percent), neighbour (36 percent), or religious leader (20 percent). The majority who disclosed to someone within the community received some form of support and only 5 percent actually experienced a negative reaction. Non-disclosure to someone in the community was mainly due to fears of isolation, gossip, verbal abuse, and rejection of the family in the community (Kaai et al. 2005). These findings highlight the need to address internalised stigma in treatment education with people living with HIV, particularly women, in conjunction with efforts to increase HIV and treatment-related awareness in the community. The 12-month follow up data will provide more information on changes in internalised and experienced stigma among clients as a result of treatment education and ART availability in the community.

A situation analysis of the newly introduced national Thai ART programme in 2002, conducted in 15 hospitals in five Northern provinces of Thailand, also revealed the importance of treatment education to ART adherence and effectiveness for individuals initiating ART. The researchers documented a high drop-out rate of 30 percent of patients in the first six months of the programme. The primary cause for this was the severity of side effects experienced by clients. During the first month of

treatment, 15 percent of patients reported severe side effects and 43 percent reported moderate side effects. Seventy-four (74) percent of care providers interviewed as part of the same study indicated that they had difficulties providing counselling on medication side effects and 43 percent of doctors admitted that they had some difficulties diagnosing and managing side effects and medication interactions. These difficulties often occurred in the first month when more than half of the patients had adverse medication reactions. Varying patterns of non-adherence to ART, which included missed doses over the last four days (13 percent), not taking medication on time (25 percent), and not following instructions (25 percent), were also reported (Panpanich et al. 2004).

A recently concluded assessment on adherence to treatment in India revealed gaps in the treatment information provided to patients on ART by treating physicians. While more than 90 percent of the 310 respondents knew that a CD4 count test had been undertaken, 60 percent did not know what CD4 counts measure or how CD4 counts are expected to change with treatment. In addition, more than half of the patients did not know the names of the antiretrovirals (ARVs) that they were receiving. Although the numbers are small women were less likely to know the names of the medications they were receiving than men. Respondents who knew the names of their medications were more likely to report adherence greater than 90 percent compared to those who did not (59 percent vs. 44 percent;  $p = .05$ ), highlighting the value of comprehensive treatment education (Sarna et al. 2006b).

## Individual and Community Treatment Education Initiatives

### Individual Approaches

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As new ART programmes are rolled out and existing programmes scaled up in many countries, a variety of treatment education initiatives are being undertaken. While basic information on ART is generally provided to persons with HIV initiating treatment, many programmes have also introduced specific treatment education interventions at the individual level to support treatment adherence, such as peer support, treatment “buddies,” visits by community health workers, and formal adherence counselling.

Formal adherence counselling includes an adherence risk assessment of the patient, education and counselling to prepare patients to initiate ARV treatment, and follow-up counselling to support patients with problems they may face after starting ART (e.g., side effects, opportunistic infections, work or daily life schedules, drug or alcohol consumption, medication burden, immune reconstitution, etc.). In general, the programmes examined for this paper include more than one preparatory counselling session (e.g., the programmes in Kenya [Mombasa], South Africa [Khayelitsha], and northern Thailand provide three pre-treatment counselling sessions for HIV-positive patients followed by ongoing adherence counselling at follow-up visits). As part of their training on ART provision for health providers (doctors, nurses, clinical officers, pharmacists, field health officers, etc.), the programmes also include a component on adherence to treatment.

### Community Education and Preparedness

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WHO and UNAIDS have emphasised community preparedness as a strategy that determines how people understand and accept treatment and that influences their health-seeking behaviour. An important factor in meeting the goals set by the “3 by 5” initiative and more recently the UNAIDS initiative on Universal Access, the PEPFAR programme, and GFATM is ensuring that people who are infected come forward to learn their HIV status and seek care. WHO estimates that nine out of ten people who urgently need care are not being reached (UNAIDS 2004). In addition to efforts to increase access, there is a growing realisation of the need to educate and prepare communities to support people living with HIV, address stigma, encourage counselling and testing, reduce risk behaviour, and foster linkages between prevention and care services.

Botswana, with a population of 1.7 million, has one of the highest HIV prevalences in the world – nearly 40 percent of the adult population is living with HIV. It was

the first country in southern Africa to scale up ART. Despite provision of ART through the public sector, initial uptake has been slow. Stigma and inadequate capacity to rapidly increase people's awareness of their HIV status were identified as major barriers to expanding access. In an effort to address these barriers, Botswana has instituted routine HIV testing in clinical settings, engaged traditional healers to educate communities and increase referrals, strengthened and accelerated the "Total Community Mobilization Programme" that takes HIV education to the individual and strengthened youth-focused HIV and AIDS education programmes, including a Ministry of Education-supported teacher capacity building programme, radio programmes such as "Talk Back," and street theatre (UNAIDS 2004, AIDS Botswana 2006).

Similarly, the Mombasa public sector ART pilot project had a slow uptake of services initially. The project largely focused on the preparation of the health facilities, training of health providers, and provision of ART. Despite the availability of free ARVs and the involvement of community health workers providing home-based care to recruit patients, Coast Province General Hospital had only 494 HIV-positive persons on ART in the first year and a half; more than half the patients were women. Uptake of services did pick up in 2005; women still make up more than half the HIV-positive patients receiving ART. According to Dr John Adungosi, who worked as Director of Clinical Care Programmes for Family Health International (FHI)/IMPACT, one of the implementing organizations:

*We realized the need for community involvement to improve uptake of ART services. Working with home-based care workers alone was not enough. We are now also working with [PLHIV] support groups organized through treatment centres and post-test clubs at selected sites in Western Kenya.*

In South Africa, TAC has been very active in community mobilisation for treatment and prevention. TAC describes the link between education, treatment, and prevention as a social contract: the clinics provide effective care and life-saving treatment; the community breaks the silence, fights stigma and discrimination, and through education, promotes understanding and HIV prevention.

Central to TAC's activities is an HIV and treatment literacy programme, "Project Ulwazi" (knowledge). Through a cadre of volunteers, the majority of whom are HIV positive, the programme reaches the community with information via high schools, public sector health clinics, shopping centres, workplaces, churches, the media, and other fora. Activities include workshops, talks, door-to-door contacts, beading groups, sports activities, and radio programmes. Educational materials, such as pamphlets and posters on HIV transmission, VCT, ART, and PMTCT of HIV, are also distributed. In addition, the programme uses HIV-positive "treatment

supporters,” including some on ART, to promote adherence to ART and prevention for and by PLHIV (positive prevention) among clinic clients, and uses HIV-negative peers to deliver prevention messages at youth clinics and schools. In Lusikisiki, a site where TAC’s Project Ulwazi was implemented, the demand for VCT services greatly increased; the number of persons tested in 2004 doubled compared to the previous year. This may reflect the effectiveness of community treatment education efforts that were intensified during 2004.

TASO in Uganda uses HIV-positive peers, several of whom are on ART, to conduct community education and mobilisation activities. These activities include drama, talks, school lectures, church meetings, community centre meetings, and discussions at private sector enterprises, such as construction companies, etc. Community health workers, known as field health officers (FHOs), conduct community outreach and education. In addition to supporting people on ART, FHOs have conducted around 5,000 HIV tests for relatives and friends of patients at people’s homes. Faith-based organizations also have been participating in promoting HIV and AIDS awareness. While an evaluation of the community intervention is planned, Dr. Etukoit Bernard Michael, TASO’s ART coordinator, highlighted some of the visible effects of their efforts thus far:

*For the moment, effectiveness can be assessed from the increasing number of requests for community education activities, from the large number of patients coming in for antiretroviral treatment; and from a shift in counselling needs of clients from initiating ART towards issues such as wanting to get married, have children, going back to work, moving out of the area for employment; and the dramatic improvements in the health status of patients.*

In Zambia, the ACER project uses a variety of community resources to conduct treatment education. For example, the project engages traditional healers to raise awareness and increase referrals to the public ART facilities; church groups to spread HIV and treatment-related awareness in the community while providing home-based care services for HIV-positive persons; Networks of people living with HIV to conduct street plays to reduce stigma and increase knowledge about treatment; treatment supporters at health facilities to provide adherence support for patients on ART; and community health workers to support patients at home. An endline survey to evaluate the impact of this intervention was conducted in mid 2006 and results are forthcoming.

A review of the literature shows that ART community education initiatives are taking place in other countries as well: in Cambodia through monks and networks of people living with HIV (Rosenberg 2004), in Haiti through community health workers (WHO and Partners in Health 2003), in Poland and former Soviet Union

countries through NGO activists (Skonieczna 2005), in Tanzania through traditional healers and traditional birth attendants (Nguma et al. 2001), and in Thailand through peer educators (WHO 2004).

### **Linking with Other Programmes**

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Interviews with programme managers at TASO and TAC/Khayelitsha revealed that information on the availability and use of ARVs is provided at PMTCT and VCT sites. At the TASO PMTCT site supported by the US Centers for Disease Control and Prevention (CDC) and WHO, HIV-positive pregnant women are screened for ART eligibility. Those found eligible initiate ART and those who do not need ART are offered treatment education and enrolled into the ART waiting list register. TASO is also incorporating treatment literacy and positive prevention messages into its support groups for people living with HIV, where HIV-positive peers, some of whom are on ART, offer treatment education.

### **Use of Community Resources for Treatment Education**

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Health staffing is crucial to increasing access to ART. Unfortunately, health workforces are shrinking in many low-income countries, and a key reason is migration of staff to obtain more lucrative employment and better working conditions. An uneven distribution of health workers between urban and rural areas also contributes to shortages. In addition, HIV and AIDS have taken a toll on health care workers. Overburdened health workers can rarely extend their reach beyond the limits of the health facilities in which they work. ART programmes are finding that community health workers (CHWs) and people living with HIV are useful resources to help mitigate the shortage of health workers by providing outreach support near patients' homes, and in the case of peers, serving as role models for others living with HIV.

Haiti's Equity Initiative is well known for using CHWs, also called *Accompagnateurs*, in its TB and HIV DOT programme. The programme has been successful in fostering high levels of adherence and positive treatment outcomes, and the intervention has been recognised as a best practice (WHO 2003c).

The Mombasa ART pilot project also uses CHWs, half of whom are men. Originally they began working as "tracers" – verifying addresses of patients initiating ART, tracing patients who missed clinic appointments, carrying medications for sick patients who were unable to visit the clinic, and conducting unannounced pill counts as part of a study on adherence. They also informed clinic staff in a timely manner about patient illnesses, hospitalisations, deaths, and relocations – all of

which proved to be invaluable information. The role of CHWs, however, has gone beyond providing information to and forth the health care system. CHWs are playing a larger role in providing treatment education and social support to their clients by linking them to home-based care services, food donation programmes, and church groups. Community health workers report satisfaction with their greater role in patient care and acceptance in the community (Munyao et al. 2005).

In Thailand, the national ART programme is using peer educators, both men and women, to support people living with HIV on ART in the northern provinces of the country. Using peer educators not only benefits clients in the programme but also benefits the peers themselves by improving their self-confidence and self-esteem, and in some cases providing a source of income. Peer educators in Thailand reported satisfaction with their role as treatment supporters for patients. Focus group discussions to assess their activities revealed that peer educators felt proud to be contributing to the ART programme, were gratified by the increased acceptance they received from the hospital teams, and reported greater confidence in public speaking and more acceptance and credibility by the community and their peers. According to one peer educator, "earlier they [patients and health workers] only believed 2 to 3 out of 20 words we told them; now they believe all we are telling them."



## **Gaps and Challenges of Treatment Education**

Although treatment education initiatives in the community cover a wide range of activities, as illustrated by the examples discussed in this report, as the programmes mature, a number of challenges and gaps have emerged. Interviews with programme managers highlight some of these that exist in the field.

### **Reaching marginalised groups and key populations**

Managers of the community-based treatment education programmes interviewed highlight the need to reach key populations, such as MSM and IDUs. Information about these groups varies by country. While in countries like Brazil groups such as MSM access services fairly openly, in African countries these populations remain largely invisible. Recent reports from Senegal and Kenya (Onyango-ouma et al. 2005; Niang et al. 2001) suggest that many MSM have little access to information or care services. According to Mandla Majola, a TAC coordinator in South Africa, “The only way we can reach them presently is through radio programmes.” Similarly, IDU populations remain invisible; there is very little information on them in Africa and therefore no programmes in operation. Programme staff also highlighted the need to widen outreach in the community to access other key populations, such as sex workers and populations displaced by conflict, as in northern Uganda. The ability to reach all persons in the community is particularly challenging for most programmes.

### **Expanding treatment education in the private sector**

Most NGO programmes operating in communities are linked with public sector health facilities. Although the private sector provides services to a significant portion of the population, private sector health facilities, employer-based health programmes, and workplace interventions are often left out of HIV education and awareness programmes due to problems of access. Although TASO in Uganda and TAC in South Africa provide treatment education in some workplace settings, programme managers felt much more needs to be done to reach private sector health providers and more employer-based programmes.

### **Offering treatment education at educational institutions**

A large number of community initiatives provide HIV and treatment education in schools. But managers felt that programmes were limited in their reach and confined to a limited number of schools within small geographical areas. For example, TASO is currently providing HIV and AIDS education to schools in a radius of 75 kilometres of their offices; these activities need to be made available in all schools across the country. The Departments of Health and Education have a role to play in

systematically scaling up programmes to all schools and providing a uniform curriculum that includes treatment education across the country.

### **Improving coordination among agencies that provide HIV and treatment education in the community**

There are often several agencies operating within a given community and programme managers stressed that there is frequently very little coordination among them, giving rise to inconsistent and conflicting education messages being sent out to the field. In interviews, the programme managers highlighted the need for better coordination between organizations and for uniform messages to be delivered to the community. According to Etukoit Bernard Michel, ART coordinator for TASO, “Some organizations have updated information while others may carry on with old information; we need a system where updated information is available to all.” This is especially important in the field of treatment education, in which information can change rapidly.

### **Developing and disseminating literacy materials**

Programme managers of the three community-based programmes interviewed for this paper (TAC, TASO, and ACER) noted shortages of literacy materials and funds to reprint materials. Programmes also lack resources to translate literacy materials into local languages. As noted by Etukoit Bernard Michel of TASO:

*“Uganda has 52 local languages and we need material in those languages – we need experts who could help translate literacy materials and also check if the translation is culturally appropriate and conveys the desired message.”*

Non-availability of age-appropriate materials was also mentioned as a gap by programme managers. Ms. Vuyiseka Dubula, a treatment literacy coordinator for TAC, mentioned the need for literacy materials for children:

*We need materials that are visual, easy to understand, and appealing to children who are on ART. There is a critical need for basic literacy material for children without sexual content, especially for younger children 7 to 10 years of age – right now we are using adult literacy material.*

### **Maintaining ongoing services while expanding into new areas**

Treatment education is an ongoing process that requires a repetition of education sessions. The need for repetition and reinforcement of messages within the same community raises the issue of resources. All programme managers highlighted the challenge of conducting ongoing services in the face of resource constraints.

Shortages of literacy materials, education tools for health workers, and materials in local languages, and the need for updating literacy material to reflect recent developments were mentioned.

### **Extending ARV treatment literacy and education to HIV prevention settings**

An important priority is for other HIV prevention services, such as VCT and PMTCT, to include treatment education. An ongoing study assessing the needs of HIV-positive women at PMTCT sites in three states in India reveals that the focus of counselling is on the pregnancy, prevention of transmission of HIV infection to the child, and infant feeding. Few HIV-positive women receive information on ART, prevention and management of opportunistic infections, or referral to ARV programmes (Mahendra et al. 2006). Treatment literacy for individuals who test HIV-positive but may not yet need ART, such as women who receive PMTCT services, is extremely important because they require regular clinical check ups to avoid any delay in seeking health care and ART when the need arises; robust referral links are essential.

### **Addressing gender gaps in HIV knowledge and service utilisation**

Demographic and health survey data from six African countries show that women tend to have less HIV prevention knowledge than men (Glick et al. 2005). Young women are also disadvantaged compared to young men; data from 35 of 48 countries in sub-Saharan Africa reveal that, on average, young men were 20 percent more likely to know how to prevent the sexual transmission of HIV than young women (UNAIDS 2005). In some communities, women may be more likely to seek treatment, such as in Mombasa, Kenya, through the ART public sector pilot project, or take advantage of support services, such as post-test clubs or peer support, therefore, programmes may need to reach out more to men. Thus, treatment education efforts need to be responsive to gender differences in access to and utilisation of information and services

### **Meeting other needs**

As programmes mature and patients are living healthier lives, programme managers encounter new challenges beyond providing information about HIV and treatment. These often relate to the need for providing a complete package of care that takes into account the economic and nutritional needs of people living with HIV and those on ART. Such challenges are coming up in India, Kenya, and Zambia and other developing countries. Cynthia Bowa, the programme coordinator for the ACER project in Zambia, highlights some of the difficulties programmes are facing:

*New challenges are emerging as people on treatment get better. People are out looking for employment, economic issues are coming up – people need to buy food, medicines alone are not enough; how do we support for a complete package of care?*

## Effectiveness of Treatment Education

Because most programmes being implemented in communities in resource-constrained settings have been in existence for a relatively short period of time, the focus has largely been on initiating and carrying out treatment education activities. Therefore, research to assess the effectiveness of AIDS-related treatment education in developing countries is limited. The following findings are from ongoing studies or recent assessments of interventions profiled in this paper, and highlight associations between exposure to treatment education and various outcomes.

### HIV and Treatment-related Knowledge

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One objective of treatment education is to equip patients with an understanding of the long-term nature of treatment; the knowledge that ART is not a cure; and awareness of the links between effective treatment and improved immunity, a reduction in the number of opportunistic infections, and viral load suppression. Such knowledge about ART has been shown to improve adherence (Weiss et al. 2003).

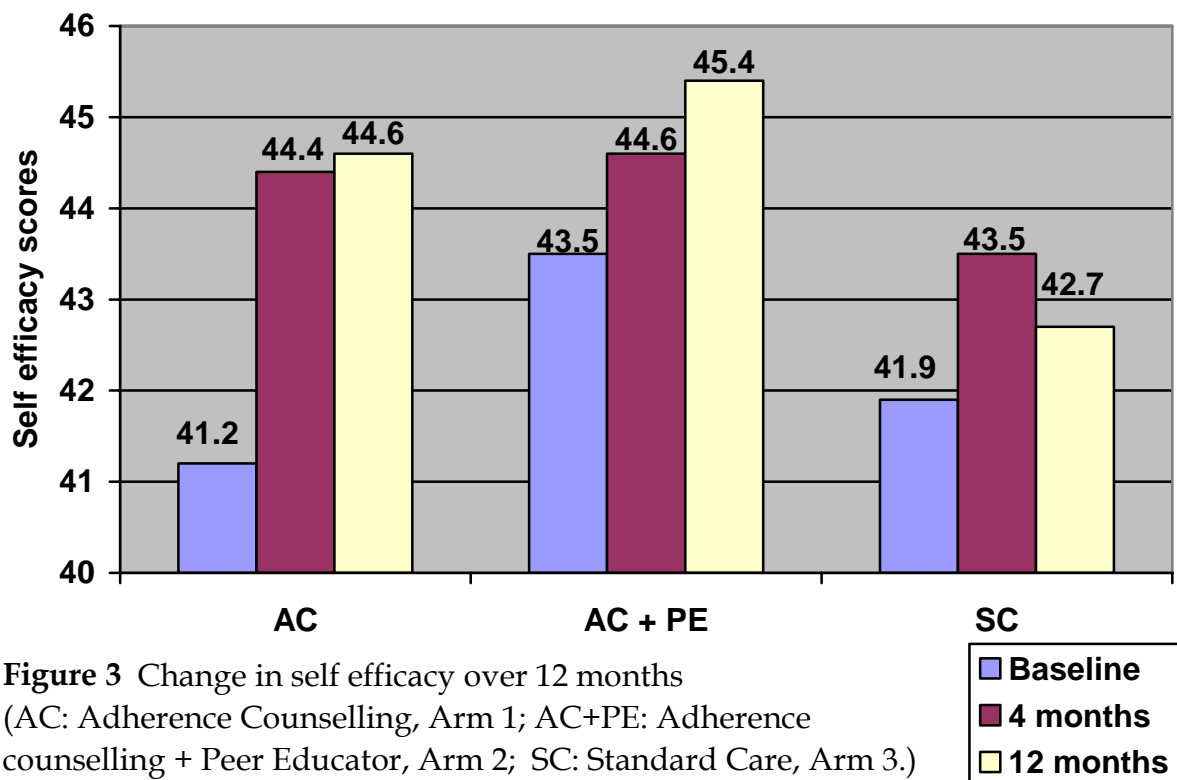
A US-based study measured the effectiveness of a treatment education intervention on HIV knowledge and treatment-related outcomes among low income immigrant Latino HIV positive, mostly male patients. The intervention consisted of five sequential sessions over a 5-week period that aimed to increase patients' HIV knowledge and abilities to communicate with health providers, followed by a 6-month nurse case management component focused on strategies to minimize barriers to adherence. The control group received routine case management. Eighty-five patients were followed over six months. HIV knowledge was assessed using an HIV adapted REALM (Rapid Estimate of Adult Literacy in Medicine) screening instrument that scores participants on recognition and understanding of key HIV- and treatment-related terms. HIV illness and treatment knowledge was assessed using a 17-item survey instrument quantified into five measures: general information on HIV and AIDS, HIV treatment-related knowledge, recognition of HIV terms, understanding of HIV terms, and knowledge of the health risks involved with discontinuation of treatment.

The intervention group scored significantly better on three of five measures at six weeks and two of five measures at six months compared to the control group. The intervention group scored higher than the control group (indicating greater knowledge) at six months on recognition of HIV terms (4.66 vs. 1.34;  $p < .001$ ) and understanding of HIV terms (6.16 vs. 1.91;  $p < .001$ ). The intervention group also reported higher adherence over the past four days at six months compared to the

control group, but the difference was not statistically significant. Over the course of the study, participants in the intervention group also showed significant improvement compared to the control group in their scores that measured communication with their HIV treating physician (7.09 vs. 1.17;  $p = .04$ ) and with other medical staff (5.28 vs. 1.11;  $p = .004$ ) (Servellen et al. 2005). These results have implications for less developed country settings since the study was conducted among an immigrant population whose treatment education needs were likely different from the typical US population because of their low socio-economic status, low literacy levels and poor access to health care.

### Self-efficacy

Adequate preparation of the patient through treatment education prior to initiating ART and adherence support thereafter influences the extent to which the patient feels confident in their ability to manage treatment. A high level of self-efficacy to manage treatment is known to influence adherence positively (Ickovics et al. 2002).



**Figure 3** Change in self efficacy over 12 months  
(AC: Adherence Counselling, Arm 1; AC+PE: Adherence counselling + Peer Educator, Arm 2; SC: Standard Care, Arm 3.)

In Thailand, researchers conducted a randomised, controlled, three-arm study in which they followed 752 patients in 45 hospitals in four northern provinces of Thailand over 12 months. The three arms were standard care, enhanced adherence counselling, and enhanced adherence counselling plus peer support. The study

revealed that those patients receiving more intense treatment education through enhanced adherence counselling plus peer support had significantly higher mean self-efficacy scores at 4 months and 12 months compared to standard care ( $p = .002$ ); patients receiving only adherence counselling did better than those receiving standard care but the difference was not statistically significant (Figure 3).

Despite higher levels of self-efficacy in the arms that received more intense treatment education, the Thai study showed little difference in self-reported adherence. More than 90 percent of the patients in all three arms reported perfect adherence at four-month follow-up. High levels of adherence in all groups could be explained by the fact that patients initiated treatment with very advanced disease stage (median CD4 counts of 50 cells/mm<sup>3</sup>) that may have motivated them to take treatment seriously. Long-term adherence and its relationship to the intensity of treatment education will be evaluated at 18 months (Chariyalertsak et al. 2006).

### **Adherence to Treatment**

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A primary objective of treatment education for patients is to achieve high rates of adherence (> 95 percent) leading to successful treatment outcomes and preventing the emergence of resistant viral strains.

The Mombasa ART adherence study is evaluating the impact of treatment education on treatment adherence. The randomised controlled study compares treatment education provided through adherence counselling to adherence counselling supplemented by a directly administered antiretroviral therapy strategy (DAART).

All participants received intensive treatment education through three preparatory adherence counselling sessions prior to initiating ART and received ongoing counselling at routine monthly visits at the treatment centre thereafter. For the first 24 weeks, participants in the DAART arm received additional support during twice-weekly visits to a health centre close to their homes and of their choice. During these visits, the DAART subjects discussed treatment problems with a health worker, collected medications, and ingested one dose of medication in the presence of the health worker. The DAART intervention has been designed to provide additional treatment education and interaction with health workers with the objective of developing good treatment-taking behaviour. After 24 weeks, the DAART group received routine monthly care.

Adherence is assessed using self-reports once every eight weeks and monthly clinic-based pill counts. Twelve-month data from pill counts show that mean adherence was higher in the DAART group compared to the non-DAART group over the 24 weeks of the intervention (96 percent vs. 90 percent;  $p = 0.042$ ) and over the next 24



weeks after the DAART intervention was withdrawn (96 percent vs. 93 percent;  $p = 0.059$ ) indicating sustained adherence behaviour (Figure 4) (Sarna et al. 2006a).

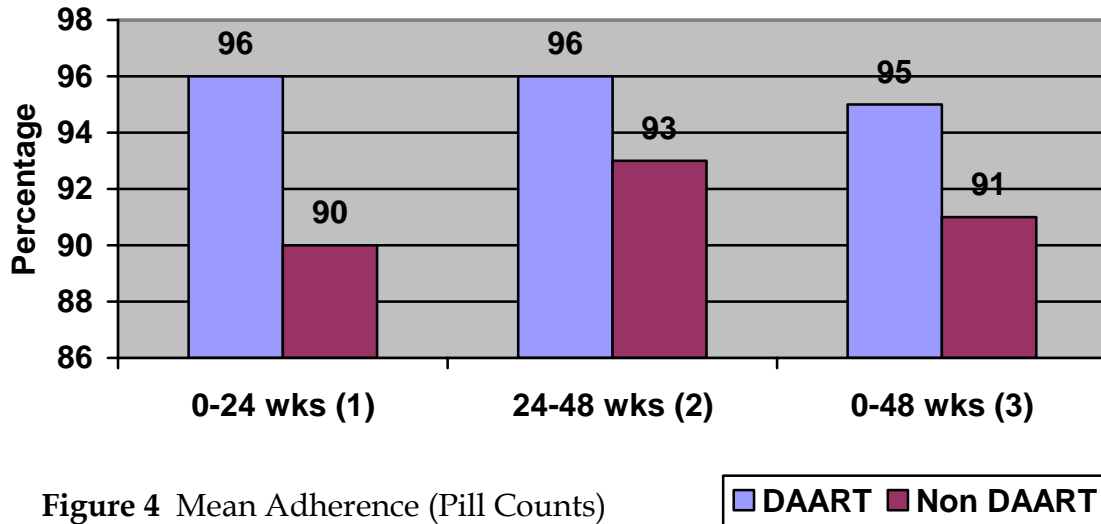


Figure 4 Mean Adherence (Pill Counts)

Data from pill counts also show that a significantly greater proportion of DAART clients ( $n = 91$ ) achieved a total adherence  $\geq 95$  percent over 24 weeks than non-DAART clients ( $n = 98$ ) (92 percent vs. 80 percent;  $p = .012$ ). A significantly higher proportion of DAART patients ( $n = 91$ ) were also able to consistently achieve  $\geq 95$  percent adherence over 24 weeks compared to non-DAART patients ( $n = 98$ ) (DAART: 67 percent vs. non-DAART 27 percent;  $p < .001$ ) (Sarna et al. 2005a).

Treatment naïve patients initiating treatment may not be able to internalise all the information provided to them at the start of treatment. Patients are also faced with problems of initial but transitory side effects for which they need guidance and support. The DAART study findings support the view that patients with additional treatment education and support from health workers through frequent contact during the initial months on treatment achieve higher adherence levels. This view is supported by qualitative data from the current study (Munyao et al. 2005).

*It [DAART visits to the clinic] reduced my anxiety about drugs. I got used to taking drugs. Also the drug dose timing; I was able to follow the time strictly.*

*(33-year-old male patient)*

*DAART has helped me take my drugs regularly. Besides, I was able to meet the doctor any time I wanted to.*

*(56-year-old male patient)*

Health providers also felt that DAART offered additional opportunities to provide treatment education to patients, which was extremely useful (Munyao et al. 2005).

*DAART is very beneficial; we have been able to reach patients with difficulties with adherence. It assists the patients with low literacy levels to adhere as they take quite some time to understand. Sometimes patients make very big mistakes at home and we get a chance to correct them before these mistakes go far.*

*(Pharmacy technologist, Bomu Clinic)*

*DAART should continue to enable close follow-up of some of our patient who have problems taking their pills. It is very unfair to let a confused patient go home alone....*

*(DAART observer, Likoni Health Centre)*

### **Immunological and Virological Health Outcomes**

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The ultimate goal of ARV treatment programmes is to achieve high rates of successful treatment outcomes in terms of retention of clients on treatment, high adherence rates, clinical improvement, and no viral resistance. Monitoring and evaluation data and health service statistics provide service delivery programmes with information on these outcomes.

At the programme level, the Khayelitsha project in South Africa has had major success with treatment outcomes. The project provides comprehensive treatment education and ongoing adherence support by treatment assistants for people living with HIV. The first patients in the programme have been on ART for more than three years. Of the 1,731 patients enrolled by the end of 2004, 73 percent remained virologically suppressed (viral load < 400 copies/ml). The cumulative probability of survival in care at 36 months for treatment naïve adults is 81.5 percent (95 percent; CI 77.6 - 84.8).

The immunological profile of patients accessing services has changed over time. The average CD4 cell counts of patients initiating ART has gone up from 42 cells/mm<sup>3</sup> in 2002 to 81 cells/mm<sup>3</sup> in 2004, indicating that patients are seeking care earlier and that faster enrolment has allowed clinics to catch up with the backlog of patients waiting for treatment. At the end of three years on ART, around 59 percent of patients remain on their starting treatment regimen; most changes in treatment regimens are due to contra-indications or side effects (Khayelitsha 2005). Although programmatic data suggest a positive role for the treatment education intervention, a research evaluation study would be able to better substantiate these findings.



At an individual level, treatment education was associated with improved virological outcomes in the US study. This research, which evaluated an adherence enhancement intervention that promotes HIV-related health literacy, found that patients in the intervention group achieved a significantly larger decrease in viral load at six months compared to the control group (37 percent of patients in the intervention group vs. 11 percent of patients in control group achieved > 1 log decrease in viral load;  $p < .01$ ) (Servellen et al. 2005).

The Mombasa study also examined virological outcomes and immunological changes. In both arms of the study, significant improvements in median CD4 counts were observed over 24 weeks. The intervention group, which received additional treatment education and adherence support from health workers, had a slightly higher median change in CD4 counts compared to the control group, but the difference was not statistically significant (DAART [ $n = 88$ ]: 153 cells/mm<sup>3</sup> vs. Non-DAART [ $n = 93$ ]: 141 cells/mm<sup>3</sup>;  $p = .422$ ) (Sarna et al. 2005). An evaluation of the intervention at 48 weeks showed that a higher proportion of patients in the intervention group were virologically suppressed and achieved viral loads < 400 copies/ml as compared to the control group (88 percent vs. 78 percent respectively;  $n = 137$ ;  $p = .127$ ), but the difference was not statistically significant due to small sample sizes (Sarna et al. 2006a).

### **Health Related Quality of life**

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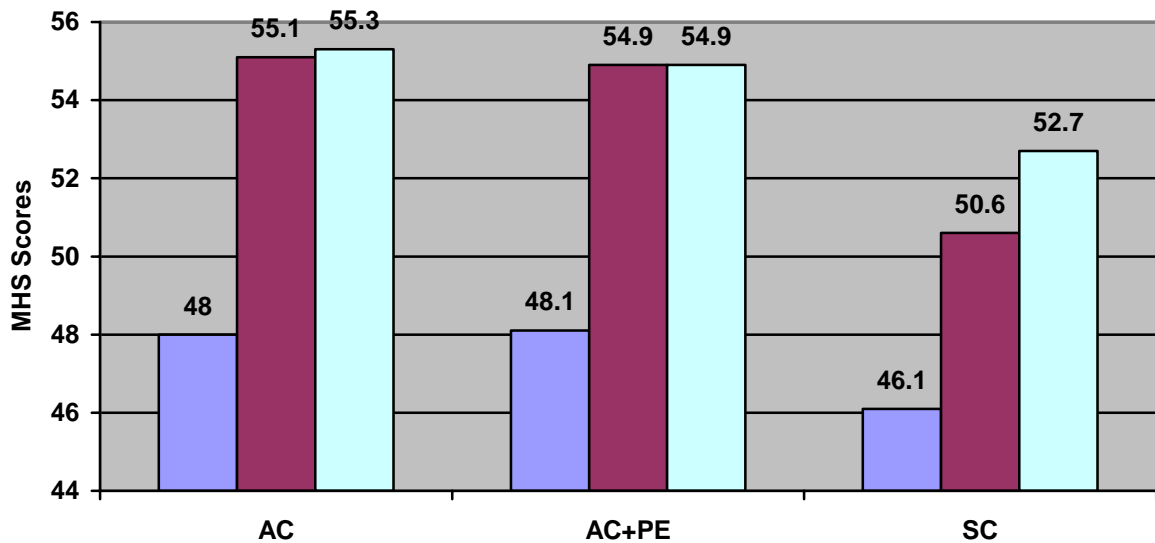
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ART has changed the course of HIV and AIDS by dramatically reducing morbidity and mortality. Perceived quality of life (QOL) is an indirect measure of the impact of ART on the daily lives of HIV-positive individuals. Marked improvement in health-related QOL measures among HIV-positive persons on ART has been shown in the MSF programme in Khayelitsha, South Africa, where a cohort of HIV-positive persons initiating ART was compared to a cohort of HIV-positive people in the community who were not on ART and not receiving treatment education from the programme (MSF et al. 2005).

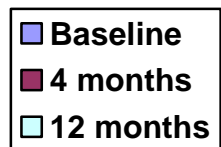
A more direct association between treatment education and adherence support and health-related QOL for HIV-positive patients is available from the Mombasa and Thai adherence research studies. In the Mombasa study, DAART patients visit health facilities and meet health workers more often and thereby receive more treatment education and adherence support compared to non-DAART patients. Six month follow up data show that while patients in both arms had marked improvements on all QOL domains, DAART patients had significantly greater improvement in scores on the dimensions assessing pain (DAART: 38 vs. Non-DAART: 28;  $p < .05$ ) and mental health (DAART: 22 vs. Non-DAART: 15;  $p < .05$ ) at six months compared to non-DAART patients (Sarna et al. 2005a). The results

suggest a positive role of intense treatment education on patients' mental health and tolerance to pain.

The Thai ART study compares treatment education provided through enhanced adherence counselling plus peer support, to enhanced adherence counselling alone, to standard care at public facilities. Perceived health-related QOL was assessed using the 35-item Medical Outcome Study (MOS) HIV scale. The study showed significant improvements in mental health scores (MHS) and physical health scores (PHS) at 4-month and 12-month follow up among patients in all three arms. Participants receiving intensive treatment education through enhanced adherence counselling or enhanced adherence counselling plus peer support had significantly higher mean mental health scores and mean physical health scores compared to participants in the control arm (standard care) at four months (PHS  $p = 0.000$ ; MHS  $p = .000$ ). Patients receiving intensive treatment education continued to do significantly better on mental health scores at 12 months compared to participants in the control arm (MHS  $p = .000$ ). The differences in physical health scores between the intervention arms and the standard care arm were minimal at 12 months (Figure 5). These results suggest that intensive treatment education has a greater impact on quality of life initially when patients start antiretroviral therapy when compared to standard care; however, the effect plateaus over time. Research with longer periods of follow up would permit an evaluation of the long-term impact of the different strategies (Chariyalerstak et al. 2006).



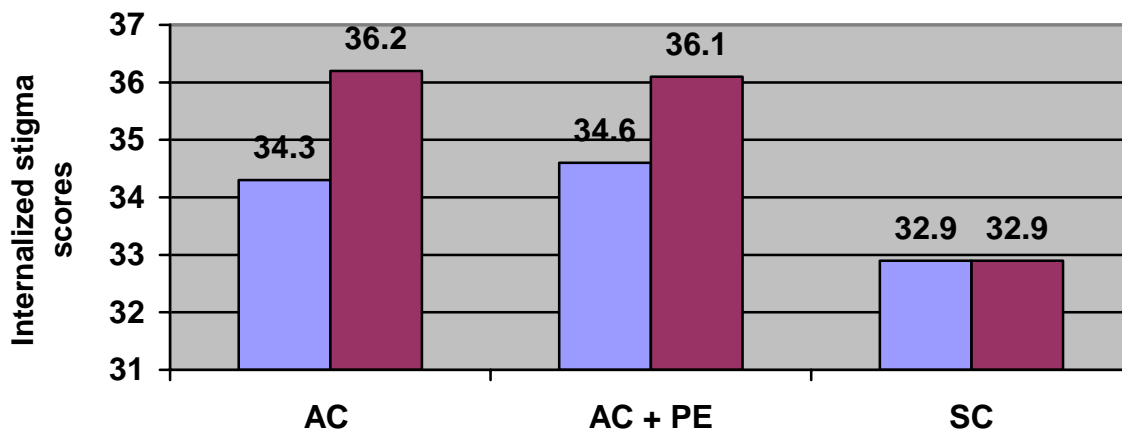
**Figure 5** Mean Mental Health Scores over 12 months  
 (AC: Adherence Counselling, Arm 1; AC+PE: Adherence counselling + Peer Education, Arm 2; SC: Standard Care, Arm 3.)  
 MHS  $p < .001$ ; PHS  $p < .05$



## Stigma

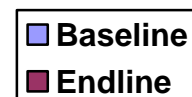
Although stigma has been widely discussed as a barrier to accessing treatment, there is an overall perception among the programme personnel and health providers interviewed for this paper that stigma levels have declined as a result of wider availability of ARVs and improved awareness about HIV and AIDS in communities. “Partners in Health” in Haiti report that the stigma associated with AIDS has declined as a result of individuals’ dramatic response to therapy. Decreased stigma is reflected in an increased willingness of patients to discuss their diagnosis openly, an increased demand for HIV testing, and a reduced number of patient complaints regarding abusive behaviour of family members or neighbours (WHO and Partners in Health 2003).

The Thai ART study provides evidence for the role of treatment education and peer support in reducing internalised stigma. Internalised stigma refers to the perceptions of stigma that people living with HIV develop based on experiences with, feelings about, and opinions of how people react to their HIV-positive status. Internalised stigma was evaluated using a 13-item index (alpha = .85) adapted from the Berger scale; higher scores indicate lower internalised stigma. Figure 6 shows that the mean scores for the groups that received more intensive treatment education (enhanced adherence counselling or enhanced adherence counselling plus peer support) increased significantly (implying reduced internalised stigma) whereas there was no change in the group receiving standard care.



**Figure 6** Change in Self-stigmatization

(AC: Adherence Counselling, Arm 1; AC+PE: Adherence counselling + Peer Education, Arm 2; SC: Standard Care, Arm 3)  
Anova;  $p < .001$



The Mombasa ART study is also documenting changes in internalised stigma as well as experienced stigma among patients receiving treatment education and ART over

48 weeks. Internalised or perceived stigma is measured using items from the Berger scale (Berger et al. 2001) to provide scores on domains related to serostatus disclosure-related concerns, negative self-image, and public attitudes about people living with HIV. The results reveal that the proportion of all study participants reporting moderate to high internalised stigma scores declined significantly over 48 weeks (78 percent vs. 56 percent;  $p = .004$ ). With regard to rights-based issues, there was a significant increase in the proportion of respondents who felt that people living with HIV could have sex (59 percent vs. 85 percent;  $p = .000$ ), have children (62 percent vs. 79 percent;  $p = .001$ ) and get married (65 percent vs. 82 percent;  $p = .000$ ). Self reported incidents of experienced stigma remained unchanged at 10 percent over 12 months. Further analysis is being undertaken to assess the impact of the intensity of treatment education on internalised and experienced stigma.

### **Practice of Preventive Behaviours**

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As a result of the success of ART in dramatically decreasing morbidity and mortality, many PLHIV are now living longer, healthier, and more sexually active lives. However, unprotected sex by people living with HIV (who know their status) is an area of concern because of the risk of transmission to serodiscordant partners and re-infection with new, drug resistant viral strains. Also of concern is that recent research has found a reduction in protective and preventive behaviours among PLHIV once their physical condition improved in response to ART (Chen et al. 2002; Katz et al. 2002; Van der Ven et al. 2002). Although these findings come largely from studies conducted among Western gay men, other research has documented the challenges associated with the consistent practice of HIV/STI protective and preventive behaviours among PLHIV. In her review of studies on sexual risk behaviour among PLHIV by Crepaz et al. (2002) suggests that a considerable percentage (range 10-60 percent, depending on the specific sex acts of seropositive individuals continue to engage in unprotected sexual behaviours that place others at risk for infection and place themselves at risk for contracting secondary infections (e.g., syphilis, gonorrhoea, herpes; Kalichman et al. 2000, Marks et al. 1999, Stolte et al. 2001) Again most of these studies have been conducted in western countries and among MSM populations.

Most ARV programmes include messages on HIV prevention and condom use in treatment education and counselling sessions. The extent to which this information is emphasised depends on health provider training and motivation. Findings from a situation analysis of the ARV programme in five northern provinces of Thailand showed that nearly half of the health workers (nurses, counsellors, and pharmacists) did not feel confident about providing safer sex counselling, highlighting the need for adequate training of health workers to address this issue during treatment education (Panpanich et al. 2004).

Researchers from the Thai ARV intervention study followed PLHIV on ART and documented changes in sexual risk behaviour over 12 months. Six hundred and thirteen patients completed 12 months of follow up. All patients received treatment education that included messages on safer sex and HIV protective behaviours. Preliminary data from the study show an increase in rates of disclosure of HIV status to regular partners (88 percent to 98 percent;  $p < 0.001$ ); there were no significant differences between men and women. Furthermore, the proportion of participants reporting knowledge of their regular partner's serostatus increased from 68 percent to 72 percent. Women, however, were less likely to know their partner's serostatus even after 12 months on ART compared to men (62 percent women reported knowing their partner's HIV status vs. 82 percent men at 12 months follow up;  $p < .01$ ), highlighting the difficulties women face in persuading their partners to get tested. More importantly, there were significant increases in self-reported condom-use at last sexual contact (67 percent vs. 90 percent;  $p < 0.001$ ) and consistent condom use with regular partners (56 percent vs. 83 percent;  $p < 0.001$ ); there were no significant differences between men and women. The proportion of clients reporting a non-regular partner remained stable over 12 months. Although the study demonstrates a decrease in sexual risk behaviours among PLHIV receiving ART, the study highlights the need to promote partner testing and consistent condom use (Oberdorfer et al. 2006).

In Uganda, TASO has designed an intervention to reduce sexual risk behaviour among PLHIV receiving ART. Through its home-based care programme, FHOs support patients on ART through home visits. At the start of treatment each HIV-positive person is encouraged to draw up an individual sexual risk reduction plan with measurable goals. FHOs then encourage and support the patient to stick to his/her plan and achieve the preset goals. FHOs deliver a treatment package to patients in their homes, which include condoms along with ARVs.

To assess the programme, a prospective cohort study was conducted that followed 926 HIV-positive adults on ART for six months. These patients received prevention counselling, VCT for cohabiting partners, and condom provision. Results reveal a 70 percent reduction in risky sexual behaviour (defined as unprotected sex with partners). Estimated risk of HIV transmission from cohort members to sexual partners decreased by 98 percent. Of the risky sexual acts documented by the study, over 85 percent occurred between married couples, highlighting the need to emphasise prevention in regular partner relationships (Bunnell et al. 2006).

Both the Thai intervention study and the Uganda cohort study documented a reduction in sexual risk behaviour among PLHIV on ART who have received treatment education and counselling on prevention. However, the studies also show that a fair amount of risk still remains, especially in regular partner relationships.

These findings highlight the need for greater emphasis on prevention within treatment education, with a special focus on regular partner relationships. Interventions such as couple counselling, which promotes partner testing, disclosure of serostatus to sexual partners, and consistent condom use with all partners, are needed.

### **Uptake of services**

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Wider access to ART in conjunction with treatment education could bring millions of people into health care settings, providing new opportunities for health care workers to deliver and reinforce HIV-prevention messages and provide life-saving medicines and care. A health survey conducted in eight sites in South Africa after the introduction of MSF's ART programme found that those respondents living in the site with the community literacy intervention had the highest level of willingness to join AIDS clubs and to be tested for HIV (UNAIDS 2004). Similarly, in the first year of the HIV Equity Initiative, an ART programme run by Partners for Health in Cange, Haiti, that had a strong community support and education intervention, demand for voluntary counselling and testing increased more than threefold (WHO 2003).

## Conclusions and Recommendations

This paper documents the importance of treatment education as part of ART service delivery and the variety of approaches being used worldwide for treatment education in health care settings and in communities. These approaches often include the use of community resources, such as peer educators, community health workers, treatment “buddies”, and support groups for people living with HIV, to help those on ART take medications correctly and adhere to treatment and to increase awareness and knowledge about HIV and ART in the wider community. Using community resources to carry out treatment education has multiple benefits that include a reduction in workload of facility-based health workers, the expansion of outreach in the community, the provision of adherence support for patients at home and in the clinic, and early referral to a health facility of patients experiencing side effects, break through infections, or complications. Several of the programmes profiled target a wide range of populations through schools, markets, workplaces, homes, health facilities, and the community, using a range of activities such as street plays, radio and television media, school education programmes, and home visits, among others. Shifting the burden from the health services to the community raises the question of remuneration for outreach and community health workers and long term sustainability of interventions; these issues warrant discussion at the national level.

Because many programmes in developing countries are in their early stages, documentation and availability of information on their effectiveness is limited. Monitoring and evaluation is necessary to provide evidence-based information for programmes. Evidence-based information is also necessary to identify successful interventions and best practices that can be disseminated widely for replication, adaptation, and scaling up in other areas. The importance of targeted evaluation research in identifying problems in service delivery, testing strategies to address these problems, and scaling up successful interventions is evident from the research presented in this paper. More programmes need to commit resources for monitoring and evaluation research activities.

Despite limited research, the paper does document some successful outcomes associated with treatment education, such as accessing HIV services, adhering to treatment, achieving successful treatment outcomes, and reducing internalised and overall stigma. To facilitate replication and adaptation of successful treatment education efforts, consideration should be given to organising site visits by programme managers to programmes that have documented positive changes as a result of treatment education.

The paper highlights important gaps in and challenges to treatment education interventions. Innovative strategies to reach key neglected populations such as MSM, IDUs, sex workers, migrant workers, and persons displaced by conflict, need to be piloted and evaluated. There is also the need to tailor treatment education efforts to meet women's and men's needs and concerns. The private health sector, which provides health care to a significant proportion of the population in many countries, has been neglected. Linking private sector health facilities with treatment education initiatives and support groups is needed. Similarly, private enterprises employ large numbers of people, and efforts to provide HIV and AIDS awareness and treatment literacy to them have been limited. A greater effort to reach out to private businesses to set up workplace interventions is needed. At the national level, the departments of industry and labour need to be engaged to institute HIV-related policies to help expand treatment education to these sectors.

An important gap identified by programme managers and of relevance to UNESCO is the absence of treatment education in higher educational institutions such as universities, vocational training centres, and adult education institutions. The involvement of the education sector in general needs a renewed focus. While there are some treatment education efforts in primary and secondary schools, more could be done with these institutions as well. In most countries, the education system is the largest public sector employer and has the capacity to reach many people. A uniform national HIV and treatment education programme run through the Department of Education that reaches students of many age groups and in different contexts warrants consideration.

Other important challenges faced by treatment education initiatives are shortages of educational materials, limited availability of materials in local languages, insufficient resources for translation of materials, and lack of literacy materials targeted to different populations. More resources need to be committed to these areas within programmes. UNESCO in collaboration with WHO and UNICEF has a role to play in helping to meet the growing need for treatment literacy materials that are relevant to local country contexts.

Most ART programmes have largely focused on providing treatment education, counselling, and support for people living with HIV initiating ART. PLHIV using VCT, PMTCT, and STI services who do have advanced HIV disease that needs treatment tend to receive less information on ART, where and when to access care, and how to remain linked with the health system for regular monitoring of their disease. It is recommended that a greater effort be made to ensure that treatment education is provided to these individuals and that strong referral links to care services that they will likely need in the future be established.



In conclusion, treatment education for individuals and communities is an important component of HIV and AIDS programmes. Several successful strategies are being implemented across countries. There is a need to document and disseminate these experiences to maximise replication and scale up at other sites.

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## Annex 1: Overview of Projects

<b>ACER Project, Zambia</b>	
<b>Intervention study</b>	
<b>Project Collaborators</b>	Institute of Economic Growth and Social Research (INESOR) at the University of Zambia, the International HIV and AIDS Alliance, and the Horizons Programme.
<b>Objectives</b>	Develop and implement treatment education and a community preparedness strategy that promotes adherence and prevention among PLHIV on ART, and that improves health literacy, health-seeking behaviour, access to care and treatment, and uptake of services among the wider community.
<b>Programme Activities</b>	<p>PLHIV at ARV treatment clinics and urban health centres receive treatment education through adherence counselling, ongoing adherence support through 'treatment supporters' (often PLHIV) and community health workers (CHWs) who visit them at home. Treatment education is also provided to caregivers. CHWs form a crucial link between the clinic and the community.</p> <p>Trained staff of collaborating local partners carry out the community education and referral activities, working with CHWs, PLHIV support groups, traditional healers and faith based organizations with the objective of educating the community about HIV and AIDS, prevention, VCT, the availability of ARV treatment and the impact of stigma and discrimination. Activities include one-on-one education, group education, street plays, etc.</p>
<b>Local Implementing Partners</b>	Network of Positive Persons (NZP+), Catholic Diocese of Ndola, Archdiocese of Lusaka (through HBC), Traditional Healers and Practitioners Association of Zambia, and local health clinics in N'kwazi compound in Ndola and N'gombe compound in Lusaka.
<b>Evaluation</b>	<p>Quasi-experimental, pre-test and post-test comparison between two intervention sites (N'gombe compound in Lusaka, Nkwazi in Ndola) and one control site (Bauleni compound in Lusaka). Evaluation at community level and at individual (PLHIV) level after 16 months of the intervention. Community survey of 1200 respondents, PLHIV survey of 375 patients on ART (125 at each site).</p> <p>Baseline data from the community survey and PLHIV survey has been collected.</p>

<b>Khayelitsha Programme in South Africa</b>	
<b>Clinic and Community based Programme</b>	
<b>Project Collaborators</b>	MSF, the Provincial administration of the Western Cape, and Treatment Action Campaign (TAC).
<b>Background</b>	The programme was set up initially as a pilot project to establish dedicated HIV clinics in primary health care centres to demonstrate that treating HIV and AIDS with low cost ARV medication in a resource constrained setting was feasible and replicable. The programme now serves a poor township of about 500,000 residents. Eligibility criteria for treatment initiation include clinical criteria of WHO disease stage III or IV and CD4 counts below 200 cells/mm <sup>3</sup> and social criteria relating to number of dependants, disclosure of HIV status to partners, income and activism and evidence of prior adherence to co-trimoxazole prophylaxis and tuberculosis treatment and regular clinic visits. HIV services in Khayelitsha were developed alongside strong civil society pressure and community-based education. TAC, a grass roots HIV advocacy organization, has acted at provincial and national levels to increase community awareness of HIV as a political issue and mobilize community members to pressure the government to develop a comprehensive response.
<b>Programme Activities</b>	<p>ART provision with strong, multi-pronged adherence support components. Clients receive 'patient-centred' adherence counselling at clinics, and adherence support at home from 'treatment assistants'. Each patient is required to identify a 'treatment assistant,' who are often family members or friends and may or may not be HIV positive. Pill boxes are provided to assist with correct treatment taking. Peer support through monthly support group meetings of people on ART is also offered.</p> <p>TAC runs '<i>Project Ulwazi</i>' (knowledge) to mobilize communities and provide treatment literacy through peer volunteers. Peer educators educate communities on HIV and AIDS, prevention, and ARV therapy. Activities include workshops, door-to-door contacts, mass media (e.g., radio programmes) and outreach to clinics, churches, workplaces, schools etc.</p>
<b>Evaluation</b>	Service statistics, monitoring data, quantitative and qualitative research.



<b>The AIDS Support Organization (TASO) in Uganda</b>	
<b>Community-based Programme</b>	
<b>Background</b>	The AIDS Support Organization (TASO) was established in 1987 as a care and support NGO; it now serves 22,000 people living with HIV in Uganda. The organization aims to help people live positively with HIV, and to improve the quality of life of persons and communities affected by HIV and AIDS.
<b>Programme Activities</b>	ARV treatment provision and home-based care services. People living with HIV receive treatment education through adherence counselling at the health facility and ongoing adherence support through home visits by dedicated field health officers (FHOs) who are community health volunteers with a secondary school level education. FHOs bring antiretroviral medications to clients' homes, saving them frequent trips to the health facility. The programme uses an individualized approach to adherence and sexual risk reduction for each HIV positive client. FHOs are also trained in VCT and have tested around 5000 persons at home, mostly family members and friends of HIV-positive persons. TASO actively engages and educates communities about the availability of ARV treatment and HIV prevention through a core group of HIV-positive "literacy activists," who conduct treatment education through plays and workshops in schools, community centres, churches, workplaces, social clubs, etc. Their goal is to increase uptake of HIV testing, and care and ARV treatment services.
<b>Evaluation</b>	Service statistics. A formal evaluation is being planned.

## Public sector ARV program, Northern Thailand

### Intervention study

<b>Background</b>	In 2001, Thailand became one of the first developing nations to provide ART to HIV-positive persons. Evidence from an assessment conducted early on in the public sector programme revealed a high drop out rate among patients on HAART . In response, Chiang Mai University, Ministry of Public Health, and the Horizons Programme are collaborating on a project to develop and test strategies to promote adherence and reduce programme dropout.
<b>Study Design</b>	Three-arm, randomized controlled study that compares enhanced adherence counselling (arm 1), enhanced adherence counselling and peer support (arm 2) with standard care (arm 3) offered at control sites. Standard care includes routine treatment education. 45 district hospitals in 4 northern provinces of Chiang Mai, Chiang Rai, Lamphun and Lamphun have been randomized into the three arms. 752 patients on ART are being followed over 12 months.
<b>Intervention</b>	Adherence Nurses provide treatment education at health facilities through formal adherence counselling based on motivational interviewing and a conceptual model of behavior change. Patients are taken through a preparatory stage, action stage and maintenance stage along the way to developing permanent behaviors. Patients are also counseled on prevention and safe sex. In the peer intervention, trained volunteer peers provide treatment education and adherence support in the clinic and through monthly home visits for patients on ART.
<b>Evaluation</b>	Adherence, ARV related knowledge, perceptions of ART effectiveness, sexual risk behaviour, perceived quality of life (QOL), and other variables are assessed at 4, 12 and 24 months. 4-month data available.

## Pilot public sector ARV Programme, Mombasa, Kenya

### Intervention study

<b>Background</b>	The Government of Kenya ART Pilot Project was initiated in partnership with USAID as a learning site for introducing ART services in public sector health facilities. FHI/IMPACT and MSH RPM Plus provided technical assistance in setting up services, training staff, and procuring medication, and arranging logistics. The Horizons Programme conducted operations research to provide evidence-based information for programme scale-up. Services were initially set up at a provincial hospital and later extended to two other hospitals.
<b>Study Design</b>	A two-arm, randomized controlled study that compares adherence counselling with adherence counselling and a directly administered antiretroviral therapy (DAART) adherence strategy. 116 patients in each arm are followed for 6 months while the DAART intervention is ongoing, and then for 12 months after DAART ends and both groups receive only adherence counselling. In addition to adherence, the study is also examining sexual risk behavior, perceived and experienced stigma, and the economic impact of ART on the household.
<b>Intervention</b>	Treatment education is provided through adherence counselling for all patients: 3 preparatory sessions and ongoing need based counselling at monthly visits provided by trained nurses. Patients in the DAART arm also visit a peripheral health centre of their choice near their home, twice a week to collect medications, discuss any treatment related problems and take a dose in the presence of a health worker. Community health workers support the intervention by conducting home visits to trace patients and carry medications for sick patients.
<b>Evaluation</b>	Adherence is evaluated at 6, 12 and 18 months. Sexual risk behavior and stigma are evaluated at 12 months. Six-month and 12-month data are available.

## Adherence enhancement

### Intervention study

<b>Description</b>	A treatment adherence enhancement programme research study aimed at improving HIV-related health literacy and strengthening patient provider relationships among Latinos was undertaken in California, USA.
<b>Study Design</b>	A two arm randomized controlled, research study comparing the effectiveness of a health literacy enhancing and adherence support intervention to standard care (control arm).
<b>Intervention</b>	A 5-week instructional support modular programme with a 6-month follow up nurse case management component that focuses on the barriers to adherence and strategies to minimize these barriers.
<b>Evaluation</b>	HIV-related health literacy and patient-provider relationships assessed at 6-weeks and 6 months.

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UNESCO  
Education Sector  
Division for the Coordination of UN Priorities  
Section on HIV and AIDS  
7, place de Fontenoy  
75252 Paris 07 SP  
France

Website: <http://www.unesco.org/aids>

E-mail: [aids@unesco.org](mailto:aids@unesco.org)

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