GLOBAL AIDS: MYTHS AND FACTS

Tools for Fighting the AIDS Pandemic

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global AIDS pandemic. We hope you find a cautious optimism here that will encourage you either to join, or continue, in the struggle to end the suffering, devastation, and death wrought by AIDS.

Preface

by Zackie Achmat

More than 28 million people on the African continent are infected with HIV, including some five million people in South Africa alone. Without treatment, most of these people will die over the next decade. This constitutes a crime against humanity. Governments, multilateral institutions, the private sector, and civil society both in and outside Africa must act without delay to stop a holocaust against the poor. This book is a call to join the struggle and build a movement of international solidarity against AIDS.

To fight back against the tide of death by promoting access to effective treatment for all HIV-positive South Africans is the mission of the Treatment Action Campaign. TAC was launched on December 10, 1998, International Human Rights Day. Its objectives are: to ensure access to affordable, high-quality treatment for all people with HIV/AIDS; to prevent new HIV infections; and to improve health-care access for all South Africans. TAC was founded by a handful of activists; today, its members and supporters number in the tens of thousands.

Our movement has achieved many successes and met many challenges over the last few years. From 1999 to 2001, TAC led the international campaign that forced the withdrawal of pharmaceutical companies' lawsuit against the South African government that put profits before people's lives by challenging the legal framework that

could provide inexpensive generic AIDS medications to poor South Africans. Later, TAC's pressure in the courts, the media, and the streets forced the South African government to accept responsibility for providing all HIV-positive pregnant women with access to therapies shown to dramatically reduce mother-to-child transmission of the AIDS virus. In August 2002, we joined with representatives from 20 other African countries to launch a Pan-African HIV/AIDS Treatment Access Movement dedicated to mobilizing our communities and our continent to ensure access to HIV/AIDS treatment for all our people who need it.

The past years have seen victories, but also the loss of too many friends and comrades, struck down by AIDS in the midst of their productive years, or even before they could reach adulthood. The greatest challenge lies ahead: the challenge of saving millions of lives by expanding access to AIDS treatment to all those who need it, while simultaneously fighting the social and economic forces that have accelerated the spread of HIV/AIDS.

Alleviating the effects of the AIDS epidemic will demand political leadership and greater accountability from national governments, international organizations, the private sector, especially the pharmaceutical industry, and wealthy countries—particularly the US and the countries of the European Union. We confront enormous barriers: national governments do not prioritize HIV/AIDS treatment; donor countries refuse to fulfill commitments to mobilize necessary resources; pharmaceutical companies deny access to essential medicines and diagnostics by charging exorbitant prices; and debt owed by poor nations to rich countries and international financial institutions hampers financing of vital social services, including health care. Community mobilization and civil society action are essential for forcing change and ensuring greater accountability from all these institutions.

When the XIIIth International Conference on AIDS met in Durban, South Africa, in 2000, TAC and other AIDS treatment activists had hope and ethical arguments for HIV treatment. Today we have facts. In Khayelitsha, outside Cape Town, a pilot treatment program run by Médecins Sans Frontières (MSF) has demonstrated that people with HIV/AIDS, a majority with severely damaged immune systems, can recover life, health, and dignity when treated using advanced antiretroviral medications (ARVs). This follows on the success of Paul Farmer, Partners In Health, and the people of Haiti. So today when we speak to you of AIDS treatment access in poor countries, we speak not only with ethical arguments, not only with hopes, not only with desperation, but with facts and the lives of the people themselves.

From a pure public health perspective, it is shortsighted not to treat AIDS, to say that we must focus on HIV prevention and exclude treatment. On the other hand it is unconscionable, because we are speaking not about cold statistics, but our lives. Our lives matter. The five million people in South Africa with HIV matter, and the millions of people throughout the world already infected with HIV matter. So it is not simply a question of cold statistics we are putting to you, but a question of valuing every person's life equally. Just because we are poor, just because we are black, just because we live in environments and continents that are far from you does not mean that our lives should be valued any less.

In the words of the labor movement, "an injury to one is an injury to all." *Global AIDS: Myths and Facts* challenges complacency and clarifies the tasks that lie ahead for those who want to make international solidarity a reality in the age of AIDS. Such solidarity must be built from the ground up. Over the last few years it has been the power of ordinary people that has begun to hold drug companies and governments accountable, and to awaken the global

community to its responsibility. Bayard Rustin (whom historians will know as a black gay man and chief organizer of the march on Washington led by Dr. Martin Luther King Jr.) said protest confers dignity on a people whose dignity is denied. TAC believes that it is an individual's responsibility to study ethics, science, law, politics and economics, medicine and history. This is the duty of every HIV/AIDS activist, whether HIV-positive or -negative, literate or illiterate, and it is the key to stopping the epidemic. Our education takes place on picket lines, on marches, and in workshops. We use handwritten posters, printed propaganda, the Internet, phones, songs, pen and paper, and faxes. To the public in South Africa and other countries, and to the readers of this book, we say: Correct us when we make mistakes. Or better yet: Join the struggle, make mistakes—and make history—with us!

Introduction

by Paul Farmer

Medical science alone cannot overcome AIDS. Tools to contain the spread of HIV and prolong life for people with AIDS exist. Yet in 2002 an estimated five million new HIV infections occurred, and three million men, women, and children died of AIDS.[1] One reason for this failure is that prevention efforts are underfunded and rely, in the absence of a vaccine, on barrier methods requiring male assent. Another reason HIV has become the world's leading infectious cause of adult deaths is that most of the 42 million people now infected live in the developing world and cannot afford the drugs that might extend their lives. Health professionals seeking to serve these patients stand by helplessly, absent the financial resources and political will required to deliver prevention, care, and treatment within the poor communities that have borne the brunt of AIDS.

To fight the plague on a global scale, we need a massive international campaign able to pressure political and economic power holders to take AIDS seriously and to sustain such commitment until the pandemic is brought under control. The medical and public health communities cannot hope to lead such a campaign alone. Nor is it reasonable to expect those already gravely ill with complications of HIV infection to go it alone. Over the past 15 years, a vibrant international AIDS activist movement has emerged. The movement, which has brought together people living

with HIV and many who seek to make common cause with them, has scored dramatic victories. The Pharmaceutical Manufacturers Association lawsuit against the South African government, withdrawn in April 2001 largely because of a mobilization spearheaded by the Treatment Action Campaign (TAC) and other civil society groups committed to equity of access to care, stands as an important case in point.[2] Yet the international fight against AIDS will fail, in the long run, without intensified grassroots activism in countries like the US, where a disproportionate share of global wealth and political power is concentrated.

Among the greatest obstacles to a broad mobilization against HIV/AIDS is misinformation about the pandemic. To act effectively, people must have sound knowledge. Ignorance breeds passivity, pessimism, resignation, or a sense that AIDS is someone else's problem. Accurate knowledge may awaken a sense of urgency about global AIDS and enable effective action. To disseminate such activist-oriented knowledge and to combat ignorance about AIDS are the goals of this book.

It is important to be clear about whose ignorance we are referring to. Perhaps more than any other recent health crisis, AIDS has spawned intellectual confusion and unsubstantiated theories—here termed "AIDS myths." By myths we do not refer to beliefs about AIDS in so-called traditional societies, whose ignorance of Western science has sometimes been decried by health experts as a reason for the failure of AIDS control efforts. We mean instead the myths that often dominate discussions among the experts themselves, as well as among political leaders and ordinary citizens in wealthy countries. Myths such as the belief that the HIV/AIDS pandemic is driven primarily by promiscuity; that endemic corruption in poor countries dooms AIDS control efforts to failure; that developing countries must view AIDS prevention and treatment as mutually exclusive options;

or that AIDS treatment with antiretroviral medications is not feasible in resource-poor settings. And there are other, more subtle distortions. What does it mean, for example, to consider AIDS prevention primarily in terms of individual psychology or suspect "cultural practices"? Does such an analysis reflect genuine cultural competence, or does it in fact distort facts, amplify prejudice, and erase important considerations of poverty and inequality? Is it true, as certain high-ranking US officials have argued recently, that antiretroviral agents cannot be used on the world's most HIV-affected continent because Africans "have a different concept of time"?[3] Or is this claim an example of yet another AIDS myth, one expedient to those who wish to hide the real reasons that these life-saving medications are not more readily available?

This book examines and refutes 10 such prominent misconceptions about HIV/AIDS. Taken together, these beliefs constitute a stock of conventional wisdom about the disease drawn upon by many political and health officials and ordinary citizens in wealthy countries. To debunk each myth, the book combines lessons from medicine, public heath, epidemiology, and the social sciences relevant to these disciplines. We also draw upon our own experiences as AIDS activists and as providers of integrated prevention and care services in settings of great poverty. Our goal is to expose what is wrong with received wisdom and to replace it with accurate information that can foster a more robust response to the pandemic. We hope readers of *Global AIDS: Myths and Facts* will become protagonists of that response—educators and advocates in their turn. We hope that readers will use these lessons and rectifications to refute mistaken claims about AIDS when they encounter them in publications, policy debates, classrooms, or daily conversations.

AIDS myths are only part of the problem. Another is that debates about HIV have become overly fragmented. Some

discussions of HIV focus only on the clinical aspects of the disease. Others, especially those heard in resource-poor settings, focus only on prevention. Others raise questions regarding the feasibility of integrated HIV prevention and care as a means of stopping rather than starting a conversation.

Today, it is no longer tolerable to evade such questions as they relate to the politics both of HIV prevention and AIDS treatment. We will argue here that entrenched poverty, economic inequality, racial discrimination, the subordination of women, and other forms of structural injustice contribute overwhelmingly to the spread of HIV infection and render current prevention efforts less effective than they are in other settings. At the same time, we will challenge the willingness of many power holders to deny lifesaving AIDS treatment to poor people.

Since 1996, combination antiretroviral therapies, the so-called AIDS "drug cocktails," have dramatically increased life span and life quality for patients who can afford them.[4] Yet today these expensive therapies remain beyond the reach of the vast majority of people living with AIDS. Many international health officials, particularly from the US and Europe, have argued that state-of-the-art AIDS treatment is too complicated for people in the developing world and not "cost-effective" enough to be implemented in resource-poor settings. Such claims lead some policymakers and ordinary citizens to conclude that tens of millions of people are in essence "too poor to treat."[5] This book seeks to refute these positions with analyses based on clinical experience, on public health arguments, and on moral principles.

Those who contributed to this book argue that it is unwise in a mature epidemic to focus exclusively on preventing new infections. The hour is late. The devastation of HIV/AIDS can best be countered, we conclude, through a combination of (1) vigorous preventive

measures to protect the uninfected; (2) treatment, including antiretroviral therapy and prophylaxis and treatment of opportunistic infections, for those with advanced HIV disease; and (3) a sustained attack on the poverty and inequality that have fueled the pandemic from the beginning. To speak of radically expanded AIDS treatment for the poor and of a united global fight against the disease will appear utopian to some. Yet what can be more pragmatic than to expand access to tools that could reduce the number of new infections, relieve suffering, and prevent premature deaths? As we confront a scourge that has claimed millions of human lives and now menaces tens of millions more, it seems no exaggeration to say that history will judge us by our response to a crisis that not only challenges our scientific capabilities, but reveals the scope—and the limits—of our moral vision.

Global AIDS: Myths and Facts emerges from a collaborative effort involving contributors from many different professional backgrounds. Our team includes physicians, medical anthropologists, microbiologists, epidemiologists, and specialists in religion and ethics. Some members have for many years provided medical care to patients suffering with HIV/AIDS and other infectious diseases in Haiti, Peru, Russia, and elsewhere. Other contributors have worked on AIDS prevention campaigns or have conducted anthropological research on HIV transmission in African countries. Some are involved locally in the work of activist organizations like ACT UP. Many of us are teachers.

We are connected through the organization Partners In Health (PIH) and its research arm, the Institute for Health and Social Justice. PIH was founded in 1987 to provide high-quality medical treatment to undersereved areas in some developing countries and in poor neighborhoods of North American cities. At the core of PIH's philosophy is the commitment to a "preferential option for the poor" in health care, a concept adapted from Latin American liberation theology. In cooperation with sister organizations such as

Zanmi Lasante (Haiti) and Socios En Salud (Peru), PIH links the resources of wealthy medical and academic institutions with the experience and aspirations of people living in poverty. The goal is to overcome health problems conventional wisdom currently deems "insoluble." PIH's major projects include treating multidrug-resistant tuberculosis in squatter settlements in Haiti and Peru and delivering HIV care, including antiretroviral drugs, to patients in a destitute region of Haiti's Central Plateau.

At PIH, experience has repeatedly shown us that when the courage and determination of poor communities are brought together with the resources of people and medical institutions from the global North, the limits of "what is possible" in the health field can be retraced. *Global AIDS: Myths and Facts* is written in this spirit.

No single book can dismantle all the myths and mystifications that surround HIV/AIDS, and this becomes increasingly true as AIDS myths change over time.[6] There are two main areas of AIDS mythology we do not explore here. The first is the question of the origin of HIV (including beliefs that the virus was intentionally unleashed by organizations like the CIA). The second is the territory of HIV and AIDS "denialism," claims either that the AIDS epidemic is a hoax and the disease doesn't really exist or that AIDS is not caused by the virus known as HIV. Readers can consult the large body of literature on these topics.[7]

Denialist positions and conspiracy theories about the origin of AIDS have sparked debate in a variety of settings. In South Africa, a few government officials until recently showed undisguised sympathy for certain denialist views, and combating denialist claims has been an important task for some AIDS advocacy organizations. Yet conspiracy and denialist myths are not the ones that have been most influential in shaping mainstream opinions about HIV/AIDS in high-income countries. In this book, we focus on myths with

wide credence today among the general public in the US and other affluent countries. These are the misconceptions US—and Europe–based activists must seek to expose and refute as we work to build support for the international AIDS struggle in our communities and among political officeholders.

As we make choices about fighting AIDS, we are doing more than deciding how to confront the most devastating infectious disease of modern times. We are shaping the moral character of the world we and our children will inhabit. The choice before us is stark. We can accept a world of radical polarization between haves and have-nots, in which the calculus of cost-effectiveness determines that poor people must die of diseases for which the affluent are successfully treated as a matter of course. Or we can work for a world of solidarity, in which people from different backgrounds cooperate to mobilize resources and build the foundations of a dignified life for all, prioritizing the needs of the most vulnerable. The global AIDS struggle moves us toward this horizon of pragmatic solidarity.

HIV/AIDS Basics

What is HIV?

Human immunodeficiency virus (HIV) is the virus that causes AIDS. Once introduced into the bloodstream, HIV attacks certain cells of the immune system called the "helper T-cells," or CD4 cells, which are responsible for helping the body to fight off infections. HIV invades CD4 cells, reproducing within the infected cells, and then bursting out into the bloodstream. The immune system responds by producing antibodies to fight the virus and making more CD4 cells to replenish those killed. But this immune response is ultimately ineffective. In the late stages of infection, HIV destroys increasing numbers of CD4 cells until the body's capacity to fight other viruses and bacteria gradually begins to decline. Eventually, the immune system stops functioning, leaving the body defenseless against other infectious agents.

What is AIDS?

Acquired Immunodeficiency Syndrome (AIDS) is the medical designation for a set of symptoms, opportunistic infections, and laboratory markers indicating that a person is in an advanced stage of HIV infection, with an impaired immune system. Although some people may develop AIDS much sooner, it takes an average of 10 years from the time one is infected with HIV to develop clinical AIDS. As immune functions begin to decline, the

body becomes prone to certain opportunistic infections, so called because they are able to cause illness as a result of a weakened immune system. The characteristic spectrum of opportunistic infections that a person is likely to get will vary in different regions of the world, depending upon the locally predominant infectious agents. For example, although tuberculosis (TB) is not frequently encountered in North America or Europe, it is a common opportunistic infection in many developing countries.

What does it mean to be HIV-positive?

An HIV serologic test looks for the presence of antibodies against HIV in the blood. A person who is HIV-positive (or seropositive) has been infected but does not necessarily have AIDS. Because of the long delay between the time of infection and onset of disease, the number of HIV-positive people in a population is always much greater than the number of people with AIDS. In the absence of treatment, however, nearly everyone who is HIV-positive today will develop AIDS within the next decade.

How is HIV transmitted?

HIV is spread through having unprotected sex with an infected partner, sharing needles or other drug injection equipment previously used by an infected person, or receiving a transfusion of blood or blood products contaminated with HIV. The virus can also be passed from a mother to her infant before or during birth or through breast-feeding. The fact that HIV-positive people can remain free of symptoms (asymptomatic) for years greatly increases the chances that they may unwittingly pass the virus to others through sexual contact, needle sharing, or breast-feeding.

How can infection be prevented?

Risk of contracting HIV through sex can be sharply reduced by the use of barrier methods such as male or female condoms. Transmission among intravenous drug users can be blocked by eliminating the sharing of needles and other injection equipment. Administering a short course of antiretroviral medications to an HIV-positive mother at the time of delivery dramatically reduces transmission of HIV from mother to child. Proper monitoring of blood supplies virtually eliminates the risk of contracting HIV through transfusions. Unfortunately, while methods for preventing new HIV infections are clear in theory, social and economic constraints complicate the practical application of all these strategies.

What is the current medical management of AIDS?

The drugs used to treat HIV/AIDS are called antiretrovirals (ARVs); they work by stopping HIV from replicating. The most effective treatments are combinations of these drugs, referred to as highly active antiretroviral therapy (HAART). Treatment with HAART usually reduces the amount of virus in a patient's bloodstream, allows the CD4 cells to be replenished, and restores immune function. However, HAART is not a cure. Patients must remain on lifelong treatment, and ARV drug regimens can produce debilitating and, rarely, dangerous side effects. Over time, most patients develop resistance to at least some of the medications. Despite such shortcomings, antiretroviral therapy has slashed AIDS death rates in wealthy countries and has dramatically enhanced life quality for many of those able to obtain treatment.

What is the difference between risk and vulnerability?

Risk of HIV infection is defined as the probability that a person could become infected. Epidemiologists often look for "risk factors," or characteristics that correlate with an increased risk of infection. Behaviors associated with the transmission of HIV, such as having multiple unprotected sexual contacts or using intravenous drugs, are some of the risk factors for HIV infection. But looking at individual risk factors alone provides only a limited understanding of how to control the spread of HIV. Underlying socio-

economic factors—including poverty, discrimination, and gender inequality—continue to drive the pandemic. It is these socioeconomic determinants that often lead people to adopt "risky behaviors" and render them vulnerable to HIV infection. Rather than focusing narrowly on efforts to change individual risk-taking behaviors, prevention programs must be directed towards reducing vulnerability.

What is prevalence and how does it differ from incidence?

Prevalence is the percentage of people in a population with a specific disease or condition at a given moment in time. When we talk about the prevalence of HIV infection in a community or country, we mean the percentage of the total population that is HIV-positive. Prevalence is useful for describing the overall burden of disease, but a low prevalence of HIV/AIDS can be falsely reassuring for two reasons. First, because prevalence is an average value, a low prevalence of HIV/AIDS in a population with widely varying risks of HIV infection can mask small high-risk groups with high prevalence of HIV/AIDS. Secondly, countries with a low prevalence of HIV/AIDS but a very large population can have more total cases of HIV/AIDS than countries with a high prevalence but much smaller populations. Moreover, prevalence does not provide information about the trends of an epidemic over time. If we would like to know about the dynamics of an HIV/AIDS epidemic—if it is declining, stable, or growing—we would need to look at the rates at which new infections are occurring. This number, called the incidence, is usually expressed as the number of new HIV infections per year. By comparing the annual rates of new HIV infections, we can learn how an epidemic is proceeding.[1]