# Peru Journal - Part 2: Diseases of the Poor

By Louise Lief | January 08, 2010 | IRP


Tuberculosis poster in Carabayllo photo: Louise Lief

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Today we are exploring Lima's other reality, far from the lovely parks and fabulous seaside restaurants near our hotel in Miraflores. Of the city's 9.5 million inhabitants, some estimate that as many as half live in slums and shantytowns ringing the city. We will visit Carabayllo, one of the poorest of these growing pueblos jovenes ("young towns") on the northern outskirts of Lima. In 1994, Carabayllo had a population of 124,000. Peasants fleeing violence in the countryside and more recently, poverty and unemployment in the Andes have caused its population to more than double since then. Slums like these are now so populous they have become major voting blocs in the country's elections.

Many of Carabayllo's residents spend hours each day commuting to work in the city's more affluent neighborhoods. As we travel north past the crush of aging minibuses idling in traffic as they head downtown, the vegetation diminishes and gradually ceases. Lima is built in a coastal desert and in Carabayllo, the desert reasserts itself. We cross bridges over the Rimac "river", today a dry riverbed, and I wonder where the city's residents find water every day.

Workers from Socios en Salud (SES), a non-profit Peruvian medical organization, accompany us on our journey. SES is affiliated with Partners in Health, the Boston-based health care NGO founded by physician and Harvard medical school professor Paul Farmer. (Farmer's life and work in Peru and elsewhere is chronicled in author Tracy Kidder's award-winning book Mountains Beyond Mountains.)

Like Partners in Health, SES focuses on providing health care and support services to the poorest of the poor, a population that often has no other access to health care.

Today we will explore the problem of tuberculosis. Peru has the second highest infection rate for tuberculosis in the Americas after Haiti. In the mid 1990's, after an American priest in Boston working in Carabayllo died of tuberculosis that did not respond to standard treatments, Farmer and Peruvian doctor Jaime Bayona discovered an epidemic of multi-drug resistant tuberculosis (MDR-TB) and the even worse, extensively drug resistant TB (XDR-TB) in Carabayllo. Two decades of civil war, a collapsing healthcare system that interrupted the standard treatment for tuberculosis and a population on the move helped spawn these new mutant strains.

For all the progress Peru has made economically in the last decade, a quarter of Peru's children still suffer from malnutrition, and that is considered a conservative estimate. Hunger contributes to the spread of the disease. Add HIV/AIDS to the equation and the infection rate explodes.

As we drive into the settlement located in the Andean foothills, we enter a moonscape. There are no trees or vegetation, only barren hillsides. The poorer the residents, the higher up the mountain they live, their homes accessible only by steep walking trails. Water comes through a communal garden hose or is brought in by tanker. Over a million people in Lima get their water this way at a cost of $8 a month, more than a day's wage for those who have work. The jerry cans they use to carry water to their homes for drinking, washing and bathing are breeding grounds for mosquitoes that transmit dengue fever, another infectious disease that has found a home here.

At the Carabayllo Cultural Center, we meet Dr. Carole Mitnick, a Harvard medical school professor and researcher specializing in MDR-TB for the past 12 years. She gives us some background on the disease. There are over 9 million cases of active tuberculosis worldwide (over 1.8 billion people are infected with TB mycobacterium, which remains dormant in most people.) Every year, at least 500,000 new cases of drug-resistant TB are diagnosed, over half of them in China, India and the Russian Federation. All forms of TB are contagious, spread through the air by coughing,sneezing or spitting. Each year over 2 million people die from the disease.

Treatable tuberculosis requires a six-month daily treatment course called DOTS (Directly Observed Treatment Short-Course). MDR and XDR-TB require 18 months to two years of treatment with drugs so toxic they have driven people mad and to the brink of suicide, in addition to other side effects like ulcers, hearing loss and burning skin.

Doctors still use drugs developed 40 years ago to treat TB, but a breakthrough may be on the horizon. Mitnick tells us of two promising new drugs in Phase II clinical trials. One is being developed by Tubotec, a subsidiary of Johnson and Johnson, the other by Otsuka Pharmaceuticals, a Japanese firm. If the trials go well and if the drugs are affordable, it could change the TB treatment landscape.

After our short orientation session, we divide into small groups to go out into the community. My group is accompanied by David Flood, a young University of Michigan graduate who read Dr. Farmer's books and decided to become a doctor. He's volunteering in Carabayllo while waiting to hear from medical schools in the US.

Our first stop is the Sergio Bernales Hospital that serves Carabayllo. Housed in a modest series of barracks-style buildings, with peeling paint and wards filled with narrow metal bed frames, it reminds me of a 1930's hospital in the United States. But through its partnership with the Brigham and Women's Hospital in Boston, Partners in Health and Socios en Salud, Sergio Bernales has become one of the world's premier hospitals for treating drug resistant TB, claiming an 86 percent success rate – the world's highest -- in treating MDR-TB and XDR-TB. It has been so successful, in fact, that its treatment plans are being emulated in Russia and in several African countries.

Our group dons face masks and we visit the TB ward, where emaciated patients lie in oxygenated rooms to ease the effort of breathing with damaged lungs.

**Climbing the Mountain**

Gatekeeper editors interview multi-drug resistant TB patients in their homes photo: Louise Lief

Our group's first home visit is to Angel Serrubio, a 46-year-old construction worker from the remote northern Amazonian town of Iquitos. His sister brought him to Lima seeking treatment for his MDR-TB after doctors there gave him up for dead.

Our van cannot make it up the hillside, and in any event, there is no road. It's a steep climb, and I can't imagine how TB patients who have trouble breathing do this every day, but they do. Dogs guard each shack and growl at us as we climb towards Angel's compound at the top of the hill.

Homes here are most often a warren of shacks with walls made of woven palm fronds, salvaged wood and bricks. Fifteen or more family members may live in each settlement. Sanitation is a pit dug into the rocky hillside. Ventilation is poor, food is often scarce, and the TB bacteria flourish in these conditions.

Angel is gaunt and sinewy, puzzled that a group of gringos would be interested in climbing the hill to meet him. He tells us he believes he contracted MDR-TB in Iquitos when he helped a neighbor from Lima who said she had "asthma" go to the hospital. She was bleeding from her ears, nose, and mouth. Three months later she was dead, he felt ill, and the standard TB treatments failed.

Until recently, under established World Health Organization medical protocols, patients who didn't respond to DOTS were given a repeat dose. In Peru with its MDR-TB problem, that was exactly the wrong thing to do. The resistant TB bacteria got stronger. Bayona, Farmer and their colleagues were only able to develop successful treatments for MDR and XDR-TB by flouting the international protocols Peru's medical establishment had proudly implemented for many years and collecting date to prove their alternate approach worked. WHO eventually changed their protocols in recognition of this new scientific evidence.

Angel is one of the lucky ones in Peru to be treated for MDR-TB. Not only has his MDR-TB been cured, but SES has provided him with the almost unheard-of luxury of psychological counseling and support groups, and a tiny shack built of plywood to separate him from his relatives.

He is now president of a patient advocacy group at the hospital. In Iquitos he says, "I felt as if I didn't exist… Every time I asked them to explain what was happening, no one told me anything." He doesn't like Lima, so different from the lush and tropical Amazonian jungle. He wants to return to Iquitos, and after three years of illness, to work.

We have visited many countries and many NGO projects on these gatekeeper trips, and one thing that strikes me about the SES projects in Peru is the sense of ownership people in the community seem to have about the programs. In return for a monthly food basket, neighborhood women serve in an SES network of volunteer community health workers called promotoras who seek out those who need help, advocate for them at the hospital, and even go beyond medical issues to check on their children or assist with financial issues such microloan repayment problems. Many of these promotoras operate tiny storefront pharmacies called botiquines. Neighbors come to have wounds stitched, or get aspirin or insulin injections. The promotoras seem to greatly enjoy their work, and enjoy great respect in their communities.

Still, even these dynamic women cannot escape the realities of life in Carabayllo. Our next visit is to the home of a woman who is president of her street committee and a volunteer for Vaso de Leche ("glass of milk"), a government-sponsored breakfast program for poor school children (there is no government school lunch program). At 46, she is a mother of six and a grandmother many times over. Fifteen people live in her household. We have come to see her daughter Rosa, a 19 year-old single mother of two who is HIV positive. Teen pregnancies, domestic abuse, and alcoholism are also part of life in Carabayllo.

Rosa gave birth to her first child at age 15. She split with the boy's father because he cheated on her. Unbeknownst to her, he also infected her with the AIDS virus.

Rosa soon met another compañero, a 31-year-old moto taxi driver. When at 7 months she went for her first prenatal exam, she discovered she was HIV positive. Her son M., an adorable 15 month-old with bright dark eyes, has AIDS. SES promotoras, scouring local hospital waiting rooms found her, in shock and depressed by her own diagnosis, trying to get treatment for her baby who suffered from throat ulcers, respiratory infections, and flesh-eating bacteria. They brought her under their wing, and began the battle to get her and her baby health care.

To access the state healthcare services in Peru, a child needs a birth certificate. In Carabayllo and elsewhere, many children don't have them. Getting one involves a long, expensive trek to city hall, documents, fees and often, the father's consent. It's just too much for many mothers. Rosa has a birth certificate for M., but not for her older child P. SES helped her access care for M. at Lima's children's hospital. He is now on anti-retrovirals. He has already had several long hospital stays and wears a colostomy bag. He will need more surgery soon. Rosa tells us her story with tears coursing down her cheeks. She doesn't want us to use her full name or photograph. While her mother and sisters know her diagnosis and support her, her father, male relatives and the neighbors don't know she is HIV positive, and she's terrified they'll find out.

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