Mystery kidney disease killing Sri Lankan farmers

January 18 2015, byMargie Mason

In this July 24, 2014, photo, V.G. Karunawathie, a patient suffering from a chronic kidney disease of unknown etiology, rests after returning home from a dialysis session at a nearby hospital, in Konketiyawa village in Padaviya, Sri Lanka. She received treatment on her second visit the same day as there were not enough dialysis units to go around. Dialysis is supposed to be given three times a week, but some patients only go once a week, while others are forced to burn their savings traveling hours by bus only to be too exhausted afterward to return home. (AP Photo/Eranga Jayawardena)

Karunawathie isn't hungry for breakfast. She rarely is these days, but she

forces herself to choke down a few bites of rice, dried fish and a simple coconut mix. The doctors say it's better to have something in her stomach before the four-hour dialysis treatments.

She's going for her second session of the week, dressed all in pink, right down to her flip-flops. Her fingers and toes are fat with fluid, and her spongy arms feel like soft water balloons. Since she can no longer pass liquids on her own, doctors have told her to drink only 500 milliliters a day—equal to less than a can and a half of soda.

As she walks unsteadily to the door, her two youngest children, 16 and 11, kneel before her and place their heads at her feet in a traditional show of respect.

V.G. Karunawathie is only 40 years old, but she is dying, and no one knows why. Her kidneys have stopped working, and now she's kept alive by a pump that filters waste from her blood twice a week through a snorkel-like tube implanted into her neck.

The cause of her disease, which affects an estimated 70,000 to 400,000 people in Sri Lanka's rice basket, has baffled doctors and researchers for two decades. Even the World Health Organization hasn't been able to pinpoint what's killing as many as 10 people a month in Karunawathie's village—ravaging one house while sparing the next—as it creeps farther and farther into neighboring areas.

The disease mirrors equally confounding conditions plaguing thousands of farmworkers in parts of India, Egypt and Central America. Suspected causes include chronic dehydration and the heavy use and misuse of agrochemicals. In Sri Lanka, fertilizer use is among the heaviest in the world.

No one cause has been identified, but theories abound. Many believe a

combination of factors could be at play—from toxic algae and hard ground water to heavy metal exposure and high fluoride in drinking water.

But to Karunawathie, there is no mystery at all. She understands more about this so-called chronic kidney disease of unknown etiology than anyone should.

It killed her father, mother and five brothers. Three other siblings have been sickened.

As the youngest of a dozen children, Karunawathie was diagnosed with the disease 12 years ago in her impoverished farming village. Since then, she's been told to stop eating fish and lotus root and to abandon her aluminum pots and pans for clay cooking utensils.

She's heard arsenic is to blame along with cadmium, lead and even home-brewed alcohol. Like most, she believes there's something in the water. But she has long given up trying to determine the source of her family's killer. Instead, she lives day to day at the mercy of a machine. And even that's not a sure thing.

Dialysis is supposed to be given three times a week, but most Sri Lankan patients get it only twice since just 183 machines exist nationwide—even though 2,000 new patients are in need annually. Critics say it's just one area where the government is failing the sick. Clean drinking water still isn't available in all affected areas, only a handful of kidney specialists practice in public hospitals and there's no national donor transplant program.

With few options, many desperate patients are forced to burn through their meager savings, traveling hours every week by bus for treatment only to be too exhausted afterward to return home. Instead, they sprawl

out on hospital grounds or in hallways for the night. Or they simply stay home and wait to die.

Karunawathie is fortunate to live only 10 kilometers (6 miles) from basic care. But the ride on the back of her son's motorbike is a torturous trip across scabbed pavement framed by a tangle of trees alive with monkeys and peacocks.

When she reaches the hospital on this day, there's bad news: All the dialysis units are being used.

Karunawathie is told to come back later. But with each step, her strength is dying.

This Dec. 9, 2013, photo shows the swollen feet of Seneviratnalage Jayatillake, a Sri Lankan farmer suffering from a chronic kidney disease of unknown etiology, as he rests in his house in Padaviya, Sri Lanka. The cause of his disease, which

affects anywhere from an estimated 70,000 to 400,000 people in Sri Lanka's rice basket, remains an enigma without a name. Jayatillake died in February 2014 after a prolonged illness. (AP Photo/Eranga Jayawardena)

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More than a half-century ago, after Sri Lanka gained independence from Britain, farmers were encouraged to move to the hot, dusty North Central province with offers of free land.

Driven by the Green Revolution of the 1960s, the teardrop-shaped island south of India abandoned ancient farming practices for modern techniques and adopted chemicals that promised the dream of self-sufficiency.

Rice paddies and vegetable fields soon dotted the vast, flat land irrigated by large reservoirs. And today, Sri Lanka produces enough rice to feed its 20 million people.

In this Feb. 5, 2014, photo, villagers carry the coffin containing the body of Seneviratnalage Jayatillake, a Sri Lankan farmer who suffered from a chronic kidney disease of unknown etiology, during his funeral in Padaviya, Sri Lanka. The cause of his disease, which affects anywhere from an estimated 70,000 to 400,000 people in Sri Lanka's rice basket, remains an enigma without a name. (AP Photo/Eranga Jayawardena)

Karunawathie's father was among those who moved from the cool, airy mountains to claim a piece of this harsh ground. He earned good money farming tobacco when she was a child, and the whole family helped harvest and handle the pesticide-coated leaves often stacked in a bedroom to dry.

Then in 1987, her father died after his kidneys suddenly gave out. He was one of the first in Konketiyawa village to succumb.

The unexplained disease wasn't noticed by doctors until a few years later, after it started popping up elsewhere in the area. Unlike most kidney

cases, there was no link to diabetes or hypertension. Instead, patients arrived at hospitals complaining of fatigue, loss of appetite, joint pain and difficulty passing water.

In this Dec. 9, 2013, photo, Appuhamige Pinhami, a Sri Lankan farmer suffering from a chronic kidney disease of unknown etiology, lies on a bed as family members sit by his side chanting religious scriptures expecting his death anytime, at their house in Kebithigollewa, Sri Lanka. The cause of his disease, which affects anywhere from an estimated 70,000 to 400,000 people in Sri Lanka's rice basket, remains an enigma without a name. Pinhami died after few months later. (AP Photo/Eranga Jayawardena)

Within months, they were dead. Many were men in their 30s and 40s who had labored in the paddy fields from the time the searing sun awoke until it faded red in 100-plus degree temperatures. No cases were detected outside the so-called dry zone, even though farming is practiced

across the island famous for its teas.

By 2003, Dr. Tilak Abeysekera was alarmed by the growing number of patients he was seeing, including family clusters. He began traveling to affected areas to screen entire villages. A telltale protein was found in about 10 percent of the urine samples, and biopsies later revealed that something was destroying tissue that supports the kidney's filters, causing the organ to shrink.

In this July 24, 2014, photo, a Sri Lankan farmer walks past an advertisement promoting agrochemicals in Padaviya, Sri Lanka. A chronic kidney disease that has already killed up to 20,000 people over the past two decades and affects anywhere from 70,000 to 400,000 more in the country's North Central rice basket, remains an enigma without a name. Many in Sri Lanka, including the World Health Organization, have pointed to heavy use and misuse of agrochemicals as a possible culprit in a country that's among the world's top fertilizer users. (AP Photo/Eranga Jayawardena)

He diagnosed Karunawathie that same year. But more than a decade later, he is no closer to understanding the cause.

"That type of disease you get in response to toxin exposure," says the aging, bespectacled doctor, who heads the kidney department at the Teaching Hospital in Kandy. "That's what led us to think this is an environmental disease from exposure to a toxin. How it gets into the human body is still debatable."

While the death rate has climbed to as many as 20,000, the source continues to baffle, just as it does along Central America's Pacific coast. A similar number of mostly sugarcane farmers have died there during the past two decades.

In this July 23, 2014 photo, V.G. Karunawathie, a patient suffering from chronic kidney disease of unknown etiology, rests in her house with her family member in Konketiyawa village in Padaviya, Sri Lanka. Her kidneys stopped working nearly a year ago, and now she's kept alive by a pump that filters waste from her blood twice a week through a snorkle-like tube implanted into her neck. (AP Photo/Eranga Jayawardena)

The problem has become so dire in one part of Nicaragua, it's been dubbed the "island of widows." Two areas in India and a pocket of Egypt have also been hit.

Despite millions spent on numerous studies in Sri Lanka—some led by distinguished local researchers and others conducted using questionable methodology—new cases continue to emerge.

The media have reported voraciously on all probable causes, including one group's claim that a vision from God led them to discover arsenic as the source.

The latest paper blames glyphosate, the country's top weed killer that's well-known worldwide as Roundup. That hypothesis, published in a little-known open access journal last February, suggests the agrochemical, introduced by U.S.-based Monsanto, forms a bond with heavy metals in food and drinking water that eventually destroys the kidneys. Glyphosate has been detected by the WHO in 65 percent of those sickened by the mystery kidney disease.

Although the theory has never been proven and Monsanto dismisses the claim, a minister announced in March that after seeing the report, then-President Mahinda Rajapaksa decided to ban the herbicide. The order was never enforced following industry protests and the chemical wasn't

even officially outlawed until last month, in what was seen largely as a political move to win votes ahead of January's election. Glyphosate is still being sold in Sri Lanka.

In this Feb. 5, 2014, photo, family members weep around the body of Seneviratnalage Jayatillake, a Sri Lankan farmer who suffered from a chronic kidney disease of unknown etiology, during his funeral in Padaviya, Sri Lanka. The cause of his disease, which affects anywhere from an estimated 70,000 to 400,000 people in Sri Lanka's rice basket, remains an enigma without a name. It mirrors an equally confounding condition plaguing thousands of farmworkers in parts of India, Egypt and Central America, where chronic dehydration is one suspected cause. (AP Photo/Eranga Jayawardena)

Everyone is in agreement about one thing: Farmers living in the affected area douse their fields with too many chemicals, mixing up concoctions that sometimes include kerosene and multiple poisons. Most workers rarely, if ever, wear protective gear.

"You would think that this is such a major health issue that there would be a tremendous outpouring of sympathy and support, but instead there is all these political and economic interests behind the scenes that is sort of blocking addressing this issue," says Asoka Bandarage, a Sri Lankan academic in the U.S. who has written about the problem.

"Even if it's not a definitive link, I think there's enough evidence or suspicion that they should really try to find alternatives to such heavy use of pesticides."

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The nonstop swirl of confusing information has fueled fear, especially since the affected area has expanded from two districts to seven.

At the first sign of a simple backache or stomach cramp, villagers worry they've got "the kidney disease." Some try to drink as little from their wells as possible and give the only bottled water they can afford to their children, leading to chronic dehydration that exacerbates the condition.

Others living in the hard-hit area of Padaviya, where Karunawathie's village is located, are concerned about marriage prospects due to growing stigma. Women are wary of moving there, and in some places, young men are fleeing to cities in hopes of escaping their family medical histories.

"They are the farmers who have fed the nation for the last three or four decades," says Hemantha Withanage, head of the nonprofit Center for Environmental Justice. "Now they are dying, and the country is not looking after them."

The health ministry is expanding screening to try to figure out just how many people are affected and to improve early detection. It also plans to

supply more medicine and dialysis machines, adding nearly a third of the country's units in 2013. But the kidney disease is already gobbling up to 5 percent of the health budget.

Newly elected President Maithripala Sirisena is a former health minister who hails from one of the hardest-hit areas. As part of his campaign, he donated money received for election posters to a fund set up for kidney patients. He also has promised to do more to address the problem.

The WHO report published two years ago is seen as the most credible research so far.

It found disease in 15 percent of adults in three affected districts, hitting male farmers over 39 years old the hardest even though more women with less-advanced disease were seen overall. Elevated cadmium and pesticide residues were detected in urine, leading the authors to surmise that they may be damaging patients' kidneys over time, in combination with other factors such as arsenic.

Water—the source widely suspected as the culprit—came up clean. However, the WHO study's Geneva-based author, Shanthi Mendis, says it could still be playing a key role when combined with other factors. She adds that the government must provide safe drinking water and regulate the use of agrochemicals. Pesticide bans and plans to truck in water are not solutions.

"This drinking water should have been put right years ago," she says. "Nobody's really taking any real action. They're just talking."

Fertilizer is another issue. For years, the government has heavily subsidized imports coming mostly from China. Rice farmers currently only pay about $2.70 for each 50-kilogram bag. If that suddenly stopped, protests would likely follow.

Although the U.N. Food and Agriculture Organization ranked Sri Lanka among the world's top 30 users of fertilizer per hectare in 2011, the Agriculture Ministry has slowly started decreasing how many bags it distributes—amounting to about 750,000 metric tons annually at a cost over $300 million. It says it's pushing for a gradual return to the old ways of chemical-free cultivation.

But farmers, worried about their yields and meager bottom lines, aren't keen to go back. They say agrochemicals are far cheaper and easier than manual labor and produce just enough output for their families to survive, especially during a recent drought that turned once-verdant fields into endless acres of abandoned brown stalks.

In this July 24, 2014, photo, V.G. Karunawathie, left, a patient suffering from a chronic kidney disease of unknown etiology, leans on her son as she rides home from a hospital after a dialysis session in Konketiyawa village in Padaviya, Sri Lanka. She received treatment on her second visit the same day to the tiny nearby hospital as there were not enough dialysis units to go around. (AP Photo/Eranga Jayawardena)

Karunawathie's husband and brother, who has early stage kidney disease, both work seasonally on farms, earning about $150 a month. They never used to wear masks or gloves when spraying chemicals, but take precautions now.

Her brother says the poisons cause people to lose their appetite, and he sometimes vomits into the dirt. As a result, he never eats or drinks while spraying.

Like everyone else in the village, the family has always relied on foul-tasting well water, heavy with calcium and magnesium that turn the water hard. They gladly abandoned it last year, when the government set up a filtration plant just down the road.

Karunawathie says it tastes much better, but she doesn't know if it's the answer. She's sure it's too late for her and many neighbors who are already sick, but she hopes the clean water will keep her three children from becoming the next generation to suffer.

"I don't feel any different since I started drinking the filtered water," she says. "I've seen a lot of deaths in the family, and I also think I will go through the same thing."

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Despite recently emerging from a quarter-century of civil war, Sri Lanka has managed to build and maintain a strong health system that's the envy of its neighbors. Child and maternal survival rates are among the best in Asia, and most care is free.

The Buddhist-dominated country also has a long history of eye donation

through a local nonprofit that's made it one of the world's top cornea providers, yet no national kidney cadaver transplant program exists to help save lives.

It's a frustration that overwhelms doctors who say until the cause of the mystery is found, the government's focus must switch from searching for the reason to providing the only long-term solution available. Less than 50 transplants have been performed at Anuradhapura Teaching Hospital, the affected area's main health facility, while desperate patients post daily newspaper ads with their photos and blood types, pleading for someone to help.

"Four or five people are added every week to dialysis, a minimum of three a week," says Dr. Charitha Weesasinghe, a kidney surgeon at the hospital. "But without transplant, you just wait for them to die."

Karunawathie's brother is the only family member lucky enough to get a kidney after a well-off man in their village came forward. As a police officer, he was well cared for in a special hospital until he recovered.

In this July 16, 2013 photo, Kumaradasa, a Sri Lankan farmer suffering from a chronic kidney disease of unknown etiology, bathes helped by his wife outside their house in Medavachchiya, Sri Lanka. The cause of his disease, which affects anywhere from an estimated 70,000 to 400,000 people in Sri Lanka's rice basket, remains an enigma without a name. Kumaradasa died on June 8, 2014. (AP Photo/Eranga Jayawardena)

Karunawathie herself is not even hoping for a donor, and says she would refuse even if someone offered such a precious gift. The person would need to be properly cared for after surgery, and she has no money to offer.

Instead, she weakly straddles the motorbike at dusk and rests her head on her son's shoulder after her second trip to the hospital for treatment today.

As the oldest child, 21-year-old B.R. Pradeep Nuwan Weerawansa says

he is treasuring whatever time he has left with his mother. But it's hard to watch her strength wither, with each lifesaving treatment leaving her weak.

"I want to give her whatever I can while she's still living," he says. "She's gone beyond the stage of recovery."

On this day, she finally gets her time with the machine, but all has not gone well. Karunawathie's skin is clammy, and she complains it's so hot, she feels as if steam is coming out of her body. Pinches of electric shock pulse through her arms.

By the time she gets home, her eyelids are heavy, and she's breathing hard through her mouth. Her mother-in-law, who's been losing weight lately from her own advancing kidney disease, helps drag her into the house, where she collapses onto a bed by the front door.

In this July 16, 2013 photo, Kumaradasa, a Sri Lankan farmer suffering from a

chronic kidney disease of unknown etiology, bathes helped by his wife outside their house in Medavachchiya, Sri Lanka. The cause of his disease, which affects anywhere from an estimated 70,000 to 400,000 people in Sri Lanka's rice basket, remains an enigma without a name. Kumaradasa died on June 8, 2014. (AP Photo/Eranga Jayawardena)

She whimpers and calls for a fan to try to move the suffocating air, but there is no relief. Her children kneel and stroke her head, trying to offer the only comfort they can.

Karunawathie knows it won't be long now. She's seen this disease enter her village too many times, always with the same cruel ending.

"When the call comes, we have to be prepared to go," she says, softly. "We can't run away and escape."

In this Dec. 12, 2013, photo, Seneviratnalage Jayatillake, a Sri Lankan farmer suffering from a chronic kidney disease of unknown etiology, rests in his house in Padaviya, Sri Lanka. The cause of his disease, which affects anywhere from an estimated 70,000 to 400,000 people in Sri Lanka's rice basket, remains an enigma without a name. Jayatillake died in February 2014 after a prolonged illness. (AP Photo/Eranga Jayawardena)

That night, she's rushed back to the hospital where doctors work to stabilize her. She fights through the pain only to wake the next morning to learn that death has found someone else.

Another neighbor is gone. She wonders if she'll be next.