

Hair loss. Memory problems. Strange rashes. COVID-19 patients report a litany of symptoms outside official criteria

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Credit: CC0 Public Domain

Julie Sciascia-Van Horn was hospitalized with COVID-19 in early April, suffering from some of the typical flu-like symptoms associated with the

virus since its discovery: fever, severe cough and shortness of breath.

Then came a litany of more unusual ailments the 51-year-old from southwest suburban Bridgeview, Ill., had never experienced before catching the novel [coronavirus](#).

She described a strange burning sensation on the soles of her feet, as if she were walking on coals. Two weeks after discharge from the hospital, she began noticing odd memory lapses—inexplicably forgetting phone numbers and similar routine facts once recalled without effort.

Then over the summer her hair began falling out in chunks, with long chestnut-colored strands suddenly filling a brush or circling the shower drain.

"I had a different symptom each day," Sciascia-Van Horn said. "I was wondering, what is this?"

As medical experts and scientists grapple to understand the new virus, some patients are reporting a great variety of symptoms that fall outside the official lists issued by the Centers for Disease Control and Prevention and other major health authorities.

Often these conditions seem to appear or subside without warning, sometimes lingering for months after the virus is supposedly gone.

Earlier in the pandemic, most medical efforts were focused on keeping the sickest patients alive and relieving overwhelmed hospitals. But now there's a growing need for research on the long-term health of those who survived the virus but don't seem to be fully recovering, said Natalie Lambert, associate research professor at Indiana University School of Medicine.

"It's easy to forget that all we know about medicine and every medical treatment that has ever been developed, it's ... because a patient somewhere was suffering and needed help, needed treatment," said Lambert, who is studying the long-range health consequences of COVID-19. "The only reason that we have medicine and a way of treating patients is research was done with patients in the first place."

Many sickened by coronavirus express frustration as they battle a new and mysterious illness with no road map and very little history. Unpredictable symptoms—often outside the typical diagnostic criteria—are cited as a common source of stress.

In her work, Lambert has been struck by the spectrum of medical problems patients report, as well as how many different systems of the body appear to be taking a hit.

Hair loss. New rashes and skin conditions. Unexplained cognitive troubles. Heart problems. Increased anxiety. Strange smells and tastes that don't go away. Unrelenting insomnia.

In some cases, these maladies seem to appear or persist months after the virus is supposedly gone, with no clear timeline for when they might abate.

"Has anybody experienced a sulfur smell in their nose and breath?" one woman wrote on the Facebook page of Survivor Corps, a grassroots group of more than 100,000 members who have been affected by the virus. "Tested positive, I'm 29 days since my first symptoms of COVID and last seven days I've had this terrible odor."

"Numbness in my body and face—as of this morning 80% of my body is completely numb," another member posted on the site. "I have been battling horrible post-COVID symptoms since June. They have ebbed

and flowed, I've felt better (then) crashed, up and down, up and down."

"I say we all send our massive amounts of hair to the CDC," someone else wrote, beneath a photograph of a hand clutching a large clump of hair.

Survivor Corps founder Diana Berrent on Friday will moderate a webinar with Dr. Anthony Fauci, asking the nation's top infectious disease expert questions about the virus on behalf of the group.

Fauci has repeatedly warned the nation about potential long-term health effects of COVID-19, most recently at a U.S. Senate subcommittee hearing last week.

"A number of individuals who virologically have recovered from infection in fact have persistence—measured in weeks to months—of symptomatology that does not appear to be due to persistence of the virus," said Fauci, director of the National Institute of Allergy and Infectious Diseases.

Sciascia-Van Horn is also a member of Survivor Corps, where she said she has found support and treatment suggestions.

"I know what I was and I'm not the same," she said. "And I'm tired of being not the same. I want to be what I was before."

Spectrum of symptoms

Some COVID-19 patients will have no symptoms. Others will get sick but recovery relatively quickly. Some 200,000 Americans—more than 8,000 from Illinois—have died from the virus. The pandemic's international death toll exceeded a million as of Tuesday.

But there's another category of patients like Sciascia-Van Horn, those who survive but don't seem to fully recover weeks or even months later.

They've been dubbed the COVID-19 "long-haulers," and their experiences don't seem to always align with the CDC's current list of roughly a dozen coronavirus symptoms. The agency notes, though, that this description "does not include all possible symptoms," and the list will be updated as new information about the virus surfaces.

Lambert began studying the plight of long-haulers shortly after the pandemic struck, partnering with Survivor Corps to learn more. In a July, she and Survivor Corps conducted a survey of more than 1,500 patients who identified 98 symptoms experienced after contracting coronavirus, most falling outside the official CDC list.

"It became clear almost immediately that the list of symptoms on the CDC website and the symptoms that patients were reporting were not a perfect match, by any means," Lambert said.

The self-reported ailments cover a wide range: 924 respondents said they had difficulty concentrating; 714 described memory problems; 566 said they were suffering from joint pain; 509 experienced heart palpitations; 423 reported hair loss; 418 said their vision had become blurry and 247 developed some kind of a rash, among dozens of other conditions.

The span of concerns and limited information can make it hard to seek treatment.

Some long-haulers find "physicians are sometimes unable or unwilling to help patients manage lesser-known COVID-19 symptoms due to lack of research," said a report based on the survey. "Until research into long-term COVID-19 symptoms is conducted, these results indicate that an ever-increasing number of COVID-19 patients continue to suffer from

their untreated symptoms."

So many questions loom following the survey. How many of these conditions are directly related to COVID-19? Are trauma and anxiety factors? Does the underlying health of the patient correlate in any way with symptoms? Are there common themes or patterns that can offer scientists clues about the virus?

To delve deeper, Lambert said she's coordinating another survey with more in-depth questions about patient demographics, underlying health conditions and detailed information about each reported [symptom](#). The eventual goal would be predictive modeling: To try to anticipate what ailments different types of COVID-19 patients might experience, possibly determining sequencing of symptoms.

"Imagine if we knew a particular patient was likely to get hair loss or likely to have heart problems," she said. "We could really try to help people head off these symptoms."

Another benefit could be ranking the severity of ailments, so medical experts can better target the most painful or disruptive problems.

"To make sure that COVID-19 research going forward really meets patients' most dire needs," she said.

Mysteries of the virus

Sciascia-Van Horn said she was surprised when she tested positive for coronavirus, in part because so many of her ailments didn't line up with the official criteria at the time.

In addition to flu-like illness, she complained of nausea, gastrointestinal distress, congestion and a temporary loss of taste and smell. All of those

symptoms are now on the CDC list, but weren't added until after Sciascia-Van Horn became symptomatic in late March.

COVID-19 was primarily considered a respiratory disease in late 2019, when the first human cases emerged in Wuhan, China.

"Coronaviruses are a class of respiratory viruses that range from the common cold to more serious illnesses like SARS and MERS," the Illinois Department of Public Health said in a January news release announcing the first patient in the state to test positive for the virus. "They can cause fever, cough, difficulty breathing, and pneumonia."

The description has evolved as scientists and physicians learned more from the experiences of patients. But that process can be slow and frustrating for those who are sick and feeling confused or marginalized when the official guidelines don't match their reality.

In late March, the American Academy of Otolaryngology-Head and Neck Surgery said coronavirus patients were increasingly experiencing a lost or reduced sense of taste or smell.

"We propose that these symptoms be added to the list of screening tools for possible COVID-19 infection," the organization of ear, nose and throat specialists said in a news release.

The CDC added loss of taste and smell and several other symptoms to the list in mid-April, though many local doctors and hospitals reported already using this criteria prior to the change. Congestion, runny nose, nausea and diarrhea were added in mid-May.

Now more COVID-19 patients are describing extreme hair loss, rashes and other new skin problems. A video of actor and political activist Alyssa Milano displaying her post-COVID-19 hair loss went viral last

month.

"Wear a damn mask," she said at the end of the clip.

Dermatologists around the world are seeking more information about [hair loss](#), rashes and a condition dubbed "COVID toes"—toes that become swollen and discolored—after contracting the virus. The American Academy of Dermatology, based in northwest suburban Rosemont, includes on its website photos of some of the itchy, bumpy or hives-like rashes dermatologists are seeing in COVID-19 patients.

The organization is compiling a COVID-19 registry, encouraging physicians across the globe to answer a survey on the experiences of their patients. One question reads: Did the patient have new skin, nail, hair, mucous membrane or other dermatologic changes in the setting of possible or confirmed COVID-19?

As for Sciascia-Van Horn, her sense of taste and smell have returned. Her feet no longer feel as if they are on fire. She said her hair is slowly growing back, with some sections noticeably shorter than the rest.

But she described persisting memory problems, chronic fatigue, breathing difficulties and higher levels of anxiety. She still can't take a deep breath and often feels winded after climbing one flight of stairs or walking her dog to the end of the block.

Six months after her first symptoms, she said she is far from recovered.

"Please be safe," she said. "Please take care of yourself. Please wear the mask. Listen to those of us who have COVID and are still having symptoms. And those people who lost their lives. Is not wearing a mask really worth it? We all don't know what this virus truly is."

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