Why Are So Many Of Our Long Covid Patients White Women?

Follow-up care has become a luxury of the well resourced.
Two years ago, during the worst of the Covid-19 pandemic, my colleagues and I told ourselves what now seems like a naive story.

In the wake of this virus, we would develop a robust system of follow-up care for the patients who had been sickest in our hospital, many of whom were from medically underserved communities. We knew that survivors of severe illness and lengthy hospitalization were likely to be affected by the unintended legacy of critical care, termed post-intensive care syndrome — anxiety, depression, post-traumatic stress and cognitive dysfunction. To say nothing of the scarred lungs and profound weakness that could come from weeks on a ventilator.

With this in mind, we developed the Covid Recovery Center, a clinic like many others throughout the country dedicated to serving patients who had been stricken with Covid-19 and its aftereffects. Surely those who bore the brunt of this illness would benefit from dedicated screening and follow-up that might not otherwise be accessible to them.

And yet, when it opened, the clinic was deluged with self-referrals from patients who had not been hospitalized. Instead, they were experiencing what we now know as “long Covid” — a constellation of debilitating fatigue, shortness of breath, neurologic symptoms and more that can occur even after mild infection.

Many came to the clinic desperate. Their symptoms — racing hearts and brain fog so devastating that they were unable to work — needed to be addressed. But we were left wondering about everyone we weren’t seeing in that group: all the people we treated in the I.C.U., the non-English-speaking patients who had been transferred to us from hospitals in outlying communities.

“You need to be very intentional about making efforts to reach certain patient populations, addressing barriers like language and transportation,” said Elizabeth Gay, who directs the center. To that end, she and her team have built up partnerships with community-based organizations to get the word out.

Still, of the more than 1,200 patients seen at our clinic between April 2021 and April 2022, nearly 80 percent were white and just over 70 percent were female. In contrast, it seemed those that we cared for in the hospital, particularly in the first pandemic wave, were disproportionately Black and Hispanic men.

“Looking at the data, we know we’re not see-

ing the patients who bore the brunt of Covid hospitalizations,” Dr. Gay told me.

The experience at my hospital is far from unique. I heard similar stories from doctors caring for post-Covid patients throughout the country, from New York to California. Those who were most severely affected by this virus in the acute setting are largely underrepresented in specialized Covid follow-up care.

There are two issues here, distinct but intertwined. One is how to best serve those who were sick enough to experience lengthy hospitalizations but, for unclear reasons, appear less likely to experience long Covid (or at least are not among the long Covid patients securing appointments). The other question is whether the burden of long Covid is being felt, but not addressed, in minority populations. How do we ensure that those who bore the brunt of this disease have the best chance to thrive afterward?

At the University of California, Los Angeles, Nisha Viswanathan finds that she disproportionately sees long Covid patients in her post-Covid clinic, who are well off and adept at navigating the health care system and — in a few cases — can even arrange a private jet to fly from their homes to Los Angeles. If Covid-19 was a disease of the vulnerable, Covid follow-up has become a luxury of the well resourced. These are patients who can call the clinic repeatedly, waiting for a spot to open, who can afford to take days off work for pulmonary rehab and other appointments.

“How do you provide care to the neediest individuals when you have this competing crowd?” Dr. Viswanathan asked.

This is particularly troubling given the data from her own institution, surveying Covid patients after their hospital discharge, which found that Black and Hispanic patients had lingering symptoms such as fatigue and shortness of breath at similar rates as their white peers. While expectations of the health care system and the experience of illness are different across cultures, inequities in health care access could have an effect on whether patients seek care. The suffering is out there.

Indeed, at the Covid-19 Recovery Clinic at Montefiore Medical Center in New York City, long Covid is not a disease of the privileged. At the clinic, in the Bronx, the population reflects the diversity of their surrounding community: About half of the patients are Hispanic, a quarter Black and about 15 percent Caucasian. Thanks to doctors who are familiar with the challenges of navigating Medicaid, these patients receive referrals to physical therapy and sub-specialists that they’re able to access.

But even then, it remains a challenge to bring those at risk for post-intensive care
syndrome back for a clinic visit. “What happened to all the critically ill patients who were supposed to make it to our clinic?” asked Marjan Islam, a critical care doctor who co-directs the Covid-19 Recovery Clinic. “They must have providers somewhere. But where are they now?”

Though National Institutes of Health research funding has in part resulted in hospitals building clinics for those with long Covid, there haven’t been the same incentives to care for patients with post-intensive care syndrome. As a result, even established post-intensive care clinics — like the one that Carla Sevin runs at Vanderbilt in Nashville — continue to struggle for patients to be seen in a timely fashion.

“These patients are young and are extremely debilitated, and they are coming to me six months too late — because we don’t have the resources to follow them and schedule them, so they fall through the cracks,” said Dr. Sevin. “Yes, we have a new problem, long Covid, but we also have an old problem, post-intensive care syndrome, that is still not getting attention, even though many more people are now suffering. And it’s a travesty.”

In a way, none of this is specific to Covid-19. Access to care for chronic conditions has, sadly, long been the purview of the well resourced. So too has access to physical therapy, to psychiatry, to the sub-specialists who might make the difference between surviving catastrophic illness and thriving.

But there is another layer of complexity that is unique to the aftereffects of this virus, which is that, for both post-intensive care syndrome and long Covid, more research on treatments is needed. Much of what we offer now is education and reassurance. Determining if we can help, and how, can happen only through thoughtful research endeavors with a range of participants whose demographics truly reflect the burden of this disease.

At every turn, Covid-19 has revealed the fault lines in our health care system and society. It should come as little surprise that the care delivered in the wake of this virus threatens to further entrench pre-existing disparities.

But this is not the way it has to be. The story of this pandemic and what happens after is still unfolding. And while recognizing and acknowledging these inequities is not enough, it is a necessary start.