

ALL IS NOT LOST

Initiatives to ensure equal access have begun and while it is too early to draw conclusions, we can learn from these reports from Africa and Brazil.



Peter Williams/WCC

Drug use in Uganda and Ivory Coast

The Drug Access Initiative enrolled its first patients in Uganda and Ivory Coast in 1998.

Some important lessons have already been learnt about the operational aspects of the initiative from the experience of Ivory Coast and Uganda, where currently about 600 and 900 patients respectively are receiving antiretroviral therapy.

Advisory boards in both countries defined treatment policy, and training efforts were successful in ensuring physicians compliance with the proposed treatment guidelines in the referral centres participating in the initiative. The guidelines and training took a comprehensive approach to the management of patients with HIV, including their opportunistic infections



and diseases. However, the procurement guidelines focused almost exclusively on antiretroviral therapy until 1999. Since then, at the insistence of UNAIDS, both countries have shown a greater interest in the management of opportunistic diseases. Anticipating the March 2000 consultation on cotrimoxazole prophylaxis, Ivory Coast and Uganda adopted guidelines on using this drug combination for the prevention of opportunistic infections in people with HIV. The increased emphasis on drugs for opportunistic infections will make the Drug Access Initiative more relevant to clients who cannot afford antiretroviral drugs, and to follow up centres where antiretrovirals are not prescribed.

Efforts to increase drug affordability

Uganda, a relatively poor country, opted not to use any public funds to subsidize antiretrovirals supplied through the initiative (the cost being borne by the patients). In Ivory Coast, a richer country, the government committed itself to shoulder part of the cost for selected patients. However, the allocation of treatment subsidies was very slow. While an in-depth analysis of the use of antiretrovirals outside the initiative was not conducted, the fact remains that the programme in Ivory Coast attracted fewer clients than that in Uganda.

Strengthening the health sector

The educational efforts of the initiative were assessed as positive in both countries. In Uganda, laboratory follow-up was strengthened by the donation of CD4 counting equipment. The growing interest of the countries' advisory boards in opportunistic disease management has resulted in more operational follow up centres.

Societal impact

In both countries, the presence of the initiative galvanized people with HIV and AIDS by holding out some hope for them, and led to a wide mobilization of health sector staff around HIV and AIDS. It also resulted in a great deal of discussion of AIDS in the media, not only about the cost of HIV treatment but



Don Edkins/WCC

also HIV prevention. By raising the visibility of the epidemic, this level of discussion may enhance prevention efforts and yield significant benefits that extend beyond the clients and health care providers of the initiative.

Generic alternatives in Brazil

The government of Brazil has a policy of universal access to antiretroviral drugs that currently benefits nearly all AIDS patients in the country (about 85,000). The introduction of combination antiretroviral therapy nearly halved the annual number of AIDS deaths between 1996 and 1999 and reduced the incidence of opportunistic infections by 60-80% over the same period.

The universal access programme would not have been possible without significant decreases in the cost of antiretroviral drugs. The government decided to start local manufacture of drugs that were not patent-protected, and for which it had the know-how and infrastructure. Local production, combined with bulk purchases of imported antiretrovirals, led to significant decreases in the programme's drug costs. The annual cost of double therapy with nucleoside analogues decreased on average by 80% between 1996 and 2000, from US\$3812 to US\$763. For triple therapy with two nucleosides and one protease inhibitor, the cost reduction was 36% over the same period (from US\$7342 to US\$ 4717) and for triple therapy with two nucleosides and one non-nucleoside it was 34% from US\$ 4584 to US\$ 3009).

The programme's annual drug costs were approximately R\$611 million (US\$

339 million) in 1999, and are expected to rise to R\$831 million (US\$ 462 million) for the year 2000, taking into account both a higher proportion of patients on triple therapy and a larger overall number of patients. Between 1997 and 1999, approximately 146,000 AIDS-related hospitalizations were averted, resulting in savings of approximately R\$521 million (US\$289 million). This has partly offset the high cost of antiretroviral therapy. At the same time, condom sales increased by nearly half (from 216 million to 320 million pieces) between 1996 and 1999, and demand for voluntary HIV counselling and testing rose 35% between 1996 and 1998.

Courtesy: UNAIDS Website: www.unaids.org

SECOND TO NONE

In Africa, where often local village heads and elders are blinded by customs and superstitions, women are marginalized. It is not an easy task to break these barriers.

Stripped of the basic dignity to life, women with HIV/AIDS are doubly burdened – first as unequal citizens and second, by the unequal access to medicines.

*The following two stories by **Patricia Nickson** are poignant accounts of how women who were condemned to live on the fringes of society, have rallied back with support and love. These examples show how the church can also turn the tables.*

Rosie from West Africa

Rosie is a widow, the mother of two teenage children living in West Africa. Her husband died five years ago after a long illness. A few years later Rosie became engaged and, as marriage plans were progressing, her pastor requested that she have an HIV test. The positive result was devastating as it meant the end of her engagement and the sudden realization that her husband had died of



Danida



aunt's family for her education. As a teenager she was often left to fend for herself and to look for her own costs of training. Because she wanted some professional training, she "sold herself" so that she could pay for her studies. Part way through her nurses' training she became unwell. A doctor found that she was HIV positive, but she was not informed. However, the head of her training institute discovered her status, arranged for counselling with the institute's chaplain and assured her of the institute's on going support and concern. She responded well, and developed a new courage and determination. Within a few weeks she informed all the staff of her HIV status – the first person in the area known to have made a public declaration of her infection. She has since developed an interest in becoming a counsellor to those living with HIV/AIDS.

Points to ponder

- Both cases indicate a lack of access to necessary information
- Both lacked access to pre and post-test counselling which would have prepared them for the shock which was coming to them.
- Rosie was rejected by her church friends and her employer, while Janet was accepted and reassured: accessibility to community acceptance is important in ensuring the well-being of people living with HIV/AIDS.

Dr Patricia Nickson, IPASC, 89 Upton Park Drive, Upton, Wirral CH49 JW, UK Tel: 44-151-708-9393 E-mail: ipasc@liverpool.ac.uk

AIDS, and that she was also likely to become chronically ill.

Rosie's problems did not end there. Others in her community must have passed around the news of her HIV status. In church, people no longer came to sit next to her and her employer eventually sacked her. Fearful that her children would hear the news, she sent them to stay with relatives. Rosie became severely depressed, but was carefully and patiently counselled by a pastor with a concern for those living with HIV/AIDS. With his help, she gained courage and a renewed self-respect. She changed churches and found new friends, and is now looking for ways in which she can break the barrier to accessibility to friendship, timely counselling, support and hope.

Janet from East Africa

Janet left her parents' home when she was 7 years old, having been sent to an



Let us share the burden.



Where there is no artist

“IT IS ALL VERY WELL TO IMPROVE ACCESS TO MEDICATION...”



*The greatest enemy is the enemy within us. While access to medicines is important to clamp HIV/AIDS, **Nicci Stein** insists we need to also break away from the fetters of stigma that has pegged us down for so long if we are to achieve a break through.*

I work in an NGO in South Africa called Triangle Project. We have a community development stance in all our work and I am concerned mostly about the underlying social and personal issues regarding access to treatment.

It is all very well to improve practical access to medication, and that obviously needs to happen, but we are facing a situation where, even if there were free access to treatments, many people would not benefit from this. Denial (and fear which creates denial) are enormous problems. The level of social stigma about HIV is still very high. We have an enormous number of TB cases and we know from experience (without the stigma) that a large percentage of people do not complete their course of treatment. MDR-TB is increasingly becoming an issue, which is almost impossible to deal with. For people living without a job, with inadequate or no housing, HIV falls quite low on their list of priorities. For people without running water or regular food intake, taking medicines is not a priority. Neither is practising safe sex. Also, if people are not even going to talk about the issue of HIV, then they are certainly not going to take medication.

We recently held a discussion workshop on HIV testing for gay men living in African township areas. All the men stayed away and when we asked

individual people afterwards what had happened, they said that they were all too afraid to even think about HIV, let alone discuss it. Many of these men are probably HIV positive and are too afraid to be tested. A number of them are positive and know it and yet are afraid to be involved in these discussions.

We know that one has to have a certain level of acceptance, self-esteem and the will to be proactive about one's life, to successfully engage in a treatment regimen. The people I work with are far from this position.

They are dealing with very low self-esteem (as a result of years of apartheid and because of the unacceptance of homosexuality in African cultures); little knowledge about HIV and a huge amount of fear. The bottom line is that we cannot ignore these issues when discussing access to treatment. I would welcome any other comments/experiences on this subject.

Ms Nicci Stein, Director, Triangle Project, Cape Town, South Africa.

Triangle Project is a gay and lesbian health and development NGO.
Tel: +27+21 4483812
Fax: +27+21 4484089
E - m a i l : triangle@icon.co.za
Web: http://www.icon.co.za/~triangle/

If people are not even going to talk about the issue of HIV, then they are certainly not going to take medication



Where there

BUILD BRIDGES NOT WALLS

Inability to access drugs is not the only reason why so many are dying of HIV/AIDS. Social stigma can kill too and is often the cause of unequal access to treatment. A meeting on Stigma and HIV/AIDS in Africa was convened in Dar-es-Salaam, Tanzania in June 2001. Excerpts:



UNICEF

We are all directly or indirectly affected by HIV/AIDS, and the accompanying stigma, characterized by silence, fear, discrimination and denial which fuels the epidemic. These same factors also undermine prevention, care and support and worsen the impact of the epidemic.

Stigma in the health care setting

Health care workers represent the front line in HIV/AIDS care and prevention, and therefore, while possibly perpetuating stigma they may also endure stigma from colleagues and from the societies in which they work and live. Health care workers accordingly have a responsibility to overcome stigma within their professions and workplaces. This can be accelerated through their roles as carers for people living with HIV/AIDS and as educators and role models for their communities.

To counter stigma:

- Ensure codes of ethics and professional conduct, offer sufficient forms of redress for professional violations.
- Encourage practical and attitudinal HIV-related training for all health care providers. Promote voluntary counselling and testing and care.
- Establish and mainstream HIV/AIDS care within the existing health systems and develop discharge and referral systems.

- Scale up voluntary counselling, testing and care and support services.

Stigma and faith-based organizations

Faith-based organizations have a responsibility to promote prevention, and to provide care, comfort, and spiritual support to HIV-infected and affected communities.

To counter stigma:

- Provide HIV/AIDS training in basic and on going formation for all religious leaders, including counselling skills, in order to make religious leaders 'AIDS-competent'.
- Identify information on religious language and doctrines that are stigmatizing, and promote alternative non-judgmental language.
- Integrate wholistic care and support programmes including life-skills for youth, home-based family care, and support groups for affected persons.
- Promote humanitarian and spiritual values of compassion for marginalized and stigmatized groups.

Conclusion

All those with understanding and authority on HIV/AIDS have a responsibility, individually and collectively, to act to reduce stigma within their spheres of influence.

For more information about the consultation, please see the website: <http://www.hdnet.org>



Peter Williams/WCC

PATENT SITUATION OF HIV/AIDS-RELATED DRUGS

More than 95% of all HIV-infected people now live in the developing world, which has likewise experienced 95% of all deaths to date from AIDS. In developed countries, the introduction of highly active antiretroviral treatment and the availability of drugs led to a substantial reduction in AIDS mortality. In developing countries, however, access to these drugs is seriously lacking.

Several interrelated factors determine access to essential drugs. Among them are appropriate use, supply management, economic issues, legislation and regulation, manufacturing, research and development decisions. But affordability perhaps, is the catch word.

Most of the drugs created especially to treat HIV infection are patented. This makes the treatment less affordable than drugs for which generic alternatives exist. Since patent protection allows exclusive rights to an invention, it is one of the possible reasons for limited availability and affordability of drugs.

Patent regulations

Patent ensures exclusive rights over the manufacture. A patent is **national** and applications for patents must be filed in every country (or regional offices, where they exist) where protection is desired for a specific invention. **There is no international patent.**

Review of patent expiry dates of HIV/AIDS drugs

WHO has prepared a detailed table to indicate expiry dates of the basic substance patent protecting some HIV/AIDS related drugs. It also indicates countries in which this patent has been applied for and granted.

To get an approximate idea of the date on which generic competition can start for a specific drug, the most useful

approach is to locate the date of application for the first patent, usually protecting the basic substance of the drug.

To get an approximate idea of when a patent granted for the same drug in other countries will expire add 20 years to the date of application and take into account the one-year period of priority (20+1).

As from this expiry date of the substance patent, copies of the basic substance of this drug may be produced, although other patents may protect a manufacturing process. But the basic substance at least is in the public domain. This applies only to countries where a patent has been granted and where the patentee regularly pays the maintenance fees to keep the patent "alive".

However, it is possible to obtain patent extension beyond 20 years in some countries, to compensate for time spent in R&D or the registration process to obtain marketing authorization.

The study, is extremely useful for those interested in an update on patent implications for HIV-related drugs. (*Given below is an example of the table contents*).

For more information contact: Dr Brian Pazvakavambwa, World Health Organization (WHO), Department of HIV/AIDS Global and Inter-Regional Coordination, 20 Avenue Appia, CH-1211 Geneva 27, Switzerland Tel: +41-22-791-4564 Fax: +41-22-791-4834 E-mail: pazvakavambwab@who.int http://www.bpazva.8m.com



UNAIDS

Drug Name	Patent owner	Basic Patent priority date	Max. 20yrs patent prot.	US patent expiry date	French or Europe patent expiry date	Countries where similar patents have been filed or granted*
<i>Anti-infective drugs</i>						
Albendazole	SmithKline	19 June 74	19 June 1995	19 June 94, but excl. marketing rights until 11 June 2003 (as an orphan drug)	N/A	Australia, Belgium , Canada , Cyprus, Denmark , Finland, France, Germany , Hong Kong, Hungary, Ireland, Israel, Italy , Japan , Kenya, Luxembourg, Malaysia, Mexico, Netherlands , Norway, Philippines, Portugal, USSR , South Africa , Sweden, Switzerland , UK , US, Yugoslavia
* Countries in bold are those where a patent was granted (Derwent database), as compared with other countries where data are available regarding patent applications only (Derwent + European Patent Office website).						