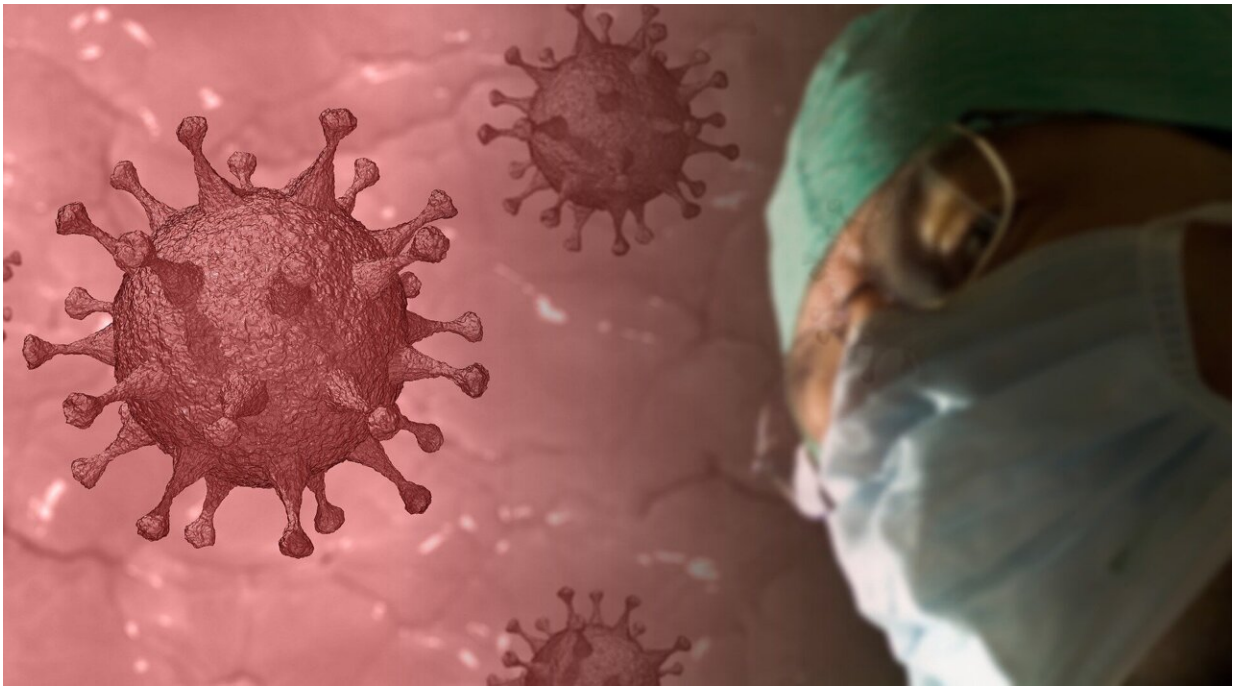
Much has been learned about long COVID, and much remains to be learned

February 27 2023, by Michael Merschel



Credit: Pixabay/CC0 Public Domain

This much researchers agree upon: Long COVID is a serious and sometimes debilitating condition that can strike previously healthy people after even mild bouts of COVID-19. And rapid progress is being made in understanding it.

But three years into the pandemic, much about long COVID—what

causes it, how to treat it, even what to call it—is still being sorted out.

"We've stopped arguing over whether it's real or not," said Dr. Leonard H. Calabrese, professor of medicine and head of clinical immunology at the Cleveland Clinic Lerner College of Medicine. "Now we're trying to define it better," and learning how to address it. "Is it treated as one disease? Or do we treat it as 10 diseases? Or more?"

The Centers for Disease Control and Prevention says long COVID is an assortment of symptoms and conditions that continue four weeks or more after the initial phase of infection with SARS-CoV-2, the virus that causes COVID-19. It is also referred to as post COVID-19 conditions or post-acute sequelae of SARS-CoV-2 infection.

"Lots of different names, a lot of different definitions," said Dr. Jeffrey Hsu, an assistant clinical professor of medicine at the David Geffen School of Medicine at the University of California, Los Angeles. "I do think that's been a challenging area for research in this space."

The varying definitions have led to a range of estimates on how common long COVID is. "Some studies make it seem like the number is low," Hsu said. "Other studies make it seem like the number of people with long COVID is quite high."

The White House's National Research Action Plan on Long COVID, released last August, noted that risk estimates varied from 5% to 30% of COVID survivors. One large CDC study estimated that 1 in 5 survivors ages 18 to 64 had at least one health condition related to prior COVID-19. For people 65 and over, it was 1 in 4. And women may be at higher risk.

"You can see patients that were completely healthy before having a COVID-19 infection and now are completely disabled," said Dr. Cyndya

A. Shibao, an associate professor of medicine at Vanderbilt University Medical Center in Nashville, Tennessee.

Doctors' challenge: Diagnosing long COVID

More than 200 symptoms have been associated with long COVID. "The list is very long," Shibao said, including cardiovascular, gastrointestinal and cognitive problems, and more.

That's not surprising, given how the coronavirus infiltrates our systems. "We know the virus can spread widely throughout our body," Hsu said, and linger for months.

The challenge in making a diagnosis, Calabrese said, is that doctors "don't really have crisp classification or diagnostic criteria that are universally accepted." In some cases, the connection to COVID-19 is obvious. These people are "sick from the get-go," he said, and never get back to where they were before COVID-19. Other times, it's more insidious.

He knows this firsthand.

After a mild case of COVID-19 in July 2021, Calabrese developed an accelerated heart rate, then started having cognitive problems. "I had a million excuses of why it was probably something else," he said. He was busy, he was stressed. Once it became clear what was happening, it took "a good part of a year for me to regain that part of my health back."

Treatment by clusters

As researchers' understanding has progressed, they have started grouping patients based on their dominant symptoms. That, Hsu said, will help

them figure out what's causing each cluster.

Hsu said "brain fog" is one cluster. Another subgroup has cardiac issues—difficulty with exercise, heart palpitations and symptoms that get worse when they're standing upright, which can be part of a condition known as postural orthostatic tachycardia syndrome, or POTS.

Overwhelming fatigue is another subgroup. "This is not just fatigue where you're tired and don't feel like getting out of bed in the morning," Hsu said, but fatigue that prevents normal daily activities, such as going to the grocery store.

Understanding the cause of each symptom cluster could drive better treatments, he said.

For example, as a cardiologist at UCLA's long COVID clinic, Hsu often sees patients with POTS. Their recovery might be aided by cautious amounts of exercise. But people with extreme fatigue need help learning how to pace themselves to manage their energy reserves, he said, and pushing exercise—as some were advised early in the pandemic—can actually make things worse.

To Calabrese, long COVID is "clearly not one disease." It follows patterns seen in other viral infections, although it's not clear what the exact mechanism is. Leading hypotheses, he said, include the idea of a lingering virus; microscopic clots in the bloodstream; and low-grade inflammation within the central nervous system.

It's possible each causes a different set of problems, but that's not clear. "This is still very much a work in progress," he said.

Hsu, whose research is exploring whether long COVID might be caused by fragments of the virus in the body, said damage to the lining of blood

vessels is another possible root cause.

Just understanding the different possibilities is progress, he said, but "it's still baffling" as to why long COVID affects some people who have few apparent risk factors but not others who would seem to have many.

Shibao, meanwhile, is studying possible causes and treatments for long COVID-related POTS. Shibao and Hsu's research projects are among the long COVID studies being funded by the American Heart Association.

Shibao said the number of publications about long COVID treatment has significantly increased in recent months.

Not all of them, she warned, are based in solid science. Some studies included small numbers of patients without comparison groups, but patients are so desperate that even if a treatment has not been rigorously tested, they are asking about them, Shibao said. "And that's very disheartening."

What to do if long COVID is suspected

For reliable help, someone who thinks they have long COVID can start with their primary care physician. But the demands and need for referrals might quickly overwhelm a single doctor, Shibao said. A patient "can have problems with shortness of breath, and they may need to see a pulmonary specialist. At the same time, they can have gastrointestinal symptoms, or they can have chest pain."

That's why she recommends, when possible, seeking out a long COVID clinic, which can draw on specialists from multiple backgrounds.

Hsu agreed. He said that if nothing else, people should look for "a place

where you feel like clearly they have your best interests in mind, and they're not trying to sell you something." A major research institution also can help connect patients with scientifically sound clinical trials.

It's still early in the game

Long COVID researchers have made a lot of progress in three years of the pandemic, Hsu said, but in evaluating how far there is to go, he used a baseball metaphor: We're barely out of the first inning.

"It's really tough to identify an effective therapy for a disease that has just one type of presentation," he said. "But we're talking about this syndrome that has several different ways of presenting itself."

Calabrese thinks we are at "the beginning of the beginning" of understanding it. But he's optimistic.

Long COVID is going to be with us indefinitely. But "there is no disease in the history of medicine that has been more studied in such a short period of time than COVID-19," he said. "And I look forward to seeing highly productive research that will impact patients in the very near future."

Provided by American Heart Association

Citation: Much has been learned about long COVID, and much remains to be learned (2023, February 27) retrieved 7 August 2024 from https://medicalxpress.com/news/2023-02-covid.html