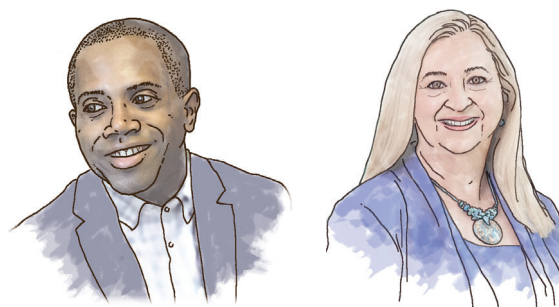


# Editorial

## TESTIMONIES FROM THE PANDEMIC SHORE

By Aluko A. Hope, MD, MSCE, and Cindy L. Munro, PhD, RN, ANP



From the shoreline looking back at the first year of the coronavirus disease 2019 (COVID-19) pandemic, we struggle to predict how the pandemic will change health care in the United States. We have all adapted and responded heroically: health administrators developed and implemented surge plans for the unprecedented numbers of patients moving through their health systems<sup>1,2</sup>; clinicians increased their use of telehealth visits and educators increased their use of virtual curriculum innovations to address the change in space that was needed because of social distancing; and research scientists built on what they had learned from previous pandemics to conduct large-scale collaborative clinical trials that led to effective therapies<sup>3,4</sup> and effective vaccines during the first year of this pandemic.<sup>5</sup> And yet, we wonder whether these responses and adaptations can be leveraged to make lasting improvements in our health care system.

Testimonies from survivors of COVID-19 are now emerging that will improve our understanding of the long-term health effects of acute COVID-19 infection. For many survivors, symptoms can linger for weeks to months after their acute infection. For these COVID-19 survivors with protracted symptoms

(termed *COVID long haulers*), the long-term effects of acute COVID-19 can mean relapsing and remitting symptoms including shortness of breath, chest pain, fatigue, palpitations, headache, sleep problems, dizziness, or brain fog.<sup>6</sup> There is no medical consensus definition for what constitutes this long COVID syndrome. Recent research suggests that 1 in 10 patients with COVID-19 will report symptoms that last for more than 3 weeks and 1 in 20 will report symptoms lasting for more than 8 weeks.<sup>7</sup> In another study of symptomatic outpatients with COVID-19, 35% had not returned to their normal state of health after 3 weeks; the most common enduring symptoms were fatigue, cough, and shortness of breath.<sup>8</sup>

In early December 2020, the National Institute of Allergy and Infectious Diseases convened a workshop on the postacute sequelae of COVID-19 aimed at summarizing existing knowledge and identifying key knowledge gaps on the postacute manifestations of COVID-19. During this workshop, we heard from patients who spoke of their symptoms and of the challenges they encountered in getting adequate care. These patients described how they felt excluded from the epidemiologic language of “mild” and “severe” infection, which often presumes that those patients who were never hospitalized for their acute infection should be able to return to normal function after several days or weeks. For many of these patients,

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doi:<https://doi.org/10.4037/ajcc2021989>

## “ For many [COVID-19] survivors, symptoms can linger for weeks to months after their acute infection. ”

the lingering effects from COVID-19 may feel worse than the acute infection.

Miranda Fricker defined *testimonial injustice* as a kind of injustice that occurs when a speaker is not given the credibility that they deserve because of their membership in a particular social group.<sup>9</sup> Typically, such injustice occurs because of negative stereotypes about particular social groups, such that members of that group are treated as if their information or ideas should not be trusted or are not worth taking seriously. We think there is testimonial injustice when clinicians systematically discount the subjective complaints of COVID-19 survivors with protracted symptoms. We think there is testimonial injustice when clinicians too quickly diagnose these protracted symptoms as functional or psychosomatic only because the physical or laboratory examination does not reveal abnormalities. We would argue that the harm inflicted to our survivors is akin to a stifled scream, a harm that was termed *diminished subjectivity* by philosopher Gail Pohlhaus.<sup>10</sup>

Fricker defined *hermeneutic injustice* as a kind of injustice that occurs because of a gap in communal knowledge that makes it difficult for someone or a group of people to make sense of their experiences.<sup>9</sup> The fact that COVID-19 survivors with lingering symptoms are presenting to the medical community just as the medical community is struggling to understand the nature of their illness puts them at a disadvantage in trying to make their symptoms understood to clinicians. The fact that clinicians have no diagnosis code with which to get reimbursed for treating these patients means that clinicians may struggle with how to label these patients in the medical records, and this may make it harder for administrators and researchers to fully grasp the burden of these long-term effects on the health system. Here, the harm that results extends beyond the diminished subjectivity of the individual patient to the larger health care and scientific community that loses the capacity to learn from these patients' testimonies.

The Critical and Acute Illness Recovery Organization (CAIRO), by providing an infrastructure

for innovators in after-care treatments to share their ideas and identify best practices, are poised to help COVID-19 survivors and the health care community resist these testimonial and hermeneutic injustices.<sup>11</sup> Complex interventions such as peer support can be helpful in bridging the gap between the medical and the existential dimension of surviving COVID-19.<sup>11-13</sup> The biomedical view that is prone to equate illness with physiological dysfunction will not know what to do with a breathless COVID-19 survivor whose lung examination, chest radiographs, and pulmonary function tests all show normal results. In the intersubjective domain of peer support, such a problem of attribution is not a problem at all.

In peer support groups, COVID-19 survivors can come together to give and listen to each other's testimonies. Such communal testimonies offered in peer support groups to COVID-19 survivors may provide several mechanisms for survivors to forge justice from their illness stories.<sup>13</sup> First, peer support groups for COVID-19 survivors invite these survivors to shift their focus away from the objective world of disease and diagnosis toward the subjective lived experience of their unique illness story. Second, the peer support infrastructure may allow survivors to attend closely to the cognitive, emotional, and moral aspects of their illness.<sup>13</sup> Such a posture of attention welcomes the multiple perspectives on the patient's illness that can come from clinicians, caregivers, and other survivors. Third, peer-support challenges allow COVID-19 survivors to leverage their understanding of the illness to change how they present themselves to the world.

How would our health system be transformed if all of us (clinicians, educators, and researchers) were to engage in a similar kind of rigorous reflexivity, attention, and meaning making that COVID-19 survivors are afforded in peer support groups? From the fluidity and instability of such a vantage point, the pandemic crisis will not be simply viewed as an interruption of the status quo but as a form of existence worthy of attention. With such attention, we might then be able to acknowledge the importance of rigorous scientific investigations, including large collaborative clinical trials, for getting us through health care disasters. We might then find the emotional vulnerability to mourn the many thousands of lives that have been lost or irrevocably broken by the effects or aftereffects of COVID-19. We might then be able to acknowledge the structural aspects of our health system that all but ensured that COVID-19

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# “ No consensus has been reached on the medical definition for what constitutes this long-COVID syndrome. ”

was to be felt more disproportionately by the socially vulnerable in our midst. Perhaps with this kind of attention, we might be able to transform ourselves and our health systems to be more resilient and more just.

The statements and opinions contained in this editorial are solely those of the coeditors in chief.

## FINANCIAL DISCLOSURES

None reported.

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