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THE SCIENCE OF AIDS: A TALE OF TWO WORLDS

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PETER PIOT, *a Belgian physician and microbiologist, has worked in the HIV/AIDS field for over a decade. A codiscoverer of Ebola virus in 1976, he later headed a series of collaborative projects on AIDS in Africa. He was president of the International AIDS Society from 1992 to 1994, and since January 1996 has served as executive director of the Joint United Nations Programme on HIV/AIDS (UNAIDS).*

AIDS continues to be an unprecedented challenge to individuals, science, and society. One of the main conclusions I have reached is that the global research and development (R&D) agenda for human immunodeficiency virus (HIV) needs to be turned on its head. Ignoring the needs of 90% of the individuals affected by the epidemic is not only unethical, it is irrational, for a pandemic such as AIDS can only be stopped if the problem is tackled on all fronts. There is an urgent need to focus epidemiologic intelligence on the constantly shifting global picture, to direct R&D to technologies that will be globally relevant and affordable, and to undertake product evaluation together with the developing countries.

Let us have a quick look at some sobering facts. In less than 20 years over 40 million people have become infected, and UNAIDS estimates that every day 16,000 people become infected with HIV, 90% of whom live in the developing world. AIDS is now one of the leading infectious causes of death in the world and has brought down life expectancy at birth in the worst-affected African countries to levels of the 1960s. Directly and indirectly, it is costing billions of dollars to individuals, families, companies, and governments, and has become a major obstacle to social and economic development, especially in Africa. In addition, it has everywhere acutely challenged individuals' and societies' attitudes and practices on sex. It is thus no exaggeration to call it a global crisis. I believe that without immediate, massive investments in a much stronger response, supported by renewed international solidarity, the AIDS crisis will continue to grow.

At the same time, the rate of scientific progress on HIV and the rate at which advances are applied for the prevention and treatment of HIV infection are with few precedents in the history of biology and medicine. We know more today about the biology of this recently discovered virus and the infection it causes than for most other microorganisms and infectious diseases, demonstrating the power of modern biology when applied with intensity and the necessary resources. A diagnostic test became available very soon after identification of the causal agent, thereby practically eliminating HIV infection acquired through blood transfusion. New data on antiretroviral resistance patterns or mechanisms have almost instantly influenced therapeutic approaches. As a result of newly developed therapies, the quality of life for many patients with HIV infection has drastically improved in most Western countries, where there has recently been a remarkable decline in mortality from AIDS. However, such scientific progress has been of little benefit to the millions of men, women, and children in poorer countries, who do not have access to highly active combination therapy or for whom regimens to prevent HIV transmission from mother to child used in the West are not a realistic option.

Furthermore, it sometimes seems that solid scientific evidence has no impact on policy. I have often seen science being neutralized by ideology when it comes to issues that are difficult for some members of our society. For example, harm reduction among injecting drug users, including needle-exchange programs, has been shown in numerous studies to reduce the risk of HIV infection, and yet in many, if not most countries in the world, such programs are not supported by the government, or are even against the law. Another critical area for HIV prevention is sex education for school-aged children. Again, there is sound evidence from numerous studies that sex and life-skills education for children promotes safer sexual behavior, but does not lead to earlier onset of sexual intercourse or to increased sexual activity. We know that condoms protect against transmission of HIV, that they literally save lives. Why is it, then, that in many countries promotions of condom use are not allowed during prime-time television viewing? The majority of educational authorities in the world deny their children access to sex education, mostly on ideological grounds. In general, it appears that the broad societal response to this new epidemic has been slow and has lagged behind the successes of biomedical research. This unresponsiveness is particularly sobering in badly affected developing countries, where earlier action might have prevented the current large-scale catastrophe—with some notable exceptions such as in Thailand and Uganda.

If biomedical research on HIV has been so successful, it is largely due to four reasons. First, it is capitalizing on the formidable progress in the application of disciplines such as molecular biology and immunology of infectious diseases. Second, research agencies made early and substantial commitment to HIV research under pressure from an influential sector of the public in the face of the threat of a new contagious disease. Third, it stemmed from the drive of multidisciplinary teams of scientists—often young scientists who took their chances. Finally, it benefited from the existence of a new market for HIV-related drugs. Thus, societal pressures and choices, as well as market forces, have clearly

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moved the HIV science agenda. Unlike any other health problem before, there has been a uniquely close involvement of and pressure from individuals and groups infected with or affected by HIV—mainly gay men in the industrialized world—in setting the agenda for AIDS research and pressing for the immediate application of the results. This engagement is illustrated by (i) the organized lobbying for increased funds for targeted research on HIV (such as by TAG, the Treatment Action Group of New York); (ii) the participation of people living with HIV/AIDS in setting the research agenda in clinical trial committees, boards of foundations, advisory boards of pharmaceutical companies, and scientific conferences; and (iii) the part played by groups of patients as channels for distributing the latest scientific information (largely through the Internet). Such participatory and activist approaches have become the norm not only in research and the industrialized world, but extend into many international organizations. This approach is increasingly being accepted in developing countries as well, where representation is largely heterosexual (reflecting the nature of the epidemic in these countries).

AIDS provides a new paradigm for the interaction between science and society, between caregivers and patients, and between public health departments and affected communities. In this it may well have an influence beyond HIV infection and disease, promoting not only a more appropriate doctor-patient relationship, but also the participation of affected communities in public-health programs (with a potential downside that the most vocal and influential groups in society may define priorities). AIDS has also resulted in a more open discussion of and research into sexuality, and in more attention being given to a rights-based approach to health issues. In some developing countries, it may be contributing to the democratization process through the genesis and strengthening of numerous community and self-support groups.

Some lessons can be learned from the AIDS epidemic that may be applied to other emerging health threats. First, never underestimate the potential for a global and massive epidemic. In 1981, when AIDS was first described, I never thought that 17 years later over 40 million people would have become infected with HIV. One problem is that predicting the ultimate extent of a disease in its early days of emergence is very difficult, if not impossible. Consider, for example, the current uncertainty regarding future impact of the new variant of Creutzfeldt-Jakob disease that is related to "mad cow" disease. Second, invest enough and with sufficient speed in the science of the problem to guide policy. Third, scientists and public health practitioners need to invest equally in informing the public and mobilizing critical decision makers inside and outside the government. Without their understanding and support, the response to emerging problems may be nil, exaggerated, or counterproductive. Finally, affected communities need to be involved from the start in planning and implementing the response, be they hospital staff when confronted with a nosocomial infection, or young people affected by an emerging sexually transmitted infection. The effectiveness of control programs will depend highly on such involvement.

Scientific progress in AIDS research will probably continue at a rapid pace, but a current attitude of hubris prevailing among some biomedical researchers is inappropriate. Big gaps remain in our knowledge of HIV, and it may be that we need a more complex response in terms of therapeutic approaches. A true cure—eradication of the virus from the body—should remain an important goal. Similarly, prevention has focused largely on fairly simple psychological approaches to influence individual risk behavior. Yet these have ignored the need for something far more complex, something which simultaneously promotes an environment that reduces people's vulnerability to HIV infection and supports them in safe behavior. At the research level, a renewed and rigorous effort in the social sciences will be required.

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The gaps are even bigger in determining how to prevent 6 million people from becoming infected with HIV this year, as occurred in 1997, and at the same time to care for the nearly 30 million people with HIV living in developing countries. This calls for the establishment of partnerships between developed and developing countries. The latter have a far greater capacity to contribute than is appreciated in the West. Besides requiring a new culture of international cooperation with increased emphasis on sustained interventions and strengthening local research institutions, it will be necessary to face increasingly difficult ethical questions on how to ensure the highest attainable standards in research. Recent evidence of this can be seen in the controversy in the United States regarding the ethics of placebos in trials of short regimens for the prevention of mother-to-child transmission of HIV in developing countries. Thanks to this controversial research, programs to reduce HIV transmission from mother to child are now being put in place in several countries, often with the assistance of the international community. Current ethical guidelines on human experimentation should form the basis for human clinical trials, but they need clarification on several issues, such as the meaning of what is "attainable" in countries where resources for health are severely constrained.

The ultimate challenge for HIV research will be the development of an effective and affordable vaccine. Without a vaccine, HIV will continue to spread at an unacceptable pace in many populations, and the global imbalance in terms of AIDS prevention and care will continue. Resources in research institutions and industry should be drastically increased to make President Clinton's pledge to develop an HIV vaccine a reality. The ability of our rich societies to achieve this goal will be a touchstone of our commitment, at the turn of this millennium, to the application of the most advanced science to a social good, to investment in the future of our children and grandchildren, and to the globalization of social benefits.

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