



Copyright © 2000 SAGE Publications (London, Thousand Oaks, CA and New Delhi)
Vol 1(2): 183-216[1466-1381(200012)1:2;183-216;014917]

The consumption of the poor Tuberculosis in the 21st century

■ Paul E. Farmer
Harvard University, Boston, USA

ABSTRACT ■ In an era in which we have effective therapies, why has tuberculosis remained the leading infectious cause of young adult deaths in much of the world? This article argues that in order to answer such a question, we must explore not only the life experiences of those sick with tuberculosis, but also the larger social contexts in which they become infected, fall ill, and meet with a series of therapeutic misadventures leading to complications, ongoing transmission to others and, often enough, death. The 'ethnographically visible' is only part of the story, since the experiences and commentaries of the sick and their providers must be embedded in broader analyses informed by history, political economy, epidemiology and a sociology of knowledge. Such an analysis brings into relief not only cultural specificity but also jarring similarities: living with both poverty and tuberculosis means poor outcomes whether you live in rural Haiti, urban Peru or the inner-city United States.

KEY WORDS ■ tuberculosis, suffering, epidemics, social inequality, poverty, pragmatic solidarity, Haiti, Peru, United States

Are you unaware that vast numbers of your fellow men suffer or perish from need of the things that you have to excess, and that you required the explicit and unanimous consent of the whole human race for you to appropriate from the common subsistence anything besides that required for your own?
(Jean-Jacques Rousseau, 1755)

Back with a vengeance?

The World Health Organization recently announced that, in 1999 alone, nearly 2 million persons died of tuberculosis (World Health Organization, 2000). Not since the turn of the century, when tuberculosis was the leading cause of young adult deaths in most US cities, has the disease claimed so many lives. Tuberculosis, we are told, has returned 'with a vengeance' (*Washington Post*, 3 August 1996; A19). In the language of the day, it is an 'emerging infectious disease'. In scientific publications and in the popular press, the refrain is the same: tuberculosis, once vanquished, is now resurging to trouble us once again.

Yet tuberculosis has been with us all along; only from a highly particular point of view can it be seen as an emerging, or even 're-emerging', disease. 'Thinking in terms of a returned tuberculosis', objects Katherine Ott, 'obscures the unabated high incidence of tuberculosis worldwide over the decades' (Ott, 1996: 157). 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 (Bloom and Murray, 1992).

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 enter a new century, it is instructive to compare our circumstances to the situation that prevailed at the end of the 19th century. At the 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' (Ryan, 1993: 8).

Although TB's victims during the 18th and 19th 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' (Dubos and Dubos, 1992: xiv-xv, n. 1). 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, the infection 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 (quoted in Dubos and Dubos, 1992: xxi.), 'the figure was 400 deaths per 100,000, approximately the same level recorded in the middle of the 19th century for the population as a whole.' Black Americans were enjoying the fruits of medical progress with a 50-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 the Second World War, those with access to the new antituberculous medications could expect to be cured of their disease. Who had access to streptomycin and PAS (para-aminosalicylic acid, one of the first antituberculous drugs) 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' (Feldberg, 1995: 1). The reasons for this invisibility stem in part from the decreasing absolute incidence in wealthy nations and in part in 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' (Dubos and Dubos, 1992: 22). 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 re-examined 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 *re-emerged from the ranks of the poor* (see Farmer et al., 1991; Spence et al., 1993). 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? I propose to rethink these issues by drawing on life histories of people afflicted with tuberculosis and by seeking to ground their experience in the political economy of this plague.

For more than a decade, I have worked as both ethnographer of and physician to populations bearing excess burdens of tuberculosis. In central Haiti, where I have worked since 1983, I have conducted hundreds of open-ended interviews with people afflicted with tuberculosis, hearing not only their stories but also coming to understand their own complex views of disease causation. In Peru, I have served as medical director of an effort to treat one of the most dreaded forms of the disease – multidrug-resistant tuberculosis (MDR-TB). In the process, I have learned a great deal about how social inequalities come to have pathogenic effect. In the United States, where tuberculosis is a rare disease, I have been privileged to meet those for whom it is not: poor people of color and recent arrivals from areas in which tuberculosis remains endemic. More recently, my work in tuberculosis has taken me to jails and prisons in these countries, and to others in Russia, Azerbaijan, and Latvia.¹

***Pwatinè* in Central Haiti: Jean Dubuisson**

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 has '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 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



Photo 1 Erased people: displaced by a hydroelectric dam, a Haitian family has reason to fear that someone will die of tuberculosis.

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 for the children. Jean did not seek medical care; instead he 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. This 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 nonetheless evinced a keen appreciation of its total lack of relevance. In order to follow these instructions, the family would have had 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

Haiti: basic statistics

• Population (1997)	7.5 million
• GDP per capita (1997)	US\$258 (in 1987 US\$)
• Average annual rate of change of GDP, 1975-97	-1.4%
• Life expectancy at birth (1997)	53.7 years
• Percent of total population not expected to survive to age 40 (1997)	26.7%
• Human Development Index Value (1997)	0.430; ranked 152 out of 174 countries
• Percent poor	65% total (1987); 81% rural (1995)
• Population without access to safe water (1990-7)	63%
to health services (1981-92)	55%
to sanitation (1990-7)	75%
• Underweight children under age five (1990-7)	28%

Note: Statistics on 'population' and 'percent poor' are from World Bank, 1999; all others are from United Nations Development Program, 1999.

records, but 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 per 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 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 having reached home, Jean, bedridden, was visited by a cousin who lived in Bois Joli, a small village served by a Haitian organization which was then sponsoring a comprehensive tuberculosis treatment project. 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 16 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, so 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 18 pounds in his first 3 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.'

MDR-TB and *Fujishock* in urban Peru: Corina Bayona

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 20.

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; her husband 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 struck the city.

Unemployment was high in Carabaylo, 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 Carabaylo. 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.² Soon Carlos was out of work.

Implemented in 1990 under pressure from the World Bank, International Monetary Fund, United Nations, and other multilateral agencies, the 'shock therapy' for Peru's inflationary crisis created an economic recession through a number of economic policies: the government ended price supports for fuel and food, devalued the currency, and imposed a 14 percent sales tax on all domestic purchases. Another key component of the reform plan involved privatization of state industries; by 1997, these reforms expanded to encompass the health sector. Whatever the long-term budgetary advantages reaped by this drastic and sudden overhaul of the

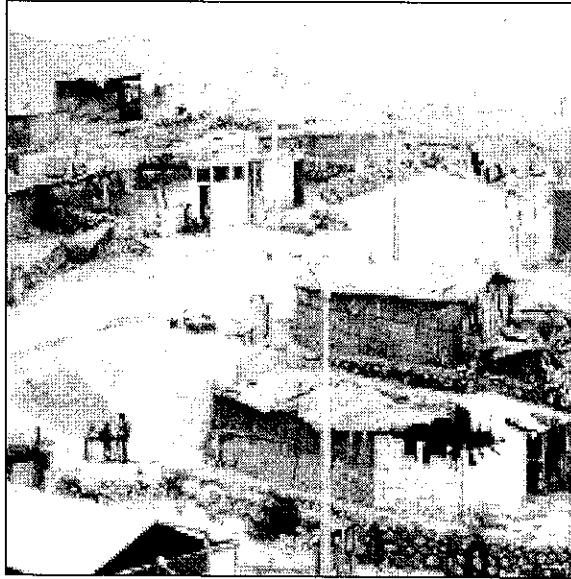


Photo 2 On the margins: residents of this 'invasión' on the northern outskirts of Lima have rates of tuberculosis tenfold greater than those faced by residents of its wealthy neighborhoods.

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, director of a Peruvian community-based organization, 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 non-compliant.' Thus branded, Corina 'felt attacked'. 'She was filled with fear', continued Dr García. 'She 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, it was 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 very same 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 but that 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 caretaker 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 care for 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 provided for 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. She did not have long to wait.

From Harlem to Vietnam and back: Calvin Loach

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 toiled 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 19, he was drafted into the US Army.

Calvin spoke rarely 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 him.

Another problem stemming from Calvin's tour of duty concerned heroin. In one telling, the former soldier linked the use of opiates to the chronic pain

Basic indicators: Harlem vs. Manhattan, 1990

A look at the 1990 US Census report provides insights into indexes of poverty in different neighborhoods in New York City. The information below compares two sections of New York City: a typical neighborhood in Harlem (labelled as 'tract 230' in the report), and Manhattan (reported as New York County, New York City).

	Neighborhood	
	in Harlem	Manhattan
Population	7,450	1.49 million
Per capita income	\$7,867	\$27,862
Percent civilian labor force unemployed	24%	8%
Percent below poverty level	49%	21%
Percent white	2%	59%
Percent black	94%	22%
Percent high school graduate or higher	57%	75%
Percent bachelor's degree or higher	11%	42%

Source: Bureau of the Census (1993)

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 US soldiers.

In 1972, Calvin returned to New York City, 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; upon returning, 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 suggested 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 over three years of full-time employment in a furniture warehouse. At the 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 (infection of the bone) 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 'non-compliant' 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. As 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 also received 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 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: from ethnography to political economy

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 20th 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 link ethnography to political economy and ask how large-scale 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, 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. Much could be said about Jean's experience in rural Haiti. Looking at ethnographic literature, much has been said, but most anthropologists have focused on 'voodoo' and sorcery accusations. After a decade of living in the same region, I was accustomed to ferreting out accusations of sorcery and had previously spent some years trying to make sense of them. And that, paradoxically, is the primary function of such accusations: to make sense of suffering. But the causes of that suffering are less often commented upon. As Haiti produces few non-agricultural products, it is safe to say that Jean is a member of its only truly productive class: the rural peasantry. But membership in that class brought 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 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 (World Health Organization, 1996). 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 epidemiological 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; only a few 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 of rural Haiti)? Calvin was probably registered as one of the thousands of 'excess'⁴ cases in 1991 reported to the US Centers for Disease Control. As an African American and an injection drug user, he fits the bill: the brunt of the recent epidemic has been borne by US citizens living in poverty, many of them people of color, as a review by McBride (1991) makes clear.

Nor was Calvin's clinical course atypical of the lot of the US poor with tuberculosis. Although his fate is unknown, he clearly received inappropriate care and was 'lost to follow-up'. This is 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 (Frieden et al., 1995). In one study conducted in Harlem Hospital, almost 90 percent of patients did not complete therapy for their disease (Brudney and Dobkin, 1991). An overview from the New York City Department of Health painted a grim picture:



Photo 3 Galloping consumption: in the city of Lima, with its booming financial market, the poor still die of tuberculosis.

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. (Frieden et al., 1995: 229)

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 (1993) discovered an average of 3.9 physician-directed errors per patient.

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 non-compliance. 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 non-compliant. 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 'non-compliant' as he built no such addition on to his two-room hut. Most important, he was instructed to go to a hospital. Jean was 'grossly negligent' and dragged his feet for months.

Can we, in good conscience, blame failures to make new technologies available on our patients? Is the locus of blame to be found in the hearts and minds of the sick? Can we claim that personal motivations or cultural beliefs will determine the efficacy of medical interventions when we can-

readily document that economic and logistic barriers to access continue to play a major role in the delivery of health care? A broad view of tuberculosis brings into relief the political, cultural and economic barriers to effective tuberculosis treatment (and chemoprophylaxis). Such a view reveals 'compliance' to be an analytically flimsy, even vacuous, concept in countries such as Haiti, where the poor are put systematically at risk of tuberculosis and then denied access to adequate care. Horton writes of the 'institutional inertia' impeding effective tuberculosis control, identifying not patients but rather national governments, science policy makers, the market and national health infrastructures as the chief impediments (Horton, 1995). Yet all too often, the notion of patient non-compliance is used as a means of explaining away program failure. Patient-dependent failure should be a 'diagnosis of exclusion' – invoked only *after* poor program design and lack of access are excluded.

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 wondered more than once 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 very same forces that drove his parents out of the Jim Crow South, as the army ranks were disproportionately filled with young African Americans. And among the

troops, those with the grimmest prospects back home seemed to be those most likely to use heroin or opium.

From ethnography to social history

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' (cited in Feldberg, 1995: 214). It would appear that diseases predominantly afflicting the poor are unlikely to garner funding – unless they begin to 'emerge' into the consciousness and space of the non-poor.

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 US deaths, and this remained true even in the latter part of the century, when rates began to fall sharply.⁵ 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' (Feldberg, 1995: 11–12, emphasis added). But interpretations of these differences, continues Feldberg (1995: 11–12), 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.'

For example, 'Southerners commonly believed that blacks suffered from a distinctive form of consumption, known as "negro consumption"' (Feldberg, 1995: 23).⁶ Susceptibility, in this view, was genetically determined. This construct not only demonstrated a vested interest in an agrarian, slave-holding 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' (cited in Feldberg, 1995: 14). Feldberg (1995: 26) 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.⁷

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 in the native peoples was so clearly linked to a rapid decline in their standards of living that hereditary arguments were widely seen as less compelling.⁸

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' (cited in Feldberg, 1995: 439).

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' (Henry Wiley, cited in Feldberg, 1995: 30). By 1900, observe Dubos and Dubos (1992: 210),

... 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.

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 20th 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. (Cited in Feldberg, 1995: 101)

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' (cited in Feldberg, 1995: 105). Feldberg (1995: 4), 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'. As one example, she cites (Feldberg, 1995: 4) 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.'

Hybrids of these positions also emerged. Barbara Rosenkrantz (quoted in Dubos and Dubos, 1992: xxii) writes of Ellen N. LaMotte's *The Tuberculosis Nurse (a 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.

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' (cited by Rosenkrantz in Dubos and Dubos, 1992: xxv-xxvi). In a 1926 paper called 'Vital Capacity of 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' (Smillie and Augustine, 1926: 2058).

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 (cited in Feldberg, 1995: 48) wrote of 'the blind love of "the average proletarian . . . for the chorus of citylife."' High rates of tuberculosis among immigrants were commonly blamed on their 'lifestyles' and lack of cleanliness (Kraut, 1994). 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 (cited in McBride, 1991: 46) entitled '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.

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 – due in part to 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,⁹ such as black people or foreigners. In a 1923 address to a state medical society (cited in McBride, 1991: 61), 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'. Such interpretations were common well into the 1960s. 'In the South', McBride (1991: 51) points out, 'segregationists attempted to turn blacks' excessive tuberculosis mortality rates into justification for keeping white and black youths from attending integrated schools.'

Racial differentials, tightly tied to class divisions, became further entrenched as effective therapies were developed. Although tuberculosis continued to decline among all US citizens, rates among blacks remained relatively high, particularly among young black adults: tuberculosis remained their leading cause of death even during the Second World War (see Table 1). A 1946 study by Yerushalmy found that, although tuberculosis mortality in relation to overall mortality in whites declined substantially in the period 1900–1940, this encouraging progress was not noted for non-whites. In fact, not only was mortality from tuberculosis among non-whites not declining as rapidly as overall mortality, in 1938 a three-decade downward trend was reversed, and by 1943 the tuberculosis death ratios surpassed those from 1930. Deaths were highly concentrated in the large industrial cities to which blacks had been drawn 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. (McBride, 1991: 126)

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

Table 1 Leading causes of death by age, color, and sex, United States, 1940 (Rate per 100,000 population)

Non-whites 25–34 years		Whites 25–34 years	
Cause of death	Rate	Cause of death	Rate
1. Tuberculosis	196.3	Tuberculosis	40.0
2. Major cardiovascular-renal diseases	120.6	Major cardiovascular-renal diseases	39.3
3. Homicide	75.2	Other accidents (non-vehicular)	25.3
4. Influenza and pneumonia	57.6	Motor vehicle accidents	24.4
5. Other accidents (non-vehicular)	44.1	Malignant neoplasms	16.3

Source: Grove and Hetzel (1968)

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. (Cited in McBride, 1991: 129)¹⁰

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 (1991: 151), '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.' 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 (1994), 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, 1987 tuberculosis deaths among Native Americans exceed those among 'all races' by 400 percent. Thus tuberculosis still tops the list of disorders *disproportionately* killing Native Americans.

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' (Snider et al., 1989: 647). Increasing inequalities of risk belie the claim of a 'national problem' of excess cases; they reveal, rather, a scenario in which long-standing inequalities of risk are now being further accentuated.

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 make-up. 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 (1996: 7) puts 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'.¹¹

What is to be done? The role of pragmatic solidarity

As a new century opens, 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 immunofluorescence 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 24 hours. We have the scientific knowledge – but the hard truth is that the 'we' in question does not include the vast majority of the 2 million people who died from tuberculosis in 1999. We must acknowledge that our guilt surpasses that of earlier generations, who lacked our resources: Michael Iseman (1985), 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.

Looking to the future, it is difficult to muster optimism. The arrival of strains of *M. tuberculosis* 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 prior to 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. In Haiti, we showed that listening to people with tuberculosis meant listening to stories not only of sorcery, but of hunger and bad harvests and leaky roofs and dirt floors. We discovered that attending to these problems during the course of treatment could double cure rates (Farmer et al., 1991). We knew that merely listening to such stories could be termed solidarity, but believe that *pragmatic solidarity* is what the afflicted were demanding. 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. Even in settings of relative affluence, the impact of modest interventions can be substantial. 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 (Curry, 1968). 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 (Frieden et al., 1995). Especially critical – and important to



Photo 4 Matter of life and death: a young Haitian woman with extrapulmonary tuberculosis before and after treatment.

underline when confronted with claims that treating susceptible disease will somehow make MDR-TB go away – were efforts in New York to speed the rate at which resistant strains were identified and treated with antibiotics to which they had demonstrated susceptibility (Telzak et al., 1995).

Pragmatic solidarity means preventing the emergence of drug resistance whenever possible, but it also means treating people like Corina Valdivia. Currently, a massive pandemic of MDR-TB in Russia and other countries of the former Soviet Union is becoming even more massive – with minimal public comment and even less public action.¹² Problems of this dimension call for public subsidies of costly second-line drugs as well as for the development of new drugs.¹³

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 (1995: 38) argues, that 'scientific professionalism ... fundamentally eroded the therapeutic impulse to social reform', 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 (cited in Feldberg, 1995: 107) made the following 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.' This statement remains as true today as it was 75 years ago.

At the same time, it is necessary to avoid 'public health nihilism'.¹⁴ 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 are 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 funded 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 (1992: 225) mistakenly identify tuberculosis with a time – the 19th 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.

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? Increasingly, it is the pharmaceutical and insurance and health-care industries, and also international agencies (including most prominently financial institutions) who determine who will have access to effective medical care. But the power of technological advancement stems not merely from the wonders of science. It stems, too, from the power of moral persuasion. We can call for certain measures not because they are 'cost-effective' – the current and unchallenged mantra – but because they are the best we can do for the sick.

A focus on complex epidemics – including not only tuberculosis, but also HIV – offers a stinging rebuke to the 'cost-effectiveness' argument advanced in public policy debates. At least four sets of reasons – one clinical, one



Photo 5 Last Supper: even before trial, Russian detainees face the possibility of drug-resistant tuberculosis as punishment.

epidemiologic, one analytic, and one moral – lead us to conclude that ignoring these plagues is an unacceptable strategy. The clinical reasons, as noted, are straightforward – we have effective therapies to cure even drug-resistant strains of tuberculosis, and the anti-HIV armamentarium is expanding rapidly. People like Jean, Corina and Calvin exist, and they matter. Cost-effectiveness arguments against treating such maladies are epidemiologically flawed: in this era of increasing global travel, ‘local’ epidemics rarely remain local for very long. The oft-heard insistence that treatment of MDR-TB, for example, is too expensive to treat in poor countries is also a failure of social analysis in at least two ways. First, there are few data to support the hypothesis that there are insufficient means to cure all tuberculosis cases, everywhere. In fact, the degree of accumulated world wealth is altogether unprecedented. Second, such a head-in-the-sand approach also represents a failure of ethnographic analysis. As we have seen, and as social scientists who study the therapeutic itineraries of tuberculosis patients know, a slow death from the disease is not quietly accepted by the young adults who are its chief victims. Thanks to increased access to information, patients and their loved ones know that MDR-TB can be treated with second-line drugs, just as AIDS patients in many poor countries now know about the existence of effective antiviral therapies. In middle-income countries like Peru, which are in reality inegalitarian settings where wealth and poverty are in close juxtaposition, second-line antituberculous drugs are in fact already available – for sale at exorbitant prices.

Finally, arguments against treating disease in settings of poverty are morally unsound. Through analytic chicanery – the claim that the world is composed of discretely bounded nation-states, some rich, some poor – we are asked to swallow what is, ultimately, a story of growing inequality and our willingness to caution it. But careful systemic analysis of pandemic disease leads us to see *links, not disjunctions*. When the above failures of analysis are pointed out, the real reason that MDR-TB and HIV are treatable in the United States and ‘untreatable’ in Peru or Haiti comes into view. Opposition to the aggressive treatment of such afflictions in developing countries may be justified as ‘sensible’ or ‘pragmatic’ but, as a policy, is tantamount to the differential valuation of human life, since those advocating those policies, regardless of their nationalities, would never accept such a death sentence for themselves. It is because the afflicted tend to be poor, and also from marginalized and stigmatized groups more generally – thus less valuable – that such policies appear reasonable.

Addressing these issues may get at the heart of the meaning of tuberculosis as we begin the 21st century. If tuberculosis could once be termed (Dubos and Dubos, 1992: 207) ‘the first penalty that capitalistic society had to pay for the ruthless exploitation of labor’, what does it mean now? Is it perpetually the lot of the poor to pay this penance?

Notes

- 1 This work has been explored in a number of books and articles: Farmer (1992, 1999b); Farmer et al. (1998); Farmer et al. (2000); Becerra et al. (2000). An earlier version of this essay appeared in Farmer (1999b).
- 2 For an in-depth exploration of the effects of *fujishock* on the health of Peru's urban poor, see Kim et al. (2000b).
- 3 Current standards would favor initiation of empiric treatment with four drugs to avoid the development of resistant strains of *M. tuberculosis*.
- 4 'Excess cases' was the term used by the US public health officials who calculated the difference between the number of cases predicted (if downward trends had persisted) and those actually reported.
- 5 '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' (Feldberg, 1995: 13).
- 6 Feldberg (1995: 24–5) 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."' See McBride (1991) for a more thorough review of this subject.
- 7 Not all Southern physicians shared the locally dominant explanatory models, however. Feldberg (1995: 26) 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.'
- 8 For a review, see Rieder (1989).
- 9 On the relationship between xenophobia and tuberculosis, see Kraut (1994).
- 10 Preferential attention to polio continued, as Feldberg (1995: 2) noted: '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 exceed that for polio almost threefold.'
- 11 The impact of neoliberal economic policies on the health of the poor has been explained in *Dying for Growth* (Kim et al., 2000a), which includes case studies from Haiti, Peru, Mexico, Senegal, Cuba, Russia, and El Salvador. In each setting, a decline in social spending has been associated with dramatic declines in the health status of people living in poverty.
- 12 For a comprehensive review of the problem of tuberculosis and MDR-TB in Russia, see: Farmer et al. (1999); Farmer (1999a, 1999c, 1999d).
- 13 'No new antituberculous compounds have been developed by the pharmaceutical industry since the 1970s', noted Cole and Telenti in 1995 (701), although researchers have serendipitously found certain antibiotics that have activity against *M. tuberculosis*. Reichman (1997: 7) 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.'

- 14 The term 'public health nihilism' was coined by Ron Bayer of Columbia University; as regards tuberculosis, it is discussed in Farmer and Nardell (1998).

Acknowledgements

Writing about tuberculosis necessarily engenders great debt, and I am most grateful to the hundreds of patients – yes, I call them patients – who were willing to speak with me about their illness experience. I am also indebted to medical colleagues in Haiti, Peru, Boston and Russia. For help with this essay, I thank Mercedes Becerra, Haun Saussy, Loïc Wacquant (who inspired me to rework it), Sarah Widmer and Paul Willis. Last but not least, I thank Jen Singler, who goads me into keeping promises.

References

- Becerra, M.C., J. Freeman, J. Bayona, S.S. Shin, J.Y. Kim, J.J. Furin, B. Werner, A. Sloutsky, R. Timperi, M.E. Wilson, M. Pagano and P.E. Farmer (2000) 'Using Treatment Failure under Effective Directly Observed Short-Course Chemotherapy Programs to Identify Patients with Multidrug-resistant Tuberculosis', *Int. J. Tuberc. Lung Dis.* 4(2): 108–14.
- Bloom, B.R. and C.J.L. Murray (1992) 'Tuberculosis: Commentary on a Reemergent Killer', *Science* 257: 1055–64.
- Brudney, K. and J. Dobkin (1991) 'Resurgent Tuberculosis in New York City: Human Immunodeficiency Virus, Homelessness, and the Decline of Tuberculosis Control Programs', *Am. Rev. Respir. Dis.* 144(4): 745–9.
- Bureau of the Census (1993) *1990 Census of Population and Housing*. Washington, DC: US Dept. of Commerce, Economics and Statistics Administration, Bureau of the Census.
- Chaulet, P. (1996) 'Les nouveaux tuberculeux', *Le Journal de la tuberculose et du SIDA* 6(4): 6–8.
- Cole, S.T. and A. Telenti (1995) 'Drug Resistance in *Mycobacterium tuberculosis*', *Eur. Respir. J.* 8(S 20): 701S–13S.
- Curry, F.J. (1968) 'Neighborhood Clinics for More Effective Outpatient Treatment of Tuberculosis', *N. Engl. J. Med.* 279(23): 1262–7.
- Dubos, R. and J. Dubos (1992) *The White Plague: Tuberculosis, Man, and Society*, 2nd edn. New Brunswick, NJ: Rutgers University Press.
- Farmer, P.E. (1992) *AIDS and Accusation: Haiti and the Geography of Blame*. Berkeley: University of California Press.

- Farmer, P.E. (1999a) 'Cruel and Unusual: Drug-Resistant Tuberculosis as Punishment', in V. Stern and R. Jones (eds) *Sentenced to Die? The Problem of TB in Prisons in East and Central Europe and Central Asia*. London: Penal Reform International.
- Farmer, P.E. (1999b) *Infections and Inequalities: The Modern Plagues*. Berkeley, CA: University of California Press.
- Farmer, P.E. (1999c) 'Managerial Successes, Clinical Failures', *Int. J. Tuberc. Lung Dis.* 3(5): 365-7.
- Farmer, P.E. (1999d) 'TB Superbugs: The Coming Plague on All Our Houses', *Natural History* 108(3): 46-53.
- Farmer, P.E. and E. Nardell (1998) 'Nihilism and Pragmatism in Tuberculosis Control', *Am. J. Public Health* 88(7): 4-5.
- Farmer, P.E., J. Bayona, M. Becerra, J. Furin, C. Henry, H. Hiatt, J.Y. Kim, C.D. Mitnick, E. Nardell and S. Shin (1998) 'The Dilemma of MDRTB in the Global Era', *Int. J. Tuberc. Lung Dis.* 2(11): 869-76.
- Farmer, P.E., J.J. Furin and S.S. Shin (2000) 'Managing Multidrug-resistant Tuberculosis', *J. Respir. Dis.* 21(1): 53-6.
- Farmer, P.E., A.S. Kononets, S.E. Borisov, A. Goldfarb, T. Healing and M. McKee (1999) 'Recrudescence Tuberculosis in the Russian Federation', in *The Global Impact of Drug-Resistant Tuberculosis* (Program in Infectious Disease and Social Change). Boston, MA: Harvard Medical School and the Open Society Institute.
- Farmer, P.E., S. Robin, S.L. Ramilus and J.Y. Kim (1991) 'Tuberculosis, Poverty, and "Compliance": Lessons from Rural Haiti', *Semin. Respir. Infect.* 6(4): 254-60.
- Feldberg, G.D. (1995) *Disease and Class: Tuberculosis and the Shaping of Modern North American Society*. New Brunswick, NJ: Rutgers University Press.
- Frieden, T.R., E. Fujiwara, R. Washko and M. Hamburg (1995) 'Tuberculosis in New York City: Turning the Tide', *New England Journal of Medicine* 333(4): 229-33.
- Grove, R.D. and A.M. Hetzel (1968) *Vital Statistics in the United States, 1940-1960*. Washington, DC: US Department of Health, Education, and Welfare.
- Horton, R. (1995) 'Towards the Elimination of Tuberculosis', *Lancet* 346: 790.
- Iseman, M.D. (1985) 'Tailoring a Time Bomb: Inadvertent Genetic Engineering', *Am. Rev. Respir. Dis.* 132(4): 735-6.
- Kim J.Y., J.V. Millen, A. Irwin and J. Gershman (eds) (2000a) *Dying for Growth: Global Inequality and the Health of the Poor*. Monroe, ME: Common Courage Press.
- Kim, J.Y., A. Shakow, J. Bayona, J. Rhatigan and E.L. Rubin de Celis (2000b) 'Sickness Amidst Recovery: Public Dept and Private Suffering in Peru', in J.Y. Kim, J.V. Millen, A. Irwin and J. Gershman (eds) *Dying for Growth: Global*

- Inequality and the Health of the Poor*. Monroe, ME: Common Courage Press.
- Kraut, A. (1994) *Silent Travelers: Germs, Genes, and the 'Immigrant Menace'*. New York: Basic Books.
- McBride, D. (1991) *From TB to AIDS: Epidemics among Urban Blacks Since 1990*. Albany: State University of New York Press.
- Mahmoudi, A. and M.D. Iseman (1993) 'Pitfalls in the Care of Patients with Tuberculosis: Common Errors and their Association with the Acquisition of Drug Resistance', *Journal of the American Medical Association* 270(1): 65–8.
- Michael, J.M. and M.A. Michael (1994) 'Health Status of the Australian Aboriginal People and the Native Americans – A Summary Comparison', *Asia-Pacific Journal of Public Health* 7(2): 132–6.
- Ott, K. (1996) *Fevered Lives: Tuberculosis in American Culture Since 1870*. Cambridge, MA: Harvard University Press.
- Reichman, L.B. (1997) 'Tuberculosis Elimination – What's to Stop Us?' *Int. J. Tuberc. Lung Dis.* 1(1): 3–11.
- Rieder, H.L. (1989) 'Tuberculosis among American Indians of the Contiguous United States', *Public Health Report* 104(6): 653–7.
- Ryan, F. (1993) *The Forgotten Plague: How the Battle Against Tuberculosis Was Won – and Lost*. Boston: Little, Brown.
- Smillie, W.G. and D.L. Augustine (1926) 'Vital Capacity of the Negro Race', *Journal of the American Medical Association* 87(25): 2055–8.
- Snider, D.E., Jr, L. Salinas and G.D. Kelly (1989) 'Tuberculosis: An Increasing Problem among Minorities in the United States', *Public Health Report* 104(6): 646–53.
- Spence, D.P., J. Hotchkiss, C.S. Williams and P.D. Davies (1993) 'Tuberculosis and Poverty', *BMJ* 307: 759–61.
- Telzak, E.E., K. Sepkowitz, P. Alpert, S. Mannheimer, F. Medard, W. El-Sadr, S. Blum, A. Gagliardi, N. Salomon and G. Turett (1995) 'Multidrug-resistant Tuberculosis in Patients Without HIV Infection', *N. Engl. J. Med.* 333(14): 907–11.
- United Nations Development Programme (1999) *Human Development Report 1999*. New York: Oxford University Press.
- World Bank (1999) *World Development Indicators 1999*. Washington, DC: World Bank.
- World Health Organization (1996) *Groups at Risk: WHO Report on the Tuberculosis Epidemic*. Geneva: World Health Organization.
- World Health Organization (2000) *Tuberculosis and Sustainable Development: The STOP TB Initiative 2000 Report*. Geneva: World Health Organization.
- Yerushalmy, J. (1946) 'The Increase in Tuberculosis Proportionate Mortality among Nonwhite Young Adults', *Public Health Reports* 61(8): 251–8.

■ **PAUL FARMER** is an anthropologist and an infectious disease physician who divides his clinical time between Haiti, Boston and Peru. He is the author of *AIDS and Accusation* (University of California Press, 1992), the first full-length ethnographic study of AIDS in a poor country; *The Uses of Haiti* (Common Courage Press, 1994); and *Infections and Inequalities: The Modern Plagues* (University of California Press, 1999). He teaches at Harvard Medical School, where he directs the Program in Infectious Disease and Social Change, and was founding director of Partners In Health, an organization committed to 'pragmatic solidarity' with the destitute sick. *Address:* Program in Infectious Disease and Social Change, Department of Social Medicine, Harvard Medical School, 641 Huntington Avenue, Boston, MA 02115, USA. [email: pihpaul@aol.com] ■