

Infections and Inequalities

THE MODERN PLAGUES

PAUL FARMER

UNIVERSITY OF CALIFORNIA PRESS
Berkeley Los Angeles London

Material included in Chapters 2, 3, 4, 6, and 9 has been adapted from earlier work by the author, which appeared in the following publications: "Social Inequalities and Emerging Infectious Diseases," *Emerging Infectious Diseases* 2, no. 4 (1996): 259-69; "Women, Poverty, and AIDS—An Introduction," in *Women, Poverty, and AIDS: Sex, Drugs, and Structural Violence*, edited by P. E. Farmer, M. Connors, and J. Simmons (Monroe, Maine: Common Courage Press, 1996); "The Exotic and the Mundane: Human Immunodeficiency Virus in Haiti," *Human Nature* 1, no. 4 (1990): 415-46; "Sending Sickness: Sorcery, Politics, and Changing Concepts of AIDS in Rural Haiti," *Medical Anthropology Quarterly* 4, no. 1 (1990): 6-27; and "Social Scientists and the New Tuberculosis," *Social Science and Medicine* 44, no. 3 (1997): 347-58.

University of California Press
Berkeley and Los Angeles, California

University of California Press, Ltd.
London, England

First paperback printing 2001

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Library of Congress Cataloging-in-Publication Data
Farmer, Paul, 1959-

Infections and inequalities : the modern plagues / Paul Farmer.
p. cm.

Includes bibliographic references (p.) and index.

ISBN 0-520-22913-4 (pbk. : alk. paper)

1. Poor—Health and hygiene. 2. Socially handicapped—Health and hygiene. 3. Communicable diseases—Social aspects. I. Title.

RA418.5.P6F37 1998

306.4'61—DC21

98-23807

Printed in the United States of America

09 08 07 06 05 04 03 02 01

9 8 7 6 5 4 3 2 1

The paper used in this publication meets the minimum requirements of ANSI/NISO
Z39.48-1992 (R 1997) (*Permanence of Paper*). ∞

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7 The Consumption of the Poor

TUBERCULOSIS IN THE LATE TWENTIETH CENTURY

Like the philosopher's stone, a cure for
consumption will continue, we apprehend,
to be a desideratum for ages yet to come.

*Boston Medical and Surgical
Journal, 1843*

In 1995, more people died of TB than in any
other year in history. At least thirty million
people will die from tuberculosis in the next
ten years if current trends continue. Millions
more will watch helplessly as friends and
family members waste away, racked with
coughing and sweating with fever. They may
wish that medical science could cure this
terrible disease. The truth is, medical science
can. Since 1952, the world has had effective
and powerful drugs that could make every
single TB patient well again.

WORLD HEALTH
ORGANIZATION, 1996

BACK WITH A VENGEANCE?

The World Health Organization recently announced that in 1996 alone some three million persons died of tuberculosis.¹ Not since the turn of the century, when tuberculosis was the leading cause of young adult deaths in most U.S. cities, has the disease claimed so many lives. Tuberculosis, we're told, has returned "with a vengeance."² In the language of the day, it's an "emerging infectious disease." In scientific publications and in the popular press, the refrain is the same: tuberculosis, once vanquished, is now emerging to trouble us once again.

According to many of the voices echoed in this book, tuberculosis has been with us all along; only from a highly particular point of view can it be seen as an emerging, or even a "reemerging," disease. "Thinking in terms of a returned tuberculosis," objects Katherine Ott, "obscures the unabated high incidence of tuberculosis worldwide over the decades."³ Those who experience tuberculosis as an ongoing concern are the world's poor, whose voices have systematically been silenced. Yet they deserve a hearing, if for no other reason than that the poor infected with the tubercle bacillus are legion. Some estimate that as many as two billion persons—a third of the world's population—are currently infected with quiescent but viable *Mycobacterium tuberculosis*. This figure corroborates another: tuberculosis remains, at this writing, the world's leading infectious cause of preventable deaths in adults.⁴

Tuberculosis is thus two things at once: a completely curable disease and the leading cause of young adult deaths in much of the world. As we approach the end of the millennium, it's instructive to compare our circumstances to the situation that prevailed at the end of the previous century. At that time, Robert Koch had recently identified the tubercle bacillus, but no effective treatment existed. "Consumption" was the leading cause of death and the most feared of diseases. "During the late nineteenth century," notes Ryan, "there was a growing fear that the disease might destroy European civilization."⁵

Although TB's victims during the eighteenth and nineteenth centuries included members of all classes, it has always disproportionately affected the poor. In the 1830s, for example, English mortuary registers revealed that although tuberculosis deaths were common, they were increasingly

so at the lower end of the social ladder: "the proportion of 'consumptive cases' in 'gentlemen, tradesmen, and laborers' was 16, 28, and 30 percent respectively."⁶ The affluent could "take the cure" in a number of ways—they could travel to different climes or enjoy protein-rich diets—but case-fatality rates were high among all those with "galloping consumption."

With the advent of improved sanitary conditions and the development of food and trade surpluses, tuberculosis incidence declined in the industrializing nations, particularly in those communities and classes that enjoyed the greatest benefits of these transformations. Still, tuberculosis remained common and patterned in its distribution. In 1900, annual death rates from tuberculosis for white Americans approached 200 per 100,000 population. "Among black Americans," adds historian Barbara Rosenkrantz, "the figure was 400 deaths per 100,000, approximately the same level recorded in the middle of the nineteenth century for the population as a whole."⁷ Black Americans were thus enjoying the fruits of medical progress with a fifty-year lag.

Technology has often been presented as the remedy for social ills, and the development of effective tuberculosis chemotherapy was hailed as the beginning of the end of the disease. But the poor remained much more likely to become infected and ill with *M. tuberculosis*. When they were sick with complications of tuberculosis, they were more likely to receive substandard therapy—or no therapy at all. In the years after World War II, those with access to the new antituberculous medications could expect to be cured of their disease. Who had access to streptomycin and PAS in the late 1940s? Fortunate citizens of the United States and a handful of European nations, all with well-established and encouraging trends in tuberculosis incidence that predated effective chemotherapy. Thus risk, though never evenly shared, became increasingly polarized.

By mid-century, tuberculosis was still acknowledged as a problem in certain quarters, but it was becoming less and less of a concern. One historian has argued that "TB had all but disappeared from public view by the 1960s."⁸ The reasons for this invisibility stem in part from the decreasing absolute incidence in wealthy nations and in part from persistent patterns of differential susceptibility. Writing in 1952, René and Jean Dubos observed that "while the disease is now only a minor problem in certain parts of the United States, extremely high rates still prevail in the

colored population." Nor were poor outcomes distributed merely by race. Within racial categories, differential risk remained the rule. The case-fatality rate in whites, noted these authors, was "almost seven times higher among unskilled laborers than among professional persons."⁹ Ironically, then, the advent of effective therapy seems only to have further entrenched this striking variation in disease distribution and outcomes. Inequalities operated both locally and globally: the "TB-outcome gap" between rich and poor grew, and so too did the outcome gap between rich countries and poor countries.

In short, the "forgotten plague" was forgotten in large part because it ceased to bother the wealthy. In fact, if tuberculosis is reexamined from the point of view of those living in poverty, a radically different picture emerges. In this century, at least, tuberculosis has not really emerged so much as *reemerged from the ranks of the poor*.¹⁰ One place for diseases like tuberculosis to "hide" is among poor people, especially when the poor are socially and medically segregated from those whose deaths might be considered more significant. Who are these throwaway people? We begin our process of rethinking by examining the life histories of some people afflicted by the disease.

JEAN

Jean Dubuisson, who has never been sure of his age, lives in a small village in Haiti's Central Plateau, where he farms a tiny plot of land. He shares a two-room hut with his wife, Marie, and their three surviving children. All his life, recounts Jean, he's "known nothing but trouble." His parents lost their land to the Péligre hydroelectric dam—a loss that plunged their large family into misery. Long before he became ill, Jean and Marie were having a hard time feeding their own children: two of them died before their fifth birthdays, and that was before the cost of living became so intolerable.

And so it was a bad day when, some time in 1990, Jean began coughing. For a couple of weeks, he simply ignored his persistent hack, which was followed by an intermittent fever. There was no clinic or dispensary in his home village, and the costs of going to the closest clinic (in a nearby

town) are prohibitive enough to keep men like Jean shivering on the dirt floors of their huts. But then he began having night sweats. Night sweats are bad under any conditions, but they are particularly burdensome when you have only one sheet and often sleep in your clothes.

Marie insisted that it was time to seek professional treatment for Jean's illness. But it was already late September, Jean argued, and school would be starting soon. There would be tuition to pay, books and notebooks to buy, school uniforms to sew. Jean did not seek biomedical care; he instead drank herbal teas as empiric remedies for the *grip*, a term similar to "cold" in North American usage.

Jean's slow decline continued over the course of several months, during which he lost a good deal of weight. The next event, in the story told by Jean and Marie, was when he began to cough up blood, in late December of 1990. Hemoptysis is common in rural Haiti, and most people living there do not believe that the *grip* can cause it. Instead, Jean and his family concluded that he was *pwatrinè*—stricken with tuberculosis—and they knew that he had two options: to travel to a clinic or to seek care from a voodoo priest. These were not mutually exclusive options, but, as Jean had no enemies, he concluded that his tuberculosis was due to "natural causes" rather than to sorcery. Emaciated and anemic, he went to the clinic closest to his home village.

At the clinic, he paid \$2 for multivitamins and the following advice: eat well, drink clean water, sleep in an open room and away from others, and go to a hospital. Jean and Marie recounted this counsel without a hint of sarcasm, but they nonetheless evinced a keen appreciation of its total lack of relevance. In order to follow these instructions, the family would have been forced to sell off its chickens and its pig, and perhaps even what little land they had left. They hesitated, understandably.

Two months later, however, a second, massive episode of hemoptysis sent them to a church-affiliated hospital not far from Port-au-Prince. There Jean, still coughing, was admitted to an open ward. We were unable to review his records, but we know that he stayed for a full two weeks before being referred to a sanatorium. During his stay, Jean was charged \$4 per day for his bed; at the time, the per capita income in rural Haiti was about \$200 a year. When the hospital's staff wrote prescriptions for him, he was required to pay for each medication before it was administered.

Thus, although Jean could not tell us exactly what therapies he received while an in-patient, he knew that he actually received less than half of the medicine prescribed. Furthermore, the only meals Jean ate in the hospital were those prepared by Marie; most Haitian hospitals do not serve food.

Jean continued to lose weight, and he simply discharged himself from the hospital when the family ran out of money and livestock. He did not go to the sanatorium. Needless to say, the cough persisted, as did the night sweats and fever. "We were lucky, though," added Jean. "I stopped coughing up blood."

After reaching home, Jean, bedridden, was visited by a cousin who lived in Bois Joli, a small village served by Proje Veye Sante, which was then sponsoring the comprehensive tuberculosis-treatment project described in the next chapter. The program, which included financial aid and regular visits from community health workers, had been designed for people like Jean Dubuisson and for a country like Haiti—that is, it was designed for poor and hungry people with tuberculosis who receive shabby treatment wherever they go. Unfortunately, the project then served the permanent residents of only sixteen villages and was based in a village over two hours from Jean's house. "Several [villagers] had benefited from it," recalled Jean's cousin, "so I suggested that he move to Bois Joli, as then he would be eligible for this assistance."

Marie Dubuisson "took down the house" and moved her husband and children to Bois Joli. "We didn't have a tin roof or good land," she added philosophically, "so it wasn't as bad as it might have been. And Jean needed the treatment." The skeletal man with sunken eyes and severe anemia began therapy in May of 1991. Jean gained eighteen pounds in his first three months of treatment. His oldest daughter was found to have tuberculosis of the lymph nodes, and she too was treated.

Jean was cured of his tuberculosis, but this cure, in many respects, came too late. Although he is now free of active disease, his left lung was almost completely destroyed. He is short of breath after only minimal exertion. Marie now does most of the manual labor, depending on her daughter (who was also cured) for assistance in carrying water and hoeing. "I have a hard time climbing hills," Jean reports, surveying the steep valley before him. "And that's a bad thing when you're trying to get by up in the hills."

CORINA

Corina Bayona was born in 1942 in Huánuco, in Peru's Central Sierra. Like most of the region's poorer peasants, her parents found it increasingly difficult to wrest a living from the unforgiving countryside. When Corina married Carlos Valdivia, both had dreams of escaping the harshness of rural life. A son, Jaime, was born before Corina was twenty.

In 1974, the three of them emigrated to Carabayllo, the new and sprawling slum north of Lima, one of Latin America's most rapidly growing cities. The edges of the settlement consisted of "invasiones"—dry and dusty slopes dotted with ramshackle shelters built first of straw and cardboard and plastic and then rebuilt in dun-colored brick only years later, when the squatters no longer feared that they would be removed by force. To settlers and to visitors alike, the steep and treeless fringes of Carabayllo looked like the surface of the moon.

Soon Corina, Carlos, and Jaime moved into a one-room house. During the 1970s and 1980s, Corina worked as a maid in a schoolteacher's house; Carlos worked as a night watchman in the industrial area south of Lima. Their house eventually had electricity, if no running water, and Corina and Carlos were able to send Jaime to high school. Carlos recalls this time as relatively secure, despite the political violence that often marked the city. Unemployment was high in Carabayllo, although not as high as it would later become, and they were lucky to have two jobs, especially since their son's new wife and baby precipitously added two more mouths to feed in the mid-1980s.

At some point in 1989, Corina began coughing. Initially, she attempted to treat herself with herbal remedies, primarily because she was unable to visit the clinic. Although a public health post was based nearby, it was closed during the hours that Corina was in Carabayllo. What Corina lacked most was time: it took her more than two hours on public buses to commute to work each day. When her cough worsened, she finally went to the post, where a doctor raised the possibility of tuberculosis. A smear of her sputum revealed the tubercle bacillus, and she began standard antituberculous therapy.

In August of 1990, shortly after Alberto Fujimori was elected president of Peru, the urban poor underwent what they later termed *fujishock*—the

rapid implementation of one of the most draconian structural-adjustment policies in the hemisphere. Inflation spiraled, and public services, including health care, were trimmed back sharply.¹¹ Soon Carlos was out of work.

In the midst of all these problems, Corina began coughing again. More sputum was collected for a smear, which was positive, and for culture. When Carlos later returned for the culture results, however, he was informed that the specimen had been misplaced. In April of 1991, after more delays and worsening symptoms, Corina was formally diagnosed with relapsed pulmonary tuberculosis. Given the health post's inconvenient hours and long waits—and also, as one of her doctors noted, the significant stigma associated with tuberculosis—she began receiving treatment at a private clinic.

What Corina gained in privacy and convenience she lost in increased costs. As was not uncommon in those months after *fujishock*, the family's meager savings were soon expended; Corina was unable to complete her treatment. As her husband recalls it, they could afford to buy only two of the four drugs prescribed.¹² Corina's condition worsened, and she became unable to work. When she next sought care, this time in a public health center in Carabayllo, physicians there discovered that she did not respond to standard therapy. When her condition worsened still further, in April of 1991, she was advised to seek care in a hospital.

Corina first presented to a private university teaching hospital, but she was unable to purchase the medications and supplies prescribed. She was referred to the public facility not far away. At the private hospital, Corina had been told that she would have to pay for supplies; at the public facility, where supplies were extremely scarce, she was told that she must bring her own—including syringes, gloves, and gauze. Further, Corina had the ill fortune to arrive at this hospital just before the national health workers' strike, which was called in response to the new government's massive cuts in public spending. During the strike, most ambulatory treatment was simply suspended; Corina received, in essence, no care for her tuberculosis during this time.

In August of 1991, shortly after the strike ended, Corina returned for her medications. A physician roundly upbraided her: "Señora, it's your own fault that you did not complete your treatment. Why didn't you

come before?" Brusquely, he sent her to yet another facility on the grounds that she was not from that hospital's catchment area. This third hospital, though close to the Valdivia household, was not highly regarded, and Corina complained that there too she received a cool welcome. She was summarily referred back to the local health post for her care.

Dr. Raúl García, who directs *Socios en Salud*, the Peruvian community-based organization described in Chapter 1, had just initiated a health survey of Carabayllo. He met Corina in the course of inquiring about drug-resistant tuberculosis in the area. She was, he recalls, scarred by her interactions with the health care system. "Every time she went to the hospital, the physicians were mean or impolite to her. They had labeled her as noncompliant." Thus branded, Corina "felt attacked." "She was filled with fear," continued Dr. García. "She had resolved not to return to seek care at the health center."

Carlos Valdivia was troubled by this resolution, for Corina continued to worsen. She coughed incessantly and became short of breath, even at rest. Her son, still living at home, worried for his mother. "You should go back to the health center," he pleaded, "so that they will cure you." But soon Jaime began to cough as well. "He didn't want to go either," recalled Dr. García, "because he didn't want to be treated the way they had treated his mother." Eventually Jaime sought treatment at the local post, but he too failed to respond to standard therapy.

For the next three years, Corina and Jaime lived with active pulmonary tuberculosis. Their household, wracked by coughing, was increasingly tense. Jaime's wife left, leaving behind their two infants, and Carlos began to drink. Late in the summer of 1994, Corina began to cough up blood. When at last she sought care for this condition, physicians documented that her infecting strain had become resistant to all first-line anti-tuberculous drugs except ethambutol. For reasons that remain unclear, the doctors then prescribed those same ineffective medications for her again. Corina of course failed to respond to these agents—and, worse, she had a life-threatening reaction to one of them in November. Shortly thereafter, Corina was advised to give up completely on her "futile" efforts to treat her disease.

But Corina and her family were not so easily dissuaded. Upon inquiring, they learned that other drugs were available, although the public

health system could not provide them free of charge. Among the drugs prescribed by a pulmonologist were two new agents, ciprofloxacin and ethionamide, with an estimated cost of 500 *soles* a month—eight times her husband's income when he'd been fortunate enough to have a job.

Carlos Valdivia, seeing his family dying before him, each month searched high and low for 500 *soles* for his wife and for his son, because by then it had become clear that Jaime also had drug-resistant tuberculosis. Sometimes Carlos succeeded; often he did not. "What unemployed person in Carabayllo could find 1000 *soles* a month?" reflected Carlos sadly. His son died in December of 1995, leaving behind two small children.

Corina, finding herself the primary caregiver for her grandchildren, found new reasons to fight for survival. Dr. García recalls her saying, "I thought that I'd lived long enough until I had these two children to take care of. All I ask is for God to let me live in order to take care of them." Through the efforts of a local community-based organization, Corina eventually received therapy with a multidrug regimen designed for resistant tuberculosis disease. The medications were free, but she soon had another adverse reaction: bruises erupted on her legs. A pulmonologist advised her to stop taking all of her medications and recommended another culture of her sputum.

In February 1996, one week before Corina died, Carlos went to the health post with yet another sputum sample. The plan, he knew, was to find other medications that his wife might be able to take. Suddenly, however, Corina became severely short of breath. Carlos took her to the clinic, and an auxiliary nurse subsequently tried to place her in two different hospitals. In the emergency room of the teaching hospital, the staff informed Corina: "We have nothing we can do for you; your case is too chronic." After that, Corina stated that she would not return to the local public hospital, to which she had been again referred. "I would rather wait for the end at home than go back there," she said. This time, she did not have long to wait.

CALVIN

Calvin Loach was born in New York City in 1951. His parents were both from the Carolinas. Shortly before Calvin's birth, they had emigrated to

the city hoping to find steady work and respite from the racism that had so limited their economic opportunities in the South. New York, they found, was not much better. As Calvin and his two sisters were growing up, their father worked in a series of unrewarding and short-lived jobs; later, and for many years, their mother worked in the medical records department of a Brooklyn hospital.

Calvin attended public high school, where his academic performance was fairly unremarkable, and graduated in 1969. There was talk, at the time, of his attending a local community college, but Calvin never completed an application. In the second month of his second job, at age nineteen, Calvin was drafted into the U.S. Army.

Calvin rarely spoke about his tour of duty in Vietnam. He saw active combat in April 1971 and was part of a platoon that sustained heavy fire and loss of life. Calvin was not wounded by gunfire, but during a march in rough terrain he sustained a penetrating wound to the sole of his right foot. This injury soon became infected, eventually requiring surgery and intravenous antibiotics. It subsequently became the source of many problems for Calvin.

Another problem stemming from Calvin's tour of duty concerned heroin. In one telling, Calvin linked the use of opiates to the chronic pain that resulted from his injury; in another account, his regular use of heroin preceded this injury by several months. In any case, it was in Vietnam, and not in New York, that Calvin first used the drug, which was inexpensive, readily available, and (according to many) widely used by the increasingly demoralized U.S. soldiers.

In 1972, Calvin returned to New York, where he lived with his mother and one of his sisters; his father had returned to North Carolina. Although he did drink and smoke, sometimes heavily, Calvin initially did not use heroin in the United States; at that time, he knew no one else who was involved with the drug. It was during a visit to Boston, where his mother's cousins owned part of a convenience store, that Calvin was reintroduced to heroin and also to cocaine. From the late 1970s until 1992, Calvin used heroin, sometimes steadily and sometimes intermittently.

Most social histories obtained from his medical records suggest that Calvin never had a steady job after Vietnam, but a more thorough interview, by a social worker at a Boston-area Veterans' Administration

hospital, documented more than three years of full-time employment in a furniture warehouse. At that time, Calvin was living with a woman who had previously worked for his cousins. His girlfriend told another social worker that Calvin had turned again to heroin after he lost this job in 1982. This girlfriend strongly discouraged his drug use, and it led her to leave him.

In 1991, Calvin was hospitalized for an episode of staphylococcal endocarditis, which permanently damaged one of his heart valves. During this hospitalization, Calvin's old foot injury became increasingly painful and began to drain pus. He was diagnosed with osteomyelitis and received two months of therapy for the infection.

It was during this hospital stay, which lasted almost a month, that Calvin developed a dislike for the hospital milieu; the feeling, it seems, was mutual. Medical records describe Calvin as "difficult" and, in one instance, "verbally abusive." The word "noncompliant" is found throughout his records, although it is not entirely clear why: Calvin was well on his way to completing difficult therapy for endocarditis and osteomyelitis, and in the previous year he had used an antihypertensive medication with regularity.

By the time Calvin was referred for expert management of his addiction, he had already spent a month withdrawing from narcotics, without the help of opiates or benzodiazepines. By his account, he did not use heroin again, although he later received methadone.

Some months later, in the spring of 1992, Calvin began to cough. A heavy smoker, he initially attributed the cough to bronchitis, which he'd had intermittently for years. He was reluctant to return to the VA clinic. When he began to experience fevers and drenching sweats, Calvin was sure that he had AIDS; this made him even less enthusiastic about seeking medical care. These symptoms eventually drove him to the emergency room, however, and there he was promptly diagnosed not with AIDS but with pulmonary tuberculosis.

Calvin initially responded to a three-drug regimen, which he took for several weeks. He felt that one drug—it's not clear which one, though it was not isoniazid—made him itch, and so he stopped taking it. Cultures later revealed that his infecting strain was resistant to isoniazid. Thus, although public health officials believed that Calvin was taking two

effective agents, he was actually taking only one. It is difficult to know, in retrospect, how much of the incorrect treatment Calvin received was physician-directed. It is clear that he reported his distressing itch to his private physician and was instructed to "take pyridoxine with isoniazid"—even though it had been demonstrated by then that his strain of TB was resistant to isoniazid. Calvin was also given conflicting information regarding the interaction of methadone with his antituberculous drugs: the public health nurse, who seemed concerned and better informed than his doctor, worried about such an interaction; his internist dismissed this possibility.

About six months into therapy, Calvin noted that his cough was worsening. A chest radiograph suggested relapse, although sputum studies, urged by a tuberculosis outreach worker, did not reveal the tubercle bacillus in his lungs. His internist then added another drug to Calvin's regimen. Although his laboratory results were reviewed, his documented resistance to isoniazid must have been missed again, because the drug was continued.

Calvin felt better, but his improvement was short-lived. By December 1992, reported the tuberculosis outreach worker, Calvin "felt as sick as he had ever been." He continued to take his medications, but he did not return to either the public health clinic or the VA clinic. In January, quite possibly with active pulmonary disease, Calvin "took off," by bus or by train, for New York City.

Calvin's internist, an affable but busy man, subsequently attributed his patient's poor response to "his HIV infection." When reminded that, in fact, multiple serologies had revealed Calvin to be HIV-negative, the physician recalled that his patient's infecting strain of *M. tuberculosis* was "mildly resistant." He further ventured that Calvin, "notoriously non-compliant," was just "not with the program."

In any case, Calvin's doctor never heard from him again. When New York public health authorities created a central information bank about tuberculosis patients, Calvin Loach's name was not among those listed.

MAKING SENSE OF MISERY:

CRITICAL PERSPECTIVES ON TUBERCULOSIS

Jean, Corina, and Calvin all had unfavorable outcomes. At what point in the trajectories of their lives were their fates sealed? Were their experi-

ences typical of what it's like to have tuberculosis at the end of the twentieth century?

Dr. García, who met Corina near the end of her life, remarked that her experience revealed to him "the significance of external factors and their effects on the lives of poor people. These factors determined whether Corina lived or died." Critical perspectives on tuberculosis must ask how social forces become manifest in the morbidity of unequally positioned individuals in increasingly interconnected populations. Poverty, social inequality, economic policy, war, discrimination along lines of race and gender and class, medical incompetence—which forces were significant in structuring the risks faced by Jean, Corina, and Calvin as well as their poor outcomes?

Take the cases one by one. Jean's experience is typical of those who suffer from tuberculosis in Haiti. As Haiti produces few nonagricultural products, it's safe to say that Jean is a member of its only truly productive class: the rural peasantry. But membership in that class brought him certain "birthrights." For example, Jean is, *de facto*, a member of the poorest class in the hemisphere. From the day he was born, he was ensured the "right" not to attend school, to have no access to electricity or safe drinking water, and to have little access to medical care. Jean was also ensured no role whatsoever in the running of the country that he and those like him were supporting. He was born, as the Haitians say, with a *baboukèt*, a muzzle, on his mouth. In fact, Jean fared better than many Haitian peasants, since tuberculosis is the leading cause of death in his age group. But delays in therapy meant permanent damage to Jean's lungs, forever compromising his ability to feed his family—a precarious enough enterprise in contemporary Haiti, even for the hardy.

Corina similarly typifies the experience of Latin Americans living with multidrug-resistant tuberculosis. Although she may have been originally infected with a drug-resistant strain of *M. tuberculosis*, it is equally probable that her disease became resistant during the course of intermittent and poorly conceived therapy. Her son Jaime, however, was likely to have been infected with a drug-resistant strain from the beginning. How common are such experiences in Peru? The country has been praised for its greatly improved tuberculosis-control program, which has systematized the diagnosis and treatment of the disease, made first-line medications more widely available, and instituted directly observed therapy.¹³ But

Corina did not fit into the prevailing algorithm, which does not take account of increasing drug resistance on the part of the bacillus; subsidized retreatment schemes, while available, are inadequate for patients like her.

Indeed, while attention is focused on the detection and control of susceptible tuberculosis disease, cases such as Corina's will inevitably take on greater epidemiologic significance. Corina was sick and infectious for at least six years, as Jaime's tragic death reveals. She worked during most of those years, taking crowded buses across Lima twice a day. At this writing, hundreds of cases of highly resistant tuberculosis have been documented in northern Lima; with the exceptions noted in Chapter 1, virtually none of these patients are receiving appropriate therapy. All of them may be presumed to be infectious.

What of Calvin's experience in the United States, a country vastly more wealthy than Peru (although Peru itself boasts a per capita income ten times higher than that registered in rural Haiti)? Calvin was probably registered as one of the thousands of "excess cases" in 1991. As an African American and an injection drug user, he fit the bill: the brunt of the recent epidemic has been borne by U.S. citizens living in poverty, many of them people of color, as a review by McBride makes clear.¹⁴

Nor was Calvin's clinical course atypical of the lot of the U.S. poor with tuberculosis. Although his fate is unknown, he clearly received inappropriate care and was "lost to follow-up." This was much less common in Massachusetts than in New York, where dismantling of the tuberculosis-control program had made it difficult to ensure successful completion of therapy. In 1989, for example, fewer than 50 percent of New York tuberculosis patients who began treatment could be declared cured.¹⁵ In one study conducted in Harlem Hospital, almost 90 percent of patients did not complete therapy for their disease.¹⁶ An overview from the New York City Department of Health paints a grim picture:

By 1992, the situation in New York City looked bleak. The number of cases of tuberculosis had nearly tripled in 15 years. In central Harlem, the case rate of 222 per 100,000 people exceeded that of many Third World countries. Outbreaks of multidrug-resistant tuberculosis had been documented in more than half a dozen hospitals, with case fatality rates greater than 80 percent, and health care workers were becoming ill and dying of this disease.¹⁷

Did Calvin also have multidrug-resistant tuberculosis? Although resistance to more than one drug was never documented, Calvin was put at high risk of developing resistance and of infecting others when his physician continued to give him a medication to which the strain was resistant and later added a single drug to an already failing regimen—a well-known recipe for generating drug resistance. In reviewing the histories of patients with drug-resistant tuberculosis who had been referred to a leading hospital in Colorado, Mahmoudi and Iseman discovered an average of 3.9 physician-directed errors per patient.¹⁸

Medical errors are readily discerned in the other cases as well, and this mismanagement is linked to the patients' poverty. Jean saw a nurse and two physicians and spent two weeks (along with all his family's savings) in a hospital before receiving effective antituberculous therapy elsewhere. Furthermore, the long duration of his active disease, including his time on an open ward, helps to explain why transmission continues apace in settings like Haiti. Corina's initial sputum sample was lost, and her providers mistook drug resistance for noncompliance. When she was at last correctly diagnosed, she was prescribed an inadequate regimen, which she took when she could afford it—a good way to engender resistance to even second-line drugs.

In each case, the patients were blamed for their failure to respond to therapy. In each case, the patients' agency—their ability to comply with costly and difficult regimens—was exaggerated. Certainly patients may be noncompliant. But how relevant is such a notion in the case of Jean Dubuisson? Biomedical practitioners told him to eat well. He "refused." They told him to drink clean water, and yet he persisted in drinking from the only stream near his village. He was instructed to sleep in an open room and away from others, and here again he was "noncompliant," as he built no such addition onto his two-room hut. Most important, he was instructed to go to a hospital. Jean was "grossly negligent" and dragged his feet for months.

One can also exaggerate the effects of medical mismanagement, which does not by itself explain skewed rates of tuberculosis distribution. Physician-directed errors do not create poverty or social inequalities, and it is along these lines that rates of tuberculosis vary. Other questions raised by these cases are harder to answer but nonetheless worth

considering. For example, did Peru's structural-adjustment plan increase Corina's risk of a tuberculosis death? Corina was driven from the Peruvian Central Sierra by the collapse of the agrarian order and other complex economic transformations. But once in Carabayllo, she and her family were subjected to a new set of vagaries; they were beset no longer by drought and storm but rather by equally uncontrollable, and even less predictable, shifts in economic policy. Decisions made in far-off World Bank headquarters, for example, led to significant changes in the employment structure of Lima and to massive fluctuations in the price of key commodities. Corina soon found herself the maid to a woman who was to become only slightly less poor than she—*fujishock* took its toll on schoolteachers, too. When Corina became ill with drug-resistant tuberculosis, she and her family were in essence helpless to combat it.

In Calvin's experience, what role did racism play? He more than once wondered about its contribution to his care. In the VA hospital, he felt punished because of his history of drug use, and he was irritated by the predominantly white staff's relative tolerance of alcoholism—the ranking substance-abuse problem of most of the other patients, who were also largely white. But the more important effects of racial discrimination may have been those that led to his becoming infected with tuberculosis in the first place. As a black Vietnam veteran living in the inner city and injecting drugs, Calvin was certainly in a high-risk group. Furthermore, conscription for this war was to some extent distributed by the same forces that drove his parents out of the Jim Crow South, as the army ranks were disproportionately filled with young African American men. And among the troops, those with the grimmest prospects back home seemed to be those most likely to use heroin or opium.

A LOOK BACK

In reflecting on tuberculosis mortality in the world today, a troubling question comes to the fore: does TB's association with poverty damn it to irrelevance in the eyes of the powerful, who, after all, control funding for everything from treatment to research? In August 1994, an official of the International Union Against Tuberculosis and Lung Disease seemed to

say as much. "You never hear about TB in North America," he commented to a journalist, "because of who gets it these days: immigrants, natives, poor people and AIDS patients for the most part."¹⁹ It would appear that diseases predominantly afflicting the poor are unlikely to garner funding for research and drug development—unless they begin to "emerge" into the consciousness and space of the nonpoor.

A look back over past professional commentary on the differential distribution of tuberculosis reveals that this neglect was not always the case. A huge literature documents the pernicious synergy between poverty and tuberculosis. During its first 150 or so years, the United States, like Europe, counted tuberculosis as its number one killer. Lemuel Shattuck's *Report of the Sanitary Commission of Massachusetts, 1850* named consumption as the leading cause of U.S. deaths, and this remained true even in the latter part of the century, when rates began to fall sharply.²⁰ But tuberculosis rates differed variably between the sexes and reliably along lines of race and class.

Perhaps not surprisingly, given TB's importance, differences in mortality and susceptibility among various social groups occasioned much comment. In fact, notes historian Georgina Feldberg, "concern about differential susceptibility *dominated* American discussions of tuberculosis from the mid-nineteenth century onward."²¹ But interpretations of these differences, continues Feldberg, depended on the social perspectives of the commentators: "As each generation attempted to make sense of this preferential, or differential, susceptibility, the explanations they offered reflected and reinforced their uncertainties about a changing scientific and social order."²²

For example, "Southerners commonly believed that blacks suffered from a distinctive form of consumption, known as 'negro consumption.'"²³ Susceptibility, in this view, was genetically determined. This construct not only demonstrated a vested interest in an agrarian, slaveholding social order but also reflected, to some extent, prevailing medical views. An 1844 editorial in the *Boston Medical and Surgical Journal* noted that the "reality of hereditary influence on the production of phthisis [as tuberculosis was then known] is so universally admitted, that it would seem a sort of scientific heresy to doubt it."²⁴ Feldberg summarizes these views:

The hereditarian/environmental debate persisted as Northern commentators regularly attributed excessive mortality to the "general insalubrity of the sections of the city inhabited by [blacks], the crowded conditions of their dwellings, insufficient nourishment, and the other influences of poverty," while Southerners more typically cited the "habitual improvidence" of the black races.²⁵

Similar theories abounded in discussions of why such great numbers of Native Americans died of tuberculosis. Although solid evidence from Peru documents TB's pre-Columbian existence in the hemisphere, there is less evidence of tuberculosis among the native population in North America before the arrival of the Europeans, and there is little doubt that rates increased dramatically after contact. But TB's rise among the native peoples was so clearly linked to a rapid decline in their standard of living that hereditary arguments were widely seen as less compelling.²⁶

The belief that tuberculosis was hereditary was dealt a near-lethal blow by Robert Koch's discovery of the tubercle bacillus in 1882. "One has been accustomed until now to regard tuberculosis as the outcome of social misery," Koch wrote, "and to hope by relief of distress to diminish the disease. But in the future struggle against this dreadful plague of the human race one will no longer have to contend with an indefinite something, but with an actual parasite."²⁷

Paradoxically, perhaps, but fortuitously, the idea of tuberculosis as "the outcome of social misery" was not undermined by the discovery of its etiology. In the latter part of the century, persistent poverty and rising inequality were increasingly believed to contribute to differential mortality. One prominent physician "venture[d] to assert that the necessary privations of poverty on the one hand, and the absurd excesses of wealth on the other, tend more to the formation of tubercles in children than all other causes combined."²⁸

By 1900, observe Dubos and Dubos, "it had become obvious that tuberculosis was most prevalent and most destructive in the poorest elements of the population, and that healthy living could mitigate its harmful effects. Reformers could attack the disease from two directions, by improving the individual life of man and by correcting social evils."²⁹ Both of these approaches, never neatly demarcated, were advocated by public health officials, most of whom were physicians.

Many in the nascent antituberculosis movement, which in the earlier part of the twentieth century was linked to the establishment of sanatoriums, believed that education was the key to curing the disease. One side effect of this belief was a habit of infantilizing the sufferers. Reformers wrote of "careless consumptives" who needed above all to be trained. As one classic statement of this view would have it, "People are now infected by consumption through ignorance on the part of those who give and receive infection. Each man whose habits have been corrected, even by a short residence in the sanatorium will neither do nor willingly permit to be done by others acts which before would have seemed perfectly natural."³⁰

But other medical reformers continued to argue that "tuberculosis is closely associated with all the social problems of housing, food, wages, rest, clothing, and insurance and can in no way be separated from them."³¹ Feldberg, whose excellent work has restored to the historical score the voices of physicians whose understanding of tuberculosis was firmly biosocial, points out that "well into the twentieth century, American physicians held fast to an etiology that included microbes but also found room for malnutrition, unemployment, crowding, the living conditions in slums, and other social ills."³² As one example, she cites a 1921 publication by pathologist Allen Krause, director of the Johns Hopkins University tuberculosis laboratories: "The solution of the tuberculosis problem is partly dependent on the removal of other evils and inequalities which constitute, no doubt, a more fundamental problem than does tuberculosis itself."³³

Hybrids of these positions also emerged. Barbara Rosenkrantz writes of Ellen N. LaMotte's *The Tuberculosis Nurse (Handbook for Practical Workers in the Tuberculosis Campaign)*, published in 1915:

LaMotte assembled facts showing that tuberculosis was principally a disease of the poor, afflicting both those who were "financially handicapped and so unable to control their environment," and "those who are mentally and morally poor, and lack intelligence, will power, and self control." Her conclusion that "people of this sort . . . constitute almost the entire problem—otherwise the situation would be so simple that the word problem would not apply" conflicted uncomfortably with her intention of encouraging nurses to go forth and help the poor to defend themselves against tuberculosis.³⁴

The increased susceptibility of the African American population continued to engender racial speculations. Huber's popular 1906 text derided discriminatory "phthisophobia" but argued that "the negro's small lung capacity, as compared with that of the white, and his deficient brain capacity render him less resistant to the disease when once acquired." Huber concluded by warning that "unless the hygienic and moral surroundings of the race are improved there is danger of its extinction."³⁵ In a 1925 paper called "The Vital Capacity of the Negro Race," two Alabama physicians published their findings (based on research conducted on prisoners and children) that "low vital capacity is a racial characteristic, and that vital capacity standards applied to white people cannot be directly applied to the negro race."³⁶

When anatomic considerations could not be invoked, commentators speculated about the "bizarre beliefs" of the afflicted. In seeking to explain the persistence of tuberculosis among the urban poor, Edward Livingston Trudeau wrote of "the blind love of 'the average proletarian . . . for the chorus of citylife.'"³⁷ High rates of tuberculosis among immigrants were commonly blamed on their "lifestyles" and lack of cleanliness.³⁸ It was widely argued that "superstition" and "conjuring" were to some extent responsible for poor health outcomes among African Americans, views that were echoed even among black professionals. For example, a survey titled "Superstition and Health," conducted in 1926 by the National Urban League, cites a young black physician practicing in New York:

Ignorance, cherished superstitions and false knowledge often govern Negroes in illnesses and hamper recoveries. Young Negroes show patriarchal obeisance to the aged—the aged are, in a large measure, fatalists. They are willing to leave all to whatever their fate may be, the fatalism that has cursed the Orient for centuries. This fatalism exasperates the physician, for it ties his hands and tends to nullify his efforts.³⁹

Strong associations between tuberculosis and race and class did not weaken as the century progressed, but calling attention to such associations did not often lead to compassionate responses. Changing conceptions of tuberculosis transmission—a result in part of the frenetic campaign against spitting in public places—led many to regard with hostility and fear those who were popularly held to have high rates of tuberculosis, such as black people or foreigners.⁴⁰ In a 1923 address to a state medi-

cal society, one physician observed that "tuberculosis continues to be a serious problem with [Negroes], and because of their association with whites . . . as cooks, nurses, maids, [and] laundresses," black people represented a "menace to whites."⁴¹ Such interpretations were common well into the 1960s. "In the South," McBride points out, "segregationists attempted to turn blacks' excessive tuberculosis mortality rates into justification for keeping white and black youths from attending integrated schools."⁴²

Racial differentials, tightly tied to class divisions, became further entrenched as effective therapies were developed. Although tuberculosis continued to decline among all U.S. citizens, rates among black people remained relatively high, particularly among young black adults, for whom tuberculosis remained the leading cause of death even during World War II. Deaths were highly concentrated in the large industrial cities that had attracted black workers throughout the first decades of the century:

From 1938 to 1939 black TB mortality rose in New York City from 949 deaths to 1,036. In numerous other major cities, blacks were more than one-half of those dead from TB in 1939. That year blacks suffered 50 percent of the TB deaths in Baltimore; 58 percent in New Orleans; 72 in Washington, D.C.; 78 in Birmingham; 78 in Atlanta; and 79 in Memphis. Nationally, blacks suffered 5,925 deaths or 32 percent of the TB deaths reported in the nation's 46 largest cities.⁴³

In 1946, one prominent Harlem physician took city, state, and federal authorities to task for ignoring the tuberculosis problem among African Americans, which during the war years had claimed thousands of lives: "Here is a contagious disease killing people in the low income brackets at an outrageous rate, yet health authorities don't get excited. Several days ago, a plane flew experts from Boston to Texas because of 5 children ill with infantile paralysis—not a death but just becoming ill. They wanted to protect the other children. We in Harlem want protection too, not from just a paralyzed limb but from death itself."⁴⁴

But afflicted communities had never been less likely to be construed as such. With the development of effective therapy, which began in 1943, energies turned increasingly toward treatment of the *individual* case. "At the national meetings of public health officials and TB experts," recounts McBride, "this optimistic and narrow concept of public health, which

focused on the patient and not groups at risk or conditions and social behaviors that created this risk, prevailed."⁴⁵ By the late 1950s, tuberculosis was regarded as a disease well on its way to being eradicated, and little interest remained in attacking the disease at its roots.

If individuals, and not the conditions endured by entire communities or classes, are increasingly seen as the sole repositories of risk, has there at least been a corresponding decrease in the differential risk so well described for the pre-antibiotic era? On the contrary, inequalities of risk seem to be increasing. For example, tuberculosis rates have dropped substantially among Native Americans, but less rapidly than among other groups. Michael and Michael, in reviewing the health status of contemporary Native Americans, note, as do others, their increased morbidity and decreased life expectancy. And although tuberculosis plays a small role in these grim figures, it takes on a new significance if disparities of risk become the focus. In looking at age-adjusted mortality rates, for example, 1987 tuberculosis deaths among Native Americans exceeded those among "all races" by 400 percent. Thus tuberculosis still tops the list of disorders *disproportionately* killing Native Americans.⁴⁶

The story is similar for other minorities in the United States, where "the decrease [in tuberculosis] has been considerably greater among whites than nonwhites. As a result, the ratio of the annual risk of tuberculosis among nonwhites to the risk among whites has risen from 2.9 in 1953 to 5.3 in 1987."⁴⁷ Increasing inequalities of risk belie the claim of a "national problem" of excess cases; instead they reveal a scenario in which long-standing inequalities of risk are now being further accentuated.

As the next two chapters document, similarly desocialized readings of tuberculosis continue to hold sway today. The reasons for treatment failures and for TB's persistence are often sought in the psychological traits of individual "defaulters" or in the cultural attributes of groups held to be "at risk." And yet in no instance has it been clearly demonstrated that rates of tuberculosis vary by beliefs or by psychological makeup. In no instance have educational interventions for those deemed "at risk" been shown to inflect trends in tuberculosis incidence. The occurrence of tuberculosis has varied primarily with economic development; tuberculosis case-fatality rates have varied with ready access to effective therapy. Pierre Chaulet put it well: as an "index of poverty, [tuberculosis] under-

lines inequalities of income and in the distribution of wealth. . . . In a world both off-track and 'deregulated,' TB persists and spreads, striking always the poor."⁴⁸

THE ROLE OF PRAGMATIC SOLIDARITY

At the close of the twentieth century, we are challenged not only to explain the uneven distribution of tuberculosis but also to explain poor therapeutic outcomes in a time when effective treatments have existed for decades. Between 1943, when Selman Waksman and co-workers discovered streptomycin, and the late 1970s, over a dozen drugs with demonstrable effectiveness against tuberculosis were developed. New diagnostic methods, including immune-fluorescence staining and new culture methods, are equally impressive. In fact, in 1997 the FDA approved a test that can identify and amplify mycobacterial gene sequences in a matter of minutes. Now in the pipeline are tools that might identify resistant strains in less than twenty-four hours. We indeed have the scientific knowledge—but the hard truth is that the "we" in question does not include the vast majority of the three million people who died from tuberculosis in 1996. We must acknowledge that our guilt surpasses that of earlier generations, who lacked our resources: Michael Iseman, one of the world's leading authorities on tuberculosis, is right to use the word "shameful" in describing our failure to touch tuberculosis prevalence in much of the world.⁴⁹

Looking toward the next millennium, it is difficult to be optimistic. The arrival of strains of *M. tuberculosis* that are resistant to all first-line and many second-line drugs is surely a harbinger of pan-resistant strains to come. And HIV looms: ever-increasing numbers of co-infected individuals, most of them poor, promise millions of cases of reactivation tuberculosis. These "excess cases" will in turn infect tens of millions. In failing to curb tuberculosis before the advent of these truly novel problems, it seems clear that a window of opportunity has slammed shut.

Although tuberculosis is inextricably tied to poverty and inequality, experience shows that modest interventions have effected dramatic changes in outcome. Pragmatic solidarity means increased funding for

tuberculosis control and treatment. It means making therapy available in a systematic and committed way. For example, we now know that short-course, multidrug regimens can lead to excellent outcomes in even the most miserable settings. In rural Haiti, as Chapter 8 explains, we learned that cure rates could increase from under 50 percent to nearly 100 percent if comprehensive supports, including financial and nutritional aid, are put in place while patients are being treated.⁵⁰

In San Francisco, one project addressed poor attendance at tuberculosis clinics by moving the clinics to the times and places desired by the patients and by replacing staff who placed the blame for poor outcomes on the patients.⁵¹ In New York, where the chances of compliance among injection drug users with tuberculosis were wearily dismissed as hopeless, one clinic more than trebled rates of completion. Much of the success was due to directly observed therapy, but a comprehensive, convenient, and user-friendly approach clearly had an impact, too.⁵² Especially critical—and important to underline when confronted with claims that treating susceptible disease will somehow make MDRTB go away—were efforts in New York to speed the rate at which resistant strains were identified and then treated with the antibiotics to which they had demonstrated susceptibility.⁵³

Pragmatic solidarity means preventing the emergence of drug resistance whenever possible, but it also means treating people like Corina Valdivia. As this book goes to press, a massive pandemic of MDRTB in Russia and other countries of the former Soviet Union becomes even more massive—with minimal public comment and even less public action. Problems of this dimension call for public subsidies of costly second-line drugs as well as for the development of new drugs. “No new antituberculous compounds have been developed by the pharmaceutical industry since the 1970s,” observed Cole and Telenti in 1995, although researchers have serendipitously found certain antibiotics that have activity against *M. tuberculosis*.⁵⁴ Reichman sounds a pessimistic note: “Most of the drug companies that publicly announced a quest for TB drugs at the time of the recent resurgence have been noticeably quiet. Few have even shown interest in developing such drugs.”⁵⁵

In identifying the microbiological cause of consumption, Koch had hoped to end the era in which tuberculosis could be addressed only “by

relief of distress." But tuberculosis remains, at this writing, "the outcome of social misery." If it is true, as Feldberg argues, that "scientific professionalism . . . fundamentally eroded the therapeutic impulse to social reform,"⁵⁶ surely it would be an error to divorce efforts to confront tuberculosis from broader efforts to confront social misery. We still have something to learn from the analysis of those who did not have our tools at their disposal. In 1923, pathologist Allen Krause made this observation: "More or less poverty in a community will mean more or less tuberculosis, so will more or less crowding and improper housing, more or less unhygienic occupations and industry."⁵⁷ This statement remains as true today as it was seventy-five years ago.

At the same time, it is necessary to avoid "public health nihilism."⁵⁸ Even if we lack the formulas necessary to "cure" poverty and social inequalities, we do have at our disposal the cure for almost all cases of tuberculosis. Those who remain committed to addressing tuberculosis by championing increased access to effective drugs must resist restricting their field of analysis of the tuberculosis problem. We are told to choose, in Haiti and in much of Africa, between treating tuberculosis and treating malnutrition. We are told to choose, in Peru, between treating those with susceptible and resistant strains. We are told to choose, in Harlem, between more funding for tuberculosis and more funding for affordable housing. Calls for more ambitious interventions are trumped by a peculiarly bounded utilitarianism: such interventions, we're told, are not "cost-effective." The inadequacies, the multiple ironies, of such analyses are not lost on the poor. In Peru, for example, it is impossible to ignore that a much-praised tuberculosis program is supported in part by the World Bank, one of the institutions that mandated the structural-adjustment program that led to increased suffering—and perhaps increased tuberculosis risk—for the Peruvian poor.

It is possible, of course, to exaggerate the significance of any one policy change. To cite Dr. García again: "If there had not been *fujishock*, it would have been something else. In Peru, there's always something beating down the poor." Although Dubos and Dubos mistakenly identify tuberculosis with a time—the nineteenth century—rather than with the inhumane conditions faced by billions on this planet, on another score they are right: "It is only through gross errors in social organization, and

mismanagement of individual life, that tuberculosis could reach the catastrophic levels that prevailed in Europe and North America during the nineteenth century, and that still prevail in Asia and much of Latin America today."⁵⁹ As decision-making power—about social organization *and* about individual life—comes to be increasingly concentrated in the hands of a very few, we must ask, Who gets to determine the boundaries of analysis? Who is to determine what is "cost-effective" and what is not? As a global economy is "restructured," is there no room for alternative strategies of development? Alternative visions of providing health care to the poor?

Addressing these questions may get at the heart of the meaning of tuberculosis at the close of the twentieth century. If tuberculosis could once be termed "the first penalty that capitalistic society had to pay for the ruthless exploitation of labor,"⁶⁰ what does it mean now? Is it perpetually the lot of the poor to pay this penance?

Notes

INTRODUCTION

1. For a review of my conclusions, see Farmer 1992, chap. 18.
2. World Health Organization 1996.
3. Bloom 1992, p. 538.
4. These estimates are from the World Health Organization, which further reports that acute lower respiratory infections, diarrhea (including cholera, typhoid, and dysentery), tuberculosis, malaria, hepatitis B, HIV/AIDS, measles, neonatal tetanus, pertussis, and intestinal helminthiases top the list of infectious killers; see "Infectious Diseases" 1996.
5. Friedman, Williams, Singh, and Frieden 1996.
6. Sen 1992, p. ix.
7. Fineberg and Wilson 1996, p. 859.
8. There are, of course, many exceptions to this general rule. There are also signs that an anthropology of suffering and a greater attention to the sicknesses of the poor are of increasing importance in anthropology and medicine, respectively; see, for example, Kleinman, Das, and Lock 1997. That growing numbers of U.S. physicians are impatient with a health care system that fails to address the

needs of the poor is suggested by statements such as that recently made by the Ad Hoc Committee to defend Health Care (1997).

9. Scheper-Hughes 1992, p. 21.

10. Wagner 1975, p. 2.

11. Starn 1992, p. 168.

12. *Ibid.*, p. 163.

13. See Fabian's 1983 essay on "how anthropology makes its object." On ethnographic writing and its canon, see Geertz 1988, which offers a fairly complete, if somewhat dismissive, listing of other studies of the subject.

14. Asad 1975, p. 17.

15. Marcus and Fischer 1986, p. 134.

16. For a review of this literature, see Farmer, Connors, and Simmons 1996, chap. 5.

17. I have used the term "exaggeration of personal agency" throughout this book to indicate the failure, widespread in the social sciences and in popular commentary, to incorporate an understanding of how individual agency is constrained by poverty and inequality. In anthropology, such exaggeration was linked to the use of the notion of a "culture of poverty" (see Lewis 1969 and Valentine 1968). For a helpful overview of the ideological legacy of the "culture of poverty" debate, see Morris's trenchant 1996 essay.

18. It is important to note that risk for coronary artery disease, at least in the United States, is borne disproportionately by men in lower income brackets, not by prosperous businessmen with so-called Type-A personalities. For a review of the association between heart disease, race, and social class, see Ayanian, Udvarhelyi, Gatsonis, Pashos, and Epstein 1993; Escobedo, Giles, and Anda 1997; Giles, Anda, Caspar, Escobedo, and Taylor 1995; and Ferguson, Tierney, Westmoreland, Mamlin, Segar, Eckert, Zhao, Martin, and Weinberger 1997. See also two editorials on this topic by John Ayanian (1993, 1994). Some of the mechanisms underlying these associations are explored in Kawachi, Kennedy, Lochner, and Prothrow-Stith 1997.

19. Again, note that in the United States local inequalities—along lines of race, for example—are clearly associated with poor access to interventional cardiology. See, for example, the studies by Ayanian, Udvarhelyi, Gatsonis, Pashos, and Epstein (1993) and Giles, Anda, Caspar, Escobedo, and Taylor (1995).

20. Eisenberg 1984, p. 526.

21. Farmer 1992, p. 8.

22. I will draw upon this vast and heterogeneous literature throughout this book. For overviews, see Antonovsky 1967; Bunker, Gomby, and Kehrer 1989; Dutton and Levine 1989; Evans, Barer, and Marmor 1994; Haan, Kaplan, and Camacho 1987; Hahn, Eaker, Barker, Teutsch, Sosniak, and Krieger 1995; Kitagawa and Hauser 1973; Kosa, Antonovsky, and Zola 1969; Krieger, Rowley, Herman, Avery, and Phillips 1993; Pappas, Queen, Hadden, and Fisher 1993; Syme and Berkman 1976; Thiede and Traub 1997; Wilkinson 1992. A special issue of *Dædalus* (Fall 1994, vol. 123, no. 4) also reviews the subject of "health and wealth."

23. Lerner 1969, p. 111. See also Adler, Boyce, Chesney, et al. 1994, p. 15.
24. Dutton and Levine 1989, p. 31.
25. Ryan 1971, p. 163.
26. The often linear relationship between poverty and sickness changes as basic nutritional and sanitary needs are met. Wilkinson (1996) offers a critical overview of the association between income distribution—a key marker of social inequality—and health outcomes in wealthy and middle-income nations. In many of these settings, he argues, “health is almost unrelated to measures of economic growth and yet closely related to income distribution” (p. 221). For more on the association between high grades of inequality and increased morbidity and mortality, see Kawachi, Kennedy, Lochner, and Prothrow-Stith 1997; and Kennedy, Kawachi, and Prothrow-Stith 1996. In *Infections and Inequalities*, I have attempted to explore this topic from a transnational perspective, shedding light on some often obscured links between Latin America and the industrialized countries.
27. Nardell and Brickner 1996, p. 1259.
28. Wise 1993, p. 9.
29. Compare Paul Wise on infant mortality: “In a setting of profound poverty, the intention of clinical interventions is not to alleviate poverty but reduce its power to alter health outcomes; thus, clinical interventions’ attack on the tragedy of infant mortality will be successful only when social influences are no longer expressed in differential outcomes” (ibid., p. 12).
30. See, for example, Farmer, Robin, Ramilus, and Kim 1991.
31. Chaisson, Keruly, and Moore 1995.
32. Sen 1992, p. 69.
33. Wilkinson 1996, p. ix.
34. Kadlec 1997, pp. 59–60.
35. In keeping with convention, all of the names of patients and informants have been changed, as have certain identifying details and place names.

CHAPTER 1

1. Weise 1971, p. 6.
2. Diederich and Burt 1986, p. 366.
3. Feinsilver 1993, p. 103.
4. See Feilden, Allman, Montague, and Rohde 1981. For a review of health conditions in rural Haiti, see also Farmer 1992, chap. 5, and Farmer 1996a.
5. The lack of interest in tuberculosis has been the subject of much commentary. Laurie Garrett also captures nicely some of the professional attitudes toward other topics of interest to me: “If many young scientists in the mid-1960s considered bacteriology passé—a field commonly referred to as ‘a science in which all the big questions have been answered’—the study of parasitology was thought to be positively prehistoric” (Garrett 1995a, p. 37). The young scientists of the mid-1960s

were, of course, my professors in the early 1980s. I should add, however, that any faculty as large as that of Harvard Medical School has committed and enthusiastic exceptions to this rule, and I am grateful to Arnie Weinberg, Jamie Maguire, Ed Nardell, Bob Moellering, and the late Ed Kass for their steering.

6. I have explored the differences between charity, development, and social justice efforts in Farmer 1995b.

7. Calling such positions "Luddite critiques" is, in a sense, generous, since many who espouse them are discussing the health conditions of people living in poverty. That is, they deem advanced technologies too expensive (not "cost-effective") specifically for the poor. These positions are, as noted, frequently encountered in what is now termed "international health"; they are endemic among the development set. Too seldom do these professionals oppose the lavish deployment of expensive technologies in their own—our own—communities.

8. See Chapter 5 for more information about the village. The history of the dam project and its effects on the people of Do Kay are documented in Farmer 1992.

9. For an attempt at drawing a Wallersteinian analysis of Haiti's place in the global economy, see Farmer 1988b. Like many anthropologists, I was attempting to show that locales such as Haiti are not merely "swept up" into global capitalism, but rather formulate local (and quite unforeseen) responses to large political-economic systems. See Mintz 1977 and Roseberry 1988 for elaborations of this position. Dupuy (1997) offers a more comprehensive analysis of Haiti's place in the modern world economy.

10. The work of some of the pioneers *à la* Wallerstein has since been complemented by a number of social theorists who study diverse "cultural phenomena." (One recent sampling is contained in King 1997.) Although it is difficult to classify these writers, "all share, to a greater or lesser extent, at least two perspectives: the rejection of the nationally constituted society as the appropriate object of [scholarly] discourse, or unit of social and cultural analysis, and in different ways and to varying degrees, a commitment to conceptualizing 'the world as a whole'" (King 1997, p. viii).

11. Garrett 1995a, p. 618.

12. Again, this disenchantment was not original; for a discussion of recent theoretical trends in anthropology, see Marcus and Fischer 1986, as well as Escobar 1992, Ortner 1984, and Roseberry 1988.

13. Scheper-Hughes 1993, p. 967.

14. In adopting such an approach, I was following trends widespread in my generation of anthropologists. We were responding to a lack of such analyses: Marcus and Fischer had argued, in a widely read essay, that "an interpretive anthropology fully accountable to its historical and political-economy implications . . . remains to be written" (1986, p. 86).

15. We have jointly explored some of these questions (for example, in Farmer, Robin, Ramilus, and Kim 1991; Farmer and Kim 1991; Farmer and Kim 1996) but

know that others will necessarily remain unanswered. For instance, our own privileged status means that, although we have at times derided the "development set," we critics fit into our own lofty stratum. On this subject, Nancy Rose Hunt (1997) has written compellingly about "AIDS derivatives"—people whose livelihood depends somehow on the suffering of others.

16. For an overview of this work, see "Ten Years of Commitment" 1997. This article (and the *PIH Bulletin*) may be obtained from Partners in Health, 113 River Street, Cambridge, MA 02139.

17. De Cock, Soro, Coulibaly, and Lucas 1992.

18. Pape, Liautaud, Thomas, Mathurin, St Amand, Boncy, Pean, Pamphile, Laroche, and Johnson 1983. For example, we have seen HIV-TB co-infection presenting as tamponade (tuberculous pericarditis), paraplegia (tuberculous osteomyelitis of the spine), and even renal failure (a result of tuberculous nephritis rather than HIV nephropathy). For a detailed account of the presenting illnesses of two hundred patients with HIV disease, see Farmer 1997c.

19. Thanks are owed especially to the sustaining support of Tom White, who has made it possible for us to preferentially serve the destitute sick, and to the Episcopal Diocese of Upper South Carolina, who financed the new in-patient facility.

20. For a review of such patterns in poor urban communities generally, see Geiger 1992 and McCord and Freeman 1990.

21. See Martinez 1980 for an evaluation of the context of internal migration in Peru.

22. Starn 1992, p. 159.

23. Cited in "Peru: Politics and Violence; Sendero's Strategy from Close Up; Study Recommends Looking Beyond 'Terrorist' Label" 1989, p. 5. On the origins of Peruvian peasant revolt, see McClintock 1984 and Palmer 1986. For more on Sendero Luminoso, see Bourque and Warren 1989 and Degregori 1986.

24. These estimates vary. The figure cited comes from Paul Nunn, chief of the Tuberculosis Research and Surveillance Unit of the World Health Organization Global Tuberculosis Programme (see, for example, World Health Organization 1997b). See also Blower, Small, and Hopewell 1996.

25. Zimmerman 1997, p. 45.

26. Centers for Disease Control and Prevention 1992.

27. In a study of trends in U.S. tuberculosis from 1993 to 1996, 33 percent of patients with culture-positive tuberculosis and susceptibility results were foreign-born (Moore, Onorato, McCray, and Castro 1997).

28. See Farmer, Bayona, Becerra, et al. 1997. This work would not have been possible without the pragmatic solidarity of both Tom White and the Massachusetts State Laboratory Institute's Mycobacteriology Laboratory.

29. See Alexander 1997.

30. Farmer, Bayona, Shin, Alvarez, Becerra, Nardell, Nunez, Sanchez, Timperi, and Kim 1998.

31. Whether the concept of nation-state functions as an analytic framework or an ideology is open to debate. Wallerstein observes that, in the current historical system, "one key geocultural value has been that every state should be a nation. This is what we mean by 'citizenship,' and it forms in turn the basis of the widely accepted myth of the primacy and sovereignty (with each state)" (1994, p. 9).

32. See Angell 1997b; Angell justified her analogy by comparing, point by point, the AIDS trials to the infamous Tuskegee syphilis study. Angell was taken to task for this comparison by prominent figures in the scientific community (see, for example, Varmus and Satcher 1997), and two influential AIDS specialists resigned from the editorial board of the *New England Journal of Medicine* (see Saltus 1997). The debate continued on the front page of the *New York Times* with an exploration of the ironies of U.S.-funded AIDS research in the Ivory Coast (see French 1997). See also Lurie and Wolfe's original critique (1997) and Angell's editorial in the *New England Journal of Medicine* (1997a).

33. A sharply worded editorial in *Lancet* questioned the "ethics industry": "Did ethicists know nothing about these trials (which seems unlikely, given their persistent rooting for ethically dubious medical practices), or was the fate of impoverished Africans thought not worthy of ethical consideration?" ("Editorial: The Ethics Industry" 1997).

34. Anthropologists, in a zealous quest to promote cultural relativism, have at times contributed to this confusion. For example, Hammel (cited in Handwerker 1997, p. 799) asks, "By what principle short of imperialism do we insist on the application of civil or human rights in societies that have not come to these ideas through their own histories?" In so doing, he contributes to the two-worlds myth mentioned earlier. In most cases, the societies in question, and thus the ethically objectionable practices in question, are tightly linked to the (often powerful) society of the observing anthropologist. In an increasingly connected world, radical cultural relativism persists in the face of overwhelming evidence that we inhabit a single world. In adopting a world-systems approach to medical ethics, it is important not to erase the culturally specific experiences of any local moral world. As Kleinman notes, "Radical cultural relativism is a serious misinterpretation of what ethnography, cultural analysis, and cross-cultural comparison have contributed: the idea that before we apply an ethical category we hold to be universal, we had better understand the context of practice and ideas that constitute a local moral world" (1995a, p. 1672).

35. Saba and Ammann 1997.

36. Wallerstein 1995, p. 269.

CHAPTER 2

1. Morse 1995, p. 9.

2. Lederberg, Shope, and Oaks 1992, pp. 34-112. Oldstone (1998) takes a similar broad view of the emergence of viral hemorrhagic fevers.

3. Morse 1995.
4. Eckardt 1994, p. 409.
5. Levine 1964.
6. *Ibid.*
7. Garrett 1995a, p. 47.
8. Levine 1964, p. 3.
9. For a helpful look at malaria as a reemerging disease, see Olliaro, Cattani, and Wirth 1996. For a critical review of recent malaria-control failures, see Garrett 1995a, chap. 2.
10. Note that mine is a fairly innocent rereading of the term "tropical medicine," which has well-known roots in the colonial enterprise. Sheldon Watts offers a more trenchant and informed reevaluation of tropical medicine. He writes: "From its very onset tropical medicine was thus an 'instrument of empire' intended to enable the white 'races' to live in, or at the very least to exploit, all areas of the globe" (1998, p. xiii). See also Cueto 1992 and Solórzano 1992.
11. See Frenk and Chacon 1991. See also Kleinman's excellent critique of "objectivity" in international health (Kleinman 1995b, pp. 68-93).
12. See Gwatkin and Heuveline 1997.
13. McCord and Freeman 1990.
14. Satcher 1995, p. 3.
15. MacKenzie, Hoxie, Proctor, et al. 1994.
16. Lurie, Hintzen, and Lowe 1995.
17. World Health Organization 1992a; McCarthy, McPhearson, and Guarino 1992.
18. Goma Epidemiology Group 1995.
19. McMichael 1995, pp. 633-34.
20. Bifani, Plikaytis, Kapur, Stockbauer, Pan, Lutfey, Moghazeh, Eisner, Daniel, Kaplan, Crawford, Musser, Kreiswirth 1996.
21. B. Kreiswirth, personal communication to the author.
22. Johnson, Webb, Lange, and Murphy 1977.
23. Lederberg, Shope, and Oaks 1992, p. 223.
24. Preston 1994, p. 68.
25. *Ibid.*, p. 71.
26. The 1978 report by the World Health Organization also underlined (if less eloquently than Richard Preston) the failure to follow contact precautions. "In some cases," observes Preston, "the medical system may intensify the outbreak, like a lens that focuses sunlight on a heap of tinder" (1994, p. 68).
27. Garrett 1995b.
28. Lederberg, Shope, and Oaks 1992, p. 213.
29. Ryan 1993, p. 384.
30. DiBacco 1998.
31. Iseman 1985, p. 735.
32. Bloom and Murray 1992.
33. Murray 1991, p. 150.

34. Snider, Salinas, and Kelly 1989, p. 647.
35. Ibid.
36. Friedman, Williams, Singh, and Frieden 1996.
37. Ott 1996, p. 158.
38. Ibid., p. 157.
39. McKenna, McCray, and Onorato 1995, p. 1073. Historian Katherine Ott notes sharply, "It is not being foreign-born that puts a person at risk but the likelihood of repeated exposure to risk, compounded by poverty and ill health" (1996, p. 163).
40. See Farmer 1992.
41. Farmer 1990b.
42. Mann, Tarantola, and Netter 1992, p. 1.
43. Lederberg, Shope, and Oaks 1992, p. 39.
44. United Nations Development Program 1992, p. 13.
45. Sampson and Neaton 1994, p. 1100. They missed one study, however, as did my co-authors and I in our 1996 review (Farmer, Connors, and Simmons 1996). In a short communication published in 1990, Krueger, Wood, Diehr, and Maxwell reported from Seattle "an independent effect of self-reported income on HIV-antibody status." They get to the point in their conclusion: "Since poverty spans the lines of age, ethnicity and sexual orientations, programs targeted specifically to the impoverished may be difficult to devise and implement" (p. 813).
46. Chaisson, Keruly, and Moore 1995; Farmer, Connors, and Simmons 1996; Fife and Mode 1992; Wallace, Fullilove, Fullilove, et al. 1994.
47. Waldholz 1996. Some of the newer agents are even more costly.
48. Zinsser 1934, p. 87.
49. For case studies of the ways in which anthropologic methods and concepts can inform epidemiology, see Janes, Stall, and Gifford 1986; see also Inhorn and Brown 1997. In addition, I critically reexamine the epidemiology of HIV in the Caribbean in Chapters 4 and 5 of this book.
50. Centers for Disease Control and Prevention 1993a.
51. Field 1995; Patz, Epstein, Burke, and Balbus 1996.
52. McMichael 1995, p. 634. See also Krieger and Zierler 1996.
53. Garrett 1995b, p. 147. Garrett's comprehensive and engaging *The Coming Plague* (1995a) does an excellent job of highlighting many of the social factors central to disease emergence. See also the essay by Poinsignon, Marjanovic, and Farge (1996).
54. In addition to the Institute of Medicine publications, see also the statements by the Centers for Disease Control and Prevention (1994a) and by the National Academy of Science (Roizman 1995).
55. See Wilkinson's 1996 review of the mechanisms by which inequality and the resulting lack of social cohesion adversely affect health in "developed" societies. The topic has also been explored by Aiach, Carr-Hill, Curtis, and Illsley (1987) and by Fassin (1996a).

56. Krieger, Rowley, Herman, Avery, and Phillips 1993, p. 99. On this topic, see also Navarro 1990 and Marmot 1994.
57. Satcher 1995, p. 2.
58. Wilson 1995, p. 39.
59. Haggett 1994.
60. Horton 1995, p. 790.
61. Warner 1991, p. 242.
62. Small and Moss 1993.
63. Levins 1995, p. 50.
64. Lederberg, Shope, and Oaks 1992, p. 33.
65. Latour 1988, p. 243.
66. World Health Organization 1992b.
67. Berkelman and Hughes 1993, p. 427.
68. Eisenberg and Kleinman 1981, p. 11.

CHAPTER 3

1. Farmer, Connors, and Simmons 1996.
2. Centers for Disease Control and Prevention 1981.
3. See Oppenheimer 1988 for a review of how data gathering was structured in the early years of the epidemic.
4. Langone 1985, p. 52. As Paula Treichler points out concerning this essay, "Though more vivid and apodictic (i.e., presented as unarguable), Langone's conclusion parallels the conclusion of many scientists" (1988, p. 250, n. 72).
5. For a review of data documenting these trends, see Slutsker, Brunet, Karon, et al. 1992, pp. 610-14. It should be noted, however, that changing AIDS incidence was patterned among gay men: decreases were registered among those who were white and middle class, whereas for gays of color, as well as for those who were poorer, no such declines occurred. See Lemp, Hirozawa, Givertz, et al. 1994; Osmond, Page, Wiley, et al. 1994.
6. Cited in Treichler 1988, p. 193. The image was epidemiologically inaccurate as far as HIV was concerned—white, yuppie couples were not those falling ill with heterosexually acquired HIV infection—but was probably accurate in its depiction of which "us" concerned the editors of the magazine.
7. Treichler 1988.
8. Fumento 1993, p. 32. The first edition of Fumento's book was published in 1990. The 1993 paperback edition is prefaced with unrepentant claims that heterosexual AIDS remains a myth.
9. Slutsker, Brunet, Karon, et al. 1992, pp. 612, 613.
10. See Selik, Chu, and Buehler 1993. In 1991, the CDC reported that in fifteen U.S. cities AIDS had become the leading cause of death among women of the ages 25 to 44.

11. Treichler 1988, p. 193.
12. An editorial in the *American Journal of Public Health* (Stein 1994) would seem to support these claims, as it notes that only at the 1994 HIV/AIDS conference in Yokohama were women's voices at last heard.
13. See Centers for Disease Control and Prevention 1995; Gwinn, Pappaioanou, George, et al. 1991; Wasser, Gwinn, and Fleming 1993. For a comprehensive review, see Farmer, Connors, and Simmons 1996, chap. 2.
14. These figures are taken from reports by the U.S. Centers for Disease Control and Prevention and from the overview by Mann, Tarantola, and Netter (1992). Also see Centers for Disease Control and Prevention 1997, p. 37, which details a male:female HIV infection ratio of about 3:1; as expected, this report merely confirms—tardily, in my view—the points raised in this text and in Farmer, Connors, and Simmons 1996.
15. Global AIDS Policy Coalition 1995.
16. United Nations Development Program 1992, p. 2.
17. World Health Organization 1995b.
18. For more ethnographic detail about Darlene's story and the effect of AIDS in this community, see Pivnick 1993 as well as Pivnick, Jacobson, Eric, et al. 1991. The sociography of AIDS in New York is compellingly detailed in the work of Mindy and Robert Fullilove (see, for example, Fullilove 1995; Fullilove, Fullilove, Haynes, et al. 1990; Fullilove, Lown, and Fullilove 1992), Michael Clatts (1994; 1995), Alisse Waterston (1993), Samuel Friedman (1993), Donald DesJarlais (DesJarlais and Friedman 1988; DesJarlais, Friedman, and Ward 1993; DesJarlais, Padian, and Winklestein 1994), and Rodrick Wallace (1988; 1990; Wallace, Fullilove, Fullilove, et al. 1994; Wallace, Huang, Gould, and Wallace 1997; Wallace and Wallace 1995), among others.
19. For more on sexual unions in rural Haiti, see Chapter 5 of this volume as well as Allman 1980 and Vieux 1989.
20. See the fine ethnographic study by Sarthak Das (1995), who collected the material presented here. For overviews of the AIDS situation in India, see Farmer, Connors, and Simmons 1996, chap. 2; Naik, Sarkar, Singh, et al. 1991; Mathai, Prasad, Jacob, et al. 1990.
21. See Hunter 1995, p. 37.
22. Mitchell, Tucker, Loftmann, and Williams 1992; cited in Schneider and Stoller 1995, p. 4.
23. Centers for Disease Control and Prevention 1995. For a review of these data, see Lewis 1995, p. 57.
24. Preliminary data from this study, known as the Human Immunodeficiency Virus Epidemiology (HER) study, suggest that 60 percent of the patients were African American, 17.5 percent Latina, and 21.5 percent white (Paula Shuman, personal communication to the author). See also Smith, Warren, Vlahov, Schuman, Stein, Greenberg, and Holmberg 1997.
25. Wallace 1988.

26. See Fullilove 1995, p. 46, and Fullilove, Fullilove, Haynes, et al. 1990. The Fulliloves draw heavily on the work of Wallace (e.g., 1988 and 1990). See also the 1990 study by McCord and Freeman, cited in Chapter 2, which reports that for some groups age-specific mortality rates are higher in Harlem than in Bangladesh. For an excellent and responsible ethnographic account of injection drug users in New York, see the work of Anitra Pivnick, cited earlier (1993; Pivnick, Jacobson, Eric, et al. 1991), and that of Alisse Waterston (1993). For an overview of AIDS in U.S. African American communities and public health responses, see McBride 1991 as well as Wilson and Pounds 1993.
27. For an overview of the study, see Farmer 1995a.
28. See the review by Das (1995).
29. See the account by Shyamala Nataraj (1990) and the helpful review by Priscilla Alexander (1995).
30. Denison 1995, p. 205.
31. Ward 1993, p. 61.
32. Schoepf 1993, p. 57.
33. Ellerbrock, Lieb, Harrington, et al. 1992, p. 1707; emphasis added.
34. The women in the HER study have even lower per capita incomes (Paula Shuman, personal communication to the author).
35. On the rural-urban distribution of AIDS, see Wasser, Gwinn, and Fleming 1993. The HER study also suggests that geography as a determinant of AIDS risk is far less significant than many other criteria. Although results from this study have not yet been published, the "risk profiles" and AIDS outcomes of the women enrolled in it are similar to those of the women studied in Florida, although all the women in the HER study are from urban settings scattered across the United States (Paula Shuman, personal communication to the author).
36. See, for example, Miller 1993.
37. Zierler 1997, p. 209. Zierler later humanely adds: "These strangling forces of disenfranchisement are likely to include partners of women as well, given class and racial/ethnic distribution of women most at risk for HIV and violence. People who are violent against women may have experienced assaults against their own humanity, through racial discrimination, economic impoverishment and the social alienation that accompanies it" (p. 217).
38. Treichler 1988, p. 194.
39. *Ibid.*, p. 207; emphasis added.
40. For more about this group and about their AIDS prevention efforts, see Farmer, Connors, and Simmons 1996, chap. 8, "Zanmi Lasante" entry; see also Farmer 1997b. The document quoted in the text is my translation.
41. Many other assessments concur: "It is worth noting that despite the portrayal of prostitute-as-vector, as of January 1989, in the United States, '... there [had] been no documented cases of men becoming infected through contact with a specific prostitute'" (Carovano 1991, p. 136).

42. Ward 1993, p. 60.
43. Wyatt 1995.
44. Grover 1988, p. 30.
45. The effects of these (witting and unwitting) obfuscations on explorations of suffering are examined in Farmer 1996b. For an overview on the inattention to class in U.S. health data, see Krieger and Fee 1994 as well as Navarro 1990.
46. Schoepf 1993, p. 59. For a critical rereading of the literature on drug addicts in the United States, see Waterston 1993 and Bourgois 1995.
47. See Krieger, Rowley, Herman, Avery, and Phillips 1993, p. 99.
48. Nyamathi, Bennett, Leake, et al. 1993, p. 68.
49. *Ibid.*, p. 70.
50. Holmes and Aral 1991, p. 337. It should be noted, however, that these interventions do not really square with these authors' excellent analysis of the nature of the problem. See, for example, the volume in which the Holmes and Aral essay appears (Wasserheit, Aral, and Holmes 1991).
51. Denison 1995, p. 205. This phenomenon is by no means unique to AIDS. Waterston powerfully argues that street addicts, too, "have, de facto, joined hands with the larger public in *believing* the ideology of deviance and the myth of the defiant dope fiend. As such, their roles in social reproduction are obscured, actual resistance is subverted, and other alternatives are suppressed" (1993, p. 245).
52. A 1994 study conducted in the state of Nebraska revealed that a single woman with two children needed an annual income greater than \$21,887 to make ends meet—about \$9,000 more than the 1994 federal poverty level. "These numbers are a conservative estimate of a decent but no-frills standard of living," noted the report's author. "There's no room here for savings to buy a home, pay for college or build up a nest egg for retirement—all items which have typically defined a middle-class standard of living" ("Federal Poverty Level" 1994, p. 9).
53. Polakow 1995b, p. 592. See also Polakow 1995a. For more on this subject, refer to Lykes, Banuazizi, Liem, and Morris 1996, an excellent collection. Other important studies of this subject include those by Kluegel and Smith (1986) and Morris and Williamson (1982).
54. In a moving and lucid essay, William Ryan (1971) explores the theme of blaming the victim and its significance in twentieth-century American thought. On blaming the victim in the context of the AIDS pandemic, see Farmer 1992, pt. 4. See also the studies by Brandt (1988), Kraut (1994), and Zyporyn (1988).
55. See Plummer 1998. For more on the reduction of HIV transmission through effective treatment of sexually transmitted diseases, see Laga, Alary, Nzila, et al. 1994; Laga, Manoka, Kivuvu, et al. 1993; and Grosskurth, Mosha, Todd, et al. 1995.
56. For an overview of these studies, which come from both Europe and North America, see the recent work of Don DesJarlais and co-workers (DesJarlais and Friedman 1988; DesJarlais, Friedman, and Ward 1993; DesJarlais, Padian, and Winklestein 1994).

57. For examples of AIDS-related repression against sex workers, and for insights concerning the importance of organization among prostitutes, see the papers by Priscilla Alexander (1988, 1995) and Gloria Lockett (1995). It is important to underline the enormous differences in the constraints faced by sex workers in different settings. As Alexander (1995, pp. 107-13) shows, prostitutes have had an easier time organizing in Europe, North America, and Australia; the lot of women in the sex industry in poor countries has been far bleaker. Within poor countries, there is also immense variation in the nature of sex work.

58. Alexander 1995, p. 105; Alexander provides an excellent overview of the effects of providing poor care to sex workers.

59. Several studies have investigated the underrecognition of HIV infection among poor women living in the United States. Schoenbaum and Webber (1993), for example, reported that in one Bronx emergency room serving the poor, only 11 percent of women were assessed for HIV risks. Other studies continue to reveal significant variation in the knowledge of AIDS management in the United States, with the expected attendant results. See Farmer, Connors, and Simmons 1996, chaps. 4 and 7, for an overview.

60. Centers for Disease Control and Prevention 1995.

61. These are preliminary data from the HER study and were obtained unpublished from the CDC. Some of the data were published in Smith, Warren, Vlahov, Schuman, Stein, Greenberg, and Holmberg 1997.

62. An important study by Chaisson, Keruly, and Moore suggests that if first-rate HIV care is provided to a cohort of poor persons, then "access to medical care is a more important predictor of survival than are sex, race, and income level" (1995, p. 755). This is a remarkable claim and, if true, heartening news for physicians and other providers. It is particularly important coming from one of the groups that in 1991 reported significant race-based differences in outcomes (Eastbrook, Keruly, Creagh-Kirk, et al. 1991).

63. See Nina Glick-Schiller's 1993 study of this phenomenon.

64. In July 1997, the CDC reported that 30,700 U.S. citizens died from AIDS during the period from January to September of 1996, which was 19 percent fewer than the 37,900 who had died during the same period in 1995. "We have entered a new era in the HIV epidemic," announced the CDC. As might be expected, however, these gains were not experienced evenly: AIDS mortality dropped 22 percent among gay men but only 7 percent among women; it dropped 28 percent among whites but only 10 percent among blacks and 16 percent among Hispanics. See "Significant Drop Seen in AIDS Cases" 1997; see also Fleming 1996. For more on the implications of these statistics for women, see Stolberg 1997.

65. Although there are, as yet, no studies of the rates of HIV transmission in serologically discordant couples in which the infected partner is receiving highly active antiretroviral therapy, most AIDS clinicians believe that an undetectable viral load in plasma signals suppression in other tissues and fluids. It is of note,

however, that even among patients receiving these regimens, suppression of plasma viremia has not prevented recovery of replication-competent virus from CD4-positive T-lymphocytes. See, for example, Finzi, Hermankova, Pierson, et al. 1997; and Wong, Hezareh, Günthard, et al. 1997.

66. Das 1995, p. 8.

67. Hollibaugh 1995, p. 225. Hollibaugh's essay does not cite data to suggest that lesbians of color account for a large number of the U.S. women living with HIV, but her comments are helpful in their clarity and candor. Other writers do underscore divisions between white and black feminists. "When it came down to it," notes Veronica Chambers, an African American feminist, "I could not trust most white women to have my back" (1995, p. 25).

68. Lee 1995b, p. 205. Nancy Krieger and Sally Zierler point out that "although women, as a group, may share experiences of being biologically female, these experiences occur in diverse gendered societies, located within a global economy, and simultaneously split, internally, by social class, race/ethnicity, and other social divisions" (1995, p. 251).

69. Schoepf 1993, p. 70.

70. Collins 1990, p. 10.

CHAPTER 4

1. Viera 1985, p. 95. These speculations were republished in a subsequent revised edition of the book, rather unrepentantly, I thought.

2. Kleinman and Kleinman 1997, p. 103.

3. This phrase is the felicitous subtitle of an essay by Allan Brandt (1997).

4. *AIDS and Accusation* (Farmer 1992) was published in a French edition in 1996 as *Sida en Haïti: La Victime Accusée* (Paris: Karthala).

5. For an excellent, harrowing account of the experience of Haitians who were suffering from tuberculosis while in detention at the Krome Avenue facility, see Nachman 1993.

6. Cited in Abbott 1988, pp. 254-55.

7. Dr. Bruce Chabner of the National Cancer Institute, cited in the *Miami News*, 2 December 1982, p. 8A.

8. The physicians also made the following, apparently offhand, comment: "If the syndrome originates in rural people, and it seems likely that it does, it occurs among those who have had little or no direct or indirect contact with Port-au-Prince or other urban areas" (Moses and Moses 1983, p. 565; emphasis added). As Chapter 5 describes, no data ever existed to suggest that AIDS spread from rural to urban Haiti.

9. Métraux [1959] 1972, p. 15.

10. Glick-Schiller and Fouron 1990, p. 337.

11. The exoticization of Haiti, especially as regards U.S. foreign policy, is the subject of Farmer 1994. The elaboration of North American folk models of Haiti and Haitians is the subject of an excellent and comprehensive review by Lawless (1992).
12. The first description is cited in Allman 1989, p. 81; the second is from Lief 1990, p. 34.
13. In *The Uses of Haiti* (Farmer 1994), I explore the symbolic uses of Haiti over the course of the past five centuries.
14. The World Bank defines "generalized epidemic" in the context of HIV as a situation in which "5 percent or more of women attending maternity clinics are infected" (World Bank 1997). According to the latest available statistics, Haiti's rate of infection was 8.4 percent (1993), Guyana's was 6.9 percent (1992), and Brazil's was 5.1 percent (1996); no other country in the Americas topped 3.6 percent (World Health Organization 1998).
15. Liautaud, Laroche, Duvivier, and Péan-Guichard 1983.
16. Oncologists initially suspected that Kaposi's was somehow related to previous infection with cytomegalovirus. For a review of data on this topic, see Groopman 1983. For a study revealing a lack of association of cytomegalovirus with endemic Kaposi's, see Ambinder, Newman, Hawyard, Biggar, et al. 1987. More recently, evidence has been reported for a causative role for human herpesvirus 8 in Kaposi's (André, Schatz, Bogner, et al. 1997).
17. See Pape, Liautaud, Thomas, Mathurin, St Amand, Boncy, Péan, Pamphile, Laroche, and Johnson 1983.
18. In rural Haiti, our own work eventually revealed a similar preponderance; see Farmer 1997c.
19. Pape, Liautaud, Thomas, Mathurin, St Amand, Boncy, Péan, Pamphile, Laroche, and Johnson 1983, p. 949.
20. *Ibid.*, p. 948.
21. Stephen Murray (personal communication to the author; see also Murray and Payne 1988 as well as Payne 1987) poses sharp questions regarding the statistics used in various publications by Haitian researcher-physicians, including Pape and his GHESKIO co-workers. For example, Murray notes that it is not possible to go from an *N* of 34, of whom 13 are bisexual, to an *N* of 38, of whom 19 are said to be bisexual (compare Pape, Liautaud, Thomas, Mathurin, St Amand, Boncy, Pean, Pamphile, Laroche, and Johnson 1984 with the 1986 study by the same authors). Dr. Murray's queries, which concern the relevance of bisexuality to the epidemic, deserve careful consideration and a reply in the scholarly literature. It should be noted, however, that the GHESKIO group worked with a gradually enlarging pool of ill informants, some of whom later and reluctantly revealed a history of bisexuality. In many countries, early reports on the AIDS epidemic were equally tentative and subject to revision (see Altman 1986, Oppenheimer 1988, Panem 1988, and Shilts 1987).

22. In another review, Pape and Johnson state that "in 1983, the majority of male patients with AIDS were bisexuals who had at least one sexual encounter with visiting North Americans or Haitians residing in North America" (1988, p. 32).
23. The Collaborative Study Group of AIDS in Haitian-Americans (1987) was similarly unable to find a single Haitian with AIDS who had a history of residence or travel in Africa
24. Guérin, Malebranche, Elie, et al. 1984; Johnson and Pape 1989.
25. Johnson and Pape 1989. Although the two populations are by no means comparable vis-à-vis established risk factors for HIV infection, it is instructive to compare these findings to contemporary studies from North America. In one retrospective study of 6875 "male homosexuals and bisexuals," 4.5 percent were already seropositive in 1978 (Jaffe, Darrow, and Echenberg 1985).
26. Johnson and Pape 1989, p. 67.
27. For example, in a letter of response to the 1983 article by Pape and co-workers in the *New England Journal of Medicine*, two researchers from Yale University suggested that "Pape *et al.* do not convincingly exclude malnutrition as a cause of immune deficiency and opportunistic infection in the patients described" (Mellors and Barry 1984, p. 1119). An earlier letter to the same journal suggested that "malnutrition is likely to be present in Haitians recently immigrated to Europe, Canada, or the United States," which might explain AIDS in Haitian infants (Goudsmit 1983, p. 554). The theory was echoed by Beach and Laura (1983) in the *Annals of Internal Medicine*. The advent of antibody tests put an end to suggestions that malnutrition or some other disorder was masquerading as AIDS: among the GHESKIO patients, fully 96 percent of those diagnosed with AIDS on clinical grounds were found to be seropositive for HIV.
28. This is the thesis of Leibowitch's (1985) review, and it is reiterated in Shilt's (1987) best-selling account of the pandemic.
29. Greenfield 1986, p. 2200.
30. Moore and LeBaron 1986, pp. 81, 84.
31. Chaze 1983.
32. Gilman 1988, p. 102.
33. Pape and co-workers also tested sera collected for other diagnostic tests and found that, of 1037 adults phlebotomized during the first six months of 1986 by three commercial laboratories in Port-au-Prince, 8 percent had antibodies to HIV (Pape and Johnson 1988). The health status of these persons was not known, but since none of the three laboratories performed HIV serology at the time of the phlebotomy, the samples had not been collected to diagnose HIV infection.
34. World Health Organization 1998.
35. A group of researchers based in Cité Soleil reported that 8.4 percent of 1240 healthy women receiving prenatal care in 1986 were seropositive for HIV (Halsey, Boulos, Brutus, et al. 1987; Halsey et al. 1990). In 1987, 9.9 percent of 2009 "sexually active women" in Cité Soleil were HIV-positive; in 1989, 10.5 percent of 1074

such women were found to have been exposed to HIV (Brutus 1989b). In Gonaïves, 9 percent of 1795 patients reporting to a clinic that served a predominantly low-income clientele tested seropositive in 1988 (Brutus 1989a).

36. Pape and Johnson 1993, p. S344.

37. Jean et al. 1997, p. 605.

38. Pape and Johnson 1989, p. 70.

39. Pape, Liautaud, Thomas, Mathurin, St Amand, Boncy, Péan, Pamphile, Laroche, and Johnson 1986, p. 7.

40. Ibid.

41. Early in the epidemic, it was noted that another mode of transmission of HIV was through the use of contaminated needles. In Haiti, intramuscular injections may be given either by medical personnel or, in areas without access to medical facilities, by those known as *pikiris* ("injectionists"). Disposable needles and syringes, which are relatively rare in Haiti, are frequently reused without sterilization. Pape and colleagues (ibid.) found that during the five-year period before the onset of AIDS symptoms, 83 percent of male and 88 percent of female AIDS patients had received parenteral medications. Although the figure is by itself suggestive, more than 67 percent of controls (seronegative siblings and friends) also reported injections, suggesting that other factors were involved in HIV transmission.

42. Ibid., p. 6.

43. An analogous mode of transmission has been described for HTLV-1—also a retrovirus—for which female-to-male transmission is thought to occur rarely, if at all. See Kajiyama, Kashwagi, Ikematsu, et al. 1986 and Murphy, Figueroa, Gibbs, et al. 1989.

44. See Peterman, Stoneburner, Allen, et al. 1988. In a colloquium held at Harvard University, Dr. Andrew Moss, director of the Department of AIDS Epidemiology at San Francisco General Hospital, observed that women are ten times as likely to become infected as men upon sexual exposure to HIV: "It worries me that the number of sexual partners is a risk factor for transmission [even among those who use intravenous drugs], and it worries me that the rate is twice as high in women as in men because this indicates that heterosexual transmission, not needle sharing, is responsible for new infections" (Harvard AIDS Institute 1990, p. 5). These data are reviewed in Farmer, Connors, and Simmons 1996.

45. Mellon, Liautaud, Pape, and Johnson 1995. See also Deschamps, Pape, Hafner, and Johnson 1996.

46. McBarnett 1988, p. 71.

47. The persistent conception of women as "AIDS transmitters"—a result, in large part, as Anastos and Marte note, of "deeply ingrained societal sexism as well as racism and classism"—has skewed readings of U.S. epidemiology as well: women with HIV disease "are regarded by the public and studied by the medical profession as vectors of transmission to their children and male sexual partners

rather than people with AIDS who are themselves frequently victims of transmission from the men in their lives" (Anastos and Marte 1989, p. 10). The tendency of North Americans to "blame the victims" is further examined in Farmer 1992, chap. 21. For comprehensive studies of misreadings of HIV epidemiology among women, see Farmer, Connors, and Simmons 1996.

48. The percentage of AIDS patients with Kaposi's decreased from 15 percent of cases occurring before and during 1984 to 5 percent in 1986-88, a shift later noted among North Americans with AIDS; see Franceschi, Dal Maso, Lo Re, Serraino, and La Vecchia 1997.

49. Pape and Johnson 1988, p. 36.

50. In Haiti, the decreasing *relative* significance of same-sex contacts in the spread of HIV is the cause, it seems, for a decreasing incidence of Kaposi's sarcoma. Among North Americans with AIDS, Kaposi's sarcoma is seen almost exclusively among gay men (rather than among injection drug users, for instance).

51. Studies of U.S. press coverage of AIDS suggest some of the reasons for the public perception of Caribbean AIDS as largely a Haitian problem. When CBS News ran a story about HIV transmission in Australia on 25 July 1985, "it was the network's first mention of AIDS outside the United States, Africa, or Haiti" (Kinsella 1989, p. 144).

52. Pape and Johnson 1988, p. 32. Ironically, given the extreme poverty of Haiti, Haitians with AIDS stand a better chance of receiving an adequate workup than do the citizens of several other Caribbean nations. Although Haiti has the weakest health infrastructure in the region, it has had the largest number of cases, and the greatest amount of international scrutiny as "the source of AIDS," and it has sustained the most substantial economic blows relative to GNP. Perhaps as a partial result of these negative forces, Haitian physicians and researchers have been centrally involved in the professional response to the epidemic. Haitians publish more HIV-related studies than do researchers in other Caribbean countries, and the GHESKIO-run national laboratories are among the most experienced in diagnosing AIDS and other forms of HIV disease.

53. Lange and Jaffe 1987, p. 1410.

54. Perez 1992.

55. Garris, Rodríguez, De Moya, et al. 1991.

56. Osborn 1989, p. 126; emphasis added.

57. As my critique of conventional epidemiology suggests, it is perilous to classify people with AIDS into "risk groups." Efforts to do so, however, have supported the hypothesis that very similar trends occurred in the Dominican Republic. In a study by Perez (1992), for example, AIDS incidence among "heterosexuals" increased from 31 percent to 59 percent between 1987 and 1991, while "homosexual" cases decreased from 43 percent to only 6 percent. His conclusion: "The AIDS epidemic in the Dominican Republic seems to have completed its transition from WHO Pattern I to Pattern II."

58. Pape and Johnson 1988, p. 36.

59. Bartholemew, Saxinger, Clark, et al. 1987.

60. Ibid., p. 2606.
61. Merino, Sanchez, Muñoz, Prada, García, and Polk 1990, pp. 333-34. Such has also been the case in Denmark, where sexual contact with a North American gay man, rather than "promiscuity" per se, was an important risk factor in the first cases of AIDS (Gerstoff, Nielsen, Dickmeiss, Ronne, Platz, and Mathiesen 1985).
62. Koenig, Pittaluga, Bogart, et al. 1987, p. 634.
63. Ibid. When questioned by Payne (1987) regarding the ethnographic validity of their observations regarding homosexuality in the Dominican Republic, Koenig and co-workers replied that their "information on the Dominican Republic [came] from on-site visits to hotels that cater to the gay tourist trade. These places are frequented often by visitors from the United States and Caribbean countries" (Koenig, Brache, and Levy 1987, p. 47). In a retrospective assessment that seems to support Koenig's argument, García writes: "In the 1970s, [Puerta Plata] was favored by gay tourists and is considered to be one of the initial ports of entry for HIV in the Dominican Republic. During the 1970s, tourists were predominantly gay, over-sixty males who engaged in sex with local teenaged male prostitutes" (1991, p. 2).
64. García 1991, p. 2.
65. Ibid.
66. Jean et al. 1997, p. 600.
67. Hospedales 1989; Pape and Johnson 1993, p. S342.
68. Carpenter 1930, p. 326.
69. Haitians, notes Métraux, are "irritated—understandably—by the label 'Voodoo-land' which travel agencies have stuck on their home" ([1959] 1972, p. 359).
70. Francisque 1986, p. 139.
71. The protagonist of Graham Greene's *The Comedians* (1966) is a Port-au-Prince hotelier who in 1961 remembers fondly the days when tourists flocked to his bar and made love in the pool. "The drummer's fled to New York, and all the bikini girls stay in Miami now," he explains to two prospective clients. "You'll probably be the only guests I have" (p. 11).
72. Cited in Trouillot 1990, p. 200.
73. Barros 1984, p. 750.
74. Cited in Altman 1983, p. 1.
75. Abbott 1988, p. 255.
76. Métellus 1987, p. 90.
77. Greco 1983, p. 516.
78. d'Adesky 1991, p. 31.
79. Cited in Moore and LeBaron 1986, p. 82.
80. Murray and Payne 1988, pp. 25-26. Payne had previously observed that "several gay travel guides, such as the *Bob Damron Guidebook* for 1982, contain as many as ten entries for the Bahamas, but only four for the Dominican Republic and one for Haiti" (1987, p. 47). Significantly, as Lange and Jaffe (1987) note, the AIDS attack rate in the Bahamas was then even higher than that in Haiti.

81. Guérin, Malebranche, Elie, et al. 1984, p. 256.
82. Ibid. Interestingly, Murray and Payne cite an American journalist's interview with Guérin and not the research published in the *Annals of the New York Academy of Sciences*: "At the Haitian end of the hypothesized transmission vector, Dr. Jean-Michel Guérin of GHESKIO told [journalist Anne-Christine] d'Adesky that 'all his patients—without exception—had denied having sex with tourists'" (1988, pp. 25-26). It is important to note that the *Annals* article, which brought together the research of ten physicians, clearly specifies which patients acknowledged sexual relations with gay tourists from North America. It is thus evident that Guérin meant that these patients *initially* denied such contacts. As described earlier, this initial denial was registered among other Haitians who were ultimately shown to have had histories of homosexual contact. It is not clear why such a misreading persisted, but d'Adesky has abandoned this tack, as her later essay underlines the sex-for-money exchanges that took place between tourists and poor Haitian men; see d'Adesky 1991, p. 31.
83. Langley 1989, p. 175.
84. Patterson 1987, p. 258.
85. See the summaries of trade statistics and their directions in International Monetary Fund 1984. Similar exercises have helped reveal other socioeconomic webs that are important to the shape of the AIDS pandemic. For example, geographer Peter Gould links the density of air traffic in and out of Abidjan, Côte d'Ivoire, to the transnational spread of HIV in and across Europe and Africa (Gould 1993, p. 82).
86. Liautaud, Pape, and Pamphile 1988, p. 690. Even by 1997, the HIV infection rate had increased only marginally in Cuba to 0.013 percent, with about 1,400 reported in a country of 11 million (World Health Organization 1998). Due largely to political upheaval during the late 80s and early 90s—events that have themselves favored increased transmission of HIV—there have been no recent serosurveys in Haiti. In 1997 the WHO estimated nationwide seroprevalence at 5 percent of the adult population, which would make Haiti one of the hemisphere's only countries with a "generalized epidemic" (World Health Organization 1998; see also Deschamps, Pape, Hafner, and Johnson 1996). Note that this figure of five percent aggregates rural and urban seroprevalence statistics; since rural areas are less affected, in relative terms, it may be taken as a certainty that the incidence of HIV in Haitian cities has risen significantly over the last decade. The forward march of HIV into rural Haiti will be explored in the next chapter.
87. Wolf 1982, p. 4.

CHAPTER 5

1. In their consideration of unequal exchange and the urban informal sector, Portes and Walton (1982, p. 74) designate Haiti as the most rural of all Latin Amer-

ican nations: in 1950, the nation was described as 88 percent rural; in 1960, 85 percent; in 1970, 81 percent.

2. Pape and Johnson 1988.

3. See Farmer 1992.

4. See Allman 1980 and Vieux 1989 for extended discussions of *plasaj*.

5. See Pape and Johnson 1988.

6. Desvarieux and Pape 1991, p. 275.

7. GESCAP (whose name is translated as "Study Group on AIDS in the Peasant Class") was founded with the generous support of the World AIDS Foundation.

8. Given that the staff of the clinic and of Proje Veye Sante are accountable to the communities served rather than to funding organizations or to research institutions, and given the poverty and non-HIV-related sickness in the region, it is not surprising that research as such is not seen as a high priority. In order to meet our obligations to the community, all serologic studies became part of a *dossier préventif*. This instrument included a series of laboratory examinations (such as hematocrit and RPR), a chest radiograph, and a physical examination. Any abnormal findings were to be pursued aggressively; free dental care was also offered as part of the program. This proposal was presented to members of the community in four different public meetings, engendering considerable enthusiasm for the undertaking.

9. One additional young woman, the regular sexual partner of a truck driver, was also found to be seropositive. She died suddenly during the course of the study, however, less than a week after a negative physical examination. Although the cause of death is unclear—she had explosive, watery diarrhea and presented in shock—she is not considered in this cohort.

10. Farmer 1992, p. 262.

11. Feilden, Allman, Montague, and Rohde 1981, p. 6.

12. *Ibid.*, p. 4.

13. Locher 1984, p. 329.

14. Neptune-Anglade 1986, p. 150.

15. "Note that, in the cities, the [economically] active 10-14-year-old girls are essentially all domestics. . . . These 'restaveks' find themselves at the very bottom of the social hierarchy" (*ibid.*, p. 209). My translation.

16. See Farmer 1988b for a review of data concerning the Haitian economy. In a personal communication on 18 September 1998, a desk officer at the US State Department's Haiti desk offered an annual per capita income estimate of \$175 (not adjusted for Purchasing Power Parity); she cited internal IMF memos from April 1998 as her source.

17. Girault 1984, p. 177.

18. *Ibid.*, p. 178. For a critical perspective on more recent "food security" issues, see Woodson 1997.

19. Trouillot 1986, p. 201. My translation.

20. Population Crisis Committee 1992.
21. Moral 1961, p. 173. My translation.
22. Allman 1980.
23. But see Laguerre 1982
24. This is a cursory discussion of a very complex—and changing—subject. For a more complete discussion of sexual unions in Haiti, see Lowenthal 1984, Murray 1976, Neptune-Anglade 1986, Sylvain-Comhaire 1974, and Vieux 1989.
25. United Nations Development Program 1992, p. 6.
26. See Mintz 1964, Neptune-Anglade 1986, and Nicholls 1985.
27. See Murray 1986.
28. Neptune-Anglade 1986, p. 155. My translation.
29. Maria de Bruyn offers a helpful review of these issues as they affect women in developing countries. She writes: "Even if they dare suggest avoiding risky sexual acts or using condoms, they often encounter male refusal, are accused of adultery or promiscuity (the desire to use condoms being interpreted as evidence of extramarital affairs), are suspected of already being infected with HIV or are said to accuse their partners of infidelity" (1992, p. 256). The mechanisms by which gender inequality conspires with poverty to enhance women's risk for HIV are the subject of Farmer, Connors, and Simmons 1996.
30. Desvarieux and Pape 1991, p. 277.
31. Farmer 1992.
32. Collaborative Study Group of AIDS in Haitian-Americans 1987, p. 638.
33. On American "folk models" of Haitians, see Lawless 1992 and, as related to AIDS, Farmer 1992.
34. The word "*sida*" is derived from the French acronym SIDA, for *syndrome immunodéficience acquise*. The French acronym is commonly rendered as S.I.D.A., SIDA, or Sida; *sida* is the Creole orthography. I have adopted the latter here in order to reflect the substantial difference between the terms as used in different national and cultural settings.
35. See Farmer 1996a for a more complete discussion of "Haiti's lost years."
36. Farmer 1996a examines the effects of the 1991 coup d'état on rates of HIV diagnosis in the Kay region.
37. de Bruyn 1992, p. 253.
38. See, for example, Laga, Manoka, Kivuvu, et al. 1993.
39. Poor, young women may be especially at risk of genital trauma: "Non-consensual, hurried or frequent intercourse may inhibit mucous production and the relaxation of vaginal musculature, both of which would increase the likelihood of genital trauma. A lack of control over the circumstances in which the intercourse occurs may increase the frequency of intercourse and lower the age at which sexual activity begins. A lack of access to acceptable health services may leave infections and lesions untreated. Malnutrition not only inhibits the production of mucus but also slows the healing process and depresses the immune system" (United Nations Development Program 1992, pp. 3-4).

40. For example, see Liautaud et al. 1992; Deschamps, Pape, Williams-Russo, Madhavan, Ho, and Johnson, 1993; and Behets, Desormeaux, Joseph, et al. 1995.
41. We do know that in one study of one hundred women presenting to our women's health clinic in 1991 fully 25 percent had trichomoniasis. GESCAP thanks Dr. Anna Contomitros for conducting this study, which included Pap smears. See also Fitzgerald 1996.
42. Data from GHESKIO (e.g., Deschamps et al. 1992) suggest, however, that those ill with HIV disease continue to have sex.
43. DiPerri, Cade, Castelli, et al. 1993.
44. Lief 1990, p. 36.
45. For a review of recent anthropological writings on AIDS, see Farmer 1997b.
46. Benoist and Desclaux 1995, p. 363. My translation.

MIRACLES AND MISERY:
AN ETHNOGRAPHIC INTERLUDE

1. Farmer 1992, pp. 43-45. I wrote myself out of this text not so much in naïveté as in reaction to the self-indulgent divulgements of reflexive anthropology, which has often confused the readers' interest in the subject at hand—presumably, the famous Other—with patience for the Self-referential writer.
2. Geertz 1988, pp. 4-5.
3. Kleinman 1995b, p. 76. He continues: "Context and interpersonal dialogue are understood to shape the knowledge so that it is always particular to a local world."

CHAPTER 6

1. Several of the concepts in this chapter—cultural model, prototypical model, semantic network, social construction, and so on—have been used in different ways in medical anthropology. This chapter is informed by the critique of an "empiricist theory of language," offered by interpretive paradigms (for example, Good and Good 1982) and also by work in cognitive anthropology, which has begun shifting its attention from the formal properties of illness models to their relation to natural discourse and thus to context and performance characteristics of illness representations (see, for example, Price 1987). A focus on *lived experience* is crucial to this view, even in a study of the emergence of a collective representation. (For a forceful statement of such a position, see Kleinman and Kleinman 1989.) We can now make headway by merging these groups of concerns with an accountability to history and political economy. One important "bridge concept" might be the cultural model—an idea formalized by cognitive anthropologists seeking to show how "cultural models frame experience, supplying interpretations of that experience and inferences about it, and goals for action" (Quinn and Holland 1987, p. 6).

But as the case of HIV-related disorders shows, cultural models and theories about them need constant correction by the nosological and social environment itself (Farmer and Good 1991).

2. This processual ethnography of changing understandings of AIDS in Do Kay is based on a large body of interviews, most of which are not cited here, although they all inform my understanding of the significance of the comments that are cited. This larger project was initiated in 1983. At least once during each of the subsequent six years, I interviewed the same twenty villagers regarding tuberculosis and AIDS; most of these conversations were tape-recorded. (In 1988, a research assistant took my place with seven of the informants.) During three of these years, a third disorder (*move san*) was also discussed. The taped exchanges were initiated by me and took place in a variety of settings, most often in the informants' houses. Of the twenty adults, two have died, and one has left Do Kay. The interviews were open-ended and usually focused on specific "illness stories." We always discussed the following topics for each of the three illnesses: its key features (including typical presentation, causes, course, understandings of pathogenesis when relevant), the appropriate therapeutic interventions, its relation to other sicknesses common in the area, and questions of risk and vulnerability.

In addition to these interviews, the research involved lengthy conversations with all villagers afflicted with tuberculosis and AIDS and the majority of those with *move san*. I also interviewed members of victims' families as well as other key actors in the events described here. These qualitative data were complemented by information from several structured surveys and an annual census, conducted by myself and other members of *Proje Veye Sante*. And, of course, I personally witnessed the changes described here, having spent an average of six months per year in Do Kay since May of 1983.

3. For discussion of the political changes during this period, see Farmer 1994.

4. See Centers for Disease Control and Prevention 1982a and Nachman and Dreyfuss 1986.

5. The anti-Haitian backlash may have been felt as keenly in New York, Miami, Boston, Montreal, and other North American cities in which large numbers of Haitians now reside. See Farmer 1990a, Farmer 1992, and Sabatier 1988 for a review of AIDS-related discrimination against Haitians.

6. Three of the five who had never heard the term were men who "never traveled to Port-au-Prince." Such homebodies are rare in the Central Plateau, whose inhabitants are highly involved in the marketing of produce.

7. In Haiti, market women are known for their up-to-date information. Their "frequent trips to neighboring cities and to Port-au-Prince make [them] aware of everything—not just the rise and fall of prices, but also national events, not only the genuine ones, but the false rumors that spread through the marketplaces" (Bastien [1951] 1985, p. 128). My translation.

8. It should be noted, however, that Ti Malou was widely believed to have *move san*, a common disorder that is treated by herbal medications and not transfusion (Farmer 1988a).
9. For more on *move san*, see Farmer 1988a.
10. Weidman 1978. For more information about the blood paradigm, see also Farmer 1988a and Laguerre 1987.
11. Such commentaries are not without a basis in truth. Ferguson (1987) and Hagen (1982) document the role of *duvaliériste* Luckner Cambronne in a trade in Haitian blood, which was used for medical experiments and for its antibody-rich serum. Thus, the antigenic challenges of daily life in Haiti could become a source of wealth—though not for the blood donors, who were paid a pittance.
12. See Gaines and Farmer 1986 for a discussion of rhetorics of complaint and their relevance to illness representations. It has long been noted that Haitians have complicated, multifactorial ideas about illness causation. A large body of ethnographic literature shows that rural Haitians often entertain explanatory frameworks that make room for “naturalistic” causation as well as lines of causality dominated by human agency. Particularly relevant is Coreil’s (1980) study of an anthrax epidemic in rural Haiti.
13. For discussion of health care practitioners in rural Haiti, see Coreil 1983 and Laguerre 1987.
14. As Sabatier notes, “Syphilis was referred to by the Spanish as ‘the sickness of Hispaniola,’ believing it to have come from what is now Haiti when Columbus returned from his voyage to the Americas” (1988, p. 42).
15. The advent of AIDS to this village is more fully described in Farmer 1992.
16. The term “expedition” is also used to describe this process, which requires the services of a *houngan*, or voodoo priest. In translating the term “*voye yon mò sida*,” I have used the less accurate “send a *sida* death” rather than the more cumbersome “send a dead person who has died from *sida*.”
17. Métraux [1959] 1972, p. 274.
18. This story is told more fully in Farmer and Kleinman 1989.
19. Things do not appear to have changed altogether. Ethnographic research conducted decades ago led Métraux to observe that “in everyday life the threat of charms, sorcery and spells makes it but one more care to be listed with drought and the price of coffee and bananas. Magic is at least an evil against which man is not entirely powerless” ([1959] 1972, p. 269). Hurbon offers a similar insight when he notes that “spells are part of the daily struggle in a world already littered with traps” (1987, p. 260). My translation.
20. See Garro 1988.
21. Good 1977, p. 54.
22. Métraux [1959] 1972, p. 274.
23. Taussig 1980, p. 7.

24. See Moore 1987.

25. This expression is borrowed from Bateson and Goldsby 1988. A similar image has been used by Lindenbaum in her classic study of sorcery and the advent of kuru, another novel infectious disease, in rural Papua New Guinea: "A geography of fear tracks unequal relations" (1979, p. 146).

CHAPTER 7

1. World Health Organization 1996.
2. "TB Returns with a Vengeance" 1996.
3. Ott 1996, p. 157.
4. Bloom and Murray 1992.
5. Ryan 1993, p. 8.
6. Dubos and Dubos 1992, pp. xiv-xv, n. 1.
7. Rosenkrantz is quoted from her introduction to Dubos and Dubos 1992, p. xxi.
8. Feldberg 1995, p. 1.
9. Dubos and Dubos 1992, p. 22.
10. See Farmer, Robin, Ramilus, and Kim 1991; Spence, Hotchkiss, Williams, and Davies 1993.
11. For an in-depth exploration of the effects of *fujishock* on the health of Peru's urban poor, see Kim, Shakow, Bayona, et al. 1999.
12. Current standards would favor initiating empiric treatment with four drugs to avoid the development of resistant strains of *M. tuberculosis*.
13. World Health Organization 1996.
14. McBride 1991.
15. Frieden, Fujiwara, Washko, and Hamburg 1995.
16. Brudney and Dobkin 1991a.
17. Frieden, Fujiwara, Washko, and Hamburg 1995, p. 229.
18. Mahmoudi and Iseman 1993.
19. Cited in Feldberg 1995, p. 214.
20. "Whether as a result of changing definitions of disease, new methods of record-keeping, or actual changes in mortality, the number of recorded deaths dropped by almost one-third between 1850 and 1890" (ibid., p. 13).
21. Ibid., pp. 11-12; emphasis added.
22. Ibid.
23. Ibid., p. 23. Feldberg further notes that many Southern antebellum physicians "believed that the physician could make no greater error than to treat 'negroes' as though they were 'white men in black skins'" (ibid., pp. 24-25). See McBride 1991 for a more thorough review of this subject.
24. Cited in Feldberg 1995, p. 14.

25. *Ibid.*, p. 26. Not all Southern physicians shared the locally dominant explanatory models, however. Feldberg notes that in 1873 one doctor from Richmond, Virginia, trenchantly observed that "the most marked difference between the diseases of the two races is in the far greater prevalence and mortality of tubercular diseases amongst the blacks."
26. For a review, see Rieder 1989.
27. Cited in Feldberg 1995, p. 439.
28. Henry Wiley, cited in Feldberg 1995, p. 30.
29. Dubos and Dubos 1992, p. 210.
30. Cited in Feldberg 1995, p. 101.
31. Cited in *ibid.*, p. 105.
32. *Ibid.*, p. 4.
33. Cited in *ibid.*, p. 4.
34. Rosenkrantz is quoted from her excellent introduction to Dubos and Dubos 1992, p. xxii.
35. Huber cited by Rosenkrantz, in *ibid.*, pp. xxv-xxvi.
36. Cited in McBride 1991, p. 58.
37. Cited in Feldberg 1995, p. 48.
38. Kraut 1994.
39. Cited in McBride 1991, p. 46.
40. On the relationship between xenophobia and tuberculosis, see Kraut 1994.
41. Cited in McBride 1991, p. 61.
42. *Ibid.*, p. 151.
43. *Ibid.*, p. 126.
44. Cited in *ibid.*, p. 129. Preferential attention to polio continued, as Feldberg notes: "In 1949, as polio cases rose to the 'epidemic' rate of 30/100,000, the tuberculous case rate exceeded 90/100,000; in 1951 alone, there were 119,000 new cases of tuberculosis. Tuberculous mortality also exceeded that for polio almost threefold" (1995, p. 2).
45. McBride 1991, p. 151.
46. Michael and Michael 1994.
47. Snider, Salinas, and Kelly 1989, p. 647.
48. Chaulet 1996, p. 7. My translation.
49. Iseman 1985.
50. Farmer, Robin, Ramilus, and Kim 1991.
51. Curry 1968.
52. Frieden, Fujiwara, Washko, and Hamburg 1995.
53. Telzak, Sepkowitz, Alpert, et al. 1995.
54. Cole and Telenti 1995, p. 701s.
55. Reichman 1997, p. 7.
56. Feldberg 1995, p. 38.
57. Krause cited in *ibid.*, p. 107.

58. The term "public health nihilism" was coined by Ron Bayer of Columbia University; it is discussed in Farmer and Nardell 1998.
59. Dubos and Dubos 1992, p. 225.
60. *Ibid.*, p. 207.

CHAPTER 8

1. Third East African/British Medical Research Council Study 1980; Cohn, Catlin, Peterson, Judson, and Sbarbaro 1990; Hong Kong Chest Service/British Medical Research Council 1982; Snider, Graczyk, Bek, and Rogowski 1984; Singapore Tuberculosis Service/British Medical Research Council 1988.
2. See "If More Widely Used" 1997, p. 14.
3. World Health Organization 1997c.
4. Murray and Lopez 1996.
5. See Farmer 1997d for a review of immodest claims of causality about the persistence or reemergence of tuberculosis.
6. Menzies, Rocher, and Vissandjee 1993, p. 33. See also Addington 1979; Fox 1983; Kopanoff, Snider, and Johnson 1988; Yeats 1986; and Haynes 1979.
7. World Health Organization 1991.
8. Snider 1989, p. S336.
9. Wiese 1971, p. 38. Regarding the European introduction of tuberculosis to Haiti, Kiple concurs: "Tuberculosis and bacterial pneumonia apparently were fairly new to the region when the first Europeans arrived—and in fact those Europeans probably brought the diseases to many" (1984, p. 13). The Africans in the Caribbean were not, however, as susceptible as their Indian predecessors; some note that the Africans were also less susceptible than their oppressors. As Kiple writes, "the Spanish quickly noticed how durable [the African slaves] were in the face of illnesses that were felling Indians" (1984, p. 12). Kiple argues that the slaves constituted "an immunological elite as survivors of one of the most formidable disease environments in the world." If this is true, the appalling death rates of the plantations must have been almost wholly due to "work" conditions.
10. Service d'Hygiène 1933, p. 12.
11. Moreau de Saint-Méry 1984, p. 1068. A review of the literature from colonial times and extensive fieldwork in contemporary Haiti led Wiese to assert that "the disease took its place in their medical beliefs and practices, many of which have remained essentially unchanged down to the present" (1971, p. 100).
12. Tardo-Dino 1985, p. 198.
13. Cauna 1984.
14. Foubert 1987, p. 3.
15. Bordes 1979, pp. 16-17; my translation. Bordes fails to note that many of these health workers were not allowed to "bleed or to bandage" white patients; see Moreau de Saint-Méry 1984, p. 559.

16. In a devastating review, Jean-Louis states that only 5 percent of rural Haitians have access to potable water. He then compares this figure to that of neighboring islands: 60 percent in the Dominican Republic; 62 percent in Panama; 86 percent in Jamaica; 99 percent in Trinidad and Tobago; "almost the entire population" in Cuba (1989, p. 14).
17. Feilden, Allman, Montague, and Rohde 1981, p. 1.
18. Dr. Henec Titus, at a conference entitled "Santé, Médecine et Democratie," held on 10 November 1988 in Port-au-Prince, offered the following data: as of late August 1988, 202,700 infants had been born in Haiti during that year; 30,360 were stillborn. Furthermore, 38,000 children aged 1 to 4 years had also perished. Dr. Titus continued: "If we combine these two figures, that would give more than 50,000 deaths per 200,000 births, yielding a mortality of 250 percent. In 1965, during the Decade of Nutrition, I conducted a study on infant mortality, which at that time was estimated at 203 percent. This means that, despite certain progress in the environment, despite the important development of vaccination . . . we have not really improved our situation on this score" (p. 2 of the proceedings of this conference, *Forum Libre* 1). My translation.
19. "Haitian Child Dies Every 5 Minutes" 1987. See the reviews by Beghin, Fougère, and King 1970 and by Feilden, Allman, Montague, and Rohde 1981.
20. Wiese 1971, p. 40.
21. Leyburn 1966, p. 275.
22. United Nations 1949, pp. 70-72.
23. Pan American Health Organization 1967, p. 290.
24. See Feilden, Allman, Montague, and Rohde 1981 for a review of these data.
25. Desormeaux, Johnson, Coberly, et al. 1996.
26. Pape and Johnson 1988.
27. Long, Scalcini, Manfreda, et al. 1991.
28. Scalcini, Carré, Jean-Baptiste, et al. 1990. Until recently, multidrug-resistant strains have not been reported, but this is probably because they have not been sought out. We readily identified eight cases in our small group of patients in the Central Plateau; see Farmer, Bayona, Becerra, et al. 1997.
29. Shears 1988.
30. Wiese 1974.
31. Farmer and Nardell 1998.
32. Proje Veye Sante and the region it serves are described more thoroughly in Farmer 1992.
33. Note that apparent inconsistencies between this essay and Farmer, Robin, Ramilus, and Kim 1991 are the result of an increase in the number of villages served by Proje Veye Sante.
34. Rifampin has since replaced streptomycin in the initial treatment of adults with tuberculosis. The clinic also stocks second-line drugs for culture-proven cases of MDRTB.

35. One person who initially lived in Sector 1 later moved out of the catchment area and was no longer served by a community health worker. This patient, rumored to have died some months after leaving the area, is not considered in any of the data analysis of either group.
36. See Kleinman, Eisenberg, and Good 1978 for a concise review of this methodology. See Kleinman 1995b, pp. 5-15, for his assessment of the methodology's limitations.
37. The preponderance of women waned over subsequent years, suggesting a backlog of untreated women facing significant barriers to care.
38. The presence of acid-fast bacilli in a sputum sample usually signals the presence of active pulmonary tuberculosis. Although it is an imperfect test for tuberculosis—as all patients with extrapulmonary disease and many with pulmonary disease will have falsely negative smears—sputum microscopy is the standard test in most settings in the developing world, including Haiti.
39. Farmer 1990c.
40. Murray, Styblo, and Rouillon 1990.
41. Styblo 1989.
42. Murray, Styblo, and Rouillon 1990.
43. Brudney and Dobkin 1991a; see also Brudney and Dobkin 1991b.
44. Menzies, Rocher, and Vissandjee 1993, p. 36.
45. Reichman 1997, p.11.
46. Chaulet 1987, p. 21.
47. Horton 1995.
48. Sumartojo 1993, p. 1318. Dr. Sumartojo prefers the term "adherence."
49. World Health Organization 1991.
50. Weil 1994.

CHAPTER 9

1. Dubos and Dubos 1992, p. xxxvii.
2. Snider and Roper 1992.
3. Mann, Tarantola, and Netter 1992.
4. In large part because of increasing co-incidence of HIV and TB infections, especially in the poorest parts of the world, Schulzer and co-workers, using mathematical models, predict a 60 percent increase in smear-positive tuberculosis among young adults by the end of the millennium (Schulzer, Fitzgerald, Enarson, Grzybowski 1992). It is this upsurge that led editorialists writing in *Lancet* to ask, "Is Africa Lost?" (Stanford, Grange, and Pozniak 1991).
5. A third mechanism, exogenous reinfection with a resistant strain, has recently been described among those with HIV infection; see Small, Shafer, Hopewell, et al. 1993. Exogenous reinfection may even occur in immunocompe-

tent patients but appears to be rare (Peter Small, personal communication to the author).

6. Farmer, Bayona, Becerra, et al. 1997.
7. Frieden and co-workers recently reported that "the tide is turning" as a result of improved tuberculosis-control strategies; see Frieden, Fujiwara, Washko, and Hamburg 1995.
8. For an excellent overview of the effects of these changes in TB policy, see Brudney and Dobkin 1991b.
9. Garrett 1995a, p. 523.
10. See Goble, Iseman, Madsen, et al. 1993.
11. Iseman 1993, p. 785.
12. For additional information about the incidence of tuberculosis in Haiti, see Chapter 8.
13. Scalcini, Carré, Jean-Baptiste, et al. 1990, p. 510.
14. The case of Robert David led us to search more aggressively for other cases of MDRTB. We discovered six other patients who were also sick with this disease. The resistance patterns in these cases were different from those of the strain that infected Robert David. Two additional cases were referred to us by other clinics.
15. Iseman 1993, p. 784.
16. Scalcini, Carré, Jean-Baptiste, et al. 1990, p. 509.
17. See Weil 1994 for more on the global supply of antituberculous drugs. The situation is even worse in Russia, where the collapse of the Soviet-era TB-control infrastructure has led to increasingly erratic tuberculosis treatment. Acquired MDRTB strains have become epidemic, in part through institutional amplification inside prisons and detention centers; see Englund 1998.
18. Farmer and Kim 1998.
19. Iseman 1985; Maloney, Pearson, Gordon, Del Castillo, Boyle, and Jarvis 1995.
20. Centers for Disease Control and Prevention 1990b.
21. McKenna, McCray, and Onorato 1995.
22. Chaulet 1996, p. 8. My translation.
23. For an ethnographically rich exploration of official silences about the scale of epidemic disease, see Briggs and Briggs 1997.
24. Weis, Slocum, Blais, et al. 1994; Frieden, Fujiwara, Washko, and Hamburg 1995.
25. Patients with cavitary tuberculosis are believed to be highly infectious because each cavity may contain billions of organisms.
26. Rullán, Herrera, Cano, et al. 1996, p. 125.
27. At this writing, I have just returned from a fact-finding mission in Siberia, where outbreaks of tuberculosis in prisons have veered out of control. Attempts to treat all prisoners diagnosed with TB with an empiric regimen of first-line drugs have led to an amplification of resistance—which was already at daunting levels—and low cure rates. In the Tomsk prison system, for example, a 1998

cohort study of 212 prisoners with active tuberculosis reveals that most have been previously treated and that most have drug-resistant disease.

28. Snider, Kelly, Cauthen, Thompson, and Kilburn 1985.
29. DiPerri, Cade, Castelli, et al. 1993.
30. Beck-Sague, Dooley, Hutton, et al. 1992; Pearson, Jereb, Frieden, et al. 1992.
31. Rullán, Herrera, Cano, et al. 1996.
32. Kritski, Ozorio-Marques, Rabahi, et al. 1996.
33. Weis, Slocum, Blais, et al. 1994, p. 1182.
34. Brudney and Dobkin 1991a, p. 749.
35. Weis, Slocum, Blais, et al. 1994, p. 1183.
36. Weise 1974, p. 359.
37. Rubel and Garro 1992, p. 627.
38. de Villiers 1991, p. 72.
39. Nightingale, Hannibal, Geiger, Hartmann, Lawrence, and Spurlock 1990, p. 2098.
40. Packard 1989, p. xvi.
41. Mata 1985, p. 57.
42. *Ibid.*, p. 59.
43. *Ibid.*, pp. 62, 60, 61, 58.
44. *Ibid.*, pp. 62, 63.
45. Barnhoorn and Adriaanse 1992, p. 296.
46. *Ibid.*, pp. 299, 302.
47. *Ibid.*, pp. 291 (emphasis added), 301, 302.
48. Rubel and Garro 1992, p. 630, referring to a paper by R. Lieban (1976); emphasis added.
49. Valeza and McDougall cited in Sumartojo 1993, p. 1314.
50. Rubel and Garro 1992, p. 630.
51. Friemodt-Möller 1968, p. 22. In most studies, improving the quality of services inevitably results in drastically improved outcomes. In discussion of tuberculous meningitis in urban India, where access to care was significantly better, one large study found that "default was not a very serious problem, despite the fact that about half the patients come from outside Madras City. Patients attended punctually on 90% of occasions. Furthermore, in 95% of the remaining unpunctual occasions, drugs were missed for less than a week which, as there was no proper retrieval action, is very commendable. All those who attended late had valid reasons for their unpunctuality" (Ramachandran and Prabhakar 1992, p. 171). See also Grange and Festenstein 1993.
52. Chaulet puts this sharply in an editorial castigating health care professionals for *their* noncompliance: "It is only after these general measures have been applied that we can turn our attention to improving compliance" (1987, p. 20).
53. McKeown 1979. Note, however, that McKeown's position lends itself to the Luddite position I criticize in this book.

54. For sharply divergent interpretations of tuberculosis control, see the disturbing essay by Steven Nachman, an anthropologist who worked briefly among Haitians detained by the U.S. Immigration and Naturalization Service (Nachman 1993). Nachman offers compelling ethnography without making immodest claims of causality. For a review stressing the importance of patients' perspectives, see Conrad 1985. Too few of the papers reviewed underline the enormous difference between failure to adhere to an isoniazid prophylaxis regimen and failure to adhere to treatment for active disease.
55. Collando cited in Rubel and Garro 1992, p. 627.
56. Rubel and Garro 1992.
57. Sumartojo 1993.
58. Onoge 1975, p. 221. Medical anthropologists are not the only ones who lend importance to factors that cannot be considered central in the shaping of tuberculosis pandemics. While René Dubos was at times tough-minded in his assessments, calling TB "the first penalty that capitalistic society had to pay for the ruthless exploitation of labor," he saw the disease as a reflection of the human failure to adapt harmoniously to the environment. This failure was most obvious in the "anonymous gloom of the industrial cities" of the nineteenth century that had replaced the more sensible pastoral lifestyle of the days before the Industrial Revolution: "The most destitute villager in his native land had learned to adorn the dullness and drudgery of existence with bright ribbons and jolly tunes, and with the pageantry of his church." See Dubos and Dubos 1992, pp. 207, 202. René Dubos tended, at times, to adopt a Luddite stance, even after the development of effective antituberculous chemotherapy. As regarded smallpox, he once wrote that "eradication programs will eventually become a curiosity item on library shelves, just as have all social utopias" (cited in Oldstone 1998, p. 41).
59. For a helpful review, see Porter and McAdam 1994.
60. Addington 1979, p. 741.
61. Sumartojo 1993, p. 1312.
62. Rosenkrantz is quoted from her excellent introduction to Dubos and Dubos 1992, p. xxi.
63. See McMichael 1995.
64. Margono, Garely, Mroueh, and Minkoff 1993. Although biological universals are important—cell-mediated immunity wanes during pregnancy—TB is strikingly patterned even among pregnant women. Poor, urban women of color are disproportionately affected among U.S. women. See also Snider 1992. It is important to note, however, that the majority of U.S. cases have in recent years been among men.
65. See, for example, Patel 1987.
66. Farmer 1991.
67. See, for example, the review by Small and Moss 1993.
68. Sumartojo 1993, p. 1318.

69. Rosenkrantz is quoted from her introduction to Dubos and Dubos 1992, p. xxxiv.

CHAPTER 10

1. Of course, estimates of world prevalence and incidence of HIV infection are the subject of much debate. If we rely, however, on the Joint United Nations Program on HIV/AIDS, this estimate of 30 million is conservative. UNAIDS and the WHO have estimated that 5.8 million people were infected with HIV in the course of 1997. "The more we know about the AIDS epidemic, the worse it appears to be," commented Peter Piot, in releasing these figures. "We are now realizing that rates of HIV transmission have been grossly underestimated—particularly in sub-Saharan Africa, where the bulk of infections have been concentrated to date. South Africa now estimates that one in 10 adults are living with HIV—up by more than one-third since 1996. And in Namibia, AIDS now kills nearly twice as many people as malaria, the next most common killer." See "HIV Claims" 1997, pp. 14, 29.
2. "Successes Offer Hope" 1996. Several articles and editorials along these lines appeared in the press. For example, see Warsh 1997; noting the gloom of previous world AIDS conferences, Warsh writes: "From the vantage point of 1997, however, the 15-year search for a treatment has turned out to be—suddenly, amazingly—successful."
3. See Charnow 1996, Stephenson 1996, and Fauci 1996.
4. Barnett 1996.
5. Sanford 1996, p 1.
6. Leland 1996.
7. O'Brien, Hartigan, Martin, et al. 1996.
8. See, for example, Ho 1995.
9. Historian Sheldon Watts puts it well: "The last half-century has seen the triumphal emergence of medicine as a fully scientific discipline of proven effectiveness in curing and preventing life-threatening diseases. Yet it has *also* seen the emergence of a widening gap in the provisioning (and non-provisioning) of effective health services for the privileged few and the underprivileged many" (1998, p. 269).
10. Mann, Tarantola, and Netter 1996.
11. Centers for Disease Control and Prevention 1995.
12. See Bastian, Bennett, Adams, et al. 1993; Lemp, Hirozawa, Cohen, et al. 1992; Easterbrook, Keruly, Creagh-Kirk, et al. 1991; and Hogg, Strathdee, Craib, et al. 1994.
13. Centers for Disease Control and Prevention 1994b.
14. Soto-Ramírez, Renjifo, McLane, et al. 1996.

15. See Farmer, Connors, and Simmons 1996, pt. 2, for a critical review of these hypotheses.
16. Chaisson, Keruly, and Moore 1995, p. 755.
17. Bloom and Murray 1992
18. World Health Organization 1996.
19. Wise 1993, p. 13.
20. Group Interassociatif TRT-5/Traitements et Recherche Thérapeutique 1996.
21. Waldholz 1996, p. 1.
22. Ibid.
23. See Sontag and Richardson 1997, pp. 1, 31.
24. Leland 1996, p. 68.
25. For reviews, see Mushlin and Appel 1977; Wardman, Knox, Muers, and Page 1988. Fortunately, some physicians active in planning HIV care are aware of their inability to predict future compliance. "I don't think we have a right or a scientific background to exclude anyone as a general rule," said Dr. Charles Carpenter, chairman of the National Institutes of Health panel that is writing guidelines for the use of AIDS drugs. "I have been astonished by how many people, including those who are using IV drugs, have been able to stick to the regimen. I don't think we can tell a good or bad candidate in advance" (Sontag and Richardson 1997, p. 31). Recently, a strong appeal for access to highly active antiretroviral therapy for the U.S. poor has come from San Francisco, where Bangsberg and colleagues argue that "clinicians treating an indigent, largely minority population like the homeless should take a determined approach to making effective therapy possible" (Bangsberg, Tulskey, Hecht, and Moss 1997, p. 63).
26. Sanford 1996, p. A12.
27. See Richardson 1997, p. 25.
28. Waldholz 1996.
29. Leland 1996.
30. "For Mississippi AIDS Patients" 1997.
31. Brandt 1988, p. 168.
32. Reichman 1997.
33. Ibid., p. 4.
34. Iseman 1985, p. 735.
35. Hopewell, Sanchez-Hernandez, Baron, and Ganter 1984.
36. Hopewell, Ganter, Baron, and Sanchez-Hernandez 1985.
37. World Health Organization Global Tuberculosis Programme 1997.
38. Weil 1994, p. 124. This opposition has not been subtle. In a May 1998 interview with *TB Monitor* (see "Money Isn't the Issue" 1998), the deputy director of WHO's Global Tuberculosis Programme "singled out for criticism those who advocate treatment for MDRTB patients." I am identified as "chief among critics" of arguments against treating patients with MDRTB.
39. Blower, Small, and Hopewell 1996, p. 500.

40. McKenna, McCray, and Onorato 1995.
41. Economist Intelligence Unit 1997.
42. The "bargain" may have backfired, notes the *New York Times*: the jets, purchased from Belarus, came without a warranty or service contract. See "Peru's Cut-Rate Fighter Jets" 1997.
43. Nancy Tomes has recently written about a "socialism of the microbe," whose proponents argued that the health problems of the poor and the immigrant should be central to the grand project of social revolution; see Tomes 1998, chap. 9.
44. Budd [1874] 1931, pp. 174-75.
45. Hirsh and Kladman 1997, p. 42.
46. Hasan 1996, p. 1055.
47. Rousseau [1755] 1994, pp. 81, 85. "Rousseau is often considered a rebel against inequality," notes Louis Dumont, "but in reality his ideas remained very moderate and were to a large extent traditional" (Dumont 1970, p. 12).
48. Documentation on the impact of growing inequality is wanting. For more on the health effects of some recent large-scale economic policies, see Kim, Millen, and Gershman 1999. On the simultaneous growth of poverty and wealth in the United States, see Krugman 1990. The U.S. Congressional Budget Office offers the following data: between 1977 and 1992, the poorest 10 percent of the population lost 20.3 percent of its post-tax income, while the top 10 percent gained 40.9 percent, and the top 5 percent gained 59.7 percent. The top 1 percent gained 135.7 percent. See Piven and Cloward 1996, pp. 74-75.
49. Wilkinson 1996, p. 212.
50. *Ibid.*, p. 216.
51. McMichael 1995, p. 634.
52. Kleinman 1995b, p. 69.
53. Bourdieu 1993, p. 944. My translation.

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