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Treatment preparedness for ART

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Community preparedness for antiretroviral treatment

Tanne de Goei

At the XIV International AIDS Conference in Barcelona in 2002 the World Health Organization (WHO) announced its goal of scaling up access to antiretroviral treatment for HIV-positive people in developing countries to three million people by 2005. At the moment only a mere 350,000 people in developing countries are having access to treatment; this is only 50,000 more than when the so-called "3 by 5" goal was set. This means that reaching the WHO goal will require a massive effort. Not only by international agencies, governments, NGOs, doctors, nurses and health workers, but also by private foundations, national and international companies, unions, faith-based organisations, women's organisations, the pharmaceutical industry, community-based organisations and associations of people living with HIV/AIDS (PLWHA).

So far, only a few developing countries have managed to guarantee access to antiretroviral treatment for those who need it. Brazil is the most cited example, with 130,000 people on treatment, due to the government-owned production of generic HIV inhibitors which makes treatment much cheaper. Other countries are rapidly increasing the number of people on antiretroviral treatment (ART): Thailand more than 20,000, Nigeria over 10,000, Botswana 6,300. Recently Mozambique, Rwanda, Tanzania and even South Africa decided to start programmes aiming to treat everyone in need. Clear guidelines from WHO are available to facilitate this process and more and more organisations are training doctors, nurses and other health-care workers to facilitate quality care and treatment.



Photo: WHO/Eric Miller



SAFAIDS

"A critical element to be able to deliver treatment to people will be treatment literacy programmes. Every day in our communities we are able to educate people in workshops about Nevirapine, about AZT and about side-effects. We are able to sing songs about these drugs; we are able to educate people about fluconazole and co-trimoxazole.



Zackie Achmat

These are things that none of us knew, medical terms and pharmacological names that none of us knew when we were first diagnosed or even much later. But fighting for our lives has made it essential and necessary for us to learn these things. Everyone can learn them. In our communities we have done workshops with people who have never opened a pharmacological textbook but most of our people can speak eloquently and articulately about the medicines that they need for their side-effects and how to look after themselves."

Zackie Achmat, chairman of TAC (Treatment Action Campaign), South Africa in his message for the Barcelona conference, July 2002

Increased funding for treatment has been offered through the Global Fund to Fight AIDS, Tuberculosis and Malaria, although this fund is now facing hard times getting funds itself. Possibly more funding for treatment will come available through President Bush's 15 billion dollar Emergency Plan on AIDS Relief. Médecins Sans Frontières (MSF) has set up 23 pilot projects in 14 countries, treating some 4500 people, showing that access to treatment in resource-poor settings is possible. Also companies as the brewery Heineken proved that it is possible for private companies to treat their employees and their dependants.

Quality care

However, attention to availability and affordability of ART should not draw away attention from comprehensive HIV/AIDS care. Comprehensive care should consist of medical care (ART, treatment of opportunistic infections, prophylaxes, treatment of side-effects, etc.), laboratory monitoring (of CD4 counts, viral load – if possible – side-effects, etc.), information and education (on ART, adherence, living positively and healthy, prevention, etc.), psychological support (e.g., through support groups), food support, and so on. Treatment should therefore be seen as part of a continuum from prevention to care. For instance there is a strong relationship between ARV treatment and prevention: if people use ARVs they become less infectious, and are

more likely to practise safer sex. On the other hand, we have also seen in developed countries that the availability of ART makes people less worried about contracting the virus, and this has led to an increase in HIV and STI rates in the general population. Therefore it is important to regard treatment, education and prevention in a comprehensive way. Especially the involvement of the community is regarded as crucial for this continuum of quality care.

Treatment preparedness

"Treatment preparedness" is a term used to describe HIV/AIDS treatment education and advocacy efforts that are designed to increase access to and demand for ARV treatment and prepare communities for safe and effective use of ARV drugs. The terms treatment preparedness and community preparedness for treatment were used for the first time at the Barcelona conference by a group of AIDS activists. Their meeting resulted in the International HIV Treatment Preparedness Summit which was held in Cape Town, South Africa, in March 2003.

The conference was organised by an ad hoc group of people from community organisations and logistical support was provided by Gay Men's Health Crisis (GMHC) in New York and Treatment Action Campaign (TAC) of South Africa, which also hosted the meeting. At the summit, 125 community-based AIDS treatment advocates and educators from 67 countries discussed their needs and strategies as the scale-up of access to ARV treatment proceeds. Representatives from several international and funding organisations attended the summit as observers in addition to the participants.

The main goal of the summit was to develop a framework for the creation, maintenance and enhancement of local and regional treatment preparedness efforts around the world. However, even more important was to discuss what has been done on treatment preparedness worldwide and what lessons could be learned from other countries and other organisations.

Advocacy and education go hand in hand

The summit made clear that there is a need for advocacy and education on both macro and micro levels. There is a need to get government and industry to respond to the overall epidemic. Equally important is the need to teach PLWHA about symptom recognition and treatment options and teach people to advocate for their needs on an individual level within health-care systems. Knowledgeable patients change the perceptions of and relationships with health-care providers and knowledgeable leaders in the community can advocate within health-care systems. While many treatment advocates tend to focus on broader issues, the issue of advocating for patient needs on an individual basis emerged as a key priority for many people. It is an important component of treatment education and it is the point where education and advocacy merge.

Treatment advocacy

The goal of treatment advocacy is to meet the health and social care needs of the communities, including both prevention and treatment. Treatment literacy is needed not only to provide PLWHA with necessary information

about their disease and how to treat it, but also to support and inform advocacy efforts. Treatment literacy is a powerful tool in advocacy work as information can support arguments and counter opponents' arguments. Access to information tells that generics are not "counterfeits" and that monotherapy is not appropriate, and it gives people the tools to decide what complementary and traditional medicines are effective for what conditions, to avoid wasting resources.

Appropriate advocacy strategies will vary from region to region and from community to community depending on many factors, including the political situation, the stage and size of the epidemic, the make-up of the at-risk populations and the needs of those infected and affected. Strategies must be tailored to best address that audience and to best accomplish the particular goal. Advocacy includes policy development and these policies should be science and evidence-based. The media play a crucial role in educating the public about HIV risk and treatment and in carrying the advocates' messages to the public, government and pharmaceutical industry. Advocates need to be proactive in their use of the media and see it as an important tool.

Legal forums have proven very successful in moving forward the advocacy agenda. Advocates need to understand the legal system and determine how it can be used effectively to further their agenda. Also, it is essential to build strong and broad coalitions. Labour and trade unions, religious organisations, health-care providers, youth groups, women organisations and others are important allies. It is needed to find common ground with these groups and show them why they need to be concerned about treatment. There are many social, political and health issues that require attention and that cause pain and suffering. HIV is not the only one. Many of the conditions that fuel the HIV epidemic also fuel other health and social crises. AIDS advocates should find the links between these issues and work together with all involved to further an agenda of social justice, economic equality and public health.

Treatment literacy

It is important for people considering treatment to understand how ART works, what the side-effects may be and how to recognise them, which pills to take and when to take them, the need for good adherence to medication, etc. Without this information, patients cannot make informed decisions about treatment and will not understand why good treatment adherence is essential to effective therapy. HIV therapy is not limited to ART. Prophylaxis and treatment of AIDS-related opportunistic infections, tuberculosis, hepatitis and other co-morbidities is an essential and life-saving component of AIDS care. Treatment education programmes must include information about the signs and symptoms of opportunistic infections and the ways to prevent and treat them. Treatment may provide hope to people, but is also frightening. Correct treatment information reduces that fear and stress.

Not only PLWHA need to be educated about treatment options, also their relatives and community members benefit from this education. Information about treatment helps to reduce AIDS-related stigma and discrimination within communities. When HIV is seen as a treatable illness, people are less frightened of it, more apt to learn about HIV/AIDS and less afraid of those who are infected. The knowledge that treatment for AIDS exists provides hope for people and encouragement to learn their HIV status and seek out care. This not only can improve the health of individuals, but also can further prevention education efforts.

Therefore it is necessary to also increase and improve Voluntary Counselling and Testing (VCT) services, as better access to and knowledge of ARV treatment leads to more demands for VCT, and on the other hand, more testing leads to more demands for ARVs. However, the basics of VCT should be reconsidered as treatment options are a different reason to go for VCT as when no treatment is available. As the MSF project in Khayelitsha in South Africa has shown, at the moment that medication for the prevention of mother to child transmission (PMTCT) became available, there was an enormous rise in the uptake of VCT.

Vaccines research

As ARV treatment is saving lives and is needed by many people now, in the long run it is also important to have effective vaccines against HIV. As this may take many years and a lot of research and vaccine trials to reach this goal, it should not be separated from access to treatment. First, treatment education and advocacy can also raise vaccine awareness and help preparing communities to take part in vaccine research. Second, vaccine research sites can help the scaling up of access to treatment. There are several ways in which this can be done: by starting to provide treatment too; by training doctors, nurses and pharmacists; and by reducing fear, stigma and discrimination in the community and at political, social, traditional and religious levels. ❖



"Give us access to treatment now!"

Photo: Treatment Action Campaign

Community preparedness for ARV treatment – the role of people living with HIV/AIDS

Mandeep Dhaliwal

Community preparedness for ARV treatment is about realising rights and is essential for the safe and effective delivery and use of ARV treatment. Community preparedness is also critical for reducing stigma and discrimination. Community preparedness will help to relieve the burden on over-stretched public health-care systems, support good prevention and treatment outcomes, and build social capital in communities. Ensuring greater involvement of people living with HIV/AIDS (GIPA), a true sign of political commitment, is a key component of community preparedness for ARV treatment. It is also a core principle of the International HIV/AIDS Alliance's work. This article draws from the experiences of this organisation.

Using a draft of the handbook *Mobilising NGOs, CBOs and PLHA groups for improving access to HIV/AIDS-related treatment* during four workshops in India, Zambia, Cambodia and the Philippines, the International HIV/AIDS Alliance worked with 84 participants from 55 NGOs, community-based organisations (CBOs) and groups of people living with HIV/AIDS in those countries to increase involvement of people living with HIV/AIDS in improving access to treatment. Using the tools in the handbook, participants identified barriers to treatment and developed practical strategies to ensure greater involvement of people living with HIV/AIDS and improve their access to treatment.¹

People living with HIV/AIDS have a vital role in fostering the development of AIDS competent and ARV competent communities. Either as individuals or members of support groups, they have a part to play as active, informed participants in their own treatment; treatment service providers; treatment educators & counsellors; managers; planners; evaluators and treatment advocates. More specifically, this can include involvement in planning and implementing ARV treatment programmes, developing selection criteria and monitoring fair application of these criteria, providing peer support/support groups (supporting people on ARV treatment with health education and adherence counselling), participating in community education and sensitisation of health-care workers. A participant of the Zambian workshop said: "*People with HIV should be involved in deciding who gets treatment and in the implementation of the treatment*

programme. It validates and gives power to messages of community preparedness." (Member Network of Zambian People Living with HIV/AIDS – NZP+).

Benefits

A diagnostic study conducted by the Alliance and the Horizons Project in Burkina Faso, Ecuador, India and Zambia revealed that involving PLWHA in treatment can offer many benefits, not only related to the improvement of health and social services, but also for other PLWHA and themselves.²

Improvement of services – PLWHA can improve treatment services by ensuring that they are relevant, credible and friendly. For example, the involvement of some 120 PLWHA in the evaluation of the Ministry of Health / NGO Home Care Programme in Cambodia proved invaluable, helping to identify the strengths of the initiative and relevant next steps, such as building partnerships with TB services and expanding the use of community volunteers. PLWHA can also be involved in education and training of health-care workers. Besides, they are well placed to add authenticity to advocacy work as their personal experience lends credibility to advocacy.

Positive role models – PLWHA can be positive role models. The role of "patient-teachers" can be further explored. For example, stories of personal experiences help to reduce the stigma surrounding HIV/AIDS and treatment. Many of the respondents who were on ARV treatment in the Community Consultation on ARV Treatment in Zambia (see also Country Watch) reported that they had been inspired to start treatment by listening to the testimonies of others who were using ARVs successfully. However, stories about people having difficulties in managing side-effects of ARV treatment also prevented other people living with HIV/AIDS from accessing treatment. PLWHA can combine technical knowledge with their unique first-hand experience, for example of managing side-effects and adhering to treatment, to support other PLWHA in their treatment.

Personal benefits – PLWHA who are involved in treatment can benefit from improved information, including on how to access treatment. For example, in Ecuador the Horizons Project found that people living with HIV/AIDS gained many tangible benefits from involvement in treatment services, including more and better access to medicines due to increased contacts and access to up-to-date information. They also enjoy improvements in their physical health. For example, in Zambia at the Salvation Army's Chikankata Health Services, involvement in the Care and Prevention Teams (CPTs) has helped PLWHA to identify infections at an early



Explaining ARVs to a patient in Ithembalabantu ("People's Hope") AIDS treatment clinic, South Africa

Photo: AIDS Therapeutic Treatment Now (ATTN)

stage and seek medical attention as soon as they became sick. An HIV-positive member of a CPT said: "My health has really improved because I have now learnt how to look after myself properly. I used to be sickly, I was in and out of hospital... but now my health has really improved ... I know how to prevent some of these opportunistic diseases." No less important, they also enjoy improved psychological health because of increased peer support and decreased isolation.

One of the main disadvantages is that people with HIV often encounter difficult emotional experiences when they are involved in caring for PLWHA who are ill.

Main barriers

According to the abovementioned study conducted by Horizons and the Alliance, the main barriers that prevent the greater involvement of PLWHA in treatment programmes are a lack of a supportive environment, including stigma, discrimination and lack of access to treatment; and a lack of appropriate information, skills and training. In order to support GIPA on treatment issues, people living with HIV/AIDS must be able to access the relevant resources – information, skills, training, and an enabling, supportive environment that includes access to treatment. Issues of stigma and discrimination should be addressed through systematic education of the community, health-care workers and PLWHA about HIV/AIDS and ARV treatment availability, accessibility and adherence. Information on HIV/AIDS and HIV-related treatment should be provided at every level of the community with people living with HIV/AIDS, family members and health-care workers forming significant focal points.

As the global epidemic increases and greater numbers of people are being infected by HIV, the need for effective treatment in resource-poor settings is becoming more urgent than ever. People with HIV can play a key role in the provision of effective treatment and care. Developing pathways for their effective involvement can ensure that their role is recognised and actively supported. ❖

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Consulting the community on ART perceptions in India

An example of a pathway to involving PLWHA in treatment work:

- 1) Agree on value added by PLWHA involvement and sensitise management and staff
- 2) Identify possible areas for PLWHA involvement in improving access to HIV/AIDS-related treatment and develop policies for this involvement
- 3) Allocate budget for remuneration of PLWHA; including medical benefits
- 4) Inform PLWHA about possibilities for being involved in activities and/or recruit PLWHA as paid employees – or as unpaid volunteers with clearly defined roles and some form of financial compensation
- 5) Extend non-discriminatory employment policies to management and decision-making positions
- 6) Do a needs assessment of skills and training needs of PLWHA; provide up-to-date and accurate information on HIV/AIDS and treatment issues; allocate training budget and provide training on e.g. treatment delivery, design and planning, management
- 7) Monitor and evaluate
- 8) Mobilise PLWHA by supporting the formation of networks and support groups and provide any necessary training

Source: Improving access to HIV/AIDS-related treatment, a report sharing experiences and lessons learned on improving access to HIV/AIDS-related treatment, International HIV/AIDS Alliance, 2002.

1. Based on the results of these workshop, the handbook was finalised in 2002. It was published as a Best Practice together with WHO and UNAIDS: www.unaids.org/publications/documents/health/access/NGOtoolkit/index.html
2. *The Involvement of People Living with HIV/AIDS in Community-based Prevention, Care and Support Programs in Developing Countries. A Multi-country Diagnostic Study*, www.aid alliance.org/_docs/_languages/_eng/_content/_3_publications/download/Research/PLHA_International_Report.pdf

Treatment preparedness in Eastern Europe: the need for international co-operation

Mauro Guarinieri

As in other parts of the developing world, access to antiretroviral treatment in the countries of Eastern European and the Newly Independent States (EE/NIS) is still limited. Likewise, the treatment advocacy and literacy movement in this region is still very weak. The European AIDS Treatment Group, Europe's oldest network on access to treatment issues, is currently expanding to these countries, in order to assist in the building up of treatment preparedness in the region.

Although initially isolated from the global HIV pandemic by draconian Soviet restrictions on contact with foreigners and harsh social control, there has been a growing epidemic in Eastern Europe since the mid-1990s. The first outbreaks were reported in 1995 among injecting drug users in Odessa and Mikolayev in southern

Ukraine. They were rapidly followed by other drug-related HIV outbreaks, notably in the Russian territory of Kaliningrad in 1996, and a few months later in other regions of the Russian Federation (Krasnodar, Rostov on Don, Tver) and in neighbouring Belarus and Republic of Moldova.

Programme
Feature

Since then, the situation has continued to grow rapidly worse, affecting more regions and countries. UNAIDS and WHO stated that, with an estimated 1.2 million HIV-positive individuals at the end of 2002 (compared to only 30,000 at the start of 1995), Eastern Europe and Central Asia are the regions of the world with the fastest growing HIV epidemic. Russia is facing an HIV epidemic of such proportions that the World Bank predicts that, unless the government quickly undertakes pragmatic prevention and treatment interventions, the Russian economy will suffer tremendously.

There are big differences in wealth and poverty, HIV prevalence and access to treatment between the Eastern

European countries of the Warsaw Pact (e.g., Romania, Bulgaria) and the Newly Independent States that were once part of the Soviet Union, such as Ukraine, Belarus and Russia. Since a total of 291 million people live in the EE/NIS region, 1.2 million means that 0.6% of the adult population is HIV-positive. The average national spending on health care per capita in these states ranges from US\$ 16 to US\$ 181 per year. Only a couple of thousand people are using antiretroviral therapy. According to the Central and Eastern European Harm Reduction Network (CEE-HRN, see Box), countries where injecting drug users make up two-thirds or more of the total number of HIV/AIDS cases provide almost no ARV treatment at all, and if treatment is available, injecting drug users are often excluded. Existing barriers to access to care and treatment include inadequate government policies, high costs of drugs, and lack of technical capacity and appropriate infrastructure to manufacture and distribute these drugs.

Access to ARV and exclusion of drug users in Eastern Europe and Central Asia

In its report *Injecting Drug Users, HIV/AIDS treatment and primary care in Central and Eastern Europe and the Former Soviet Union*, the Central and Eastern European Harm Reduction Network (CEE-HRN) states that injecting drug users (IDUs), who form the biggest part of PLWHA in the region, have the least access to antiretroviral therapy.

ARV access for PLWHA is greatest in countries where IDUs are the smallest percentage of HIV/AIDS cases; countries where IDUs are two-thirds or more of total cases provide almost no ARV of any kind, or exclude IDUs from the little treatment available. Overall, IDUs account for 82% of all HIV/AIDS cases in the region, but only 23% of those receiving antiretroviral medicines. In Belarus, where 78% of HIV/AIDS cases are IDUs, none are using combination therapy. While IDUs are 93% of cases in Russia, programmes report that only 13% of those receiving triple combination therapy are IDUs. In Ukraine, 20 out of 24 programmes including government HIV/AIDS and harm reduction programmes alike report that IDUs are informally discouraged or prohibited from receiving care.

These data come from a survey of 132 organisations in Central and Eastern Europe and the countries of the former Soviet Union, which assessed the accessibility of among others HIV medications for injecting drug users in the region in May 2002. Organisations surveyed included harm reduction programmes and government HIV/AIDS programmes such as national, regional or municipal AIDS centres, as well as UN agencies.

Other findings include that access to ARVs of any kind, particularly triple combination therapy, is highly limited for all PLWHA across the region. Respondents in 24 countries in this region reported that less than 7,000 people – 2% of registered HIV/AIDS cases – were receiving triple combination therapy. However, more than three-quarters of these were living in only two countries, Romania and Poland. In the European Newly Independent States (Belarus, Moldova, Russia and Ukraine), the countries where HIV prevalence and incidence is highest, only 0.3% of PLWHA who are registered received triple therapy in 2002. No ARV of any kind was available in countries such as Albania, Azerbaijan and Tajikistan.

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Injecting Drug Users, HIV/AIDS treatment and primary care in Central and Eastern Europe and the Former Soviet Union, CEE-HRN, 2002, www.ceehrn.it/EasyCEE/sys/files/CEE-HRN.EN.pdf



One step beyond

Scaling up ARV therapy goes beyond the mere availability of antiretroviral medicines: also issues such as infrastructure, skills-building of health care providers, and treatment education of patients, their families and the larger public is necessary in order to ensure safe and high-quality use of ARVs and increased usage. So far, limited efforts have been undertaken in the EE/NIS region to prepare the community and PLWHA for antiretroviral treatment. Among others, there is a high need for treatment education.

Recent research in the US showed that HIV-infected people with lower health literacy levels had lower CD4 cell counts, higher viral loads, were less likely to be taking antiretroviral medications, reported a greater number of hospitalisations, and reported poorer health than those with higher health literacy levels. Treatment literacy for both health-care providers and PLWHA is essential if we expect treatment to be effective. Treatment literacy for the government and the public is also essential. Knowledge that effective treatment exists will alleviate the fear and stigma associated with AIDS and encourage people to learn about HIV, and utilise counselling, testing, care and support services. Finally, science represents our greatest advocacy tool. Advocates' efforts are supported by scientific evidence that confirms the importance of health literacy in maintaining the well-being of PLWHA. To be effective and develop sound policies, advocates should first learn, understand and disseminate scientific knowledge on HIV/AIDS.

The European AIDS Treatment Group

The European AIDS Treatment Group (EATG) was founded in 1991 as a group of people affected by HIV/AIDS in Europe and concerned about treatment issues. Over 100 people from 20 different countries are individual members, and the majority work for AIDS Service Organisations in their own countries. The EATG was the first, and is still the only, pan-European organisation advocating for the interests of PLWHA on treatment issues in Europe.

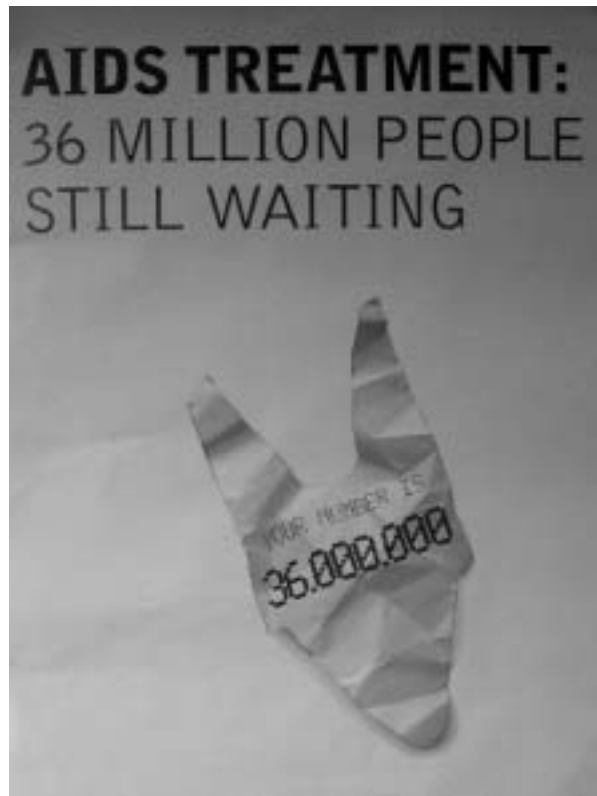
From 3-5 October 2003, the EATG held a regional conference on Access to Treatment and Harm Reduction in Kiev, Ukraine. The seminar was designed and organised in full cooperation with the All-Ukrainian Network of People Living with HIV/AIDS (see Country Watch). The meeting provided advocacy and treatment

literacy training, and allowed participants to further develop their advocacy agenda and strategise toward the implementation of that agenda. This seminar was part of a broader strategy undertaken by the EATG to give technical assistance and support to the growing PLWHA advocacy movement in Eastern Europe.

With the primary aim of mobilising most of its resources to Eastern Europe and the Newly Independent States, the European AIDS Treatment Group established a new working group in May 2003 to coordinate all EATG action in this region. The objectives of this EATG Eastern European States Working Group are to:

- ❖ Advocate for greater involvement of PLWHA in the EE/NIS region in all decision-making processes
- ❖ Push for the rights of all those living with HIV/AIDS, with a special focus on drug users, gay men, sex workers, women, inmates etc. to access treatment
- ❖ Acknowledge and address the existence of discrimination within the PLWHA and larger AIDS advocacy community, specifically around populations such as injecting drug users, refugees and sex workers
- ❖ Empower its members from the region to develop the regional policy priorities and recruit other organisations in the region to join the EATG
- ❖ Offer annual or semi-annual "train the trainers" treatment education seminars in the region and set up a clearinghouse of information in Russian
- ❖ Assist its members in advocating for the registration of generic drugs and to campaign for this where it is possible
- ❖ Work with its members to ensure that good and sound treatment plans to cover all aspects of HIV/AIDS care, including antiretroviral treatment, palliative care, psychosocial care and treatment and prevention of opportunistic infections are included in the national AIDS strategies of these countries
- ❖ Endorse the use of methadone and other substitution therapy as an issue of access to essential medicines.

The development and dissemination of treatment education materials and training specifically designed and culturally adapted to meet the needs in the region will represent a crucial component of our ambitious programme. The European AIDS Treatment Group does not consider "stand-alone" trainings, where a group from a developed nation comes in, provides some brief training and then leaves, useful and cost-effective. The need to provide ongoing support and have training tied to longer-term efforts will be thus essential to meet the above mentioned goals.



MSF Campaign for Access to Essential Medicines, www.accessmed-msf.org

The HIV epidemic arrived in Eastern Europe later than in other parts of the world. This gives the region a unique potential and the opportunity to take advantage of lessons (as well as of the many mistakes) already learned by the global community and to prevent the death toll that has been seen in other parts of the world. Although this potential has still to be realised, actions must be promptly undertaken to increase treatment literacy, capacity building and community mobilisation to secure the region free and universal access to treatment and good health for those living with HIV/AIDS. ❖

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Ukraine

The All-Ukrainian Network of PLWHA

Since its establishment in December 2000, the All-Ukrainian Network of People Living with HIV/AIDS has sought to be acknowledged as a partner in the nation's response to HIV. It applied to international organisations, including the European AIDS Treatment Group, for advocacy training. It identified key stakeholders and institutions and began to work with them. In 2001, network representatives met with the Minister of Health and asked for treatment, receiving no answer. Later, after a letter-writing campaign demanding access to treatment and a more proactive governmental response to HIV/AIDS, the government began to take the group seriously and include them in meetings and planning.



It is important to have educational materials on antiretroviral treatment in local languages

Country
Watch

Consequently, the All-Ukrainian Network provided key input in the country's Global Fund application, which includes 60% of funds for treatment. It took part in a UN initiative to reduce drug prices resulting in a reduction of prices by some pharmaceutical companies. The Network also received a grant of US\$ 50,000 to purchase ARVs for people without access through governmental programmes. It works with the private sector, state government, and international organizations.

With financial help from the Global Fund, the Ministry of Health is preparing to put 4,000 HIV-positive people on ARV treatment by the end of 2003. For reference, less than 100 people out of the estimated 300,000 PLWHA in Ukraine received such treatment in 2002. Additionally, in cooperation with the Ministry, the All-Ukrainian Network has recently started a programme of treatment education and adherence support for people preparing to initiate ARV treatment. In the framework of this project called "Complex Socio-Psychological Support for People Living with HIV/AIDS with Emphasis on HAART Adherence" which runs from November 2003 to November 2004, social workers will be trained to support people using antiretroviral drugs, their families and close friends. Also peer support programmes and self-help groups will be developed, as well as trainings and seminars for informative, educational and explanatory work with clients. ❖

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More information on HIV/AIDS and the Ukraine's response in *Sexual Health Exchange 2003-1*, www.kit.nl/exchange

Zambia

Is the community prepared for ARVs?

The need for information on antiretroviral treatment has been brought to the fore by the introduction of the ARV treatment programme by the Government of Zambia to mitigate the high burdens of morbidity and mortality resulting from HIV/AIDS. The Ministry of Health estimates that there are over one million people living with HIV/AIDS in Zambia, and that the number of people developing AIDS will rise from 93,000 in 1999 to 101,000 in 2004 and 123,000 in 2014.

Thanks to the drastic drop in prices of antiretroviral drugs, the government has initiated a programme to provide ARV treatment through the public health facilities. The programme is targeting 10,000 people. Currently over 40 public health professionals have been trained and more people will be trained in the near future. As much it

is important to train medical staff, experts in the field of HIV/AIDS agree that for the programme to succeed there is need to prepare the communities in terms of information provision, mobilisation of people living with HIV/AIDS, and mobilisation of existing structures on the issue of ARV treatment.

Community consultations

In order to support the government's ARV programme, the International HIV/AIDS Alliance carried out community consultations in Zambia in 2002. This exercise in Lusaka and Ndola involved the Network of Zambian People Living with AIDS (NZP+) and other AIDS service organisations. The consultation aimed to develop an understanding of community perceptions, knowledge and experience about ARV treatments, and encourage the involvement of people living with HIV and communities in the planning, development and implementation of ARV treatment programmes.

Approximately 200 people were consulted, including PLWHA, equal numbers of women and men, children and adolescents, older people, people with low incomes or not formally employed, professional and business people, church and other community leaders, and the military. Confidentiality was maintained at all times. The key tools used were in-depth interviews (IDIs), focus group discussions (FGDs) and some informal conversations.

Participants discussed the following needs: for correct information; increased co-operation between community structures and health systems; scaling up of VCT services; education of relatives; more community mobilisation on HIV/AIDS issues and antiretroviral treatment. They also expressed several worries related to: uncertainty about medicine supply; selection criteria for treatment and transparency of the process; less access of women to information; and the role of stigma in preventing people to access ARV treatment.

Mobilizing existing community structures

The consultation clearly showed that communities in Zambia are keen to be involved in supporting delivery and use of ARV treatments. Mobilizing existing community structures and increasing community involvement in ARV treatment will reduce the burden of public care and will support systems that will be under pressure to provide additional HIV testing, monitoring and counselling as well as treatment. Community involvement will contribute to the reduction of stigma by encouraging people to come forward for services. It will also support safe and effective delivery and use of treatment. Co-ordination of different levels of the community is essential, and organisations like NZP+ should play an important part in this process.

In the final analysis, it is evident that safe and effective ARV treatment and community preparedness (including the involvement of PLWHA) will form two sides of the same coin of improved health for people infected with HIV. ❖

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Consulting the community on ART perceptions

Thailand's ARV treatment programme and drug users

Policy
Notes

Karyn Kaplan & Paisan Tan-Ud

Thailand is on the brink of becoming the next middle income country – after Brazil – to demonstrate the possibility of universal access to treatment for people living with HIV/AIDS (see Box). While political commitment to treatment and affordable, accessible drugs are fundamental factors in a national treatment plan, the ultimate key to a successful treatment roll-out programme is to ensure the full participation of PLWHA. They are a key human resource in the treatment infrastructure. Yet a number of factors persist in blocking an ideal government-civil society partnership. The marginalisation and discrimination of certain groups, such as drug users (and particularly injecting drug users) is one of them.

While Thailand has received global recognition for its prevention interventions such as the "100% Condom Use" brothel-based programme (a UNAIDS Best Practice) and for significantly reducing sexual transmission of HIV overall, averting millions of new infections, the needs of other highly-vulnerable groups such as injecting drug users have been virtually ignored at the national level. Though high prevalence (currently around 50%) among IDUs has been reported since the 1990s, no effective policy or intervention has led to a decline in HIV transmission in that group. In fact, IDUs make up the largest number of new HIV infections, and this percentage (33%) is growing. Researchers recently commented that if Thailand continues to ignore the epidemic among drug users, the country's AIDS epidemic may be maintained "for many years to come".¹

Pushing drug users underground

Repressive drug policies, combined with a lack of harm reduction programmes such as sterile syringe and needle provision or non-judgmental counselling services and health-care provision, ensure that drug users face a significant challenge if their "full participation" in government HIV/AIDS treatment and prevention efforts is to happen.² Recent data on the impact of the Prime Minister's plan to fight narcotics (launched February 1, 2003) shows drug users were made even more vulnerable to HIV infection. This stepped-up government War on Drugs is characterised by extrajudicial killings, false charges and blacklisting. As a direct result of the government policy, users were pushed further underground and away from critical support and services, by trying to escape police arrest and forced rehabilitation.

The Thai Drug Users' Network

Recently, a group of present and former drug users organised to address the deplorable health and human rights situation in their community. The Thai Drug Users' Network (TDN), formed in Bangkok in December 2002, comprises over 70 individuals representing every region of the country. One of its initial core demands was to withdraw the criteria in Thailand's national ARV implementation guidelines that excluded "high-risk behaviour" groups, specifically injecting drug users, from accessing ARV therapy. In addition to lobbying government health and drug control officials, TDN held several public demonstrations and delivered letters to the Minister of Public Health and the Prime Minister, to bring attention to the historic discrimination of this group in national AIDS policy and the lack of a multi-sectoral approach to resolving it.

At the most recent National AIDS Conference (July 2003), the government declared that only medical criteria,



MSF Campaign for Access to Essential Medicines, www.accessmed-msf.org

such as CD4 count, would be used to determine with the PLWHA whether they are ready for ARV therapy, and the guidelines were revised. Whether the motivation was from an ethical or practical standpoint (Thailand wants to meet its goal of treating 50,000 people by 2005, requiring a rapid expansion of the current programme), social exclusion criteria are no longer recommended. However, rampant discrimination in the health-care setting still needs to be addressed. Often drug users are denied health care or social services on the grounds that they "must quit" first, yet drug treatment effectiveness using currently available options is poor. Treatment is often compulsory and is not client-centred, and counselling often consists of advice to play sports instead. Public campaigns describe people involved with drugs as a threat to family stability and national security, and communities are encouraged to implement social sanctions such as denying drug users (even former drug users) access to village-based revolving-loan schemes.

Unhealthy policies

TDN focuses on building the capacity of drug users to access and share information and skills necessary for reducing the health and other harms associated with drug use, and for advocating against unhealthy policies

The Thai ARV programme

With supplementary funds from a successful first round proposal to the Global Fund, the government plans to scale up the provision of free antiretroviral therapy to 50,000 individuals by 2005, at a cost of 1.5 Billion Thai Baht (46 Baht = 1 Euro). Currently, approximately 10,000 people receive treatment from the government. Thailand's ability to provide triple therapy to its PLWHA is also contingent on its local generic production capacity: the Government Pharmaceutical Organisation manufactures GPO-vir, a triple therapy of d4T-3TC-Nevirapine, which sells for 1,200 Baht/month.

that impede their realisation of the highest attainable standard of health care and treatment, and other human rights. They work with the government, NGOs and international allies toward the resolution of their six main demands:

- 1) Eliminate the policies that promote violence in addressing the drug problem. Investigate each case of murder or other negative consequence following the government's announcement of its War on Drugs.
- 2) Promote educational campaigns about drugs and drug use that provide comprehensive and factual information. This will result in a well-informed public and not cause drug users to be disliked and discriminated against by society.
- 3) Change any law or policy that violates or leads to the violation of drug users' human rights, such as mandatory HIV-antibody testing, exclusion from antiretroviral therapy access for HIV-positive drug users, etc.
- 4) Urgently implement harm reduction programmes that aim to reduce the dangers associated with drug use, and provide information to prevent the spread of HIV among drug users. Establish programmes to make clean needles and syringes available, which will reduce the spread of HIV and hepatitis among injectors.

- 5) Cover costs related to prevention, care and treatment for drug users, including rehabilitation, detoxification, and substitution therapy, under the national health-care plan.
- 6) Involve both active and former drug users at all levels to address drug-related problems in Thailand, including policy development.

Thailand's experience of government-civil society partnership will become increasingly significant as it is made more visible at the upcoming International AIDS Conference in Bangkok in July 2004. The very factor that can ensure its success is the full participation of the key human resource, PLWHA, as part of the treatment infrastructure. PLWHA, including drug users, must be empowered to understand and constructively confront the core issues affecting their lives.

The Thai Drug Users' Network works with its key allies in the government as well as NGOs such as the Thai Network of People Living with HIV/AIDS (TNP+), the Thai AIDS Treatment Action Group (TTAG), Médecins Sans Frontières (MSF) Belgium/Bangkok, and the Thai NGO Coalition on AIDS (TNCA), to make Thailand's treatment programme more inclusive and respectful of dignity and equal rights, through focusing on strengthening the capacity of people with HIV/AIDS to play a central role. ❖

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Research Notes

Using untapped resources

An expanded concept of infrastructure for community-based ARV advocacy

Mary Ann Torres & Sumita Banerjee

There are some 40 million people living with HIV in the world, and yet only a tiny fraction receives life-sustaining antiretroviral treatments. Access to care, treatment and support is thus a central focus of advocacy efforts. Drug pricing, in particular, has been taken up by the advocacy community resulting in recent decreases in the cost of ARVs. However, cost and availability are not the only determinants of access. A study conducted by ICASO in 2002 identified several other barriers to access ARV treatment, notably related to the issue of infrastructure. The results of this exploratory, community-based research point towards the outline of an expanded framework of infrastructure that could provide a solid foundation for accessing ARVs.

In the advocacy debate, infrastructure is an elastic term with many connotations: for instance, lack of infrastructure has been used as a rhetorical device to justify political inaction to respond to the enormous challenges of the HIV pandemic. Generally speaking, the concept has largely been understood in terms of a "gold standard" comprising a set of medical goods and services seen as the essential prerequisites for the effective delivery of ARVs in the clinical setting.

In order to find out what the experiences are regarding access to ART of people currently using antiretroviral medicines, the International Council of

AIDS Service Organizations (ICASO) conducted a research, focusing on enablers and barriers to access ARVs.¹ Data were obtained from in-depth interviews with PLWHAs primarily in low-income countries. The methodology was developed through consultations at AIDS conferences in 2001. The interviews were conducted between February and May 2002.

In 11 countries in three regions (Africa, Asia/Pacific, and Latin America/Caribbean), sixteen PLWHAs were interviewed by in-country interviewers. Although the goal was to interview participants from developing countries, an Aboriginal man from Australia was also

included in the study to explore issues of discrimination and treatment access that may be experienced by marginalised communities in developed countries. Twelve of the participants self-identified as female. Participants ranged from 24 to 47 years old. Approximately half of the participants were involved in community-based advocacy, whereas the other half has had little experience with organised HIV/AIDS activities.

Different understandings

The research points out that for some of the participants, their understanding of the concept of infrastructure included progressive policies, formal drug delivery systems, full diagnostic and monitoring equipment and well-trained health professionals. For others, the infrastructure required consisted of nothing more than a creative "suitcase system" bringing left over ARVs from countries in the North:

Cynthia from Trinidad and Tobago has access to ARVs through a precarious medium. Her access requires that she either makes trips to a country in the North every six months, or has her monthly medication sent by family members living in that country. She has received her medication on an ad hoc basis, resulting in a failure to strictly adhere to the drug regimen.

Others identified supportive family members and friends as a component of infrastructure:

Sma from Swaziland reports that her children provide the greatest support for her adherence to her medications. "Everyday after breakfast the youngest shouts, 'Emaphilisi mama!' ('Pills mommy!') and the older children bring me water and the tablets."

But family members can also play influential roles in blocking access to care:

When Ntokozo from South Africa was visiting the local clinic, her counsellor advised her to think about treatment. Ntokozo started on the ARV programme. Ironically, Ntokozo's brothers "asked (her) to stop seeing the doctor at the local clinic and to stop taking ARV drugs" – an example of how complex coping with a family members' HIV-positive status can be. Even the family doctor supported their decision.

Towards a new definition?

Thus, our research highlighted the need for a broader understanding of infrastructure and suggested that we include more elements than just clinical factors. Our findings suggest that a definition of infrastructure be explored that includes individual, family and community resources that have been largely ignored in the debate over ARVs and infrastructure. We conceptualise infrastructure not as a "gold standard" which may or may not be in place, but rather as a broad ranging set of systems, people, commodities and policies which may be more or less present along a continuum. From this perspective, at least some elements of infrastructure will always be in place.

Three-legged stool

This study did not aim to exhaustively analyse all the barriers that hinder access to ARVs. Rather, the sample size is illustrative and can reveal new ways of thinking about old problems. As opposed to examining barriers to access, this study sought to explore the experiences of people living with



Health workers reviewing record books at the health centre in Majeleko village, Tanzania

Photo: IFAD/C. Nesbitt

HIV/AIDS who have accessed ARVs. The data support the development of a definition of infrastructure that includes everything that it takes to get HIV care, treatment and support to the people who need it.

The framework we propose may be thought of as a three-legged stool that sits on a base (see Figure). The seat of the stool represents all of the HIV services that people may need, and the three legs and base are the infrastructure that supports these services. The three legs represent: a) human resources; b) commodities/supplies; and c) systems/facilities. The base represents the legal framework (policies and laws).



Recommendations

Based on the findings of the research, the recommendations are as follows:

- 1) An expanded definition of infrastructure needs to be widely communicated and used as a tool for community-based advocacy to expand the availability of care, treatment and support services to people living with HIV/AIDS.
- 2) Advocacy at all levels must include calls for improving the coordination and collaboration of existing health care services, increasing support to community education and other outreach activities, and involving people living with HIV/AIDS more meaningfully in the provision of care and treatment services.
- 3) Global and local efforts need to be reinforced to advocate for decreased prices of treatments (ARVs and other medications), commodities and supplies.
- 4) Increased efforts should be made to create and disseminate information about ARV treatment that is culturally appropriate; and ensures that participants have opportunities to make informed decisions about ARV treatment, and their involvement in clinical trials, including access to medicines post-trial.
- 5) Laws at national levels need to be reviewed and reformed to ensure that they are consistent with international human-rights obligations. It is important to compel national governments to implement human-rights protections at both national and local levels.

Regarding the first point, the advocacy challenge is to identify which elements of infrastructure, if enhanced, could best improve access to care, treatment and support in particular settings. Treatment advocates, NGOs and CBOs, and civil society in general, can and should highlight in their petitions and actions to their governments the elements of infrastructure that are in place in a particular setting and that could enhance access to care, treatment and support. For example, a strong PLWHA movement, a high-quality hospital network, dedicated doctors and nurses and a good legal framework.

We can also use the infrastructure discourse spelled out in the Declaration of Commitment as a result of the United Nations General Assembly Special Session (UNGASS) on HIV/AIDS. The Declaration recognises that all the elements of the "stool" that ICASO is proposing to illustrate the expanded concept of infrastructure are important, and that these are needed to effectively respond to the epidemic.

Scaling up access to treatment requires more than drugs at an affordable price. As discussed in the report, it demands political commitment and leadership; effective management of available resources; successful prevention, care, support and treatment strategies; information and education/training initiatives; collaborating with communities, civil society, people living with HIV/AIDS and other vulnerable groups and the active promotion and protection of human rights. ❖

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The report entitled *Adding Infrastructure to the Advocacy Agenda* (ICASO 2002) can be accessed at www.icaso.org/icaso/docs/Adding%20Infrastructure.pdf (60 p.). You can also request a hardcopy at: icaso@icaso.org. In the report's appendices, there is a questionnaire that could be adapted to conduct interviews with PLWHA on their experiences with accessing ARVs.

Programme Feature

Faith-based community mobilisation and education for antiretroviral therapy in Uganda

Magid Kagimu

People's faiths are among the greatest avenues available for community mobilisation and education. When there is happiness such as in marriages, people congregate in places of worship to perform the ceremonies. When there is a crisis in the family such as illness or death, people call upon their faith leaders for support. Faith leaders regularly educate their communities during congregation prayers and other gatherings. Therefore, forming partnerships with faith leaders can go a long way to enhance community mobilisation and education around issues including HIV/AIDS and antiretroviral therapy. One example is the community mobilisation programme of the Islamic Medical Association of Uganda.

Antiretroviral therapy is a relatively new issue to most communities in Africa. The main barrier to accessibility has been the high costs involved. Nevertheless, through technical advances and lobbying by various stakeholders the costs have been reduced and funds are being mobilised to increase

accessibility to antiretroviral drugs. However, there is a big issue of stigma associated with HIV/AIDS and use of the drugs, which needs to be addressed by faith-based organisations (FBOs).

One of the causes of stigma in AIDS is that HIV is sometimes transmitted by behaviours which are regarded as sinful as taught by various faiths. For example sex outside marriage is regarded as a sin by most faiths, and it is one of the routes through which HIV transmission can occur. Therefore, PLWHA have sometimes been stigmatised as of lower moral character who cannot control their sexual behaviour. As a result there is a tendency to hide HIV infection and consequently reduce access to HIV management. On the other hand most faiths teach about the imperfections of human beings who constantly need to ask for forgiveness from God. An example of this from the Islamic faith is in the Qur'an (39:53): "*O my servants who have transgressed against their souls! Despair not of the Mercy of Allah for Allah forgives all sins for He is Oft-forgiving, Most Merciful.*"

The faiths also teach charity and compassionate care of the needy who include those afflicted by diseases. For instance, the Qur'an (2:177) says: "*It is righteousness to believe in Allah and the Last Day and the Angels and the Book and the Messengers; to spend of your substance out of love for Him for your kin, for orphans, for the needy, for the wayfarer, for those who ask and for the ransom of slaves...*"



Community leader and educator at work

Another reason why AIDS is stigmatised is that it is associated with early death. Therefore, people with AIDS are sometimes regarded as of low value since they are on their way to death. To avoid this perception there is a tendency to hide HIV status. However, most faiths teach that death is close to everyone and that it is inappropriate to stigmatise those who appear close to death.

Faith-based community mobilisation

In Africa, a significant proportion of health care is provided by faith-based health units. These units were established in response to faith teachings that call for the care of the needy. With appropriate capacity building, many of these could deliver antiretroviral drugs and support PLWHA in their treatment. Since antiretroviral therapy is relatively new especially in Africa, many FBOs have not yet fully utilised their potential for advocacy and education of the community on this issue.

However, there are some FBOs that are beginning to build their capacity to address antiretroviral treatment-related issues. An example is the Ugandan project "Community Mobilization Model for Prevention of Mother to Child HIV Transmission (PMTCT) and Antiretroviral Therapy (ART)" of the Islamic Medical Association of Uganda (IMAU).

In Uganda it is estimated that about 1 million people are living with HIV/AIDS. Of these, about 100,000 have symptoms of AIDS and are in need of antiretroviral therapy. This number is expected to increase every year. It is estimated that only about 10% of those who need the drugs are actually using them and most of these people are living in urban areas. They meet most of the treatment costs privately. The IMAU project was designed to complement government efforts to increase awareness and utilisation of PMTCT and ART services. This pilot project was started in 2002 in Kampala District. A rapid appraisal was first done to assess the knowledge of the communities on PMTCT and ART. The knowledge was found to be low. A curriculum was then designed to address various issues related to PMTCT and ART. The topics in this curriculum included: Voluntary Counselling and Testing, infant feeding, PMTCT and ART. Twenty-five trainers were selected from Christian and Muslim faiths depending on their competence and availability to train the community educators. The main objective of the education was to increase awareness and promote demand for ART services. A total of 750 community educators of both Muslim and Christian faiths were trained together. These community educators included religious leaders and their assistants. These educators then started educating their communities about PMTCT and ART issues through sermons, group talks and home visits.

Demanding services

The educators record their activities on monitoring forms which they return to IMAU staff during monthly meetings. According to these records, they have so far educated over 100,000 men and 150,000 women. They report that their communities are demanding services including PMTCT and ART to be brought nearer to them at more affordable costs. They also report that their communities are now looking out for opportunities to get low-cost or free antiretroviral drugs. They believe that increased availability of



Involving religious leaders in access to treatment

Photo: Treatment Action Campaign

antiretroviral drugs will be an incentive for utilisation of other services including VCT and PMTCT. They say that the project has contributed to increased openness and reduced stigma around HIV/AIDS. Some community educators have reported that people are more willing to go for VCT in clinics because antiretroviral drugs to help them are becoming available. One community leader said: *"AIDS is becoming a chronic treatable disease like diabetes and hypertension. There is no need to stigmatise people anymore."*

There is increasing demand to expand the project to other parts of the country. This will require more

IMAU's HIV/AIDS activities

The Islamic Medical Association of Uganda (IMAU) is a faith-based NGO of Muslim health professionals, which was established in 1988. IMAU started working on HIV/AIDS issues in 1989. This was in response to the national call for all sectors including faith-based organisations to rise and address the challenge of AIDS in the country. IMAU had the comparative advantage of having a working knowledge of both scientific and Islamic teachings related to HIV/AIDS. It started its work by organising a dialogue for the top Muslim leaders in the country to discuss the scientific and Islamic aspects of AIDS. As a result of the dialogue, the leaders of the Muslim community declared a "Jihad on AIDS". This was the rallying call for Muslims to increase self discipline to control behaviour in order to prevent HIV and care for those infected and affected.

Following partnership with the top Muslim leaders, IMAU moved down to the grassroots Muslim leaders at the mosque level called the Imams. IMAU trained trainers who in turn trained the Imams in how to address HIV/AIDS issues. The Imams and their assistants then educated their communities during sermons, group talks and home visits. This approach for mobilising the Muslim community to address HIV/AIDS was recognised and documented as one of UNAIDS Best Practices in a booklet entitled *AIDS Education Through Imams: A spiritually motivated community effort in Uganda* (online available at www.comminit.com/Materials/sld-4239.html).

IMAU started getting interested in antiretroviral drugs in the late 1990s when they became more available. In 2002 IMAU designed an inter-faith-based community mobilisation and education project to increase awareness and utilisation of antiretroviral drugs.

resources to train more trainers and community educators. The project was funded by CDC in collaboration with UNAIDS and UNICEF. Plans are underway to look for resources from both within and outside the communities to sustain and scale up the project activities. The estimated cost for educating an individual regularly so far is about 1 US\$ per year.

In conclusion, faith-based organisations have a great potential to deliver ARV-related services through

their health facilities and religious establishments. This potential needs to be utilised by forming partnerships with FBOs and building their capacities to deliver these services. The example from Uganda shows that this can be done. ❖

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Programme Feature

The MAF People Living with HIV/AIDS Drug Assistance Scheme – shared burdens, shared responsibilities

Indra Nadchatram

By 1998, zidovudine (AZT) was the only antiretroviral medication being offered free by the Malaysian government to HIV-infected people who met its Treatment Guidelines. The other two drugs needed for combination therapy to be effective, had to be bought at commercial prices by the patient. At the time, there was no sign that the government would ever be able to offer free therapy to the relatively small number of Malaysian PLWHA. It was also clear that the large majority of them could not afford these medicines. Additional input was therefore necessary. The Malaysian AIDS Foundation (MAF) Drug Assistance Scheme was first introduced in 1998 to meet the gap in treatment accessibility for PLWHA. The Scheme sought to share the burden of ART costs between government, patients and MAF.



Buy one, get two for free!

Photo: WHO/Eric Miller

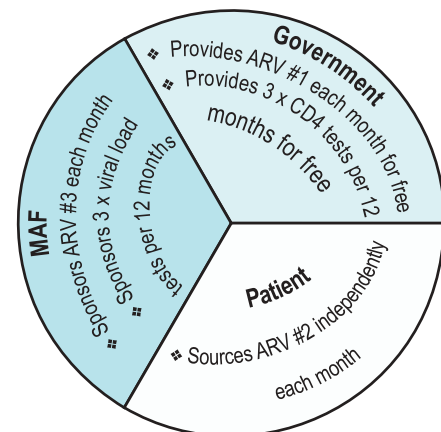
In 1998, a PLWHA would have to pay US\$ 421 a month for two additional ARVs to undergo triple therapy. This cost could increase to US\$ 553 a month should the patient not respond to AZT in the regimen and be required to purchase all three ARVs. Treatment accessibility at US\$ 5,000 to US\$ 6,600 a year was clearly beyond the reach of many HIV-positive Malaysians who earned on average about US\$ 3,120 per year. This cost would not include other expenses that may be incurred by the patient such as undergoing viral load tests to monitor response to the therapy or treatment of opportunistic infections and hospitalisation.

Cost of ARVs is one of the main factors that determine how and where PLWHA access treatment. Many have resorted to treatments with unfounded claims of being able to cure HIV or based on unproven or minimally established clinical data, primarily because these treatments are less expensive than antiretroviral treatment. Some people are also known to self-administer their treatment without supervision of a doctor, using

generic ARVs accessed from abroad through friends. At the same time, people on supervised antiretroviral therapy are prepared to travel long distances to seek treatment in hospitals located away from their towns and cities for fear of discrimination should their status be discovered locally.

The Drug Assistance Scheme

In response to the situation in Malaysia, MAF initiated its "People Living with HIV/AIDS Drug Assistance Scheme" to improve drugs affordability using a partnership framework with the responsibility shared across the stakeholders:



Drugs accessibility has generally improved in the years since MAF's Drug Scheme was introduced, due to the government's commitment and the role of several pharmaceutical companies in the country who have reduced the price of their ARVs as well as introduced new ARV formulations that help enhance treatment compliance. The government today provides five categories of PLWHA with free therapy: 1) HIV-infected

children; 2) persons who acquire infection through contaminated blood and blood products in Malaysia; 3) health-care workers infected through occupational exposure in Malaysia; 4) women who are detected HIV-positive through the antenatal surveillance programme of the Ministry of Health; and 5) civil servants. All other PLWHA managed at Ministry of Health hospitals are provided with one ARV only. This could be AZT or one of the other seven selected medicines.

Beneficiaries

The programme provides sponsorship based on established medical and socio-economic criteria developed by a team of doctors. The socio-economic criteria comprise: being a Malaysian citizen above the age of 13 (HIV-positive children in Malaysia receive free combination therapy); and having a monthly household income of US\$ 526 net and below.

Since the start of the programme, the average cost for triple therapy (ARVs only) has reduced by about 40% to US\$ 315 per month. The total cost for treatment including CD4 and viral load tests is USD 338 per month. The government subsidises slightly more than a third of this cost for all patients who meet the National Treatment Guidelines. Should the patient also be a beneficiary of the MAF Scheme, the cost is further reduced by approximately 70%. Consequently, programme participants pay about US\$ 100 per month.

Beginning small in 1998 with support to 30 poor Malaysians, the programme has since increased its support to benefit 100 Malaysians at any one time. All applications to the scheme, which must be submitted by the patients' doctor, are provided with code names to maintain confidentiality. A lottery system is employed for selection as applications outnumber spaces available. Unsuccessful applicants are maintained on a waiting list and accepted in chronological order as and when spaces are made available.

Sustainability – financing the programme

A seed grant from the Association of Ministers Wives, Malaysia helped initiate the programme. Sustainability in the years since has been dependent on fundraising activities, donations and investments, all of which are carried out in Malaysia. In addition, MAF developed a policy whereby twenty percent of all non-designated donations are channelled to support the programme. The global call for ARV price reductions enabled the government and civil society the opportunity to negotiate for more affordable ARV prices in Malaysia. Several pharmaceutical companies responded to these negotiations favourably by reducing their prices by 20-60%.

Achievements

Seventy percent of people who started with CD4 counts of below 200 today have counts of 300 and above, many with undetectable viral load levels. Data collected over the years also indicate that recipients have been able to source for one ARV on their own, as treatment has been made more accessible with 70% of its costs being sponsored collectively by the government and MAF. Experience has also demonstrated that patient buy-in has ensured a higher level of adherence to the regimen.

This programme has provided MAF with a platform and a legitimate voice to address its concerns and to get more involved in HIV treatment efforts in Malaysia.



Amongst others, the scheme has provided us opportunities to advocate on HIV treatment issues to the government as well as with pharmaceutical and diagnostic companies, including negotiating ARV price reductions. More importantly, the programme has enabled better accessibility to drugs for several Malaysians, and demonstrated the value and benefits of treatment, thus encouraging HIV testing. MAF's evaluation in 2001 also revealed that recipients were heartened by the progress of their health and were encouraging their peers to seek treatment as well.

Moving forward

While some benefits have been achieved to date in Malaysia, more should be done to improve treatment accessibility. There are some 1500 people currently on ART in Malaysia, of whom 106 are able to access ARVs as a result of the Scheme. The others receive only one ARV from the government. MAF estimates that another 3000 people would need antiretroviral therapy now and are not on it, either because they cannot afford to buy the other two ARVs on their own or because they are not visiting their doctors. Over 70% of Malaysia's reported HIV/AIDS cases are amongst injecting drug users, who have very poor track records with clinical follow-up. Amongst others, continued efforts in lowering the costs of drugs; expanding and improving ARV delivery to include more diagnostic facilities in the country as well as providing structures that will ensure better compliance to treatment regimens will be necessary.

At the national level, the Malaysian government is commended for its continued commitment to

Malaysian AIDS Foundation

The Malaysian AIDS Foundation (MAF) is a Charitable Trust, originally formed in 1993 by the Malaysian AIDS Council (MAC) as its fundraising and grant-making arm.

MAF raises funds to finance three of its special schemes that meet the needs of PLWHA in Malaysia, and their families. These are the *Paediatric AIDS Fund*; *People Living with HIV/AIDS Drug Assistance Scheme* and the *People Living with HIV/AIDS Business Assistance Scheme*. In addition, MAF channels grants to the MAC and MAC Partner Affiliates for HIV/AIDS programmes that are unable to attract government funding or located in areas where financial resources are scarce as well as for scholarships to local and international HIV/AIDS-related meetings and conferences.

improving treatment affordability by negotiating for lower prices for branded drugs and exploring avenues to introduce generic ARVs into the local market. We hope this will encourage more PLWHA to access ARV treatment rather than treatments with little clinical data on efficacy. At the same time, prevention and awareness efforts that include addressing stigma and discrimination are being scaled up by MAF's parent organization, the Malaysian AIDS Council (MAC) in collaboration with MAC Partner Affiliates.

At the international level, international agencies and developed countries need to continue their pressure on the pharmaceutical industry to further lower ARV prices while introducing new ARVs at affordable prices. Policies as well as frameworks are also needed to enable governments committed to delivering

treatment including the ability to introduce generic ARVs without fear of negative repercussions.

Our ultimate aim is to work towards the abolishment of this Scheme where all PLWHA are able to access free treatment in Malaysia. ❖

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1. HIV prevalence was 0.25% in 2002. Though this appears to be low, infection rates have risen substantially. Malaysia recorded its highest number of HIV cases (7,218) in 2002 alone. Heterosexual transmission increased by 46% (source: Ministry of Health Malaysia, statistics December 2002).

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❖ From the WHO Series "Perspectives and Practice in Antiretroviral Treatment" case studies:

- *A Public Health Approach to Antiretroviral Treatment: Overcoming Constraints.* WHO/International HIV/AIDS Alliance, 2003 (16 p.): www.who.int/hiv/pub/prev_care/en/PublicHealthApproach_E.pdf
- *Saving Mothers, Saving Families: The MTCT-Plus Initiative.* WHO, 2003 (20 p.): www.who.int/hiv/pub/prev_care/en/Saving_Mothers_E.pdf
- *Antiretroviral Therapy in Primary Health Care: Experience of the Khayelitsha Programme in South Africa.* WHO, 2003 (16 p.): www.who.int/hiv/pub/prev_care/en/South_Africa_E.pdf
- *Scaling Up Antiretroviral Therapy: Experience in Uganda,* WHO, 2003 (16 p.): www.who.int/hiv/pub/prev_care/en/Uganda_E.pdf
- *Access to Antiretroviral Treatment and Care: The Experience of the HIV Equity Initiative, Cange, Haiti.* WHO, 2003 (16 p.): www.who.int/hiv/pub/prev_care/en/Haiti_E.pdf

❖ Other WHO publications:

- *A Toolkit for Scaling-Up ARV Treatment in Resource Constrained Settings* (draft August 2003): www.who.int/entity/hiv/pub/prev_care/arvtoolkit/en
- *Handbook on Access to HIV/AIDS-Related Treatment. A collection of information, tools and resources for NGOs, CBOs and PLWHA groups.* UNAIDS Best Practice Collection, UNAIDS/WHO/International HIV/AIDS Alliance, 2003 (130 p.): www.who.int/hiv/pub/prev_care/HandbookAccess_en.pdf

❖ International HIV/AIDS Alliance publications:

- *Improving Access to HIV/AIDS-Related Treatment – A report sharing experiences and lessons learned on*

improving access to HIV/AIDS-related treatment, 2002

- *Voices from the Community – A Report of a Community Consultation on Antiretroviral Treatment in Zambia, 2002*

These publications can be accessed at www.aidsalliance.org.

- ❖ *HIV & AIDS Treatment in Practice* is a free e-mail newsletter for doctors, nurses, other health-care workers and community treatment advocates working in resource-limited settings which is published twice a month by the British information service NAM. Sign up at www.aidsmap.com/components/subscribe.asp or send an e-mail with name, e-mail address and country to: hatip@nam.org.uk with the words "add HATIP list" in the subject line.
- ❖ Final report International HIV Treatment Preparedness Summit, March 13-16, 2003, Cape Town, South Africa: www.ajf.gr.jp/hiv_aids/treatment_access/finalcapetownreport.html or www.fcaids.org/pubs/FINALCAPETOWNREPORT.pdf
- ❖ *Improving access to care in developing countries: lessons from practice, research, resources and partnerships.* Report from a meeting: Advocating for access and sharing experiences, 29 November – 1 December 2001, Paris, France. UNAIDS/WHO/ Ministry of Foreign Affairs, France, 2002 (140 p.): www.unaids.org/publications/documents/care/acc_access/JC809-Access-to-Care-E.pdf
- ❖ Delivering the goods: HIV treatment for the poor, February 2002, *Insights Health Issue #2*, www.id21.org/insights/insights-h02/index.html
- ❖ The website of the Treatment Action Campaign (TAC) offers access to useful resources on ARVs: www.tac.org.za
- ❖ Fact sheet *Access to HIV Treatment and Care*, UNAIDS, September 2003: www.unaids.org/html/pub/Publications/Fact-Sheets03/FS_Care_2003_en_doc.htm

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