contact

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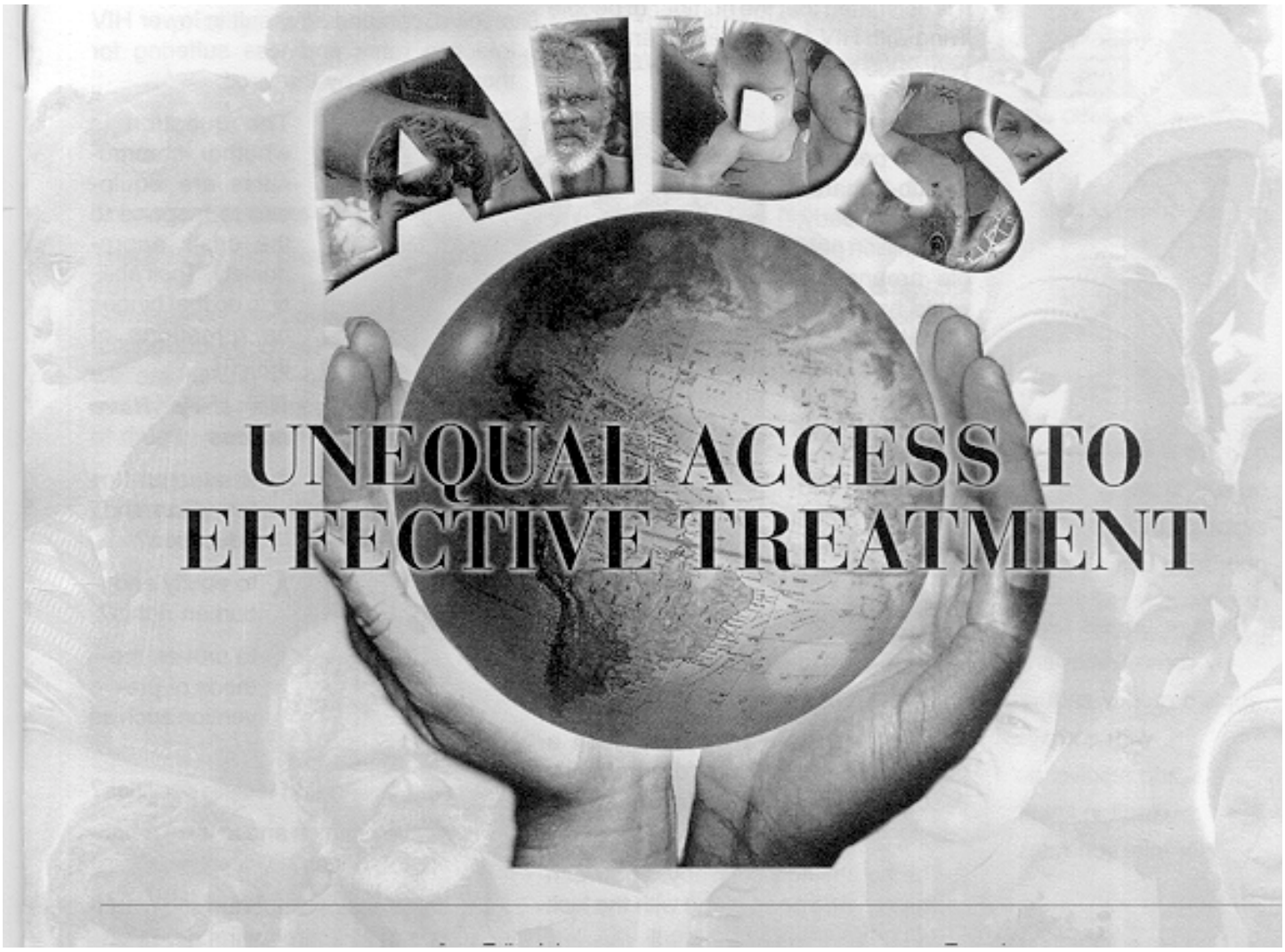

No **171**

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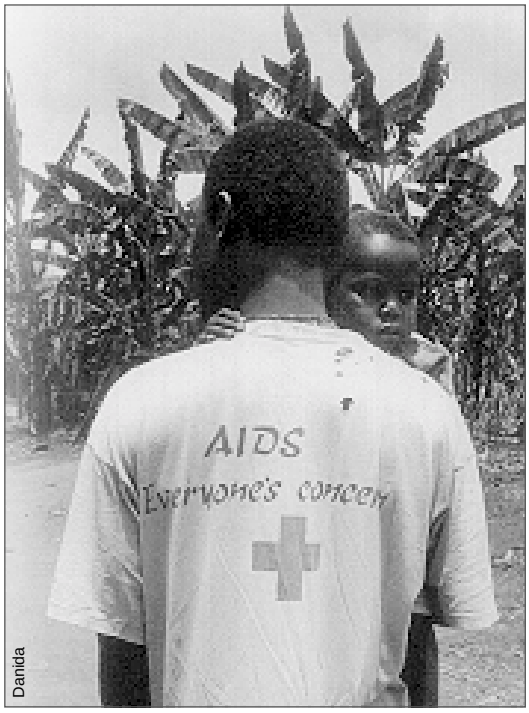
When AIDS emerged two decades ago, it could not be predicted how the epidemic would evolve. Now, it is obvious that apart from the colossal loss in human lives and the suffering the pandemic brings to societies, it can devastate whole regions and wipe off decades of national development. In consequence the poor and marginalized become poorer, pushing them further to the fringes of society.

It is estimated that the number of people living with HIV or AIDS at the end of the year 2000 stood at 36.1 million — 90 per cent in developing countries and 75 per cent in sub-Saharan Africa. Already, 21.8 million people around the world have died of AIDS, 4.3 million of them children. This pandemic has also orphaned 13.2 million children. The recent estimates show that in the year 2000 alone, 5.3 million people were newly infected with HIV.



Danida

Right responses taken by communities and applied quickly enough with courage and resolve, do result in lower HIV infection rates.

The HIV/AIDS pandemic has been a great revealer. It has dramatically exposed a spectrum of gross flaws in our societies

- the increasingly deep abyss between the rich and poor, along with the lack of commitment to bridge it
- the non availability of the basic health services and the collapse of existing systems in many parts of the world
- the lack of women's rights and opportunities to resist infection, or to assert their reproductive choices or to demand safe sex
- the long and deafening silence of churches, civil society and of their respective leadership to face up to the issues of sexuality and the fundamental preventive aspects of HIV/AIDS
- the alarming rise in the number of injecting drug users, with a distressing fall in the age at which people start injecting drugs in many countries

But at the same time the pandemic has also revealed that the right responses, taken by communities and applied quickly enough with courage and resolve, can and do result in lower HIV infection rates and less suffering for those affected by the virus.

The question is whether communities are equipped to respond to the crisis appropriately. Their ability to do that hinges on questions of access.

Do they have access

- to adequate information and education?
- to equity and human rights?
- to proven methods of prevention such as condoms?
- to counselling and testing facilities?
- to sterile needles and to drug rehabilitation facilities?
- to drugs against opportunistic infections and to antiretroviral drugs?

This issue of *Contact* deals mainly with the topic of access to treatment. However, it is important to see this within the wider context of accessibility. It is vital to mobilize our communities to address these issues, to ensure we are equipped to respond to the crisis appropriately and able to act decisively without delay.

Manoj Kurian
Guest Editor

Cover
A HIV/AIDS imperiled world, held together by hope.
Credit: WCC

ACCESS TO DRUGS FOR HIV PATIENTS

Access to treatment for HIV/AIDS is without doubt essential. But the exercise is not so simple. In Africa, where the average spending on health per person is just $10 (£7) — in some other countries it is as low as $3 (£2.10) — even generic drugs, which will cost between $350-$500 (£250-£350) per person per year, will remain inaccessible. Unless sustainable solutions and health spending in these countries get priority, antiretroviral drugs will remain unaffordable, irrespective of whoever manufactures them. ***Eva Ombaka*** elaborates:

Eva Ombaka

Treatment options

There is yet no preventive vaccine or cure for AIDS in the sense of permanently destroying the virus. In talking about access to HIV/AIDS drugs, we are talking of options to improve quality of life. There are five categories of drugs:

- Drugs such as antibiotics to treat sexually transmitted infections (STI). Treating STI can reduce the risk of transmission of HIV in the community.
- Prophylactic (preventive) drugs for HIV positive. These include isoniazid to prevent tuberculosis and cotrimoxazole to prevent pneumonia.
- Drugs for palliative treatment, which relieve the distress. These include painkillers, anti-diarrhoea, anti-histamines or lotions to stop itching

HIV/AIDS is today, a major cause of human suffering. Vital sectors like health and education are being pushed to breaking point

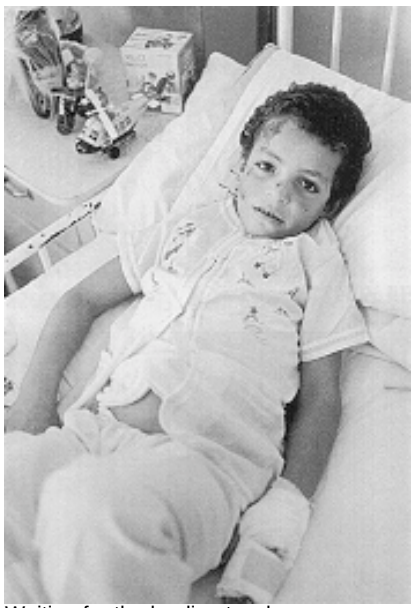
Peter Williams/WCC

Many countries do not have easy access to modern medicines.

What is needed is political will and well-designed and adequately financed international efforts to improve the health systems.

and drugs to stop convulsions.

- Drugs to treat opportunistic infections (OI). The common OI include tuberculosis (TB), pneumonia, thrush and other fungal infections, various skin diseases and herpes.
- Antiretrovirals (ARV), which slow down (but do not eliminate) the virus, thus holding the disease at bay. These are used as a 'cocktail' regime (mixture of 2 or 3) in order to delay emergence of drug resistance. Known as Highly Active Antiretroviral Therapies (HAART), these drugs reduce the mortality and morbidity of people with AIDS. Short courses of ARV, e.g. Nevirapine, can also prevent HIV being passed from mother to baby during birth. **(See box 1)**



Peter Williams/WCC

Waiting for the healing touch.

The Bottlenecks to access

Most drugs needed for palliative care, prophylaxis or for opportunistic infections, which have been in use for decades, are on the WHO Essential Drugs List and are available at low prices. But access to them is not always assured. Weak management and inadequate financing often clamp the supply of vital antibiotics.

In the case of ARVs, however, the main bottleneck has been the very high pricing of these drugs. There has also been resistance to introduce ARV in poor settings due to difficulties in adhering to complicated treatment and monitoring regimes which, if not observed, would lead to promotion and spreading of drug resistant viruses.

There are now compelling arguments in favour of widespread use of ARV. The falling prices are removing one of the major obstacles. It is proposed that availability of ARV would in turn lead to greater participation in Voluntary Testing and Counselling and therefore positively impact on prevention programmes. Recent development of new fixed-dose combinations taken once or twice daily are making treatment regimes less complicated. What is needed is political will and well-designed and adequately financed international efforts to improve the health systems.

BOX 1

The Antiretrovirals

Nucleoside analog Reverse Transcriptase Inhibitors (NRTIs)

Didanosine (ddI) Lamivudine (3TC) Stavudine (d4T)
Zalcitabine (ddC) Zidovudine (AZT)

Non-nucleoside analog Reverse Transcriptase Inhibitors (NNRTIs)

Delavirdine (DLV) Efavirenz (EFV) Nevirapine (NVP)

Protease inhibitors (PIs)

Indinarfvir (IDV) Nelfinavir (NFV) Saquinavir (SQV)
Ritonavir (RTV)

Treatment regimen (HAART) involves two different types of drugs i.e. 2NRIs + 1PI or 2NRTIs + 1NNRTI.

The patent angle

New medicines, or new processes seen as inventions, are subject to patent protection. The patent, meant as a reward to the inventor, encourages research and covers development costs. During the period of patent, the inventor has exclusive marketing rights. At the end of the patent period, other companies can also make the drug. Such drugs are known as generics. These are usually much cheaper than the branded drugs and, as more companies produce them, competition pushes the prices further down as much as ten fold or more.

Until recently, all governments were free to decide how much patent protection to give, e.g. how much time or whether to grant patent for process and not the product. However, this changed with the new rules of World Trade Organization (WTO) and the agreement on Trade- Related aspects of Intellectual Property Rights (TRIPS). Now all members must grant patents for both process and product for a period of not less than 20 years. Production of generics during the time will therefore be illegal unless certain provisions are made in the national legislation. These provisions are recognized in the TRIPS agreement and are meant to balance the intellectual property rights with public health needs.

The main safeguards are compulsory licensing, where a country can override the patent without permission of patent holder, in order to meet public health emergencies. This is subject to various conditions. Also provided for, are parallel importing, which allow countries to "shop around" for lower-priced versions of the patented medicines and the Bolar (early working) provision, which allows preparatory work (for production of generics) to begin before the patent expires.

However, in order to be put into practice, these safeguards must be written into countries' national patent laws. Although transition periods vary between countries, all signatories of WTO are required to comply with the TRIPS agreement by 2006. Countries changing their laws must therefore consider these safeguards now.

BOX 2

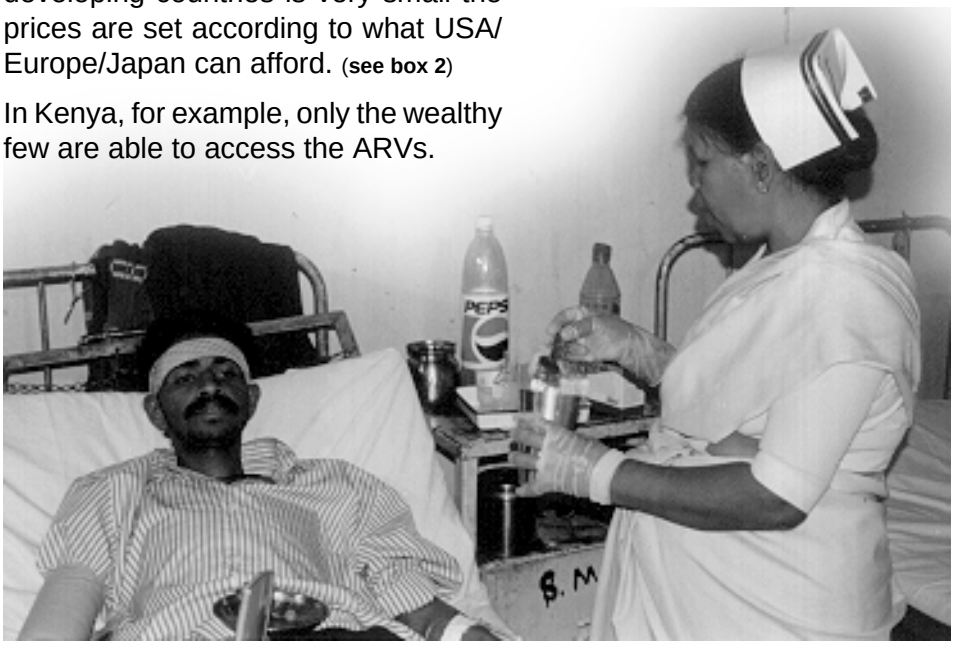
Prices after 80-85% price reduction (June 2001, Kenya)

D4T + ddI	+ Nelfinavir	USD	4009	per year
AZT + 3TC	+ NVP	USD	1272	per year
D4T + ddI	+ Indinavir	USD	1008	per year
3TC + D4T	+ NVP	USD	819	per year
3TC + D4T	+ NVP (Cipla offer)	USD	350	per year

Drug pricing

Patents tend to lead to high drug prices. This is because profits are the main motive. Prices are set according to what the market can pay, not according to production costs. Since the market of developing countries is very small the prices are set according to what USA/ Europe/Japan can afford. (**see box 2**)

In Kenya, for example, only the wealthy few are able to access the ARVs.



CMAI

ARVs can hold AIDS at bay.

The vast majority has no option but to let nature take its course, with disastrous consequences. In these circumstances, physicians are facing a dilemma on whether or not to inform the patients about the drugs!

Other pricing factors include the pharmacy mark-up and taxes and tariffs on imports. The development and implementation of appropriate national laws and National Drug Policies (NDP) which would regulate the drug market, local production and use of drugs is therefore mandatory to address the pricing and access issues.

Prices are set according to what the market can pay, not according to production costs

TRIPS and ACCESS to MEDICINES


CMAI

The recent controversy around the excessive price of patented HIV/AIDS medicines illustrated the negative impact of Trade-Related aspects of Intellectual Property Rights (TRIPS) on access to medicines. It also demonstrated the way in which powerful corporations use legal pressures to reinterpret TRIPS in their own interests.

Treatment of AIDS with a combination of drugs — called Highly Active Antiretroviral Treatment (HAART) — has decreased mortality from AIDS by 84% in developing countries. Unfortunately less than 5% of AIDS infected people across the globe have access to such treatment, because the estimated cost of this treatment is about $12,000 per person per year.

At present rates, Zimbabwe, Uganda and Ivory Coast would require to spend 265%, 172% and 84% of their respective Gross National Products, just to buy drugs to treat all their AIDS patients! This issue has been the rallying point of a major global campaign that today is demanding a closer, critical look at the TRIPS agreement.

Thirty-nine pharmaceutical companies sued the South African government in Pretoria's High Court for allowing the country access to cheaper anti-AIDS drugs. This evoked a massive counter-response across the globe and in April 2001, the companies capitulated to mounting anger and disgust and agreed to withdraw the case unconditionally.

Brazil too moved a resolution at the UN Human Rights Commission. They called upon all States to ensure that "the application of international agreements is supportive of public health policies which promote broad access to safe, efficient and affordable preventive, curative or palliative pharmaceuticals and medical technologies..."

The truth is, present day drug-research has little relevance to real medical needs. Medicines required to treat diseases that predominantly occur among the poor are not researched at all. Instead drugs that are being researched today, are drugs used for "lifestyle" diseases like baldness, impotence, obesity etc.


Peter Williams/WCC

Responses to the pandemic

There has been dramatic success in the fight against HIV/AIDS in developed countries arising from availability of the various treatments and especially the ARVs. This is not so in the poorer countries where most people with HIV/AIDS live. Yet treatment is needed to treat the 36 million infected people to optimize preventive efforts, and maintain economic development.

This has meant a call for global commitment and action across the board and from all stakeholders. Where this is supported, two areas of concern have been expressed by the NGOs and civil society.

First, the initiatives taken by the pharmaceutical industry to offer discounts for ARVs. NGO's and civil society accept that these are temporary solutions. These offers are often linked to difficult conditions and are not sustainable. They argue therefore that sustainable

and mental illness, improving prevention and recovery from substance abuse, reducing teen health risks, reducing risk of suicide, longevity and improving health behaviours.

Research also identifies some negative health outcomes of religious/spirituality, hindering rather than helping treatment or recovery. For example, certain religious groups who reject medical interventions for only 'faith healing', can lead to earlier death from diseases that are often treatable.

Negative religious coping, such as seeing illness as a punishment from God or questioning God's power or love was linked with increased depression, poorer quality of life, and callousness towards others in a study of hospitalized patients. Another study described individual psychopathology linked with families whose enmeshment, rigidity, and emotional harshness were supported by enlisting spiritual precepts. Thus, religion can certainly have its downsides and be linked with clinical problems, if not worsening of one's condition.

Claudia Waehrisch-Oblau\VEM

***Contact**:* Since most of the studies so far are US specific, do you think the results will have the same relevance in other countries and cultures?

David Larson: The World Health Organization notes, that the relevance of religion and spirituality to patients'

WCC

Believe it or not…

- A study of 62 Muslim patients with generalized anxiety disorder were randomized to receive either a traditional treatment of supportive psychotherapy with anxiolytic drugs or traditional treatment plus religious psychotherapy, involving use of prayer and reading verses of the Holy Koran specific to the person's clinical condition. The study reported that patients receiving supplemental religious psychotherapy showed significantly more rapid improvement in anxiety symptoms than those receiving traditional therapy alone.
- A comprehensive study with a one-year follow-up in the Netherlands found that people who indicated that "a strong religious faith" had only 38 per cent of the odds of becoming depressed in comparison with those who did not ascribe such importance to their religious faith. Also, among those who were depressed at the beginning of the study, those who ranked their religious faith as highly important recovered faster from their depression.
- Similarly, in a British epidemiology study, attending church and a vital religion were found to be protective factors from vulnerability to depression in both an urban and a rural community.
- In a study of suicide rates in the Netherlands, a decrease in suicide mortality was linked with a religious revival among the young, pointing to religion/spirituality serving as a protective factor.
- A 16-year study in Israel found a distinct lower rates of early death in religious *kibbutzim** compared to those living in secular *kibbutzim*, evident in both genders, at all ages, and with remarkable consistency over all causes of death. The magnitude of the protective religious effect wiped out the usual gender advantage: secular women did not live longer than religious men did.

*village

The power of prayer

Longevity Religious attendance surfaced as a strong predictor for living longer. The meta-analysis summing study totalling nearly 126,000 people found active religious involvement increased the chance for living longer by 29 per cent.

Recovering from Surgery A study at Dartmouth Medical School found that elderly heart patients were 14 times less likely to die following surgery if they found strength and comfort in their religious faith and also remained socially involved, as well.

Improving Immune Functioning A study of 1,700 elderly found that persons who attended church to any degree were only half as likely as non-attenders to have elevated levels of a blood protein that can reveal problems in immune system functioning.

John Taylor/WCC

Children worship at Kimbanguist Church, Zaire

Lowering Risk of Depression A review of more than 80 studies appearing over the last 100 years found a factor steadily linked with lower rates of depression — religious participation.

Coping with Cancer A survey of 108 women undergoing treatment for various stages of gynecological cancer revealed that more than 90 per cent of these cancer patients said their religious lives helped them sustain their hopes.

Reducing Risk of Substance Abuse A review of nearly 40 studies found that people with stronger religious commitment are consistently less likely to become involved in substance abuse.

Reducing Teen Health Risks A national study of 5,000 high school seniors found those who attend church weekly and report that religion is important to them are much less likely to engage in binge drinking, smoke or use marijuana.

Reducing Risk of Suicide A recent large national study, as well as a large-scale regional study thirty years earlier, found that persons who did not attend religious services were four times more likely to kill themselves than those who did.

Claudia Waehrisch-Oblau/VEM

lives goes beyond the United States. Spirituality and religion remain highly relevant factors among large numbers of people across the globe and potentially play a significant role in a person's sense of wellbeing.

To date most research has been conducted in the US, yet the few studies done in other countries point to similar findings. A huge opportunity awaits researchers to investigate spiritual and religious factors in various cultures. Recently, more international health leaders are calling for attention to spirituality/religion in both training, clinical practices, and research.

A position paper from the World Health Organization (WHO) on how to assess quality of life across cultures noted the importance of including persons' religion/

spirituality and personal beliefs. Interestingly, religion/spirituality was not included initially by the researchers in their proposed statement about the key components of one's quality of life. But the WHO 'grassroot' regional centres in various countries, in reviewing the proposal, consistently suggested this as an important dimension. As a result, WHO's six broad domains of quality of life seen as significant across cultures include: 1) the physical domain, 2) the psychological domain, 3) one's level of independence, 4) social relationships, 5) one's environment, and 6) one's spirituality/religion/personal beliefs.

Peter Williams/WCC

Believers from the Pokrovskaia church in Moscow.

For many people religion, personal beliefs and spirituality are a source of comfort, security, meaning, sense of belonging, purpose and strength. However, the report noted some people feel that religion can have a negative influence on their life. Consequently researching benefits and harms will allow each facet to emerge.

Unfortunately, medical clinicians and researchers often lag behind the patients they serve in recognizing the relevance of spiritual/religious commitment in dealing with illness, pointing to a need for training in this area.

Ahmed Okasha, an Egyptian psychiatrist and past president of the World Psychiatric Association (WPA), stated that religion has remained "an important factor in most patients' lives, no matter where in the world they live."

In Britain, the Royal College of Psychiatrists identified the need to consider spiritual issues in 1992, about the same time as psychiatric residency training programmes in the US made similar recommendations. They recognized the need to emphasize the physical, mental and spiritual aspects of healing in the training of doctors in general and psychiatrists in particular. Religious and spiritual factors influence the experience and presentation of illness.

Dr Crossley followed up in 1995 in the *British Journal of Psychiatry*, underscoring both the clinical and research neglect of attending to religion and identified steps to take to address this neglect.

Yet apart from these statements, we are unaware of any international recommendations in training or research that might begin to rectify the clinical and research oversights concerning patient spirituality. Other countries may be attending to these factors in their training programmes, but unfortunately we are unaware of such needed steps.

Research also identifies some negative health outcomes of religious hindering rather than helping treatment.

David B. Larson is the President and primary founder of the National Institute for Healthcare Research (NIHR) at Rockville. The Duke University trained psychiatrist and geriatrician is also an epidemiologist who has pioneered research in spirituality and health.

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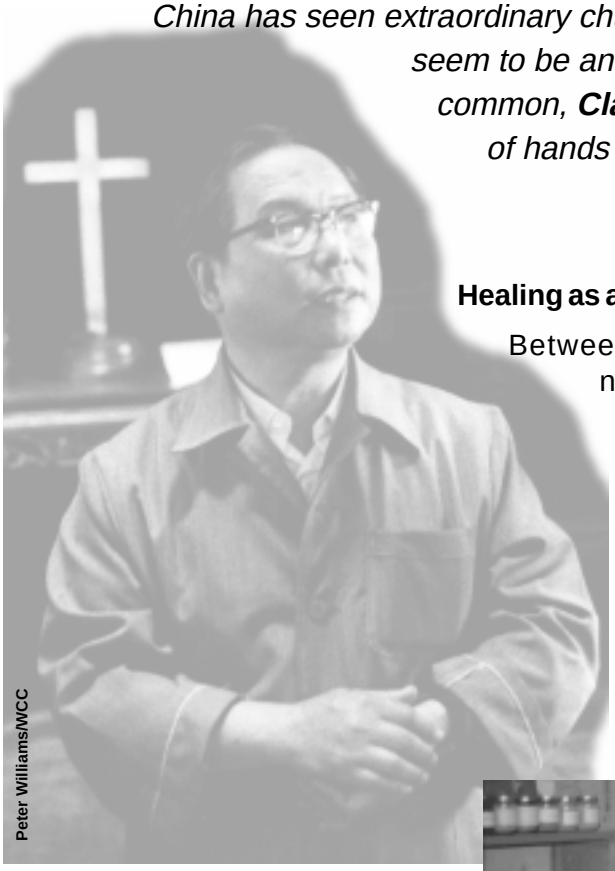
"GOD CAN MAKE US HEALTHY THROUGH AND THROUGH"

China has seen extraordinary church growth in the last 20 years, and faith healing experiences seem to be an important catalyst for this growth. While prayers for the sick is common, ***Claudia Wäehrisch-Oblau*** *explains there is rarely any laying-on of hands or anointing with oil as is the practice in some other countries.*



Peter Williams/WCC

Healing as a means of church growth

Between 1980 and 2000, the number of Protestant Christians skyrocketed from an estimated three million to probably 20 million. Representatives of the China Christian Council estimate that about half of the new conversions of the last 20 years have been caused by faith healing experiences, either one's own or that of a family member or close friend.

Claudia Waehrisch-Oblau/VEM

Large-scale, public evangelism meetings are not legally possible in China. Evangelistic meetings do take place occasionally within church buildings, but cannot be publicly advertised. Most evangelism in China therefore happens on a personal, one-to-one basis. It is in those encounters that Jesus is witnessed as the healer, while sermons in front of a larger audience would rather stress Jesus as the saviour of souls. Neo-Pentecostal style healing crusades are unknown in China. But travelling evangelists who preach in house churches and smaller gatherings are often asked for healing prayers, and they testify of many healing experiences.

There can be no doubt that the expectation of miracle healings in China and their experience directly corelate with the unavailability of medical services. For hundreds of millions of Chinese, there are few options when they fall ill, and where medical services are not available, people will turn to anything else that promises help.

While Christian councils in recent years, have founded a sizeable number of small church-run clinics and health services, and the Amity Foundation – the development arm of the China Christian Council – has organized and sponsored large-scale training programmes for rural doctors, these efforts have not made a tangible impact on the overall situation.

Individual Christians and churches in China respond to this need by preaching Jesus as the healer. Prayers for the sick and healing testimonies are an important element of personal evangelism. Christian believers will tell neighbours and friends who are ill that they should believe in Jesus for their recovery.

Prayers for the sick and healing testimonies are an important element of personal evangelism

Reversely, due to the numerous faith healing experiences, especially in the countryside, non-Christians who fall ill and cannot be helped by a doctor – be it that they cannot afford treatment, or be it that treatment fails – often seek out Christians and ask them for prayers so that they can be healed.

The practice of prayers for the sick

Within the Chinese churches, prayer for the sick is practised universally and as a matter of course, and healing as a

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.

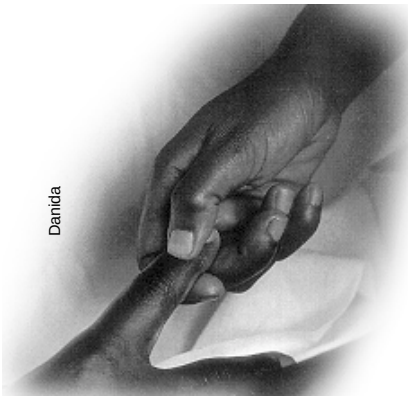
Courtesy: UNAIDS Website: www.unaids.org

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

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.

Let us share the burden.

Janet from East Africa

Janet left her parents' home when she was 7 years old, having been sent to an 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, UKTel: 44-151-708-9393 E-mail: ipasc@liverpool.ac.uk

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.
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Fax: +27+21 4484089
E-mail: 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

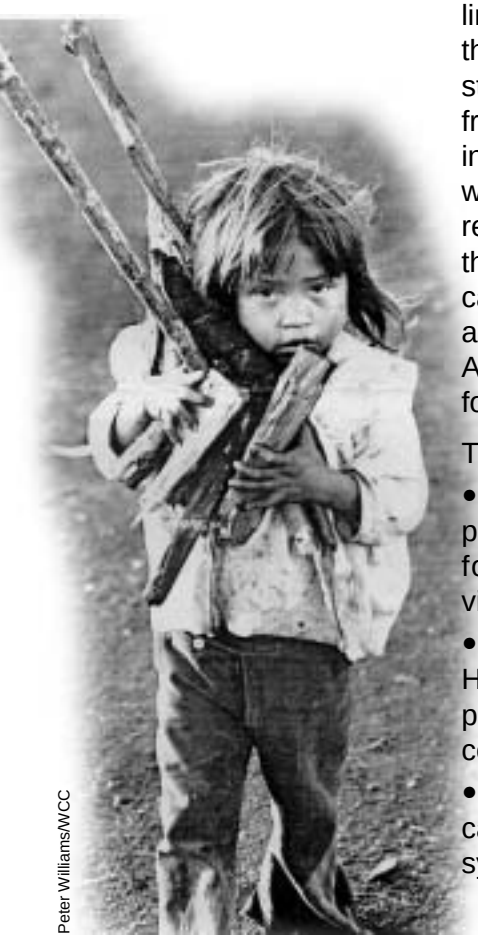
We are all directly or indirectly affected by HIV/AIDS, and the accompanying stigma, characterized by silence, fear, discrimination and denial which fuels the epidemic. These same factors also undermine prevention, care and support and worsen the impact of the epidemic.

Stigma in the health care setting

Health care workers represent the front line in HIV/AID 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.



Peter Williams/WCC

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

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*
Anti-infective drugs						
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).

"DO YOU SEE THE TROUBLE WE ARE IN?"

NEHEMIAH 2:17

Rev Gideon Byamugisha *chose to go public about his HIV status in 1995. He now heads Integrated Health Programme on HIV/AIDS.*

Nearly 50 years after King Nebuchadnezzar had captured Jerusalem and Cyprus; the King of Persia captured Babylon and took over the whole empire. A year later, he issued a decree that "the Jews could go back home and rebuild the city".

The task of rebuilding the city was not easy. The exiles that returned were few and poor while the "Stayees" had been crippled economically. So twelve years after the events recorded in the Book of Ezra, the walls of the city were still broken and the burned gates had never been replaced (Nehemiah 1:2-3).

That situation, bad as it was, was not the most painful thing for Nehemiah. What pained him most was the fact that many Jews seemed to be oblivious of the bad situation they were in.

Now for one to be in a problem is bad enough. But for one to be in a problem and not realize either the existence of the problem or its magnitude is double tragedy.

This is why Nehemiah, after a thorough inspection of the city, questioned: "Do you see the trouble we are in?" (Neh. 2:17)

Why don't people see obvious trouble?

Hunger, disease, and oppression are so common and recurrent that many accept them as routine. In addition, disease and pain often lead to an inability to think positively.

In Africa, disease and preventable deaths are so common that many people take it as the will of God. That is what preachers often say at the funerals and it may be a very good defense mechanism for communities which either do not comprehend well the causes of their troubles, or are too margnalized, sick or too paralyzed to think beyond the surface.

The curse of not knowing

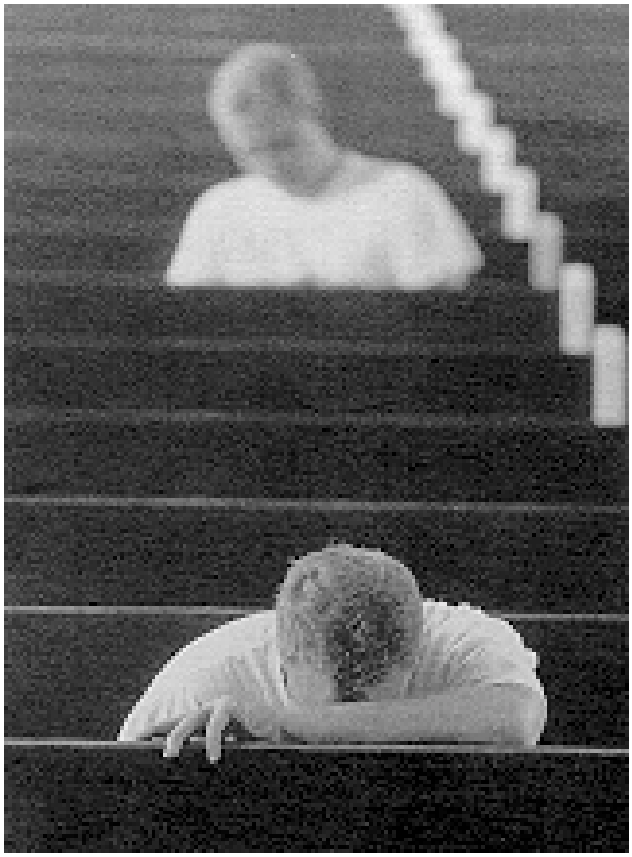
No matter however much aid is given, unless local communities know why they are in the situation they are in, progress is likely to be slow, and constrained. That is why it is pertinent that leaders, at every level and from every sector, should take it upon themselves to explain: (i) what HIV is, (ii) what it does to the body, (iii) how likely are they to become infected or to infect others and what they can do to avoid being infected or giving the virus to the others, if they are already infected.

Do you see the trouble we are in?

In Uganda, where we are hailed as making progress against HIV/AIDS — the maternal mortality ratio still stands at the very high figure of 506 deaths per 100,000 live births.

Teenage pregnancies are still the highest in Africa at 43 girls in every 100 and with 1.5-2 million people infected with HIV/AIDS. The HIV prevalence (though down now) still stands at the high rate of 8 per cent. Forty five per cent of the children below 5 years are chronically malnourished. The country now has between 1.5 - 1.8 million children, who have already lost either parent and nearly half the number have lost both parents. Expenditure on health care per capita is US $ 5.65 far below the absolute world minimum of US $ 12 and 80 per cent of the people are very poor, earning less than US $1 per day.

The country records 100 million malaria cases each year, which cause many disabilities, malnutrition and deaths. Unfortunately this pattern of deprivation, illness and death is repeated in many other African, Asian and Latin American countries with similar economic and social characteristics as Ugandans. In many other countries, the situation is actually worsening.



Jean-Claude Lejeune/WCC

But why are we so sick?

Many preachers have localized the problem in us, the sick individuals. Many say we are sick because, we refused to repent and accept Jesus as our personal Saviour. Others say we do not pray enough. Some say, we do not know how to claim the biblical promises of healing and wholeness and ask me: *"Don't you know that there is healing oil. Why haven't you asked for anointing?"* "Were you infected before or after you became a priest? "Have you repented?"

Such questions often asked at the various meetings where I disclose my HIV-positive status might be well-intentioned. But they have always left me wondering why some of the countries one wouldn't call so religious or 'born again' enjoy disproportionately higher standards of living, higher life expectancies and are almost HIV free.

It is time, I think, that we the church leaders and the laity together study the real causes of vulnerability to preventable diseases and deaths in countries where these diseases and deaths are rampant.

To condemn an individual or a community by linking global problems with an individual's behaviour, is insensitive and extremely myopic. If we have not realized that an individual's behaviour is shaped largely by what goes on around him, we have perhaps missed the wider lessons being taught by the HIV/AIDS virus.

In fact in Nehemiah 4:11, the enemies of Israel bragged about this situation where people remain oblivious of the real nature, extent and causes of their problems: *"And our enemies said: They will not know or see till we come in their midst and kill them and* stop *their work"* (RSV)

Whether we are in the North or South, we have a duty as church leaders and as Christians to know and see the real factors fuelling the pandemic rather than just issuing simplistic moral statements.

We should understand that there are two types of suffering in the HIV/AIDS:

Self-inflicted suffering — where individuals, families, and whole communities have access to inform-ation, skills and services to control HIV/ AIDS but choose not to act.

Suffering caused by others — where individuals, families and whole communities are deprived or denied access to the right information, skills, services and incomes to protect themselves from infection, however worried and self-motivated they may be.

Let us remember that what pained Nehemiah most was not the problems of his fellowmen, but the fact that his kinsmen could not sufficiently analyze the nature, magnitude and impact of the problems.

Questions for reflection

1. Do you see the trouble we are in?
2. Are we using the church to control AIDS or we are using AIDS to control the church?

CONTACTS

Population Service Int.
1120 19th Street N.W.
Suite 460, Washington, USA
Tel: 202-785-0072
Fax: 202-785-0120
E-mail:info@psi.org

Population Service International – Among the first organization in the world to make a significant use of social marketing in the fight against AIDS. It has continued to be a pioneer and innovator in the field for more than a decade A non profit group based in Washington DC, Population Service International is the leading AIDS crusade with projects in almost 50 countries. For more information please see the website: www.psi.org

WCC PUBLICATIONS

World Council of Churches
P.O. Box 2100,
1211 Geneva 2
Switzerland
Tel: 41 22 791 6111
Fax: 41 22 791 0361
E-mail: publications@wcc-coe.org

Facing AIDS –The Challenge, the Churches Response This WCC document is the fruit of two years of intensive consultation by an inter-national group of pastors, theologians and ethicists, scientists, doctors and nurses living with AIDS and persons working with those touched by it. Successive chapters focus on the scientific facts and social, economic and cultural context; theological perspectives; ethical and medical-ethical issues; human rights and responsibilities; and pastoral care by the church as a healing community.
Second printing, ISBN: 2-8254-1213-9 Price:US$9.95, Sfr15.00, £6.50 plus 20% postage. Also available in French and Spanish. For Spanish copy contact: CLAI, Casilla 17-08-8522 Quito, Ecuador Fax: (593-2) 256 8373.

WHO PUBLICATIONS

World Health Organization
1211 Geneva 27
Switzerland
Fax: 41 22 791 4167.
E-mail: austinm@who.ch

The Use of Essential Drugs
Ninth Report of the WHO Expert Committee (Including the Revised Model List of Essential Drugs).
Presents and explains the eleventh model list of essential drugs issued by WHO as a part of its effort to extend modern drugs to the world's population.
Intended to guide the selection of drugs in countries where the need is great and resources are small.
Technical Report Series No. 895 2000, V+ 61 pages
ISBN 924 1208953 Order no. 1100895. Available on the net: http://w3.whosea.org/rdocl

Home-based Long-term Care Report of a WHO study group 2000.
Records the conclusions and recommendations of a study group commissioned to explore the use of home-based care as a strategy for coping with the growing number of individuals in need of long-term care.
Addressed to policy makers the report is in keeping with diverse demographic needs.
+43 pages ISBN 92 4 120898 8 RS 280 Contact: http://w3.whosea.org/rdocl

OTHER PUBLICATIONS

R Macintyre
Rutgers, New Brunswick
New Jersey
USA

Mortal Men: Living with asymptomatic HIV by R Macintyre.
'Mortal Men' is an account of qualitative research among gay men with HIV/AIDS. Based on ten interviews, the book examines the relationships of the interviewees with systems and agencies of health care and in particular, accounts of long term survival.
While the stories are replete with physical experiences, there is a focus on management of immune systems, and difficulties with treatment decisions.
Macintyre, a long-term survivor (he was diagnosed in 1985) shows how to live with AIDS and experience its effect in one community.
Published in 1999 256pp (hardback) $26.00.

Joe Catalan (Ed)
UCL Press
London
United Kingdom

Mental Health and HIV Infection
This book provides a valuable, up-to-date summary of what is no longer a new field. The edited volume aims to review the main issues in mental health and the kinds of approach that have been most effective in relieving emotional distress.
The book also includes detailed considerations of HIV-related mental disorders and ends with a chapter on psycho-immunology.
All the contributors have been closely involved with the day-to-day care of people with HIV. Some of its insights would be valuable for professionals working with any group of patients struggling with chronic, life-threatening illnesses.
Published in 1999, 241pp, £7.99.

USEFUL PUBLICATIONS

The Persistence and Mutation of Racism

This short document published in English, Spanish and French surveys some of the main issues that preoccupy people who suffer from racism or study its effects.

It helps to highlight what often goes unnoticed except when violence is involved. Further, it also helps to bring into focus the problems of the victims of racism for those who do not experience it.

In context of the UN world conference on Racism and Xenophobia in 2001, this document serves as an excellent backgrounder.

The International Council of Human Rights Policy, PO Box 147, 1290 Versoix, Switzerland

ISBN 2-940259-09-7, Sf15 (+3p&p)

LETTERS

Health Consequences of Violence against Women

Dear Editor,

I read with interest Erlinda Senturius's article 'Health Consequences of Violence against Women' (Contact -164 March 1999) and feel it is a pity women have to endure this prejudice.

With the AIDS pandemic already threatening the present world's population, we are heading for a disaster, unless attitudes change radically.

I work with several women's groups involved in self-reliant activities in Africa and many of us have experienced violence in some form or the other. However, high on our list of objectives is to fight HIV and AIDS especially among rural African woman.

We will be very grateful if you can channel more literature on violence against women for us to share in our women's groups.

Alice Saliki
P.O. Box 5069, Bamenda, NW Province, Cameroon

Thank you for your letter. We are happy to learn that Contact is encouraging women to stand up for what is right. In this issue, among other things, we have tried to draw attention to the need to fight stigma. I hope you and your friends will gain from it. With best wishes.

Editor

Contact Solidarity Appeal

Where there is no artist

Contact is expanding, rising to the challenges of regionalization and strengthening the network of health workers.

Will you help us in this? A donation of just US $10/British Pound 8/SFr 18/Rs. 460 will enable one more health worker to receive *Contact* free of charge.

You can send your contribution to the *Contact* Solidarity Fund, to (please mark *'Contact'* in your covering letter):

1. **World Council of Churches**

For Swiss Francs:
Union de Banques Suisses (UBS), CH-1211 GENEVA 2, Switzerland
Account No.: 240-695. 149.00A

For US $:
Union de Banques Suisses (UBS), CH-1211 GENEVA 2, Switzerland
Account No.: 240-695. 149.60X

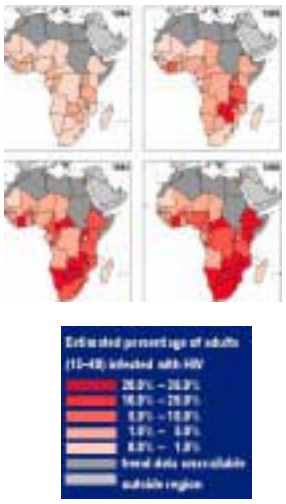
2. **Christian Medical Association of India**

For US $: SB 4790 (in favour of "Christian Medical Association of India"), Syndicate Bank, Janakpuri New Delhi 110 058

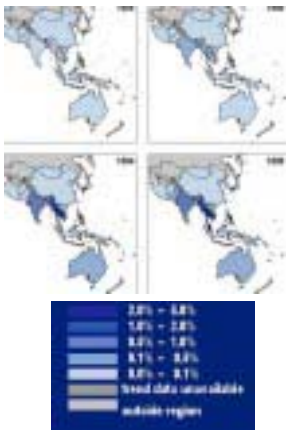
For Indian Rupees:
SB 17999, Indian Bank A-3 Local Shopping Centre,Janakpuri New Delhi 110 058

ANNOUNCEMENTS

Spread of HIV/AIDS in sub Saharan Africa from 1994 to 1999.



Spread of HIV in Asia from 1994 to 1999.



Second International course on promoting rational drug use in the community at Entebbe, Uganda, 11-24 November 2001

The course is hosted by Makerere University's Child Health and Development Centre along with WHO's Department of Essential Drugs and Medicines Policy. The University of Amsterdam has developed the course in collaboration with experts.

It is intended for staff from ministries of health, universities, development agencies, non-governmental and other organizations, and interested individuals.

The fee of US$2,950 covers tuition, course materials and shared hotel accommodation. Single rooms are available for an extra US$ 20 per night payable by participants. The fee for local participants without accommodation, breakfast or dinner is US$ 1,500. The course flyer and application forms can be found on the EDM website: http://www.who.int medicines/organization/par/second course. Or contact: University of Amsterdam Faculty of Social and Behavioural Sciences PRDUC course, Attn. Dr Ria Reis Oudezijds Achterburgwal 185, 1012 DK Amsterdam, The Netherlands Tel: +31-20 5254779 Fax: +31-20 5253010.

UNAIDS

5th International Conference on Home and Community Care for Persons Living with HIV/AIDS - December 17-20, 2001.

The Insight Initiative Team, Thailand, is conducting the Fifth International Conference on Home and Community Care for Persons Living with HIV/AIDS, at Chiang Mai, Thailand from December 17-20, 2001. The theme of the conference is 'The Power of Humanity' and it is being organized by the Thailand Red Cross Society, the World Health Organization and the Royal Thailand Government. Email:insight@hdnet.org.

12th International Conference on AIDS and STDs – December 9-13, 2001

The conference at Ouagadougou, Burki Faso is meant to assess the fight against the HIV/ AIDS epidemic in Africa. The theme for the conference is: 'The communities commit themselves' – relevant in the present context, with AIDS inflicting great damage on the African economy and destroying their social framework.

Contact deals with various aspects of the churches' and community's involvement in health, and seeks to report topical, innovative and courageous approaches to the promotion of health and healing.

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Contact is also available on the World Council of Churches' website: http://www.wcc-coe.org/wcc/news.contact.html