

VIEWPOINTS/CONTROVERSIES

**UNESCO VERSUS HIV/AIDS: THE HISTORY AND TEN LESSONS
Gudmund Hernes**

On 5 June 1981, Michael Gottlieb, an assistant professor of immunology at the UCLA School of Medicine, published an article in the Center for Disease Control's Morbidity and mortality weekly report on five cases of a rare disease, *Pneumocystis carinii* pneumonia among homosexual males. These were the first five cases of what later was to become known as the acquired immune deficiency syndrome-AIDS. What was not known at this time was that although only five cases were reported, thousands more people were already infected with the human immuno-deficiency virus-HIV. The nature of the disease inhibits discovery-the incubation period between the infection and its manifestation is long-and at the time we did not even know what the agent of infection was. Moreover, not only do the infected not know, but neither can those not infected because for so many years there are no outward signs of the disease.

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Lesson 1: The virus has always been way ahead of the disease

Now, twenty years after the first discovery, some 60 million people are infected-corresponding to the whole population of France, of the United Kingdom or of Thailand. The number who have died is nearly the same as the population of Norway, Sweden, Finland and Denmark added together. The number presently infected-more than 36 million-is more than the whole population of Canada. The number of AIDS orphans-some 14 million-is already more than the total population of Ecuador. Over the coming decade or so this figure may rise to a staggering 50 million. In other words, the epidemic is unprecedented in human history. And the worst is yet to come: Many millions more will be infected, many millions more will die, many millions more will be orphaned. On the 11 September 2001 some 3,000 people were brutally torn away. Every day about five times that number are infected

by HIV. Not only are individuals at risk-the social fabric of whole societies is threatened. The disease is likely to be a scourge throughout our lifetime.

Lesson 2: The disease has always been way ahead of the response

The response has been delayed-particularly when the silence of leaders has helped the virus spread. The remedies for treatment have been under-funded-the resources have been made available in the North while most of the disease is in the South. The resources that have been committed were inadequate to cope with the increasing burden of the infected and affected, ranging from treating those that as a consequence of HIV are inflicted with a broad range of opportunistic diseases to providing for the growing number of orphans. Funds are also lacking for countermeasures against the institutional impacts of the disease, such as the death of teachers.

Lesson 3: It is not only a disease, it is a development disaster

HIV/AIDS is not just a health problem-in less than two decades it has become a social catastrophe of unprecedented proportions with an impact as ravaging as any war. It not only hampers development, it reverses it by destroying productive capacity, both by loss of the most productive people in society and by increasing the burdens of caring for the sick and providing for the orphans. AIDS is wiping out decades of investment in education and in human resources. Even rich countries would be hard put to cope and to care with the situation, as well as to afford the treatments that are now available if their infection rates were as elevated as those in poor countries. AIDS attacks not only human bodies, but the body politic as well. Its effects vary greatly, but in many countries, particularly in Sub-Saharan Africa, it has already had an unprecedented institutional impact, not only on the organizations most needed for development, but also on those most needed for preventing the spread of the disease. In some countries, the capacity to cope may be overwhelmed.

Lesson 4: The virus is not particularly contagious

The spread of HIV/AIDS is at the same time the most devastating and the most paradoxical of epidemics. The greatest killer epidemic in modern history-and the worst ever by the time it comes under control-is due to a virus that is not particularly contagious. Many infectious diseases-such as the influenza or children's diseases, like measles or mumps-are highly contagious. For some of them, just being in the proximity of an infected person may be sufficient to fall ill. The spread of HIV, on the other hand, is relatively easy to prevent-and informed and motivated individuals can protect themselves. This is why everyday social interaction with and care for the infected is safe. Moreover, for those most at risk, as long as sex is voluntary, people can on the whole choose not to be infected if they are aware of how the disease is transmitted.

Most of those infected by the disease do not know it. They have undergone no test-there may be no medical service to do it and the incentives to take tests may be low because of the social stigma associated with knowing that one is infected. The nature of the disease also inhibits discovery-the incubation period between the infection and its manifestations is long. Because for so many years there are no outward signs of disease, those infected and those around them are unaware of their status.

Most of those affected do not know what the disease is-neither do most of those immediately at risk. Even in the most advanced education systems children learn little about infections or viruses during their first five years of schooling. And very many of those exposed to the virus do not even have five years of education. The 1 billion people in the world who are illiterate most often do not have access to scientific information. Even among literate populations many are scientifically illiterate-unfortunately, also including many teachers.

In many communities beliefs about what causes AIDS are wrong. Actions taken to avoid it or the attempted cures can be misguided, counterproductive for those infected with the virus and might lead to others being infected. Misconceptions, beliefs and customs include the use of ineffective or damaging concoctions, and resorting to sexual practices involving children.

Misconceptions lead to prejudice, discrimination and exclusion. Social silence favours infection. Inadequate knowledge results in careless behaviour. Lack of knowledge leads to lack of care for those that are infected-and to stigmatization that make the infected into social outcasts. Denial may hasten death. The uneven infection rates worldwide are in no small part due to an uneven distribution of knowledge. The need for preventive education flows from the particular types of ignorance closely associated with the epidemic, particularly in the most affected developing countries.

Lesson 5: A major reason why the epidemic is out of control

There are millions who know about the virus and the risks involved-and yet do not adopt safer practices. They either close their eyes to the risks or even expose themselves to infection with eyes wide open. In some Western countries, exposed groups have reverted to unsafe practices thinking that new treatments now mean that the risk has diminished. Hence, prevention must address mentalities and the culture within which they are embedded in order to generate the attitudes, provide the skills and sustain the motivation necessary for changing behaviour. This is how to reduce the risk and the vulnerability.

Lesson 6: The message must be appropriate to the audience

Changing conceptions and attitudes requires effective communication-knowing the audience, formulating the message and getting it across. The validity of the message is essential. But what is understood and absorbed depends not only on its scientific soundness, but also on the frame of reference within which it is interpreted. Comprehension and appreciation depend on many social factors, such as age, gender, educational opportunities, economic status and religious beliefs. The message must be customized to the recipients-it should reflect what kind of understanding the audience already possesses and the material context and social environment in which they live. The essential thing is that those who receive the message grasp it, act on it and pass it on. If the knowledge, attitudes and skills transmitted are not culturally adapted, preventive education can be blocked and defied by traditional creeds and customary ways of life. Precepts and practices are embedded in local mores and reinforced by more comprehensive systems of behaviour and thinking. They are also buttressed by norms of propriety, customs of marriage and religious beliefs which may sustain the silence about the epidemic, its causes and its consequences. Communities and cultures interact with the epidemic

and undergo changes from this interaction. Preventive education must likewise keep pace with the dynamic of the epidemic.

Lesson 7: Knowledge is not enough to change behaviour

If preventive education is to be effective, the specifics of the social and cultural context within which the communication takes place must be actively taken into account, not just as possible obstacles to be overcome but also as potential resources.

There is no cure for HIV. Of the millions of people infected, not one has been able to get rid of it. There is at present no way of eradicating the virus from the body. The HIV virus can be held at bay and progression towards AIDS can be slowed. But treatments are still costly-and least available where they are most desperately needed. Neither is any vaccine in sight. Vaccination has provided protection against many infectious diseases, from smallpox to polio. But against HIV it is still only an expectation. And treatments are still too costly, particularly for developing countries with high infection rates and low incomes-and a quarter of the world's population lives on less than one dollar a day. But change in behaviour can stop the spread-preventive education is so far the most effective vaccination. In many countries preventive education works. In most Western countries the spread of the disease began to slow down early on. In Uganda death rates were cut by half in five years; in Brazil in three years, with a combination of education, prevention and medicine. Measures taken in Senegal and Thailand have had a great impact.

Lesson 8: Preventive education works

If preventive education is done right, it is effective. If done immediately, it will have a long-term impact. If done massively, it can turn the tide.

Given the cost of treatments-sometimes forbidding in developing countries-a debate has arisen whether money should be directed towards prevention and cutting down the number who will be infected or towards treating those that are already infected so that they may continue to play a role as parents and workers. Treatment can turn a deadly infection into an admittedly problematic, yet manageable, chronic disease. There are three types of arguments for treatment:

o *The humanitarian argument:* We cannot just let millions of people die-they have a human right to receive treatment, help and care.

o *The economic argument:* Lack of treatment means that the loss of breadwinners, parents and professionals would become unbearable-and the cost of replacing people who die, when it can be accomplished, is often greater than providing medical treatment for those who are ill.

o *The prevention argument:* If knowing you are HIV-positive makes your life more negative, there is no incentive to do anything to change your situation. If others knowing you are infected results in being discriminated against and receiving no help, it means that people will not divulge information about the disease. Treatment provides hope for a longer life, a better life, for a productive life. When treatments are available, there are benefits to knowledge.

Lesson 9: Treatment is not only possible-it is imperative!

There is no contradiction between prevention and treatment. The HIV/AIDS epidemic is not only dynamic-it is complex. Indeed, one could argue that it is not just one epidemic, as it takes many forms between countries and groups. Intravenous drug users must be approached in a different way from sex workers, and teenagers differently from pensioners (who also get the virus). This also means that there is neither one 'silver bullet' to stop infections nor one marksman that can do the job. Indeed, it is an epidemic of such proportions-and is going to be with us for so many decades-that everyone has to become involved and contributions from all quarters must be welcomed. There is enough to do and enough honour to be shared. Yet, those who become involved must work closely with affected countries and groups, work closely with civil society and NGOs, and work closely with UNAIDS and its co-sponsors based on a clear division of labour and a sharp commitment to tasks.

Lesson 10: There is no single programme and no single actor

UNESCO, as one of the co-sponsors of UNAIDS, has decided to focus its activities on five core tasks:

1. Advocacy at all levels, particularly to mobilize unrelenting support for preventive education from all those in positions of authority in its areas of competence (education, science, culture, communication).
2. Customizing the message to reach targeted audiences, particularly the young at risk, whether they are in school or not.
3. Changing risk behaviour and vulnerability by effective programmes of preventive education that can reach all, particularly those most exposed, vulnerable and at risk.
4. Caring for the affected and infected by the virus through supporting affordable treatments and providing information to reduce stigma and trauma.
5. Coping with the impact, particularly protecting the core functions of institutions, notably within the field of education.

The year 1900 began the most amazing century in the history of human health. Never before have so many survived infancy, never before have so many lived so long, never before have so many led such healthy lives. The devastating effects of many infectious diseases were reduced or halted. Vaccines were invented. Treatments were improved. Enormous gains were made in reducing infant mortality and enhancing life expectancy. Much of the gains were achieved outside the health sector-by progress in the economy, in nutrition and in sanitation.

The beginning of this twenty-first century brings with it the broad realization that we are facing the most devastating epidemic in human history. In less than two decades, HIV/AIDS has been transformed from a medical curiosity to an international emergency.

The epidemic is unprecedented in human history. And the worst is yet to come-many millions more will be infected, many millions more will die, many millions more will be orphaned.

The epidemic is unprecedented in human history. The mobilization now taking place is unprecedented in the history of the United Nations. Twenty years after the disease was first identified, a Global Fund for AIDS, Tuberculosis and Malaria has been set

up. All member countries of the United Nations are summoned to do their utmost at home and to support generously those most severely affected. Non-governmental organizations are called upon to take action. Private corporations and individual citizens are urged to join. All United Nations agencies are enlisted to do their utmost where they can make the greatest difference.

Much is still not known about the epidemic-much is yet to be learned. But enough is known to act, and we know we must act immediately, decisively and massively: to offer treatment, to provide care and to maintain institutions, while respecting human rights for all.

Above all, we must do the utmost to stop the spread of the epidemic through programmes for preventive education that reach all, and particularly those most at risk from the virus. There is no time to be lost. There are no lives not worth saving.

Now is the time not for complacency, but for compassion. Now is the time not for hesitation, but for action. I pledge the full support of UNESCO where it can make the greatest difference. The Organization will mobilize all of its sectors for effective preventive education for all at risk around the world.¹

A coherent overall strategy is crucial. Yet the critical test of UNESCO's efforts will be the impact of its efforts in the countries with the highest levels of infection, in the most affected communities and for the most vulnerable groups.

Not acting now on what we know would be a moral failure of unprecedented proportions. Every moment lost can be counted in increasing misery and more deaths. Hence we have to act together-urgently and decisively.

Note

1. See, on this subject:

<http://www.unesco.org/culture/aids/index.shtml>

and

http://www.unesco.org/education/efa/wef_2000/press_kit/aids.shtml