

Medical News & Perspectives

An Inside Look at a Post-COVID-19 Clinic

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For some patients, COVID-19 is the uninvited visitor who won't leave. These survivors have described a troubling array of persistent symptoms, including fatigue, insomnia, changes in smell and taste, shortness of breath, chest pain, palpitations, dizziness, depression, and anxiety.

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In some cases, the symptoms are disabling, preventing them from working or even going about their normal daily activities. In late February, the National Institutes of Health (NIH) gave this novel constellation of symptoms a formal name: postacute sequelae of SARS-CoV-2 infection (PASC).

To help guide and coordinate care for the large number of people with these COVID-19 aftereffects, outpatient clinics dedicated to PASC have sprung up around the country. As of April, 33 states in the US had at least 1 such clinic. In New York City, pulmonary and critical care specialist Aluko Hope, MD, helped launch the Montefiore-Einstein Department of Medicine's COVID-19 Recovery Clinic. Now at the Oregon Health & Science University, he spoke recently with JAMA about how the Montefiore-Einstein clinic helps people whose COVID-19 symptoms persist, sometimes for months. The following is an edited version of that conversation.

JAMA: Can you tell us about the history of your PASC recovery clinic?

DR HOPE: We started in late June 2020. The idea filtered down from the leaders at Montefiore very early on in the pandemic, recognizing that we were so hard hit in the Bronx with patients coming into the hospital with acute COVID that we wanted to be prepared to engage COVID-19 survivors back into clinical care. A second component was the recognition that, at least at the height of the pandemic, a lot of patients were choosing to leave the hospital maybe earlier than would have typically been recommended. We also knew that there were patients at home during the peak of the pandemic who were actually quite sick and may have been

worthy of being in a hospital and yet were never treated in the hospital setting. So I think those were some of the motivating factors that made the leaders of Montefiore very interested in starting the COVID Recovery Clinic quite early. What was interesting is that once we started it, about 3 or 4 months after the beginning of the pandemic, a lot of the patients who were self-referring were treated for relatively mild COVID infections at home but were really troubled by their persistent symptoms.



JAMA: Can you discuss the types of clinicians involved in caring for patients at the clinic?

DR HOPE: We designed a structured approach to assess patients who came to the clinic around the domains of health that we thought could be relevant for the post-acute sequelae of COVID-19. In development of the clinic, we collaborated very closely with psychiatry, neuropsychology, geriatricians, and rehabilitation and occupational therapists so that we could have facilitated referrals for patients.

JAMA: What are your thoughts about the estimate that between 10% and 30% of people who survive COVID-19 develop PASC and how many of these people will need to be seen in a post-COVID clinic?

DR HOPE: It seems believable to me that about 10% would have symptoms 8 weeks out. If you have some appropriate shortness of breath or fatigue but you're able to get back to work, you may be concerned by it and yet not need medical attention. But if you were a physically fit athlete and now you can barely walk a block, that's going to be very debilitating, both from the physical and existential standpoint. I think those people will come to treatment settings.

JAMA: What can you tell us about the demographics of the patients being seen in the COVID-19 recovery clinic?

DR HOPE: It's very interesting because the inpatient demographics for COVID-19 seem to skew toward men. And yet, in the clinic, it's about 70% women. Women may be more burdened by postacute sequelae of COVID-19 and it may be that women are more willing to engage in care around their symptoms. So that's an area that's worth looking into carefully to understand why that disparity exists.

JAMA: Are you finding that many of these patients with PASC didn't have severe COVID-19 symptoms?

DR HOPE: A lot of the patients with the most troublesome symptoms may not have been hospitalized for severe infection. Particularly in the beginning, we told people, "Stay home. There's nothing to do, and you'll get better in a few days or a few weeks." The challenge is often these people might not have even been tested for [SARS-CoV-2] because, in the beginning, we were not encouraging people to come out and get tested if the symptoms were relatively mild. So I think that does present some challenges in terms of how you ascertain that they had COVID-19 as the cause for their symptoms now.

JAMA: Do they get antibody tested in your clinic if they haven't had a polymerase chain reaction or rapid test for COVID-19?

DR HOPE: Yes. We use the timing from their memory of their symptom onset and order antibody testing to confirm that they were exposed. So I think 95% of the time, in our

patient population, we can confirm that they were previously infected with [SARS-CoV-2] because that's helpful. People may become infected who have chronic illnesses and you don't want to necessarily be attributing every symptom to their infection if it could have been from something else.

JAMA: Can you describe a typical evaluation for patients coming to your COVID-19 recovery clinic for the first time?

DR HOPE: We do a detailed assessment of symptoms in the days or weeks before coming into clinic. We do structured assessments around their ability to do their usual activities of life, shopping or preparing food, which can help us understand whether they need physical therapy or occupational therapy. We do some screening of their cognitive function with a structured assessment that takes about 5 to 7 minutes to see whether there's any hint of new cognitive impairment. With a combination of both the screening test and the subjective concerns, we make decisions about who warrants more detailed evaluations around neuropsychology, for example. And we're using some validated screening tools for depression and anxiety and posttraumatic stress. You'd be surprised to see how prevalent posttraumatic stress might be in a person who had very mild infection but for whom there were loved ones in the hospital dying. We ally with our psychiatry colleagues to make sure that they have referrals for treatment, if needed.

And as a result of some of those screening tools, we started a peer support program primarily for women at this point because the preponderance of our patients are women. That's been a very active way to help patients who are not necessarily severely psychiatrically impaired but who want to connect with others who are struggling with symptoms, and that happens every week.

And then we do structured screening around the social determinants of health. A lot of patients after COVID might suffer from financial toxicity. For example, they might struggle with paying for their medications, or some may have immigration or housing issues as a result of COVID or completely independent of COVID. So referring them to community health workers or social workers to address some of those needs is part of what we try to do as well.

JAMA: Can you discuss how some common symptoms of PASC are being treated?

DR HOPE: A good 70% of our patients are experiencing fatigue. We look at their sleep hygiene and try the usual pharmacologic or nonpharmacologic approaches to make sure that people are sleeping well. If there's depression, anxiety, there are well-validated approaches to treating those symptoms, whether it be pharmacologic or nonpharmacologic. Our approach has been to use the symptom survey as a way to understand what's going on, and then focus on the diagnostic assessment to understand what's contributing to that symptom and then making some complex decisions with the patients about what's potentially available to treat the symptom. And as you're doing that, the reality is, some people are getting better just because of time.

JAMA: In your experience, how are these patients recovering?

DR HOPE: I would say the overwhelming majority are improving, and there's probably a troubling small minority of patients for whom the symptoms are going to remain or are going to be up and down over many, many months. That's something the system will have to plan for.

JAMA: Do these patients come to your clinic just once, is there routine follow-up, or does it depend on the individual patient?

DR HOPE: I think about 40% of the time, we're seeing patients more than once. A good chunk of people are seeing us for just 1 visit, for 1 set of evaluations, and then they can reengage with their primary care team. And then for some people, we're ideally suited to follow them because the symptoms are not something that a subspecialist is well-equipped to understand better than we are. Also, we wanted to make sure that we understood how things were evolving with our patients. I think for both those reasons, we ended up following a lot more people than maybe, in the initial vision of the clinic, we had intended. But the spirit of it was never to take over the role of the primary care doctor or the subspecialist.

JAMA: Any thoughts on how long these COVID-19 recovery clinics might be needed?

DR HOPE: My sense is that it will probably be for a while. The NIH recently launched a research initiative to study PASC. So, many of these clinics may become part of this multicenter initiative. Beyond the research

needs, however, even beyond the pandemic, these clinics may become a great infrastructure for treating survivors of acute or critical illness. And to the extent that we want to be able to understand and follow the different symptoms over time, maybe over many, many years, I think the clinics will become very useful to us. I suspect that the research part will become more important as time evolves. In urban settings where there are a lot of patients in very dense areas, I think it's easy to justify starting a clinic and sustaining it for many years.

JAMA: Are you keeping a registry and is any research going on with these patients?

DR HOPE: Yes, we are keeping a registry of the patients, and we have IRB [institutional review board] approval to be able to disseminate the results of the clinical assessments that we're doing in the COVID recovery clinic. We're hopeful that, with the infrastructure coming from the NIH, we will be well-poised to use the registry as a base to be able to add on more formal research studies within the framework of the COVID recovery clinic.

JAMA: Do you think that the NIH's official designation of PASC will help physicians and the general public to become more aware of this constellation of symptoms?

DR HOPE: Yes. I think that will go a long way. Also, for health systems, even if it's just an electronic way to capture that this person had COVID, I think that might be helpful so we can better understand if they're using the health system in different ways.

JAMA: Is there anything else to mention about COVID-19 recovery clinics?

DR HOPE: I think it will behoove all of us, whether you're a gastroenterologist or a psychiatrist, to think carefully about the impact of PASC on your expertise and not miss the opportunity to really listen and be a good witness to these patients when they present to you. Because often, we're seeing them months out, and their reflection is that providers they saw before us were easily willing to misattribute the symptoms to something else. That's a failing of the health system that I think we need to quickly stop because that's making the patients feel more marginalized. ■

Note: Source references are available through embedded hyperlinks in the article text online.