They Had Mild Covid. Then Their Serious Symptoms Kicked In.

A new study illuminates the complex array of neurological issues experienced by people months after their coronavirus infections.

Samar Khan expected to recover fully from a mild case of Covid-19, but before long her symptoms multiplied, including a “really intense brain fog.” Taylor Glascock for The New York Times

By Pam Belluck

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In the fall, after Samar Khan came down with a mild case of Covid-19, she expected to recover and return to her previous energetic life in Chicago. After all, she was just 25, and healthy.

But weeks later, she said, “this weird constellation of symptoms began to set in.”
She had blurred vision encircled with strange halos. She had ringing in her ears, and everything began to smell like cigarettes or Lysol. One leg started to tingle, and her hands would tremble while putting on eyeliner.

She also developed “really intense brain fog,” she said. Trying to concentrate on a call for her job in financial services, she felt as if she had just come out of anesthesia. And during a debate about politics with her husband, Zayd Hayani, “I didn’t remember what I was trying to say or what my stance was,” she said.

By the end of the year, Ms. Khan was referred to a special clinic for Covid-related neurological symptoms at Northwestern Memorial Hospital in Chicago, which has been evaluating and counseling hundreds of people from across the country who are experiencing similar problems.

Now, the clinic, which sees about 60 new patients a month, in-person and via telemedicine, has published the first study focused on long-term neurological symptoms in people who were never physically sick enough from Covid-19 to need hospitalization, including Ms. Khan.

The study of 100 patients from 21 states, published on Tuesday in The Annals of Clinical and Translational Neurology, found that 85 percent of them experienced four or more neurological issues like brain fog, headaches, tingling, muscle pain and dizziness.

“We are seeing people who are really highly, highly functional individuals, used to multitasking all the time and being on top of their game, but, all of a sudden, it's really a struggle for them,” said Dr. Igor J. Koralnik, the chief of neuro-infectious diseases and global neurology at Northwestern Medicine, who oversees the clinic and is the senior author of the study.

The report, in which the average patient age was 43, underscores the emerging understanding that for many people, long Covid can be worse than their initial bouts with the infection, with a stubborn and complex array of symptoms.

This month, a study that analyzed electronic medical records in California found that nearly a third of the people struggling with long Covid symptoms — like shortness of breath, cough and abdominal pain — did not have any signs of illness in the first 10 days after they tested positive for the coronavirus. Surveys by patient-led groups have also found that many Covid survivors with long-term symptoms were never hospitalized for the disease.

In the Northwestern study, many experienced symptoms that fluctuated or persisted for months. Most improved over time, but there was wide variation. “Some people after two months are 95 percent recovered, while some people after nine months are only 10 percent recovered,” said Dr. Koralnik. Five
months after contracting the virus, patients estimated, they felt on average only 64 percent recovered.

“We are seeing people who are really highly, highly functional individuals,” said Dr. Igor J. Koralnik, chief of neuro-infectious diseases at Northwestern Medicine, “but, all of a sudden, it’s really a struggle for them.” Northwestern Medicine

Across the country, doctors who are treating people with post-Covid neurological symptoms say the study’s findings echo what they have been seeing.

“We need to take this seriously,” said Dr. Kathleen Bell, the chairwoman of the physical medicine and rehabilitation department at the University Texas Southwestern Medical Center, who was not involved in the new study. “We can either let people get worse and the situation gets more complicated, or we can really realize that we have a crisis.”

Dr. Bell and Dr. Koralnik said many of the symptoms resembled those of people who had concussions or traumatic brain injuries or who had mental fogginess after chemotherapy.
In the case of Covid, Dr. Bell said, experts believe that the symptoms are caused by “an inflammatory reaction to the virus” that can affect the brain as well as the rest of the body. And it makes sense that some people experience multiple neurological symptoms simultaneously or in clusters, Dr. Bell said, because “there’s only so much real estate in the brain, and there’s a lot of overlap” in regions responsible for different brain functions.

“If you have inflammation disturbances,” she said, “you can very well have cognitive effects and things like emotional effects. It’s really hard to have one neurological problem without having multiple.”

Dr. Allison P. Navis, a neuro-infectious disease specialist at Mount Sinai Health System in New York City who was not involved in the study, said that about 75 percent of her 200 post-Covid patients were experiencing issues like “depression, anxiety, irritability or some mood symptoms.”

Participants in the study were overwhelmingly white, and 70 percent were women. Dr. Navis and others said that the lack of diversity quite likely reflected the demographics of people able to seek care relatively early in the pandemic rather than the full spectrum of people affected by post-Covid neurological symptoms.

“Especially in New York City, the majority of patients who got sick with Covid are people of color and Medicaid patients, and that’s absolutely not the patients one sees at the post-Covid center,” Dr. Navis said. “The majority of patients are white, often they have private insurance, and I think we have to figure out a little bit more what’s going on there with those disparities — if it’s purely just a lack of access or are symptoms being dismissed in people of color or if it’s something else.”

In the Northwestern study, Dr. Koralnik said that because coronavirus testing was difficult to obtain early in the pandemic, only half of the participants had tested positive for the coronavirus, but all had the initial physical symptoms of Covid-19. The study found very little difference between those who had tested positive and those who had not. Dr. Koralnik said that those who tested negative tended to contact the clinic about a month later in the course of the disease than those who tested positive, possibly because some had spent weeks being evaluated or trying to have their problems addressed by other doctors.

Ms. Khan was among the participants who had a negative test for the virus, but she said she later tested positive for coronavirus antibodies, proof that she had been infected.

Another study participant, Eddie Palacios, 50, a commercial real estate broker who lives in Naperville, a Chicago suburb, tested positive for the coronavirus in the fall, experiencing only a headache and loss of taste and smell. But “a month later, things changed,” he said.

“I was cleaning my gutters and I forgot where I was, I forgot what I was doing on the roof,” Mr. Palacios said. When he remembered, he added, the idea of doing “something as simple as climbing on a ladder all of a sudden became a mountain.”
In his job, “my clients would tell me things like a passcode or an address and I couldn’t remember it,” he said.

Eddie Palacios, a commercial real estate broker in Naperville, Ill., participated in the study. “I did the cognitive tests, and I failed them all,” he said. Taylor Glascock for The New York Times
At Mr. Palacios's first appointment with the Northwestern clinic, “I did the cognitive tests, and I failed them all,” he said. On a return visit, he did another battery of tests, he said, “and I didn't do so hot on that, either:"

Mr. Palacios was referred for cognitive rehab at a long-established program in Chicago that helps give patients strategies to manage and improve memory, organizational and cognitive difficulties. But he didn't go, he said, because “I completely forgot.” He plans to go now.

In the Northwestern study, 43 percent of the patients had depression before having Covid-19; 16 percent had previous autoimmune diseases, the same percentage of patients who had previous lung disease or had struggled with insomnia.

Experts cautioned that because the study was relatively small, these pre-existing conditions might or might not be representative of all long-term patients. “We are all seeing very small pieces of the elephant in terms of the long Covid group,” Dr. Bell said. “Some of us are seeing tail; some of us are seeing trunk.”

Along with neurological symptoms, 85 percent of the patients were experiencing fatigue, and nearly half had shortness of breath. Some also had chest pain, gastrointestinal symptoms, variable heart rate or blood pressure. Nearly half of the participants were experiencing depression or anxiety.

Ms. Khan said that she experienced “heart palpitations if I just got up to open the curtains.” Her cardiologist said she was the fifth previously healthy young person to walk into his office that week. In the beginning, her fatigue was so severe that walking two or three laps around her 600-square-foot apartment would exhaust her for the rest of the day. In addition, she said that she had “really intense mood fluctuations that don't feel like they’re mine.”

“Waking up every day in this body, sometimes hope feels a little dangerous,” said Ms. Khan, who will soon start the cognitive rehab program. “I have to wonder: Am I going to recover, or am I going to just figure out how to live with my new brain?”