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*

Paul Farmer, "The Consumption of the Poor: Tuberculosis in the Late-Twentieth Century," in *Infections and Inequalities: The Modern Plagues*, Berkeley, Los Angeles and London: University of California Press, 1999, pp. 184-210.

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 antituberculous 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 noncompliant," 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 experiences 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 medical 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 longstanding 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] underlines 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?

8 Optimism and Pessimism in Tuberculosis Control

LESSONS FROM RURAL HAITI

We know most things about it,
but TB still kills more people
than any other pathogen, far
more than alcoholism, AIDS,
malaria, tropical diseases and
Ebola combined, and nobody
seems to care. . . . Where is the
shame? Where is the outrage?

LEE REICHMAN, *1997*

What the social world has made,
the social world, armed with
knowledge, can undo.

PIERRE BOURDIEU, *1993*

A survey of the current literature reveals discordant views on the question of progress in the control of tuberculosis. On the one hand, optimistic observers point with understandable pride to advances in our understanding of mycobacterial pathogenesis and to the elaboration of shorter but more effective treatment regimens. Recent years have seen a growing consensus that even six-month-long, multidrug regimens will lead to high cure rates if therapy is directly observed by medical personnel or