

Long Term COVID Patient Engagement:

Best Practices Informed By Patients' Experiences Seeking Medical Care

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Survivor Corps

Founded by Diana Berrent in March 2020, Survivor Corps is now the largest grassroots movement in America dedicated to actively ending the COVID pandemic. Our mission is to connect, support and educate those affected by COVID-19. We aim to mobilize as many as possible to support all ongoing scientific, medical and academic research.

Our work is influencing the development of new therapeutics for those with COVID and improved care for those suffering from Long Term COVID/PASC. As of July 2021, there are over 170,000 members of Survivor Corps.

Survivor Corps Priorities

1

Refocus on Research Efforts

2

Moving Forward with Treatments

3

Research Funding \$ Need to Be Unleashed

Long Term COVID Patient Engagement: Best Practices Informed By Patients' Experiences Seeking Medical Care

Today's Talk:

- ▶ Background: Long covid symptoms and health impacts reported by long haulers
- ▶ Research of patients' dissatisfaction with medical care for long covid
- ▶ Best practices for engaging with patients with long covid

COVID-19 Symptom Impact Survey Findings

- ▶ 5,163 long haulers reported on average 21.4 symptoms
- ▶ The most common long-term symptoms were: fatigue (79.0%), headache (55.3%), shortness of breath (55.3%), difficulty concentrating (53.6%), cough (49.0%), changed sense of taste (44.9%), diarrhea (43.9%), and muscle or body aches (43.5%).
- ▶ The longest lasting symptoms on average for all participants (in days) were "frequently changing" symptoms (112.0), inability to exercise (106.5), fatigue (101.7), difficulty concentrating (101.1), memory problems (100.8), sadness (99.2), hormone imbalance (99.1), and shortness of breath (96.9).

COVID-19 Symptom Impact Survey Findings

- ▶ The symptoms that affected ability to work included the relapsing/remitting nature of illness (described by survivors as “changing symptoms”), inability to concentrate, fatigue, and memory problems, among others.
- ▶ Symptoms causing the greatest level of distress (on scale of 1 “none” to 5 “a great deal”) were extreme pressure at the base of the head (4.4), syncope (4.3), sharp or sudden chest pain (4.2), brain pressure (4.2), headache (4.2), persistent chest pain or pressure (4.1), and bone pain in extremities (4.1).

Long Covid Patients' Reports of Experiences Seeking Medical Care

- ▶ 80.4%% of long haulers (n = 4,151) reported seeking medical care for their symptoms
- ▶ Of those, 2,016 were referred to a specialist for care

When you sought medical attention for COVID-19, how often did you feel your health problems were taken seriously by medical providers (doctors, nurses, medical staff, etc.)?

How knowledgeable did you find your doctor or specialist to be about COVID-19?

How satisfied are you with how your doctor or specialist treated your symptoms?

Has your ability to get medical care been hindered by insurance issues or lack of health insurance?

If you are unsatisfied with how your doctor or specialist responded to your request for medical care, what was the problem? (Grounded Theory analysis – Dimensionalization)

Context: Long haulers seeking medical care and being dissatisfied with their

Difficulty getting covid tests and doctors' appointments

Being understanding that doctors won't have all the answers about covid

Feeling their concerns are not taken seriously during doctors' visits

Believing they are being misdiagnosed (primarily for anxiety)

Long haulers report being dismissed by the medical system

Feeling alone after doctors' visits

Being dissatisfied with quality of care

Switching providers and self-advocating

Best Practices for Engaging with Long Haulers

- ▶ **Validate long haulers' experiences by telling them you believe them and that you can tell they have been through a lot.** Long haulers want their symptoms to be taken seriously, even if there are few treatments. Trust between long haulers and medical providers is very low and needs to be rebuilt.
- ▶ **Long haulers want providers to run tests to rule out medical problems.** Long haulers do not trust diagnoses that are given without running tests related to the symptoms they report.
- ▶ **Schedule in-person visits for long haulers.** Many long haulers felt that telehealth visits made it difficult for providers to observe their symptoms.
- ▶ **Biological impacts of long covid are underdiagnosed compared to anxiety.** When anxiety is the sole diagnosis for a long covid patient, long haulers believe they have been misdiagnosed and many change providers. While many long haulers report anxiety, long covid science has found evidence of many serious biological health impacts of long covid. Providers should not assume these symptoms are caused by anxiety.

Heidi Ferrer:

Mother, Wife, Screenwriter, Blogger, COVID Long Hauler



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Brain tires trying to process anything, at times, this is hard to type, hands feel very weak

Can't enjoy anything or feel happy. Only rarely lifts. This may be the worst symptom. A cloud over my brain. I'm not myself.

Ovary pain deep ache or cramping, inflammation in vagina feels like referral nerve pain coming down from left ovary. This comes and goes, sometimes feels sharp nerve pain like cystitis uti. Like urination triggers it, inflamed nerves in skin.

Polynuropathy sharp nerves pains in body not just feet, abdomen, connected to pulse in my head, worse later at night

Inflammation in body overall, skin hurts. Endothelial lining inflamed? Feels vascular. Even in eyes.

Feel hot sometimes chills very temperature sensitive but it happens out of nowhere, often within a few hours

Numbness and tingling neuropathy in hands

More sensitive to loud noises, bright lights

Ear fullness, clicking

Enlarged veins (see on hands) vein inflammation

Feeling of inflammation in lungs on back.

Rapid heartbeat trying to go to bed with inner vibrations, body pain

Waking up every 2-3 hours, new insomnia since the vaccine

Sometimes increased urination and sometimes decreased urination. When inflammation in evenings can't feel when I have to pee.

Underarms (lymph nodes?) get sore/inflammation since vaccine

Vision off, sort of mild flashes, hard to describe. Blinks in brain.

These symptoms all come and go, I'm much much worse since the vaccine. Every day now. Much worse since beginning of March but my health has rapidly declined in the last three weeks, especially in the last two weeks.

I am very very scared for my health and family. I feel like I'm declining rapidly and can't function normally at all. Even small tasks like teeth brushing or washing my face are very hard to do.

My current symptoms: Severe Neurological PASC or long haul Covid. CNS damage? Post vaccine neurological disorder?

Increasing nerve pain and weakness moving up from my feet and ankles to lower legs, walking and standing is painful and balance is difficult. Gullaine Barre? Or CIDP? Developed 6 weeks after the vaccine.

Electrical storm vibrations in arms and legs.

I'm in pain every day and not sleeping. My brain is not right. Sometimes feels like it's swelling. Brain fog.

Had seizure like episode of uncontrollable upper body muscle twitching

Debilitating fatigue, eyes closing involuntary or feel the need to close my eyes almost all day

Tremors in hands, especially right.

Strong metallic taste inside teeth, every day, nerve pain in gums

Inner vibrations or inner tremors in arms/legs/torso, can get overwhelming like fizzing bubbles in veins overwhelming my body and brain. This comes on worst in the evenings, especially after 10pm and when eating solid food at dinner. I have to force myself to eat. Autonomic Dysautonomia?

A sick sad feeling in my arms

A strange invisible feeling of being squeezed in my arms shoulders and torso, brain

Foot pain, small nerve fiber neuropathy, like bees are stinging me in my feet and ankles when I walk and sit

Ankle pain and weakness, can stand but hurts after 3 minutes. Can only stand about 5-10 minutes then must lie down

Histamine feeling mostly in left nasal passage, it has sometimes scabbed and bled. Burning feeling in mucus membranes

Weakness overall body

Loss of appetite/food aversion, have to force myself to eat and only liquids or very soft foods during the day.

Bladder function affected, autonomic dysfunction. Often can't feel when I have to pee.

Tachycardia or elevated pulse like POTS/Dysautonomia on standing 20-30 points. This went away after the summer and just came back.

Brain fog, feels like brain damage or inflammation, mild headache occasionally front of forehead. Rash on back of neck, soreness and weakness in neck and cervical spine

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