Q&A: Treating long COVID requires a patient-centered approach

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Many people infected with SARS-CoV-2 have experienced lingering symptoms such as brain fog, loss of taste and smell, and shortness of breath. Even mild cases have led to long COVID, leaving many feeling the effects of this ongoing condition.

While many patients with long COVID—also referred to as COVID long-haulers—feel as though they have to suffer alone, the Atlantic COVID Recovery Center offers a way for patients to easily get help and find relief from their ongoing symptoms.

Since opening in October 2020, the physicians and other health professionals at the Atlantic COVID Recovery Center have treated over 900 COVID long-haulers. While physicians can refer patients with COVID-19 long-haul symptoms to the center, many patients often reach out on their own. This is because the center ensures there are few barriers to patients being seen.

Three physicians from the Atlantic Health System in New Jersey—a member of the AMA Health System Program—took time to discuss the Atlantic COVID Recovery Center, their goals for the year, what they are seeing and the impact of the COVID-19 Omicron variant. They are:

- Federico Cerrone, MD, a pulmonary critical care and sleep medicine specialist with Atlantic Medical Group and center co-director.
- Scott Lauter, MD, an internist and chief medical officer of the Atlantic Medical Group.
- David Sousa, MD, a pulmonologist and critical care physician at Atlantic Medical Group as well as center co-director.

AMA: Last year, we spoke about why a holistic view is needed to treat COVID-19 long-haul symptoms. What have you seen in the year since then?

Dr. Cerrone: Taking that holistic approach—breaking it down, just kind of looking at everything—is really beneficial because they usually come in with more than one symptom. Even though the
prevailing ones are still the fatigue, maybe the brain fog, maybe the breathing issues, they still tend to have multiple. So that approach has worked well, and the patients are very appreciative of that approach as well. And that's the feedback we get—that they've been really happy with coming through and getting the attention that they have gotten with that approach.

Dr. Sousa: From our end on the intake side and the initial evaluation, it's actually caused us to be even more broad in our screening because we've seen how many systems are affected, how many different symptoms people can have, and just making sure that we're really broad in our evaluation. And then as Dr. Cerrone said, tailoring the approach of that individual.

Dr. Lauter: This program is really focused on the patient, assessing their needs, meeting those needs and trying to ensure the best possible health outcomes for that patient. And I really give Dr. Cerrone and Dr. Sousa credit for taking that approach to what they're doing.

AMA: What specialties and disciplines are involved in this care process?

Dr. Cerrone: Obviously pulmonary, but neurology as you would expect from the memory, brain fog kind of issues. Behavioral health colleagues are also a huge part of this with their peer-support groups and the individual approaches with the anxiety, depression and, of course, the sleep aspect of things and helping the patients heal through sleeping better. And cardiology too.

Dr. Sousa: What we did is we built this collaborative of doctors who are interested in helping these patients. The initial intake is performed by pulmonologists, but we don't work as pulmonologists when we do that intake. We try to find individual symptoms and make as needed referrals to specialists. Our COVID Recovery Collaborative meets monthly to discuss our approach.

If you look at symptoms, there's two big buckets. There are physical symptoms. The most common physical symptoms are fatigue, shortness of breath, chest pain and cough. And then there are the psychological/neurologic symptoms, which are most commonly post-traumatic stress disorder, concentration, memory, anxiety and depression.

Our biggest needs have been pulmonologists, cardiologists, neurologists and behavioral health. But we do have other specialties involved, and abilities to refer people as needed.

AMA: When starting out, you defined prolonged symptoms as more than 30 days after illness, but some organizations are pushing it to about 60 days. Are you still sticking with 30 days or has that evolved?

Dr. Sousa: We've taken a different approach in the sense that we always said 30 days in the beginning. And if you look at the Centers for Disease Control and Prevention definition now, it's four weeks of acute illness, plus two months of persistent symptoms. So, essentially three months since
you were diagnosed.

The hard thing with I post-COVID conditions is we don't really know if this is similar to recovery from other viral illnesses or if it's its own unique syndrome. These patients don't feel well and they're pretty symptomatic, so from our perspective we just felt having them wait three months before they come in was not the approach we wanted to take. The other part of that is, a lot of times we find things that people didn't know they had that may not be related to post-COVID conditions but are causing symptoms. So as long as we can still help these people, we haven't pushed back our timeline.

**Dr. Lauter:** That reflects our patient-centric approach that it doesn't do anybody good to tell a patient you have to wait three months if they're feeling bad.

**AMA:** Can you share a little bit more about the sleep side of long COVID?

**Dr. Cerrone:** It's a couple different things. One is just ... exacerbations of underlying conditions that the patient had like sleep apnea or insomnia—especially on the sleep apnea side—that all their fatigue may not be from COVID. It may just be poor sleep or insufficient sleep. We've been screening our patients, and a large percentage do have sleep apnea.

Then the insomnia side, obviously, whether it's because of post-traumatic stress, anxiety, depression or they had it before and it became exacerbated, we can help them with that too. And it does help the healing process. We do know you need to sleep to help everything such as with sleep apnea. It's an inflammatory state if you don't treat it, so it just exacerbates everything.

We've had some success with these patients looking at the sleep side of things, treating them and helping them. If nothing else, it helps their fatigue and their tiredness. Sometimes their memory, sometimes other things, but it at least helps their fatigue.

**AMA:** What are you hearing from your patients who are experiencing these symptoms?

**Dr. Sousa:** People just want to be better and they're happy to have the resources like peer support, but they're very motivated to get better. And it's hard because sometimes these symptoms take a while to resolve. That's why working with them, getting the team together, getting them resources they need, is the approach we've always taken and continue to do, but people just want to feel better.

**Dr. Cerrone:** And trying to help them develop some kind of recovery plan. Obviously if they can see some daylight—the old proverbial light at the end of the tunnel—then that also helps with them too. We've seen plenty of people who lost their jobs because of this and other things going on with that part of their life, so it's about helping them with that.

**AMA:** What is the first step in post-COVID-19 recovery?
Dr. Sousa: Recognition that you have symptoms, whatever they are. And then really getting somewhere. We’re very lucky to have this center and to have the support we’ve had from Atlantic to do this. But not everywhere is going to have that. This is something now where we’re beginning to have a lot of data to come in, and more description of what is going on. But it’s about getting someone who’s going to really look at you head to toe, figure out your symptoms and plug you in somewhere where you can get the treatment you need.

Dr. Cerrone: We did a symposium led by Dr. Sousa a couple months ago on COVID and it is amazing because we have many states—even countries—participate since it’s virtual. It’s amazing to me what a scarcity there was for these centers to go to or availability and access to get help in treatment. Thank goodness for telehealth, but there’s still a lot of gaps in care for these patients.

AMA: What are the plans for the Atlantic Health COVID Recovery Center for this year and beyond?

Dr. Sousa: Here’s the thing. We would all love to be put out of a job—COVID goes away, people get better. That would be outstanding. And sometimes when you think about building an infrastructure like this you wonder: If the disease is going to go away—hopefully—why would I build it?

What we did is we have this unique part of our program where we’ve been doing post-ICU syndrome—post-ICU recovery—and this is a model that can sustain for that. Because, if you think about it, before COVID more than 5 million patients are admitted to the ICU every year. And you look at the symptoms that people have post-ICU, it’s pretty significant. It’s this idea of having someone come in after an ICU stay doing a full system screen, screening them for all of those domains—physical, behavioral health, neurocognitive issues—that they have. And having this collaborative to address that is something that is not wasted and something that can be a lasting legacy from a program like this. So, we’ve been doing them in parallel. Hopefully COVID does go away and this isn’t something we do forever, but the post-ICU part of this is something that we will do forever.