COVID-19 "Long Hauler" Symptoms Survey Report

7/25/2020

A Study Conducted by Dr. Natalie J. Lambert and Survivor Corps





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> www.survivorcorps.com www.nataliejlambert.com

COVID-19 "Long Hauler" Symptoms Survey Report

Data collected: 7/25/2020

Source: Survivor Corps 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 communities, 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

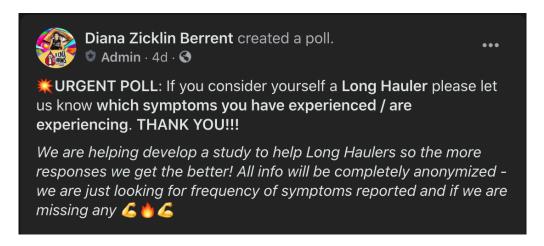




Dr. Lambert collected and analyzed the survey responses. The results are broken down in the following figures:

- 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 experienced 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.

Survivor Corps Facebook Group: www.facebook.com/groups/COVID19survivorcorps/



Figure 2. The 50 Most Common Long Hauler Symptoms

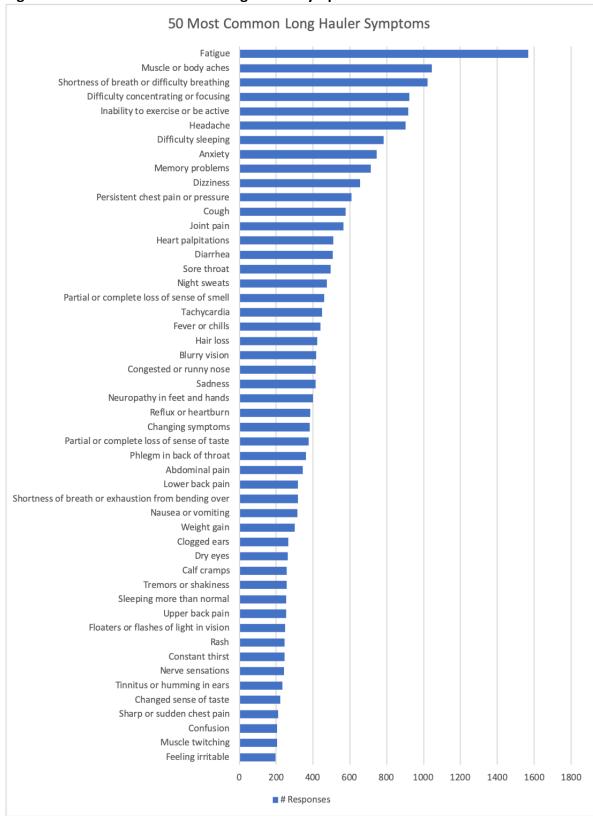




Figure 3. COVID-19 Symptoms According to the CDC

Source: www.cdc.gov/coronavirus/2019-ncov/symptoms-testing/symptoms (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 Reported vs. Long Hauler Reported COVID-19 Symptoms

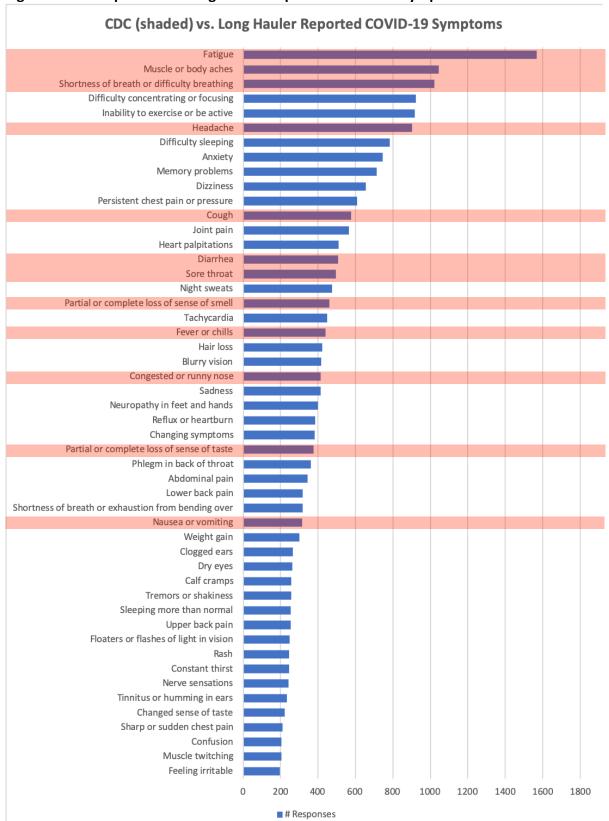






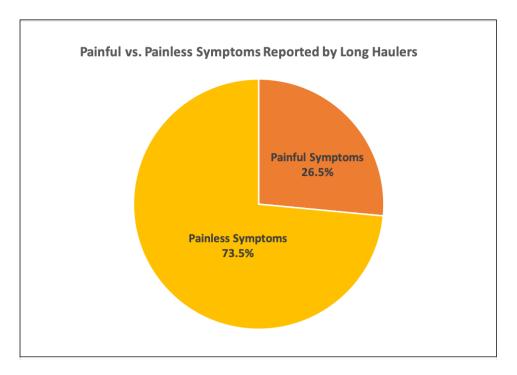
Figure 5. COVID-19 Symptoms Reported by Long Haulers by Quartile

Fatigue: 1,56	
Muscle or body aches: 1,04	
Shortness of breath or difficulty breathing: 1,02	
Difficulty concentrating or focusing: 92	
Inability to exercise or be active: 91	
Headache: 90	
Difficulty sleeping: 78	
Anxiety: 74	
Memory problems: 71	Quartile: 16,429
Dizziness: 65	Quartile. 10,429
Persistent chest pain or pressure: 60	
Cough: 57	
Joint pain: 56 Heart palpitations: 50	
Heart papitations: 5c	
Sort Invast: 45	
Night sweats: 4	
Partial or complete loss of sense of smell: 46	
Tachycardia: 44	
Fever or childs: 44	
Hair loss: 42	
Blury vision: 41	
Congested or runny nose: 41 Sadness: 41	
Samess: 4 Neuropathy in feet and hands: 40	
Reflux or heartburn: 3t	
Changing symptoms: 30	
Partial or complete loss of sense of taste: 3	
Phlegm in back of throat: 34 Abdominal pain: 3*	
Lower back pain: 31	
Shortness of breath or exhaustion from bending over: 3'	
Nausea or vomiting: 3'	
Weight gain: 30 Clogged ears: 20	
Original value. Dry opes: 2	Quartile: 6,905
Calf cramps: 28	Quartile: 6,905
Tremors or shakiness: 2t Sleeping more than normal: 2t	
Gleeping Inde trial Infilia	
Floaters or flashes of light in vision: 24	
Rash: 24 Constant thirst: 2-	
Constant times: 2 Nerve sensitions: 2	
Tinnitus or humming in ears: 20	
Changed sense of taste: 2: Sharp or sudden chest pain: 2	
Confusion: 2	
Muscle twitching: 20	
Feeling irritable: 1 Weight loss: 1	
Post nasal drip: 15	
Dry throat: 19 High blood pressure: 11	
nyi bood pressue: n	
Swollen hands or feet: 1	
Heat intolerance: 10 Mouth sores or sore tongue: 10	
Neck muscle pain: 1	
Chills but no fever: 1 """Ho!"" blood rush": 1	Quartile: 3,372
Phantom smells: 1	
Bone aches in extremities: 1	
Feeling of burning skin: 1 Extreme pressure at base of head or occipital nerve: 1	
Swollen lymph nodes: 1.	
Brain pressure: 1 Kidney pain: 1	
Spikes in blood pressure: 1	
Costochondritis: Hand or wrist pain:	
Bulging veins:	
Abnormally low temperature: Mid-back pain at base of ribs:	
Mild-back pain at base of nos: Burning sensations:	
Painful scalp: Jaw pain:	
Arrhythmia:	
Low blood oxygen:	
Cold burning feeling in lungs: Cracked or dry lips:	
Goiter or lump in throat:	
Foot pain: (Eye stye or infection:	Quartile: 1,347
Covid toes:	Qualtile, 1,047
Low blood pressure: Dry scalp or dandruff:	
Kidney issues or protein in urine: 4	
UTI: Hormone imbalances:	
Thrush: 4	
Personality change (drastic): Gerd with excessive salivation:	
"Herpes, EBV, or Trigeminal neuralgia": 3 Anemia: 3	
Elevated thyroid: Bilateral neck throbbing around lymph nodes: 3	

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

Lower back pain: 3 Upper back pain; 3 High block prain at base of ribs: Animia: High blood pressure: 1 Spikes in blood pressure: 1 Low blood pressure: 5 Low blood pressure: 6 Inability to exercise or be active: 9 Inability to exercise or be active: 9 Night sewals: 4 Fever or chilis: 4 Changing symptoms: 3 Changing symptoms: 4 Changing symptoms	Back: 656 Blood: 37 Blood vessels: 526
Mid-back pain at base of ribs: Anomia: High blood pressure: 1 Pind* blood and 1 Spikes in blood pressure: 1 Low blood pressure: 5 Faligue: 1,5i Inability to exercise or be active: 9 Night sewaits: 4 Fever or chilis: 4	Blood: 37
Anomia: High blood pressure: "Hot" blood rush: 1: Spikes in blood pressure: Low blood pressure: Fatgue: 1,5% Fatgue: 1,5% Inability to exercise or be active: 9 Night sweats: 4* Fever or chilis: 4*	
High blood pressure: 11 Phot' blood units 11 Spikes in blood pressure: 15 Low blood pressure: 15 Syncope: Fatigue: 1,5i Inability to exercise or be active: 9 Night sewats: 4 Fever or chills: 4	Blood vessels: 526
"Hot" blood nush: 1 Spikes in blood pressure: 1 Low blood pressure: 1 Syncope: Fatigue: 1,54 Inability to exercise or be active: 9 Night sewasts: 4 Fever or chilis: 4	Blood vessels: 526
Low blood pressure: Syncope: Fatgue: 1,5% Fatgue: 1,5% Fatgue: 1,5% Inability to exercise or be active: 9 Night sewarts: 4* Fever or chilis: 4*	
Syncope: Fatigue: 1,5i Inability to exercise or be active: 9 Night sweats: 4 Fever or chills: 4	
Fatigue: 1,5/ Inability to exercise or be active: 9 Night eweats: 4 Fever or chills: 4	
Inability to exercise or be active: 9 Night events: 4: Fever or chills: 4*	
Night sweats: 4 Fever or chills: 4	
Night sweats: 4 Fever or chills: 4	
Night sweats: 4 Fever or chills: 4	
Fever or chills: 4-	
	Body: 5,107
Changing symptoms: 31	
Weight gain: 3	
Tremors or shakiness: 2:	
Weight loss: 19	
Heat intolerance: 14	
Chills but no fever: 1!	
Abnormally low temperature:	
Burning sensations: Hormone imbalances:	
Herpes, EBV, or Trigeminal neuralgia:	
Bone aches in extremities: 13	Bones: 139
Difficulty concentrating or focusing: 9:	
Difficulty sleeping: 74	
Anxiety: 7-	
Memory problems: 7	
Dizziness: 6l	Brain: 6,505
Partial or complete loss of sense of smell: 4t	
y attest or conjugete rises of series. Safetes: 4	
Partial or complete loss of sense of taste: 3:	
Sleeping more than normal: 2t	
Constant thirst: 2-	
Changed sense of taste: 2:	
Confusion: 2d	
Feeling irritable: 11	
Phantom smells: 1 Brain pressure: 1	
Personally drastic):	
Persistent chest pain or pressure: 6t	
Sharp or sudden chest pain: 2	Chest: 917
Snap of support control of the contr	
Clogged ears: 2	
Tinnitus or humming in ears: 2:	Ears: 500
Blurry vision: 4'	
	Eyes: 994
Dry eyes: 24	Ly65. 354
Floaters or flashes of light in vision: 2· Eye stye or infection:	
Diarrhea: 54	
	GI tract: 1,246
Reflux or heartburn: 31	Griffett. 1,640
Nausea or vomiting: 3	
Gerd with excessive salivation:	Hair: 423
Hair loss: 4:	Hair: 423
Foot pain: Hand or with pain: 4	
Neuropathy in feet and hands: 4	Hands or Feet: 733
Swollen hands or feet: 14	
Headache: 90	Head: 982
Paintul scalp:	
Heart palpitations: 5	
Tachycardia: 4	Heart: 1,035
Arrhythmia: * Jaw pain: *	Jaw: 80
Joint pain: 54	Joints: 566
Nichae pain: 1	
Notery parr. Kidney issues or protein in unine:	Kidneys: 162
Cracked or dry lips:	.ips: 73
Shortness of breath or difficulty breathing: 1,0:	
Cristians of dream of unicony preasuring. Fig.	
Cough: 5	.ungs: 2,066
Shortness of breath or exhaustion from bending over: 3	
Low blood oxygen:	
Cold burning feeling in lungs:	
Swollen lymph nodes: 1:	ymph nodes: 125
Mouth sores or sore or	Mouth: 204
Muscle or body aches: 1,0-	Muscles: 1,508
Calf gramps: 2:	1,000
Cari carings. 2 Muscle twitching:	
wusele witching. 1	
Extreme pressure at base of head or occipital nerve: 1/	Neck: 315
Bilateral neck throbbing around lymph nodes:	
Nerve sensations: 2	Nerves: 243
Congested or runny nose: 4	Nose: 605
Post nasal drip: 11	1000.000
	Skin: 613
Rash: 2·	
Rach: 2 Dry or peeling skin: 1 Feeling of burning skin: 1	
Rash: 2 Dry or peiling skin: 1' Feeling of burning skin: 1' Dry scalip or dardrult'	
Rach: 2 Dry or peeling skin: 1 Feeling of burning skin: 1	
Rash; 2 Ory or peeling skin: 1 Feeling of burning skin: 1 Dry scalp or dandurf: 1 Sore throat-4	Throat: 1,117
Rash: 2 Dry or peeling skin: 1 Feeling of burning skin: 1 Dry scalp or dandruft : Sore throat: 3 Phlegm in back of throat: 3	Throat: 1,117
Rash: 2 Dry or pealing skin: 1 Feeing of burning skin: 1 Dry scalp or dandruft : Sore throat: 4 Phiegm in back of throat: 3 Dry throat: 14 Goter or Jump in throat: 5	
Rash; 2 Ory or peeling skin: 1; Feeling of burning skin: 1; Ory scale of admitth; Ory scale or admitth; Ory scale or admitth; April or admitth; Ore throat: 4! Prilegm in back of throat: 3!	Throat: 1,117 Thyroid: 33 Toes: 59

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



Slooping more than normal	254
Sleeping more than normal Upper back pain	254
Floaters or flashes of light in vision	249
Rash	249
Constant thirst	246
Nerve sensations	243
Tinnitus or humming in ears	233
Changed sense of taste	233
Sharp or sudden chest pain	210
Confusion	205
Muscle twitching	203
Feeling irritable	197
Weight loss	195
Post nasal drip	193
Dry throat	191
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
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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

