



COVID's Chronic Collateral Damage: Considering the Real Cost of the Pandemic

Special article by Melanie K. B. Willis, Ph.D.

I don't recall exactly when I first noticed the warnings from the chronic disease community. I do know that the early dialogue felt very far removed from the bleak reality of COVID-19 as it abruptly upended our lives. As the pandemic virus transitioned from an abstract risk to an immediate threat in Canada, we collectively fixated on the acute presentation, the worst-case scenarios triaged in ICUs around the world, as concepts like case fatality rate became household topics. They became a litmus test of sorts that calibrated our expectations, our fears, and the measures that we as a society were willing to take in order to mitigate viral transmission. In crisis mode, it was hard to look beyond the immediate alarm. Only now that much of the world has grappled with SARS-CoV-2 for months are we coming to terms with collateral damage that we were quietly warned about months ago – prolonged disease and disability arising in some seemingly mild cases. Patient accounts are increasingly surfacing and forming a common narrative. Compared to headline-worthy cases, these are relatively straightforward. Yet, over time they evolve into profound, oscillating, and sometimes baffling symptoms that far surpass the two-week window of predicted recovery.

This is not a new phenomenon. The pattern – a flu-like illness that never really resolves, and instead becomes a chronic, sometimes deteriorating and debilitating affliction – was even documented during the last great pandemic of 1918. In contemporary times, this is a common trajectory of patients who are eventually diagnosed with Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS) and related diseases like fibromyalgia (FMS). Devastating, controversial, poorly understood, and often mismanaged, these syndromes are estimated to affect around half a million Canadians, while the mechanisms of disease, and opportunities to intercept them, ultimately remain unknown. Not new, then, but still vexingly mysterious. And not, until now, a biomedical research priority.



As the director of the G. Magnotta Lyme Disease Research Lab at Guelph, I am no stranger to complex and chronic complications of infectious diseases, nor am I naïve about their propensity to be systematically dismissed. While Canadians are increasingly encouraged to be vigilant about the tick-borne summer sickness, there is a concerning lack of clarity around some of its most pernicious manifestations – post-treatment and chronic Lyme disease. This poorly charted territory often intersects ME/CFS and FMS, not only in presentation, but also in the stigma attached to the illness, and the challenges and frustrations experienced by patients seeking care. These diseases have become an intertwined web of biomedical uncertainty.

An early and specific warning sign about the potential wrath of the novel coronavirus came from its close relative, SARS, in the aftermath of the 2003 outbreak in Toronto, ON. Largely contained to hospitals in the provincial capital, SARS disproportionately affected frontline healthcare workers, a number of whom later reported a familiar constellation of ongoing symptoms – pain, fatigue, sleep disruption - and an inability to resume their duties. When COVID-19 appeared on the world's stage in early 2020, the messaging from some prominent voices in the ME/CFS community was clear. We've walked this road before. For them, a viral illness had morphed into an unrelenting nightmare, and they wondered how many more would now follow in their footsteps.

There are also disconcerting parallels between the self-declared COVID “long-haulers” and the longstanding Lyme patients who participate in our studies. Some have laboratory evidence of the infection, but other don't, and were diagnosed on clinical suspicion alone after they failed to meet a (somewhat arbitrary) case definition that would qualify them for testing, or they came up clean on tests known to yield a considerable number of false negative results (~30% for COVID-19, ~50% in acute Lyme). They now suffer profound symptoms that interfere with activities of daily living and diminish quality of life, but often lack objective signs (e.g. rash, fever) that orient clinical decision making. All too often, this leads to denial and dismissal. Even when caregivers want to help, the toolbox is limited.

Regardless of whether post-COVID syndrome is a unique entity or just another node in the bigger web of infection-related chronic illness, it has started to unearth the history of biomedical neglect in this area. A year ago, labs like mine that study longstanding disability associated with infectious diseases might have been considered boutique curiosities. Indeed, prominent experts have attributed the ongoing symptoms of Lyme to nothing more than the ‘aches and pains of daily living’, dismissing deeper biology



and the depth of human suffering. Hardly worthy of discussion, let alone research investment. If chronic illness becomes another dark legacy of COVID-19, may it focus a spotlight on a phenomenon that has stagnated in the shadows. May it change the culture to mobilize compassion, responsibility, and ingenuity. A sobering reminder from previous victims of life-altering infections: had they been taken seriously 10, 20, 30 years ago, COVID patients might have a very different prognosis today. While we can't change the past, we can and must do better for the future.

More information: Dr. Melanie Wills and the [G. Magnotta Lyme Disease Research Lab.](#)