Medical Xpress

Long COVID: A public health expert's campaign to understand the disease

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Credit: Artem Podrez from Pexels

On March 20 2020, while the UK was anticipating its first national lockdown to control the coronavirus pandemic, I started feeling unwell with what felt like a COVID-19 infection.

Over the next couple of days, I developed a collection of symptoms: fever, chills, cough, chest heaviness, exhaustion, diarrhea, abdominal

pain and bad muscle aches, particularly in my legs. Since the UK government had stopped lab testing for those who were not hospitalized for COVID-19 on March 12, the vast majority of community infections in March remained unconfirmed by testing, including mine. The instruction then was that if you were not ill enough to go to hospital, you should stay at home and wait to get better.

While I isolated at home with my three children, I was optimistic that the infection would pass, like other flu-like illnesses I'd had in the past, because I had no underlying risk factors for severe COVID-19. But I became nervous with every new day that passed while I was not recovering.

At the end of the third week, I was still concerned, but consoled by others posting on social media describing their frustration with an illness that would not go away. They were describing a fluctuating experience like mine. One day you would feel like you were on the mend, the next day, symptoms hit you badly again. Little did I know at the time that these relapsing symptoms would stick with me for the next nine months.

COVID-19 is not black and white

By summer 2020, I was struck by how coronavirus risk was still communicated as a black and white picture. As a public health researcher, I could see that there was a clear oversight in how this new disease was being classified: the public messaging was that you either have a high risk of severe initial infection, or it hardly affects your health. This was certainly not my experience nor that of the thousands of others in long COVID social media support groups.

So how common is long COVID? This is the million-dollar question, and for a long time we had no idea. But in recent months, studies of the conditions have been trickling in.

Today, there are a number of estimates out there, which vary because of different definitions of the condition, the length of follow up, a different range of methods of measurement and groups of people who were studied.

We know that recovery is not guaranteed for those who were treated in hospital for COVID-19. In a large study in England where the average follow-up period was 20 weeks, almost one in three patients got re-admitted to hospital and one in eight died after discharge from hospital.

Long-term illness is not restricted to people who experienced severe symptoms when they first got infected with COVID-19. The UK's Office for National Statistics (ONS) has published estimates based on its COVID-19 Infection Survey, which measures the rate of coronavirus in the general population. These estimates can be considered more reliable than others as the survey is based on a random sample of people.

The survey estimates that one in five of those who tested positive for coronavirus were still symptomatic by week five, and one in ten by week 12.

The ONS further broke down the five-week figures by age and sex. They found that about one in four women and one in five men have at least one symptom five weeks after testing positive. Although long COVID was less prevalent in children (around one in seven) than adults aged between 25 and 69 years (one in four), the figures still did not fit with the narrative that this a hardly noticeable illness for the youngest cases.

Counting long COVID

Over the past year, government pandemic responses have been designed around monitoring the number of deaths, hospital admissions and lab-confirmed cases of COVID-19. But without national surveillance

systems to track prolonged illness and organ damage due to COVID-19, how will health and care systems prepare and accommodate for the sheer demand on services? How will the economy accommodate for the loss in productivity due to sickness?

It is also essential for prevention efforts to convey the reality of prolonged illness as a quantifiable outcome in those infected, even if they were previously healthy and of younger age. People need facts to inform their decisions.

That's why I have been calling for illness caused by coronavirus to be measured in the same way as deaths and for national and international surveillance systems to monitor recovery from COVID-19. I have also argued for the use of long COVID patient registers. Otherwise, how can we address what we are not measuring?

By properly measuring recovery, taking into account the relapsing nature of the illness, we can find out how many of us have not fully recovered and come up with ways to support people living with long COVID.

The road to recovery

So what next? I am hopeful that complete recovery is possible for many with long COVID. I am thankfully feeling better now, as I was able to adapt my life to avoid triggering my symptoms.

But there will be many who are not able to do so due to their work or personal circumstances, and there are those who will require long-term medical attention and care. They will also need the welfare system to support them—they should not live with the threat of losing their livelihoods due to a poorly understood disease.

Our pandemic response must be informed by the amount of chronic

illness it generates, not just deaths with COVID-19 and hospital capacity. We must count long COVID if we truly want to know what we are up against.

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