

COVID-19 “long-haulers” publish patient-led research paper drawing attention to chronic illness

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In May, a group of COVID-19 survivors—referring to themselves as “long-haulers”—published a patient-led research paper calling attention to and seeking to understand the phenomenon of extended, sometimes debilitating, illness ranging from weeks to months after initial COVID-19 infection.

A Slack group, which currently houses over 7,000 active members, was started in February by an online media group, Body Politic. Some of these members identify as long-haulers, a term used to describe people who have lasting symptoms two weeks past initial infection. These long-haulers used the channel to discuss their symptoms and personal backgrounds, attempting to find similarities that could explain the phenomenon.

Members of this group with backgrounds in qualitative and quantitative research created a survey tool through which group members could systematically share data. The group then published a report based on 640 survey responses that illuminates the clinical course of COVID-19 and the return to baseline health. The report is titled, “What does COVID-19 Recovery Actually Look like; an analysis of the prolonged COVID-19 symptoms survey by patient-led research team.”

It is important to mention that half of the respondents in the survey were not tested for COVID-19. The researchers made the decision to include them in the study due to the fact that testing was and is severely limited and did not and do not capture a large subset of COVID-19 patients.

All those surveyed were self-reported to be experiencing COVID-19 symptoms for over two weeks. Below are some highlights from the study.

- Fifty-eight percent of respondents reported at least one preexisting condition. The most prevalent conditions were asthma and vitamin D deficiency.

- Over 70 percent of participants experienced fluctuating long-term symptoms. Both the type of symptom and the severity would change day to day.

- At the time the survey was taken, 90.6 percent of the respondents had not yet recovered. Out of the 640 participants, only 60 self-reported a full recovery. Those who had recovered

stated an average symptomatic period of 27 days.

- Those not recovered by the time of the survey had been symptomatic for an average of 40 days.

- The most frequently reported symptom was a low-grade fever below 100.1°F. Other highly reported symptoms include fatigue, severe fatigue, concentration difficulties, memory loss, chills/sweats, insomnia, anorexia, shortness of breath, chest tightness, joint pain and headache.

- The symptoms that respondents reported to be the most distracting and challenging were concentration challenges, memory loss, dizziness, insomnia and problems with balance.

- A majority of respondents were never hospitalized.

- A decline in physical activity level was frequently reported, with 65 percent of respondents reporting a decline from moderately active to sedentary.

Other long-haulers have organized on Facebook and elsewhere to share stories of their struggle with prolonged COVID-19 symptoms. One group, in Britain, known as LongCovidSOS, is working to pressure the government to provide funding for researching the phenomenon.

The patient-led research and organization of long-haulers did gain attention from the scientific community. Shortly after its publication, a formal research study from the US Centers for Disease Control published data that appears to support the existence of the long-hauler phenomenon.

The CDC published a report in June based on telephone surveys with COVID-19 survivors, two to three weeks after a positive test result. Out of 240 people surveyed, 65 percent reported a return to baseline health after a median of 7 days from the day of a positive test result. Thirty-five percent reported they had not yet returned to baseline. This survey also showed that extended recovery was not

limited to elderly individuals or those with comorbidities. Among those surveyed who were aged 18-34 with no chronic health problems, 1 in 5 had not yet returned to baseline health.

A Journal of the American Medical Association (JAMA) study from Italy published in July also worked to better understand the persistent symptoms of COVID-19. A group of 143 patients were assessed a mean of 60.3 days following the onset of first COVID-19 symptoms. Only 12.6 percent reported being completely symptom-free, 32 percent reported 1 or 2 symptoms, and 55 percent had 3 or more symptoms. Forty-four percent of patients also reported a “worsened quality of life.” The most common symptoms reported in evaluations were fatigue, dyspnea, joint pain and chest pain.

And while the concept that viral infections can morph into chronic health issues is not new or unresearched, the scientific understanding of the specific manifestation of the post-viral conditions of COVID-19 is still in the early stages. Experts are, however, beginning to warn that the pandemic could lead to a significant surge of chronic illnesses across the globe.

To a certain extent, the current gap in the research on the subject of persistent COVID-19 symptoms is expected, as data on long-term consequences of COVID-19 can only be gathered as the pandemic continues.

On the other hand, mistakes made in the early stages of the pandemic continue to haunt research today. Poorly organized and unavailable testing has created a subset of long-haulers who were never able to get tested and whose persistent symptoms can thus not be technically defined as stemming from an initial COVID-19 infection. Recovery data is also faulty, with many states defining patients as “recovered” if they are simply not dead after 30 days, without accounting for a return to baseline health.

It is also possible that signs and symptoms of long-term infection are under- or misreported. When seeking medical attention many patients have complained that their lasting symptoms are not taken seriously. They are often sent home from appointments with referrals to psychiatrists or simply told there is nothing that can be done for them.

It is speculated that lasting symptoms could be a result of organ damage from the COVID-19 virus itself, caused by the effect of COVID-19 on the immune system and/or damage caused by the treatment of COVID-19, such as intubation or medications. Some of the most common areas of the body where COVID-19 damage is seen are the pulmonary, cardiovascular and immune systems.

There are still a limited number of peer-reviewed studies published on the long-term effects of COVID-19 on the lungs. However, the available data as well as data from other coronaviruses such as SARS show evidence of month- to years-long damage to the lungs. An Austrian study from the European Respiratory Society showed that, after COVID-19 infection, damage to the lungs persisted but also lessened overtime. After six weeks from hospital discharge, 88 percent of patients still sustained lung damage. After 12 weeks, 56 percent still maintained signs of lung damage. On the level of daily life, this lung damage could mean patients still suffer from mild or moderate shortness of breath or continue to use an oxygen tank months after discharge.

It is not uncommon for a virus to cause lasting damage to the

immune system. Long-term studies of the effects of SARS on the immune system have shown that the virus decreases the immune system’s activity by slowing down certain signaling proteins. It is not yet known if this will be the case for COVID-19.

A virus can also kick an immune system into overdrive, triggering an increase in inflammation throughout the body, eliciting symptoms not unlike those caused by some autoimmune disorders. This severe inflammation appears to come on after the virus has run its course and it is not yet known how long it will take the immune system to settle down after initial infection.

A few examples of cardiovascular conditions caused by COVID-19 include cardiomyopathy, pulmonary embolisms, and damage to the lining of blood vessels. It is speculated that the aforementioned overactivation of the immune system could play a role in the damage to the cardiovascular system. How long these effects will last is still unknown.

How many people across the globe will suffer from continuing symptoms? While this is largely unknown, many experts agree that the range affected could be similar to previous viral outbreaks, with roughly 5-10 percent of those infected experiencing continuing symptoms.

With 6.64 million cases reported in the United States and 29.8 million cases reported internationally, even the low end of that range would mean roughly 330,000 people in the US and 1.5 million people across the globe could experience chronic symptoms of COVID-19. Of course, the pandemic is far from over, and rates of chronic illness can only be expected to rise.

A wave of chronic illness for years following the pandemic will continue to overwhelm the already crumbling health care system in the United States. The care of the chronically ill is notoriously unprofitable for hospital systems, and research and treatment in the area will likely not be prioritized. Conversely, chronic illness is notoriously expensive for the average worker, and it burdens people with hundreds of thousands of dollars in medical debt.

As the death toll across the world rises, so too will the number of walking dead, those saddled with severe chronic health issues, unable to work, unable to rise from bed, unable to afford the help of medical specialists or pay for prescription medications. They, too, have the global ruling elite to blame, whose policy of “herd immunity” has allowed the disease to spread without restraint, a response driven not by social need and public health but by profit alone.



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