

Jennifer:

Hello, you are listening to Stanford Medcast, Stanford CME podcast, where we bring you insights from the world's leading physicians and scientists. If you're new here, consider subscribing to listen to more free episodes coming your way. I am Jennifer John, a Stanford undergraduate student in human biology and the guest host for this podcast episode. When a patient makes a doctor's appointment, they usually do so because they expect their physician will be able to provide them with answers. But what happens when the science is unknown, doctors have more questions to offer their patients than answers, and patients might even know more about their own conditions than their doctors. In episode 26 of Stanford Medcast, we spoke with Dr. Linda Geng and Dr. Hector Bonilla the directors of Stanford's Post Acute COVID 19 Syndrome Clinic, which provides medical care to COVID long haulers. They shared with us the complexities of conveying uncertain prognosis within the expectations of the patient physician dynamic. Here's part of what Dr. Gang had to say.

Dr. Geng:

I think it's very important for us as the physicians, to be able to be humble and say, sometimes we reach the limits of our current medical knowledge although it is actively growing on this topic, but then to talk them through what we do know. And even if we don't know all the answers yet, I think imparting what knowledge we do have and helping guide them about how to obtain reliable resources of information and addressing their misconceptions and fears can help mitigate some of that anxiety.

Jennifer:

In this episode, we'll hear from two patients in this clinic about their experiences grappling with the uncertainty of long COVID. Continue listening to hear their stories.

Rosie Flores (guest speaker):

I actually been living in Mountain View for 11 years, the bay area, pretty much my whole life, but born in Southern California. I'm a project coordinator for an academic hospital in the accreditation department and quality patient safety, but mostly accreditation department. In the beginning, I guess I was like everyone else in the world. I was receiving different news from the news outlets about this virus. I didn't know what was happening. One moment we're supposed to wear a mask. We're not supposed to wear a mask. Is it aerosol? Is it a droplet? You try to be patient, right? But you want to get as much information as you can. Just like everybody else, I was just sitting by the TV waiting just for more information. I was very, very careful in the heat of the warnings about not going out, but I did have to go into work one day, and I was masked up, gloved, everything.

Rosie Flores (guest speaker):

But then I came home a few days later, sick. I woke up kind of just feeling a bit blah. And then within two hours, I felt feverish. I had a migraine, sensitivity to light, a little bit of wheezing. And the temperature is really what gave it away. I rarely have a temperature. I was tested that day and received an answer within three days that I was positive. I felt like the symptoms were not as bad as everyone said they could have been for me. I never lost my taste. Never lost my sense of smell. I just felt like I had a bad fever, and I had insomnia. So I felt it was like moderate, but then it changed after that. My fever kept coming back. It just would leave, and then come back four or five days later. I was in isolation for like 46, 47 days in my home by myself.

Rosie Flores (guest speaker):

So you can imagine living by yourself, and there's no one around to help you. By the fourth day, I just took a nose dive, no energy. A year later, I had an MRI because I couldn't walk. They found a blood clot, even though I don't have high blood pressure or history of high cholesterol or diabetes. I don't think the long COVID or long haulers term was even coined yet because I don't think it'd been that long that I recall. I tried to go back to work after the isolation period. It was only for four hours a day. I couldn't make it past the three days that they had me working. I had a call and say, I can't do it. I couldn't look at the screen. My eyes were killing me. I was exhausted just looking at the screen for those four hours. I knew something was wrong.

Rosie Flores (guest speaker):

I was tired. I was wheezing. I had a hard time comprehending instructions. I had loss of hearing. Didn't know that until I actually finally left the house and was able to talk to my family. And they kept saying, why are you yelling? And I'm like, what? What are you talking about? I just thought it was my TV not working well. I finally was able to walk a little bit more. And then I noticed that I had gait issues. I was stumbling over my feet a little bit. I always did word puzzles every day. And I would look at words and say, what? I know this word, but I couldn't recognize it. Or I couldn't pronounce it right. Or I wouldn't remember the definition. And I am someone that reads almost a novel a day. So I should have a huge vocabulary. I cannot remember words. I was pausing a lot.

Rosie Flores (guest speaker):

My friends were really worried because they said they would talk to me, and I wouldn't remember the conversation during that time. And so I knew there was something more because I felt I should have been feeling better, and I was not. In many ways, I felt like I was getting worse. I spoke to one of the doctors at the Chronic Fatigue Clinic, and they put me into a study. And so I was able to get a little bit more answers. They were able to tell me, this is part of post COVID symptoms. It was distressing, especially when new symptoms started popping up as time went by like loss of hair. I lost so much of my hair, I had to go out and buy a wig, ended up having to chop it off. I became weaker and lost my appetite. So it just seemed like one symptom after another kept popping up.

Rosie Flores (guest speaker):

And I didn't know whether it was related to COVID or if it was stress. I always tried to maintain an optimistic attitude, but when all these other symptoms kept coming up, it was hard to maintain an optimistic attitude. My friends, they didn't understand what was going on. They felt like well, you're not sick anymore, what's happening? Why are you still off work? When a tornado comes through a city and damages it and wrecks it, right? It's active. And then when it's gone, it just leaves everything destroyed in its path. That's how I felt with the virus. I don't know what damage it did when it was active, but these symptoms were manifesting. And I just kept thinking, what else is going to pop up? Is it COVID related or not? I had a stroke. Was that COVID related? Recently, that's what I've been asking myself. Will I have another one?

Rosie Flores (guest speaker):

Or if I get COVID again, will I have another blood clot? Even though I try not to be anxious and I try not to think about it, I felt like these questions were always in the back of my mind. You would think it's been over a year that I would have no more symptoms, but in many ways my symptoms are still there, and some of them feel like they're worsening. It almost feels like when will this end? It's unfortunate that my uncertainties have intensified since receiving the diagnosis about the blood clot. It just threw

me for a loop. That was scary. I was alone by myself, and no one had seen me. Right. I didn't see a physical nurse or doctor until three months into the pandemic. It's hard for me to maintain that optimism now that I had earlier, where I felt like I could at least fully recover because now I see that they might find something later on that I don't even know about.

Rosie Flores (guest speaker):

I hated the fact that I couldn't see anybody in the beginning, right. Everything had to be done online. I feel like some things were missed because of that. I never felt like I was that bad to go to the emergency room. I was very fortunate in that I had a primary care physician that admitted, I don't know much, but please email me every day. Let me know how you're feeling. I felt more reassured because I felt like, okay, now we're in the same boat. She can monitor me, and maybe she'll see something that I might not. But knowing that there was someone there to contact who had my back and was supportive, that meant a lot to me. She was almost like a lifeline. Unfortunately, she ended up leaving the country, and then I felt like I kind of felt there was a cracks for a while.

Rosie Flores (guest speaker):

I felt like a little lost in the way, so to speak, right? Like this little bottle just here or there and everywhere. And not all doctors have been supportive. I felt like if I said this might be COVID related with the loss of hearing, some of them didn't even bother looking at my history, like the blood clot. I took all this time to fill out my history. And then when I found out I had a stroke through my health, the app, all it said was, hey, you had a stroke. You can just start monitoring your blood pressure. And I thought, wow, are strokes not serious anymore? That's the one line that I'm going to get. And did you not read my history and see that I have no history of high blood pressure? So didn't that alert you to think that it might be something else?

Rosie Flores (guest speaker):

And it made me feel empathetic to everyone else out there that's dealing with this, that doesn't have this type of care. Doesn't live near a academic hospital. But even then with the top elite doctors, that's the answer that I got. And it was very disappointing. As COVID patients with the chronic fatigue, it takes so much out of us to fill off these forms to go to the doctor. It took me three hours to get ready. I did my job. Can you please do yours? Dig a little deeper. I wanted to advocate for myself, but at the same time, I had to learn how to be patient because these doctors, this was new for them. And they only had so much information at the time to give me. And I think that was one of the things I learned was learning how to be patient and wait to get an answer.

Rosie Flores (guest speaker):

Maybe they'll find out that more people have lost their hearing. Maybe they're not finding it now. Maybe they'll find it out later. I appreciate it when doctors say we don't know that much, but as soon as I find out, I'll share that with you or we're in this together. We should have a partnership. And I think that's what it's all about. Doctors go into medicine to try to make patients better to heal them. It's okay to be humble. It's okay to be modest. It's okay to say you don't have the answer. I prefer that instead of someone disregarding what I have to say, because they don't feel comfortable telling me that they don't know. Patients I feel just want to be heard. I want to be on the same team.

Rosie Flores (guest speaker):

I'm really hoping that I can recover. I know there is some damage that will always be there, but as long haulers, maybe the government or someone will put money towards our long term care if we need it. I want answers. Is this going to be permanent? Will more things pop up later on in life? It's the unknown. I hate that. The unknown what's going to happen that I don't know about. And do I need to prepare myself, right? I don't want to be pessimistic. I'm trying to be a realist, but yet maintain optimism, but it's scary. Right? Because I don't know how this is going to affect me. And I'm just hoping that I improve.

Brandie Parshall (guest speaker):

I'm from the Central Valley. I live in California. I'm 43 years old. I have four boys. Their ages are 13 to 25. I am married. Prior to COVID, I enjoyed vacationing and bootcamp working out and just being outdoors. I did a lot of stuff with my 13 year old. I would go just road trips, and we did a lot of stuff together so that's been really hard. In the beginning, I thought it was obviously serious because things were shutting down. But I didn't think that it would affect me the way it did. I thought with being healthy and on the younger side, I didn't think that I was at risk for getting long haul COVID. In the beginning, the only impact really for me and my son started, I started working remote off and on, and then he was doing school from home. It wasn't a huge impact.

Brandie Parshall (guest speaker):

I had COVID in December of 2020. At that time I heard people were passing away from it and stuff like that, but I didn't realize how severe it was. It was pretty mild. I had high heart rate, but I just thought it was from being weak. So I was extremely weak, just a severe weakness. A postnasal drip, no appetite. I had lost a significant amount of weight, just a lot of fatigue. It was probably two or three weeks after I had tested positive, it was plateauing. Like it wasn't getting better. I was working remote at the time, even during infection because I worked in accounting. It was year end. So I worked like 12 hour days, but I talked with them that maybe I needed to rest more. I took a leave on January 6th from work. I was just not feeling well, just going and laying down a lot.

Brandie Parshall (guest speaker):

I just thought, oh, I just need to take some downtime because my body's not feeling like it should. The high heart rate continued. I ended up in the ER a few times with that. It was probably February I started seeing a cardiologist. At that point, they had done the heart monitor, and they'd done the stress test. I started getting worse. I started getting worse, like more debilitating. The severe weakness, no energy. Walking up the stairs, my heart rate would go to 160. I had 180 heart rate when I was doing dishes. Some people had said, oh, it might take four to six weeks to get better. And then that's when I was like, there's something wrong. So I started researching and realizing that this wasn't the typical case of COVID. It was hard. I just kept thinking about my kids and not being the mom that they need or being a good wife.

Brandie Parshall (guest speaker):

I don't know if I'm going to get better. I don't know if I'm going to have a normal life again. And I mourn the life that I had so much. I don't know if I have to live with this for the rest of my life or this is the new normal. It's definitely something that I can't think about too much because if I do it's hard. And I end up in a deep depression over it. I just hope and pray that in time these doctors figure it out and can help. I've been very thankful for my GP. From day one, he believed that there was something wrong, and he didn't dismiss me at all. He gave me his number to text him if I had anything. So that was kind of

reassuring and gave me some peace. But I definitely have had some issues with doctors not believing me.

Brandie Parshall (guest speaker):

I've had several times where I went to the hospital thinking I had a stroke or just other issues and the high heart rate, they think it's anxiety or that I was having PTSD from COVID. And I tried to explain to them that I felt sick. It's nothing that's in my head. It's just, I feel sick. The doctors in Stanford have been great. All of them have listened and believed me and know what I'm going through is real. The cardiologist in the beginning, I was the first patient she had seen. Within the follow up two months later, she's like, you're right. When I first seen the infectious disease doctor at the PAX clinic, she told me that it's going to be about treating the symptoms. I don't know why that helped so much, but it really did. One of the diagnosis I got was pons. So the doctor is treating it with a beta blocker.

Brandie Parshall (guest speaker):

So that helps knowing that they're trying to figure it out and to make things a little bit better for us without having all the answers, it helps when I go to the ER. It has to be really bad for me to go to the ER. Like when I thought I was having a stroke in October, I was taken by ambulance, and that's hopeless that like knowing that there's nothing they can do for me. They've tried to give me fluids and nothing helped. Normally you go to the hospital, they give you antibiotics or they can treat it and move on. It's such a different experience now. It's a horrible situation to be in. It really is, knowing that they don't know what to do to help you. That the ER just says, there's nothing we can do. It's scary, but it's what I'm going through. I have a few groups on Facebook that I follow now. There's three women that I keep in contact with weekly.

Brandie Parshall (guest speaker):

It's nice to have them to lean on for support and them to know what I'm going through and vice versa. We can relate and talk about our issues and oh, this didn't work or whatever. And just be there for one another. That's been honestly, one of the things that's probably kept me going is knowing that I have people that understand what I'm going through. I don't have much of a life right now, honestly. Going to the grocery stores is a job. I probably went a handful of times in the last year. It literally just takes the energy out of me. I walk around there with my heart just pounding. Even going to the pharmacy, I hardly even do that. I have to send somebody because I'm just too weak to drive. Every day's different. Some days I have days where it's moderate symptoms, and then some days it's severe. Every day, I just don't know what I'm going to get.

Brandie Parshall (guest speaker):

So it's hard to plan anything. One of the doctors had said, it kind of got me the other day. If you plan on going on vacation, make sure you da da, da. And I'm thinking I haven't went on vacation in a year, and there's no way I could go on a vacation. I've been in my job for 20 years almost. And I had to resign yesterday. And that was a hard one, a really hard one because I loved working. I loved my job. I enjoyed going to work every day, and I have a 13 year old that plays football. I made it to a few of his games, but I wasn't able to make it all. Like normally I would go to his practices, and I would go to his games. If you do see me out, it's because I'm trying so hard for my son.

Brandie Parshall (guest speaker):

I went to the parade the other day, and it took every bit of energy I had to go just to memories with him, especially my younger one because he's the one that's suffering the most. I drive him to school in the morning and literally it's a three mile drive and a lot of mornings I'm just like, let me get back home. Don't let me collapse in front of my son. I try to do other things like movie night with hot cocoa and little things like that or things that don't take a lot of my energy or playing a board game. I was so dedicated to my job too, dedicated to everything. I just want to be back to the mom and wife and the employee that I was.

Jennifer:

These are stories from just two patients with long COVID out of the potentially millions who are presenting with variations of long COVID symptoms. We hope that sharing these stories can give clinicians a glimpse into the individual experiences of these patients beyond what might be seen in clinic. Thanks for tuning in. This podcast was brought to you by Stanford CME. To claim CME credit for listening to this episode, click on the claim CME button below or visit [medcast.Stanford.EDU](https://medcast.stanford.edu). Check back for new episodes by subscribing to Stanford Medcast wherever you listen to podcasts.