

# CLINICIANS AS PUBLIC HEALTH ADVOCATES:

## *The Need for Health Professionals to be More Vocal in Campaigns to Extend Access to Effective HIV/AIDS Treatment*

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HIV/AIDS presents a health and development emergency of unprecedented proportions. In the words of epidemiologist Kevin de Cock, it 'threatens to do more to undermine development in Africa in the 21st century, than slavery did in the nineteenth' (comments made at the UNAIDS/WHO Consultation on HIV Reporting and Disclosure, October 1999). Faced with this threat an extraordinary duty falls on health professionals.

The formation of the Southern African HIV Clinicians Society has been a very important step in the regional response to the AIDS epidemic, and the emergence of this institution invites a frank discussion of the responsibilities of 'clinicians' who work in the field of HIV/AIDS.

The aim of this article, therefore, is to elucidate some of these responsibilities from a human rights perspective and to argue that clinicians must more visibly confront different responsibilities at different ends of the spectrum in the continuum of care for people with HIV/AIDS. The AIDS epidemic dictates that clinicians engage with public health, and not just confine themselves to medicine.<sup>1</sup>

Underlying this discussion is an appeal for better collaboration between 'activists' and clinicians around a plan to improve understanding of HIV in society as rapidly as possible and to discuss treatment possibilities. This is a necessary step in the campaign to extend access to effective treatment against HIV to all people with HIV/AIDS in South Africa. In this context three major issues must be considered:

- The clinician's duties in relation to HIV testing, particularly in relation to confidentiality and informed consent;
- The suitability of the available health care infrastructure with regard to expanding access to treatment; and
- The role that clinicians should play in advocacy directed at pharmaceutical companies and the government.

### HIV TESTING – CONFIDENTIALITY AND INFORMED CONSENT

HIV is an unusual disease. Because of the long asymptomatic phase of HIV infection, infection with HIV requires a higher degree of self-management and understanding of the condition on the part of the person infected than is the case in many other illnesses. This is one reason for the emphasis that has evolved on pre-test counselling, a duty that has not only become a part of medical ethics (first elaborated in 1993 in the South African Medical and Dental Council Guidelines on the Management of Patients with HIV and AIDS), but also a legal requirement.<sup>2</sup> There is no dispute that with regard to HIV the continuum of care starts before the HIV test is even performed – with thorough counselling.

Regrettably, however, the provision of pre-test counselling remains the exception rather than the rule. In reality the unlawful malpractice of private and public clinicians often coincides from different vantage points. In the private sector it seems that the objective of getting people in and out of the surgery door within pre-set times does not allow for effective counselling. This occurs particularly in relation to antenatal screening. In the public sector, in contrast, the genuine lack of trained counsellors and the pressure of large numbers of patients are used to justify the frequent argument that obtaining informed consent is 'not realistic'.

The consequence is that many people are diagnosed with HIV without an understanding of their status. These people are later accused of causing new HIV infections because of their inability to disclose their HIV status to their sexual partners; something that could have been avoided if they had been properly pre-test counselled.

The same arguments could be made in relation to confidentiality. The promise of confidentiality (even if not absolute) is necessary to encourage wider take-up of HIV testing and treatment. Yet breaches of confidentiality and a profound lack of appreciation of its importance – even from a medical perspective – remain the norm.

It is therefore vital for the HIV Clinicians Society to take a very public stand on these psychotherapeutic ingredients of good practice, and to defend confidentiality and informed consent as essential aspects in the care and management of people with HIV. Among other things this means lobbying for increased public health expenditure and sufficient resources for the provision of counsellors, as well as ensuring knowledge of and compliance with the Guidelines of the HPCSA.<sup>3</sup>

### THE CAPACITY OF SA'S HEALTH INFRASTRUCTURE TO EXPAND ACCESS TO TREATMENT

During the management of most HIV-infected people, clinicians will reach a point where 'care' requires access to prophylaxis for the treatment of opportunistic infections (OIs), and ideally to antiretroviral (ARV) therapy. At the moment, however, only two groups of people are able to access effective ARV treatment: the small minority who can afford it and a small minority of poor people who are taking part in clinical trials.

In the context of the current scientific knowledge about the benefits of effective management of OIs and the proper use of ARVs, this is a profound challenge to the principles of medicine and public health.

Regrettably, when calls are made by groups such as the Treatment Action Campaign (TAC) to expand access to ARV treatment, HIV/AIDS clinicians, government officials and

pharmaceutical companies respond with a joint refrain: 'insufficient infrastructure and the dangers of poor adherence in developing countries.' However, as recent research in poor communities in the USA and Brazil has shown, there is no inherent barrier to drug adherence among poor people – pointing to an important role for clinicians. Where an effort is made to raise the level of understanding with regard to HIV disease and treatment by assisting community-based organisations to raise levels of 'treatment literacy', compliance is improved.

'Infrastructure', on the other hand, is evoked to draw attention to a lack of capacity to diagnose HIV and to counsel and monitor compliance, as well as to lack of sophisticated laboratory facilities to measure CD4+, viral load and drug resistance. This response does not stand up to scrutiny.

Health infrastructure should not be assessed using the lowest common denominator. Debates about infrastructure should not exclude the capacity of the private health sector to provide services and treatment. In 1998, South Africa had 162 private hospitals (with a total of 21 000 beds),<sup>4</sup> 68 regional hospitals, 281 district hospitals, and approximately 3 000 clinics. There is also an extensive network of private laboratory services. If we are really dealing with a national emergency, all of these resources should be marshalled towards assisting with HIV prevention and care.

If a horizontal approach is taken towards available infrastructure (i.e. if one that looks in all directions rather than merely up and down), then the reality quickly emerges that South Africa already has surplus capacity with which to expand access to HIV testing, counselling and effective medicines.

Between 1990 and 1998 the private hospital sector grew by 33%, and increased by 8 000 beds.<sup>5</sup> This is evidence that health infrastructure can be quickly expanded – particularly if the expansion is dictated by the need to prevent and treat illness rather than by profitability.

On this basis, with government commitment and commitment on the part of the private sector and private practitioners to a genuine partnership against AIDS, it would be possible to expand access to treatment immediately.

## BRAZIL

The Brazilian experience is relevant to this discussion from a number of perspectives. Like South Africa, Brazil is a developing country. It, too, has only recently emerged from years of dictatorship and its government faces a legacy of foreign debt, wide income disparities and a profound disjuncture between the metropolitan and rural areas.

In many ways the Brazilian and South African epidemics have followed similar courses. Both epidemics began in the early 1980s among men who have sex with men (MSM) (and in Brazil also among injecting drug users), and moved increasingly into the rest of the population, particularly among the poor and marginalised.<sup>6</sup>

However, Brazil differs from South Africa in its consistent response to AIDS – a response that has by no means halted the epidemic, but has slowed it down and made it more manageable. What is unique about Brazil's response has been its commitment to integrating and expanding access to treatment into its general HIV/AIDS prevention strategy. In a recently published UNAIDS Best Practice booklet this is described as 'a degree of national daring ... that goes against many of the recommendations on how a developing country ought to manage the epidemic.'<sup>7</sup>

Table I provides a brief chronology of significant developments in Brazil.

The last decade of the Brazilian experience proves conclusively that health infrastructure is not created in a vacuum. It is created by need. In the words of UNAIDS, infrastructure developed 'On becoming indispensable instruments in the clinical laboratorial follow-up of HIV patients under antiretroviral therapy ... (and) contributed to the optimization and more rational use of medicines.'<sup>8</sup>

In other words, public infrastructure develops when a government acts on the recognition that access to all dimensions of health care is a human right – as well as a public health imperative in HIV prevention.<sup>9</sup>

Other very tangible benefits have accrued from treating AIDS. Most obvious has been the government's ability to manufacture essential medicines and bring down imported drug prices once it embarked upon a real as opposed to a theoretical programme of treatment.<sup>10</sup>

Finally, the public health benefits of these policies are indisputable. In Sao Paulo and Rio de Janeiro there has been a 48% reduction in the number of deaths among male patients since 1995. Throughout Brazil there has been a reduction in rate of hospital admissions, length of stay, and incidence of opportunistic infections, with tangible cost savings such as an 11% drop in the total national consumption of ganciclovir between 1996 and 1998.<sup>11</sup> In order to achieve this government expenditure on drugs has been high – US\$356 million in 1999. However, in addition to the impact that access to treatment has had on human life and dignity, the programme has resulted in estimated savings for the government public health network of US\$422 million between 1997 and 1999. In the words of the Brazilian government: '... the savings on internments, on welfare and on the number of years-of-life gained show clear signs of a guaranteed sound cost-benefit ratio.'

The outcomes of this 'daring' policy are evident. In 1997 Brazil (68th) was relatively close to South Africa (90th) in its ranking on the United Nations Development Programme's annually-revised human development index (HDI), which includes in its measurement average life expectancy. Public expenditure on health was 2.8% as opposed to 3.2% in South Africa. At that time AIDS cases per 100 000 people were 6 and 6.8% respectively.

However, by the year 2000 the picture had changed dramatically. South Africa's position on the HDI had dropped to 103rd, a decline that the UNDP attributes squarely to 'the drop in life-expectancy due to AIDS.'<sup>12</sup>

## CLINICIANS AS TREATMENT ADVOCATES

The Brazilian experience is provided to try to convince health professionals to become better advocates for a public policy to expand access to treatment. Groups such as the South African Medical Association (SAMA) need to be more outspoken in identifying and confronting the obstacles to expanded treatment access.

The Durban Declaration is an example of an intervention that was both strategic and timely. Although the Declaration was literally trashed by the South Africa government, it was not adversarial, merely a clear statement of medical science with regard to the virology of HIV and the aetiology of HIV and AIDS.

A similar consensus statement on the efficacy of drugs used to treat HIV and the imperative to overcome obstacles to treatment would be welcome. But this would compel clini-

icians to break their silence on the unjustifiably high price of patented drugs.

A recent report by Medecins sans Frontieres (MSF) illustrates how pricing affects access.<sup>13</sup> The report states the obvious: 'doctors need drugs to care for HIV infected people. Without them they are simply managing decline and death. These drugs must be available, affordable and properly used.'

Advocacy concerning affordability is not a political issue. It is an issue of social policy and the common good. It does not require that clinicians adopt a stance that is antipatient or anti-profit – rather one that is ardently pro public health. Drastic and unconditional price reductions would allow the most rational distribution and allocation of medicine according to need and capacity to distribute and dispense.<sup>14</sup>

Unfortunately, the impression is that many HIV clinicians are unwilling to do this. The reasons are not too hard to decipher. To practice medicine it is necessary to have access to medicines. Thus far, government has failed to supply clinicians with this indispensable tool for practice. Consequently many clinicians have been drawn to the private health sector, or while continuing to work in the public sector, they have entered into relationship with pharmaceutical companies, with access to certain drugs achieved through conducting clinical trials.<sup>15</sup>

A relationship of almost feudal vassalage is at risk of developing. Fortright and sustained criticism of the price of drugs becomes difficult when major pharmaceutical companies are sponsoring clinical trials and scientific conferences. Hence, the inclination to adopt the infrastructure escape clause, rather than confront the issue of pricing.<sup>16</sup>

## CONCLUSION

On 9 July 2000 in Durban the Global March for Access to Treatment handed over a Memorandum to the Minister of Health, the director of UNAIDS and the President of the International AIDS Society (IAS). A section of this memorandum saluted the contribution of clinicians to understanding HIV and to research into treatments and vaccines. It called on clinicians to 'make your voices heard side-by-side with us in demanding additional public funding and the best use of medicines for the greatest number of people' and to 'publicly quantify and demand the funds that you consider necessary for urgent and relevant vaccine research, the development of effective microbicides and antiretroviral therapies that are easier to use by children and adults in countries where there is a shortage of food, water and electricity'. It also requested the IAS to 'Initiate and coordinate an international scientific collaboration on a plan and timeframe for research'.

The Southern African HIV Clinicians Society has an important part to play in these efforts. We believe that clinicians must base their actions on South Africa's constitutional obligation to respect equality and promote and progressively realise the 'right of access to health care services'. An alliance with public health activists around advocacy, improving treatment literacy and expanding access to treatment is a sure way of achieving these objectives.

**TABLE I. ACTIONS SPEAK LOUDER THAN WORDS: A SHORT CHRONOLOGY OF BRAZIL'S COMMITMENT TO EXPANDING TREATMENT**

1988	After years of military dictatorship Brazil adopts a new democratic constitution that defines health care as a social right.
1991	The National Programme for STD and AIDS decides to buy and distribute ARV medicines.
1996	In the immediate aftermath of the Vancouver International AIDS Conference, which reported on breakthroughs in the use of highly active ARV therapy (HAART), a law is passed establishing the right to free medication. The objective is to 'ensure access to ARVs to 100% of identified HIV patients in the country'. <sup>17</sup>
1996-2000	Measures are taken to train health professionals, manufacture generic drugs, and to develop infrastructure for drug distribution and monitoring. The decision to provide treatment also created a necessity to establish a national system of quality of laboratory tests for STD and AIDS and a system of logistic control of medicines.
1999	87 500 public patients are in receipt of AIDS-related drugs.
1999	270 services in the country have ARVs available and outpatient follow-up for people with HIV. By July 1999 the national CD4+ network had 70 units, while the viral loads network had 55 units, performing 252 000 and 165 000 tests a year.

## END NOTES

- Jonathan Mann distinguished medicine from public health as follows: 'Public health identifies and measures threats to the health of populations, develops governmental policies in response to these concerns, and seeks to assure certain health and related services. In contrast, medical care focuses upon individuals – diagnosis, treatment, relief of suffering, and rehabilitation'. *Medicine and Public Health, Ethics and Human Rights, Health and Human Rights: A Reader*, eds Mann, Gruskin, Grodin, Annas, 1999, Routledge.
- In a case known as *C v Minister of Correctional Services*, the judge found that 'it is axiomatic that there can only be consent if the person appreciates and understands what the object and purpose of the test is, what an HIV positive result entails and what the probability of AIDS occurring thereafter is'.
- The 1993 SAMDC Guidelines are currently being revised by the Health Professions Council.
- 1998 South African Health Review, Health Systems Trust, 1998, p. 148.
- HST, 1998.
- See: UNAIDS Best Practices. *The Brazilian Response to HIV/AIDS, 2000*, chapt 2, Epidemiology. The initial profile of transmission, characterised by the predominant spread of HIV among educated MSM of a high socio-economic level, similar to North America and Europe, gradually altered in the direction of heterosexual transmission concentrated in marginalised and impoverished sections of the population' p. 19.
- UNAIDS, *The Brazilian Response to HIV/AIDS, 2000*, p. 15.
- See: UNAIDS, *The Brazilian Response to HIV/AIDS, 2000*, especially Chapt 3, Care and Treatment; also Ministry of Health, *The Brazilian STD and AIDS Programme, Care and Treatment, 2000*.
- It is important to underline here that the approach adopted by the SA government, whereby 'prevention is the only cure', excludes from the national effort all those who are already infected and is a disincentive for voluntary HIV testing. By contrast the prospect of expanded access to treatment will encourage testing – and thus play a direct part in prevention.
- 'The annual cost of double therapy with nucleoside analogues decreased on average by 80% between 1996 and 2000. . . For triple therapy the cost reduction was 36% over the same period'. UNAIDS, *Report of the Global HIV/AIDS Epidemic, June 2000*, p. 102.
- UNAIDS, *The Brazilian Response to HIV/AIDS*, p. 45.
- UNDP Human Development Report 2000, 150.
- HIV/AIDS Medicines Pricing Report. *Setting Objectives: is there political will?* MSF, July 2000.
- Drug donations are (sometimes) welcome. But they do not address underlying issues. Donations to the public sector, such as the recent restrictive offer of free Diflucan by Pfizer, ignore the fact that many poor people seek health care through the private sector. Restricting donations to the public providers risks adding to the disjuncture between public and private health care, as poor people are compelled to turn back to the public sector in order to access essential medicines.
- 1998 Health Systems Trust SA Health Review shows how 'most recent graduates are employed in the public sector, and 77% of all doctors who qualified in the previous 5 years are working in this sector. In contrast 10 years following qualification, the majority are working in the private sector' p. 150.
- This situation creates a self-perpetuating vicious circle whose adverse consequences for medicine are enormous. Willing buyers are created among clinicians through the advertising and sponsorship campaigns of research-based pharmaceutical companies. Similarly, clinicians are placed in situations of very dubious ethics when they engage in 'short-course' drug trials to find a regimen of reasonable efficacy, where the main rationale for the trial is to try to make the intervention affordable – something that could be done much more easily by reducing drug prices.
- UNAIDS, *The Brazilian Response to HIV/AIDS, 2000*, p. 43.