Picking Up the Pieces

The Impact of Hurricane Maria on HIV

September 24, 2018 By Rod McCullom

Anselmo Fonseca had a plan as Hurricane Maria approached San Juan, Puerto Rico, late September 2017. The health and human rights advocate packed up his Toyota Prius and headed to a home near the iconic and mist-shrouded El Yunque Peak, the mountain located in the national forest of the same name.

The reinforced concrete house in the hills offered an ideal refuge from the storm that forecasters believed could be the most devastating in the island's history. Fonseca settled in and eventually fell asleep as the wind and rain intensified on the evening of September 20.

"I woke up at about 2:30 a.m. to this horrible sound," says Fonseca. "I peered through the wooden planks across the window and saw 50-foot-tall palm trees snapping in half."

It would be many hours before it was safe to leave the house. When he finally walked outside later that morning, "it looked like a bomb exploded," recalls Fonseca, who says he didn't recognize the land that was once a gorgeous rain forest. "The trees were stripped bare—not just of leaves but of bark too. Some were twisted like Twizzlers."

Fallen trees had barricaded the property, and the road was impassable too. When he returned to the house, there was no electrical power or phone service. Fonseca was stranded for three days.

Thankfully, he had a supply of medications and food. "I'm a long-term survivor living with HIV," he says. "I also survived a devastating natural disaster. But many other people living with HIV across the island were not as fortunate."

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Puerto Rico was already reeling from a decadelong recession and a financial crisis anchored by more than $72 billion of public debt, the soaring cost of living and high unemployment. Austerity measures threatened to exacerbate public health disparities in diabetes, asthma, cancer, infant mortality and HIV.

Puerto Rico ranks in the top 10 of all states and territories in total number of HIV cases. At nearly four times the national rate, the island's HIV mortality rate is higher than any U.S. state or

territory—except for the District of Columbia. (Guam and the Virgin Islands have insufficient data for calculating HIV death rates.)

Puerto Rico had made progress in its response to HIV. About 20,300 people are HIV positive in Puerto Rico, according to new data from the Puerto Rico Department of Health (PRDH). Last year, 355 new cases of HIV were reported. That's down from a high of about 3,000 new cases in 1992. The overall HIV diagnosis rate decreased by almost 30 percent between 2007 and 2013, according to PRDH. The mortality rate also dropped by almost one third during this same period.

However, many stakeholders across Puerto Rico—including people living with HIV, service providers, researchers, scientists, psychologists and more—believe it's too soon to know what the long-term impact will be on HIV care.

A series of overlapping humanitarian crises that have arisen in the aftermath of the storm have left many older residents and people living with HIV particularly vulnerable. The challenges have been compounded by catastrophic infrastructure failure, a generalized lack of funding and the territory's structural dependence on the United States, which some analysts have described as neocolonial.

Maria was the third major storm to threaten Puerto Rico, the Caribbean and the United States mainland within a two-week period in September 2017. Hundreds of thousands of buildings were damaged by wind, flooding and mudslides. Maria became the worst natural disaster in the history of Puerto Rico, inflicting an estimated $90 billion in damage.

The territory endured a cataclysmic lack of resources—power, water, communication, roads, food and medicine—that lasted for months. More than 80 percent of Puerto Rico's population of 3.4 million—all American citizens—lost power immediately after the storm. It was the longest and most widespread blackout in United States history. About one third of residents did not have running water.

"I felt like the entire island was going back in time. Everyone had anxiety. It was very stressful because I had to take care of myself and my family," says Ivette González, a San Juan–based health care advocate and HIV adviser to the mayor.

González is the executive director of the Asamblea Permanente de Personas Infectadas y Afectadas con VIH/SIDA de Puerto Rico (Permanent Assembly of People Infected and Affected by HIV/AIDS of Puerto Rico) and has been living with HIV for more than 25 years. González was diagnosed when she was eight months pregnant with her daughter. Her daughter—now grown with two sons of her own—and a son were born HIV negative thanks to antiretroviral therapy.

"I was without power for three weeks and without water for 17 days," adds Ángel Luis Hernández, an Arecibo-based educator and advocate with more than 20 years in health care administration. In 2003, Hernández tested HIV positive. "I'm OK now," he says. "But many others are struggling."

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The devastation extended across the territory's underfunded and understaffed health care system. Hospitals were overburdened, and people living with acute and chronic conditions—such as asthma, diabetes, kidney failure and HIV—were unable to access care (including dialysis treatment), stay cool, refrigerate medications or power asthma nebulizers or oxygen concentrators.

The official death toll after the storm was only 64. Most experts believe that closer to 5,000 people likely died as a result of complications caused by the lack of resources, according to an analysis of death records by the Harvard T.H. Chan School of Public Health, the University of Colorado School of Medicine and Carlos Albizu University in San Juan.

"The biggest public health issue around the hurricane is how many people died. The challenge is that we don't have a standard definition related to death," explains Melissa Marzán-Rodríguez, PhD, a postdoctoral research fellow at the University of Puerto Rico–Medical Science Campus.

Marzán-Rodríguez analyzed the government database of all death certificates filed between September 20, 2017, and March 31, 2018, and published what is believed to be the first data on post-Maria HIV mortality. The preliminary data were presented at the 2018 International AIDS Conference.

"I identified 89 deaths where one of the four leading causes of death was HIV-related," says Marzán-Rodríguez. "But it's highly probable that many people living with HIV who died during that period were not identified. If someone also had diabetes and that was his or her cause of death, it would not be classified as HIV-related."

By comparison, 43 people died of HIV-related causes in 2016, according to PRDH; in 2015, that figure was 45.

I'm OK now, but many others are struggling

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The storms also created an environmental crisis that will likely affect public health for years. Millions of gallons of floodwaters were contaminated with toxic chemicals, human waste, spoiled food and more. Mountains of garbage and debris loom in neighborhoods. The waters, mud and waste are breeding grounds for bacteria, infectious diseases, airborne mold spores and pollution. Meanwhile, thousands of generators spew noxious fumes as they power homes and offices.

These toxins can wreak havoc on the immune systems of healthy people, but they could be life-threatening to a person living with HIV and a compromised immune system.

“Doctors say they are seeing an alarming rise in the number and severity of asthma cases that they attribute to destruction caused by the deadly hurricane,” reported the Associated Press in June. “Puerto Rico had high rates of asthma even before the hurricane. An estimated 13 percent had asthma before Maria [compared] to 8.3 percent on the U.S. mainland in 2016.”

“The air quality is horrible,” says Rosa Rivera Aviles, who lives in Fajardo on the island’s east coast. Anselmo Fonseca, who was interpreting for Rivera, also has asthma and was experiencing complications that day too.

“It was a nightmare. I didn’t know Maria was coming because I had been without electricity since Irma [made landfall] about two weeks before,” says Rivera, who lives with her son and her emotional support pit bull terrier. Rivera tested positive for HIV 21 years ago.

“I went without electricity for 90 days and respiratory therapy for about a month and a half. I eventually got a battery-operated nebulizer from a community group.”

Several studies—most recently a December 2017 meta-analysis in The Lancet—have shown that people living with HIV are more likely to have asthma and chronic obstructive pulmonary disease (COPD), although scientists are not sure why. The data suggest that almost 20 percent of people living with HIV in the United States also have asthma or COPD.

Liz Defrain

Interviews with service providers and advocates suggest that many people living with HIV around San Juan were able to maintain uninterrupted antiretroviral therapy thanks to advance planning by community-based organizations (CBOs). Almost half of the territory’s HIV caseload—some 44 percent—is in metropolitan San Juan.

Before the storms, the AIDS Drug Assistance Program storage facility in metro San Juan had a surplus of antiretrovirals. Merck—the manufacturer of HIV therapies such as Crixivan and Isentress—also donated medications.

Those living outside the metro region had poor access to medications after the storm.

Ángel Luis Hernández says he had only about a one-week supply of Descovy and Sustiva, "so it was critical to access my clinic in Orocovis, about 50 miles away. It was difficult to get there because a mudslide blocked the roads and bridges." What should have been a 90-minute drive took almost six hours, he says, but he feels very fortunate that he had a car and gasoline to make the journey.

Many people living with HIV had a supply of HIV meds but sustained other health challenges during the hurricane. Ivette González developed the symptoms of a urinary tract infection (UTI) on the same night that Maria made landfall. Women living with HIV are at higher risk of developing UTIs.

"I was in pain and bleeding badly," she says. "When the winds subsided, I drove to the emergency room, but it was not open. Then I saw a pharmacy where people were crowded inside. The pharmacist was kind and sold me the antibiotics."

The seven-member fiscal control board that oversees all fiscal decisions on the island—locally known as "La Junta"—did not have a disaster plan in place, critics say.

"They did not anticipate a disaster of this magnitude. There also was not a clear jurisdiction of responsibilities between the local and federal governments," says José Joaquín Mulinelli Rodríguez, the executive director of Coaí, the island's oldest community-based HIV service organization. "The first response should likely be local, but the local governments do not have any money. It took about two months before the federal government established a presence."

The slow relief process was a striking contrast to that seen on the mainland. Critics have accused the Trump administration and the Federal Emergency Management Agency (FEMA) of a politicized response.

Politico found "a persistent double standard in the president's handling of relief efforts for Hurricane Harvey and Hurricane Maria. [A] comparison of government statistics relating to the two recovery efforts strongly supports the views of disaster-recovery experts that FEMA and the Trump administration exerted a faster, and initially greater, effort in Texas, even though the damage in Puerto Rico exceeded that in Houston."

The majority of Puerto Ricans who applied to FEMA for assistance have not been approved.

At least 335,748 applications from Puerto Ricans requesting disaster assistance have been denied, according to NBC News. Almost 80 percent of appeals have been denied or remain unanswered.

One major challenge is proving ownership or tenancy, which can be difficult to do in households of

extended families and/or generations, which are common across Puerto Rico.

Another problem is that documents may not reflect the affected person's gender identity.

"We had to advocate for a 72-year-old transgender woman [living with HIV] whose roof was destroyed," says Fonseca.

Fonseca cofounded Pacientes de SIDA pro Política Sana (AIDS Patients for Sane Policies) in 1999. "FEMA would not help her. The agency's online claim process [generated] a fraud alert because she did not have [official] documentation. We found help to fix her roof, provide food and a stove top."

AIDS United's Hurricane Relief Effort is among the larger community-based responses. The initiative funds HIV CBOs and people living with HIV across the Southern states, Puerto Rico and the U.S. Virgin Islands that were affected by the destruction from Hurricanes Harvey, Irma and Maria. More than $2.4 million was raised in partnership with the National Minority AIDS Council. More than $1.4 million has reportedly been allocated.

AIDS Healthcare Foundation sent 150 generators to Puerto Rico for CBOs and people with HIV, says Ivette González.

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"We don't know the hurricane's impact on HIV [care and treatment] because it hasn't been documented. We may never have the data because the government is severely under-resourced. But that's why it's important for survivors to share their stories," says Carlos E. Rodríguez-Díaz, PhD, associate professor at the University of Puerto Rico–Medical Science Campus. Rodríguez-Díaz's research focuses on populations rendered vulnerable by the HIV epidemic.

Rodríguez-Díaz and colleagues—including Marzán-Rodríguez, whom he is mentoring—are conducting focus group interviews with men who have sex with men who attempted to access HIV services after the hurricane.

"The interviews reveal something very interesting about the science of resistance. When we ask people, 'What impact did the hurricane have on your HIV care?' they will say it didn't have any impact. But then they will realize, 'Yes, it did because I had to change clinics' or 'I shared my medications.' That speaks to the resilience and resistance."

The calamities that have cascaded across this Caribbean island even before Hurricane Maria—rapid job loss, soaring cost of living, austerity—have taken their toll on the collective mental health. Public health experts believe that many residents suffer from anxiety, depression and posttraumatic stress disorder. Post-Maria, isolation, a lack of electricity and communication, and an inability to access health care have triggered a surge in suicides among older Puerto Ricans, according to the government.

Waves Ahead represents a community-based response to the mental health needs of many Puerto Ricans. The organization was cofounded by Wilfred Labiosa, PhD, a San Juan–based psychologist who, along with a small staff, is delivering mental health and case management services to older LGBT Puerto Ricans and people living with HIV. Labiosa began working with the American Association of Retired Persons and SAGE in early 2017. Together, they've provided services to about 1,200 people since October, he says.

"When the hurricane hit, we saw the need to bring those services—including water and food," says Labiosa. "We're rebuilding 10 homes that weren't approved for federal disaster relief. We're also rebuilding the mental health of older people living with HV, their partners, friends and families."

"It's heartbreaking to see so much of the work that we've accomplished in the past 20 years gone and having to start over," says Anselmo Fonseca. "I have been on the phone almost screaming, begging and pleading for more doctors and specialists. That's how we lost a lot of human lives. I'm determined not to lose more."

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