

Opinion 5 big questions we still need to answer about long covid

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We are nearly three years into the covid-19 pandemic, and the debate about the need for health measures such as vaccine and mask mandates is as hot as ever. One big reason for that: long covid.

For some, long covid is overemphasized. For others, it has been dismissed or ignored. The trouble with this debate is that there is just simply so much we still don't know.

I am hoping that by highlighting the open questions that remain unanswered, we can lower the temperature for our policy discussions. Here are five things we still don't know about this curious illness:

What even is “long covid”? Broadly speaking, the condition refers to any symptoms persisting weeks to months after an initial covid infection. But dozens of symptoms have been attributed to long covid — some mild or annoying, such as persistent loss of taste or smell, and others more severe, such as extreme fatigue or cognitive dysfunction (or “brain fog”). As a result, health agencies still do not have a uniform definition, and doctors lack clear guidance for diagnosing it. It would not be surprising to eventually find out that we have been lumping multiple distinct post-covid syndromes under one umbrella.

How many people are suffering from long covid? At the individual level, patients have struggled to get a diagnosis of long covid, since the condition has a lot of lookalikes. And at the population level, it is nearly impossible to get an accurate count of how many long covid cases there are. It is estimated that 18 million American adults (more than 1 in 20) report at least one lingering symptom after having covid-19, but this figure might not match public perception of the problem and thus generates skepticism. To be clear, there are most certainly people suffering severe and persistent consequences of covid, and even a small fraction of 18 million affected would still be a big deal.

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In what ways is long covid exacerbating or precipitating other health

conditions? A recent study by the Centers for Disease Control and Prevention made waves by suggesting that long covid has killed thousands of Americans since the start of the pandemic. But the study was more complicated than headlines suggest. While it found that thousands of people died with long covid listed as a contributing cause on their death certificates, nearly one-third of those cases recorded another cause of death, such as cancer, Alzheimer's disease and even unintentional injury. It's also important to note that the age-adjusted death rate for long covid in this study was only 6.3 per 1 million persons.

By comparison, the death rate for amyotrophic lateral sclerosis (ALS), a rare but fatal disease better known as Lou Gehrig's disease, is about 17 per 1 million persons.

This does not mean that long covid is not a problem, though, as evidenced by the thousands of testimonies from people who suffer from it. In fact, the CDC's study highlights an overlooked issue: the impact long covid is having on other chronic health conditions. This deserves more scientific research.

How can we treat long covid? The uncertainty of the disease understandably produces anxiety, despair and at times a willingness to take a chance on unproven therapies despite potential risks. Fortunately, the National Institutes of Health earmarked in excess of \$1 billion for its four-year Recover initiative, which will research long covid. Recover had a slow start but is picking up steam, and there is research outside this initiative as well.

In a preliminary search of a federal registry of clinical trials, there were about 600 studies examining different interventions for long covid. The vast majority of these trials don't have results yet, but new information is emerging, as is our ability to offer patients evidence-based treatment. Sometimes, studies investigate new drugs or a new purpose for an old drug, such as naltrexone, a medication typically used to treat opioid addiction. As with most medical treatments, there likely won't be a one-size-fits-all approach. Overall, we need larger, well-conducted studies to understand which therapies work and for whom they work best. Hopefully, the Recover initiative can fill that void.

Finally, will we learn how to respond to post-viral conditions for the next pandemic? Post-viral symptoms are not a new phenomenon (think polio or mononucleosis). In fact, prolonged periods of convalescence were well-documented during the 1918 flu pandemic. Yet covid caught us off guard. We find ourselves behind in data collection, research and, consequently, treatments. As part of our evolving surveillance and systems responses, we must leverage the vast amount of data that is at our fingertips to measure the ongoing burden of illness when outbreaks arise, not scrambling to unearth it after the fact.

Even after the pandemic ends, thousands of people are likely to deal with post-viral symptoms without knowing when their condition will improve. This will cause damage to one's physical and mental health, and in some cases, will force people to withdraw from daily life. Answering these crucial questions about long covid is essential to bringing these folks much-needed relief.