World view

By Nisreen A. Alwan

A negative COVID-19 test does not mean recovery

Pandemic policy must include defining and measuring what we mean by mild infection.

Eight months into the global pandemic, we're still measuring its effects only in deaths. Non-hospitalized cases are loosely termed 'mild' and are not followed up. Recovery is implied by discharge from hospital or testing negative for the virus. Ill health in those classed as 'recovered' is going largely unmeasured. And, worldwide, millions of those still alive who got ill without being tested or hospitalized are simply not being counted.

Previously healthy people with persistent symptoms such as chest heaviness, breathlessness, muscle pains, palpitations and fatigue, which prevent them from resuming work or physical or caring activities, are still classed under the umbrella of 'mild COVID'. Data from a UK smartphone app for tracking symptoms suggests that at least one in ten of those reporting are ill for more than three weeks. Symptoms lasting several weeks and impairing a person's usual function should not be called mild.

Defining and measuring recovery from COVID-19 should be more sophisticated than checking for hospital discharge, or testing negative for active infection or positive for antibodies. Once recovery is defined, we can differentiate COVID that quickly goes away from the prolonged form.

I had COVID symptoms of fever, cough, gastrointestinal upset, chest and leg pains in late March. But at that time, non-hospitalized patients were not tested. Since then, I have had bad days with some symptoms, then OK days, then worse days of exhaustion, making me regret what I did on the OK days, such as taking a short walk.

This is a difficult time for me as a public-health academic engaged in pandemic action while struggling with this strange pattern of illness. I don't know what it means for my long-term health, which is concerning as a mother caring for young children.

One consolation is knowing that I am not alone. There are many others who have not regained their previous health, even months after their initial symptoms. Among them, fluctuating symptoms like mine are common.

Although clinicians and researchers have an idea of who is at increased risk of dying from COVID, we don't know who is more likely to experience prolonged ill health following symptomatic, or even asymptomatic, infection. The idea of accepting certain levels of infection to run through society, while protecting the vulnerable, becomes meaningless without considering health and productivity as outcomes alongside death.

Research that follows COVID patients after discharge from hospital is starting. But there is still a gap in quantifying and characterizing COVID-related illness in those not hospitalized. The consequences of failing to do so are significant. Some people, especially the young and healthy, might not see a need to follow preventive measures, because they expect only a few days of flu-like symptoms at the worst. Sick people might not get the support they need, and the true human and economic costs of the pandemic will not be correctly estimated.

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As long as 'long COVID' is labelled as anecdotal, it will not be taken seriously, and public communication will neglect it. We need to quantify it properly and accurately. We must measure recovery in those not presenting with severe disease at the outset.

Let us start simple. With other common viral illnesses, such as flu, we would expect recovery to mean going back to pre-infection levels of functionality and quality of life. This means we must follow up all patients with confirmed (by test) or highly probable (by symptoms) COVID and find out whether they have returned to their previous normal within a specified time from the onset of their symptoms.

The 'recovery' definition must include duration, severity and fluctuation of symptoms, as well as functionality and quality of life. Everyone who is symptomatic would remain a 'case' until they fulfilled the recovery criteria or died. This is basic bread-and-butter epidemiology. We just need to apply it to this pandemic.

To do so, we must also define who had the infection in the first place. When testing is absent or inaccurate, physicians must be provided with universal and simple criteria for what constitutes clinical COVID. A good starting point are the studies characterizing typical symptoms on a population level.

Measuring recovery is not an easy ask with health and surveillance systems already struggling to cope. It makes sense to set up disease registers, akin to cancer registries, to track people over time and record their condition. This could be done through quick monthly, and subsequently annual, check-ups with health-care providers. If national registers are not quickly forthcoming, local ones could be started.

For surveillance, public-health agencies must prioritize agreement on criteria for a definition of recovery, and on the structures in which these criteria could be implemented. We must overlay research on surveillance with studies of the characteristics of those experiencing prolonged ill health. We must learn to identify and protect the most vulnerable.

The narrow narrative of death as the only bad outcome from COVID needs broadening to include people becoming less healthy, less capable, less productive and living with more pain. For that, we'll need better surveillance. The essential first step is getting clear and universal definitions for recovery and COVID severity.

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