Long COVID Wearable Study

TRANSCRIPT FOR ‘RESEARCHER USES EXPERIENCE WITH LONG COVID TO DESIGN STUDY TO HELP OTHERS WITH DISEASE’ VIDEO

Julia Moore Vogel, PhD, speaking:

A lot of people think either you're hospitalized, or you die or you're a 100 percent fine, but there's this really distinct possibility of a lifelong, as far as we know at this point, disability that should really factor into people's risk calculations.

I first got COVID-19 in July of 2020. I was very surprised to have my first symptom be that I could not taste the peppermint tea that I drink every morning. It has a very strong flavor. When I reached out to my healthcare facility to see what I should do, they said, “You're young, you're healthy. You'll probably have this as your only symptom and be fine before you know it.” I progressed in the first week or so to have some pretty severe—in my view, as someone with a past history of asthma—trouble breathing. I was lucky enough to not have to be hospitalized, but it was a very scary experience to the point I was going to bed at night wondering if I was going to be waking up in the morning.

I had very severe shortness of breath in the first week and then that slowly declined over the first six months. I had a really hard time with what a lot of people call brain fog where you have trouble with critical thinking. It really took six months to get to the point where I felt like I had my brain working something close to the way it was before. It's changed and been sort of continuous since then where my main symptoms are intense fatigue, which I had all of the time, but it changed after the first six months to a different level. I have daily headaches and also some chest pain that seems to be inflammation in different chest joints.

Estimates range from 10 to 30 percent of individuals who get COVID-19 that have it, and there are estimated to be 17 million individuals in the US with long COVID and 72 million worldwide. The scale of individual symptoms varies widely. I would say I'm on the minor end. I'm able to keep working only because I can sit at a desk and sit still all day. If I had to be on my feet somewhere, I absolutely would not be able to. Many folks are even bedbound to the point their movement is just so restricted because their symptoms are so severe. There are many neurological symptoms where people just completely can't remember things. There's a lot of different types of chronic pain and inflammation. The scale and the scope of it is quite staggering.

It was really sort of jarring as a patient to be going to physicians and having at least the good ones say, “We really don't know how to treat this. We really don't know anything about it. It's

new.” And so from the very beginning I was wondering how I could contribute to the research space, whether as a participant or eventually leading some research.

What many individuals in the long COVID community have found is the only thing that helps them is something called pacing. The idea is that you are being very careful how much mental, physical and emotional exertion you have on a given day, and that if you can really control that and keep it within your limits, you can avoid making your symptoms worse. Some people get worse right away, but many don't feel the effects until a couple days later. For me, I wasn't realizing that I was overdoing things until two days later when I would have the increase in symptoms.

We're doing a study about figuring out how we can teach people how to pace essentially. We'll be deploying just educational materials about how to pace to some participants and then educational materials and a wearable device and materials about how to use the wearable device to pace to others. The idea is to determine can we help you avoid relapses and potentially even have long-term improvement in symptoms based on being able to action this pacing advice that's surprisingly hard to implement on your own.

My favorite feature for the wearable device that I have, which is a Garmin, is called body battery. What it does is it takes into account your sleep, your stress levels, your activity, and something called heart rate variability all together in one score between zero and a hundred. That tells you how much energy you have left for that day. I often find that I overexert myself. I don't feel the symptoms until two days later, but with the Garmin body battery feature, I'm able to see my body battery's going down and I need to slow down for the day and reduce my exertion. This can help me avoid having those symptoms two days later.

Eric Topol, MD, speaking:

We did the first large scale digital clinical trial in history five years ago. We recruited many thousands of people at high risk for atrial fibrillation, a heart arrhythmia, and this was the first time it was all being done through websites and through a mobile app, getting the consent and then sending them a wearable sensor that these people would have on their chest for 10 days or 12 days. The device recorded every heartbeat, and we were able to diagnose remotely—with the participants, never having to go see a doctor or go to a medical center or clinic remotely—many people who didn't even know they were having atrial fibrillation, which is a risk factor for stroke. So that was the beginning of a whole new era in medical research for us and for others. We've adapted this approach to things like maternal health, sleep disorders, diabetes, personalized nutrition and especially in recent times to COVID.

Julia Moore Vogel, PhD, speaking:

I'm hopeful that this can basically provide scientific evidence behind what we've seen anecdotally in the community of many different people using wearables to help them with their symptom management. I'm hoping this can provide rigorous evidence for that so that it can be more broadly utilized and made aware to the physician community and the patient community so that it can be used more.

Eric Topol, MD, speaking:

This is perhaps the most exciting time in the history of medical research. In many ways, it's a reset. It's a complete rebooting of how we do medical research. The fact that we can tap into sensors that people are already wearing and collect data to determine whether that person has a possible significant infection or at risk for some other sequela is extraordinary. So we hope to continue to lead in this space and inspire others to follow because we think this is such a rich and exciting opportunity of how we can learn about ourselves and keep people healthy.