UNDERSTANDING LONG-COVID

A COVID-Related Health Crisis That Could Outlast the Public Health Emergency

Covid Patient Recovery Alliance

What Is Long-COVID?

While most COVID-19 patients go on to fully recover, research shows a significant percentage of patients who get COVID-19 continue to experience a constellation of physical and mental complications weeks and even months after acute infection. This phenomenon has been referred to as Post-Acute Sequelae of COVID-19 ("PASC"), but more commonly as "long-COVID."[i] While the science informing our understanding of long-COVID numbers continues to evolve as our understanding of this novel virus grows, published studies estimate that 10-30 percent of COVID-19 survivors may suffer from long-COVID.[ii,iii] With more than 30 million Americans reported as having contracted COVID, the number of individuals who could face lingering symptoms and long-COVID is staggering.

> "I bring to your attention the fact that a number of individuals who virologically have recovered from [their COVID-19] infection, in fact have persistence measured in weeks to months of symptomatology that does not appear to be due to persistence in the virus. They're referred to as long haulers. They have fatigue, myalgia, fever, and involvement of the neurological system, as well as cognitive abnormalities, such as the inability to concentrate."
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> Dr. Anthony "Tony" Fauci
> Testimony to the Senate HELP Committee, September 23, 2020

What Are Symptoms of Long-COVID?

While the symptoms of long-COVID vary immensely, with some studies suggesting as many as 50 different symptoms, the most common include fatigue, muscle or body aches, shortness of breath or difficulty breathing, difficulty concentrating or focusing, inability to exercise or be active, headache, and cough.[iv] Long-COVID symptoms can persist for months and range from mild to incapacitating, with some studies suggesting that a quarter of long-COVID symptoms are painful.[v] A recently study of over 200,000 individuals suggests that one in three COVID-19 patients will be diagnosed with a neuropsychiatric condition – from mood conditions to strokes or dementia – in the next six months.[vi]

Why Do Some Patients Develop Long-COVID?

It remains unclear exactly why some individuals go on to experience long-COVID symptoms when they continually test negative for the presence of the virus causing COVID-19. While further research is ongoing, researchers have offered several theories as to what may lie behind symptoms in long-COVID patients. One hypothesis is that SARS-CoV-2, the virus that causes COVID-19, or its components may be lurking in the body.[vii] A similar occurrence has been documented in both the Ebola and Zika epidemics. Another hypothesis is that long-COVID patients have developed an autoimmune response, where patients' immune systems are turning against their body and resulting in targeted, longer-term damage.[viii] One study found that 10 percent of 987 individuals with severe COVID-19 had antibodies that attacked and blocked molecules that would typically help bolster the immune response against foreign pathogens.[ix] Further research and study is needed to offer a more definitive answer.

Who Is At Risk of Developing Long-COVID?

While long-COVID can affect anyone – both young and old individuals, healthy individuals without underlying conditions, and even those with milder COVID-19 cases that did not require hospitalization – some research suggests that patients

with COVID-19 who felt more than five symptoms in their first week of illness were more likely to develop long-COVID.[x] Research has also suggested long-COVID may be more likely in patients who are older, who have higher body mass indexes, or who are women. However, other studies have shown insignificant differences between the long-COVID prevalence rates between men and women, so further research on risk factors associated with long-COVID is needed.

Does Vaccination "Cure" Patients with Long-COVID?

Based on initial research and early findings from vaccination of patients with long-COVID, it currently appears that the majority (60-70 percent) do not experience a lessening of symptoms following vaccination. While further research and control groups may be needed to rule out a potential placebo effect, at this point there is no demonstrable evidence that vaccination alleviates the symptoms patients with long-COVID face.[xi]

What Are Federal Policymakers Doing About Long-COVID?

As part of the $1.15 billion that Congress directed to the NIH to study the long-term effects of COVID, NIH launched the PASC Initiative, which provides multi-year funding to support new and ongoing research on long-COVID-related topics, including how to prevent and treat long-COVID symptoms.[xii] Dr. Francis Collins, Director of the NIH, has written and spoken repeatedly about long-COVID and noted the new funds are designed to help "learn more about how SARS-CoV-2 may lead to such widespread and lasting symptoms, and to develop ways to treat or prevent these conditions."[xiii] During a Senate Health, Education, Labor and Pensions (HELP) Committee hearing in mid-March 2021, Dr. Fauci, Director of the National Institute of Allergies and Infectious Diseases at NIH, warned that long-COVID is a "really serious and real issue" and that "it's not imaginary. It varies from person to person."[xiv]

What Are Some Implications of Long-COVID?

If 10-30 percent of COVID-19 survivors suffer from long-COVID, as is currently projected, this has important ramifications for their ability to be restored to full health, return to work, and reengage in their communities. The implications of long-COVID and the special populations it is impacting are described in detail below.

Long-COVID Impact on Return-to-Work

Many of the common long-COVID symptoms can negatively impact an individual's ability to return to work following infection and to be productive at work. Such symptoms include brain fog, dizziness, inability to focus, fatigue, anxiety and depression, and inability to exercise or be active.[xv] Many individuals with long-COVID are requesting accommodations at work as a result of these symptoms, such as shortened schedules, adjusted expectations for constant digital communication, and even maximizing possible disability benefits.[xvi] A recent study of over 1,000 hospitalized COVID-19 patients in the U.K. found that, of those previously employed, almost 20 percent have been unable to work since developing COVID.

Disparities Among Long-COVID Patients

In June 2020, the CDC released data noting that the hospitalization and death rates of COVID-19 are significantly higher for Black and Hispanic/Latino communities. Contributing factors for increased risk of getting sick, being hospitalized, and dying from COVID-19 include lack of health care access, discrimination, occupation, education, income, wealth gaps, and crowded living

circumstances.[xvii] What is currently unknown, however, is the risk of long-COVID among various racial and ethnic minority groups.

Health Care Costs and Utilization

Recent data suggests that health insurers are anticipating increased costs in 2021 – either because of deferred care or avoided preventative care for chronic conditions during social distancing lockdown periods – as well as health complications following recovery from severe cases of COVID-19. However, researchers lack data on the types of health care coverage long-COVID patients have and estimates around their health care costs and utilization following acute COVID-19 infection.[xviii]

Frontline & Essential Workers

Frontline and essential workers are those employees who stepped up to provide key public services across the nation during throughout the pandemic. They are the health care workers in hospitals and nursing homes providing health services, the police officers and firefighters ensuring safety and responding to emergencies, and the teachers who made sure children could still grow academically in a virtual environment. Such workers are often also the ones who were most vulnerable to contracting COVID-19. As Dr. Anthony Fauci, the Chief Medical Advisor to the President and the Director of the National Institute of Allergy and Infectious Diseases, stated, "We rightfully refer to these people without hyperbole – that they are true heroes and heroines."[xix]

Recent data suggests that more than 3,600 health care workers died from COVID-19 complications. Of note, two-thirds of the deceased health care workers were people of color, and those in lower-paid positions, such as nurses, support staff, and nursing home employees, were more likely to die than physicians.[xx] While it is unknown how many frontline and essential workers are suffering from long-COVID, some health systems are seeing a growing number of their frontline health care workers reporting long-COVID symptoms, with about one in ten health care workers estimated to be long-COVID patients.[xxi]

While the science evolves and research continues to inform our fight against COVID and ultimately treat and even prevent long-COVID, the health care community has a unique opportunity to collaborate to address this emerging need that impacts Americans across the country.

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[xvi] https://www.wsj.com/articles/the-challenges-of-getting-long-covid-patients-back-to-work-11613350801
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