

Tiny East Timor declares war on leprosy

October 11 2010, By MARGIE MASON , AP Medical Writer



This July 7, 2010 photo shows the feet of Luis Siqueira Aforn, 65, who's toes were chewed by rats while he was sleeping on the ground in Hauana, East Timor, south of Oe-cusse town. The loss of sensation led him to be oblivious to the nibbling of the rodents. East Timor is one of just two places worldwide where leprosy is still widespread, and the country has now declared war on the age-old scourge. (AP Photo/Wong Maye-E)

(AP) -- If there really was a place so remote it could be called the end of the earth, Adelino Quelo's shabby little hut would be prime real estate.

His thatch teepee-shaped home is the last stop in tiny East Timor. It is perched on the side of a rugged emerald mountain with a million-dollar view of neighboring Indonesia, so close you can almost touch it.

As rare visitors holler his name, a slow shuffling comes from the dirt floor inside. A minute passes and Quelo, 68, appears at the small opening carved out near the ground. He scoots on his rear and grunts

while laboriously dragging one leg, then one arm on each side, using a torn pair of mismatched flip flops as his only aid.

His fingers, toes and parts of his hands and feet are missing. Only stubby knobs remain, keeping him from standing, gripping or even bathing himself. But Quelo smiles a toothless grin and motions for his guests to come closer, apologizing for having nothing to offer but his story.

He is just one face of [leprosy](#) in a country that has declared war on the age-old scourge. East Timor is one of two places worldwide - the other is Brazil - where the disease is still widespread enough to be considered a public health threat.

But for Quelo, the fight comes far too late.

"I, myself, already suffer from this, and it's enough," he says, a dirty sarong hiked up on his right thigh, exposing a large open sore. "I hope no one else will suffer this."

Oe-cusse Enclave, a lush secluded area cut off from the rest of East Timor by the Savu Sea, is thought to have been a leprosy colony during Portuguese and later Indonesian rule.

Roughly the size of New York City, it was positioned on the front lines during the brutal fight for independence from Indonesia 11 years ago and was nearly destroyed. Monuments now mark the sites of bloody massacres.

Its 60,000 people are survivors, but they are dangerously poor. Living conditions worsen as the roads narrow and grow steeper, exposing naked children with bulging bellies and blond-streaked hair - signs of

malnutrition.

Time seems to have stopped here, and the disease believed long gone in many parts of the world continues to nibble away at lives, despite a three-pill cure recommended for the past three decades. But the number of new infections in East Timor, home to about 1 million people, has dwindled to 160 last year. It is nearly within the World Health Organization's target for elimination, or less than one case per 10,000 people.

Now leprosy specialists like Dr. Rosmini Day, who's battled the disease for 20 years across Asia, are scouring this secluded pocket for new cases to determine if East Timor will meet the mark by year's end. Since the campaign began in 1991, the number of new leprosy patients worldwide has plummeted from about 10 million to 250,000. Leprosy is virtually nonexistent in the West, with only about 150 cases reported in the U.S. annually.

Some experts argue the WHO target makes people wrongly believe that an already neglected disease has been wiped out entirely. And some question the authenticity of the count in countries driven to meet world goals.

But Day, a 62-year-old Indonesian grandmother, has come out of retirement to help East Timor with its last fight. She is a master at identifying the disease and believes no one should be overlooked, no matter how remote.

She hikes up a muddy mountain road too treacherous for even a 4X4 and examines a patient in the rain outside his hut. She interrupts a cock fight in another village to pinch and pull at the skin of a second patient's elbow to see how fast it snaps back. She stops at a third man's house and calls him out onto the road from a funeral to have a look beneath his

shirt.

Leprosy is difficult to identify in the early stages, but Day says it's important for a new generation of health workers to learn the traits to stop the spread and cure patients before damage is done. It's the only way to truly get rid of the disease.

"I use a sarong to protect my toes, but the rats still come in the nighttime and eat at my toes," says Luis Siqueira Afoan, 65, a patient who walked more than 2 miles (1 kilometer) on dry blackened nubs to see the doctor who can do nothing to help. "When I'm sleeping, I put my fingers under my head, but the rats still come and eat at my fingers."

Quelo lives a 30-minute hike down a steep hill and across three fences from Malelat village, home to the enclave's worst cases. Of the 300 families living here, nearly everyone has a relative or neighbor suffering from the lasting effects of leprosy.

Like most of them, he was infected decades ago as a farmer before medicine was available. By the time he finally received the antibiotics, the disease was already advanced, forcing him to slowly watch his limbs die.

"I use my hand with a rubber band and a spoon because I don't have fingers anymore," he says, sitting crumpled up on the ground outside his hut as two brown puppies dance around him. "I lost the ability to walk more than 20 years ago."

Leprosy is not a killer, but a chronic bacterial infection that seriously disables those not quick enough to identify and treat it. Like tuberculosis, it can stay dormant for years before attacking and slowly

shutting down the nerves that allow a hand to make a fist or a foot to flex.

It typically starts as a light-colored patch on the skin and then spreads, stopping hair from growing on affected areas and short-circuiting sweat and oil glands. Eventually, hands and feet go numb and begin to claw inward, leading to injuries that go unnoticed and become infected because no pain is felt. Sometimes, in the worst cases, fingers and toes are lost or blindness occurs.

"It maims people, it cripples them and it makes their lives shorter because they cannot work and therefore they cannot eat," says Dr. Denis Daumerie, project manager of Neglected Tropical Diseases at the WHO in Geneva, who's been working with leprosy for nearly three decades. "It kills slowly. It leads to discrimination and social exclusion, which in many societies is worse than death."

Leprosy, or Hansen's disease, is arguably one of the most feared maladies ever. It was discovered in a 4,000-year-old skeleton from India, and has continued to disfigure and ostracize those afflicted throughout the ages.

Despite its longevity, much about it remains a mystery. Scientists believe it is spread through droplets from coughing or sneezing during prolonged contact with someone infected, but they are still not completely sure. About 95 percent of people exposed to the germ never develop leprosy.

Before a cure existed, rampant fears ran wild that leprosy could easily spread through the air or by touching someone infected. Many victims were forced into so-called leper colonies, which were often faraway areas cut off from the rest of the world. One of the most well-known sites was on the Hawaiian island of Molokai, where only a few former patients still remain, voluntarily.

But active leprosy communities still exist in several countries, mainly in Asia, including Vietnam and China. Hundreds of colonies remain in India, home to half of all new cases identified last year, where even the healthy children of former patients are still discriminated against.

"Leprosy remains a word that's associated with stigma and fear - even mainstream newspapers still use the word 'leper' to denote somebody who's an outcast," says Dr. Diana Lockwood, a professor at the London School of Hygiene and Tropical Medicine who has studied the disease for 30 years. "Nobody should need to go into a leprosy community now because we have good outpatient-based treatment."

But in East Timor, and specifically Oe-cusse Enclave, leprosy is not feared as it is in richer, more educated places. Many patients here tell their friends and neighbors when they've been diagnosed, and the community becomes their support system.

"I have no problem with my schoolmates," says Paulo Colo, 17, who is finishing a nine-month course of treatment after noticing the same patches on his skin that his father and brother suffered. "They don't keep their distance from me."

No one shuns or fears Quelo either, but the remoteness of his house keeps visitors from coming around. With no wheelchair or any form of transport, the disease has jailed him inside a hillside shack that lacks water, electricity or even a chair.

But he's not alone. His watery eyes spark as he talks about his devoted wife and four daughters-in-law who care for him daily.

"If she didn't love me then maybe I would have passed away a long time

ago," Quelo says of his wife, who was out gathering food for dinner. "Our promise is: I need you and you need me, and then we take care of each other until the end of time."

He still feels pain in his stick-thin legs and his lower back often aches from sitting all day with no support. He can't read and the days are long, but he says his faith has kept him strong.

Like most people in East Timor, he was raised Roman Catholic. Every day he draws on sermons heard years ago in church. He smiles as he recalls the Biblical story where Jesus heals 10 leprosy patients, with only one returning to give thanks.

"Even though I am suffering like this, I have never blamed my God. I am satisfied with my life even though I am a leprosy patient," says Quelo, a head of gray curls surrounding his worn face. "I am thankful that he has taken care of me into old age."

He then begins to drag what's left of his body back into the hut. As he moves one foot, then one arm at a time, the sound of hard breathing slowly fades into the darkness.

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