

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



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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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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 Columbia 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:

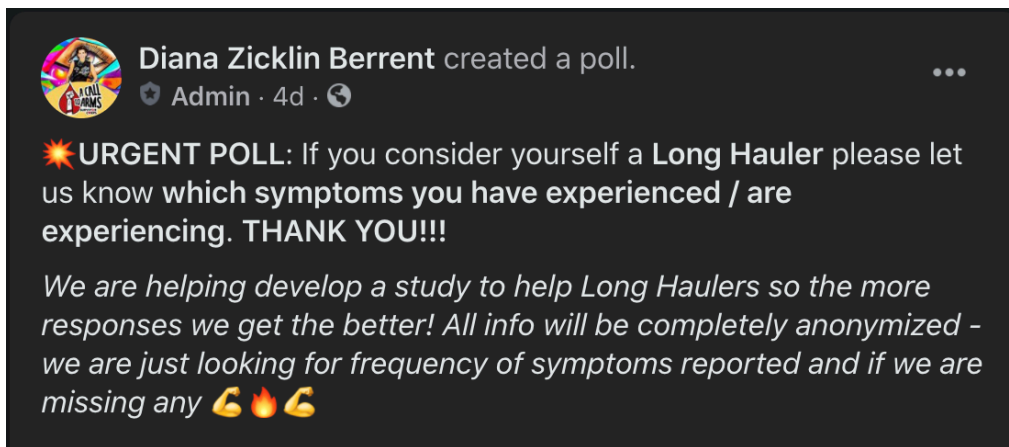
- Long Haulers’ COVID-19 symptoms are far more numerous than what is currently listed on the CDC’s website
- While the impact of COVID-19 on the lungs and vascular system have received some media and medical attention, the results of this survey suggest that brain, whole body, eye, and skin symptoms 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

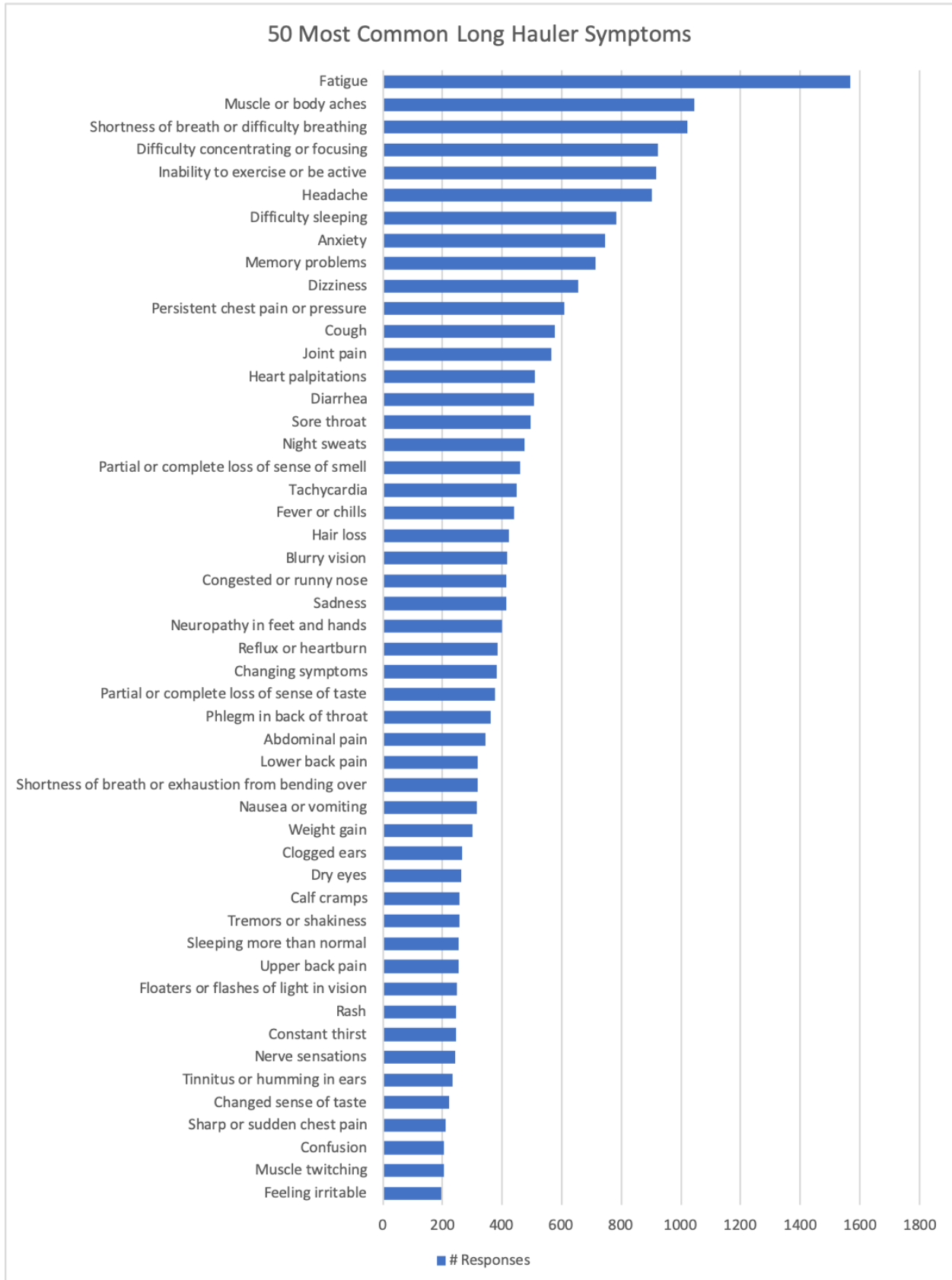


Figure 3. COVID-19 Symptoms According to the CDC

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

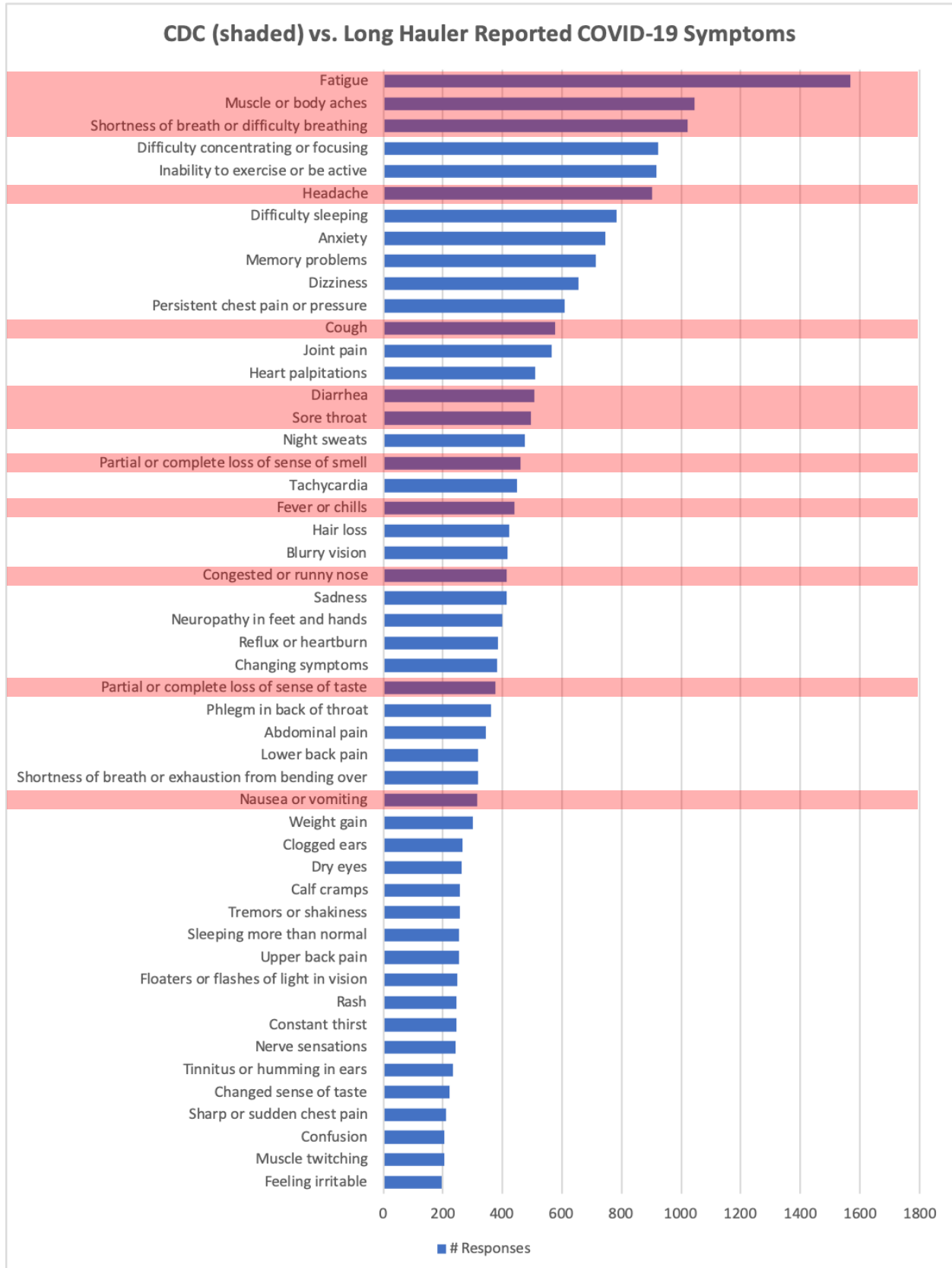


Figure 5. COVID-19 Symptoms Reported by Long Haulers by Quartile

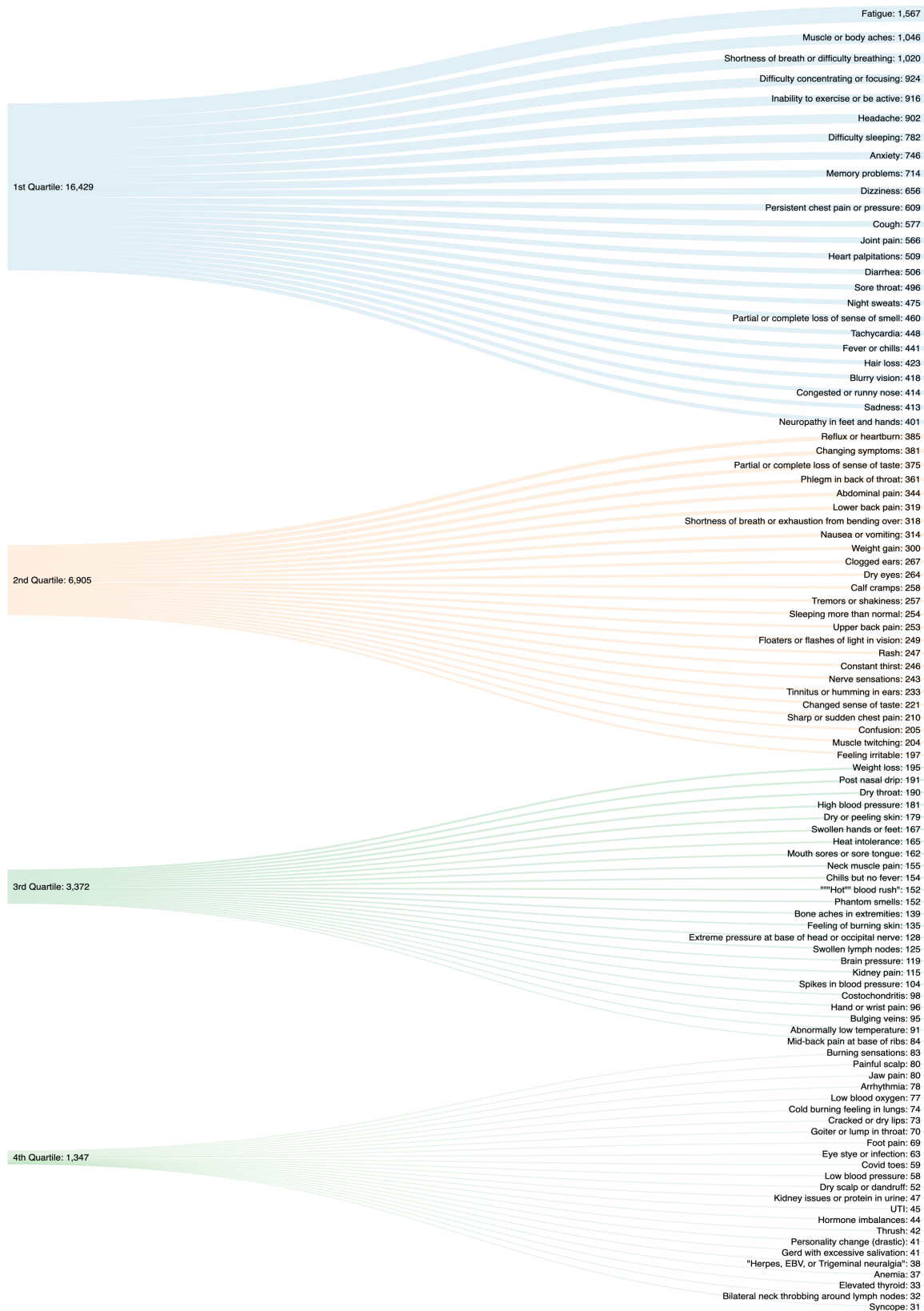


Figure 6. COVID-19 Symptoms Reported by Long Haulers by Symptom Location

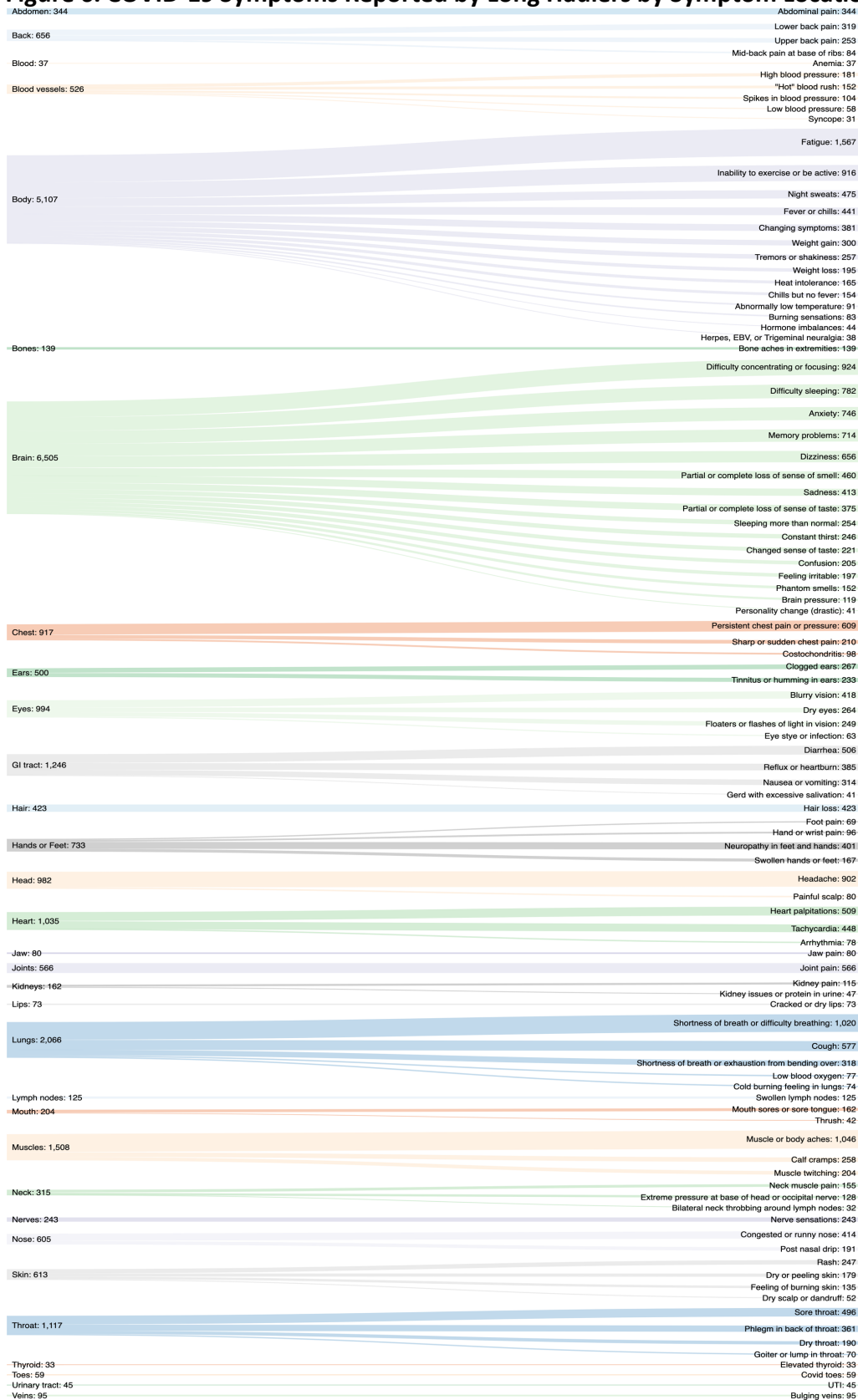
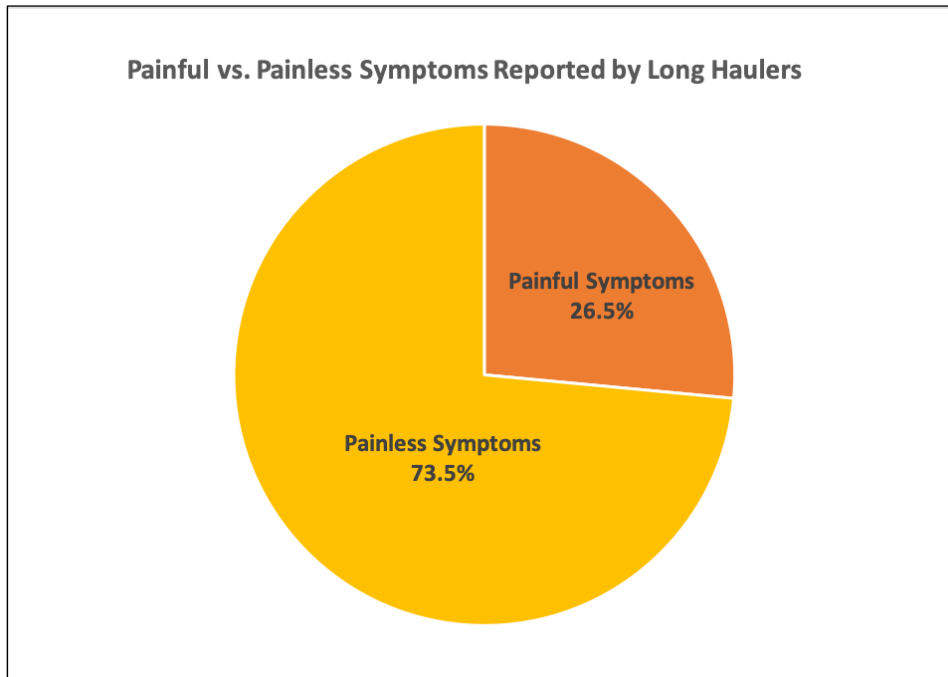


Figure 7. Painful Symptoms Reported by Long Haulers



| 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 |

