

Clinical issues

in **HIV/AIDS**

This series focuses on advances in therapy for HIV/AIDS, particularly developments in triple therapy employing protease inhibitors.

The eleventh bulletin looks at efforts that are being made to bring up-to-date therapies and healthcare

programmes to the affected populations of sub-Saharan Africa, with a feature on the establishment of an antiretroviral service in Botswana.

The review section surveys the web for the best patient information on PCP, TB and Kaposi's sarcoma.

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Commentary

There are many terrifying statistics concerning HIV and AIDS on the African continent:

- 85% of HIV deaths occur there
- 70% of AIDS cases worldwide are Africans
- One in every five deaths in Africa is caused by HIV
- Every year, 600,000 children born seropositive die there
- 95% of African orphan children lose their parents through HIV
- South of the Sahara, more than 500 people are infected with HIV every hour.

Perhaps the saddest statistic is that until 1999 only 10% of world resources to fight AIDS were allocated to the continent.

Commentary continued

To reverse this last trend, pharmaceutical companies have joined the United Nations HIV/AIDS programme (UNAIDS) and, since May 2000, have worked together with the World Health Organization (WHO), the World Bank, the United Nations Children's Fund (UNICEF) and the United Nations Population Fund (UNFPA) to fight HIV/AIDS. This public and private partnership has promoted and accelerated research and access to HIV/AIDS therapies, thus contributing significantly to the fight against the virus in developing countries. This new approach represented a kick-start for health infrastructure programmes in poor countries across the globe.

In July 2000 the Bill and Melinda Gates Foundation and the Merck Company Foundation reached an agreement with the Republic of Botswana to implement an extensive programme for prevention, education and facilitation of access to therapy for HIV patients. A well constructed and co-ordinated action plan has made it possible to create a patrimony of experience that is easily transferable to similar projects in other countries with a comparable background.

The Gates Foundation, the Merck Company Foundation and the government of Botswana have formed the African Comprehensive HIV/AIDS Partnerships (ACHAP), with the first two institutions each dedicating \$50 million over five years towards the project. Pharmaceutical companies are also donating antiretroviral medicine in accordance with nationally approved guidelines for the duration of the programme.

As an example of the initiatives arising from such partnerships of pharmaceutical, charitable and government bodies, its progress leads us to a more optimistic view for the future than current statistics would suggest.

ACHAP can provide not only the finances needed but also the equally important intelligence, expertise and knowledge for the best management and prevention of HIV/AIDS to all parties involved (visit the ACHAP website at www.achap.org).

ACHAP initiatives include:

- Recruitment of key personnel such as clinical care consultants, behavioural change advisers and communication managers

- Nationwide dissemination of the results of an annual HIV sentinel survey
- The appointment of regional HIV co-ordinators who can lead a sector response, ensuring that the issues of increasing numbers of orphans at schools, teachers including HIV/AIDS education in the school curriculum, gender relations, sexuality and safer sex can all be addressed
- Training programmes to provide current and comprehensive information on HIV/AIDS to medical and pharmaceutical personnel, and to HIV counsellors throughout the country
- Television broadcasts for use as a distance-learning tool in all public schools and colleges in Botswana
- Clinical preceptorship programmes to provide clinical expertise in HIV using senior medical staff from approved medical institutions outside Botswana, thereby enhancing HIV clinical standards and practices
- Resource centres at district hospitals to increase access to HIV/AIDS information for patients and families
- The establishment of counselling centres for people living with HIV/AIDS.

The list goes on and is testimony to the way in which profit derived from antiretroviral drugs can be effectively and efficiently used by pharmaceutical companies to enhance management of a target disease. Lowering the price of drugs in developing countries is not the only way to encourage and simplify access to therapy, showing us that hearts and minds are as important as dollars, pounds and euros.

With all this in mind, the following account by Chloe Orkin of setting up a clinic in Botswana – where she was joined by Brian Gazzard – takes on an added dimension.

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Botswana diary

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Sitting on the plane to Botswana with my colleague Flick Thorley, an HIV psychiatric nurse, we discussed what we might experience during our six-month secondment to Botswana. We imagined dusty roads, poorly staffed facilities and a population riddled with an HIV seroprevalence of 38%. Our minds were filled with determination to establish an antiretroviral (ARV) service and our suitcases were filled with toiletries, mosquito nets and as many medical books as we could carry.

A programme of improvement

In Botswana, there is an admirable political commitment to implementing a high-level HIV/AIDS prevention and treatment programme. The government has entered into partnership with various non-governmental organisations (NGOs) to plan and finance the venture. The African Comprehensive HIV/AIDS Partnerships (ACHAP) is responsible for the training of doctors and nurses. ACHAP arranged a secondment of ARV-experienced doctors and nurses to Botswana through the Chelsea & Westminster Hospital (St Stephen's AIDS trust) for a period of at least two years.

Because Botswana does not have its own medical school, the doctors there are mainly foreign. Also, nurses do not tend to specialise in one field, but are moved annually between different clinical areas, specialties and hospitals.

Standing start

Our destination in Francistown was Nyangabgwe Hospital, a large tertiary referral centre for the north of the country. We had been sent to train staff and develop the service. We arrived on 9 May 2002 and – to our horror – found that the ARV programme was to start five days later, following a presidential directive to provide ARVs from 13 May 2002.

We did a situational analysis and met urgently with the ARV committee, who had been elected by the hospital. They comprised members of all medical and surgical departments, as well as representatives from administration, pharmacy, social work and the laboratory.

Together we formulated a plan of intensive basic theoretical training for nurses, doctors, pharmacists, social workers and pharmacy technicians. We structured the training programme to minimise disturbance to the running of the general hospital. The hospital runs on skeleton staff anyway – to deploy staff for off-site training would have ground the service to a halt.

Physicians, paediatricians, obstetricians and medical officers attended training about adherence, side-effects, emergencies and prescribing of ARVs. Nurses from all departments were trained.

We had no designated clinic space in which to work, no additional staff members and no administrative staff. We opened up the ARV clinic the following week to referrals from our inpatients. A room was set up for the nurses to do adherence assessments. An injection room was converted into a clinic room (complete with obsolete photocopier, broken kettle and defunct autoclave). Doctors sat at their desks, poised to prescribe ARVs for the first time under clinical supervision.

The first patient

Our first patient arrived: a 30-year-old woman, looking frail at 35 kg. She walked through the door after her adherence assessment with a glint of determination in her eyes and an AIDS ribbon on her lapel. She told me that she accepted her status and understood she would have to take tablets for the rest of her life. She said she had children and that she wanted to live. I suddenly felt humbled by her spirit and the enormity of what we were trying to do.

At night we fought over the lap-top, trying to design training programmes for A&E about emergencies and palliation of symptoms, and for community church groups and orphanages. We sat outside our house, watching the African red-ball sun and funeral cortèges passing. Our colleagues told us that they were running out of space to bury people in Francistown. We went to the Okavango Delta for the bank holiday weekend to remind ourselves we were alive

and that, besides all the death around us, here were dugout canoes, papyrus reeds and elephants.

In due course, we were invited to ministerial meetings to discuss patient record-keeping documents at a national level. We flew to Gaborone, the capital city, to debate issues that no one had imagined would be of concern, such as how to record essential patient information! We realised how protected we are in the developed world, with our sophisticated IT systems of data capture and electronic storage. Together with local doctors and HIV specialists from the Netherlands and Harvard, we started to agree on what was really important and practical. Meetings generally lasted between eight and nine hours.

A time of growth

From our caravan (office) in Francistown, with no computer, fax or phone, we – along with the charismatic, dynamic physician appointed by the hospital to lead the Nyangabgwe ARV team – started expanding the service. Paediatrics and obstetric clinics were opened and more doctors began clinical supervision. All this occurred from the injection room in the main outpatients department. Demand for the national programme began to increase. Patients paying for treatment in the private sector started coming to the clinic wanting to receive drugs free of charge. Practice in the private sector has often been eclectic and many of the patients were already multi-treatment experienced.

Time passed but still the river beds remained bereft of water – we began to understand why the national currency consists of ‘pula’ (rain) and ‘thebe’ (raindrops). Patients would answer our questions about their traditional medications, and we became aware of customs and traditional practices that were centuries old. My understanding of culturally acceptable health-seeking behaviours had clearly changed.

My nurse colleague, Flick Thorley, visited all active community groups, including voluntary testing centres, orphanages, People With AIDS (PWA) groups and church groups. She gave basic training about adherence support and information on ARVs, which was enormously well received. At the hospital, we met with representatives from local clinics in the community and agreed to train local clinic doctors in prescribing ARVs, so that ultimately ARVs would become more accessible to patients. The local clinic doctors attended theoretical and practical training along with the community nurses.

At the weekend, we drove to the Makgadikgadi Salt Pans. Stretching as far as the eye can see, they are covered with the remnants of Stone Age tools lying embedded in the salt. When it rains, flamingos cover the vista in pink. Our thoughts were flooded with leaving the programme and handing it over.

Farewells

Our leaving party was held at the house of one of the doctors who we had trained. We celebrated the start of the programme and spoke about the difficulties ahead. Next door, a wake – referred to in Botswana as the ‘after-tears’ – was being held for a hospital cleaner who had recently died of AIDS. AIDS touches everyone. I looked at the faces of the people around me: the matron, the superintendent, adherence nurses, doctors and social workers and thought how hard they had all fought to start this clinic and how much hope and time they had invested.

Flying out of Botswana, I thought back to my last day in the clinic with the paediatricians. A woman had attended with her child. She looked well and strangely familiar. We started her child on treatment. Then I looked at her again and recognised our first patient, 20 kg heavier and five months older. I couldn’t believe it was time for us to go.

Website review

For the patient who has recently been given the diagnosis of pneumocystis carinii pneumonia (PCP), TB or Kaposi's sarcoma, the temptation must be to immediately look on the net for information.

A simple search for these diagnostic terms using Google gives interesting results. PCP in the sense of pneumocystis carinii pneumonia is not listed until about the fourth page – after the Portuguese Communist Party, Personal Construct Psychology and phencyclidine (an interesting addictive intravenous anaesthetic) – from where a link will take you to The Body website (www.thebody.com/treat/pcp.html).

From here there are links to the American Lung Association (motto: 'When you can't breathe, nothing else matters') at www.lungusa.org which has eight pages of information on PCP listed in order of 'computer relevance'. This information is described in terms of size (that is, the number of bytes) and for 15,253 bytes, the section on HIV/AIDS and Opportunistic Infection could well be described as less than useful. The answer to the question 'How are these infections treated?' informs the reader that, 'For most cases of tuberculosis and for pneumonia caused by bacteria, there are dependable drugs that have been in long use. However the same is not true for some fungal infections. Good treatment and preventive drugs are available, for PCP.'

So not much value for your bytes, and not really recommended.

The site also has 113 pages on TB and these represent a better investment per byte, covering topics from World TB Day, through new TB tests, to ethnic, racial and regional disparities in TB rates.

Having been last revised six months earlier than my visit, www.women-alive.org was not totally up-to-date. A search for PCP showed five documents of less than user-friendly information. The front page is an incredibly complex user profile identifying the number of visitors to the website, the number of document views, users' sessions from the US and abroad and the number of visitors who visit once and more than once, but other than as a technophobe this did impress me. The level and usefulness of specific information seemed poor, but the job section was instructive!

Just a note – don't type in 'www.womenalive.org' unless you require the Canadian Christian missionary for women, which does not usually cover these topics! (Although, when last accessed, it did carry a message from its president about the current HIV/AIDS situation in Uganda.)

For Kaposi's, the first site of note was www.cancerbacup.org.uk which was thoughtful, instructive and easy to read, though a deal of scrolling was required. The 'Living with cancer' page was good, as was the section on 'Cancer treatments', but the 'Links to reliable websites' section seemed limited.

The most useful connected site is www.intelihealth.com which is user-friendly, comprehensive, and not patronising. A newly diagnosed patient would be well served by a visit.

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