Tuberculosis, Poverty, and “Compliance”:
Lessons From Rural Haiti

Paul Farmer, Simon Robin, St. Luc Ramilus, and Jim Yong Kim

Tuberculosis (TB) is the leading cause of death among rural Haitian adults, and TB control in Haiti is widely acknowledged to be a failure. The causes of both the endemcity of TB and the failure of attempts to address it are briefly reviewed before data from a study conducted in rural, central Haiti are presented. Members of one group of patients with active TB were given free medical care; members of a second group were given free care as well as financial aid, incentives to attend a monthly clinic, and aggressive home follow-up by trained village health workers. Comparing the two groups shows significant differences in mortality, sputum positivity after 6 months of treatment, persistent pulmonary symptoms after 1 year of treatment, average amount of weight gained, ability to return to work, and cure rate. The roles of human immunodeficiency virus and cultural factors are also examined. When adequate nutrition and access to free care were assured, drug-dependent and patient-dependent factors were shown to be of secondary importance in determining treatment outcome. Based on these data from a small, community-based TB-control project, the authors conclude that high cure rates can be achieved if the primacy of economic causes of TB is acknowledged and addressed.

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A survey of the current literature shows discordant views on the question of progress in the control of tuberculosis (TB). Optimistic observers point with understandable pride to recent advances in our understanding of mycobacterial pathogenesis and to the elaboration of shorter but more effective treatment regimens. Pessimists, on the other hand, point to the widening gulf between advances reported in the scholarly literature and effective control in the communities hardest hit by TB. Among the world’s poor, one hears of massive drop-out from treatment programs, of noncompliance, and of prohibitively high treatment costs. Site visitors to programs in such settings also report substandard care, a failure to keep accurate records, a near-total lack of follow-up, and high mortality. In short, too few TB patients have access to care, and those who do may not be receiving appropriate care.

This gulf between the ideal and the real engenders, in seminars and in print, much discussion about the need for culturally appropriate interventions, enhanced convenience for patients, and community-based care. Although a consensus has been reached regarding certain goals, a basic disagreement as to how these might be met remains. Optimists underline cultural and logistic barriers that may be overcome. Pessimists signal the large-scale forces that immiserate entire communities, putting them at risk of TB.

Haiti, a Caribbean nation of approximately 7,000,000 inhabitants, offers a good deal of support to the more pessimistic assessment. With a rural per capita income of less than $300 per year, Haiti has long teetered on the edge of famine, and its people are faced with a long list of health problems worsened by chronic undernutrition. “Of all the health problems cited,” observes Wiese,¹ “one stands out from the others by virtue of its insidious onset, its tenacity, and its prevalence—pulmonary tuberculosis.” Indeed, the prevalence of TB in Haiti is the highest in the hemisphere and has been so for some decades. The United Nations² reported that in 1944, TB was “the most important cause of death among hospitalized patients.” Linking the high incidence of the disorder to poor sanitation and poverty, the organization predicted that “for many years to come tuberculosis will, it is feared, continue to take a heavy toll of human lives in Haiti.”

This prediction has come true. In 1965 the Pan-American Health Organization estimated prevalence at 3,862 per 100,000 inhabitants.³ TB has more recently been termed the leading cause of resort to ambulatory services in rural Haiti,⁴ and a number of studies have shown it to

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be the leading cause of death among individuals aged 15 to 49 years. Studies from Hospital Albert Schweitzer, a large referral hospital in rural Haiti, suggest that in this age group, TB causes two to three times as many deaths as the next most common diagnosis.5

The high prevalence of TB has been further augmented by the advent of human immunodeficiency virus (HIV). In sanitarium in urban Haiti, some 45% of all TB patients were reportedly seropositive for HIV; in unspecified rural regions, 15% of TB cases were associated with HIV infection.6 In another rural setting, the experience of the Schweitzer hospital shows that 24% of all TB patients were complicated (or awakened) by HIV infection. In adults between the ages of 20 and 39 years, 31% of TB cases were deemed “attributable to HIV.” The study's authors conclude that HIV seropositivity is a major risk factor for pulmonary TB among young adults in Haiti. Their data also suggest that at least one fourth of the bacillary-positive pulmonary TB among young adult Haitians would be preventable if the spread of HIV were controlled.7

Although drug resistance presents another significant problem, most studies of treatment failure show that the problem is predominantly one of designing and implementing programs appropriate to the needs of the population to be served.8 In one large town in southern Haiti, 75% of all patients had abandoned treatment by 6 months after diagnosis, and more than 93% had abandoned treatment before the end of 1 year.8 In one study documenting high rates (22%) of resistance to at least one drug, the authors nonetheless conclude that “supplies of effective antituberculous drugs must be accompanied by adequate resources to organize or supervise their use.”9 Studies among homeless North Americans with TB also suggest that logistic problems, rather than microbiological ones, are the primary cause of increased resistance in the urban United States.

The remainder of this article describes in some detail one community-based organization’s efforts to implement a TB-control program that is both culturally appropriate and cognizant of the crippling poverty that, while often ignored as a significant factor in treatment failure, clearly plays a central role in determin-

ing who does or does not benefit from these interventions.

**SETTING AND METHODS**

The experience of TB in rural Haiti, the setting for this study, is one strongly conditioned by historical contingencies and material constraints. Haiti is Latin America’s oldest nation, having been declared independent from France after a slave revolt that began in 1791. Most available documentation suggests that the slave forebears of contemporary Haitians were ill indeed:

The slaves brought from Africa to Haiti carried with them the remnants of their cultural systems, yellow fever, yaws and malaria. The Spanish gave them sugar cane, vicious slavery, a form of Catholicism, smallpox, measles, typhoid and tuberculosis. The French, in their turn, gave the Haitian a language, traces of French culture and continued vicious servitude.1

The legacy of this servitude is inscribed in the health of the Haitian people today. Over 50% of all deaths are among children under age 5, with nearly 75% of these deaths caused by or associated with malnutrition. Infectious diseases account for the majority of deaths. The major causes of childhood deaths are diarrhea, pneumonia and tetanus. The health of many of those who survive childhood is equally fragile. Tuberculosis, as noted, is the leading cause of death among adults. Life expectancy in Haiti has slowly improved, reported as between 48 and 54 years. In Guatemala, it is 61; Nicaragua, 62; Dominican Republic, 64; Trinidad and Tobago, 69; Cuba and Jamaica, greater than 70 years.

The setting for the project described here is the Peligre basin of Haiti’s central plateau, home to several hundred thousand, mostly rural, people. Although all parts of Haiti are poor, the Peligre basin region may be especially so: in 1956, thousands of families living in this region were flooded out by a hydroelectric dam. Displaced persons were all peasant farmers, and they received no compensation for their lost land. Over the years, Proje Veye Sante, a small community health program founded in 1984, has sought to serve these landless peasants and their children. In recent years, the project has grown considerably as more villages seek to participate by sending community members to be trained as community health workers. Although the project is centered around a large clinic staffed by three physicians, it is in the outlying villages that much of the work takes place: 25 village health workers form the backbone of Proje Veye Sante. All paid staff positions are filled by Haitians, most of them natives of the region.

The catchment area of Proje Veye Sante includes the settlements scattered around the reservoir and is divided into two sectors. Sector 1 rings the lake and consists of 15,000 individuals, almost all of whom are peasants living in small villages of approximately 1,000 persons. Several of these villages were formed by refugees from the rising water. Sector 2, more loosely demarcated, consists of a large number of villages and towns contiguous to sector 1. Although inhabitants of the outlying villages are offered the same clinical services as those in sector 1—consultations with a physician, laboratory work, and all medications for
about 80 cents—they are not served by community health workers, nor do they benefit from women's health initiatives, vaccination campaigns, water protection efforts, adult literacy groups, and other activities sponsored by Proje Veye Sante. These interventions, which are implemented by community health workers, have proven a powerful means of addressing malnutrition, diarrheal disease, and maternal mortality.

Although Proje Veye Sante proved effective in identifying and referring patients with pulmonary TB to the clinic, it gradually became clear that detection of new cases did not lead to cure, despite the fact that even the 80-cent fee was waived for any patient carrying a diagnosis of TB. All TB medications—isoniazid, ethambutol, streptomycin, and rifampin—are provided free of charge at the clinic. In December 1988, following the deaths from TB of three HIV-negative patients, the staff of Proje Veye Sante met to reconsider the treatment of such individuals. How had they failed to prevent these deaths, all of which were registered in adults in their 40s? Some community health workers felt that TB patients with poor outcomes were the most economically impoverished and thus the sickest; others attributed poor compliance to widespread “beliefs” about TB as a disorder inflicted through sorcery, which led patients to abandon biomedical therapy. Still others hypothesized that patients lost interest in chemotherapy after ridding themselves of their presenting symptoms.

Over the course of the next 2 months, a plan to improve services to patients with TB, and to test these hypotheses, was devised. To summarize briefly, the new program embraced the goals of case finding, adequate chemotherapy, and close follow-up. Although contact screening and BCG for infants were advocated, the staff of Proje Veye Sante was most concerned with the care of the “smear-positive and coughing” patient, the sole source of community exposure. The new program was designed to be aggressive and community based, relying heavily on community health workers for tight follow-up. All residents of sector 1 with diagnoses of pulmonary or extrapulmonary TB would be eligible to participate in a treatment program, starting during the first month after diagnosis, daily visits from the village health worker. These patients received financial aid of $30 per month for the first 3 months and were eligible for nutritional supplements. They also received a monthly reminder from the village health worker to attend clinic, and “travel expenses” (for example, renting a donkey) were defrayed with a $5 honorarium when they attended clinic. In the event that a sector 1 patient did not attend, someone from the clinic, often a physician or practical nurse, made a home visit to the no-show's house. A series of forms, including a detailed initial interview schedule and home-visit reports, formalized these arrangements and replaced the extremely limited forms used for other clinic patients.

Between February 1989 and June 1990, 30 sector 1 patients were enrolled in the program. Fully 29 of those identified had pulmonary TB. Four individuals also had extrapulmonary TB, and one had cervical lymphadenitis as the sole manifestation of TB. During the same period, the clinical staff diagnosed pulmonary TB in 55 patients from outside sector 1. Most of these patients were from sector 2, although a few had traveled greater distances to seek care at the clinic; 43 of these individuals returned to the clinic for further care. The first 30 of these patients to receive diagnoses formed the comparison group with which the efficacy of the new project was judged. They were a “control group” only in the sense that they did not benefit from the community-based services and financial aid; all sector 2 patients continued to receive free care. In addition to data concerning clinical course and outcome, all patients were interviewed regarding their own explanatory models and experience of TB.

RESULTS

The mean age of patients (45 years) and sex ratio (women outnumbered men by approximately 2:1) did not vary significantly between the two groups, but indirect economic indicators (eg, years of school attended, ownership of a radio, access to a latrine, tin rather than thatched roof) suggested that patients from sector 2 may have been slightly less poor than those from sector 1. This is unsurprising because several of the villages in sector 1 are squatter settlements dating from the year the valley was flooded.

Mortality

None of the sector 1 group died in the year following their diagnosis, whereas three of those from sector 2 died (Table 1). One of these deaths was in a young woman seropositive for HIV. One person initially living within sector 1 later moved out of the catchment area and was no longer served by a community health worker.

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<tr>
<th>Table 1. Characteristics of TB in Sector 1 Versus Sector 2 Patients</th>
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<td><strong>Sector 1</strong></td>
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<td>Mortality from TB during 18 mo after diagnosis</td>
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<tr>
<td>Sputum positivity for acid-fast bacilli 6 mo after diagnosis</td>
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<td>Persistent pulmonary symptoms after 1 yr of treatment</td>
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<td>Average weight gained/patient/yr (lb)</td>
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<td>Return to work after 1 yr of treatment</td>
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<td>Average no. of clinic visits per patient/yr</td>
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<td>Average no. of home visits per patient/yr</td>
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<td>Seropositivity to HIV</td>
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<td>No. of patients who denied possible role of sorcery in illness</td>
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<td>Cure rate</td>
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This patient, who died some months after leaving the area, is not considered in either of these groups.

**Sputum Positivity**

The clinical staff attempted to examine sputum for acid-fast bacilli whenever patients developed recrudescence symptoms, and also at approximately 6 months after the start of antituberculous therapy. None of the patients from the study area was sputum positive at 6 months. One young woman did become sputum positive during a pregnancy in the subsequent year. This patient was found to be infected with HIV. Of the sector 2 cohort, four patients had acid-fast bacilli demonstrable in sputum at about 6 months after the initiation of therapy (Table 1).

**Persistent Pulmonary Symptoms**

After a year of treatment, a thorough history and physical examination were used to screen for persistent pulmonary symptoms (e.g., cough, hemoptysis, dyspnea). Only two of the patients in sector 1 reported such symptoms, and both had developed asthma during the course of their convalescence. Fully 13 of those in sector 2 continued to complain of cough or other symptoms consistent with persistent or partially treated TB (Table 1).

**Weight Gained**

Monitoring of body weight showed marked differences in the amount of weight gained per patient per year in participants versus nonparticipants. Correcting for fluctuations associated with pregnancy, participants gained an average of 10.4 pounds during the first year of their treatment. Patients from sector 2 had a mean weight gain of 1.7 pounds per person per year (Table 1).

**Return To Work**

The vast majority of patients from both groups were peasant farmers or market women whose families relied on their ability to perform physical labor. It is of note, then, that at 1 year after diagnosis, 28 of the sector 1 patients stated that they were able to return to their work activities. In sector 2, fewer than half (14 patients) were able to do so (Table 1).

**Clinic Visits**

Because patients are given a 1-month supply of medication with each visit, monthly clinic visits were strongly encouraged by the staff of Proje Veye Sante and served as an indirect measure of blood levels of antituberculous medications among those taking their medications. In the sector 1 group, the one-visit-per-month ideal was nearly achieved: patients averaged 11.4 visits per year. In the control group, the average number of clinic visits per year was 5.8 (Table 1).

**Home Visits**

Because the treatment protocol calls for 28 days of intramuscular streptomycin, community health workers were asked to administer these injections to the patients living in their area. This is perhaps the chief reason that the number of home visits by members of the Proje Veye staff was far higher in the sector 1 group than in the sector 2 group—37.9 visits in the former versus 1.4 visits in the latter (Table 1).

**HIV Seroprevalence**

Seroprevalence to HIV was not substantially different between the two groups. Only one of the patients from sector 1 showed serological evidence of HIV infection, and that patient, a young woman, had lived in urban Haiti for extended periods. This patient again became sputum positive during a pregnancy occurring in the year after her full year of treatment. She was treated with a new multidrug regimen and remained asymptomatic some 30 months after her initial TB diagnosis. In the sector 2 group, similarly, two patients were seropositive to HIV, and both had lived in greater Port-au-Prince (Table 1).

**Etiologic Conceptions About TB**

Rural Haitians have extremely complex and changing ways of understanding and speaking of TB. Open-ended interviews with patients in both groups permitted the delineation of the dominant explanatory models adhered to by members of both groups. Because several community health workers had hypothesized that “belief in sorcery” as a cause of TB would lead to higher rates of noncompliance, some pains
were taken to address this issue with each patient. We learned that very few from either group would deny the possibility of sorcery as an etiologic factor in their own illness, and we could discern no relationship between avowed adherence to such models and degree of compliance with a biomedical regimen (Table 1).

**Cure Rate**

In June 1991, 28 of the sector 1 group remained free of pulmonary symptoms, and those with persistent cough and/or dyspnea did not meet radiological or clinical diagnostic criteria for TB (both had developed bronchospastic disease). Therefore, it was felt that none had active pulmonary TB, giving the participants an initial cure rate of 100%. One of these patients, as noted, was infected with HIV but remained asymptomatic 30 months after the initial diagnosis of TB. It was not possible to locate all 30 patients from sector 2 and elsewhere, but of 26 patients examined more than 1 year after diagnosis, only 13 could be declared free of active disease based on clinical, laboratory, and radiographic evaluation. Even if the four patients lost to follow-up were in fact cured, that would leave 13 others with signs or symptoms of persistent TB—a cure rate of, at best, 57% (Table 1).

**DISCUSSION AND CONCLUSIONS**

In an important review of the significance of TB in developing countries, Murray et al estimated that 26% of avoidable adult deaths are attributable to TB, making it the greatest cause of death in this group. Although the Proje Veye Sante project used traditional antituberculous therapy rather than short courses of new agents shown to be effective in Tanzania and elsewhere, their preliminary results would seem to be as encouraging as those recently reported by Styblo et al, who report a 90% cure rate when a 6-month course of isoniazid (INH) and thiacetazone is preceded by 2 months of inhospital, strictly supervised administration of a three-drug regimen. Given the high costs of hospitalization, the Proje Veye Sante anti-TB project suggests that a program that includes nutritional aid may be far less expensive and far more feasible than the TB-control programs now in place in many developing countries. Although such small numbers do not permit any sweeping conclusions, the project described here suggests that high cure rates are possible in a setting of extreme poverty in which hospital-based care is unavailable even for the critically ill.

The experience of Proje Veye Sante permits a number of pragmatic conclusions to be advanced after even so preliminary a study as that detailed here:

1. Projects designed to treat and prevent TB among the very poor should have altogether different priorities than projects designed for low-prevalence, high-income settings. Until there are major redistributions in the current partition of the world's wealth, chemoprophylaxis of contacts and of asymptomatic, purified protein derivative-positive patients has little role in settings like rural Haiti. For although there may be a high level of TB infection in the community, only the sputum-positive coughers may easily transmit the disease to others. Identification and treatment of patients with active pulmonary TB should be the top priority of TB control in settings like rural Haiti. Similar conclusions have been reached in Nicaragua and even among New York City's poor and have recently been advanced in a review of data from throughout the developing world.

2. The experience of Proje Veye Sante suggests that hunger and poverty are the prime culprits in treatment failure, just as they are so often responsible for the reactivation of endogenous infection. Countries held in underdevelopment would do well to invest meager resources in programs that address patients' nutritional status while assuring easy access to multidrug regimens. In rural settings, such projects would best be coordinated by village-based health workers rather than by mobile outreach workers or clinic-based staff. These health workers must of course have adequate technical and material backing to serve their communities.

3. A broad view of TB brings into relief the political, cultural, and economic barriers to compliance in TB treatment (and che-
moprophylaxis). Yet each of these factors is not evenly weighted in all settings. In fact, compliance is an analytically flimsy concept in countries like Haiti, where the poor are systematically put at risk for TB and then denied access to adequate care. All too often, the notion of patient noncompliance is used as a means of explaining program failure. Patient-dependent failure should be a “diagnosis of exclusion” and invoked only after poor program design can be excluded. Clearly, one of the chief reasons for program success in rural Haiti was the addition of direct financial aid to an already “free” treatment program long in place. Similar conclusions have been reached by those who have worked in both urban Nicaragua and New York City.4

4. Studies from urban and suburban Haiti, as in the United States and sub-Saharan Africa, suggest that a large number of persons with TB are HIV positive or have full-blown acquired immunodeficiency syndrome (AIDS). The data from Proje Veye Sante clarify to some extent the role of HIV in the epidemiology of TB in rural Haiti. Previous studies held to reflect HIV seroprevalence among rural Haitians have in fact been conducted in large referral hospitals serving a very mobile population with strong ties to (and often histories of extended residence in) Port-au-Prince, the epicenter of the Haitian AIDS epidemic.5

But the data presented here are from a clinic serving a smaller, less mobile community of rural peasants. It is a relief but no surprise that the vast majority of these patients are not HIV infected; if TB was the leading cause of death among rural Haitian adults before the advent of HIV, it makes little sense to assume that a large percentage of TB cases in the same population are now “attributable to HIV.” At the same time, the relentless march of HIV reminds us that it is necessary to coordinate AIDS-prevention efforts with TB-control programs.

5. Mycobacteria do not respect national boundaries. The fact that endemic areas like Haiti are the settings from which will come many future North American TB cases6 argues for a more systemic approach to treatment and prevention. For this reason, at the very least, cooperation between industrialized nations and poor communities hard hit by TB should be a new priority in TB-control efforts in North America.

The Proje Veye Sante experience also speaks to the relative significance of the myriad barriers to effective prevention and treatment of TB. Most studies of this subject discuss program failure as patient dependent, drug dependent, or project dependent. But underlying these distinctions are broader theories about the nature of these barriers. Many medical anthropologists would underline the importance of culture in determining the ultimate efficacy of efforts to combat disease. This argument has been made in various forms for many countries. For example, Wiese7 has argued that the failure of one TB-control program in southern Haiti was largely the result of “the clinic’s lack of knowledge about the local culture and consequent failure to operate within it.” Curiously, although the author notes that the cost of 10 weeks of treatment was equivalent to one half of a peasant family’s annual income, there is no further discussion of this significant economic barrier to care; it is only listed below several other, apparently more important, “cultural” factors that led to the failure of the program.

As noted, cultural, political, and economic factors, although inevitably important, cannot be of equal significance in all settings. Whereas cultural considerations, such as the nearly universal stigma attached to TB, may very well be of overriding significance in settings in the developed world, we would argue that they are often less so in Haiti, where so many factors (initial exposure to mycobacteria, reactivation of endogenous TB infection, complications, access to therapy, length of convalescence, development of resistance, degree of tissue destruction, and, finally, mortality) are determined chiefly by economic factors. In the Proje Veye Sante project, the relative insignificance of patients’ understandings of etiology compared with access to financial aid is one marker of the
The primary of economic considerations in impoverished settings. The hoary truth that poverty and TB are greater than the sum of their parts is once again supported by data, this time coming from rural Haiti and reminding us that such deadly synergism, formerly linked chiefly to crowded cities, is in fact most closely associated with deep poverty.

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