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Long COVID is Pitting Patients Against Doctors. That's A Problem.

Health care professionals must act swiftly to ensure frustrated patients don't fall victim to misinformation.

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As of this month, nearly 250 million people around the world have recovered from COVID-19. But here, the word "recovered" refers only to the acute phase of the illness. Somewhere between 10% and 40% of COVID patients continue to experience symptoms several weeks to months after falling sick, a nebulous condition now referred to as post-COVID condition, or long COVID.

In long COVID, we are witnessing the emergence of a legitimate new illness, officially recognized by the World Health Organization's International Classification of Diseases. Because it is difficult to diagnose and treat, however, long COVID has also become a subject of contention between the people who suffer from it and the health care professionals charged with treating them. Long COVID patients have described feeling dismissed and "gaslit" by doctors who seem to question their illness — or who seem at a loss for what to do about it.

Understandably, then, many long COVID sufferers have turned to patient and advocacy support groups for solutions. As physicians ourselves, we know that patient groups can provide needed social and emotional support, especially to patients who feel alienated and unheard by medical professionals. But we also know they can be cauldrons of misinformation — and feeding grounds for snake-oil salesmen hawking unproven treatments. And so it's critical that patients and health care professionals find ways to work with, rather than against, each other in the effort to find solutions for long COVID. Otherwise, the problem is destined go from bad to worse.

The task is made difficult by the fact that we know so little about long COVID. Although the condition is frequently marked by symptoms including fatigue, headaches, muscle pain, and "brain-fog," laboratory tests and physical examinations of long COVID patients may show nothing out of the ordinary. As a result, long COVID has drawn comparisons with so-called contested illnesses, such as myalgic encephalomyelitis (also known as chronic fatigue syndrome) and fibromyalgia, whose legitimacy are questioned by the medical profession.

There is even some evidence that some cases of long COVID may be caused by something other

than COVID-19. A recent study found that patients who believed they'd been infected with COVID-19 — but hadn't confirmed that status with testing — tended to report more symptoms of long COVID than patients who were confirmed with blood tests to have actually had COVID-19.

Collectively, this doubt and ambiguity has contributed to a potentially adversarial relationship between doctors and patients. Headlines like the one for a recent story in The Atlantic, "Long-Haulers Are Fighting for Their Future," have only contributed to the combative tone.

But it would be unfair to say that the medical community has entirely dismissed long COVID. Substantial amounts of effort and funding are now being put into long COVID research. The National Institutes of Health has announced more than a billion dollars of new funding for a program that will, among other things, follow a cohort of COVID-19 patients over time to track the evolution of long COVID symptoms and hopefully elucidate the biology of the condition. Similar research efforts are being mounted in other countries as well. In time, these efforts will help us more clearly understand the hallmarks of long COVID and develop best practices for treating it.

For now, however, the illness remains shrouded in unknowns, and there's a legitimate concern that misinformation will fill in the gaps — as it seemingly has with almost everything COVID-19 related so far. Already, we have personally seen pseudoscientific groups claiming, without evidence, to have knowledge of how to treat long COVID. We have seen discussions about unproven treatments like extreme diets and ivermectin pop up frequently on long COVID social media boards. The misinformation seems to be spreading almost as fast as the disease itself.

Fortunately, there are steps that can be taken to mend the budding rift between long COVID patients and health care professionals — hopefully in time to stop the wave of misinformation before it crests.

First, the health profession will need to make a concerted effort to communicate new findings and developments about long COVID to the public. As research progresses, there will be a steady flow of new information about this illness, its epidemiology, and how to best treat it. It is imperative that clinicians, patients, and journalists have access to updated and accurate scientific information about long COVID as it emerges. Simultaneously, it will be important to identify, and counteract, long COVID misinformation. We recommend an infodemiology model, in which community members trained in effective communication techniques engage in discussions on patient forums to contextualize new findings and help correct misconceptions before they become entrenched.

Second, physicians can treat the symptoms of long COVID, even when they are unable to make a concrete diagnosis of the disease. Some long COVID patients, for example, describe numbness and tingling in their hands or feet — a condition that may respond to appropriate medication. Brain fog and cognitive difficulties may be treatable in some patients with cognitive therapy approaches. Depression, another prominent long COVID symptom, may be treatable with psychotherapy or antidepressant medications, whether or not the underlying cause was a coronavirus infection. (In a recent essay in The New York Times, physicians Adam Gaffney and Zackary Berger noted the importance of treating the symptoms of long COVID, even when causes can be difficult to identify.)

Public health and specialist societies can aid physicians in these efforts by providing guidelines and training for safely treating long COVID symptoms in the face of uncertainty — and for helping patients manage mental health issues. (It's worth noting that the French government has already issued diagnostic and treatment guidelines for long COVID.)

But perhaps most important, doctors can listen to their patients, and show empathy. At times, health care professionals can get so caught up in the objective criteria for diagnosis that they lose the forest for the trees. The culture of "first, do no harm" can actually do harm when it leaves people suffering until a diagnosis can be made. Even if the diagnosis is uncertain, acknowledging the reality of a patient's symptoms — and the potential for those symptoms to cause significant pain and suffering — is likely to offer some therapeutic relief. Making sure that patients feel heard, understood, and validated can go a long way toward reassuring them that health care practitioners are their allies, not adversaries, in the effort to solve long COVID.

Having a chronic illness is frustrating. People suffering with long COVID are right to feel impatient with what is, in many ways, a broken medical system. But it would serve no one to have millions of people with long COVID initiating adventures with unproven and potentially dangerous interventions. And it serves no one to pit doctors against patients. COVID-19 has already sown harmful division and polarization in our society. We should not let long COVID do the same.

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