

Study names long COVID symptoms

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Findings a critical step for effective treatment

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A clearer picture of what's become known as long COVID-19 is starting to emerge, which should eventually allow researchers to treat symptoms that can devastate people's lives for months or years after a COVID-19 infection.

In a new study funded by the National Institutes of Health, researchers identified symptoms that are the most distinctive to long COVID, including: fatigue, especially after exercise; brain fog; dizziness; gastrointestinal symptoms; heart palpitations; issues with sexual desire or capacity; loss of smell or taste; thirst; chronic cough; chest pain; and abnormal movements.

Each self-reported symptom is given a score and someone with a score of 12 or more "is a person who very likely has long COVID," said Dr. Leora Horwitz, who helped lead the research from the New York University Grossman School of Medicine. "It doesn't mean these symptoms are the most common, or the most severe, or the most burdensome, or the most important to people. It just means that these are the ones that help us identify people who have long-term consequences."

More than 20% of people who've had COVID score high enough six months after their infection to meet this working definition of long COVID, although one-third of them no longer meet the criteria at nine months. But just because someone no longer meets this standard doesn't mean they are free from suffering or fully recovered, Horwitz noted.

It's not yet clear from this study whether people with long COVID can be classified into different groups according to their symptoms, Horwitz said, though other research has tried to do that. It's possible that long COVID has



Fatigue, brain fog, dizziness, thirst and heart palpitations are a few of the symptoms of long COVID. RICK CRUZ/PACIFIC DAILY NEWS VIA IMAGN CONTENT SERVICES

different causes in different people, or that some people are affected by a combination of factors.

The survey of nearly 10,000 Americans found long COVID is more common among people infected before the omicron variant emerged in late 2021 and among those who were not vaccinated. Reinfection and severity of infection were also linked to a higher incidence of long COVID, according to the study, published Thursday in the *Journal of the American Medical Association*.

Researchers now plan to connect the survey responses with biological data, such as blood samples and scans, to delve into the causes of these symptoms.

Although the process seems slow – this study was started more than a year ago – it is essential to precisely define long COVID before researchers can pursue treatments, said Andrea Foulkes, the study's other lead author. If they don't have a way to distinguish people with long COVID from those without,

they won't be able to tell if a treatment is making a difference.

"By coming up with a way of classifying people as having long COVID, we can now take the next step of really unraveling the mechanisms of disease," said Foulkes, director of biostatistics at Massachusetts General Hospital and a Harvard Medical School professor. "Knowing who has long COVID, we can start to look at what are the factors that contribute to these different manifestations. And that's of course important because ultimately it's going to inform treatments."

Long COVID has a long potential list of causes, including tiny blood clots affecting organ function, lingering virus or viral particles, and dysautonomia, where activities that happen without thought, like maintaining heart rate and blood pressure, are out of whack.

A number of the symptoms – such as gastrointestinal problems, brain fog, fatigue and thirst – are indicative of dysautonomia, said Tanayott Thaweethai,

a co-author on the study and a biostatistician at Massachusetts General Hospital and Harvard Medical School. Others, such as feeling worse after exercise, are known to occur after other post-viral illnesses like chronic fatigue syndrome.

Foulkes said she wants to continue to follow study participants to learn more about the characteristics of those who no longer meet the definition of having long COVID. It's too soon to know if the recovery seen at nine months is real or if symptoms simply ebb and flow over time, said Foulkes, who wants "to really understand what recovery means."

The RECOVER trial includes adults who were infected with the SARS-CoV-2 virus that causes COVID, along with people who were not knowingly infected and do not have COVID antibodies. Many of these people were enrolled right after getting COVID, so it was too soon to know whether they would develop long-lasting symptoms.

Of those – who began enrolling in December 2021, just as the omicron wave was sweeping the country – 10% meet the criteria for long COVID, a smaller percentage than in the group overall.

Vaccination clearly reduces the risk of long COVID, she said.

Horwitz said she's very sympathetic to the fact that people who are suffering today don't want to wait for a deeper understanding of the disease before they feel better. Science moves deliberately but, unfortunately, not quickly.

"From my perspective as a scientist, this is actually moving at warp speed," she said. "We have enrolled over 10,000 people in under a year. We have a phenomenal amount of data here, looking at all parts of the body in a way that no one has put together in a study like this before."

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