

Seasons of Coronavirus Disease 2019

Robin Macnofsky¹ and Eric J. Chow²*

¹Seattle, Washington, USA, ²Division of Allergy and Infectious Diseases, Department of Medicine, University of Washington, Seattle, Washington, USA

The coronavirus disease 2019 (COVID-19) pandemic has caused significant morbidity and mortality. Although much of the focus has been on the management and treatment of acute COVID-19, some patients have experienced prolonged symptoms after their acute infection had resolved. In this perspective, a patient shares her experience of postacute COVID-19, highlighting a journey of a revolving door of symptoms. Her infectious disease physician summarizes the next steps required to better care for this growing group of patients.

Keywords. postacute COVID-19; prolonged symptoms; SARS-CoV-2.

THE SYMPTOMS BEGIN

Robin Macnofsky

My first episode of symptoms of coronavirus disease 2019 (COVID-19) began in April of 2020: mild fatigue, body aches, headache, and upset stomach without fever, cough, or loss of taste or smell. But after 2 days, I called my primary care doctor (whom I only visited for annual checkups), who ordered a swab test for me just in case. When I felt better within a few days, I did not take the test. Save it for someone who needs it, I thought.

After a few weeks, my second wave of symptoms occurred: elevated temperatures with an odd tightness in my chest. I went in to be tested, but by the time my COVID-19 test returned negative, I was already feeling better. “Whatever this is,” I thought at the time, “at least

it’s not COVID-19”. But then came the third wave: heart palpitations, fever over 101°F, and a relentless headache with what I called “zombie-sleeping”—impossible to sit up or leave my bed for several days. I also had shortness of breath just from talking, massive body aches, and debilitating fatigue. Severe “brain fog” had become routine and my appetite was nonexistent. Three months since my symptoms began, the waves were increasing in frequency and severity. By July, my doctor believe that I should re-take the COVID-19 nasal test. This time my COVID-19 test results were positive.

I am (was) a healthy, fairly active 59-year-old, and I enjoy daily trots with my dog and occasional paddle-boarding. Other than early-stage breast cancer 12 years prior, I had no underlying comorbidities. I never smoked. I eat a balanced diet. My only daily medication was an antidepressant. Once my symptoms began, my daily routine was upended. As a self-employed writer and activist, I had to shelve my projects. Ten minutes on the computer sent me crashing to the sofa for a 2-hour nap. My short-term memory and ability to multitask were gone. Daily walks with my dog were not happening.

Late one night, I discovered an online support group called “Long-Haul COVID Fighters”. They were people like me sharing their COVID-19 journeys with similar, persistent and yet uniquely

divergent symptoms. Each person was desperate to make sense of a diagnosis yet to be described by the medical community and infrequently reported by mainstream media. People in our long-haul group were struggling: many had lost their jobs, medical insurance, home, and life-savings. I was also reading disheartening stories of perplexed and at times dismissive healthcare providers who reduced long-haul symptoms to “anxiety attacks” or “COVID-19-related hysteria”. This was a “club” that none of us “wanted” to join. I felt reassured to know I was not alone—but I also profoundly worried about the days ahead.

In mid-August, my husband had to drive me to the hospital after I passed out in my bedroom. I underwent a step-wise escalation of clinical testing eventually discovering that I had fluid in my pericardium. I underwent a pericardiocentesis, which drained approximately a liter of fluid, but the cause of my diagnosis remained elusive. I cannot accurately convey my overwhelming anxiety, sleepless nights, or general discomfort during my hospital stay. However, as my symptoms began to show improvement, the prospect of going home again filled me with an immense sense of relief. This turned out to be short lived.

Two weeks later, I was back in the hospital. My fever had returned, my previous symptoms persisted, and now I had

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Correspondence: Eric J. Chow, MD, MS, MPH, Division of Allergy and Infectious Diseases, University of Washington, 1959 NE Pacific Street Box 356423, Seattle, Washington 98195, USA (ejchow@uw.edu).

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an effusion around my left lung. At this point, I could not walk without assistance and I felt like I had aged 20 years. After the effusion was drained, a new team of specialists assembled to investigate; but again, no culprit was uncovered. What was different this time, however, was the outpatient follow-up after my discharge.

Dr. Chow and his colleagues helped me navigate my “new normal”—exploring the unknown territory of post-COVID-19 recovery and managing my “long-haul” symptoms. I described feeling like I’d been “shot by a COVID-19 bullet,” leaving devastation in its wake. We met regularly and initiated a workup to rule out other potential causes for my symptoms. This included the possible return of my breast cancer. Fortunately, cancer and other diagnoses were not found. Unfortunately, there was no alternative explanation. My inflammatory markers waxed and waned and my symptoms persisted in the following weeks. But my medical team, rather than minimizing what I was experiencing, “listened” and supported me along this unknown road.

TURNING THE CORNER

Finally, after approximately 10 months, my COVID-19 journey seems to have turned the corner. My symptoms have steadily improved and the incapacitating malaise and brain fog are slowly receding. I still practice constant vigilance not to overexert myself or risk a relapse of my “Zombie fatigue”. I no longer endure daily fevers. My appetite has returned. I’m cooking, reading, back on Zoom, and I am enthusiastically doing laundry. Best of all, I’m walking with my dog again. Although paddle boarding will have to wait, simply tackling daily activities gives me a renewed sense of normalcy. My progress over the next few months remains uncertain, but I’m feeling more optimistic. I hope that by sharing my story, I can offer a sliver of hope for others who are walking this “foggy” post-COVID-19 path.

My 2020 journey offered me some unexpected life insights: For instance, I never realized how utterly dependent I could become on the kindness and expertise of total strangers. I am humbly grateful for the amazing care I received from dedicated hospital staff, and I am genuinely hopeful that others may experience that same quality of compassion. What was more difficult for me than being virtually helpless was learning how to co-exist with uncertainty—or trying to—without grasping for answers which do not yet exist and that the healthcare community is learning right alongside me. And possibly my biggest take away: not blaming myself, or others, for events that are mainly beyond our control. Sometimes we just have to ride the waves to find that safe harbor.

THE PATH FORWARD

Eric Chow

What Ms. Macnofsky shares in her journey may be experienced by as many as 10% of people who are recovering from COVID-19 [1]. She first developed symptoms of mild acute COVID-19 in April of 2020 when the state of Washington was at its first peak of severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) infections. The SARS-CoV-2 testing at the time was frequently reserved for patients requiring hospitalization and was not tested during her acute illness. She immediately self-isolated and family members she resided with were never symptomatic. Several weeks later, she developed new symptoms in the absence of known sick contacts with measured fevers, palpitations, fatigue, and headache. By July, her symptoms persisted and she had a nasopharyngeal SARS-CoV-2 polymerase chain reaction (PCR) test that was positive. Because her symptoms reappeared long after replication-competent virus in an immunocompetent patient is generally detected [2], the positive SARS-CoV-2 test was likely the persistent detection of ribonucleic acid rather than active viral replication. The first SARS-CoV-2

antibodies test was negative 5 months after acute infection. Subsequent SARS-CoV-2 PCR and antibody tests have been negative. Over her course, she was evaluated by pulmonology, cardiology, infectious disease, rheumatology, and hematology/oncology for alternative explanations. The results of this thorough workup had been unremarkable. It is interesting to note that her erythrocyte sedimentation rate, C-reactive protein, fibrinogen, and white blood count levels have oscillated between normal and abnormal often correlating with exacerbations of her symptoms.

Although there have been no identified causes and no clear predictors of these symptoms, several explanations including persistent immune activation have been proposed [3, 4]. Some patients experience cyclical symptoms that can include fevers, fatigue, “brain fog” (a subjective inability to think clearly), and waxing and waning levels of inflammatory markers. Similar experiences of persistent symptoms after acute infection have been described in patients with a history of Lyme disease [5, 6] or gastrointestinal infection [7]. Yet what the drivers of these conditions are is not known. As such, we must take steps to address this knowledge gap.

First, we must listen to and validate what our patients are experiencing. Disregarding their true lived experience could result in untoward health consequences. Second, we must establish criteria for diagnosis of postacute-COVID-19 syndromes so that, third, it can be studied. Patients may have persistent symptoms after acute illness for different reasons, and differentiating these conditions would help with supportive therapy and treatment. Fourth, individuals should be followed by interdisciplinary teams to identify risk factors and to understand the prognosis. Finally, given the persistence of symptoms, symptom-based return to work guidance may not be applicable for this group of patients. For those needing to work, criteria may need to be established to allow

these individuals, who are unlikely to be contagious, to return to their jobs despite their symptoms. This may be especially important for healthcare providers with persistent symptoms [8].

Patient Consent Statement

Patient's written consent for publication of the clinical course was obtained and patient also is a coauthor on this manuscript.

Ethics Statement

The contents of this manuscript was not deemed to be human subjects research and as such did not require University of Washington Institutional Review Board approval.

CONCLUSIONS

With the vaccine roll out underway, there is now hopeful talk of ending the COVID-19 pandemic. However, the ripples of COVID-19 will be felt as long as patients continue to experience persistent symptoms. We must work towards a better understand the etiology of postacute-COVID-19 symptomology. The patient-physician partnership will be more important than ever to navigate those uncharted waters.

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