

A PIECE OF MY MIND

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Reflections of a COVID-19 Long Hauler

I awoke on a Monday morning with a headache, and I am not a headache person. Fever followed, and the next morning my blueberry yogurt tasted of nothing. Thick emptiness. I knew I had it. Now, after more than 3 months of living with coronavirus disease 2019 (COVID-19) and the fatigue that has kept me couch-bound, I have had ample time to reflect on what it means to be a patient, how an illness ripples through family and community, and how I will use this experience to be a better physician. Here is what I have learned.

Mild Illness Can Have Dramatic Effects

I have what is referred to as a “mild” case. I have no pre-existing conditions, was never hospitalized, had minimal respiratory symptoms, and even managed to do limited office work throughout the acute illness. For this, I am grateful because I have seen first-hand how awful COVID-19 can be for others. And yet, living with this has been anything but mild. I quarantined in the basement for 40 days, staying isolated from my family because low-grade fevers continued, and the Centers for Disease Control and Prevention guidance was unclear for people like me. I talked to my children only through FaceTime or walkie-talkies and saw my wife

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only by looking up between the balusters of the stairwell. Embraces were out of the question when what I needed most was human connection. Aside from my isolation, the effects on my family were also isolating. Even after they quarantined, my family continued to worry about whether they would become ill, whether I would get better, and whether others would be too afraid to be around them because of my illness. And, my parents, 600 miles away, were also struck with anxiety and an inability to help. These were but a few of the severe effects of a mild disease.

The Lack of Objective Data Does Not Preclude Illness

As an emergency medicine physician, I am trained to develop a hypothesis and to look for objective evidence in support to quickly identify the cause of a patient’s suffering. In the absence of objective data—laboratory tests, imaging, examination findings—we are often left to reassure patients and discharge them with a recommendation for outpatient follow-up, an outcome that too easily can feel dismissive and unsatisfying for the patient and unful-

filling for the physician. My test results were normal: nasopharyngeal swabs for severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), imaging, laboratory results, oxygen saturation were all fine. But I did not feel fine, and still do not. I have had a rotating constellation of symptoms, different each day and worse each evening: fever, headache, dizziness, palpitations, tachycardia, and others. As a result, I have been reminded of the need to listen to the patient first, even in the absence of conclusive testing. The next time I care for someone with vague abdominal pain, or fatigue, or paresthesia, or any of the myriad conditions that are uncomfortable on the inside but look fine on the outside, I will remember that these symptoms are real and impactful for patients. There is a marked difference between tests being within normal limits and a patient being well.

It Is Hard to Ask for Help

My family and I have been so fortunate to have the support of friends and family, near and far, who have helped us with messages, calls, meals, puzzles, books, and more. So many have asked, “What can we do?” But, coming from a profession focused on helping others, it was hard to accept help. I could not bear to see emails activating my colleagues who were on-call to cover my shifts day after day. In fact, I asked the department to reconsider its practice of emailing the entire faculty with the name of the person seeking coverage to assuage the guilt I was feeling. Still, as difficult as it has been to accept help, long illness is even worse without help. If people had not insisted on helping, had my colleagues not been so supportive in covering my clinical work, these 3 months would have been marked by an overwhelming amount of additional stress.

Patients Need Validation

With each negative test, my worry increased that my employer would ask me to go back to work too soon or that my primary care physician would rule out COVID-19 despite strong clinical evidence otherwise. I doubted myself multiple times—thinking if I just pushed myself harder maybe I could go back to work and to my regular life, to move on. Then I would eat something without taste, would feel my heart pounding uncontrollably for hours, or would get so dizzy that I could not even write a simple letter. Each evening as my symptoms peaked, I was reminded that my diagnosis was not in question. I am so grateful that, instead of my worries manifesting, quite the opposite was the case. Instead of doubting the diagnosis, my doctor sent me the latest medical literature on long

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COVID-19 and patiently empathized. My employer clearly understood the inaccuracies of current testing, focusing on symptoms instead. My wife reminded me that she knew what I was experiencing was real. This validation was critical, allowing me to find peace and focus on healing.

I Am Lucky

My experience is not typical. I have a home with a well-equipped basement where I could safely and completely isolate. I have a wife and children who have approached my illness with endless strength and compassion. I have an employer that recognized the need to use a symptom-based approach for making return to work decisions and that provides a generous salary continuation benefit. And, I have long-term disability insurance should this affect me beyond 6 months.

This is not the case for most patients, many of whom cannot isolate from family and cannot afford to miss even a day or 2 of work. I have not had to live with the financial and health worries that accompany a COVID-19 diagnosis for so many in this country. I am also privileged by my race, whereas so many people of color are disproportionately suffering from this disease and others due to the many manifestations of institutional racism in this country. Recognizing this fact, I know how important it will be to continue to offer help and support to others less fortunate than me who are affected by COVID-19 and other chronic illnesses.

As I continue to live with uncertainty, fear, and a certain degree of continued isolation, the silver lining is the hope that my future patient interactions will allow me to provide greater comfort and validation, even when I cannot offer objective answers or concrete healing.

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