

The mind-boggling challenge of long COVID

By [Jenny Lei Ravelo](#) // 05 January 2023



patient with COVID-19 shows a medical staffer a picture of his chest X-ray at a field hospital in Caracas, Venezuela. Photo by: Leonardo Fernandez Vilorio / Reuters

Padma Priya first got [COVID-19](#) in April 2020. The journalist living in Hyderabad, India, recovered a few weeks later. But not completely.

“I was experiencing a lot of fatigue. But ... everyone kept saying, ‘oh, you know, after a bad viral or any flu you do get that sort of fatigue.’ But I never improved,” Priya, co-founder and editor-in-chief of the digital media platform Suno India, told Devex.

And then she had a “bad crash.” She was buying vegetables in the market when her heart started racing and she fainted. This would repeat on several occasions, but no doctor could pinpoint exactly what was going on. At one point, they thought it was an adrenal gland tumor.

It was only in April 2021, after she contracted COVID-19 again amid the deadly delta variant wave in India that doctors finally figured out that she was suffering from postural orthostatic tachycardia syndrome, or PoTS, which produces an [abnormal increase in heart rate](#) after sitting up or standing. It’s a form of dysautonomia, or disorder in a person’s autonomic nervous system, and has been [reported](#) by others experiencing long COVID sufferers in different parts of the world.

Still, others with similar or other debilitating conditions may continue to be in the dark about what they’re going through, given the limited understanding globally on long COVID-19 and its symptoms, and the lack of tools to diagnose and treat them.

What is long COVID?

It goes by different names. The [World Health Organization](#) refers to it as “[post COVID-19 condition](#),” and others as post-acute sequelae of COVID-19. But it is commonly referred to as long COVID.

As per WHO, long COVID is defined as the “continuation or development of new symptoms 3 months after the initial SARS-CoV-2 infection, with these symptoms lasting for at least 2 months with no other explanation.”

The symptoms can persist for a long time. Several people have [reported symptoms for two years](#), or more.

“All we've got now are just dots in this tapestry. There are many pieces of the puzzle still not filled in because it's still early days.” — Dr. Salim Abdool Karim, a clinical infectious diseases epidemiologist

Fatigue, shortness of breath, and “brain fog” are some of the most commonly cited symptoms of long-haul COVID. Priya, who said she also suffers from brain fog, describes it as “almost like a cognitive impairment.”

“There have been moments where ... I have to read the same thing over and over again for my brain to process it,” she said. “If I'm watching a show, there have been instances where I've had to watch the same scene like 10 times to understand what is happening.”

But the range of symptoms are vast, with over 200 symptoms having been reported that affect the way people go about their lives, according to WHO.

Others are also showing to be at increased risk of heart disease and diabetes.

“We have to look at this viral infection as one that literally affects the human body, from head to toe,” said Dr. Salim Abdool Karim, a clinical infectious diseases epidemiologist who served on different task forces and commissions on COVID-19, [during a keynote speech](#) in Geneva last month.

Who has long COVID?

It's not known just how many people are suffering from long COVID globally. Countries are not reporting systematic data on post-COVID-19 conditions, and WHO is currently relying on estimates to understand the global burden, the U.N. health agency told Devex.

On its website, WHO cites estimates by the [Institute for Health Metrics and Evaluation](#) that says by the end of 2021, [3.7% or 144.7 million](#) of the 3.92 billion individuals that had been infected with the coronavirus developed long COVID as defined by the WHO clinical case definition. Of that number, 15.1% or 22 million have persistent symptoms 12 months after the COVID-19 infection.

Several countries have tried to capture the situation among their own population. For example, data from a household pulse survey in the United States shows [6.8% of American adults](#) are currently experiencing long COVID. In the United Kingdom, an estimated 2.2 million people or [3.4% of the population](#) reported experiencing long COVID as of early November 2022.

In South Africa, a study published in September found that [1,249 or 66.7%](#) of the 1,873 individuals who had COVID-19 and agreed to participate in the study, reported new or persistent COVID-19 symptoms at three months after being discharged from the hospital.

There is however a dearth of evidence of the real burden in many countries, particularly low- and middle-income countries, where it is “understudied,” according to WHO.

People's access to health facilities can pose challenges in understanding the magnitude of the problem. In Africa, many people with long COVID don't return to health facilities, making it "very difficult for us to have a clear picture of the incidence of long COVID across the continent," Dr. Ahmed Ogwel Ouma, acting director of the [Africa Centres for Disease Control and Prevention](#), said in an [article](#) published in The Lancet Respiratory Medicine journal.

In India, Priya — who founded the Twitter account @LongcovidIndia for those who have long COVID to connect and share information — said most people who experience its conditions are known through anecdotal information.

"When I went to meet a physical rehab specialist, he tells me that since the delta wave ... he has seen over 200 people with varying post-COVID complications in one hospital in one city in India," she said.

The people are in their 30s and 40s, and are suffering from varying kinds of complications, such as strokes and aneurysms. But when she asked her doctors if they are doing any studies on the matter, she was told: "Where's the time? Where's the money? We're [still] stressed."

What's needed next?

While there are multiple documented testimonies of people suffering from long COVID, a lot more research is needed to understand the burden, the conditions, and the tools to diagnose and treat them.

To create awareness about it, WHO can do prevalence studies so governments understand the scale of the problem and act on it, Priya said.

"Because otherwise this will not be a priority for any government, because everybody is now trying to only think about 'oh, how do we ... regenerate or recoup the economy that got impacted by COVID?' But they're not understanding the severity of the issue, which is that ... if previously able people are becoming disabled, that also has an impact on the economy," she said.

There's a need to accelerate research for the prevention and treatment of long COVID complications, according to WHO. And funding for clinical trials will be crucial.

"[The Bill & Melinda] Gates [Foundation] and other funders should focus on providing grants to study LongCOVID and to support [clinical] trials," Resia Pretorius, a professor and head of the Department of Physiological Sciences at [Stellenbosch University](#) in South Africa who is currently studying the role microclots play in long COVID-19, wrote to Devex. She and a whole team of clinicians and researchers are now beginning to understand the physiological reasons for post-COVID-19 symptoms, but they need more data and confirmation studies.

One "unexpected challenge" Pretorius is seeing at the moment is clinicians not believing that their patients are sick because regular blood tests show they are healthy. But in [papers](#) she and several other researchers have published, she said they're learning that microclots — tiny blood clots which are hypothesized as playing a role in long COVID symptoms — are trapping numerous inflammatory molecules, thus showing no acute inflammation in blood tests.

"Clinicians obviously are in a difficult position and they first do not want to do harm by treating without data from clinical trials. That is why we are desperately looking for well-structured clinical trials that will give clinicians the correct info to treat these patients," she said.

The world will also require “cheap, easy diagnostics,” Karim said.

“All we've got now are just dots in this tapestry. There are many pieces of the puzzle still not filled in because it's still early days. But what's becoming clear is that we're going to need a whole new push in terms of cheap, easy diagnostics for many of these conditions,” he said.

But it should be made available to everyone, not just a few, he added.

“My hope is that as these new technologies become available ... that we don't do what we did with mRNA vaccines, which is, we left it to the executives or to pharmaceutical companies to decide who gets them and who doesn't,” he said.

Amruta Byatnal contributed reporting.