

# **AIDS in Burundi and South Africa: A Day-To-Day Experience**

*Paul Kocheleff*

HIV Clinics, Greys and Edendale Hospitals, Pietermaritzburg, South Africa

## **Introduction**

Twenty-four years ago the first cases of AIDS were identified. From a small scale epidemic of little interest other than intellectual and medical, initially limited to marginal groups in developed countries, such as homosexuals and drug addicts, Haitians and later non-marginal blacks in Central Africa, we have progressed to a pandemic involving scores of millions of infected subjects, fifteen million deaths, millions of orphans the majority of whom live in Africa and an interminable procession of family dramas.

The following article is not a product of research. It is rather a testimony based on memories stretching over the years. It calls to mind how clinicians, foreign and national, in daily contact with patients affected with AIDS, lived through the different phases of this unparalleled medical disaster, first in Burundi (1984-1994), then in the South African province of KwaZulu-Natal (1996-2004). The author accepts sole responsibility for the remarks made in this article.<sup>1</sup>

## **1. Burundi 1983-1994**

### *Discovery of the existence of AIDS*

In 1983-84 strange occurrences suggested to clinicians that AIDS, which had recently been described in the United States, also existed in Burundi: increase in cases of cryptococcal meningitis, candidal esophagitis, Kaposi's sarcoma spread at a furious rate, and polyadenopathies syndrome with disturbing histological images and a rapid relapse of tuberculosis after correct treatment.

---

<sup>1</sup> I thank my colleagues whose names follow. Together we did our best to contribute to the fight against AIDS.  
- in Burundi, L E Petat, pharmacist-biologist; doctors J Perrin (Coopération médicale française); B Standaert, M de Maedg and P Negri (Coopération médicale belge); J P Collart (Bubanza Hospital); P Kabondo, A Kiromera, E Ndabanze (University of Burundi) and F Barin, virologist (University of Tours, France);  
- in South Africa: doctors P Nijs, C Armstrong, J Roberts, D Wilson, Aung, C Sinevici and J Deward; Mrs J Dixon and Sisters S Molotsoane, Shangane, Zanele and J McLoughlin (Ministry of Health, Province of KwaZulu-Natal).

*Table 1: Cryptococcal meningitis (Bujumbura)<sup>1</sup>*

Year	1981	1982	1983	1984	1985
Number of cases	–	–	2	8	24

*Table 2: Incidence of esophageal Candida diagnosed by gastroscopy (Bujumbura)<sup>2</sup>*

Year	1982	1983	1984	1985	1986
N/gastroscopies	1/601	2/888	6/1630	17/1743	83/1567
%	0,1	0,2	0,4	1	6

*Table 3: Kaposi's sarcoma diagnosis confirmed by biopsy (Bujumbura)<sup>3</sup>*

Year	1974 – 1983	1985 (January – October)
Number	39	25
Number per annum	4.8	29

In 1984, Nathan Clumeck and his colleagues published a description of twenty-three cases of AIDS which had been observed in Belgian hospitals between 1979 and 1983<sup>4</sup>. Of the twenty-three patients, fourteen men and nine women, from the Republic of Congo (18), Rwanda (2), Burundi (2) and Chad (1), not one showed any of the risk factors described in American cases (homosexuality, intravenous drug taking, blood transfusions, stay in Haiti). This publication confirmed the existence of AIDS in central Africa and showed that the epidemiological characteristics could be very different from one region in the world to another: in central Africa, heterosexual transmission seems to play a major role.

### ***Evaluation of the gravity of the problem***

At the beginning of 1985, in order to assess the gravity of the problem at the national level, a team of Belgian, French and Burundian doctors proposed to the Burundian minister of health that they carry out a study on seroprevalence in urban milieus (Bujumbura) and in rural areas in the three natural regions of the country (plains – altitude 800 metres / central plateau – altitude 1500 metres/ Congo-Nile heights – altitude 2000 metres)<sup>5</sup>. For this project, the team benefited from the technical support of the virology laboratory at the University of Tours (Francis Barrin) which carried out the tests for the identification of the anti-HIV antibody (ELISA) and the Western Blot tests.

The investigation took place from March to July 1985. At risk subjects or those who were suspected of being at risk (soldiers, doctors, nurses) were excluded from the sample as were those who had a history of sexually transmitted diseases, blood transfusions or clinical signs compatible with an HIV infection: candidose buccale, polyadenopathies, tuberculosis. A

<sup>1</sup> P Kocheleff "Aspects cliniques de l'infection par VIH, à l'exclusion du sarcoma de Kaposi", Medical Seminar on AIDS, Bujumbura, 28-29 November 1986, 26-38.

<sup>2</sup> *Ibid.*

<sup>3</sup> R. Laroche, "Le sarcoma de Kaposi". Seminar on AIDS, Bujumbura 28-29 November 1986, 39-46.

<sup>4</sup> N. Clumeck et al "Acquired immunodeficiency syndrome in African patients", *New England Journal of Medicine*, 310/8 (23 February 1984), 492-497.

<sup>5</sup> P. Kocheleff, E. Petat, J. Perrin, P. Kabondo, A. Kiromera, P. Kadende, E. Ndabeneze, F. Barrin *HTLV3/LAV infection in Burundi, Central Africa. A countrywide seroepidemiological study*, Bujumbura, 1985 (unpublished).

control test took blood samples from patients who came to Bujumbura for consultations for sexually transmitted diseases and from patients with tuberculosis.

### *A survey with unexpected results*

In 1985 the epidemic was already having a serious effect on the capital. The average level of those who were HIV positive, regardless of age or sex, was 6,1% (22/362); it reached 10,2% in those older than fifteen (19/187). In the plains as on the heights, the overall rate was extremely low (0,4%). In the central plateau the level reached 3,7% but, importantly, most of the positive blood samples came from women who lived in an area near to the Tanzanian border which was a stop-over point for truck drivers. Everywhere there was evidence of those between the ages of naught and four being HIV positive (corresponding to mother-child transmission), the absence of infection between five and fourteen, an earlier age for infection (fifteen years and twenty years respectively) and a higher level of infection in women than in men (transmission through heterosexual relations). Amongst those who had tuberculosis prevalence reached 36,6% confirming the impression that, in Africa, there is a link between AIDS and tuberculosis. Amongst those who were treated for sexually transmitted diseases the rate was 29%. There was a reassuring note: the absence of infection in those who were between the ages of five and fourteen and who lived in the plains which is a region for endemic malaria would seem to argue against the hypothesis that mosquitoes play a role in the transmission of the virus.

*Table 4: HIV prevalence according to the geographic situation (regardless of age or sex)<sup>1</sup>*

	Rural areas				Urban areas		
	Plain	Crest	Plateau	Total	Low social level	Middle social level	Total
People tested	242	235	245	722	186	176	362
HIV + people	1	1	9	11	8	14	22
%	0.4	0.4	3.7	1.5	4.3	8.0	6.1

*Table 5: Prevalence of HIV amongst those older than fifteen<sup>2</sup>*

	Rural areas (all areas)	Urban areas (Bujumbura)
Number of tests	457	197
Number of HIV-positive people	10	19
%	2,2	10,2

In their innocence, the authors of this investigation believed that this initial collection of data from the entire country showed important results. It showed that in 1985 the urban milieu – Bujumbura – was more seriously affected than rural milieus; it offered reassurance to those who feared the possibility of transmission by mosquitoes; it confirmed the existence of “mother to child” transmission; it suggested that migrant labourers were “potential disseminators” and that there was an increased risk of contamination at stop-over points for truck drivers.

<sup>1</sup> *Ibid.*

<sup>2</sup> *Ibid.*

For the future, these facts should facilitate the elaboration of a strategy for national prevention based on a policy of information, education and the promotion of the use of condoms.

To the utter astonishment of the clinicians, the Ministry of Health's reaction was totally negative. It was accompanied with an avalanche of prohibitions, particularly that of presenting the results of the investigation at the first conference on "AIDS in Africa" (Brussels, December 1985), of taking the floor during the conference and of publishing the findings in a medical journal. The clinicians were accused of cheating because, according to the Director General of Health, "[they] showed a preference for taking blood samples from at risk patients so as to exaggerate the extent of the problem"! In addition, the technical competence of the virology laboratory at the University of Tours was questioned.

Just as dismaying was the reaction of the Head of the Coopération médicale in Brussels: he showed no interest whatsoever! As for the difficulties that the Belgian doctors experienced with certain Burundian authorities, there was no end.

The attitude of denial by the Burundian authorities was doubtless the result of a fear of attracting "international" opprobrium regarding the morality and the sexual behaviour of the Burundian population. It was also because of a fear of seeing investors and tourists turn away. "It's better to ignore the problem". This political denial would last for three years and would retard the setting up of a programme of prohibition.

In 1989, a second investigation into national HIV prevalence, organised this time by the Ministry of Health, indicated that the average level in Bujumbura – regardless of age or sex – had risen from 6,1 to 11,2% and in the older than fifteen group from 10,2 to 19,5%.

The prohibition on publication in a medical journal resulted in the breakdown of links which had been established by our group and the Universities of Tours and Harvard. Interested in the results of the enquiry, they proposed the development of a research programme in Burundi.

Disgusted by the accusations of cheating, the pharmacist/biologist Éric Petat handed in his resignation. The final blow came at the beginning of 1987 when the Burundian Ministry of Health decided to interrupt brutally the investigations organised by the epidemiologist and statistician Baudouin Standaert. His office was broken into, his documents confiscated and he was asked to leave Burundi a few weeks later. Deprived of a biologist and a statistician, the Bujumbura team found itself permanently unable to function.

### *HIV infection and racism*

The already strained and politicised atmosphere deteriorated even more with the publication of the existence of close genetic links between the simian virus (SIV) and HIV which suggested that the latter was a mutation of SIV. Commentaries of a racist nature were published in the media: not only were blacks attributed with unrestrained sexuality but some of them were depicted as indulging in sexual practices with animals which would have facilitated the transmission of the simian virus to humankind and would have provoked, after mutation, the unleashing of the AIDS epidemic. These disagreeable remarks angered Africans and the resultant tension was unpleasantly felt during the visit of the director of WHO-Africa to Bujumbura. During an interview he insisted on the fact that AIDS in Africa was an African problem and he discredited the work of the foreign researchers.

### *The Catholic church's erroneous message*

Homosexuality, drugs, sexual promiscuity, blacks with "unrestrained sexuality who indulged in bizarre practices", all these characteristics were bundled together from the very beginning of the epidemic and gave rise, throughout the world, to an aggressive stigmatisation of people

infected with HIV, a stigmatisation which, in the United States, was extended to the carers of AIDS sufferers.<sup>1</sup>

In Burundi, one of the poorest African countries, with a largely Catholic population, the researchers, faced with a sexually transmitted epidemic, waited for the church to condemn the stigmatisation and to be less strict concerning the use of condoms. Sadly, instead of showing compassion and comprehension, instead of seeing humankind in its daily reality with its weaknesses and its physiological limitations, the church's message was God-fearing, moralising and accusatory, restricting itself to ideal and utopian propositions such as abstinence, chastity and absolute fidelity. In addition, it condemned the use of condoms either as a form of protection against a fatal disease or as a means of contraception.<sup>2</sup>

This stance denied the realities of life, particularly the economic ones, as much for men as for women. In fact, poverty often forced men to delay marriage or to move on their own towards the capital in search of work. The migrant worker who is separated from his family for prolonged periods often turns towards prostitutes, unaware of the risks and uninformed regarding protective measures. As for women, extreme poverty often forced them into prostitution which was frequently the only means of survival.

The church's inappropriate message, which would always remain unchanged, was proclaimed during Pope John Paul II's visit to Rwanda and Tanzania in September 1990. During this visit and on the occasion of an address to the diplomatic corps posted in Dar es-Salaam, the pope declared: "Even more harmful are the campaigns which expressly promote – by the absence of moral content and the false hopes which they engender – the forms of behaviour which have contributed to the development of the disease".<sup>3</sup> This message was repeated by Archbishop Javier Lozano Barragan, president of the Pontifical Council for Health Pastoral Care, during a meeting of theologians and doctors held at the Vatican in November 2000. "Condoms are not helping much because the disease is spreading". In the final count, "chastity is the law of God" and "condoms are morally illicit" even for couples where only one has AIDS.<sup>4</sup> At the meeting of the International Forum for Catholic Action held in Bujumbura in August 2002, Archbishop Simon Ntamwana, president of the Catholic bishops of Burundi, expressed himself in similar terms: "As far as the church is concerned, AIDS is and will remain a moral evil and the narcissism of condoms will not help at all. In fact, the condom has many uses which only confirm the egoistic and exclusive pleasure of the user."<sup>5</sup>

### *Dashed hopes*

In 1987 Professor Ziriwabagabo Lurhuma, head of the Department of Immunology at the Faculty of Medicine in Kinshasa announced that he had perfected a medication which was effective for the treatment of AIDS. This treatment, a true miracle, was well tolerated, easy to make and was particularly cheap: ten American dollars for a cure. Its name MM1 referred to Presidents Mobutu Sese Seko of Zaire and Mubarak of Egypt. What was it made of? No one knew but the reputation of the Zairian researcher and of Zaire under the direction of its guide,

<sup>1</sup> Ronald Bayer and Gerald R. Oppenheimer, "The dark years: Fear, impotence and rejection", in *AIDS Doctors, Voices from the Epidemic* (Oxford, Oxford University Press, 2000), 63-118.

<sup>2</sup> A Douwe, A. Verkuyl, "Two world religions and family planning", *The Lancet*, 342 (21 August 1993). 473-473.

<sup>3</sup> "Messages aux corps diplomatiques, Dar es-Salaam, Tanzanie, 1<sup>er</sup> septembre 1990", numéro spécial "Discours du Pape chez-nous : Tanzanie, Burundi, Rwanda et Côte d'Ivoire, 1-10 septembre 1990", *Au cœur de l'Afrique*, 58-59 (1990), 421.

<sup>4</sup> Henri Tincq, "Cacophonie dans l'Église catholique sur le sida et le préservatif", *Le Monde*, 1 December 2000.

<sup>5</sup> Simon Ntamwana, "La force du bien, les espoirs et les défis de la région du Grand Lac", address at the International Forum for Catholic Action 22-25 August 2002. <[http://www.azionecattolica.it/FIAC/Attivita/Incontri\\_continentali/bujumbura/francais/ntamwana](http://www.azionecattolica.it/FIAC/Attivita/Incontri_continentali/bujumbura/francais/ntamwana)>.

reached the peaks of glory. The news soon reached Bujumbura which teemed with desperate people. Some had money. Nobody knows how many made the journey to Kinshasa to obtain this MM1, but this so-called scientific progress, supported with much fanfare by the Zairian presidency, soon proved itself to be without foundation. It was the cold water poured onto high hopes.<sup>1</sup>

Untimely meddling in AIDS research by a political power whose sole aim is to promote the country in the media is not specific to Africa. In October 1985 the French Ministry of Social Services triumphantly announced at a press conference that French doctors had found an effective treatment against AIDS: cyclosporine. However, the unfavourable deterioration of all the patients who were treated, rapidly contradicted these optimistic conclusions: this so-called success, imprudently announced to the media, was a failure.

In 1987 the first results of the treatment of AIDS with AZT were published; they were so encouraging that the research was prematurely interrupted for ethical reasons. In the following months, in Europe and in the United States, the enthusiasm unleashed by the AZT monotherapy would cool off because of the rapid development of the virus' resistance to the medication. In Africa, the miracle of AZT which had caused so many to dream, was simply inaccessible because of its exorbitant cost. Another disappointment for those who did not want to die.

In 1990 Dr Davy Koech, director of the Kenya Medical Research Institute (KEMRI), announced the perfecting of "Kemron" an interferon alpha which was orally administered in small doses. According to him, in a group of 204 HIV-positive patients, 18 became HIV negative. After six weeks, the CD4<sup>2</sup> significantly increased and the general condition of the patients was much improved. Once again, the Burundians would make the pilgrimage, full of hope, but they too would be disappointed. No follow-up study would confirm the magnificent results observed by Dr Koech.<sup>3</sup>

### *Daily encounters with death*

From 1985 doctors would gradually discover "exotic" diseases associated with AIDS – cryptococcosis, cerebral toxoplasmosis, pneumocystis carinii pneumonia, isospora belli intestinal infection. Given the lack of infrastructure for carrying out investigations and the Ministry of Health in Burundi's very limited budget for purchasing medications, the clinicians often remained powerless and had to be satisfied with proposing diagnosis and observing. Thus cryptococcal meningitis which is common and easy to diagnose is practically impossible to treat because six weeks' of amphotericin B can cost 100 000 Burundian francs in a country where the average monthly salary is less than 10 000 francs. If the patient does survive his opportunistic infection, there is no adequate structure to ensure the continuity of the care required for his state of immunosuppression.

With the rapid increase in the number of patients who are hospitalised for AIDS and who are in a terminal state, each day brings its quota of deaths. These daily deaths which create a feeling of hopelessness, leave the nurses and doctors frustrated, discouraged and exhausted. The simultaneous infection of several members of the same family is another reason for the stress experienced by patients and medical staff: regularly father, mother and children are infected with repeated hospitalisations followed by a string of deaths. The

<sup>1</sup> Omololu Falobi, "Abalaka: Where the media went wrong". <Nigeria.aids.org. April 1, 2000>. See also in the same volume César Nkuku Khonde's contribution.

<sup>2</sup> The CD4 lymphocytes play a major role in the body's immune response. They are among the main target of the HIV virus.

<sup>3</sup> Davy K. Koech and A. O. Obel, "Efficacy of Kemron (low dose of oral natural human interferon alpha) in the management of HIV infection and acquired immunodeficiency syndrome (AIDS), *East African Medical Journal*, 67/7 (July 1990), SS64-SS70.

increase in the number of orphans is an enormous problem even for the extended African family which is traditionally ready to accept the children of brothers and sisters who have died. Finally, even the medical fraternity is being infected more and more by the disease.

In spite of this demoralising situation, neither from the Burundian government nor the Belgian volunteer services has organised a modicum of psychological support for the staff dealing with AIDS sufferers.

At the end of 1986, tired of seeing young patients passively awaiting death, the author of this article decided to institute a more positive undertaking in the hopes of improving the quality of and perhaps the hope for life. In order to achieve this aim, it was necessary to combine the prevention of certain opportunistic diseases, a period of clinical follow-up, continual information and education and basic psychological support founded on the establishment of a relationship of trust.

The prevention programme targeted tuberculosis, cerebral toxoplasmosis, non-typhoid salmonella sepsis, isospora belli intestinal infections. Often found in those who have AIDS, these infections are controllable if the patient regularly takes small doses of relatively cheap medicines (isoniazide for tuberculosis and trimethoprim-sulfamethoxazole for the others).

In 1987, in order to study the potential of ketoconazole as a primary prophylactic in cryptococcal meningitis, the pharmaceutical firm Janssens agreed to provide this medicine so that random clinical tests could be carried out. Unfortunately, the difficulties between Dr Standaert and the Ministry of Health occurred at the same time, interrupting the tests and causing another failure in the research domain for the Bujumbura team of clinicians.

With the passing years the epidemic has not ceased to spread, the number of sick people admitted each month for complications linked to immunosuppression continues to rise. AIDS patients occupy more and more beds to the extent that one begins to wonder what happened to those suffering from other illnesses.

### *The families' response*

The stigmatisation attached to those suffering from AIDS in a world-wide scourge which has not spared Burundi. However, each day clinicians witness the admirable behaviour of relatives who accept to share precariously – or rather to survive in – sometimes for weeks on end, the same room as the ill person so as to bring some little comfort. In fact, most of the classical nursing (washing the patient, changing clothes, feeding, taking him/her to the toilet, making the bed) is undertaken by family members so that the nursing staff, always too few, can get on with more medical activities (taking blood samples, inserting drips, monitoring changes, noting clinical history...).

### *End of the Burundian experience*

In October 1993, another drama exploded: civil war. According to estimates, it was responsible for approximately 200 000 deaths in a matter of weeks! Even AIDS was relegated to second place. In July 1994 all development projects were halted. With no possibility of a short or medium term political solution, the vast majority of volunteers left Burundi.

## **2. South Africa, Kwazulu-Natal, 1996-2004**

The AIDS epidemic is rife in KwaZulu-Natal: less than 2% in 1990, the level of HIV prevalence in prenatal clinics reached 19,9% in 1996. These figures have no more than an illustrative value as they include only Black and Coloured (mixed race) women of child

bearing age who attend governmental pre-natal clinics. There are no statistical data for other women and for men. Random blood samples taken since 1990 in pre-natal clinics in all the other provinces show that the distribution of the infection is not homogeneous: in 1996 the Western Cape Province was hardly affected (3,09%), whilst the provinces of KwaZulu-Natal (19,9%) and North-Western Province (25,13%) were seriously affected.

### ***Why this explosion?***

The racist political regimes which have succeeded one another since the 19<sup>th</sup> century as well as the economic changes affecting the country have created ideal conditions for the spread of AIDS which is a sexually transmitted disease. After the discovery of diamonds in 1867 and of gold in 1886 the economy was founded on the exploitation of an abundant work force which was under paid and which had no rights. Cut off from their families for long periods the workers were confined to camps with the most basic of sanitary installations and with no medical care. In 1985, 1 833 636 South Africans were migrants to which could be added hundreds of thousands of workers from neighbouring African countries (Mozambique, Botswana, Lesotho) or from countries further a-field (Angola, Malawi). Unfortunately migrant labour did not vanish with the end of the apartheid regime and this contributed to a large degree to the AIDS explosion during the 1990s<sup>1</sup>.

Other factors would play an exacerbating role. One of these is the lack of information available to the Black community. The AIDS Unit created by the de Klerk government in 1990 was charged with diffusing information on sexually transmitted diseases and AIDS amongst the population. After two years of work, this unit was disbanded, the prevention programme interrupted, financing cut off and information in the media limited to the English and Afrikaans languages.<sup>2</sup> In 1996, two years after the end of apartheid, this linguistic gap remained evident: most of the information posters on AIDS, sexually transmitted diseases and tuberculosis which adorned the walls of the largest hospital in Pietermaritzburg were written in English whereas only a minority of the patients understood this language.

The stigmatisation experienced by HIV victims from the population in general and from the health sector in particular contributes to the spread of the epidemic. This stigmatisation can be seen on a daily basis amongst nurses and doctors whether they are white, black or Asian. Afraid of being recognised as HIV positive, the patients adopt an attitude of denial which makes the clinicians' work difficult and which hampers the effectiveness of prevention programmes.

According to an investigation in a medical faculty in Johannesburg (doctors, physiotherapists, nurses, dentists, pharmacists) at the end of the 1990s, 36% of the students felt that they had the right to refuse to treat AIDS patients and 24% believed that they could retain this right after having received their diploma or degree. Furthermore, many students admitted to having witnessed discriminatory behaviour on the part of those who were supposed to be setting an example.

In 1998 a young black woman from the Durban region, a voluntary worker for a national organisation for those living with AIDS was stoned to death by her neighbours for having admitted that she was HIV positive during the ceremonies on World AIDS day on the 1<sup>st</sup> December 1998<sup>3</sup>.

---

<sup>1</sup> Tony Barnett and Alan Whiteside "Why Africa?", *AIDS in the Twenty First Century* (Basingstoke, Palgrave-MacMillan, 2002), 124-155.

<sup>2</sup> Wilson Carswell, "HIV in South Africa", *The Lancet*, 342 (juillet 1993), 132.

<sup>3</sup> Press release, Associated Press, 28 December 1998.

### ***KwaZulu-Natal***

Poverty, unemployment, dislocation of families, separation of couples for economic reasons, loss of cultural identity, low level of education, physical and sexual violence, all contributed to the spread of AIDS in the country. However, it is unclear as to why the distribution of HIV prevalence is not homogeneous or why KwaZulu-Natal figures amongst the provinces the most affected since the beginning of the epidemic (Table 7) given that there are few mines and few migrant workers. Political disturbances which continued in this province after 1994, the presence of the port of Durban, the largest in Africa, the heavy road traffic between this city and the interior of the country have all doubtless played an important role in the spread of the epidemic.

*Table 7. Level of HIV amongst women attending prenatal clinics<sup>1</sup>*

	Western Cape	Eastern Cape	Northern Cape	Free State	KwaZulu Natal	Mpuma-Langa	North	Gauteng	North West
1996	3,09	8,10	6,47	17,49	19,90	15,77	7,96	15,49	25,13
1997	6,29	12,61	8,63	19,57	26,92	22,55	8,20	17,10	18,10
1998	5,20	15,90	9,90	22,80	32,50	30,02	11,50	22,50	21,30

A factor which could facilitate the spread of AIDS is the practice of *dry sex*. Unknown to the majority of doctors, never spoken about, in other words, denied by the population, *dry sex* is difficult to evaluate. An investigation carried out by Neetha Morar for the Medical Research Council of KwaZulu-Natal amongst women and prostitutes showed that many men insist that their partners practice *dry sex*. This consists of totally drying all vaginal mucus before sexual relations take place. This drying, using different means, causes physical damage to both the women and the men thereby increasing the risk of the transmission of AIDS.

*Dry sex* is not unique to South Africa or to KwaZulu-Natal but seems to be particularly popular in this province. Despite almost daily conversations with Zulu counselors in HIV clinics in Pietermaritzburg, the author would never have heard of the existence of *dry sex* had he not have discovered, quite by accident, Neetha Morar's article in *The Lancet*.<sup>2</sup> Even if they still have to be proved, her conclusions need to be taken seriously and it would be prudent to inform those who practice this form of sex.

### ***Taking charge of AIDS in Pietermaritzburg hospitals***

With a level of HIV exceeding 30% it is not surprising that doctors' waiting rooms are packed with patients who have complications suggestive of a state of immuno-suppression. The exact number of AIDS patients who are hospitalised is unknown because many refuse to submit to an HIV test. As medical files are vague about the diagnoses of AIDS, hospital statistics have little value. If a visitor were to have the ludicrous idea of asking for facts and figures he would be given the answer: "There are a lot ... at least 50% of medical beds".

Feelings of powerlessness, of frustration, of waste of energy and money reign supreme amongst health workers, national and foreign. Communication with the families of the ill is almost non-existent. Listening to them, one would think that the patient is suffering from pneumonia, tuberculosis or diarrhoea but certainly not AIDS. Whilst one in three adult members of the Black community is infected with HIV, AIDS does not exist for the greater majority.

<sup>1</sup> Statistics provided by the Department of Health.

<sup>2</sup> A. Baleta, "Concern voiced over "dry sex" practices in South Africa", *The Lancet*, 352 (17 October 1998), 1292.

In 1997, the Department of Medicine in the two public hospitals in Pietermaritzburg – Greys Hospital and Edendale Hospital – agreed to open, in each hospital, a clinic to deal with those who are HIV positive. So as to hide their link with AIDS, these clinics were called “Communicable Diseases Clinics” or CDC. Their aim was to curb the decrease of CD4, to improve the quality of life, to keep the patients economically active for as long as possible, to increase their life expectancy hopes in spite of the impossibility of access to antiretrovirals whose cost is exorbitant.

The general approach suggested is similar to that which was developed in Burundi. It aims at reducing the impact of opportunistic infections on the viral charge and the immune system by combining prophylaxis and treatment of active infections. It also aims at improving nutrition and reducing psychological stress which is so frequently found amongst those who are infected with HIV.

Since the outbreak of the epidemic, the usefulness of a prophylactic programme has been confirmed by different studies carried out in Haiti,<sup>1</sup> Ivory Coast,<sup>2</sup> United States.<sup>3</sup> In this latter country, the survival percentage twenty four months after an opportunistic infection signaling the AIDS status was only 10-20% during the 1984-1991 period. This rate increased significantly between 1992 and 1995 and reached 20-35% with the implementation of a prophylactic programme. Since 1996 the use of tritherapies has had an even more spectacular impact: 80% survival two years after an opportunistic infection.<sup>4</sup>

Patients’ opinion of the two clinics has been favourable as is proved by the growing number of new intakes and the long distances – from 100 to 500 kilometres – that some have to travel in order to be treated. An audit undertaken by the University of Natal in 2001 confirmed this impression. The absence of stigmatisation and the possibility of asking questions affecting all aspects of infection problems are particularly appreciated.

Even though the progress of the epidemic becomes more evident and more worrying every day, the management of the two hospitals show little interest in the problem. In six years they have not once visited the clinics and, until recently, have had no idea of what the treatment consists. This lack of interest is particularly noticeable at Edendale hospital: the information board at the entrance of the main building indicates everything, including the kitchen and the morgue, but not the clinic for infectious diseases. At Greys hospital, new management and the announcement of the upcoming governmental programme for antiretroviral treatment have considerably improved the situation.

### *Waiting for an life line*

Whilst the two clinics are appreciated by those who are ill, they nevertheless have important inadequacies. They can admit only a very limited number of patients, far below the demand. For the sick who come from rural areas, the financial cost of regular visits to the hospital – travel and consultation – is too onerous and is the main reason for drop-out – 30% of the patients. There is a crying need for outlying structures to which those who do not show major clinical problems could be referred. It is for this reason that, in 1999, the author suggested to the Department of Health in KwaZulu-Natal that a system which could help more rural patients be set up, a system which would integrate all levels of care and one which would include members of the rural community. They would play a major role: distribution of

---

<sup>1</sup> N. A. Halsey, J. S. Coberty, J. Desormeaux et al., “Randomised trial of isoniazid versus rifampicin and pyrazinamide for prevention of tuberculosis in HIV-1 infection”, *The Lancet*, 351 (1998) 786-791.

<sup>2</sup> X. Anglaret, G. Chene, A. Attia et al., “Early chemoprophylaxis with trimethoprim-sulfamethoxazole HIV-1 infection”, *The Lancet*, 353 (1998), 1463-1468.

<sup>3</sup> Gerry Friedland, Yale University, “Management of HIV patients”, ECI training for KZN Health Care Workers, limited distribution document, Durban, December 2001.

<sup>4</sup> *Ibid.*

medications, ensuring that treatment was adhered to, early detection of alarming clinical signs followed by appropriate referral to higher levels of caring. The proposition was accepted by the Department of Health but could not be implemented because of a lack of funds.

In January 2002, members of the Enhancing Care Initiative project (ECI) which associates the universities of Natal and Harvard were informed of the impending launch of Global Funds for the fight against AIDS, tuberculosis and malaria, an organisation founded by the United Nations. In March 2002 the KwaZulu-Natal sites involved in the ECI project presented seventeen requests for financing. All were accepted with the promise of budget of 72 million American dollars spread over a period of five years!

After several days of joy not to mention euphoria, a period of frustration and conflict, which was to last for an entire year, began. The national Department of Health delayed signing the agreement on the pretext that the promoters of the ECI project had gone directly to the Global Fund without respecting the hierarchical route. In August 2003, the problems appeared to have been ironed out and new documents were urgently prepared. On the 1 February 2004 the first funding became available.

### *The battle for antiretrovirals*

From 1996, date of the first tritherapies, to 2000 when the International AIDS Conference was held in Durban, the hope of seeing antiretrovirals forming part of the treatment for African patients was a utopian dream: the cost of the medications and of biological tests (CD4 and viral charge) is exorbitant whilst the logistical problems appear insurmountable. On the other hand, public hospitals already guarantee prophylactic treatment (AZT+3TC) for paramedics who have come into contact with contaminated material.

After the Durban Conference, the cost of medication gradually and considerably diminished but still not enough to make it accessible to the majority of patients. Growing pressure was being put on the government by NGOs like Treatment Action Campaign (TAC) a remarkable pressure group lead by Zachie Achmat. Their aim is to get central government to develop, as rapidly as possible, programmes for “mother to child” transmission, prophylactic treatment of rape victims and, finally, programmes for the sick in public hospitals.

At the end of 1999, President Mbeki, for reasons which are still difficult to understand, threw his lot in with the “dissident” theory on AIDS which rejects the role of a virus in the development of immunodepression and attributes the disease to the evils which ravage most of Africa: poverty, malnutrition and tuberculosis. As the role of the virus is questioned, there is no reason to develop treatment programmes aimed at HIV. The usefulness of antiretrovirals is denied or denigrated whilst their toxicity is constantly brought to the fore.

Pressure groups nevertheless gained important victories: a national programme for the prevention of mother to child transmissions was finally accepted and set up in 2001; rape victims have been provided with prophylactic treatment since 2003.

Since 2001, the gradual drop in price has allowed a growing number of the sick who frequent HIV clinics in Pietermaritzburg to purchase antiretrovirals. This “favoured” group, very much in the minority (10%) provides us with the opportunity of gaining a certain amount of experience, of assessing the effectiveness of the treatment even where there is extreme immunodepression and to deal with the sometimes very serious secondary effects particularly in the least expensive way (ddi + d4T). The often very favourable progress made by those who are treated compared with the inescapable deterioration of the others is cause for anxiety amongst the medical staff.

In August 2003, the South African government announced that it would be prepared to supply free antiretrovirals to patients who are severely immunodepressed (CD4 inferior to 200/ml) and to ensure the clinical and biological surveillance (CD4 and viral charge). Each

province has to draw up a plan of action and identify the needs with regard to staff, equipment and premises. The ARV Roll-Out Programme (distribution of antiretrovirals on a massive scale) will begin in March 2004.

If the availability of antiretrovirals is a relief for daily clinical activity there is no doubt that the associated problems will be enormous and difficult to manage especially when it is a question of reaching the rural population on a large scale: several hundred thousand HIV-positive people are already potential candidates and this number will grow daily. Thrilling but worrying.

## **Conclusion**

Twenty years have gone by since the identification of the first cases of AIDS in Africa. A mass of clinical, biological, sociological and economic information has been collected. For those who live in daily contact with the sick, these years have brought an enormous amount of satisfaction on both the human and intellectual level. But they have also caused frustration, annoyance and anger.

In developed countries, and more and more in South Africa, the caring of patients has changed and long term prognosis has improved. However, the medication which is at present available is not the solution to controlling this epidemic because it does not kill the virus and it necessitates a life-long treatment. It is to be hoped that more effective medicines will become available in the not too distant future. Even more important is the perfecting of a vaccine that will be tolerated, easy to administer effective, ensure long term protection and be accessible to all.

In the mean time, all forms of the fight against the epidemic, whether they be clinical or preventative, need to be loudly and strongly supported by political, moral and religious leaders.

*(translated from the French by Carole Beckett)*