



Original Article

My experience as a long COVID patient: “Long COVID,” a hidden pandemic and the possible solution

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ABSTRACT

Objectives: To create awareness about long COVID through personal experience as it is less understood, given the nature of the disease and to suggest possible solution until the definitive measures.

Materials and Methods: I self-analyzed my symptoms and tried treatment methods over 5 months of long COVID phase which apparently started after COVID vaccination.

Results: I noticed subtle improvement in overall symptoms and significant change in neuropsychiatric symptoms such as anxiety, depression, paresthesia, and headache with antihistamines albeit temporarily.

Conclusion: Antihistamines may give temporary relief from the long COVID symptoms.

Keywords: Long COVID, COVID long haulers, Post-COVID syndrome

INTRODUCTION

Long COVID is a term coined by one of the patients during initial months of the pandemic. Although there is no clear-cut definition, long haulers are those who experience multitude of COVID symptoms beyond 3 months of acute illness.^[1] Symptoms mainly include chest pain, palpitations, breathlessness, extreme fatigue, depression, anxiety, neurological symptoms, hair loss, low-grade fever, loss of appetite, sleep disturbances, and some of them being extremely debilitating.^[2] Multisystem involvement, fluctuating symptoms with varying severity, and new symptoms each day which tend to get better only to return in cycles are the typical observation. It is also most commonly seen in women between 20 and 50 years of age, previously fit and healthy with relatively mild illness in their acute phase.

MATERIALS AND METHODS

I self-analyzed my symptoms over 5 months of long COVID phase. My long COVID journey started with the first dose of Covishield vaccine. Vaccine triggered incidental long COVID or asymptomatic COVID infection could be the most probable explanation.

RESULTS

My initial symptoms were fever and chills which lasted for 2 days to leave me with palpitation, dizziness, breathlessness, and fatigue. Gradually, these symptoms worsened. FBC, TFT, ECG, and

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echocardiogram were normal. I could not understand why there was unusual breathlessness when oxygen saturation was normal. There was no obvious cause found. Fatigue literally crippled me. Third week onwards, I started having new symptoms.

There was left-sided chest pain, sometimes radiating to neck, shoulder, and medial side of arm. It felt like angina. Pain worsened on exertion. I could attribute it to myocarditis and pericarditis but it did not show on tests. There was non-specific pricking chest pain as well. Two months later, I developed intercostal tenderness, pleuritic, and costochondritic pain which lasted for few days again to return.

Symptoms such as lack of concentration, short-term memory loss, and low mood were present since the beginning but were not paid attention to. Loss of taste, on and off low-grade fever, myalgia, insomnia, tinnitus, dysphonia, blurry vision, conjunctivitis, and dry eye were the other symptoms. Migraine such as headaches, pins and needles sensation, numbness, and burning feet and joint pain came much later. By the month end, I realized that these non-specific symptoms could be related to COVID. Chest X-ray and CT scan did not reveal anything. There comes the question, when everything is normal why am I not getting better?

To realize that it is long COVID and it could last for months was heartbreaking. When I read articles, I found that people had experiences similar to mine. I was also surprised to know how their symptoms were brought down to anxiety. It's a painful thing to hear while we suffer through physical pain which is the hardest part of any illness. Long COVID is common in young females which make them harder to make their symptoms to be believed due to misogyny.

DISCUSSION

It's not fully understood why long COVID happens to certain group of people. There is no treatment as such other than supplements and symptomatic approach. However, some of the symptoms are so debilitating that we cannot just wait them to get better. As in my case, I had to take beta-blockers for palpitations and anti-anxiety drugs like benzodiazepines for extreme low mood. I had massive mood fluctuations where nothing seemed to help. It's not just part of the illness but serotonin imbalance caused by the disease itself. Antihistamines were the first drugs I tried during the initial days which helped me with overall reduction in symptoms. Through articles later, I found out that people have already tried them and some of them have felt better. I took antihistamines daily for 2 months which helped me feel better mostly with neuropsychiatric symptoms. Fluoxetine/fluoxamine, antiparasitic drug ivermectin, and low-dose oral steroids have been tried by some patients. These medicines are prescribed by physicians now as they saw improvement

in some patients though patients had varied response to medicines. Through a peer support group page, I learned about patients experiences and analyzed them which gave me comfort as well. For some of them support groups are the only hope, when their invisible illness is not believed by family, friends, and even doctors. Even when it is believed, there is not much support in the long run.

Long COVID can happen in 10–20% of COVID patients irrespective of severity of the initial illness. In most of the cases, there is no positive test. Those who had organ damage also experience long COVID symptoms but in most of the people, there is no organ damage.^[3] It could be due to deregulated immune system or autonomic dysfunction which mostly happens in previously healthy individuals. It is important that patients are listened to and treated with empathy. As a doctor, I realized how important it is. It is extremely hard when symptoms seem to get better and come back in cycles where recovery is so slow that at times feels like no recovery at all.

Long COVID is a serious condition where patients fight with the illness as well as the unsupportive surroundings. Not being heard is the most common complaint among all. Everything that is not understood is not anxiety. It could be frustrating for both the patient and the physician as there are no guidelines for the treatment and each patient symptoms and treatment response could be different. It's crucial to understand that long COVID is a debilitating disease and not just post-viral illness. It can take months to fully recover. It's important that their pain is acknowledged and they get due care and support as there are huge psychological and financial implications as well. More research and awareness are the key.

CONCLUSION

Antihistamines could be one of the treatment options which I found helpful with significant reduction in severity of symptoms. Although it could be a temporary relief, it came as a life saver. Mast cell activation with histamine release could be the possible mechanism why antihistamines give some relief. Mast cell stabilizers along with antihistamines could be beneficial. While definite answers are still awaited, more clinical trials are required to help COVID long haulers as they cry for help.

Declaration of patient consent

Patient's consent not required as there are no patients in this study.

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Conflicts of interest

There are no conflicts of interest.

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