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The deafening silence of AIDS

By EDWIN CAMERON

It is a great honour to be asked to deliver the first Jonathan Mann Memorial Lecture. It is fitting that this remembrance should have been created to honour Mann's memory and legacy. He more than any other individual must be credited with first conceiving and constructing a global response to the AIDS epidemic.

This he did not only as founding director of the World Health Organisation's Global Programme on AIDS between 1986 and 1990, but also after he left the WHO, in his theoretical and advocacy work within the discipline of public health.

It is particularly fitting that the lecture should be initiated at the start of the first international conference on AIDS to take place on African soil.

Jonathan Mann's earliest experience with the epidemic was in Africa, where from March 1984 to June 1986 he was director of the Zaire AIDS Research Programme. It was here that Mann first confronted the social complexities and the dire implications of the disease.

Mann's work in Africa included epidemiological, clinical and laboratory components. In retrospect it is clear that it was on this continent that the motive forces impelling his insights into the epidemic were formed.

He published early research indicating that HIV transmission occurs only rarely in the home or healthcare setting. His work in Zaire subjected him to an arduous schooling in all aspects of HIV: surveillance and epidemiology, issues of testing in a developing country, case definition, condom usage, and exposure amongst commercial sex workers.

It alerted him from the outset to the fearful twinned menace of HIV and tuberculosis. His time in Africa also attuned him to questions involving children and pediatric AIDS, and he published pioneering work on what has perhaps become the epidemic's most poignant issue in Africa – transmission of the virus from mother to child.

But it was not in only the details of the epidemiology and management of HIV that Mann's years in Africa yielded insights that later proved critical. His work amongst Africa's at-risk communities, with Africans living with HIV and with those dying from AIDS, with the healthcare personnel, mothers, sex workers and government bureaucrats in Africa formed the basis of an insight he later termed a "very intense, emotional, and personal" discovery.

This was his realisation during the 1980s that there are empirical and theoretical links between human rights abuses and vulnerability to HIV/AIDS. In each society, Mann later wrote, "those people who were marginalised, stigmatized and discriminated against – before HIV/AIDS arrived – have later become over time those at highest risk of HIV infection".

Mann's statement cannot be accepted without nuance, since in Africa it is relative mobility affluence that have placed people at risk of exposure to HIV.

But Mann's analysis here had led him to a more fundamental and general insight – one that formed the focus of his future work and advocacy. This was his realisation that health and human rights are not opposing, but are complementary, approaches to what he called "the central problem of defining and advancing human well-being".

In relation to AIDS, Justice Michael Kirby of the High Court of Australia – one of the world's most eloquent voices for truth and fairness – has termed this "the HIV paradox": the insight that sound reasons rooted not only in respect for human rights, but in effective public health planning, necessitate a just and non-discriminatory response to AIDS; that recognition of and respect for individual human rights does not impede prevention and containment of HIV, but actually enhances it.

In this perception Jonathan Mann located the core of his remaining life work. And his commitment to advancing its practical realisation constitutes his most profound contribution to securing a humane worldwide response to the AIDS epidemic.

Amidst the grievous facts of the epidemic, the one gleam of redemption is the fact that nowhere have the doctrines of public health overtly countenanced repression and stigma, discrimination and isolation, as legitimate governmental responses to AIDS.

That there has been discrimination and stigma against persons with AIDS and HIV, on an enormous and debilitating scale, is certain. The death by stabbing and stoning of Gugu Dhlamini, the township activist, not twenty kilometres from here, in December 1998, provides a brutal testament of such hatred and ignorance.

But these practices have not been supported – at least officially, or in any large measure – by the institutional power of the world's public health systems. That public policy at national and international level have weighed against them, constitutes a significant portion of the legacy of Jonathan Mann.

But this does not exhaust his legacy. In the fourteen years since Mann left Zaire for Geneva in 1986, the epidemic has manifested momentous changes. The two most considerable are these: demographics of its spread; and the medical-scientific resources available to counter it.

In its demographics HIV has altered from an epidemic whose primary toll seemed to be within the gay white men of North America and Western Europe, to one that, overwhelmingly, burdens the heterosexual populations of Africa and the developing world.

The data are so dismaying that reciting the statistics of HIV prevalence and of AIDS morbidity and mortality – the infection rates, the anticipated deaths, the numbers of orphans, the healthcare costs, the economic impact – threatens to drive off, rather than engage our sympathetic imagination.

Our imagination shrinks from the thought that these figures can represent real lives, real people, and real suffering.

But amidst the welter of disheartening data, two facts stand out very clearly:

nine-tenths of all people living with HIV/AIDS are in poor countries; and
two-thirds of the total are in sub-Saharan Africa.

But the demography of HIV has been overlain by a shift even more momentous and one that in its nature is optimistic. It is the fact that over the last half-decade, various aggregations of drug types, some old and some new, have been shown, when taken in combination, to quell the replication of the virus within the body.

The result has been exciting, life altering and near revolutionary. For most of those with access to the new drug combinations, immune decline has not only halted, but been reversed.

In most of Europe, in North America and in Australasia, illness and death from AIDS have dropped dramatically. Hundreds of thousands of people who a few years ago faced imminent and painful death, have been restored to living. Opportunistic infections have diminished, and suffering, pain and bereavement from AIDS have greatly reduced.

Beneficent social effects have come with the medical breakthrough. The social meaning of the new drugs is that of the equation between AIDS and death.

AIDS can now be compared with other chronic conditions which on appropriate treatment, and with proper care, can in the long term be subjected to successful medical management. Amongst the public at large, the result has been that fear, prejudice and stigma associated with AIDS have lessened. And persons living with HIV/AIDS have suffered less within themselves and in their working and social environments.

In short, the new combination drug treatments are not a miracle. But in their physiological and social effects they come very close to being miraculous.

But this near-miracle has not touched the lives of most of those who most desperately need it. For Africans and others in resource-poor countries with AIDS and HIV, that near miracle is out of reach.

For them, the implications of the epidemic remain as fearsome as ever. In their lives, the prospect of debility and death, and the effects of discrimination and societal prejudice, loom as huge as they did for the gay men of North America and Western Europe.

This is not because the drugs are prohibitively expensive to produce. They are not. Recent experience in India, Thailand and Brazil has shown that most of the critical drugs can be produced at costs that puts them realistically within reach of the resource-poor world.

The primary reason why the drugs are out of reach to the developing world is two-fold.

On the one hand, drug-pricing structures imposed by the manufacturers make the drugs unaffordably expensive.

On the other, the international patent and trade regime at present seeks to choke off any large-scale attempt to produce and market the drugs at affordable levels.

With characteristic prescience, Mann in his address at the XIth International AIDS Conference in Vancouver in 1996 foresaw the significance of the treatment issue. He said that of all the walls dividing people in the AIDS epidemic, "the gap between the rich and the poor is most pervasive and pernicious".

It is this divide that, fourteen years after Mann left Africa, threatens to swallow up 25 million people in Africa.

I speak of the gap not as an observer or as a commentator, but with intimate personal knowledge. I am an African, proudly an African. I am living with AIDS. I therefore count as one amongst the forbidding statistics of AIDS in Africa. Including the fact that nearly five million South Africans who have the virus.

I speak also of the dread effects of AIDS not as an onlooker. Nearly three years ago, more than twelve years after I had sero-converted, I fell severely ill with the symptomatic effects of HIV. Fortunately for me, I had access to good medical care. After treatment for opportunistic infections that were making me feel sick unto death.

Then my doctor started me on combination therapy. Since then, with relatively minor adjustments, I have been privileged to lead a vigorous, healthy, and productive life. I am able to do so because, twice a day, I take two tablets – one containing a combination of AZT [zidovudine] and 3TC, and the other Nevirapine [Viramune]. I can take these tablets because, on the salary of a judge, I am able to afford their cost.

If, without combination therapy, the mean survival time for a well-tended male in his mid-forties after onset of full AIDS is 30 – 36 months, I should be dead by approximately now. Instead, I am more healthy, more vigorous, more energetic, and more full of purposeful joy than at any stage in my life.

In this I exist as a living embodiment of the iniquity of drug availability and access in Africa. This is not because, in an epidemic in which the heaviest burden of infection and disease are borne by women, I am male; nor because, on a continent in which the virus transmission has been heterosexual, I am proudly gay; nor even because, in a history fraught with racial injustice, I was born white.

My presence here embodies the injustices of AIDS in Africa because, on a continent in which 290 million Africans survive on less than one US dollar a day, I can afford monthly medication costs of approximately US$400 per month.

Amidst the poverty of Africa, I stand before you because I am able to purchase health and vigour. I am here because I can pay for life itself.

To me this seems a shocking and monstrous iniquity of very considerable proportions – that, simply because of relative affluence, I should be living when others have died; that I should remain fit and healthy when illness and death beset millions of others.

Given the epidemic's two most signal changes, in demographics and in medical science, it must surely be that the most urgent challenge it offers us is to find constructive ways of bringing these life-saving drugs to the millions of people whose lives and well-being can be spared by them.

Instead of continuing to accept what has become a palpable untruth (that AIDS is of necessity a disease of debility and death), our overriding and immediate commitment should be to find ways to make accessible for the poor what is within reach of the affluent.

If this is the imperative that our circumstances impose upon us, one would have expected the four years since Vancouver to have been filled with actions directed to its attainment by those with power to change the course of history and the force of the epidemic.

Instead, from every side, those millions living with AIDS in resource-poor countries have been disappointed. International agencies, national governments, and especially those who have primary power to remedy the iniquity – the international drug companies – have failed us in the quest for accessible treatment.

In my own country, a government that in its commitment to human rights and democracy has been a shining example to Africa and the world has at almost every conceivable turn mismanaged the epidemic.

So grievous has governmental ineptitude been that South Africa has since 1998 had the fastest-growing HIV epidemic in the world. It currently has one of the world's highest prevalences.

Nor has there been silence, as the title of my lecture suggests. Indeed, there has been a cacophony of task groups, workshops, committees, councils, policies, drafts, proposals, statements, and pledges. But all have thus far signified piteously little.

A basic and affordable humane intervention would be a national programme to limit mother-to-child transmission of HIV through administration of short courses of anti-retroviral medication.

Research has shown this will be cost-effective in South Africa. Such a programme, if implemented, would have signalled our government's appreciation of the larger problem, and its resolve to address it.

To the millions of South Africans living with HIV, it would have created a ray of light. It would have promised the possibility of increasingly constructive interventions for all with HIV, including enhanced access to drug therapies.

To our shame, our country has not yet come so far as even to commit itself to implementing such a programme. The result, every month, is that 5 000 babies are born, unnecessarily and avoidably, with HIV.

Their lives involve preventable infections, preventable suffering, and preventable death. And if none of that is persuasive, then from the point of view of the nation's economic self-interest, their HIV infections entail preventable expense. Yet we have done nothing.

In our national struggle to come to grips with the epidemic, perhaps the most intractably puzzling episode has been our President's flirtation with those who in the face of all reason and evidence have sought to dispute the aetiology of AIDS. This has shaken almost everyone responsible for engaging the epidemic. It has created an air of unbelief amongst scientists, confusion among those at risk of HIV, and consternation amongst AIDS workers.

One of the continent's foremost intellectuals, Dr Mamphela Rampele, has described the official sanction given to scepticism about the cause of AIDS as "irresponsibility that borders on criminality".

If this aberrant and distressing interlude has delayed the implementation of life-saving measures to halt the spread of HIV and to curtail its effects, then history will not judge this pronouncement too harsh.

I cannot believe that our President's address at the opening last night has done enough to alleviate the concerns.

At the international level also, there have been largely frustration and disappointment. At the launch of the International Partnership Against AIDS in Africa in December 1999, UN Secretary General Kofi Annan made an important acknowledgement. He stated: "Our response so far has failed Africa".

The scale of the crisis, he said, required "a comprehensive and coordinated strategy" between governments, inter-governmental bodies, community groups, science and private corporations.

That was seven long months ago. In seven months, there are more than 200 days: days in which people have fallen sick and others have died; days on each of which, in my country alone, approximately 1 700 people have become newly infected with HIV.

In that time, the World Bank, to its credit, has made the search for an AIDS vaccine one of its priorities. President Clinton, to his credit, in an effort "to promote access to essential medicines", has issued an executive order that somewhat loosens the patent and trade throttles around the necks of African governments.

And UNAIDS, to its credit, "has begun" what it describes as "a new dialogue" with five of the biggest pharmaceutical companies. The purpose is "to find ways to broaden access to care and treatment, while ensuring rational, affordable, safe and effective use of drugs for HIV/AIDS-related illnesses".

All these efforts are indisputably commendable. But, whether taken individually or together, they fail to command the urgency and sense of purpose appropriate to an emergency room where a patient is dying. The analogy is under-stated - for the patients who are dying number in their tens of millions.

For each of them, and for all their families and loved ones, the emergency is dire and immediate. What is more, the treatment that can save them exists. What is needed is only that it be made accessible to them.

Amidst all these initiatives, the critical question remains drug pricing. No one denies that drug prices are "only one among many obstacles to access" in poor countries. But there are many, many persons in the resource-poor world for whom prices on their own are, right now, the sole impediment to health and well-being.

A significant number of Africans with access to healthcare could pay modest amounts for the drugs now. On any scenario, therefore, lowering drug prices immediately are necessary. It should therefore be an immediate and overriding priority.

In fact, lower drug prices are an indispensable precondition to creating just and practicable access to care and treatment. This is so for a number of reasons.

First, the debate about drug pricing diverts attention and energy from the other vital issues, such as creating the institutional infrastructure for delivery and monitoring in poor countries.

Second, it has sadly provided some governments with a make-weight for delaying implementation of programmes to prevent mother-to-child transmission of the virus. It has delayed also consideration of more ambitious alternatives in anti-retroviral therapy.

Amidst all of this, it is hard to avoid the impression that the drug companies are shadow-boxing with the issues. There is some evidence that they, in turn, are using lack of governmental commitment on drug provision as a pretext for not lowering drug prices immediately.

There certainly has been no immediate follow-through to the announcement eight weeks ago that five of the largest drug companies had undertaken to "explore" ways to reduce their prices. This has devastated the hopes of many poor people who need lower prices, now, to stay alive and healthy.

It is in this context that it is also hard to avoid the conclusion that UNAIDS – whose programme leader, Dr Peter Piot, is a perceptive man of principle who worked with Jonathan Mann in Africa – has failed to muster its institutional power with sufficient resourcefulness, sufficient creativity and sufficient force.

Amidst this disappointment, it is quite wrong to speak, as the title of my lecture does, of "the deafening silence of AIDS". There has not been a silence.

Gugu Dhlamini was not silent. She paid with her life for speaking out about her HIV status. But she was not silent. And her death has not silenced many other South Africans living with AIDS, black and white, male and female – most who are less privileged than I – who have spoken out for dignity and justice in the epidemic.

There has also been the principled trumpet of treatment activism. In America, brave activists changed the course of presidential politics by challenging Vice-President Gore's stand on drug pricing and trade protection. Their actions paved the way for subsequent revisions of President Clinton's approach to the drug pricing issue.

In my own country, a small and under-resourced group of activists in the Treatment Action Campaign, under the leadership of Zackie Achmat, has emerged. In the face of considerable isolation and hostility, they have succeeded in re-ordering our national debate about AIDS.

And they have focused national attention on the imperative issues of poverty, collective action and drug access. In doing so they have energised a dispirited PWA movement with the dignity of self-assertion, and renewed within it the faith that by action we can secure justice.

In the last years of his life Jonathan Mann began speaking with increasing passion about the moral imperatives to action that challenge us all. He well understood that this involves what he called "A challenge to the political and societal status quo."

He also understood, in his last writing, the fundamental significance of human dignity in the debate about health and human rights. His work foreshadowed the transition of health and human rights and the "HIV paradox" to a full human entitlement to health care, where the means for it are available.

Ten months before his death, in November 1997, he called on an audience to place themselves "squarely on the side of those who intervene in the present, because they believe that the future can be different".

That is the true challenge to this Conference: to make the future different. Drugs are available to make AIDS, for most people with the virus, a chronically manageable disease. But for most people with the virus, unless we intervene in the present with immediate urgency, that will not happen.

We gather here in Durban as an international grouping of influential and knowledgeable people concerned about alleviating the effects of this epidemic.

By our mere presence here, we identify ourselves as the 12 000 best-resourced and most powerful people in the epidemic. By our action and resolutions and collective will, we can make the future different for many millions of people with AIDS and HIV for whom the present offers only illness and death.

This gathering can address the drug companies. It can demand not dialogue, but urgent and immediate price reductions for resource-poor countries. It can challenge the companies to permit without delay parallel imports and the manufacture under licence of drugs for which they hold the patents.

Corporately and individually we can address the governments and inter-governmental organisations of the world, demanding a plan of crisis intervention that will see treatments provided under managed conditions to those who most need them.

Vancouver four years ago was a turning point in the announcement of the existence of these therapies. This Conference can be a turning point in the creation of an international impetus to secure equitable access to these drugs for all persons with AIDS in the world.

Moral dilemmas are all too easy to analyse in retrospect. Many books have been written about how ordinary Germans could have tolerated the moral iniquity that was Nazism; or how white South Africans could have countenanced the evils that apartheid inflicted, to their benefit, on the majority of their fellows.

Yet the position of people living with AIDS or HIV in Africa and other resource-poor countries poses a comparable moral dilemma for the developed world today. The inequities of drug access, pricing and distribution mirror the inequities of a world trade system that weighs the poor with debt while privileging the wealthy with inexpensive raw materials and labour.

Those of us who live affluent lives, well-attended by medical care and treatment, should not ask how Germans or white South Africans could tolerate living in proximity to moral evil. We do so ourselves today, in proximity to the impending illness and death of many millions of people with AIDS. This will happen, unless we change the present government ineptitude and corporate blocking.

Available treatments are denied to those who need them for the sake of aggregating corporate wealth for shareholders who by African standards are already unimaginably affluent.

That cannot be right, and it cannot be allowed to happen. No more than Germans in the Nazi era, nor more than white South Africans during apartheid, can we at this Conference say that we bear no responsibility for 30 million people in resource-poor countries who face death from AIDS unless medical care and treatment is made accessible to them.

The world has become a single sphere, in which communication, finance, trade and travel occur within a single entity. How we live our lives affects how others live theirs. We cannot wall off the plight of those whose lives are proximate to our own.

That is Mann's call – the clarity of his call – his legacy to the world of AIDS policy; and it is the challenge of his memory to this Conference today.

The first Jonathan Mann Memorial Lecture delivered by High Court Judge Edwin Cameron at the AIDS2000 International Conference in Durban, on July 10, 2000.