

COVID-19 “Long Hauler” Symptoms Survey Report

7/25/2020

A Study Conducted by Dr. Natalie Lambert and Survivor Corps



SCHOOL OF MEDICINE
DEPARTMENT OF MEDICINE



To cite this report, please credit: Lambert, N. J. & Survivor Corps.
COVID-19 “Long Hauler” Symptoms Survey Report. Indiana University School of
Medicine; 2020.

COVID-19 “Long Hauler” Symptoms Survey Report

Data collected: 7/25/2020

Source: Survivor Corp Facebook group survey

Total Respondents: 1,567+

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To cite this report, please credit: Lambert, N. J. & Survivor Corps. *COVID-19 “Long Hauler” Symptoms Survey Report*. Indiana University School of Medicine; 2020.

The results of this study are the reported experiences of people suffering from long-term COVID-19 symptoms, colloquially known as “Long Haulers.” This is not a peer-reviewed study. Data was analyzed by an experienced researcher and we invite any researchers interested in Survivor Corps data to contact us at HQ@survivorcorps.com.

[Survivor Corps](#) is a grassroots movement connecting, educating and mobilizing COVID-19 survivors with the medical, scientific and academic research community to help stem the tide of this pandemic and assist in the national recovery.

Context: Many members of Survivor Corps report suffering from long-term symptoms of COVID-19 and have taken to calling themselves “Long Haulers.” The forum founder, Diana Berrent, posted a survey on the Survivor Corps Facebook page asking members who identified as Long Haulers to respond by selecting all of the COVID-19-related symptoms they have experienced. The survey symptom list was based on initial COVID-19 research conducted by researchers affiliated with Survivor Corps, Dr. Natalie Lambert at Indiana University School of Medicine and Dr. Wendy Chung at Colombia University Irving Medical Center. The survey was made “open” so that survey participants could add symptoms to the list, and then future participants could also select the participant-added symptoms.

Summary of Survey Findings:

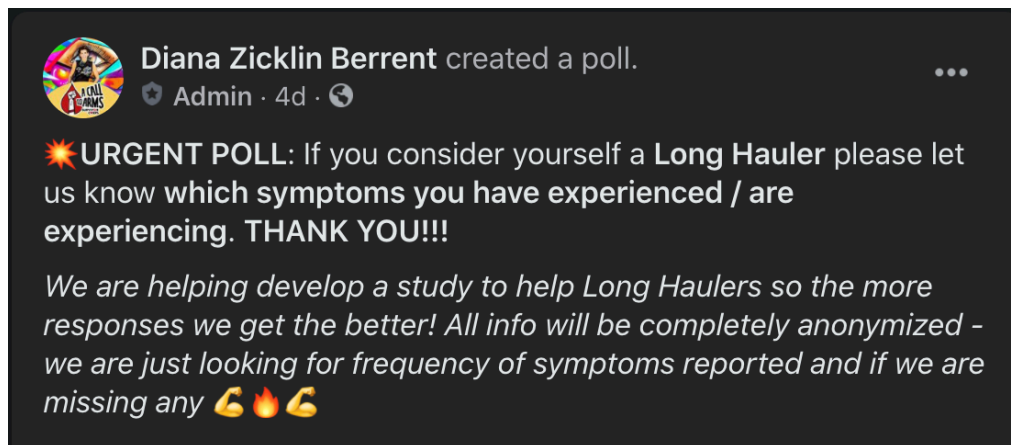
- Long Haulers’ COVID-19 symptoms are far more numerous than what is currently listed on the CDC’s website
- While the impact of COVID-19 on the lungs and vascular system have received some media and medical attention, the results of this survey suggest that brain, whole body, eye, and skin symptoms are also frequent-occurring health problems for people recovering from COVID-19
- Survivor Corp group members frequently report reaching out to primary care doctors for help managing such lesser-known and painful symptoms, but find that some physicians are unable or unwilling to help patients manage these due to lack of research
- A reported 26.5% of symptoms experienced by Long Haulers are described as painful by the group members



Dr. Lambert collected and analyzed the survey responses. The results are broken down in the following figures:

- Figure 1: Survey prompt posted in the Survivor Corps Facebook group page
- Figure 2: 50 most commonly reported Long Hauler symptoms
- Figure 3: COVID-19 symptoms according to the CDC (for reference)
- Figure 4: How the Survivor Corps survey results compare to the COVID-19 symptoms currently listed on the CDC website
- Figure 5: Flow graph which breaks the reported symptoms into quartiles to better visualize the relative prevalence of the symptoms. Symptoms in the first quartile are the most commonly reported by Long Haulers and those in the fourth quartile are the least commonly reported.
- Figure 6: Dr. Lambert first categorized each symptom according to the primary symptom location in the body and then created a flow graph to visualize which organs are most impacted by long-lasting COVID-19 symptoms
- Figure 7: Displays the of symptoms associated with pain
- Figure 8: Full list of COVID-19 symptoms (n = 98) selected by survey participants

Figure 1. Survey Prompt Posted in the Survivor Corps Group Page



Interpretation of Findings: The results of the analysis suggest that Long Haulers' COVID-19 symptoms are far more numerous than what is currently listed on the CDC's website. While the symptoms listed on the CDC's website are, except for nausea or vomiting, some of the most common COVID-19 symptoms reported by Long Haulers, the mismatch between the health problems people are experiencing and the information that they can find from official health sources is noticeable and a potential cause for concern. It is understandable that health organizations do not list symptoms until there is more research validating whether a symptom is COVID-19 related or due to another illness, but at the same time the lack of information about the broad range of long-term COVID-19 symptoms may and likely does drive people to unofficial sources of health information online. Survivor Corps, for instance, is one place online where people who believe they have COVID-19 are going for information and advice.

Additionally, while the impact of COVID-19 on the lungs and vascular system have received some media and medical attention, the results of this survey suggest that brain, whole body, joints, eye, and skin symptoms are also frequent-occurring health problems for people recovering from COVID-19. More attention and research should be focused on how the virus impacts these organs, especially in terms of giving COVID-19 patients relief from reduced cognitive functioning, sleep problems, and vision problems.

A simple coding of the participant-reported symptoms according to which caused pain revealed that 26.5% of symptoms experiences by Long Haulers are painful. There is not yet a widely-accepted narrative in the news media or medical fields that people with COVID-19 who are recovering at home - like many Long Haulers - are often suffering from painful symptoms. The survey results show that body aches, nerve pain, and joint pain are frequent, and comments within the Survivor Corps group anecdotally show that this pain can be extreme and difficult to manage. In the group posts and comments, group members frequently report reaching out to their primary care doctors for help managing such lesser-known symptoms but find that their physicians are sometimes unable or unwilling to help patients manage lesser known COVID-19 symptoms due to lack of research. Until research into long-term COVID-19 symptoms is conducted, these results indicate that an ever-increasing number of COVID-19 patients continue to suffer from their untreated symptoms.

This study was a simple survey, but yields results that can begin to guide future COVID-19 research in directions that are very meaningful for those who suffer from the disease. This research can be greatly expanded through analysis of the tens of thousands of posts in the Survivor Corps Facebook group. Survivor Corps members generously share information about the progression of their disease, their symptoms, and what medical treatments were found to be effective. We hope that this study and our future research using the Survivor Corps dataset will give back to the community that has so generously donated their time tracking and understanding a terrible disease.

Acknowledgements: We would like to thank the Indiana University Precision Health Initiative for its support and the thousands of Survivor Corps members who are fighting the virus, as well as those who have lost their lives to the disease.



Figure 2. The 50 Most Common Long Hauler Symptoms

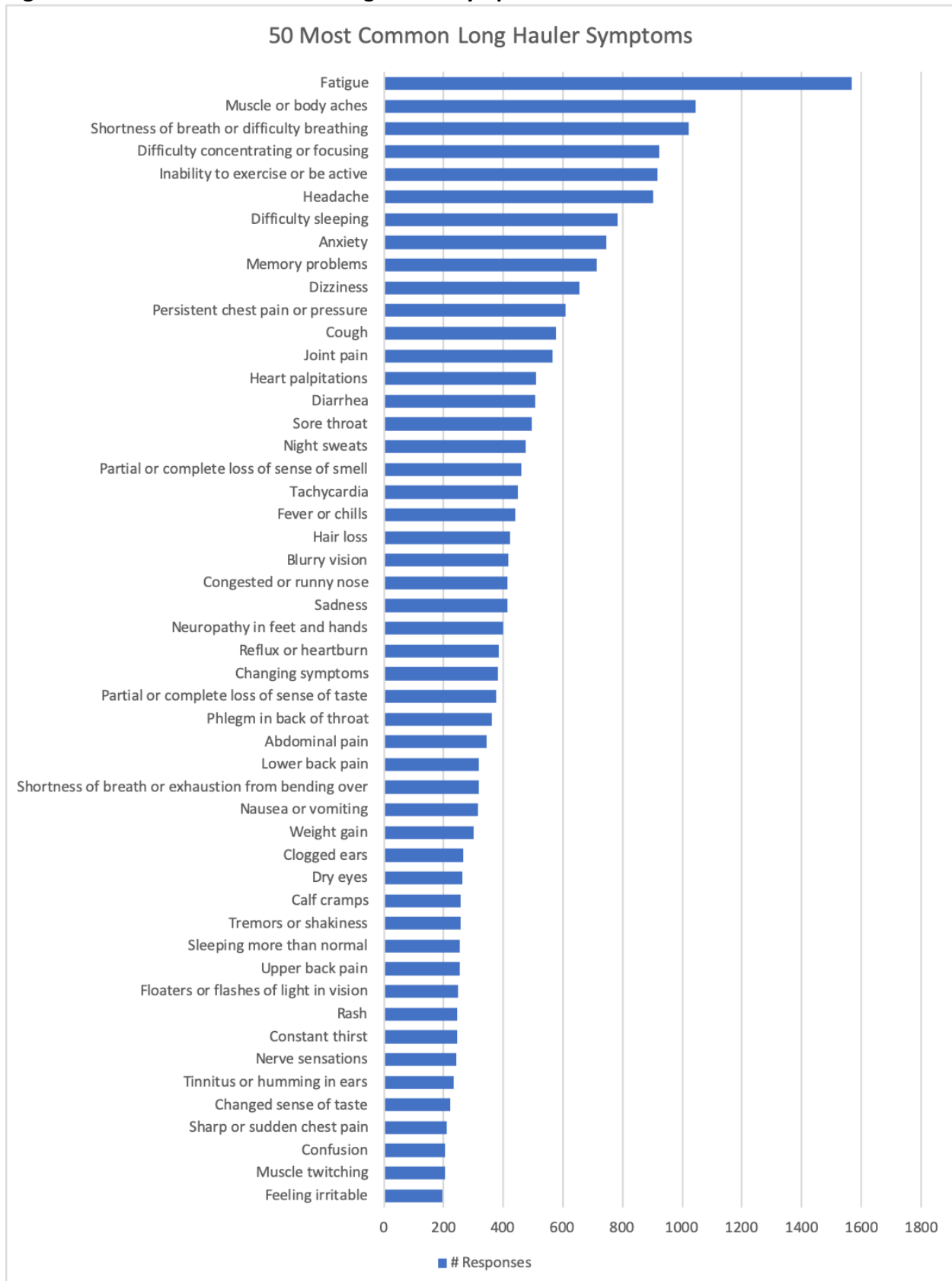


Figure 3. COVID-19 Symptoms According to the CDC

Source: <https://www.cdc.gov/coronavirus/2019-ncov/symptoms-testing/symptoms.html>
on 7/25/2020

Watch for symptoms

People with COVID-19 have had a wide range of symptoms reported – ranging from mild symptoms to severe illness. Symptoms may appear **2-14 days after exposure to the virus**. People with these symptoms may have COVID-19:

- Fever or chills
- Cough
- Shortness of breath or difficulty breathing
- Fatigue
- Muscle or body aches
- Headache
- New loss of taste or smell
- Sore throat
- Congestion or runny nose
- Nausea or vomiting
- Diarrhea

This list does not include all possible symptoms. CDC will continue to update this list as we learn more about COVID-19.



Figure 4. CDC Verses Long Hauler Reported COVID-19 Symptoms

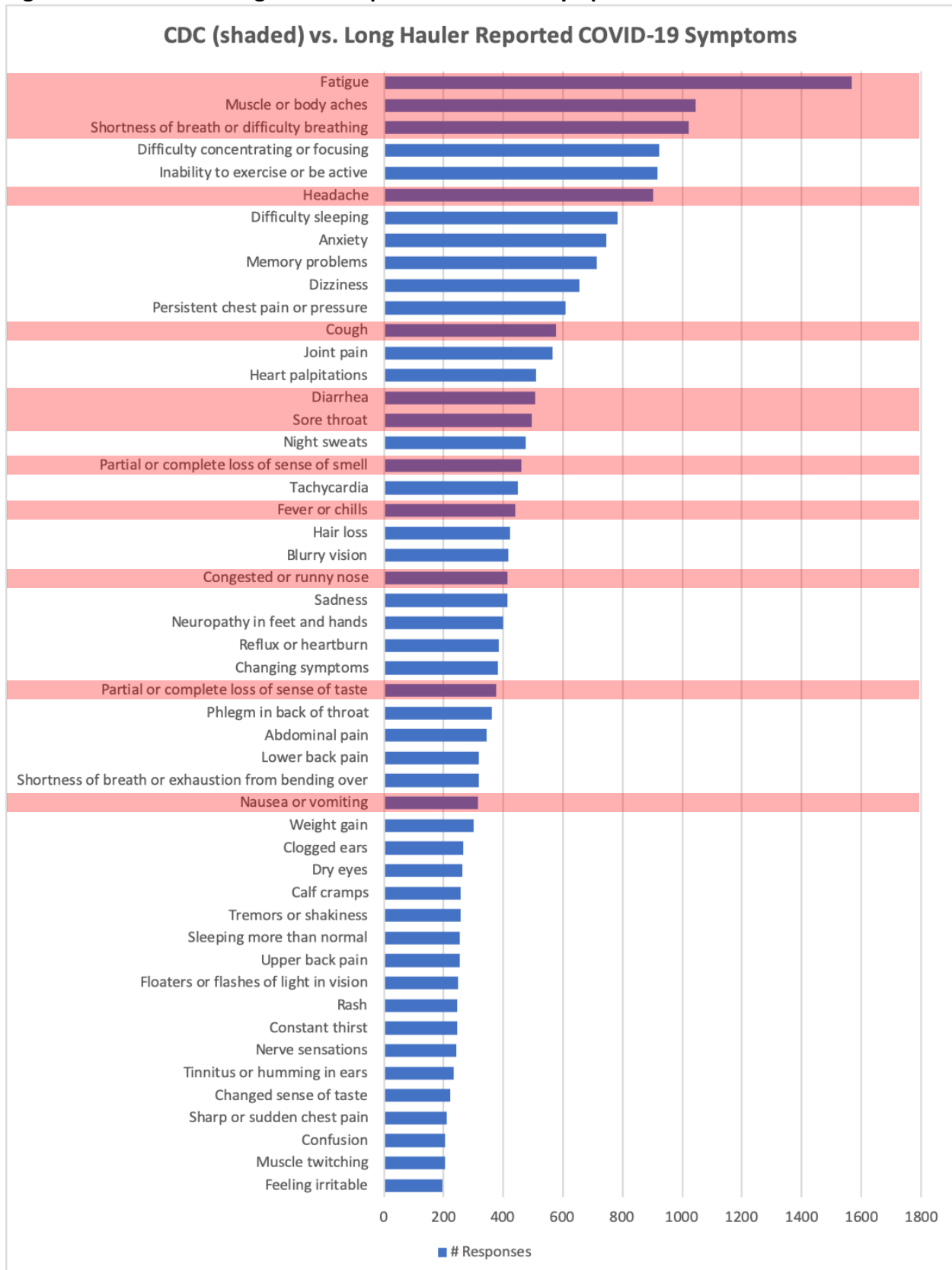


Figure 5. COVID-19 Symptoms Reported by Long Haulers by Quartile

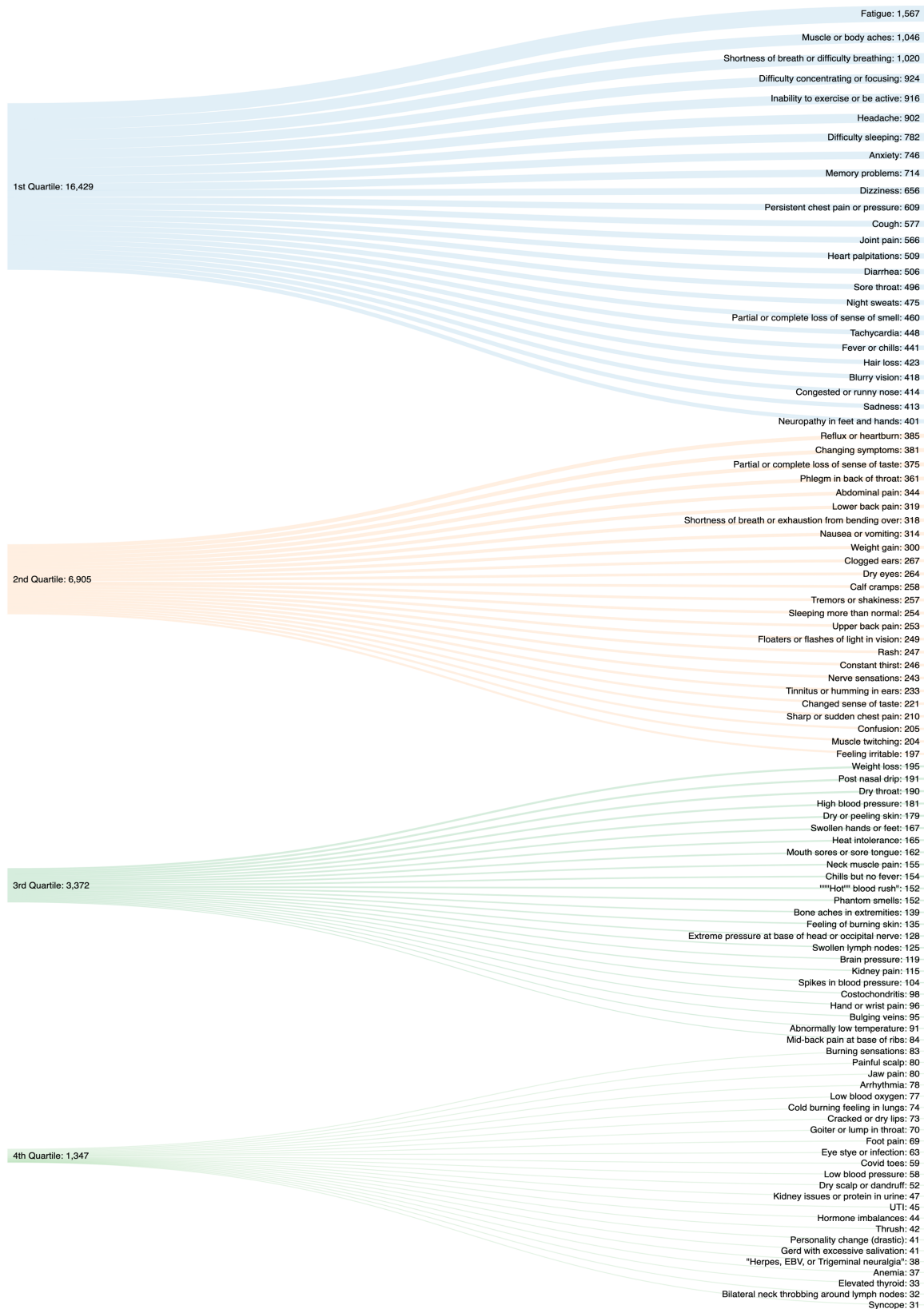


Figure 6. COVID-19 Symptoms Reported by Long Haulers by Symptom Location

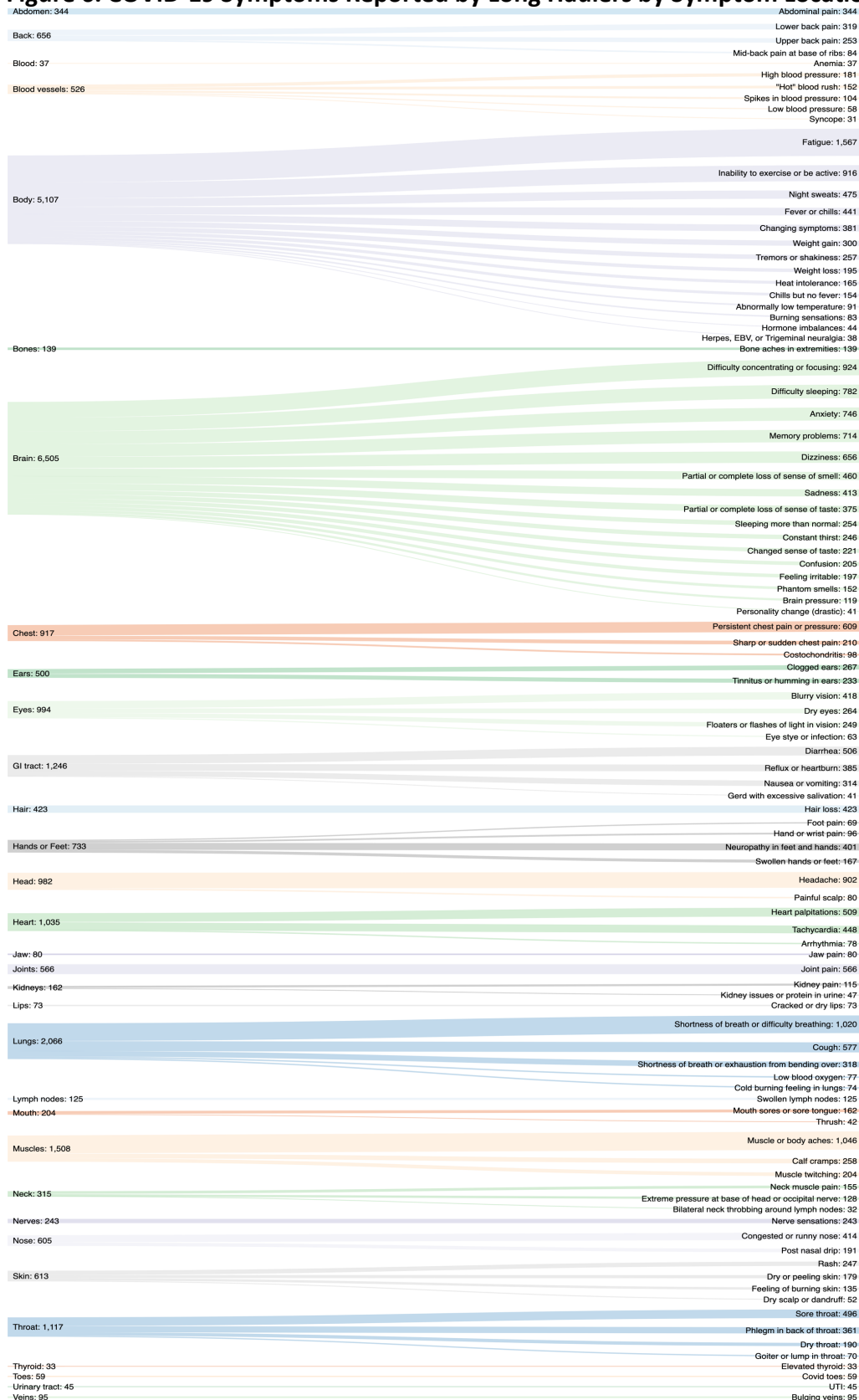
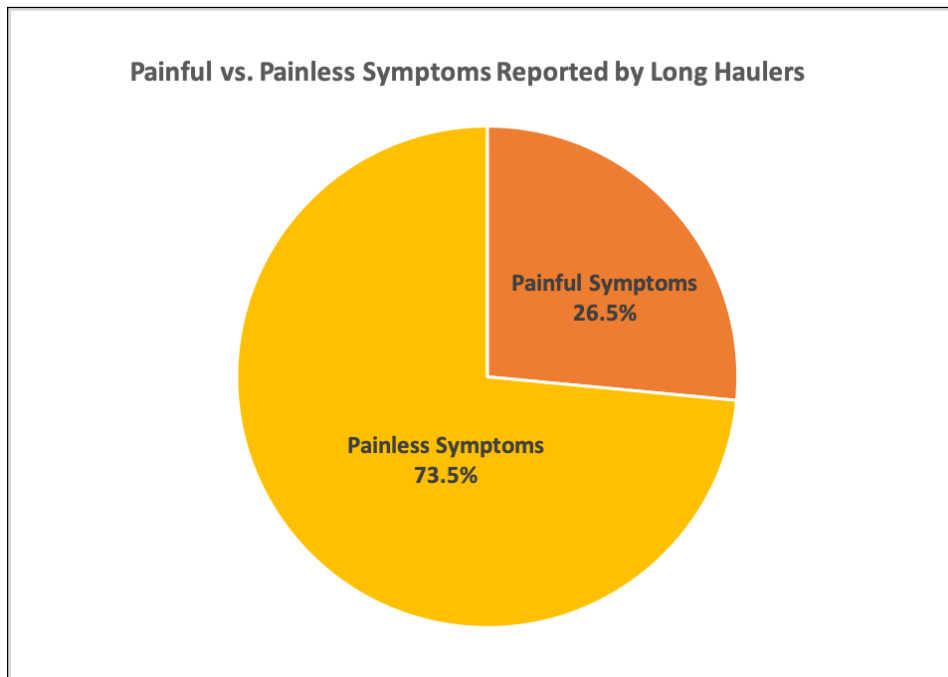


Figure 7. Painful Symptoms Reported by Long Haulers



Painful Symptoms	
Muscle or body aches	Feeling of burning skin
Headache	Bone aches in extremities
Persistent chest pain or pressure	Neck muscle pain
Joint pain	Kidney pain
Sore throat	Costochondritis
Neuropathy in feet and hands	Painful scalp
Reflux or heartburn	Burning sensations
Abdominal pain	Mid-back pain at base of ribs
Lower back pain	Jaw pain
Calf cramps	Hand or wrist pain
Upper back pain	Cold burning feeling in lungs
Sharp or sudden chest pain	Foot pain
Mouth sores or sore tongue	UTI
Low back pain	

Figure 8. Full List of Symptoms Reported by Long Haulers (n=98)

Symptom	# Responses
Fatigue	1,567
Muscle or body aches	1,046
Shortness of breath or difficulty breathing	1,020
Difficulty concentrating or focusing	924
Inability to exercise or be active	916
Headache	902
Difficulty sleeping	782
Anxiety	746
Memory problems	714
Dizziness	656
Persistent chest pain or pressure	609
Cough	577
Joint pain	566
Heart palpitations	509
Diarrhea	506
Sore throat	496
Night sweats	475
Partial or complete loss of sense of smell	460
Tachycardia	448
Fever or chills	441
Hair loss	423
Blurry vision	418
Congested or runny nose	414
Sadness	413
Neuropathy in feet and hands	401
Reflux or heartburn	385
Changing symptoms	381
Partial or complete loss of sense of taste	375
Phlegm in back of throat	361
Abdominal pain	344
Lower back pain	319
Shortness of breath or exhaustion from bending over	318
Nausea or vomiting	314
Weight gain	300
Clogged ears	267
Dry eyes	264
Calf cramps	258
Tremors or shakiness	257



Sleeping more than normal	254
Upper back pain	253
Floaters or flashes of light in vision	249
Rash	247
Constant thirst	246
Nerve sensations	243
Tinnitus or humming in ears	233
Changed sense of taste	221
Sharp or sudden chest pain	210
Confusion	205
Muscle twitching	204
Feeling irritable	197
Weight loss	195
Post nasal drip	191
Dry throat	190
High blood pressure	181
Dry or peeling skin	179
Swollen hands or feet	167
Heat intolerance	165
Mouth sores or sore tongue	162
Neck muscle pain	155
Chills but no fever	154
"Hot" blood rush	152
Phantom smells	152
Bone aches in extremities	139
Feeling of burning skin	135
Extreme pressure at base of head or occipital nerve	128
Swollen lymph nodes	125
Brain pressure	119
Kidney pain	115
Spikes in blood pressure	104
Costochondritis	98
Hand or wrist pain	96
Bulging veins	95
Abnormally low temperature	91
Mid-back pain at base of ribs	84
Burning sensations	83
Jaw pain	80
Painful scalp	80
Arrhythmia	78
Low blood oxygen	77



Cold burning feeling in lungs	74
Cracked or dry lips	73
Goiter or lump in throat	70
Foot pain	69
Eye stye or infection	63
Covid toes	59
Low blood pressure	58
Dry scalp or dandruff	52
Kidney issues or protein in urine	47
UTI	45
Hormone imbalances	44
Thrush	42
Gerd with excessive salivation	41
Personality change (drastic)	41
Herpes, EBV, or Trigeminal neuralgia	38
Anemia	37
Elevated thyroid	33
Bilateral neck throbbing around lymph nodes	32
Syncope	31

