AIDS devastates ancient culture

JOBURE DE GUAYO, VENEZUELA

An indigenous population in Venezuela is in peril as social programs collapse

BY KIRK SEMPLE

After the other villagers had drifted away to do chores, Rafael Pequeño finally found himself alone with the headman and opened the hardcover notebook on his lap. The men were sitting in a palm-thatched hut perched on stilts on the edge of a branch of the Orinoco River.

It had been two years since Mr. Pequeño, a nurse, had visited this poor indigenous village in the remote Orinoco Delta region of eastern Venezuela. His notebook contained a registry of patients who had been part of an H.I.V. treatment program that like the rest of the nation's public health system, had fallen apart.

Mr. Pequeño took a roll call of the infected.

“Armando Beria,” he said, reading from the top of the list.

“Still here,” replied the headman, Ramón Quintín.

“Ebelio Quinino,” the nurse continued.

“Still here.”

“Mario Navarro.”

“Dead.”

“Wilmer Medina.”

“Dead.”

Of the 15 villagers who had been part of the treatment program, five had died of AIDS, the disease caused by H.I.V. In all, more than 40 residents of this village, a settlement of only about 200, had died of AIDS or AIDS-like symptoms in the past several years.

“I’m very worried,” Mr. Pequeño said quietly. He looked stunned. “It’s wiping out this community.”

In recent years, amid profound shortages of medicine coupled with widespread ignorance, H.I.V. has spread rapidly throughout the Orinoco Delta and is believed to have killed hundreds of the Warao indigenous people who live in settlements like Jobure de Guayo along the serpentine channels winding through this swampy, forested landscape.

Even under the best of circumstances, it might be difficult to control the disease’s spread in such an isolated and deprived area. But the government has ignored the issue, medical specialists and Warao community leaders say, leaving the population to face a profound existential threat alone. Already, deaths and the flight of survivors have gutted at least one village.

Dr. Jacobus de Waard, an expert on infectious diseases at the Central University of Venezuela, who has worked and traveled among the Warao for years, said that nothing less than the future of the ancient culture was at stake.

“If there’s no intervention, it’s going to affect the existence of the Warao,” he warned. “A part of the population is going to disappear.”

The epidemic plaguing the Warao is a crisis within a crisis, a dramatic example of how Venezuela is failing to grapple with a resurgent AIDS emergency even as the annual numbers of new H.I.V. infections and AIDS-related deaths around the world continue to decline.

Under President Hugo Chávez, Venezuela’s H.I.V./AIDS prevention and treatment program was world class and the country seemed to have the disease under control.

But during the presidency of Nicolás Maduro, which began in 2013, Venezue-

Rafael Pequeño, a nurse, bemoaned the lack of medicine for those in the indigenous village who are H.I.V-positive: “I’m like a soldier without a weapon.”
A Venezuelan culture in peril

AIDS, FROM PAGE 1

Venezuela’s economy has crumbled, causing crippling shortages of medicine and diagnostic tests, and compelling many of the country’s best doctors to emigrate.

The government has even stopped distributing free condoms, which can help prevent the spread of HIV, activists say. The price for a pack can cost the equivalent of several days’ pay at minimum wage.

The government’s inaction, activists say, is especially egregious, considering that President Maduro — like his predecessor — has cast himself as a champion of the nation’s indigenous people.

The Maduro administration did not respond to requests for interviews with officials of the national HIV prevention program, the health ministry and the ministry of indigenous affairs.

The government has released health statistics only sporadically in recent years, and doctors often dispute their accuracy. But AIDS activists and specialists say that HIV infection rates and the number of AIDS-related deaths have skyrocketed. So, too, has the number of once stable HIV patients whose health has collapsed for lack of a regular supply of antiretroviral drugs and medicines to treat opportunistic diseases.

“It’s a humanitarian emergency — we have to be very emphatic,” insisted Jonatan Rodriguez, president of StopVIIH, a Venezuelan activist group.

Among the most disadvantaged Venezuelans, he said, are the Warao.

“It’s a population that has been totally neglected.”

AN ISOLATED PEOPLE

The Warao, Venezuela’s second-largest indigenous group, have made their home for many centuries in the soggy delta region where the muddy waters of the Orinoco River fan out into distributaries that merge with the Atlantic Ocean.

Numbering about 30,000, they live in hundreds of impoverished settlements in open-sided stilt homes perched at the edge of the region’s streams and rivers.

The area is hard to reach. There are no roads, so travel is restricted to boats, mostly dugout canoes. There are no telephone landlines, and nearly the entire region is without cellphone signal. Only the largest villages have electricity, though usually only at night — and the generators that provide it often run out of fuel or break down.

It can take several hours traveling by high-speed powerboat to reach the settlements from the state capital, Tucupita, but a fuel mafia now controls the distribution of gasoline in the region, driving costs beyond the reach of nearly every resident. River pirates make access to the delta even harder.

HIV was first detected among the Warao in 2007 and is thought to have been introduced by a returning migrant, one of many young Warao who have sought work in far-off Venezuelan cities as house cleaners, security guards, laborers, street vendors and prostitutes.

A study published in 2013 warned of a burgeoning epidemic. It found that nearly 10 percent of Warao adults living in eight villages in the lower delta region tested positive for HIV — “a dramatic high prevalence,” the researchers wrote.

By comparison, HIV prevalence among the adult population in South and Central America was 0.5 percent.

Making matters worse, the type of virus that had entered the population was particularly aggressive, with the potential to generate AIDS more quickly than other strains — within several years of infection.

The epidemic, the researchers warned, could be “devastating” for the Warao.

“The disease was also spreading in an information vacuum among the Warao.”

Some of them simply never believed me or paid attention to me,” recalled Dr. Julian Villalba, a Venezuelan who led the investigation and is now a clinical fellow at Harvard Medical School.

He also ran up against government intransigence. As officials became aware of his alarming discoveries, he said, some tried to intimidate him and impede his work.

“They didn’t want to show that the politics were failing.” Dr. Villalba said, referring to the Maduro government.

Since then, the absence of prevention programs and severe language barriers — many Warao are illiterate and do not speak fluent Spanish — have allowed ignorance about the disease to flourish.

Msgr. Ernesto Jose Romero, the apostolic vicar of Tucupita, said he has repeatedly spoken with the state governor and other officials about the crisis, to little effect.

“We have a government that wants to silence everything,” Monsignor Romero said in an interview in San Francisco de Guayo, a town in the lower delta region. “They say it will be resolved. But more and more people die.”

Dr. Villalba estimates that more than 80 percent of the Warao he diagnosed between 2010 and 2012 are now dead.

Mr. Pequeño, the nurse, knew all of those victims. They were his friends, neighbors and relatives. Many were also his patients. Born and raised in San Francisco de Guayo, Mr. Pequeño has worked for 15 years at a small medical clinic there. He has also served as the state’s point person in the lower delta region for the distribution of antiretroviral medicine.

Not that there has been much to hand out.
From time to time, he said, officials in Tucupita send boxes of medicine downriver, sometimes with visiting medical students from the Central University of Venezuela. But it is never enough to ensure a steady supply for all the H.I.V-positive patients in the area, he said, and most of the time he has none to give.

“I’m like a soldier without a weapon,” Mr. Pequeño, 34, lamented. “I can’t do anything.”

Stranded in San Francisco de Guayo for most of the past couple of years, Mr. Pequeño lost touch with many of the H.I.V. patients in villages he had been monitoring. But on a recent morning, he hitched a ride with me to go check in on some of them.

Approaching Jobure de Guayo and clutching his notebook with the patient registry, Mr. Pequeño pointed the boat toward the compound of Mr. Quintín, the headman. As the boat pattered along the waterfront, people warmly hailed the nurse from their homes.

Mr. Pequeño took a seat on the floor of the Quintín family’s communal kitchen, an open-sided platform made from hand-hewn wood planks and protected by a palm-thatched roof. The air sung with sounds of a preindustrial society: The crackle of a wood fire. A macaw’s squawk. The swish of an oar pulling through the water. The knock of a machete against raw taro.

FAMILY HIT HARD

No family in Jobure de Guayo had been hit as hard by the epidemic as the headman’s extended clan, which had lost at least 12 people to AIDS or AIDS-like symptoms in the last two years. Men, women and children died in their palm-fiber hammocks, slung in six houses clustered around the communal kitchen.

“Why? Mr. Quintín asked. “In the past, if you were sick, they did everything possible to hospitalized you. Now, no,” he said.

“My people are dying.”

Armando Beria, 25, a resident of Jobure de Guayo, was on Mr. Pequeño’s patient list. He said he first heard about AIDS when a doctor visited the settlement in 2013 and tested people. “I did the examination and he said, ‘You have it, too,’” Mr. Beria recalled.

He believes that he may have contracted it through having sex with other men when he was younger — a common practice among young Warao, especially before they are married. Researchers believe that men having sex with men was an important means of early dissemination of H.I.V. among the Warao. But the virus is now rampant in the broader population, and heterosexual sex and breast milk now appear to be other common forms of transmission.

Mr. Beria has dealt with recurring bouts of diarrhea, headaches and muscle pain, and has begun to lose weight, though he continues to have enough energy to fish and harvest taro for his wife and four young children.

His wife has twice tested negative for H.I.V., most recently a year ago. But telltale lesions have started to appear on her body. “I think she has it now,” he said, though he is powerless to know for sure in the absence of tests.

Medication adherence among the Warao — when there is medication available — is poor, Mr. Pequeño said. Patients abandon their medicine because it makes them feel nauseated, or because they start to feel better.

And in the absence of antiretroviral drugs, many Warao have sought solutions in traditional medicine, turning to a key figure in Warao society, the wisidatu, a kind of shamanic healer. The sickness, many Warao believe, is the result of witchcraft.

Some in Mr. Quintín’s family say they have fallen victim to a curse inflicted on them by a former village resident whom others accuse of being a hoarotu, a darker kind of shaman.

Mikaela Perez, 33, a granddaughter of Mr. Quintín, said the conflict originated in a dispute between her father and another villager. She said the villager put a hex on her father, whose death from AIDS-like symptoms was followed by a rash of others in the family.

“A family that’s coming to an end,” Ms. Perez said, her expression plain. “Before we all lived together very happily. But now it’s coming to an end.”

Isayen Herrera contributed reporting.