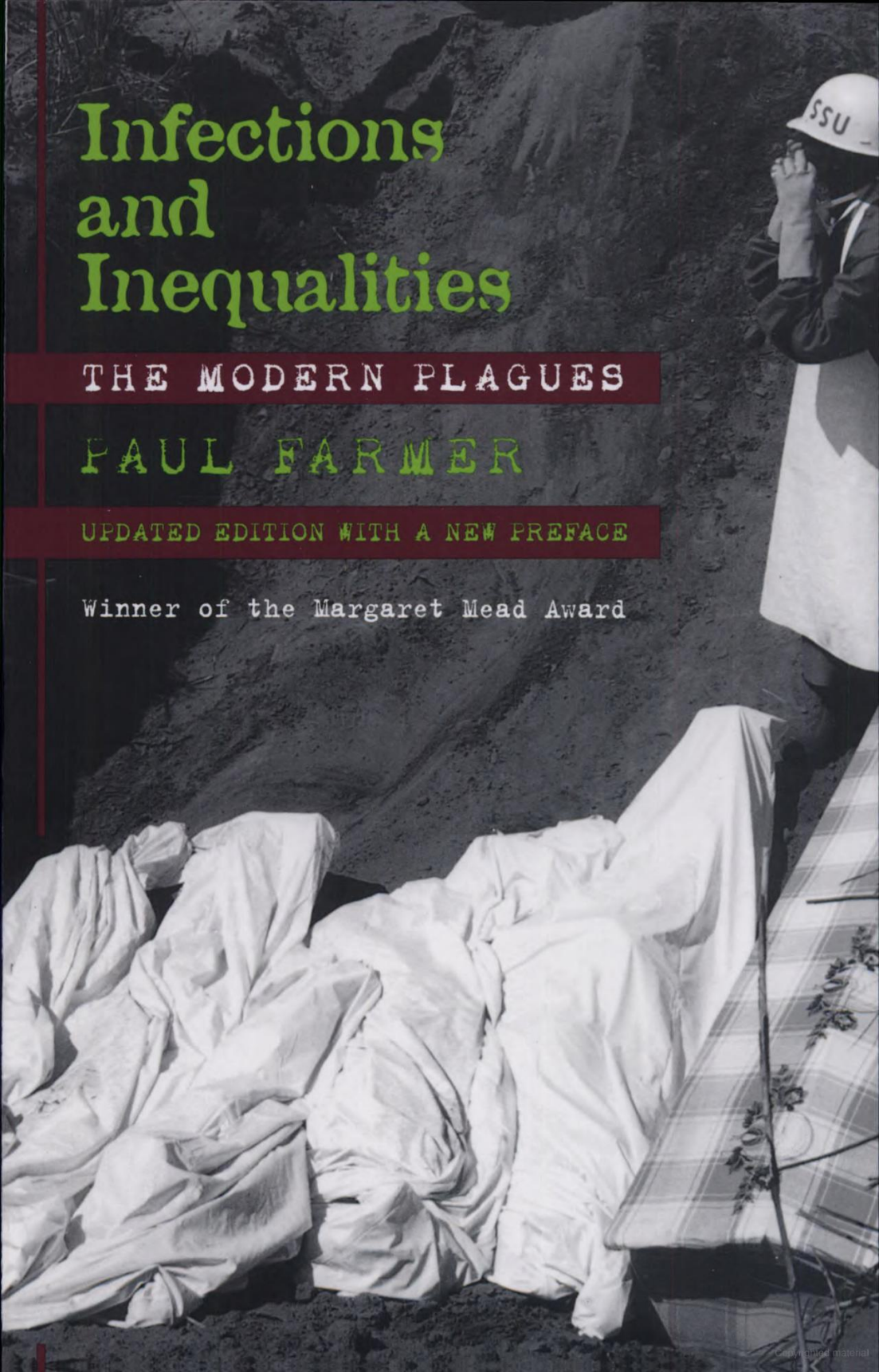
Infections and Inequalities

THE MODERN PLAGUES

PAUL FARMER

UPDATED EDITION WITH A NEW PREFACE

Winner of the Margaret Mead Award



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Preface to the Paperback Edition

Anthrax.[1] The word conjures images of germ warfare, which is pretty ridiculous when you discover that we're not really sure anthrax has ever been used in this fashion.[2*] Germ warfare is certainly not what came to mind in June of this year, when a six-year-old girl showed up in our clinic with half her face puffed up like a balloon, her right eye swollen shut. We were in rural Haiti, where a very different sort of germ warfare is the rule. So what came to mind that day was the word *epidemic*, and sure enough a young woman from the same village was also diagnosed with cutaneous anthrax—called *charbon* in Haiti, "malignant pustule" in the older textbooks—on her right chest wall. Soon after their arrival, both were receiving intravenous penicillin; they would recover completely.

Later that night, the clinic's medical staff held a meeting. Another anthrax case had been diagnosed a few days earlier, and the patient was from the same area. It seemed increasingly likely that we were dealing with an epidemic. By morning, we learned that a young man from the village had just died of *charbon*. "Why?" I asked the woman

*These words were written well over a year before anthrax-laced letters caused several deaths as well as enormous public apprehension ("hysteria" was the term encountered in the popular press) in the United States, Europe, and many other parts of the world. But these unprecedented events proved, I think, a point made in *Infections and Inequalities*: investing in robust public health infrastructures, and in global health equity in general, remains our best means of being prepared for—and perhaps even preventing—bioterrorism. Indeed, this was the refrain of several of our best public health leaders during the taxing investigations of these attacks, whose perpetrators remain unidentified.

who told me the news. "Because he didn't have enough money to get here." It costs no more than four dollars to take a truck from their village to our clinic. It was an epidemic, all right, and it had already taken a life.

In the United States, this conclusion might have provoked little short of calling up the National Guard. But in Haiti we had not triggered much in the way of government response in announcing previous epidemics of communicable disease. Just five months previously, we'd seen several cases of meningococcal meningitis, first diagnosed when a baby presented with what is called purpura fulminans—his skin was covered with distinctive patches of purple hemorrhage. He was in shock. Although he received antibiotics within minutes of reaching the clinic, the infant died while I was trying to get intravenous fluids into a vein, any vein, as his mother stood by wailing.

The baby's death was the harbinger of three more cases of meningococcal disease; the other patients survived. Since the bacterium, *Neisseria meningiditis*, is contagious, we gave family members rifampin, an antibiotic that can kill the organisms before they cause invasive disease. Rifampin, usually reserved for the treatment of tuberculosis, has few serious side effects. But it does cause one rather curious transformation: it turns urine, tears, and other body fluids reddish orange. The doctors and nurses who cared for these meningitis patients also took rifampin prophylaxis. We had so many cases that my urine ran red for a month; I don't recall ever seeing orange tears.

Epidemics of communicable and potentially lethal infections evoke very different official responses in different settings. In Haiti, very *real* epidemics of anthrax and meningococcal meningitis did not even result in an investigation. When I recently asked the beleaguered public-health officer why he did not come to investigate, he responded that, although he did have access to a jeep, he did not have money for gasoline. Meanwhile, in the United States, even the *theoretical possibility* of bioterrorism has moved hundreds of millions of dollars into research and conferences on a subject of dubious public-health significance.[3] The U.S. government has certainly poured substantial resources into preventing and responding to bioterrorism. In January 1999, President Clinton presented to Congress a budget that included $10 billion for antiterrorism

efforts, $1.4 billion of which was allocated to biological- and chemical-attack preparedness, a twofold increase from 1997. In his almost incomprehensible remarks announcing the initiative, Clinton allowed that "there is no market for the kind of things we need to develop; and if we are successful there will never be a market for them. But we have got to do our best to develop them."[4] In contrast to these hypothetical epidemics, very real epidemics are being ignored. In a recent editorial, Cohen and colleagues remark, "The proponents of antibioterrorism programmes have it backwards. Instead of pumping more resources into ill advised and risky bioterrorism programmes, we should build national and international public health systems that can adequately reduce, detect, and respond to natural disease outbreaks and industrial chemical spills. Then, in the unlikely event of a bioterrorist attack, these systems will be available to manage the challenge."[5]

Infections and inequalities: in a wealthy country, the specter of biological warfare, for which there is exceedingly slender evidence, triggers a sort of officially blessed paranoia. In a poor country tightly bound to the rich one, real infections continue to kill off the poor, and we are told sternly to look harder for cheaper, more "cost-effective" interventions. At best, those of us working in places like Haiti can hope for trickle-down funds if the plagues of the poor are classed as "U.S. security interests."[6]

I cannot look back at the predictions made in the first edition of this book with the slightest satisfaction. Oh, they've all come true: if you want to feel like a prophet these days, predict that the poor will continue to do poorly, even in boom times. Take tuberculosis. *Infections and Inequalities* made the bold prediction that the poor would continue to die of readily treated tuberculosis and that newer multidrug-resistant strains would continue to spread. On the former score, take the example of Dominique, a twenty-six-year-old man from a town far from the clinic. In chapter 8 of this book's first edition, I noted that TB deaths were exceedingly rare in the area of central Haiti served by a comprehensive, community-based TB project. But for those beyond the boundaries of our project, TB remains the scourge it has been for centuries. Just a month or so ago, Dominique reached the clinic in terrible shape,

gaunt and pale and bearded. I remarked that he looked somehow Christlike. Dominique could scarcely breathe. His chest film showed complete destruction of his left lung, even though he said he'd been sick "for only five months." He died shortly after starting therapy—collapsing in mid-sentence, as he spoke to his mother. The pain of starting therapy too late does not diminish with experience, I've learned. Nor did knowing that Dominique will be one of millions to die of tuberculosis lessen the pain. Had I still been on rifampin prophylaxis, I might have seen, just then, what orange tears look like.

Turning to the second prediction—that strains of TB resistant to rifampin and isoniazid, the most powerful antituberculous drugs, would spread—we do not need to turn to Russia or northern Lima, the "MDR-TB hot spots" mentioned in this book. Nor do we have to look to the latest global surveillance updates, which paint a grim picture of rising rates of drug resistance in these and other sites.[7] We see that this prediction has come true even in Haiti, a country with supposedly little in the way of MDR-TB, because rifampin was not routinely used there until recently. Since *Infections and Inequalities* was published, we built a TB referral hospital in central Haiti, and it is already full to bursting with young people with MDR-TB. They have been referred from all over the country, because other hospitals, including a few far better funded than our own, have decided that MDR-TB, like HIV disease, is too costly to treat. But MDR-TB, unlike HIV or Ebola, is airborne. So it does not take prophetic powers to predict that, if untreated, the disease will spread from family member to family member.

Take the Josephs, who might be termed a typical lower-middle-class Haitian family, if not for MDR-TB. They were a large family crowded into a small house in Carrefour Feuilles, a poor neighborhood in the sprawling city. Mme. Joseph sells wares in the streets of Port-au-Prince, the capital city; her husband is an irregularly employed construction worker. Although they live in poverty by any standard, theirs was a household in which it might be expected that all eight children would attend school; one or two of them might even be expected to find jobs.

One of their most talented children is Jean, in 1997 a twenty-one-year-old student. The way Jean recalls it, his family's problems began when he started to cough. At first he sought to treat his persistent hack

with herbal teas. But when his cough worsened, he began to think he might have something other than a banal cold. In the second month of his illness, with new back pain and a fever, Jean took himself to a TB hospital in Port-au-Prince. "It's not that I thought I had tuberculosis," he recalled recently, as we sat on a ledge in front of the new hospital. "Not at all. It's rather that I knew they could take a chest x-ray." But Jean did indeed have TB, and he was started that day on a four-drug regimen that included not only rifampin, but also streptomycin, a drug that is injected intramuscularly. "I took all my medications," he recalled anxiously, "but I kept coughing."

Toward the end of the year, Jean's fears were heightened by an episode of hemoptysis. Coughing up bright red blood terrified the young man, as it did his entire family. "I knew I was getting worse, so I went to a pulmonologist." The specialist wondered why streptomycin had been included in the initial regimen, since most rifampin-containing regimens do not include the injectable drug. He referred Jean to the national TB sanatorium in January 1998. There Jean was found to be floridly smear-positive—which means that there were many TB bacilli in his sputum—and admitted for further therapy.

Jean was an inpatient for almost three months, during which he received directly observed therapy with the same drugs he had received previously. He remained smear-positive throughout his time there. "I was discouraged; I wanted to stop [taking the medications]. I was sure these medicines wouldn't do anything for me, since I had taken them for over a year and been positive the whole time. I stopped taking them and went to an herbalist (*doktè fey*) for a few weeks." At the herbalist's, Jean was treated with various concoctions containing the bark and leaves of trees held, he said, to cure "tuberculosis and other lung disease." But Jean's symptoms persisted, and when he again began to cough up blood, he returned to the sanatorium. Again he was prescribed the same first-line drugs, including rifampin and isoniazid. During that time, he recalls, he was placed in an open ward with other patients, many of them, he knew, with drug-resistant disease. "None of them were getting better," Jean recounted. "They started talking about other medicines that were better, but they said that the government either didn't have the medicines or wasn't going to distribute them."

Those drugs—kanamycin, cycloserine, ethionamide, and ciprofloxacin—are far more expensive, more toxic, and less effective than are rifampin and isoniazid. Little reason, then, to take them—unless you have the misfortune to have MDR-TB. In that case, such "second-line" drugs often hold the only real hope of cure. Once Jean's parents had the names of the drugs and a prescription from one of the pulmonologists, they started selling off assets—furniture, livestock, a small parcel of land—to buy the medications. "I started taking [second-line] medicines inside the sanatorium, and I was soon [smear-]negative. In July, I went home. But after five months of treatment, my parents couldn't buy any more medicines, and so I had to stop. I became positive again."

Jean soon had fevers every night, and drenching sweats. He coughed incessantly, and lived in fear of hemoptysis (he'd learned during his sanatorium stay that this symptom could prove rapidly fatal). But the situation, Jean reports, was to become even worse. "Even though I had stopped coughing blood, my sister Maryse began coughing in about October, and then she started coughing up blood." One after another, the Joseph children became ill: after Maryse, the oldest, came Myrlene, who had for years suffered with sickle-cell anemia. Then came Kenol, the youngest. Finally, Shella started coughing.

And one by one the Joseph siblings began treatment with first-line drugs. None of them improved. "I felt terrible," Jean recalled wistfully. "I was getting sicker, but I mostly felt guilty. I just knew they had drug-resistant TB, and that's why they weren't getting better. I knew it was my fault."

Because the Joseph children did not get better on first-line drugs, the nurse who was administering their streptomycin injections referred them back to the nongovernmental organization that had originally diagnosed Jean with TB. "She knew we were failing therapy," recalled Jean, "and she knew it was MDR-TB. But she said the government could not buy the drugs for patients with MDR-TB, it could only buy first-line drugs. So she referred us to [the nongovernmental organization]." There, Jean was asked to submit a sputum sample for culture and drug-susceptibility testing. "I never got the results. I kept going back every couple of weeks, and they kept telling me to come back again in a couple of weeks."

Jean worsened. Recurrent hemoptysis and cough kept him sleepless and on edge. He woke up before dawn on those mornings he'd been lucky enough to sleep. He became wasted, gaunt. His sisters knew that Jean was deeply depressed. "He blamed himself for making us all sick," said Myrlene. "We tried to reason with him, but he didn't listen. He still blames himself."

But Jean didn't give up. "I had heard that there was one place in the country where we could be treated, and couldn't believe it. It seemed even more strange that it would be out in the middle of nowhere when the big hospitals in Port-au-Prince didn't have the medicines for anyone but people who could pay for them. So I came to see for myself."

In October 1999, Jean left for central Haiti in a crowded truck—what the Haitians call "public transport." He was coughing and short of breath, drawing the attention of the people among whom he was sandwiched. Once at the clinic, he did not speak to any of us involved in treating MDR-TB. "I just spent the morning looking around," he later recounted. He liked what he saw, evidently, because in November all of the Joseph siblings came to the Clinique Bon Sauveur and, following the requisite laboratory work, began therapy for MDR-TB. All became smear-negative within two months, and remain so after eight months of therapy.

I should add that the TB clinic does not charge for its services. What happens if diseases such as that afflicting the Joseph family are declared too expensive to treat? More honestly, since MDR-TB treatment is mandated by law in most affluent nations, what happens when people are declared too poor to treat? The cost to families of doing nothing—or, more commonly, of doing something ineffective or noxious, such as repeated courses of the wrong drugs—becomes painfully obvious from the case studies in the following chapters. It is clear that a single infectious family member can rapidly transform a cramped dwelling—or a prison cell—into a setting of daily bombardment with viable, drug-resistant bacilli. Universal infection can be expected in such households.[8]

But there are other costs to such double standards. One is the costs to caregivers: in settings throughout the world, we've met doctors and nurses who are highly uncomfortable—at times, distraught—about

lowering standards of care on the grounds of "cost-effectiveness." For example, the administration of ineffective first-line drugs or "isoniazid for life" to patients with documented MDR-TB is regarded by many as a violation of the social contract between patient and healer.[9] In the eyes of many within and without the medical profession, patients with MDR-TB have moral claims on all of those charged with treating the sick.

These patients also have claims on those charged with protecting the public health. Failure to treat patients with infectious MDR-TB means that drug-resistant strains will continue to spread. A number of positions regarding transmission of MDR-TB have emerged, but they are more ideological than evidence-based. Scarce resources and vested interests have led, as predicted in this book, to unrealistically confident claims regarding the spread of drug-resistant organisms. Slender evidence of "variable fitness" or "decreased infectiousness," inflated to suit the needs of the argument, has already engendered projections in which MDR-TB epidemics "burn themselves out" even if active cases are left untreated. When we ask to examine the data suggesting that drug-resistant strains are less readily transmitted than are drug-susceptible strains, we are steered to a small study from *rural* Mexico.[10] Meanwhile, ample evidence of MDR-TB's epidemic spread within slums and hospitals and prisons, reviewed in this book and elsewhere,[11] is discounted because so many of its victims were co-infected with HIV—as if the virus added wings to the bacterium. Such exercises would be merely wishful thinking if they did not lull us into complacency and lead to ill-conceived policies.

Failure to intervene effectively—to bring necessary resources to bear on the plagues of the poor—also undermines support for TB control and for public health in general. In setting after setting, patients like the Joseph children have remained untreated or have received regimens that could not cure them. In Peru, it has taken years to alter ineffective treatment policies—ineffective but formulated by international experts reluctant to reverse their position. In Russia, the situation—hinted at in this volume's footnotes—has gone from bad to worse. Again, substandard care—endorsed by international authorities—led to the use of the wrong drugs for the substantial fraction of patients with drug-

resistant disease. The result has been cure rates about half those registered in dirt-poor central Haiti.[12] But it doesn't much matter, it seems, if we got it wrong. Who's shedding tears over Russian prisoners? When the irrationality of improper recommendations was brought to public attention, it engendered mostly irritation, even anger. Humility has been in short supply among the experts; tears, of any color, absent. One suspects that some of the tears shed by the prisoners were orange for no good reason, since many of them were sick with strains of tuberculosis resistant to rifampin.

What, then, is to be done about MDR-TB in settings in which resources are scarce? Since *Infections and Inequalities* was written, this question has emerged as one of the new century's more important public-health dilemmas. Commentaries to date have been long on rhetoric and short on data. As predicted in chapter 2, vested interests have at times prevented clear analysis of the dynamics of emerging drug resistance. Indeed, ideological positions have at times led to confident claims unencumbered by evidence. At the same time, it has been possible to advance evidence-informed and novel strategies that promise to stop MDR-TB by bringing patients to cure. We have done so in an urban slum in Peru and in a squatter settlement in rural Haiti.[13] Successful expansion of these strategies will require global leadership from the World Health Organization and other bodies charged with formulating health policy.[14]

The justifications for such ambitious initiatives are many: the needs of those already sick, the prevention of ongoing transmission, and the rectification of previous clinical and policy errors. But perhaps the most compelling justification is to be found in considering the impact of differential standards of care for the poor. While the global era makes it increasingly difficult to live in ignorance of the suffering of others, it has not led to a more just partition of the fruits of science and technology. If we are to stay the ongoing spread of MDR-TB, global health equity must become a central component of TB-control policy in the coming years.

A similar message emerges as regards AIDS, as *Infections and Inequalities* tries to show. Forecasts were also made, in its first edition, regarding HIV. The spread of this novel pathogen has been at least as rapid as

predicted, and so has its concentration among the poor—at this writing, HIV incidence is declining in wealthy countries, and more than 95 percent of new infections occur in the developing world.[15] Close to 80 percent of cumulative AIDS deaths to date have occurred in Africa, the world's poorest continent.[16] I also predicted, in the last chapter of this book, that patients in rural Haiti would soon ask for the new antiviral "cocktails." Adeline Merçon did not ask for the medications, even though more than a decade of battle with HIV had worn her down to less than 80 pounds. Her father asked, instead, for money for a coffin: he could see, by November 1999, that Adeline wasn't going to last much longer. Instead of a coffin, however, we gave Adeline a three-drug cocktail of anti-HIV drugs. And between November 29, when she began therapy, and January 2000, she gained twenty-six pounds. Adeline is aware of the debates surrounding the use of these agents in what are euphemistically termed "resource-poor settings." She is now devoting her time to the HIV Equity Initiative based in our clinic, not far from her home village.[17] "If the drugs cost a lot, there must be a reason," she commented in a recent meeting. "Science made them, so science will have to find a way to get them to poor people, since we're the ones who have AIDS."

Attending international AIDS conferences might not bolster Adeline's optimism, since the logic of limited resources holds sway here. It is fitting, perhaps, that I am finishing this preface not in rural Haiti, but in Durban, South Africa. Outside, the XIII International Conference on AIDS is in full swing. The air in this lovely seaside city, which is prosperous compared to many, is rife with tension. And no wonder: globally, billions of dollars have been invested in AIDS prevention and treatment, but the epidemic marches on. AIDS-prevention efforts have failed in precisely those areas where they are needed most. No genuinely interested party could in all honesty deny this fact and others that bring us together in Durban:

- The increasing concentration of HIV among the poor and marginalized, most of them in the so-called developing countries.[18]
- The increasing concentration of wealth in the hands of the powerful, most of them in the industrialized nations.[19]
- The development, since the Vancouver AIDS conference ambi-

tiously titled "One World, One Hope," of new therapies that have transformed HIV from an inevitably lethal annihilation of cell-mediated immunity to a chronic illness.[20] But the benefits of these therapies are reserved for those in industrialized countries, where far fewer than 10 percent of those infected live.

- The failure of primary and, indeed, of secondary prevention, especially on this continent of Africa. In other words, not only have we failed to prevent HIV transmission, we have failed to prevent HIV progression in those already infected.[21]

As these trends become further entrenched, there has been a marked tendency to regard therapy as the province of the first world; in developing countries, we are encouraged to restrict our "AIDS-related activities" to prevention alone. Take, as an example, the world's largest pot of AIDS funding targeted to the developing world. The hundreds of millions of dollars disbursed by the U.S. Agency for International Development through Family Health International have until now gone almost exclusively for prevention, even though the efficacy of these interventions among the poor is difficult to demonstrate.[22] The exception more recently has been to fund palliative care (sometimes under the euphemism "community-based care") or low-cost prevention of certain opportunistic infections.

By this point, readers may conclude that I am making an attack on prevention or public-health approaches to HIV. Not true. I am calling instead for a redoubling of our efforts to improve prevention, including vaccine development, and even more effective educational tools. Prevention, however, will be most effective as part of a comprehensive plan to meet widespread demands for treatment and health equity in general. And it is high time to admit the limitations of existing prevention strategies.

Prevention is cheap, compared to therapy of already infected people. But what is the cost of focusing *solely* on prevention, given our current limitations? First, we fail to represent the aspirations of those already infected or sick. They will number, soon enough, more than 100 million.[23] This large number represents parents, farmers, doctors, teachers, factory workers—the very fabric of a society as we know it. Second, let-

ting HIV disease run its course in high-burden countries will mean—and has already meant—significant reductions in life expectancy, with many drastic social consequences, even if new infections were to cease immediately.[24] The number of AIDS orphans grows, with sober projections of 40 million orphans by 2010—on the continent of Africa alone.[25] Many children left to fend for themselves will eventually turn to sex work or crime, or perhaps become soldiers in some local conflicts. They will almost certainly live out their lives in poverty. And if little is done, they too are likely to die of AIDS, which is already killing ten times as many Africans as war.[26] Third, other diseases will emerge. Throughout sub-Saharan Africa and beyond, HIV is driving the frightening rise in TB incidence. The wealthy country of South Africa shows rates of TB two or three times higher than those registered in far poorer countries in which HIV is not a ranking problem.[27]

Fourth, by focusing solely on prevention, we fail to engage fully the medical and scientific community as partners in responding to this cataclysmic epidemic. The medical and scientific community finds itself unequipped to participate in the arena of primary and secondary prevention. By asking clinicians and bench scientists who wish to work in or on behalf of poor countries to put all of their weight behind "information, education, and communication," we are undermining the potential contribution of a highly skilled sector eager to help. This deprives us of sorely needed clinical and scientific abilities. Fifth, we fail to recognize that existing AIDS-prevention strategies have their limitations. The most eloquent rebuke to optimism regarding their efficacy is the rapidly rising HIV incidence in many nations. We are finally beginning to acknowledge this failure with honesty—fully twenty years into the epidemic. Health education alone does not suffice. In some settings, paradoxically, "the presence of health-education materials seemed to lead to *lower* frequency of condom use."[28] Notes a recent, candid review: "Somewhat surprisingly, towards the end of the second decade of the AIDS pandemic, we still have no good evidence that primary prevention works."[29]

Twenty years is a long time to wait for such candor. One of the reasons for this delay is that the social scientists who might have offered critical assessments in a more timely fashion were too busy scrambling

for their piece of the pie, as is argued in the chapters of this book. We undermine faith in medicine and public health whenever we make unreasonable, excessive, or propagandistic claims. Arguing, for example, that "education is the only vaccine" is neither accurate nor wise: since we cannot show that cognitive interventions have been highly effective in preventing HIV infection among the poor—the global risk group—it is surely unwise to rely *exclusively* on such methods.

Having staked these claims, allow me to make several assertions that spring from the argument that we must move beyond weak prevention programs to develop a global HIV strategy that encompasses meaningful prevention efforts and treatment of those already afflicted. It should be obvious that each of these assertions also holds true for drug-resistant tuberculosis.

1. Treatment cannot be regarded as solely the province of wealthy countries.

There are many reasons for this, some of which will be examined below. But here I will underline the painful fact that, as AIDS deaths drop in North America and Europe (a welcome trend relating to increasingly effective therapies),[30] they continue to climb in Africa and in most other settings in the world. By the end of this decade, more than 95 percent of all AIDS deaths will occur in resource-poor settings.[31] Good but prohibitively expensive therapies can only heighten this trend of concentration unless global health equity becomes more than a slogan.

How are we to respond? One of the first things we should do is listen to those infected with HIV. They are forty million strong and growing, and they are not telling us to concentrate all of our AIDS activities on prevention. They are not reminding us that antiretroviral therapy is not cost-effective. They are not arguing that costly therapeutic interventions are not "sustainable" in poor settings, not "appropriate technology" for low-tech areas of the globe. Often enough, they are saying just the contrary, because the destitute sick remind us that sacrosanct market mechanisms will not serve the interests of global health equity.[32] Show us the data to support the assertion, widespread in international financial institutions, that the neoliberal economic policies now in favor will *ever* serve the interests of those living, already, with HIV. Show us the data to suggest that declining HIV incidence—and declining AIDS

deaths—in wealthy countries will not be followed by decreasing investment in the basic research necessary for new drug and vaccine development. No such data exist. If they did, new antituberculous agents, also sorely needed, could not be termed "orphan drugs"[33]—a great irony, since TB remains, along with AIDS, the leading infectious cause of adult death in the world today.[34]

2. *Cost-effectiveness cannot become the sole gauge by which public-health interventions are judged.*

Market utilitarianism is a strange beast, since it seems to permit all sorts of inefficiencies as long as they benefit the right people—namely, the privileged. But if the goal is to heal or to ease the suffering of the destitute sick, we are asked to jump through hoops to finance what was once felt to be a public good. Show us the data to suggest that *any* costly interventions serving the destitute sick will find favor in a world in which corporate welfare goes unquestioned, but chiding rebukes follow the introduction of antiretroviral therapy to poor communities. But again, examples from tuberculosis highlight the weaknesses of cost-effectiveness argument in the arena of infectious disease: although rifampin causes orange tears, it is considered to be an integral part of "cost-effective" treatment of tuberculosis in developing countries. A couple of decades ago, however, an editorial in the *British Medical Journal* argued that the price of rifampin rendered its use "prohibitive in developing countries, certainly for routine treatment."[35] Confident claims about what is cost-effective and what is not should be viewed with some suspicion by those bent on providing quality care to the destitute sick.

3. *AIDS research in developing countries must include a social-justice component.*

It is clear that many in the community of researchers would just as soon ignore poor people's bitter criticisms of our program priorities. But what do we expect when we provide first-world diagnostics (viral-load and genomic testing, which are used to contribute to data collection) and third-world therapeutics (treatment of certain opportunistic infections or sexually transmitted diseases only, leaving HIV to progress unhindered) within the same research project? It sounds as if poor people are excellent lab rats but unlikely patients. If the press for cheaper—or

even free—medications for HIV has had resonance, it's surely because something inside all of us recognizes the fundamental unfairness of this situation. Asking the destitute sick to wait for research to pay off is also unfair. The need for reciprocity is widely acknowledged in international public health, but it rings hollow to call people to participate in research for the greater good when the poor will rarely benefit from research outcomes.

Besides, people sick with AIDS need effective treatment now, and there are more and more of them. Which groups have led this charge? Not, alas, the international health experts and responsible officials, but rather the AIDS activists and the nongovernmental organizations.[36] The fundamentally remediative nature of their work is more appropriate to this problem because it addresses widespread demands for *social justice*. If we're embarrassed by this term, then perhaps we should invent another. But show us the data to justify an absence of social-justice initiatives in even the most basic research, a dimension that must be built into all human research that involves drawing blood—or sweat or tears—from the destitute sick.

4. We need more effective prevention strategies.

The countless Knowledge, Attitudes, and Practices surveys and AIDS educational interventions derived from them have not achieved their aim, and to say so is not to object to AIDS education. Not at all. Educating everyone, and especially the young, is our civic duty, part of being human. But show us the data to suggest that, in settings where *social conditions* determine risk for HIV infection, cognitive exercises can fundamentally alter risk. We know that risk of acquiring HIV does not depend on knowledge of how the virus is transmitted, but rather on the freedom to make decisions. Poverty is the great limiting factor of freedom. Indeed, gender inequality and poverty are far more important contributors to HIV risk than is ignorance of modes of transmission or "cultural beliefs" about HIV.[37] We can already show that many who acquire HIV infection do so *in spite of* knowing enough information to protect themselves, if indeed cognitive concerns were ever central to preventing HIV among the poor. Until we have effective, female-controlled prevention, whether a microbicide or another, and an effec-

tive vaccine, nothing we do should suggest that education can substitute for, or remove the necessity of, effective therapy for AIDS. These truths are just now beginning to be acknowledged, and they are late in coming.[38]

5. We can no longer accept whatever we are told about "limited resources."

We keep hearing that we live in "a time of limited resources." But how often do physicians, anthropologists, and other researchers, or public-health specialists challenge this slogan? The wealth of the world has not dried up; it has simply become unavailable to those who need it most. Show us the data to prove that there are fewer resources than in previous decades, when we did *not* have effective therapies for many diseases. The struggle for social and economic rights for the poor must become central to every aspect of AIDS research and treatment.

Our challenge, therefore, is not merely to draw attention to the widening outcome gap, but also to attack it, to dissect it, and to work with all our capacity to reduce this gap. One way to do this is to let it be known that the community of those concerned with preventing and treating HIV—and with making common cause with the sick—is not willing to stand by idly as wealth becomes ever more concentrated. Even a doctor without formal economic training soon starts to wonder if the neoliberal agenda of the international financial institutions might be driving up HIV risks even as these institutions slap the hands of those who dare to treat the destitute sick.[39]

Another challenge is to "harmonize" a global research and treatment ethic rather than to maintain the pretense that rich and poor live in two different worlds. There is no wall between the worlds, as any honest assessment of either microbial traffic or capital flows will show. Our imperative is to develop treatment components for all research or prevention programs that involve HIV testing. As Wood and colleagues note, even "limited use of antiretrovirals could have an immediate and substantial impact on South Africa's AIDS epidemic."[40]

To unite treatment and research in this way, we need drugs, diagnostics, and increased investment in health infrastructures. We need to forge novel alliances. We need to have easier access to drugs, especially those developed with public funds.[41]

Finally, we also need pilot projects to pioneer the use of antiretroviral therapy in settings with a heavy burden of HIV but without laboratories capable of performing CD_4 counts or viral loads. We need to think ahead, to pioneer the use of new agents where they are needed most. On the basis of our experience of developing directly observed therapy for tuberculosis, we have developed such a program in one of the poorest parts of rural Haiti, the poorest country in the Western hemisphere. We are using three-drug regimens that are little more complicated than short-course chemotherapy for TB; other, simpler regimens will soon be available.[42] Our HIV Equity Initiative in rural Haiti has not replaced our prevention efforts. Rather, it has helped to revive them. At this juncture, facing catastrophe in Africa and beyond, we are asked to choose between treatment and prevention. But we cannot make this choice. We remain squarely behind efforts to prevent transmission—from vaccine trials to improved educational interventions—but believe that prevention and treatment are intimately linked. They belong together as planks of a single platform to halt AIDS.

So why is treatment *not* central to AIDS policy in resource-poor settings? Because we're told it's "not sustainable." Why? It costs too much. And why is that? To answer this question, we'd need to look at the manufacture and sale of pharmaceuticals—an industry that, as noted, has consistently had among the highest margins of profit.[43] "The pharmaceutical industry," observes Angell in a recent editorial, "is extraordinarily privileged. It benefits from publicly funded research, government-granted patents, and large tax breaks, and it reaps lavish profits. For these reasons, and because it makes products of vital importance to the public health, it should be accountable not only to its shareholders, but also to society at large."[44] A uniform ethic should become a condition for entry into any national and international marketplace, so that publicly funded research is not siphoned away for private gain or handicapped for the benefit of private-sector companies. A call for this uniform ethic has generated fear among pharmaceutical companies, leading some of them to avoid working with scientists who are funded by government agencies such as the National Institutes of Health.[45] These companies are aware that antiretrovirals manufactured without recourse to publicly funded research would be further sheltered from

legislation attempting, however timidly, to make public research lead to public good.[46]

What, then, is not sustainable? It is not the cost of HIV treatment that is not sustainable; it's rather the opposition to treatment in high-burden areas that is not sustainable. It's not morally sustainable, it's not intellectually sustainable, it's not epidemiologically or socially sustainable.

If unequal standards are to be accepted as a fact of life, then why do I feel uncomfortable that, to do summer research projects in places like this one, medical students from Harvard, say, are now required to travel with doses of "triple therapy" on the off chance that they *might* be exposed to HIV? Why do I feel uncomfortable that researchers from the same institutions dismiss as "utopian" the possibility of treatment for locals who are *already sick*? How sustainable is that?

It's my hope that *Infections and Inequalities* might serve a pragmatic end by calling into question these and other logics that promise a future in which health equity will play a shrinking role. Only by struggling for higher standards for the destitute sick will we avoid another unappealing role—that of academic Cassandras who prophesy the coming plagues, but do little to avert them. Then will come the time for more universal tears, whether orange or clear, whether scant or copious. In the interim, shoring up double standards for the poor will be identified most closely with the shedding of crocodile tears.

Durban, South Africa
July 11, 2000

NOTES

1. Special thanks to Jen Singler, David Walton, Gilles Peress, Haun Saussy, and Joia Mukherjee for their contributions to this preface.

2. In an overview of anthrax public-health management, Inglesby and colleagues note that, although it is believed that "at least 17 nations have offensive biological weapons programs . . . it is uncertain how many are working with anthrax" (Inglesby, Henderson, Bartlett, et al. 1999, p. 1736). Furthermore, continues the overview, most experts agree that most groups lack the technology and funding necessary to "manufacture" anthrax. And yet officialdom seems to fan such fears: discussions of possible bioterrorist attacks include preparations for both civilian and military preparedness (Fidler 1999). The level of panic and lack of knowledge about the dangers posed by such attacks are both marked. For example, a hospital in Florida was closed recently while doctors examined several local airport baggage holders for possible anthrax exposure, suspected after the workers handled a box from Puerto Rico containing animal skins. Although none of the individuals showed signs of exposure, and an infectious-disease specialist noted that risk of exposure was extremely low, the hospital was effectively sealed off for several hours ("Anthrax Scare Shuts Hospital in Florida," *Boston Globe*, June 21, 2000, p. A13). The lead story in the "Health, Education & Science" section of *USA Today* announces that "new foam defeats biological weapons." "A government task force has unleashed its latest weapon in the fight against bioterrorism," a chemical foam that can "neutralize," among other substances, "anthrax, a pathogen widely recognized for its ease of production and mobility." Fortunately, the foam "will be available for about $10 per gallon as soon as commercial partners sign on" (*USA Today*, June 29, 2000, p. 9D).

3. During the 1999 surge in funding for antibioterrorism efforts, John Hopkins University opened a center devoted to the subject, infused with a $150 million "emergency" appropriation allocated from Congress. The center sponsored a packed conference on the subject, where researchers issued dire warnings and "reviewed frightening scenarios" of hypothetical bioterrorist attacks (Marshall 1999, p. 1234). For reviews of recent bioterrorism efforts and concerns, see Centers for Disease Control and Prevention 2000; Fidler 1999; Fox 1999; Kaufmann, Meltzer, and Schmid 1997; Leggiadro 2000.

4. Clinton 1999.

5. Cohen, Sidel, Gould 2000, p. 1211.

6. A Central Intelligence Agency report released earlier this year warned of the threat posed by infectious diseases and biological warfare to U.S. security and interests abroad (Central Intelligence Agency 2000), and in remarks before Congress, a leading National Intelligence Council official warned that infectious diseases such as tuberculosis, malaria, and pneumonia pose a threat to U.S. security and will continue in the coming decades to harm economic and social

development in those countries in which the United States has vested interests (Tang 2000). See Henry and Farmer 1999 for an exploration of emerging infectious diseases and "national security concerns." A more thorough exploration of the topic is found in our complete paper, which is posted at http://www.sidint.org/new/globalization/presentation.htm.

7. Program in Infectious Disease and Social Change 1999; World Health Organization 2000a.

8. Although today's short-memoried epidemiologists will not be quick to point out that we have no data suggesting that universal infection will ensue, they forget that people like the Joseph family—who were receiving what amounts to no effective therapy for their tuberculosis—are in effect transported back to the preantibiotic era. There one finds ample evidence of universal infection when a household contains an untreated, coughing tuberculosis patient. For example, when, in 1936 Long and Hetherington surveyed 530 Native Americans in southern Arizona, they found that, although only 20 percent of children under five were tuberculin-positive, by the time study participants reached adulthood, 100 percent had evidence of true infection. The authors also note that infection rates among Native Americans at boarding school were lower than those documented at day schools, which they argued again suggested the role of infection within households with high rates of active tuberculosis (Long and Hetherington 1936). Even in the postantibiotic era, failure to identify and remove an active tuberculosis case leads to new infections. One Canadian study carried out in the late 1960s found household infection rates ranging from 29 percent to 61 percent for those households with a smear-positive tuberculosis case (see commentary in Rouillon, Perdrizet, and Parrot 1976).

9. I have discussed the use of substandard and frankly deleterious care among the destitute sick throughout this book, but it is discussed as a human-rights violation in Farmer 1999c. *Pathologies of Power: Structural Violence and the Assault on Human Rights*, is due from the University of California Press in 2001.

10. García-García, Ponce-de-León, Jiménez-Corona, et al. 2000. Note that I believe this to be a very important paper. What I question is its relevance to modeling the future of epidemics of drug-resistant tuberculosis, which are seated not in rural regions, but rather in prisons, slums, and, ironically enough, health-care institutions.

11. For a discussion of the problem of multidrug-resistant tuberculosis in prisons in the United States and Russia, see Farmer 1999; Coninx, Mathieu, Debacker, et al. 1999; Portaels, Rigouts, and Bastian 1999. The edited volume *Sentenced to Die? The Problem of TB in Prisons in East and Central Europe and Central Asia* (Stern 1999) also highlights the increasing spread of TB in prisons in the former Soviet Union, as do reviews in *The Global Impact of Drug-Resistant Tuberculosis* (Farmer, Kononets, Borisov, et al. 1999; Mitnick and Farmer 1999).

12. Kimerling, Kluge, Vezhnina, et al. 1999; see also Farmer, 1999b.

13. Farmer and Kim 1998; Farmer, Furin, and Shin 2000; Farmer, Kim, Mitnick, et al. 1999; Farmer, Shin, Bayona, et al. 2000.

14. Iseman 1998; Farmer, Becerra, and Kim 1999.

15. An estimated 5.4 million people were infected with HIV during the course of 1999—4 million in sub-Saharan Africa, 800,000 in Southeast Asia, and 210,000 in Latin America and the Caribbean (Joint United Nations Programme on HIV/AIDS 2000). We have attempted to explore the dynamics of HIV's rapid concentration among the poor in Farmer, Walton, and Furin 2000.

16. Of the 18.8 million HIV/AIDS deaths registered globally from the beginning of the epidemic through the end of 1999, 14.8 million have been in sub-Saharan Africa (Joint United Nations Programme on HIV/AIDS 2000).

17. Any author's royalties for this volume will be contributed directly to Zanmi Lasante's HIV Equity Initiative.

18. Joint United Nations Programme on HIV/AIDS 2000.

19. The mechanisms of growing economic inequality, and its effect on the health of the world's poor, is explored in *Dying for Growth: Global Inequality and the Health of the Poor* (Kim, Millen, Irwin, and Gershman 2000).

20. Fauci 1999; Cohen and Fauci 1998. With the advent of more effective therapies, AIDS mortality has dropped precipitously since the late 1990s in industrialized nations such as the United States (See Centers for Disease Control and Prevention 1999).

21. Farmer and Walton 2000.

22. "AIDSCAP interventions were built on three strategies for reducing HIV transmission: communication to encourage people to avoid behaviors that put people at risk of infection, improving treatment and prevention of other sexually transmitted diseases (STDs), and increasing access to and correct use of condoms. These central technical strategies were supported by policy development, behavioral research, evaluation, gender initiatives and capacity building" (Family Health International 1997). There have been calls to expand the FHI portfolio to include treatment, and an "HIV care coordinator" was recently appointed (Eric von Praag, personal communication).

23. Do the math. As of the end of 1999, an estimated 34.3 million adults and children were infected with the HIV virus; 1999 alone saw 5.4 million infections, at a rate of 15,000 new infections per day (Joint United Nations Programme on HIV/AIDS 2000).

24. The latest projections are staggering: in Botswana, where an estimated 36 percent of adults is infected with HIV, impressive gains in life expectancy over the past forty years have been dramatically reversed in the past decade: life expectancy had plummeted to 47.4 years by 1997, a 14 percent drop compared to 1975 (United Nations Development Programme 1999). In countries with adult HIV prevalence rates of 15 percent and above, current projections suggest that more than one-third of boys now aged fifteen will die of AIDS; in even harder-

hit countries, such as those in southern Africa, this proportion may exceed two-thirds (Joint United Nations Programme on HIV/AIDS 2000). See also Boerma, Nunn, and Whitworth 1998; Stover and Way 1998.

25. International Federation of Red Cross and Red Crescent Societies 2000. Global estimates for the end of 1999 put the number of AIDS orphans since the beginning of the epidemic at 13.2 million, with over 90 percent of these children living in sub-Saharan Africa (see Joint United Nations Programme on HIV/AIDS 2000).

26. In 1998, 200,000 Africans died in war, while more than two million died of AIDS (Joint United Nations Programme on HIV/AIDS 2000).

27. Relatively prosperous South Africa has one of the highest rates of HIV infection in the world. In 1998, the TB case notification rate was 326 per 100,000 population (World Health Organization 2000a); true incidence is estimated at over 500 per 100,000 population (Weyer, Fourie, and Nardell 1999). In contrast, poorer Senegal, where 1.77 percent of the adult population is HIV-positive, had a TB case notification rate in 1998 of 94 per 100,000 population (Joint United Nations Programme on HIV/AIDS 2000; World Health Organization 2000b).

28. Egger, Pauw, Lopatatzidis, et al. 2000, p. 2103; emphasis added.

29. Mayaud, Hawkes, and Mabey 1998, p. S31.

30. Moore and Chaisson 1999; Palella, Delaney, Moorman, et al. 1998; Mocroft, Vella, Benfield, et al. 1998.

31. Joint United Nations Programme on HIV/AIDS 2000.

32. The market fails when it comes to research and development—in the case of tuberculosis, for example, the last novel treatment was developed more than thirty years ago (t'Hoen 2000). Over the past two decades (1975–1996), less than 1 percent of more than 1,200 new molecular entities sold worldwide were earmarked for tropical diseases (Trouiller and Olliaro, 1999)—this despite the fact that infectious diseases remain a major cause of mortality throughout the world: in 1998, infectious diseases accounted for 25 percent of deaths worldwide and 45 percent of deaths in low-income countries (World Health Organization 1999). One candid review of drug development notes that "few developments are need-driven"—the average cost of bringing a new drug to market is approximately $224 million, costs that pharmaceutical companies argue would not be recouped for diseases endemic in poor countries with few resources and no property rights laws to prohibit far cheaper generic products from entering the market (Trouiller and Olliaro 1999, p. 164).

33. An orphan drug is defined under the U.S. Orphan Drug Act (1983) as one that affects fewer than 200,000 individuals in the United States and would not recoup development costs for domestic sales (Anonymous 1995). For more information on the Orphan Drug Act, see Asbury 1992.

34. Dye, Scheele, Dolin, et al. 1999; World Health Organization, 2000b; Joint United Nations Programme on HIV/AIDS 2000.

35. Anonymous 1973.

36. Organizations such as Médecins Sans Frontières have been at the forefront of the movement to gain equal access to effective therapies for the poor (t'Hoen 2000). One MSF spokesman argued recently, "The global HIV/AIDS-crisis has provided us with a magnifying glass under which the inequity in access to treatment became painfully clear. . . . Medicines cannot be treated as mere commodities. Often access to medicines is a question of life and death. Yet in international trade they are regulated very much the same as any other consumer good" (t'Hoen 2000).

37. For a review of the data supporting this claim, see Farmer, Connors, and Simmons 1996, which reviews more than a thousand studies and papers relevant to both HIV transmission and disease progression among women.

38. "Failure to use STD and HIV incidence as the outcome measure constitutes a major weakness in the behavioural-intervention area. Another important weakness is our failure to evaluate basic social structural interventions. We cannot know the effectiveness of interventions that have not been addressed. There is overwhelming evidence that oppression contributes to STDs and many other maladies" (Aral and Peterman 1998, p. S35). In a randomized control trial of more than twelve thousand adults in Tanzania assessing the effect of treating STDs as a means of preventing HIV transmission, Gilson and colleagues found that treating STDs reduced transmission of HIV-1 by about 40 percent. They conclude, "From a societal standpoint, therefore, the cost of the intervention is likely to be substantially less than the cost of not intervening" (Gilson, Mkanje, Grosskurth, et al. 1997, p. 1808).

39. Lurie, Hintzen, and Lowe 1995.

40. Wood, Braitstein, Montaner, et al. 2000, p. 2095. One model of the effect of antiretroviral use on the AIDS epidemic in South Africa projected that the use of short-course prophylaxis would reduce perinatal transmission by 40 percent, preventing 110,000 infant HIV infections by 2005—at a cost of less than 0.001 percent of the per-person health expenditure. In a more costly scenario, triple-combination treatment for merely 25 percent of the HIV-1 positive population would prevent both 430,000 incident AIDS cases and a 3.1-year decline in life expectancy (Wood, Braitstein, Montaner, et al. 2000).

41. For example, AZT and to a lesser extent 3TC have been developed with federal research dollars. See also comments in t'Hoen 2000.

42. Within months we will have a triple nucleoside RT inhibitor pill—AZT, 3TC and abacavir, the most potent NRTI. Such a fixed-dose combination would be easier to use and would preserve both protease inhibitors and nonnucleosides for cases of resistance. Using a nonnucleoside (e.g., nevirapine) in a three-drug regimen may be more risky than using a protease inhibitor because a single mutation confers resistance to the entire class of drugs as opposed to resistance to nucleoside analogs and protease inhibitors in which it takes multiple mutations to confer clinically meaningful resistance. (For more on readily-induced nevirapine resistance, see Becker-Pergola, Guay, Mmiro, et al. 2000.)

43. According to a report in *Fortune* magazine, in 1999 the pharmaceutical industry far exceeded all other U.S. industries in its profit margin, realizing on average an 18.6 percent return on revenues; second was commercial banking, at 15.8 percent, while other industries ranged from 0.5 percent to 12.1 percent ("How the Industries Stack Up," *Fortune*, April 17, 2000). Noting that the top ten drug companies have a 30 percent profit margin, Angell (2000, p. 1903) pointedly states, "An industry whose profits outstrip not only those of every other industry in the United States, but often its own research and development costs, simply cannot be considered very risky."

44. Angell 2000, p. 1904.

45. In a recent article in the *New York Times*, one drug-company spokesman underscored this point quite candidly: "The industry has never been philanthropic. It has always produced products with an aim to getting a return on investment" (McNeil 2000, p. 1). Some investigators charge that drug companies have stopped funding clinically important studies because of concerns that possible study results could reduce sales of the drug (Bodenheimer 2000).

46. The Bayh-Dole Act, for example.

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Acknowledgments

The writing of any book incurs obligations to friends and colleagues. Because the essays presented in this book were written about the sick, however, my greatest debt is to patients and informants, two overlapping groups. Caring for persons with HIV disease and tuberculosis has been my greatest privilege; failing to avert unnecessary deaths, such as those of Annette Jean and others described in these pages, remains my greatest regret.

Most of my patients and informants live—or have died—in poverty. Perhaps as a point of order, I'd like to respond to the question, Who are "the poor"? The objectification of the poor is, of course, a risk run by anyone who employs some sort of class analysis, and I will be specific in these essays whenever possible. At the same time, I'm not skittish about using the term: striving to understand a commonality of constraint is hardly tantamount to denying the salience of personal experience. I've been impressed, in my work in Haiti and Peru, at how often people use the label "the poor" to describe themselves. These people do not share nationality or gender or language or culture; they share only their relative

social positioning at the bottom of the ladder. And it is these people who have endured the sicknesses described in this book.

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Three community-based organizations—Partners in Health, Zanmi Lasante, and Socios en Salud—serve as the settings in which these patients' infections have been diagnosed and treated. Situated respectively in Cambridge, Massachusetts, in Haiti's Central Plateau, and in urban

Peru, these organizations (which I describe in greater detail in Chapter 1) are the tools with which we are able to intervene to prevent the embodiment of inequalities as pathologies or, failing that, to treat the pathologies. In this work, I'm most indebted to Tom White, Jim Yong Kim, and Ophelia Dahl, similarly obsessed with addressing the inequalities documented in this book. They are, most often, the other constituents of the "we" in these chapters. Colleagues and friends (happily, another overlapping group) in each of these organizations have made this work possible. Special and loving thanks are owed to Fritz and Yolande Lafontant and to Marie Flore Chipps. *Mesi anpil.* For coffee and encouragement and wise steering, I thank Jésula Pierre and Loune Viaud; for her ability to produce misplaced documents at midnight, I thank Anne Hyson. Special thanks to Jaime Bayona and the "TB team" in Peru, who have weathered the controversies born of our advocacy for those with tuberculosis, and to Jack Roussin, who paid the ultimate price for his own commitment to the poor.

Didi Bertrand deserves a thank-you paragraph all her own.

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collaboration over the years. It was Stan who encouraged me to enlarge the scope of this book, to move from the specific case—AIDS and tuberculosis in Haiti—to some of the more general questions raised both by my work and by the emergence or reemergence of modern plagues. Further, it was Stan who encouraged me to incorporate some of the indignation that any physician feels when people die of readily treatable afflictions. What place, in scholarship, for passion? Is it truly "neutral" to remain dispassionate before unnecessary suffering? Or is such studied neutrality really a concession to the inevitability of inequalities of outcome?

One model of passionate engagement in the struggle to prevent unnecessary suffering died tragically as this book was going to press. Jonathan Mann was a staunch supporter of the organizations described in Chapter 1. We will miss him sorely.

Finally, I'm pleased to acknowledge a deep debt to Haun Saussy. For almost twenty years, we've been engaged in what might seem to be altogether unrelated endeavors. But Haun has taught me that being a critical reader of Chinese literature is not unrelated to being a critical reader of medical anthropology—or of any other discipline. This book is dedicated to Haun in celebration of a long and warm and instructive friendship.

Introduction

Medical statistics will be our standard of measurement: we will weigh life for life and see where the dead lie thicker, among the workers or among the privileged.

RUDOLF VIRCHOW, *1848*

WHAT KILLED ANNETTE JEAN?

Early on the morning of her death, Annette Jean was feeling well enough to fetch a heavy bucket of water from a spring not far from her family's hut. In the weeks prior to that day, she had been complaining of a "cold." It was not serious, she thought, although night sweats and a loss of appetite were beginning to trouble her. Annette's brothers later recalled that she was cheerful, "normal," that morning. She made everyone coffee and helped her mother load up the donkey for market. It was an overcast day in October of 1994, and Haiti's rainy season was drawing to a close.

Shortly after Annette's brothers left for their garden, the young woman abruptly began coughing up blood. A young cousin, watching from across the yard, saw her throw off a bright red arc and then collapse on the dirt floor of the tiny house. The child ran for Annette's three brothers,

who tried in vain to rouse her; the young woman could do no more than gurgle in response to their panicked cries. The brothers then hastily confected a stretcher from sheets and saplings. It would take them more than an hour, carrying their inert sister, to reach the nearest clinic, situated in the village of Do Kay far below their mountaintop garden.

Halfway there, it began to rain. The steep path became slippery, further impeding progress. Two-thirds of the way there, Annette coughed up clots of darker blood and then stopped gurgling. By the time they reached the clinic, it was raining heavily. The larger clots refused to melt, hardening on her soaked shirt, and Annette was motionless in a puddle of diluted blood. She was not yet twenty years old.

I was in the clinic on that rainy day, conversing with a patient near the building's main entrance when the Jean brothers and a fourth man passed into the clinic's courtyard with their terrible cargo. A single rivulet of blood was falling from somewhere under the stretcher onto the paved courtyard. They approached me wordlessly, and I, also silent, reached for the young woman's wrist. It was an easy, joyless diagnosis—death from massive hemoptysis due, almost certainly in a woman her age, to tuberculosis—and Annette was already cold. Her brothers, who had been numbed into silence by the hope that something might still be done, began wailing, each taking up in turn a shrill cry of grief as I pronounced her dead.

One of the women from Do Kay had been mopping the floor of the clinic, but she had stopped to stare. When the men began to weep, she lifted her apron to her eyes and turned away. She had never met Annette Jean or her brothers, but she had seen plenty of tuberculosis. Her own sister, the mother of five children, had died of the same disease in October of 1988. One of those children also died years later from complications of tuberculosis, but not before going stone deaf from one of the medications used to treat it.

I had seen a lot of tuberculosis, too, even though the little clinic in Do Kay was built to serve only a tiny region of the Central Plateau. In 1993 alone, we had diagnosed over four hundred cases of tuberculosis, more than were registered in the entire state of Massachusetts that same year. Diagnosing tuberculosis is something I expect to do on a daily basis. But I too was shaken by the blood, the rain, and by the brothers' sharp grief.

The story does not end with Annette's dramatic agony. Another sister, I learned, had also succumbed to tuberculosis. And a few months after Annette's death, one of her brothers, Marcelin, returned to the clinic with a case of shingles (herpes zoster). From our interview I soon learned that he—like Annette, the child of a peasant family—had been working as a servant in Port-au-Prince, Haiti's capital city. This employment history in a person with herpes zoster has come to suggest, for many of us, early HIV disease, a suspicion confirmed in Marcelin's case by a laboratory test. Although, unlike his sisters, Marcelin was fortunate enough to receive treatment for the active tuberculosis that he later developed, he has told his family that he will die.

I could tell that Annette's family did not—*could* not—comprehend why they should be so unfortunate. To lose two young, previously healthy members of a close-knit family seemed both insufferable and unfair; so did Marcelin's illness. But their incomprehension eventually gave way first to hypotheses and then to conclusions. They were the victims of sorcery, they surmised. Someone had it in for them, and that someone was likely to be another villager.

After a decade of medical practice in the same village, I was accustomed to ferreting out accusations of sorcery and had previously spent some years trying to make sense of them.[1] And that, paradoxically, is the primary function of such accusations: to make sense of suffering. The anthropologist within me is perfectly satisfied to analyze such explanations, but to a physician it is nothing less than punishing to see preventable or treatable pathologies chalked up to village-level squabbles.

The doctor in me insists that no one should die of tuberculosis today; it's completely curable. Yet it is, at the same time, the world's leading infectious cause of death among young adults. An estimated three million people are dying each year from tuberculosis.[2] This figure comes as a surprise to many, who read more frequently in their newspapers about Ebola or "flesh-eating bacteria" than about tuberculosis. Exacting its toll among the world's poor, tuberculosis has ceased to occasion much interest, either in scientific circles or in the popular press. Barry Bloom puts it even more strongly: tuberculosis, he writes, "has been virtually ignored for 20 years and more."[3]

Many are also surprised to learn that infectious diseases remain the world's single most common cause of death. In 1995, for example, a year

in which an estimated 52 million people died worldwide, about 17.3 million of these deaths were due to bacterial, viral, or parasitic infections.[4] And although the majority of deaths occurred in the developing world, infectious diseases also remain a major killer of the U.S. poor. One study of New York City welfare recipients revealed staggeringly high rates of tuberculosis and AIDS: of 858 clients enrolled in 1984, 47 developed tuberculosis and 84 were diagnosed with AIDS. The study thus revealed tuberculosis and AIDS incidence rates well in excess of those found in many poor countries and seventy times higher than the U.S. national rate. In fact, simply being on welfare and having a history of drug or alcohol abuse were strongly associated with death: fully 183 clients—21.3 percent of the cohort—died within eight years. The mean age at death was less than fifty years.[5]

INFECTIONS AND INEQUALITIES

Amartya Sen has observed that the first question in any critical examination of equality is "equality of *what?*"[6] This book examines inequalities in the distribution and outcome of infectious diseases. It asks why people like Annette Jean and her siblings are likely to die of infections such as tuberculosis and AIDS and malaria, while others are spared this risk. It explores the creation and maintenance of such disparities, which are biological in their expression but are largely socially determined. This book also explores social responses to infectious diseases, responses ranging from quarantine to accusations of sorcery.

This exploration leads me to examine various, often discrepant explanations for these disparities of risk and outcome, including those proffered by officialdom and by academics. I argue that scholars often weaken their contributions to an understanding of infectious diseases by making "immodest claims of causality" regarding the distribution and course of these disorders. These claims are immodest because they are wrong or misleading. They are immodest because they distract attention from the modest interventions that could treat and, often enough, cure people like Annette Jean. And they are immodest because they distract attention from the preventable social disorder that exacerbates biological disorders.

Anthropology / Sociology / Medicine

"*Infections and Inequalities* does not mistake dispassionate for neutral. Its passages are unapologetically passionate—and so they should be—but well reasoned. Farmer melds the proximity of a caring physician with the reach of rigorous scientific analysis. . . . His analysis sharpens our understanding of how we must tackle the roots of health inequity. *Infections and Inequalities* deserves a place on the turn-of-the-millennium bookshelf."

The Lancet

"The strength of this book is the combination of the author's trenchant analysis, his undoubted academic credentials and his front-line experience as clinician and anthropologist. When economists tell us that a human life is less valuable in a poor country than in a rich one, we must acknowledge that those of us in the rich world certainly behave as if this is so. . . . It is recommended reading for all concerned with applying medical science to improve the lot of humanity."

Michael Marmot, *Nature Medicine*

"This book is a tour-de-force that reaches beyond traditional audiences and presents a strong argument for the significance of anthropology in confronting poverty and disease. In this personal, passionate, professional autobiography, Farmer revisits and reargues his work on Haiti and health and, in the process, reviews many concepts such as structural violence, cultural difference, and pragmatic solidarity, which he invests with insights into their development and use. Students will find the book inspiring and tremendously informative, and many will undoubtedly want to emulate the career described in it."

Medical Anthropology Quarterly

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