The Long Haul: Forging a Path through the Lingering Effects of COVID-19
Committee on Energy and Commerce, Subcommittee on Health
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Chairwoman Eshoo, Chairman Pallone, Ranking Member McMorris Rodgers, Ranking Member Guthrie, and the members of the committee, thank you for the opportunity to participate in discussion of this critical issue.

I am an Associate Professor in the Section of Pulmonary, Critical Care and Sleep Medicine at the Yale School of Medicine and the Medical Director of the Winchester Center for Lung Disease. As a group, Pulmonary and Critical Care physicians care for critically ill patients in the intensive care unit, hospitalized patients with acute respiratory issues, and outpatients with a variety of chronic lung diseases. As a result, the acute and chronic care of patients with COVID-19 has been our central focus for the last year. I have focused on the care of patients with complicated pulmonary conditions and unexplained respiratory symptoms for over a decade and would like to share my experience in caring for individuals with persistent symptoms following COVID-19.

In Connecticut, the initial surge began in March 2020. To date, our state has had over 334,000 documented cases of COVID-19 and over 8000 deaths (1). Though the spring was mostly marked by the response to the inpatient crisis, particularly for the critically ill, in the outpatient realm a second storm was brewing. Clinicians in our community reached out for assistance with patients who had passed the acute phase of COVID-19 illness but remained profoundly short of breath and generally debilitated. This was perhaps not unexpected in the wake of viral pneumonia and convalescent quarantine but was worrisome nonetheless.

My colleagues and I began to see these patients in telehealth visits in April 2020. The majority were young. Many were frontline or essential workers who had been leading active lives with minimal health issues before COVID-19 (2). With time, we did see patients with severe disease who had gone through harrowing hospitalizations with prolonged respiratory failure and classic post-intensive care physical, cognitive, and psychological sequelae (3). But patients with milder disease were struggling with identical
issues (4). In some cases, they had not been hospitalized at all. They were all extremely short of breath, but also reported a host of other symptoms (4, 5):

- A teacher experienced recurrent bouts of crushing chest pain mimicking a heart attack.
- A young mother described palpitations and dizziness while playing with her toddler.
- A local business owner could no longer remember the names of long-term customers and was unable to balance his books.
- A home health aide no longer had the stamina or strength to assist her home-bound clients.

These people were desperate to return to their everyday lives and were devastated that they could not physically or mentally resume their work. Moreover, they were young people who now had difficulty taking care of their families, shopping for groceries, or walking to the mailbox. Parallel to this early experience, data about post-COVID-19 disease emerged from across the globe that echoed these stories (6-9).

In response, we assembled a multidisciplinary team of pulmonologists, respiratory therapists, physical therapists and a social worker that could provide a comprehensive patient evaluation in a single clinical visit. We formed a broader coalition with physicians in cardiology, neurology, occupational medicine, and psychiatry with post-COVID-19 expertise and coordinated their care across disciplines. As we reopened face-to-face outpatient services and adjusted existing clinical space to meet new infection control standards, we were able to officially launch our Post-COVID-19 Recovery Program in July 2020 (10).

Our patient group is heterogeneous, but there are recurring themes. About half were never hospitalized, but their symptoms and functional limitations are like those who were. They are primarily young to middle-aged, previously healthy, and high functioning. Shortness of breath, fatigue, palpitations, mood changes, and cognitive impairments are the most common symptoms reported at initial visits that occur weeks to months after their acute illness. All dimensions of quality of life are impaired, sometimes severely. They have used up their paid sick leave, cut back hours, left or lost jobs. They have had difficulty accessing workman’s compensation and other benefits. In some cases, they have cut back on essentials such as food, rent, utilities, and medication to pay mounting medical expenses (11). As with serious coronavirus infections prior to the current pandemic (e.g., SARS and MERS) (12), we have seen patients with persistent inflammation or scarring of the lungs, persistent oxygen requirements, and abnormal pulmonary function testing, but this is not the majority of our current patients. Routine testing is frequently unrevealing, requiring more comprehensive evaluation to fully investigate their symptoms.

We have followed our earliest patients for a year now. Some have completely recovered. Others have made progress but have not yet returned to their baseline. Still others continue to have debilitating symptoms. Pulmonary rehabilitation is well known to help patients with lung disease (13). In post-COVID-19 patients, consensus practice supports rehabilitation (14), but insurance approval and coverage of these services have been challenging, and demand has outpaced availability. Some patients who do require oxygen cannot get access to portable oxygen necessary to effectively participate in rehabilitation. Many patients require evaluation and care from multiple health care professionals, which is difficult for patients suffering from fatigue or cognitive changes to navigate or tolerate.

We are a well-resourced program at an academic medical center, but we are swamped by the need in our community and have only seen the tip of the iceberg. In ten months, we have seen more referrals for post-COVID disease than for asthma and COPD combined. Looking ahead, the magnitude of the challenge is daunting. There are over 31 million survivors of COVID-19 in the United States, and, though we have
learned much in the past year, much remains incompletely understood. We do not yet know how many people will be affected by post-COVID disease, how long they will need care, and what that will entail. My colleagues and I strive to see these patients as quickly as possible, but we are the same physicians providing care for hospitalized COVID-19 patients on wards that are stretched beyond capacity.

You have provided $1.15 billion in funding for the NIH to support new and ongoing research into the long-term health consequences of COVID-19. This vital work will help us understand the origin of these symptoms, identify potential treatments, and promote the recovery of our patients. But in the meantime, care can’t wait. Therefore, we must do more:

- **We must increase public awareness about post-COVID-19 disease**, highlighting that it may occur after mild acute illness and in young individuals, and we must have a platform to rapidly share state-of-the-art information as knowledge evolves. While individual professional organizations provide one forum for this, COVID-19 conditions cross multiple specialties and disciplines. Information should be centralized and accessible to primary care providers in any community.

- **We must ensure early and equitable access to care for individuals with post-COVID-19 disease**, including not only initial evaluation and treatment, but also therapeutic services such as rehabilitation and behavioral health support. Coverage of rehabilitation services for the entire duration of need is essential, including specialty services such as pulmonary rehabilitation, cardiac rehabilitation, and cognitive rehabilitation.

- **We must appropriately resource healthcare institutions** to meet the needs of this emerging patient population. Telehealth, which has proven to be a valuable modality of care, should be supported and enhanced for evaluation and treatment of COVID-19 disease. For patients with barriers to technology access or limited digital health literacy, telephone consultation should be supported and reimbursed at equitable rates. Furthermore, clinicians must be liberated from prior authorizations and insurance coverage appeals for necessary services so that we may carry on caring for our patients.

- **We must address the socioeconomic consequences of post-COVID-19 on working-age people** including impacts on their livelihood and health insurance access. We must recognize that post-COVID-19 disease, including occupationally acquired infection, has prevented many from returning to work.

We have made great strides and accomplished a great deal in this unprecedented year. But as we move into the next phase of COVID-19 response and care, we must acknowledge that we are pacing for a marathon rather than a sprint.

Thank you again for the opportunity to take part in this important discussion.

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