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Characterization of internal tremors and vibration symptoms among people with post-acute sequelae of SARS-CoV-2: A narrative analysis of Email and social media comments in a patient advocacy group

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3 **Characterization of internal tremors and vibration symptoms**
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5 **among people with post-acute sequelae of SARS-CoV-2:**
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7 **A narrative analysis of email and social media comments in a patient**
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9 **advocacy group**
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Abstract

Objectives: To describe the experiences of patients who have post-acute sequelae SARS-CoV-2 infection (PASC) with internal vibrations and tremors as a prominent component, we leveraged the efforts by Survivor Corps, a grassroots COVID-19 patient advocacy group, to gather information from individuals belonging to its Facebook group with a history of COVID-19 suffering from vibrations and tremors.

Setting and Design: A narrative analysis was performed on 140 emails and 450 social media comments from 140 individuals collected as a response to a call to > 180,000 individuals participating in Survivor Corps between July 15 and July 27, 2021. We used common coding techniques for qualitative data synthesis and the constant comparative method of qualitative data analysis to categorize emails. Comments were analyzed using Word Clouds to visualize frequency of terms.

Main Outcome Measures: Patient-reported long COVID symptom themes and domains related to internal tremors and vibration.

Results: The respondents' emails represented 22 themes and 7 domains pertaining to their experience with internal tremor and vibrations. These domains were: (1) symptom experience, description, and anatomic location; (2) initial symptom onset; (3) symptom timing; (4) symptom triggers or alleviators; (5) change from baseline health status; (6) experience with medical establishment; and (7) impact on individuals' lives and livelihood.

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2
3 There were 22 themes in total, each corresponding to one of the broader
4 domains. Among the responses, many described symptoms that varied in
5 location, timing, triggers, occurred soon after their COVID-19 infection, and
6 were markedly debilitating. There were often frustrating experiences with
7 the healthcare system.
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15 Conclusions: This study describes key themes and experiences among a
16 group of people reporting long COVID and having a prolonged and
17 debilitating symptom complex that prominently features internal tremors
18 and vibrations.
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Strengths and limitations of this study

- This study investigated self-reported symptom experiences from the patient perspective from a convenience sample of patients experiencing internal tremors and vibration symptoms as post-acute sequelae of SARS-CoV-2.
- We used common coding techniques for qualitative data and the constant comparative qualitative data analysis method to identify themes from patients' experiences.
- This study represents a convenience sample and therefore cannot provide information on the incidence and prevalence of these symptoms.

Summary Box

What this study adds:

This study contributes to the literature an understanding of the patient perspective regarding internal tremor and vibrations, a potentially important cluster of similar symptoms reported by people with long COVID.

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Introduction

Post-Acute Sequelae of SARS-CoV-2 infection (PASC), also known as long Covid, is a condition that is marked by protean manifestation that varies considerably among individuals.¹⁻⁴ The heterogeneity of long COVID necessitates attention to specific clusters of individuals who are suffering from similar symptoms. Proper clustering may enable efforts to identify biological signatures that help elucidate underlying mechanisms to guide the development of diagnostic and therapeutic strategies.

Some individuals with long COVID manifest symptoms that they describe as internal tremors and vibrations. To date, these symptoms, as experienced by patients, have not yet been well described. There are reports of patients with myoclonus, but they are described from the perspective of clinicians.⁵⁻¹² No underlying cause of the myoclonus episodes among patients with PASC has been identified, however, other studies have reported cases of myoclonus episodes following COVID-19.¹³⁻¹⁵

To understand the perspective of patients who have PASC with tremors and vibrations as a prominent component, we leveraged the efforts by Survivor Corps, a grassroots COVID-19 patient advocacy group, to gather information from individuals with PASC who belong to its Facebook group and suffer from these symptoms.¹⁶⁻¹⁸ We conducted a qualitative analysis of responses and organized them according to prominent themes. The goal of this study was to characterize the patient perspective and identify a

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3 potentially important cluster of similar symptoms that individuals with PASC
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5 are reporting.
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10 **Methods**

11 **Study Design and Sample**

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15 This study was a narrative analysis of emails and Facebook comments
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17 that were received from members of Survivor Corps, a long Covid patient
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19 advocacy group where member interact in a Facebook group. The concept
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21 for the study originated with the experience of Heidi Ferrer and the initiative
22
23 of her husband, Nick Güthe. Heidi had severe manifestations of the
24
25 sensations of vibrations and exhibited tremors with onset early in the
26
27 pandemic. Heidi Ferrer ultimately committed suicide as she found the
28
29 symptoms intolerable. Nick Güthe spoke with Survivor Corps, which initiated
30
31 a call for individuals in its Facebook group of over 180,000 individuals to
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33 report their experience with vibrations and tremors among those with Long
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35 COVID via emails and Facebook comments (Supplemental Table 1.). The
36
37 qualitative approach was chosen because previous literature characterizing
38
39 the patient perspective on these symptoms is limited.¹⁹ In addition, a study
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41 participant, LF, was involved as a coauthor in the study design and analysis
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43 by reviewing themes before final analysis and providing feedback on the
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45 manuscript. This study received an exemption from the Yale Institutional
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47 Review Board because the comments had been posted publicly.
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Data Collection

Data were collected from unstructured responses that included 140 emails and 450 Facebook comments that occurred in response to Survivor Corps' calls for information in July 2021. Exact dates and names were removed and replaced with month and year and five-year age brackets to protect anonymity. Any information about testing and timing of acute COVID infection were based on self-report.

Survivor Corps collected data for this study in three steps. First, on June 27, 2021, the Survivor Corps founder, Diana Berrent, posted a Facebook poll, titled "Vibration/Buzzing/Pain Poll," in the Survivor Corps Facebook group (Supplemental Table 1). Responses were in a multiple-choice answer format, where respondents could also select multiple answers and add their own answer choices, too. There were 20 answer choices, each a statement relevant to vibration, tingling, buzzing, and neuropathic sensations (Supplemental Table 1). The research team included all poll responses as of July 16, 2021, which totaled 769. In addition, there were 162 Facebook comments posted by group members below the poll as of July 16, 2021, which were all included in data analysis.

Next, Survivor Corps member, Nick Güthe, posted in the Survivor Corps Facebook group on July 14, 2021, requesting that anyone with long Covid in the Facebook group who had experienced "tremors or internal

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3 vibrations” and was interested in participating in a study comment below his
4
5 post (Supplemental Figure 1). By July 16, 2021, there were 288 comments
6
7 from group members in response to Nick Güthe’s post, all of which were
8
9 included in data analysis for this study. In response to members’ comments,
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11 Nick Güthe and Diana Berrent Güthe requested that commenters share their
12
13 story of these symptoms via email to Survivor Corps for the purposes of the
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15 study.
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21 Finally, the Survivor Corps newsletter in July 2021 also included a
22
23 request for “Long Haulers” with “Neurological tremors or internal vibrations”
24
25 to send details of their symptoms to Survivor Corps via email for this study
26
27 (Supplement 1). Survivor Corps received 140 emails for this study between
28
29 July 15, 2021, and July 27, 2021. All emails were included in data analysis.
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31 Including the Facebook comments from the initial poll and the comments
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33 from Nick Güthe’s post, 450 Facebook comments were analyzed in this
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35 study.
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42 **Data Analysis**

43 Emails

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47 Email data were analyzed using common coding techniques for
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49 qualitative data and the constant comparative method of qualitative data
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51 analysis.²⁰ Coding of the data was accomplished in iterative steps. An initial
52
53 code list was generated after evaluation of the data by research team
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3 members (HMK and DM) (Supplement 2). The initial code list was created in
4
5 three steps. First, each reviewer separately read the 140 emails (with names
6
7 and exact dates redacted). Next, each reviewer separately read the 140
8
9 emails while creating themes based on the contents of each email, until each
10
11 statement about internal tremors or vibrations in every email had been
12
13 assigned to a theme. The reviewers then met to discuss shared themes and
14
15 reached a consensus on the list of themes. The reviewers then grouped the
16
17 themes into 7 larger domains. At this point, the full research team reviewed
18
19 the code structure, including a study participant (LF), for logic and breadth.
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25 Using this final version of the code structure, members of the research
26
27 team (HMK and DM) independently coded all transcripts, then met as a
28
29 group to code in several joint sessions, achieving consensus and assigning
30
31 codes to observations by a negotiated, group process. Coded data were
32
33 entered into NVivo (version 12, [company, city])[citation] to assist in
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35 reporting recurrent themes, links among the themes, and supporting
36
37 quotations.
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45 Facebook Comments

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47 We used Word Cloud methodology to visualize the prevalence of terms
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49 (Supplement 3). A Word Cloud is a visual representation of word frequency
50
51 derived from written text. The more often the word appears within the
52
53 passage being analyzed, the larger it appears in the image generated. We
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3 set the minimum frequency of words to be included in the Word Cloud to 3,
4 the maximum number of words to 200, and removed extraneous filler
5 words. Word Clouds were generated using the *quanteda*, *wordcloud*, and *tm*
6 packages in R v4version 4v4.0.3 (R Development Core Team, Vienna,
7 Austria).^{21,22}
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18 **Results**

19 Email data

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22 After review of the email data, respondents' comments reflected 7
23 domains related to their experience with vibrations and tremors. These
24 domains were: (1) symptom experience, description, and anatomic location;
25 (2) initial symptom onset; (3) symptom timing; (4) symptom triggers or
26 alleviators; (5) change from baseline health status; (6) experience with
27 medical establishment; and (7) impact on people's lives and livelihood
28 (Table 1). There were 22 themes total, each corresponding to one of the
29 broader domains. Sample quotations are listed to illustrate the themes
30 (Supplemental Figure 2).
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47 1) Symptom Experience, Description, and Anatomic Location

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3 **Theme 1. Vibrations and tremors were described concomitantly, with**
4 **descriptions of internal vibrations, visible tremors, and some people**
5 **experiencing both.**
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10 *Example 1.*

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13 "Sometimes my entire body feels like it's humming and trembling. It's like
14 I'm sitting on a huge speaker with the volume all the way up. Through the
15 progression of the last few months, the complete body humming has slowed
16 down, but still happens 5-8 times a month. My hands and legs also began
17 trembling about the same time as the whole body. My legs bob up and down
18 aggressively at times. I'm not cold, I'm not restless, but my legs visibly
19 move up and down like I'm tapping my foot. My hands have been the worst
20 of it. I felt like they had improved a few months ago, but they're back with a
21 vengeance. I'm not hungry ever. I know I need to eat, and my go-to has
22 been soup. By the time I get the spoon 4 inches above the bowl, and close
23 to my mouth, all of the broth has been "shaken" off. My handwriting.. awful.
24 Sometimes I absolutely cannot stand myself and just go to bed. That
25 happens more often than not. I usually try to hide my hands in my pockets
26 or under the table, but am not always able to do that. When my whole body
27 is trembling, I find it a lot more difficult to focus and to get anything
28 accomplished."
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54 *Example 2.*

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3 "Internal vibrations started about 3 weeks after. They started in my back
4 and back of upper thighs. It felt like I was sitting on a vibration massage
5 chair. They never went away but would vary in intensity. February 2021 I
6 started having restless left arm at bedtime where my left arm would flap
7 until I fell asleep. On [May 2021] it progressed to full body myoclonic
8 movements lasting up to 30 minutes."
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20 **Theme 2. Vibration or tremor site varied, from the entire body to**
21 **localization in extremities, chest, abdomen, and other locations.**
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24
25 *Example 1.*
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27 "I experience daily internal tremors/vibrations all over but mainly inside my
28 brain and chest. I have external tremors in my legs, arms and chest."
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35 *Example 2.*
36

37 "Still suffering with symptoms. One of which is tremors and internal
38 vibrations primarily in the legs and feet but do sometimes occur in arms."
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44 **Theme 3. Vibrations and tremors occurred with other symptoms of**
45 **varying number.**
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48
49 *Example 1.*
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3 "I also experience relentless headaches. I have had the same one, in varying
4 degrees, since October. Crushing fatigue. Vivid dreams. And the worst, word
5 retrieval."
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12
13 *Example 2.*

14
15 "Here is a list of my current symptoms that I have over a year after my
16 acute infection: 1. Extreme Fatigue 2. Exercise Intolerance/Post-Exertion
17 Malaise (Physical and Mental) 3. Short-Term Memory Loss. Must carry a
18 notebook to remember things 4. Brain Fog 5. Muscle Weakness 6. Dizziness.
19 Can't Drive 7. Seizures 8. Headaches/Migraines 9. High Blood Pressure 10.
20 Cold Hands and Feet 11. Ringing in Ears Tinnitus 12. Hoarseness/Loss of
21 Voice 13. Loss of Coordination in Hands 14. Burning Sensation on Skin
22 Lower Torso"
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37 **Theme 4. Vibrations and tremors could cause severe pain.**

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40 *Example 1.*

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42 "My brain shakes after a few hours inside my head, my face starts to tingle
43 and numb, and then the full head shaking seizures start. I have severe head
44 pain and nausea constantly from all the seizures."
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52 *Example 2.*

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3 “That week of unrelieved spasms left my body barely able to move. Like
4 paralyzed. I had 3 natural child births. I could not fake such 10/10 pain. I
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7
8 have never felt such intense pain, I thought my back would break and my
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10
11 right arm would be completely dislocated twisted out of socket. I could not
12
13 breathe at times due to the Laryngeal spasms and diaphragm spasms.”
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15

16 17 18 2) Initial Symptom Onset

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20 **Theme 5. Vibration and tremor initial onset varied, from the day of**
21 **initial infection to weeks or even months later.**
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24 25 *Example 1.*

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27 “Symptoms started on [July]. About 3 weeks later, I developed tremors. I've
28
29 had them ever since.”
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34 35 *Example 2.*

36
37 “I contracted COVID from an ICU patient in May 2020. A few days later
38
39 terrible headaches, loss smell, lung, cardio, eye damage. Ongoing problems
40
41 fatigue, Headaches, Migraines, Imbalance, Dizzy, Vertigo, SOB, COPD,
42
43 Brady/Tachycardia, SVT, chest pain, Gastric, swallow, voice, cognitive,
44
45
46 exercise intolerance, several leaves of absences off work. I had many scans,
47
48 tests, labs with both normal results and damage results. I have all Records.
49
50
51 Then few months later unrelenting Neuro issues vibrations, ripples, tremors,
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54 became intense foot cramps, painful ankle, foot drop, leg spasms started
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3 mostly r foot. I had to wear ankle brace use cane. Very difficult to sleep.
4
5 Husband could see ripples under skin and feel the vibrations at times. Body
6
7 is constantly "on", pain, numb, burning, briar patch, walking on nails, spikes
8
9 r foot, can't put r foot flat. Also forearms, hands, r side worse."
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15 **Theme 6. Vibrations and tremors occurred following or during acute**
16 **COVID-19 infections that varied from mild to severe.**
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20 *Example 1.*
21

22 "I was diagnosed with COVID-19 in July of 2020. I spent 2 months in the
23
24 ICU and 9 days on ECMO."
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30 *Example 2.*
31

32 "I had a moderate case of Covid in November of 2020 with multiple
33
34 symptoms. I was never hospitalized. I was recovered one week before my
35
36 first Long Covid symptom of shortness of breath began."
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42 3) Symptom Timing
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47 **Theme 7. Vibration and tremor episodes could be brief, or could be**
48 **prolonged, even constant.**
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51 *Example 1.*
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3 “The internal tremors in my chest generally only last for about 5 seconds or
4 so and then completely subside. The ones in my abdomen are more rare and
5
6 have lasted for longer, but still less than a minute or so in general.”
7
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9

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11
12
13 *Example 2.*

14
15 “Now here at almost 8 months post covid, I have dealt with these horrible
16 tremors daily. They are constant, they don't come and go. They are 24/7. I
17
18 feel them more when I am still and resting or at night and early morning, or
19
20 during naps. If I can just get up and get going most days, I don't notice
21
22 them much, unless the intensity increases and I get breakthrough pain or
23
24 headaches. But the night time always reminds me they are still there.”
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32 **Theme 8. Vibration and tremor episodes could occur constantly,**
33 **daily, or only when relapses occurred.**
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36
37 *Example 1.*

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40 “The tremors and the dizziness are daily challenges.”
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44
45 *Example 2.*

46
47 “Tremors and ‘vibrations’ are a few of the many ongoing symptoms. The
48 tremors I notice in my hands and toes. It lasts for about 10 seconds or less
49
50 about every 2 to 3 days. The vibrations I notice when I first lay down for bed
51
52 at night. It lasts about seconds.”
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6 **Theme 9. Vibration and tremor symptoms could completely resolve**
7 **temporarily and could return up to months later.**
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10 *Example 1.*

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13 “Even now, almost eight months out in July, I still occasionally experience
14 these. They do not occur daily, but do generally happen in conjunction with
15 the relapse of other symptoms, such as mild chest, throat, and back
16 pressure/tightness, and tingling in my extremities.”
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25 *Example 2.*

26
27 “Sometimes my entire body feels like it's humming and trembling. It's like
28 I'm sitting on a huge speaker with the volume all the way up. Through the
29 progression of the last few months, the complete body humming has slowed
30 down, but still happens 5-8 times a month. My hands and legs also began
31 trembling about the same time as the whole body. My legs bop up and down
32 aggressively at times. I'm not cold, I'm not restless, but my legs visibly
33 move up and down like I'm tapping my foot. My hands have been the worst
34 of it. I felt like they had improved a few months ago, but they're back with a
35 vengeance.”
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3 **Theme 10. People experienced vibrations and tremors over different**
4 **time periods (even if they were episodic), and some did not have**
5 **improvement in symptoms after more than a year.**
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13 *Example 1.*

14
15 "I got tremors on [December 2020] the day I got covid & it increased to
16 where I had it in my whole body vibrating on head as well increasing during
17 activity. It's been very debilitating & frustrating. I have been a patient in
18 Rochester Minnesota Mayo Covid Clinic and my symptoms have lessened.
19
20 However, it is now it is [July] and the tremors have not subsided."
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30 *Example 2.*

31
32 "I had Covid in early February 2020. I did not know I had it. Severe
33 Headache, sore throat, rash and crushing fatigue. Got better in a flash. 5
34 months later, the floor dropped out. By early October, hand tremors started.
35
36 They have diminished and come back intermittently. It is now 18 Months
37 after the initial infection."
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47 4) Symptom triggers or alleviators
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52 **Theme 11. Exercise and activity were associated for some with**
53 **onsets of tremors and vibrations.**
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3 *Example 1.*
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5 "Since then I notice that if I get my heart rate up too high (which could be
6 anything above 110-15) the tremors and vibrations are made worse."
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13 *Example 2.*
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15 "I have had long covid for 6 months now, and I get
16 tremors/vibrations/buzzing nerves whenever I overextend myself."
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22 **Theme 12. A variety of self-treatment strategies, such as diet**
23 **modifications and humming, were used to alleviate tremors and**
24 **vibrations.**
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32 *Example 1.*
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34 "Regarding the nerve issues, I have found very recently that humming in the
35 morning helps me to stop the vibrations faster. I suspect our vagus nerve is
36 being affected."
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44 *Example 2.*
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46 "I have experimented with supplements, removing medicines, and diet.
47 Removing all sugar and processed foods from my diet has reduced the
48 internal vibrations. If I ever slip up, the intensity is extreme."
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3 5) Change from Baseline Health Status
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8 **Theme 13. People with vibrations and tremors had varying health**
9 **states before their COVID-19 infection, from those who were**
10 **completely healthy to those with pre-existing conditions.**
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15 *Example 1.*
16

17 "I was a healthy [30-35-year-old] marathon runner. Now I'm a [30-35-year-
18 old] individual who is grieving who the person was, figuring out how this
19 new body works, realizing it still works differently day-to-day, while also
20 having physicians refuse to treat me."
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30 *Example 2.*
31

32 "I am an extremely physically active [50-55-year-old] peri- menopausal
33 Canadian female with no pre-existing conditions except for being a migraine
34 sufferer all my adult life."
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42 6) Experience with Medical Establishment
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47 **Theme 14. Medical testing failed to reveal the mechanism of either**
48 **tremors or vibrations.**
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51 *Example 1.*
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3 "Had a brain CT & brain MRI (all normal). 2. After a short duration of sleep
4 or a nap (15-30 minutes), upon waking I feel that my heart is racing, like
5 palpitations. I feel shaky...as if there is a fast motor running inside me. I've
6 now learned to sit up slowly and give it a few minutes and then it goes
7 away. Diagnostic cardiac/pulmonary tests I've had: EKGs, CT Thoracic Stress
8 test, Echocardiogram, Pulmonary Function & Blood Oxygen Stress (all
9 normal). Had over 50 lab/blood tests and all normal."
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23 *Example 2.*

24 "Had MRI that showed micro clots and white matter. Had an EEG but do not
25 know results."
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32 **Theme 15. Tremor and vibration symptoms were sometimes doubted**
33 **or dismissed by doctors.**
34
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36 *Example 1.*

37 "Some doctors have been very dismissive and charted that 'she just prefers
38 not to walk'. When I arrived at ER, my previous Neurology MD requested
39 Pysch consult..this delayed medical evaluation. They did not believe my pain
40 nor that I could not breathe as my husband begged them to roll me to my
41 side as they tied me flat to the bed. Most of the time I could barely speak as
42 spasms affected my mouth. The previous Neurologist told me to 'dumb
43 myself down as a nurse and quit researching and causing myself stress'.
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6 *Example 2.*
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8 "In August 2020, when my heart started racing for hours, I tried to speak to
9
10 my pulmonologist, and they had a local doctor call who was running a test
11
12 site, and wanted to assure me it wasn't possible for me to have Covid
13
14 because (1) it wasn't in our area yet, but I was in Boston the day before
15
16 they announced an outbreak, (2) that symptoms only last 2 weeks max, and
17
18 I explained Long Covid. (3) That I shouldn't read research that I can't
19
20 understand, but I used to work in a med related field, trained in pre-med/vet
21
22 including epidemiology, was part of a 2010-2015 pandemic task force
23
24 related group, and currently work in genetics research, so then she said that
25
26 (4) this is all in my head and I just need to get over myself and get back to
27
28 work full time (I was) and that work makes people better (fatigue says no).
29
30 She yelled at me for over 2 hours. She now is in charge of home bound
31
32 patient care and tells people they need to have compassion for Long Covid
33
34 as it can take 'a few weeks to recover' and then tells stories about people
35
36 who recover quickly being examples of 'good people' while insinuating that
37
38 those who stay ill don't want to heal. My doctors have run the gamut of not
39
40 believing me; to finally agreeing that Long Covid is real but that since I don't
41
42 have a positive test, I can't have it; to even if I have Long Covid, they don't
43
44 have treatment, so short of an ER admit, I just need to suck it up."
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3 **Theme 16. The vaccine was associated with both improvement in**
4 **symptoms for some people, and a relapse in symptoms for others.**
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8 *Example 1.*
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10 "I had slight tremors in my hands after originally getting sick in June 2020
11 and after my second vaccine, on [May 2021] (two days later) I started
12 having more seizure-like symptoms."
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20 *Example 2.*
21

22 "I had the internal vibrations intensely during my year of long haul. Since
23 the vaccine most of my symptoms have abated or significantly diminished. I
24 do still have some of the internal vibration though, especially after exertion."
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32 **Theme 17. Medications have been provided for tremor symptoms,**
33 **with varying results.**
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36 *Example 1.*
37

38 "They tried Gabapentin but it didn't stop them. From March through [July] I
39 had 5-9 seizures trying to fall asleep every night, but they only happened at
40 night. Since the Gabapentni wasn't working they switched me to Topamax. I
41 was ramping into Topamax throughout June but it wasn't working either. My
42 family and I got sick again at the end of June with something viral (multiple
43 negative Covid, Flu, and Strep tests that week). The same time they
44 adjusted my Topamax dosage up again. Something changed again. Suddenly
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3 I was having non-stop seizures back to back and was hospitalized [July] and
4
5 also again on [July] at two different hospitals for uncontrolled seizures. My
6
7 EEG showed normal and they switched meds again to Keppra. So far I am on
8
9 500 mg Keppra 2x day and ramping up, but my seizures are uncontrolled.
10
11 The meds work only for a few hours and I have had to go on Short Term
12
13 Disability from work.”
14
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19

20 *Example 2.*

21
22 “He also put me on the very lowest dose gabapentin 3x per day. I began the
23
24 medication the same night. The next day I had a terrible headache but
25
26 something felt different. I continued the meds 3x per day like directed. After
27
28 1 week I began to be able to get up and move a little. I began doing dishes
29
30 and light house work. My family was rejoicing. I was improving. After a few
31
32 weeks of being on the medication I could tell it was helping with all the pain.
33
34 The tremors were still there, but were farther in the background, if that
35
36 makes sense? ..as if they had been put on soft mute. The meds weren't
37
38 stopping the tremors but calmed them I guess.”
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47 7) Impact on People’s Lives and Livelihood
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52 **Theme 18. Vibrations and tremors were associated with mental**
53
54 **health effects, including anxiety, depression, and suicidal thoughts.**
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3 *Example 1.*
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5 "The psychologist who saw me for 30 minutes gaslit me saying I need to
6 exercise more as my severe depression could be the cause of my symptoms
7 when I called him on that he said he noted in his report 'as tolerated' that
8 my chronic fatigue syndrome could also be the cause but he doesn't deal
9 with that only psychological causes. My therapist says I am clearly
10 depressed because of my fatigue from what she has seen for a year. Being
11 in constant pain, unable to participate in life day after day, month after
12 month is depressing. Of course I feel useless. Of course I feel things might
13 not get better. I haven't been functioning for 16 months!"
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30 *Example 2.*
31

32 "I could not sleep and went 15 days straight with no sleep. I was suicidal in
33 addition to all the other Covid symptoms, thus one showed up two months
34 after my acute Covid."
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42 **Theme 19. Vibration and tremor symptoms caused disability for**
43 **some people.**
44

45 *Example 1.*
46

47 "I am writing to advise that I am one of the Covid long-haulers who is
48 experiencing hand tremors. I feel them in my arms also and occasionally in
49 my voice and breathing. The tremors in my hands are so severe that I
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3 cannot grip or hold a pen for any length of time before my hand writing
4
5 deteriorates to chicken scratch. I have also resorted to dictating many of my
6
7 emails and messages because my fingers don't hit the right keys. I don't
8
9 know if tinnitus qualifies as internal vibration but I do have it and it is
10
11 getting louder all the time. It causes me great anxiety and I have not been
12
13 able to discover a treatment or solution."
14
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20 *Example 2.*

21
22 "Since March, I have had limited mobility as my legs give way and do not
23
24 have the strength to walk unassisted. I have to use a chair to shower and
25
26 walk with a cane. I cannot walk across the room without falling into things
27
28 and struggle with balance. I have felt internal tremors that feel like a
29
30 fizzing/bubbling that moves through my trunk and extremities. My arms and
31
32 legs shake and I have problems even with holding my fork still to feed
33
34 myself. My mind doesn't cooperate most days and I have speech issues with
35
36 slurred speaking and stuttering."
37
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45 **Theme 20. Vibrations and tremors could disturb or prevent sleep.**

46 *Example 1.*

47
48 "Mostly Every morning waking up, there is an electrical zap from the top of
49
50 my spine to mid back. Before I knew what the correct term was, I was
51
52 telling doctors I buzz like a battery. This sensation happens first when I'm
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3 opening my eyes in the morning. It's the first conscious feeling in the
4 morning every day. If I try and go back to sleep the vibrations get more
5 intense and more upsetting. So the best thing to do upon waking up is just
6 get up and go on about my day. If I take a nap during the day. No problem,
7 no vibrations. But there is a limit that I can sleep at any time, so if I do nap
8 When I wake up, I don't try and sleep more. There is I feel, a component of
9 the vibrations That affect my sleep. I am very tired and feel most nights that
10 my brains at war with itself and I don't feel refreshed when waking up.
11 Sometimes, not very often, I will get a whole body tremor feeling it's
12 unpleasant but, doesn't last very long. I would say the ones that wake me
13 up in the morning are more bothersome because I do not wake up gently or
14 quietly. It really is internal torture."
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35 *Example 2.*

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37 "Just when I thought I was done developing new symptoms in March this
38 started, every time I start to fall asleep I get shooting pain and immense
39 pressure in my arms, legs and spine. It wakes me up instantly. Imagine all
40 the times you doze off a little in the day, times that by 20 if you are on
41 medications that make you sleepy and try to imagine how torturous that
42 symptom is when it happens to you 20 times a day. No one knows what this
43 is or how to stop it. I'm forced to take muscle relaxers, lyrica, and Ativan to
44 try to get to sleep before the symptom starts."
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6 **Theme 21. Vibration and tremor symptoms could prevent people**
7
8 **from working or carrying out daily life activities.**
9

10 *Example 1.*

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13 “I am not the person I was before Covid. I used to paint, refinish furniture,
14 hang out with girlfriends, dance, golf, bike, travel, date. Now I barely have
15 the energy to help my patient which is the only reason I have a roof over my
16 head. If I can't do it at any point, he needs to replace me and I lose my
17 place to stay. I have no income and I couldn't possibly work.”
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27 *Example 2.*

28
29
30 “I got covid [September 2020]. I'm a nurse practitioner and cared for
31 patients with Covid. I tried to go back to work. And after my psych Neuro
32 testing I was found to have cognitive decline and severe memory recall and
33 other memory issues. I was pulled from work [March], and then let go
34 [May].”
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45 **Theme 22. Vibration and tremor symptoms could cause financial**
46 **stress, through a combination of medical care costs and loss of**
47 **income from medical leave.**
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49

50 *Example 1.*

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3 “Before the pandemic was looking for another part time job so could live in a
4 better place Now am drowning in medical debt with no relief in sight or
5 ability to hold a job This has devastated my life Now am stuck living in an
6 old garage without plumbing Hauling water back and forth from a garden
7 hose and dumping dirty water takes what little energy have.”
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18 *Example 2.*

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20 “I got Covid [September 2020] and continue to have daily debilitating
21 symptoms that have prevented me from going back to work. Side note: is
22 there any government funding for those of us who are long haulers and can’t
23 get back to work yet? My short term disability ran out beginning of April and
24 I’ve been without any income since. It’s getting really tough.”
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35 Facebook

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37 For all 450 comments combined, the 10 most frequent terms were
38 tremors (64%), COVID (55%), pain (51%), vibrations (43%), months
39 (36%), burning (29%), feet (24%), hands (22%), legs (21%), and back
40 (20%). Two Word Clouds were generated based on prevalent terms related
41 to the themes found in emails.
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49 The first Word Cloud (Figure 1) analyzed 288 comments in response to
50 a post that requested people experiencing tremors or internal vibrations to
51 comment. This Word Cloud revealed that the five most common words used
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3 in comments were: tremors, COVID, vibrations, months, and pain. Words
4 included also indicated that symptoms ranged in presentation and severity,
5 and vibrations were mentioned, as were seizures, shaking, and twitching.
6
7 This Word Cloud also included other long COVID symptoms including brain
8 fog, fatigue, and anxiety. Words indicating timing and duration of symptoms
9 included months, days, and constantly. The only medication captured was
10 gabapentin. Finally, similarly to the email responses, comments included
11 mentions of sleep and being tired.
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22 The second Word Cloud (Figure 2) was created based on 162
23 comments to a Survivor Corps poll that asked respondents about vibration
24 or buzzing sensations and neuropathic pain. This Word Cloud revealed that
25 pain, burning, COVID, legs, hands, and feet were the most common terms
26 mentioned in comments. This Word Cloud included terms related to
27 sensations such as burning and symptoms such as shingles and thrush.
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40 **Discussion**

41
42 This study describes key themes and experiences among a group of
43 individuals reporting long COVID and a prolonged and debilitating symptom
44 complex that prominently involves internal tremors and vibrations. While
45 symptom experiences were heterogenous—in symptom timing, medical
46 history, and initial infection, for instance—there were also common themes
47 in how individuals described these symptoms and their effects. Individuals
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3 also reported how diagnostic evaluation and medical care have not yet
4
5 identified possible mechanisms or successful treatment for these symptoms.
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8 Although the causal pathway remains unclear from these patient
9
10 reports alone, these patient experiences demonstrate the suffering caused
11
12 by this symptom complex. Many of the themes identified in this analysis
13
14 demonstrate physical suffering, including due to severe pain (Theme 2),
15
16 constancy of the tremor episodes (Theme 7), and tremors lasting for months
17
18 or even over a year after initial infection (Theme 10). Our findings,
19
20 importantly, also demonstrate how the suffering from this symptom complex
21
22 invade peoples' lives, livelihood, and psychological wellbeing.
23
24 wellbeing. Themes included effects on mental health such as anxiety,
25
26 depression, and suicidality (Theme 18), and effects on daily functioning
27
28 including inability to exercise (Theme 11), sleep deprivation (Theme 20),
29
30 and even disability (Theme 19). The cumulative toll of these limits on daily
31
32 functioning and wellbeing led some people to have to
33
34 quit or pause working and household or family responsibilities (Theme 21)
35
36 and to fall into debt or financial distress consequently (Theme 22). Each
37
38 individual's experience with these symptoms was different, and not all
39
40 experienced the most severe effects. However, the reports revealed a
41
42 pattern that these symptoms could cause immense pain and disruption to
43
44 daily lives and livelihood.
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3 This study extends the literature in several ways. Previous literature
4 consists of case series that provide preliminary reports of patients' clinical
5 presentation, course of care, and outcomes, but information on people's
6 experience with tremors more broadly has not been described in relation to
7 PASC.⁵⁻¹² In addition, prior literature describes symptoms from the point of
8 view of healthcare providers, but not from patients themselves. Previous
9 case-series reports included a total of 16 people previously infected with
10 SARS-CoV-2 who suffered from myoclonus-ataxia syndrome between 3 days
11 to 6 weeks after acute, often mild, or moderate, infection.⁵⁻¹² Our report
12 attempts to add a larger, broader overview of experiences of these
13 symptoms. Our analysis expands upon the sensorimotor symptoms
14 described to date. Furthermore, we describe symptoms experienced by
15 individuals who might not have sought formal medical care.

16
17 This study, although limited in scope, is an effort to channel the
18 perspective of patients for a condition that has yet to be defined. The utility
19 of this study is that it may enable more formal and structured data collection
20 for individuals with this syndrome. These experiences should be more
21 rigorously characterized to develop hypotheses and understand mechanisms.

22
23 There are several key implications of the work. First, internal
24 vibrations and tremors cause severe suffering for a group of individuals after
25 self-reported SARS-CoV-2 infection. Second, while the overall scale of these
26 symptoms is still unknown, this group of people experiencing the symptoms

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3 have not recovered from the symptoms nor have they received specific
4
5 diagnoses or been given treatment that completely alleviates their suffering.
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8 Third, the descriptions of feeling internal vibrations and tremor symptoms
9
10 were similar across this group of patients and independent of one another's
11
12 responses as the emails were not seen by the other participants.
13
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15 This study has several limitations. Respondents were a convenience
16
17 sample with minimal information about their demographic or clinical
18
19 characteristics, including laboratory-confirmed infection with COVID-19. Any
20
21 information about testing is based on self-report. As such, we cannot
22
23 determine whether these symptoms were caused by their infection with
24
25 SARS-CoV-2, nor whether the symptoms reported by different people were
26
27 the same symptom complex or of the same etiology. We also cannot
28
29 determine whether the sample is representative of the source population
30
31 experiencing these symptoms. The data are self-reported and cross-
32
33 sectional; information was limited to what individuals provided in their initial
34
35 communication and there was no follow-up. This limited the scope of
36
37 findings and may have excluded information that medical professionals
38
39 would have found relevant. This sample may have been skewed toward
40
41 individuals healthy enough to be active members of a patient community
42
43 (Survivor Corps) and to email a response to the group. Finally, this study
44
45 cannot provide information on the incidence and prevalence of these
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47 symptoms.
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3 In conclusion, some individuals report experiencing internal vibration
4 and tremor symptoms, often causing intense suffering, after a self-reported
5 history of SARS-CoV-2 infection. The symptoms had some common features
6 but there was variability in timing, concomitant symptoms, and impact.
7
8 Further research is needed to understand and alleviate this suffering, by
9
10 studying the extent and scope of these symptoms, possible mechanisms,
11
12 and potential treatment.
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Competing Interests Statement

In the past 3 years, Dr. Krumholz reported receiving personal fees from the Massachusetts Medical Society, UnitedHealth, IBM Watson Health, Element Science, Aetna, Facebook, Siegfried and Jensen Law Firm, Arnold and Porter Law Firm, Martin and Baughman Law Firm, F-Prime, and the National Center for Cardiovascular Diseases in Beijing; being a cofounder of HugoHealth and Refactor Health; and receiving grants and/or contracts from the Centers for Medicare & Medicaid Services, Johnson & Johnson, Agency for Healthcare Research and Quality, National Institutes of Health, and the American Heart Association, outside the submitted work. The other authors report no potential conflicts.

Contributor and Guarantor Information

DM and HK had full access to all of the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis. DM, AB, and HK conducted the analysis and drafted the manuscript. DBG, NG, and SPS generated the study idea. MS, AB, DBG, NG, SPS, LF, CG, CC, TZ, and RS contributed to study design and writing.

Transparency Statement

DM, MS, and HK affirm that this manuscript is an honest, accurate, and transparent account of the study being reported; no important aspects

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2
3 of the study have been omitted; and there were no discrepancies from the
4
5 study as originally planned.
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10 **Funding Statement**

11
12 This study received no funding.
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15

16 **Data Sharing Statement**

17
18 Deidentified data will be shared by the corresponding author upon
19
20 request.
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30 **Ethics Approval**

31
32 This study involves human participants, but the Yale Institutional
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34 Review Board exempted this study.
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40 **Patient and Public Involvement**

41
42 Members of the patient advocacy group, Survivor Corps (DBG, NG,
43
44 SPS and LF), played a central role in this research, actively engaging
45
46 through social media and emails to disseminate surveys, collect responses,
47
48 and offer insightful feedback on comprehensive analysis drafts. The
49
50 development of research questions was profoundly influenced by the
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3 patients' priorities, experiences, and preferences, facilitated through multiple
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5 interactive sessions that prioritized domain and theme shaping.
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Supplement 1

To solicit emails for this study, Survivor Corps and Nick Güthe requested emails from Survivor Corps members via Facebook and an emailed newsletter that is also posted on the Survivor Corps website.

First, Nick Güthe posted the following in the Survivor Corps Facebook page [July 2021]:

"Hi, to anyone on this group. It's Nick Güthe, Heidi Ferrer's husband. A study is forming with a top doctor for Long Haulers with Neurological tremors similar to Heidi Ferrer's -- Tremors or internal vibrations. If you have these symptoms and want to be included please comment below. This isn't a clinical trial but an attempt to gather data and stories to help get funding, bring attention to these symptoms which are so destructive to any Long Haulers physical and mental health."

Nick Güthe and Diana Zicklin Berrent responded to Facebook comments on this post to ask members to email their story, writing: "Send your story to hq@survivorcorps.com."

Second, a [newsletter](#) sent to members included the following [July 2021]:

*"A study is forming for Long Haulers with Neurological tremors or internal vibrations. If you have these symptoms and want to be included, please **EMAIL** us with your details. This is not a clinical trial, but an attempt to gather data and stories to help get funding, and bring attention to these destructive symptoms that impact Long Hauler's physical and mental health."*

Supplement 2. Email Initial Code List

Below is listed the initial code list created by authors HMK and DM, prior to input from all team members and creation of the final code.

1) Symptom Perception and Location

Vibrations and tremors were described concomitantly, with descriptions of internal vibrations, visible tremors, and some people experiencing both.

Vibration or tremor site varied, from the entire body to localization in extremities, chest, abdomen and other locations.

Vibrations and tremors occurred with other symptoms of varying number.

Vibrations and tremors could cause severe pain.

2) Initial Symptom Onset

Vibration and tremor initial onset varied, from the day of initial infection to weeks later.

Vibrations and tremors occurred following or during acute COVID-19 infections that varied from mild to severe.

3) Symptom Timing

Vibration and tremor episodes could be brief, or could be prolonged, even constant.

Vibration and tremor episodes could occur constantly, daily, or only when relapses occurred.

People experienced vibrations and tremors over different time periods (even if they were episodic), and some did not have improvement in symptoms after more than a year.

4) Symptom triggers or alleviators

The vaccine was associated with both improvement in symptoms for some people, and a relapse in symptoms for others.

Exercise and activity were associated with onsets of tremors and vibrations.

A variety of self-treatment strategies, such as diet modifications and humming, were used to alleviate tremors and vibrations.

5) Change from Baseline Health Status

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2
3 People with vibrations and tremors had varying health states before their COVID-19 infection, from
4 those who were completely health to those with pre-existing conditions.
5

6) Experience with Medical Establishment

8
9 Medical testing failed to reveal the mechanism of either tremors or vibrations.

11 Tremor and vibration symptoms were sometimes doubted or dismissed by doctors.

13 Medications have been provided for tremor symptoms, with varying results.
14

7) Effect on People's Lives and Livelihood

17
18 Vibrations and tremors were associated with mental health effects, ranging from anxiety to suicidal
19 thoughts.
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21 Vibration and tremor symptoms could cause disability people.
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23 Vibration and tremor symptoms could cause financial stress, through a combination of medical care
24 costs and loss of income from medical leave.
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27 Vibrations and tremors could disturb or prevent sleep.
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29 Vibration and tremor symptoms could prevent people from working or carrying out daily life activities.
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Supplement 3. World Cloud Analysis Methodology

Leveraging the "quanteda" [1], "wordcloud" [2], and "tm" [3] packages in R, we constructed a Word Cloud of the most frequent words used to express some long-term effects of experiencing a COVID-19 infection among a Facebook COVID-19 survivors page. The data was converted from an xlsx to a txt file where it was then loaded as a corpus file, a specific type of file format required for Word Cloud generation, using the "Corpus" function in the "quanteda" package. To clean the corpus file, we utilized the "tm_map" function in the "tm" package to convert all text to lower case, to remove numbers, to remove punctuation and special characters, and then to collapse extra white space characters to a single blank space. Once cleaned, we built a term-document matrix which was then read into the "wordcloud" function within the "wordcloud" package. We set the minimum frequency of words to be included into the Word Cloud to 3, the maximum number of words allowed into the Word Cloud to 200, and then removed all extraneous, filler words such as "and", "comment", "view", "you." We included all adjectives, nouns, and verbs associated with COVID signs, symptoms, and experiences into the Word Cloud.

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Supplemental Table 1. Full Survivor Corps Poll for Word Cloud 2

The following poll was posted in Survivor Corps [June 2021] and was titled "Vibration/Buzzing/Pain Poll." There were 20 answer choices, each a statement relevant to vibration, tingling, buzzing, and neuropathic sensations. We have included the poll and responses for context, but for the purposes of qualitative analysis, we reviewed only the comments posted in response to this poll. These poll responses were collected as of July 16, 2021. The following text was included with the Facebook poll:

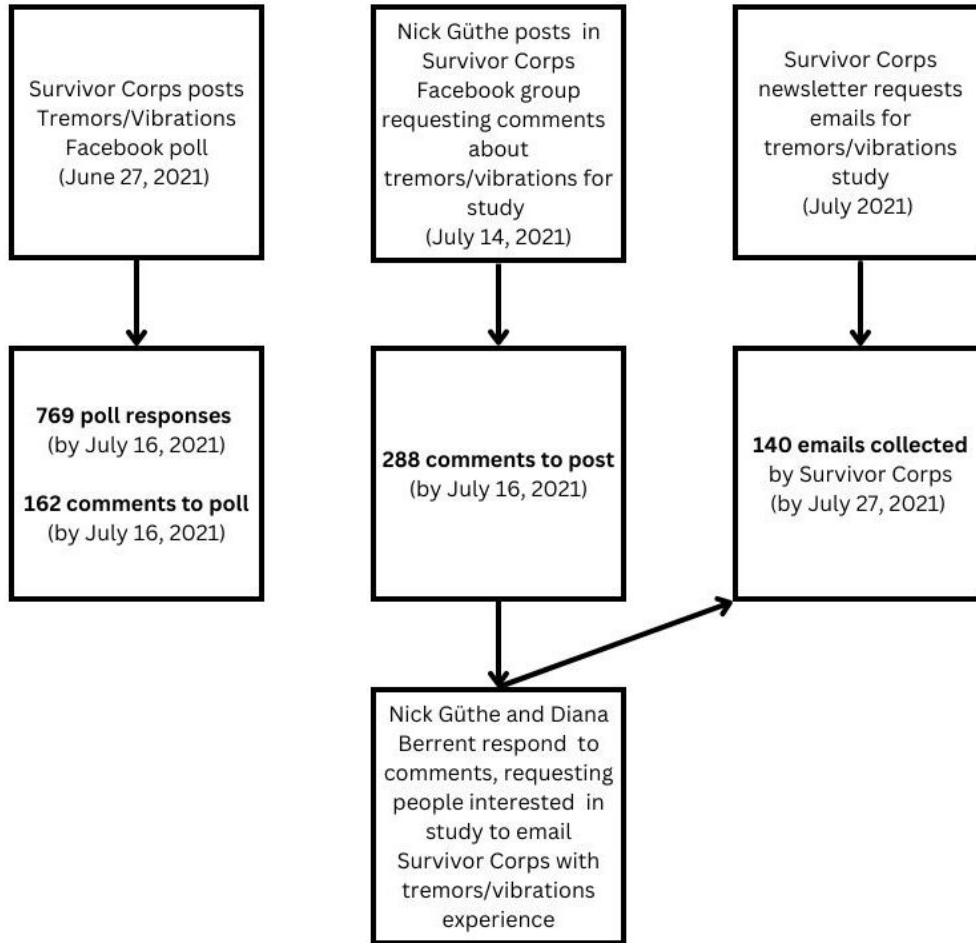
"VIBRATION / BUZZING / PAIN POLL

*SO MANY LONG HAULERS ARE DESCRIBING A BUZZING OR VIBRATION OR
NEUROPATHIC PAIN IN THEIR BODIES AND EXTREMITIES - WE WANT TO LEARN
MORE!"*

Answer Choice	Number of Votes
I am participating in this poll (please check here!)	769
I HAVE experienced new tingling / buzzing / vibrating feelings since Covid	660
These vibrating feelings come and go	590
I HAVE had neuropathic pain (burning feeling on skin) since Covid	396
These vibrations appear in different parts of my body at different times	365
The neuropathic pain (burning feeling on skin) comes and goes	345
I have these vibrating feelings mostly in my extremities	268
These vibrations bother me a great deal	252
My neuropathic pain (burning feeling on skin) has been in my hands and feet	232
The neuropathic pain (burning feeling on skin) bothers me a great deal	232
My neuropathic pain (burning feeling on skin has been all over my body)	149

These vibrations feel "like they are making me insane"	129
I have NOT had neuropathic pain (burning feeling on skin) since Covid	111
I have these vibrating feelings mostly in my chest	98
The neuropathic pain (burning feeling on skin) is excruciating / makes me feel "like I'm going insane"	67
I have NOT experienced any new tingling / buzzing/ vibrating feelings since Covid	48
The neuropathic pain (burning feeling on skin) is constant	44
These vibrating feelings are constant	35
These vibrations don't bother me	22
The neuropathic pain (burning feeling on skin) doesn't bother me very much	21

Supplemental Figure 1. Data Collection Process



Supplemental Figure 2. Roadmap of themes and domains

Domain 1. Symptom Experience, Description, and Anatomic Location

Theme 1. Vibrations and tremors were described concomitantly, with descriptions of internal vibrations, visible tremors, and some people experiencing both.

Theme 2. Vibration or tremor site varied, from the entire body to localization in extremities, chest, abdomen, and other locations.

Theme 3. Vibrations and tremors occurred with other symptoms of varying number.

Theme 4. Vibrations and tremors could cause severe pain.

Domain 2. Initial Symptom Onset

Theme 5. Vibration and tremor initial onset varied, from the day of initial infection to weeks or even months later.

Theme 6. Vibrations and tremors occurred following or during acute COVID-19 infections that varied from mild to severe.

Domain 3. Symptom Timing

Theme 7. Vibration and tremor episodes could be brief, or could be prolonged, even constant.

Theme 8. Vibration and tremor episodes could occur constantly, daily, or only when relapses occurred.

Theme 9. Vibration and tremor symptoms could completely resolve temporarily and could return up to months later.

Theme 10. People experienced vibrations and tremors over different time periods (even if they were episodic), and some did not have improvement in symptoms after more than a year.

Domain 4. Symptom triggers or alleviators

Theme 11. Exercise and activity were associated for some with onsets of tremors and vibrations.

Theme 12. A variety of self-treatment strategies, such as diet modifications and humming, were used to alleviate tremors and vibrations.

Domain 5. Change from Baseline Health Status

Theme 13. People with vibrations and tremors had varying health states before their COVID-19 infection, from those who were completely healthy to those with pre-existing conditions.

Domain 6. Experience with Medical Establishment

Theme 14. Medical testing failed to reveal the mechanism of either tremors or vibrations.

Theme 15. Tremor and vibration symptoms were sometimes doubted or dismissed by doctors.

Theme 16. The vaccine was associated with both improvement in symptoms for some people, and a relapse in symptoms for others.

Theme 17. Medications have been provided for tremor symptoms, with varying results.

Domain 7. Impact on People's Lives and Livelihood

Theme 18. Vibrations and tremors were associated with mental health effects, including anxiety, depression, and suicidal thoughts.

Theme 19. Vibration and tremor symptoms caused disability for some people.

Theme 20. Vibrations and tremors could disturb or prevent sleep.

Theme 21. Vibration and tremor symptoms could prevent people from working or carrying out daily life activities.

Theme 22. Vibration and tremor symptoms could cause financial stress, through a combination of medical care costs and loss of income from medical leave.

STROBE Statement—Checklist of items that should be included in reports of *cross-sectional studies*

	Item No	Recommendation	Page No
Title and abstract	1	(a) Indicate the study's design with a commonly used term in the title or the abstract	1
		(b) Provide in the abstract an informative and balanced summary of what was done and what was found	4
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	8
Objectives	3	State specific objectives, including any prespecified hypotheses	8-9
Methods			
Study design	4	Present key elements of study design early in the paper	9
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	9
Participants	6	(a) Give the eligibility criteria, and the sources and methods of selection of participants	9
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	10-11
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	10-11
Bias	9	Describe any efforts to address potential sources of bias	11-13
Study size	10	Explain how the study size was arrived at	9-11
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	11-13
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding	NA
		(b) Describe any methods used to examine subgroups and interactions	NA
		(c) Explain how missing data were addressed	NA
		(d) If applicable, describe analytical methods taking account of sampling strategy	NA
		(e) Describe any sensitivity analyses	NA
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	NA
		(b) Give reasons for non-participation at each stage	NA
		(c) Consider use of a flow diagram	NA
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	NA
		(b) Indicate number of participants with missing data for each variable of interest	NA
Outcome data	15*	Report numbers of outcome events or summary measures	NA

1 2 3 4 5 6 7 8 9 10 11	Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	NA
12 13 14			(b) Report category boundaries when continuous variables were categorized	NA
15 16 17 18 19 20 21 22 23 24			(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	NA
25 26 27	Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	NA
28	Discussion			
29 30 31 32	Key results	18	Summarise key results with reference to study objectives	33
33 34 35 36 37 38 39 40 41 42 43 44 45 46 47 48 49 50 51 52 53 54 55 56 57 58 59 60	Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	36
	Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	33
	Generalisability	21	Discuss the generalisability (external validity) of the study results	36
	Other information			
	Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	39

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at www.strobe-statement.org.

BMJ Open

Characterization of internal tremors and vibration symptoms among people with post-acute sequelae of SARS-CoV-2: A narrative analysis of Email and social media comments in a patient advocacy group

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Primary Subject Heading:	Infectious diseases
Secondary Subject Heading:	Qualitative research, Neurology, Immunology (including allergy)
Keywords:	COVID-19, NEUROLOGY, REGISTRIES

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3 **Characterization of internal tremors and vibration symptoms**
4 **among people with post-acute sequelae of SARS-CoV-2:**
5 **A narrative analysis of email and social media comments**
6 **in a patient advocacy group**
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Abstract

Objectives: To describe the experiences of patients who have post-acute sequelae SARS-CoV-2 infection (PASC) with internal vibrations and tremors as a prominent component, we leveraged the efforts by Survivor Corps, a grassroots COVID-19 patient advocacy group, to gather information from individuals belonging to its Facebook group with a history of COVID-19 suffering from vibrations and tremors.

Setting and Design: A narrative analysis was performed on 140 emails and 450 social media comments from 140 individuals collected as a response to a call to >180,000 individuals participating in Survivor Corps between July 15 and July 27, 2021. We used common coding techniques and the constant comparative method for qualitative data synthesis and categorizing emails. Coded data were entered into NVivo 12 to identify recurrent themes, theme connections, and supporting quotations. Comments were analyzed using Word Clouds, generated with R version 4.0.3 using *quanteda*, *wordcloud*, and *tm* packages.

Main Outcome Measures: Patient-reported long COVID symptom themes and domains related to internal tremors and vibration.

Results: The respondents' emails represented 22 themes and 7 domains pertaining to their experience with internal tremor and vibrations. These domains were: (1) symptom experience, description, and anatomic location; (2) initial symptom onset; (3) symptom timing; (4) symptom triggers or alleviators; (5) change from baseline health status; (6) experience with medical establishment; and (7) impact on individuals' lives and livelihood. There were 22 themes in total, each corresponding to one of the broader domains. Among the responses, many described symptoms that varied in location, timing, and triggers, occurred soon after their COVID-19 infection, and were markedly debilitating. There were often frustrating experiences with the healthcare system.

Conclusions: This study describes key themes and experiences among a group of people reporting long COVID and having a prolonged and debilitating symptom complex that prominently features internal tremors and vibrations.

Strengths and limitations of this study

- This study investigated self-reported symptom experiences from the patient perspective from a convenience sample of patients experiencing internal tremors and vibration symptoms as post-acute sequelae of SARS-CoV-2.
- We used common coding techniques for qualitative data and the constant comparative qualitative data analysis method to identify themes from patients' experiences.
- This study represents a convenience sample and therefore cannot provide information on the incidence and prevalence of these symptoms.

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3 **Summary Box**
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5 **What this study adds:**
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7 This study contributes to the literature an understanding of the patient perspective
8 regarding internal tremor and vibrations, a potentially important cluster of similar symptoms
9 reported by people with long COVID.
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Introduction

Post-Acute Sequelae of SARS-CoV-2 infection (PASC), also known as long Covid, is a condition that is marked by protean manifestation that varies considerably among individuals.[1-4] Common symptoms among long COVID patients encompass a range of respiratory, metabolic, neuropsychiatric, and pain-related disorders, including postexertional malaise, fatigue, dizziness, brain fog, and gastrointestinal symptoms.[5] The heterogeneity of long COVID necessitates attention to specific clusters of individuals who are suffering from similar symptoms. Proper clustering may enable efforts to identify biological, cognitive, and behavioral signatures of long COVID that help elucidate underlying mechanisms to guide the development of diagnostic and therapeutic strategies.

Some individuals with long COVID manifest symptoms that they describe as internal tremors and vibrations. To date, these symptoms, as experienced by patients, have not yet been well described. There are reports of patients with myoclonus, but they are described from the perspective of clinicians.[6-13] Although no underlying cause of the myoclonus episodes among patients with long COVID has been identified, other studies have reported cases of myoclonus episodes following COVID-19.[14-16]

To understand the perspective of patients who have long COVID with tremors and vibrations as a prominent component, we leveraged the efforts by Survivor Corps, a grassroots COVID-19 patient advocacy group, to gather information from individuals with long COVID who belong to its Facebook group and suffer from these symptoms.[17-19] We conducted a qualitative analysis of responses and organized them according to prominent themes. The goal of this study was to characterize the patient perspective and identify a potentially important cluster of similar symptoms that individuals with long COVID are reporting.

Methods

Study Design and Sample

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2
3 This study was a narrative analysis of emails and Facebook comments that were
4 received from members of Survivor Corps, a long Covid patient advocacy group where
5 members interact in a Facebook group. The concept for the study originated with the
6 experience of Heidi Ferrer and the initiative of her husband, NG. Heidi had severe
7 manifestations of the sensations of vibrations and exhibited tremors with onset early in the
8 pandemic. Heidi Ferrer ultimately committed suicide as she found the symptoms intolerable.
9 NG spoke with Survivor Corps, which initiated a call for individuals in its Facebook group of
10 over 180,000 individuals to report their experience with vibrations and tremors among
11 those with long COVID via emails and Facebook comments (Supplemental Table 1.). The
12 qualitative approach was chosen because previous literature characterizing the patient
13 perspective on these symptoms is limited.[20] In addition, a study participant, LF, was
14 involved as a coauthor in the study design and analysis by reviewing themes before final
15 analysis and providing feedback on the manuscript. This study received an exemption from
16 the Yale Institutional Review Board because the comments had been posted publicly.
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33 **Data Collection**

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35 Data were collected from unstructured responses that included 140 emails and 450
36 Facebook comments that occurred in response to Survivor Corps' calls for information in
37 July 2021. Exact dates and names were removed and replaced with month/year and five-
38 year age brackets to protect anonymity. Any information about testing and timing of acute
39 COVID infection were based on self-report.
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45 Survivor Corps collected data for this study in three steps. First, on June 27, 2021,
46 the Survivor Corps founder (DBG), posted a Facebook poll, titled "Vibration/Buzzing/Pain
47 Poll," in the Survivor Corps Facebook group (Supplemental Table 1). Responses were in a
48 multiple-choice answer format, where respondents could select multiple answers and also
49 add their own answer choices. There were 20 answer choices, each a statement relevant to
50 vibration, tingling, buzzing, and neuropathic sensations (Supplemental Table 1). The
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3 research team included all poll responses as of July 16, 2021, which totaled 769. In
4
5 addition, there were 162 Facebook comments posted by group members below the poll as
6
7 of July 16, 2021, which were all included in data analysis.
8

9
10 Next, Survivor Corps member NG posted in the Survivor Corps Facebook group on
11
12 July 14, 2021, requesting that anyone with long Covid in the group who had experienced
13
14 “tremors or internal vibrations” and was interested in participating in a study comment
15
16 below his post (Supplemental Figure 1). By July 16, 2021, there were 288 comments from
17
18 group members in response to his post, all of which were included in data analysis for this
19
20 study. In response to members' comments, NG and DBG requested that commenters share
21
22 their symptom stories via email with Survivor Corps for the study, with subjects' consent to
23
24 use their deidentified emails for research.

25
26 Finally, the Survivor Corps newsletter in July 2021 also included a request for “Long
27
28 Haulers” with “neurological tremors or internal vibrations” to send details of their symptoms
29
30 to Survivor Corps via email for this study (Supplement 1). Survivor Corps received 140
31
32 emails for this study between July 15 through July 27, 2021. All emails were included in
33
34 data analysis. Including the Facebook comments from the initial poll and the comments
35
36 from NG's post, 450 Facebook comments were analyzed in this study.
37
38
39

40 **Patient and Public Involvement**

41
42 Members of the patient advocacy group, Survivor Corps (DBG, NG, SPS and LF),
43
44 played a central role in this research, actively engaging through social media and emails to
45
46 disseminate surveys, collect responses, and offer insightful feedback on comprehensive
47
48 analysis drafts. The development of research questions was profoundly influenced by the
49
50 patients' priorities, experiences, and preferences, facilitated through multiple interactive
51
52 sessions that prioritized domain and theme shaping.
53
54

55 **Data Analysis**

Emails

Email data were analyzed using common coding techniques for qualitative data and the constant comparative method of qualitative data analysis.[21] Coding of the data was accomplished in iterative steps. An initial code list was generated after evaluation of the data by research team members (HMK and DM) (Supplement 2). The initial code list was created in three steps. First, each reviewer separately read the 140 emails (with names and exact dates redacted). Next, each reviewer separately read the 140 emails while creating themes based on the contents of each email, until each statement about internal tremors or vibrations in every email had been assigned to a theme. The reviewers then met to discuss shared themes and reached a consensus on the list of themes. The reviewers then grouped the themes into 7 larger domains. At this point, the full research team reviewed the code structure, including a study participant (LF), for logic and breadth.

Using this final version of the code structure, members of the research team (HMK and DM) independently coded all transcripts, then met to code in several joint sessions, achieving consensus and assigning codes to observations by a negotiated, group process. Coded data were entered into NVivo (version 12, [Lumivero, Denver, CO]) to assist in reporting recurrent themes, links among the themes, and supporting quotations.

Facebook Comments

We used Word Cloud methodology to visualize the prevalence of terms (Supplement 3). A Word Cloud is a visual representation of word frequency derived from written text. The more often the word appears within the passage being analyzed, the larger it appears in the image generated. We set the minimum frequency of words to be included in the Word Cloud to 3, the maximum number of words to 200, and removed extraneous filler words. Word Clouds were generated using the *quanteda*, *wordcloud*, and *tm* packages in R v4 version 4v4.0.3 (R Development Core Team, Vienna, Austria).[22, 23]

Results

Email data

After review of the email data, respondents' comments reflected 7 domains related to their experience with vibrations and tremors. These domains were: (1) symptom experience, description, and anatomic location; (2) initial symptom onset; (3) symptom timing; (4) symptom triggers or alleviators; (5) change from baseline health status; (6) experience with medical establishment; and (7) impact on people's lives and livelihood. There were 22 themes total, each corresponding to one of the broader domains. Sample quotations are listed to illustrate the themes (Supplemental Figure 2).

1) Symptom Experience, Description, and Anatomic Location

Theme 1. Vibrations and tremors were described concomitantly, with descriptions of internal vibrations, visible tremors, and some people experiencing both.

Example 1.

"Sometimes my entire body feels like it's humming and trembling. It's like I'm sitting on a huge speaker with the volume all the way up. Through the progression of the last few months, the complete body humming has slowed down, but still happens 5-8 times a month. My hands and legs also began trembling about the same time as the whole body. My legs bob up and down aggressively at times. I'm not cold, I'm not restless, but my legs visibly move up and down like I'm tapping my foot. My hands have been the worst of it. I felt like they had improved a few months ago, but they're back with a vengeance. I'm not hungry ever. I know I need to eat, and my go-to has been soup. By the time I get the spoon 4 inches above the bowl, and close to my mouth, all of the broth has been "shaken" off. My handwriting.. awful. Sometimes I absolutely cannot stand myself and just go to bed. That happens more often than not. I usually try to hide my hands in my pockets or under

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2
3 the table, but am not always able to do that. When my whole body is tremoring, I find it a
4
5 lot more difficult to focus and to get anything accomplished.”
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9 *Example 2.*

10
11 “Internal vibrations started about 3 weeks after. They started in my back and back of upper
12
13 thighs. It felt like I was sitting on a vibration massage chair. They never went away but
14
15 would vary in intensity. February 2021 I started having restless left arm at bedtime where
16
17 my left arm would flap until I fell asleep. On [May 2021] it progressed to full body myoclonic
18
19 movements lasting up to 30 minutes.”
20
21
22

23 **Theme 2. Vibration or tremor site varied, from the entire body to localization in**
24
25 **extremities, chest, abdomen, and other locations.**
26

27 *Example 1.*

28
29 “I experience daily internal tremors/vibrations all over but mainly inside my brain and chest.
30
31 I have external tremors in my legs, arms and chest.”
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33
34

35 *Example 2.*

36
37 “Still suffering with symptoms. One of which is tremors and internal vibrations primarily in
38
39 the legs and feet but do sometimes occur in arms.”
40
41
42

43 **Theme 3. Vibrations and tremors occurred with other symptoms of varying**
44
45 **number.**
46

47 *Example 1.*

48
49 “I also experience relentless headaches. I have had the same one, in varying degrees, since
50
51 October. Crushing fatigue. Vivid dreams. And the worst, word retrieval.”
52
53
54

55 *Example 2.*

1
2
3 "Here is a list of my current symptoms that I have over a year after my acute infection: 1.
4 Extreme Fatigue 2. Exercise Intolerance/Post-Exertion Malaise (Physical and Mental) 3.
5 Short-Term Memory Loss. Must carry a notebook to remember things 4. Brain Fog 5. Muscle
6 Weakness 6. Dizziness. Can't Drive 7. Seizures 8. Headaches/Migraines 9. High Blood
7 Pressure 10. Cold Hands and Feet 11. Ringing in Ears Tinnitus 12. Hoarseness/Loss of Voice
8
9 13. Loss of Coordination in Hands 14. Burning Sensation on Skin Lower Torso."
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16 17 **Theme 4. Vibrations and tremors could cause severe pain.**

18 19 *Example 1.*

20
21 "My brain shakes after a few hours inside my head, my face starts to tingle and numb, and
22 then the full head shaking seizures start. I have severe head pain and nausea constantly
23 from all the seizures."
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28

29 30 *Example 2.*

31
32 "That week of unrelieved spasms left my body barely able to move. Like paralyzed. I had 3
33 natural child births. I could not fake such 10/10 pain. I have never felt such intense pain, I
34 thought my back would break and my right arm would be completely dislocated twisted out
35 of socket. I could not breathe at times due to the Laryngeal spasms and diaphragm
36 spasms."
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44 2) Initial Symptom Onset

45 46 **Theme 5. Vibration and tremor initial onset varied, from the day of initial infection** 47 **to weeks or even months later.**

48 49 *Example 1.*

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51 "Symptoms started on [July]. About 3 weeks later, I developed tremors. I've had them ever
52 since."
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3 *Example 2.*
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5 "I contracted COVID from an ICU patient in May 2020. A few days later terrible headaches,
6 loss smell, lung, cardio, eye damage. Ongoing problems fatigue, Headaches, Migraines,
7 Imbalance, Dizzy, Vertigo, SOB, COPD, Brady/Tachycardia, SVT, chest pain, Gastric,
8 swallow, voice, cognitive, exercise intolerance, several leaves of absences off work. I had
9 many scans, tests, labs with both normal results and damage results. I have all Records.
10 Then few months later unrelenting Neuro issues vibrations, ripples, tremors, became
11 intense foot cramps, painful ankle, foot drop, leg spasms started mostly r foot. I had to
12 wear ankle brace use cane. Very difficult to sleep. Husband could see ripples under skin and
13 feel the vibrations at times. Body is constantly "on", pain, numb, burning, briar patch,
14 walking on nails, spikes r foot, can't put r foot flat. Also forearms, hands, r side worse."
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27 **Theme 6. Vibrations and tremors occurred following or during acute COVID-19**
28 **infections that varied from mild to severe.**
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31 *Example 1.*
32

33 "I was diagnosed with COVID-19 in July of 2020. I spent 2 months in the ICU and 9 days on
34 ECMO."
35
36
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38

39 *Example 2.*
40

41 "I had a moderate case of Covid in November of 2020 with multiple symptoms. I was never
42 hospitalized. I was recovered one week before my first Long Covid symptom of shortness of
43 breath began."
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49 3) Symptom Timing
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54 **Theme 7. Vibration and tremor episodes could be brief, or could be prolonged,**
55 **even constant.**
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3 *Example 1.*
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5 “The internal tremors in my chest generally only last for about 5 seconds or so and then
6 completely subside. The ones in my abdomen are more rare and have lasted for longer, but
7 still less than a minute or so in general.”
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12
13 *Example 2.*
14

15 “Now here at almost 8 months post covid, I have dealt with these horrible tremors daily.
16 They are constant, they don't come and go. They are 24/7. I feel them more when I am still
17 and resting or at night and early morning, or during naps. If I can just get up and get going
18 most days, I don't notice them much, unless the intensity increases and I get breakthrough
19 pain or headaches. But the night time always reminds me they are still there.”
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27 **Theme 8. Vibration and tremor episodes could occur constantly, daily, or only**
28 **when relapses occurred.**
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31 *Example 1.*
32

33 “The tremors and the dizziness are daily challenges.”
34
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38 *Example 2.*
39

40 “Tremors and ‘vibrations’ are a few of the many ongoing symptoms. The tremors I notice in
41 my hands and toes. It lasts for about 10 seconds or less about every 2 to 3 days. The
42 vibrations I notice when I first lay down for bed at night. It lasts about seconds.”
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48 **Theme 9. Vibration and tremor symptoms could completely resolve temporarily**
49 **and could return up to months later.**
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51 *Example 1.*
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3 "Even now, almost eight months out in July, I still occasionally experience these. They do
4 not occur daily, but do generally happen in conjunction with the relapse of other symptoms,
5 such as mild chest, throat, and back pressure/tightness, and tingling in my extremities."
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11 *Example 2.*

12
13 "Sometimes my entire body feels like it's humming and trembling. It's like I'm sitting on a
14 huge speaker with the volume all the way up. Through the progression of the last few
15 months, the complete body humming has slowed down, but still happens 5-8 times a
16 month. My hands and legs also began tremoring about the same time as the whole body.
17 My legs bob up and down aggressively at times. I'm not cold, I'm not restless, but my legs
18 visibly move up and down like I'm tapping my foot. My hands have been the worst of it. I
19 felt like they had improved a few months ago, but they're back with a vengeance."
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29 **Theme 10. People experienced vibrations and tremors over different time periods**
30 **(even if they were episodic), and some did not have improvement in symptoms**
31 **after more than a year.**
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38 *Example 1.*

39 "I got tremors on [December 2020] the day I got covid & it increased to where I had it in
40 my whole body vibrating on head as well increasing during activity. It's been very
41 debilitating & frustrating. I have been a patient in Rochester Minnesota Mayo Covid Clinic
42 and my symptoms have lessened. However, it is now it is [July] and the tremors have not
43 subsided."
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51 *Example 2.*

52 "I had Covid in early February 2020. I did not know I had it. Severe Headache, sore throat,
53 rash and crushing fatigue. Got better in a flash. 5 months later, the floor dropped out. By
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3 early October, hand tremors started. They have diminished and come back intermittently. It
4 is now 18 Months after the initial infection.”
5
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9 4) Symptom triggers or alleviators
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11

12
13 **Theme 11. Exercise and activity were associated for some with onsets of tremors**
14 **and vibrations.**
15

16
17 *Example 1.*
18

19 “Since then I notice that if I get my heart rate up too high (which could be anything above
20 110-15) the tremors and vibrations are made worse.”
21
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24
25 *Example 2.*
26

27 “I have had long covid for 6 months now, and I get tremors/vibrations/buzzing nerves
28 whenever I overextend myself.”
29
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31

32
33 **Theme 12. A variety of self-treatment strategies, such as diet modifications and**
34 **humming, were used to alleviate tremors and vibrations.**
35

36
37 *Example 1.*
38

39 “Regarding the nerve issues, I have found very recently that humming in the morning helps
40 me to stop the vibrations faster. I suspect our vagus nerve is being affected.”
41
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43
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45
46 *Example 2.*
47

48 “I have experimented with supplements, removing medicines, and diet. Removing all sugar
49 and processed foods from my diet has reduced the internal vibrations. If I ever slip up, the
50 intensity is extreme.”
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3 5) Change from Baseline Health Status
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7 **Theme 13. People with vibrations and tremors had varying health states before**
8 **their COVID-19 infection, from those who were completely healthy to those with**
9 **pre-existing conditions.**
10
11

12 *Example 1.*
13

14
15 "I was a healthy [30-35-year-old] marathon runner. Now I'm a [30-35-year-old] individual
16 who is grieving who the person was, figuring out how this new body works, realizing it still
17 works differently day-to-day, while also having physicians refuse to treat me."
18
19
20
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23 *Example 2.*
24

25 "I am an extremely physically active [50-55-year-old] peri- menopausal Canadian female
26 with no pre-existing conditions except for being a migraine sufferer all my adult life."
27
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31 6) Experience with Medical Establishment
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35 **Theme 14. Medical testing failed to reveal the mechanism of either tremors or**
36 **vibrations.**
37

38 *Example 1.*
39

40
41 "Had a brain CT & brain MRI (all normal). 2. After a short duration of sleep or a nap (15-30
42 minutes), upon waking I feel that my heart is racing, like palpitations. I feel shaky...as if
43 there is a fast motor running inside me. I've now learned to sit up slowly and give it a few
44 minutes and then it goes away. Diagnostic cardiac/pulmonary tests I've had: EKGs, CT
45 Thoracic Stress test, Echocardiogram, Pulmonary Function & Blood Oxygen Stress (all
46 normal). Had over 50 lab/blood tests and all normal."
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56 *Example 2.*
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3 "Had MRI that showed micro clots and white matter. Had an EEG but do not know results."
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7 **Theme 15. Tremor and vibration symptoms were sometimes doubted or dismissed**
8 **by doctors.**
9

10
11 *Example 1.*
12

13 "Some doctors have been very dismissive and charted that 'she just prefers not to walk.'
14
15 When I arrived at ER, my previous Neurology MD requested Pysch consult..this delayed
16
17 medical evaluation. They did not believe my pain nor that I could not breathe as my
18
19 husband begged them to roll me to my side as they tied me flat to the bed. Most of the time
20
21 I could barely speak as spasms affected my mouth. The previous Neurologist told me to
22
23 'dumb myself down as a nurse and quit researching and causing myself stress'. "
24
25
26

27
28 *Example 2.*
29

30 "In August 2020, when my heart started racing for hours, I tried to speak to my
31
32 pulmonologist, and they had a local doctor call who was running a test site, and wanted to
33
34 assure me it wasn't possible for me to have Covid because (1) it wasn't in our area yet, but
35
36 I was in Boston the day before they announced an outbreak, (2) that symptoms only last 2
37
38 weeks max, and I explained Long Covid. (3) That I shouldn't read research that I can't
39
40 understand, but I used to work in a med related field, trained in pre-med/vet including
41
42 epidemiology, was part of a 2010-2015 pandemic task force related group, and currently
43
44 work in genetics research, so then she said that (4) this is all in my head and I just need to
45
46 get over myself and get back to work full time (I was) and that work makes people better
47
48 (fatigue says no). She yelled at me for over 2 hours. She now is in charge of home bound
49
50 patient care and tells people they need to have compassion for Long Covid as it can take 'a
51
52 few weeks to recover' and then tells stories about people who recover quickly being
53
54 examples of 'good people' while insinuating that those who stay ill don't want to heal. My
55
56 doctors have run the gamut of not believing me; to finally agreeing that Long Covid is real
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3 but that since I don't have a positive test, I can't have it; to even if I have Long Covid, they
4 don't have treatment, so short of an ER admit, I just need to suck it up.”
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9 **Theme 16. The vaccine was associated with both improvement in symptoms for**
10 **some people, and a relapse in symptoms for others.**
11

12 *Example 1.*
13

14
15 “I had slight tremors in my hands after originally getting sick in June 2020 and after my
16 second vaccine, on [May 2021] (two days later) I started having more seizure-like
17 symptoms.”
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23 *Example 2.*
24

25 “I had the internal vibrations intensely during my year of long haul. Since the vaccine most
26 of my symptoms have abated or significantly diminished. I do still have some of the internal
27 vibration though, especially after exertion.”
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33 **Theme 17. Medications have been provided for tremor symptoms, with varying**
34 **results.**
35

36 *Example 1.*
37

38
39 “They tried Gabapentin but it didn’t stop them. From March through [July] I had 5-9
40 seizures trying to fall asleep every night, but they only happened at night. Since the
41 Gabapentni wasn’t working they switched me to Topamax. I was ramping into Topamax
42 throughout June but it wasn’t working either. My family and I got sick again at the end of
43 June with something viral (multiple negative Covid, Flu, and Strep tests that week). The
44 same time they adjusted my Topamax dosage up again. Something changed again.
45 Suddenly I was having non-stop seizures back to back and was hospitalized [July] and also
46 again on [July] at two different hospitals for uncontrolled seizures. My EEG showed normal
47 and they switched meds again to Keppra. So far I am on 500 mg Keppra 2x day and
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3 ramping up, but my seizures are uncontrolled. The meds work only for a few hours and I
4
5 have had to go on Short Term Disability from work.”
6
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8

9 *Example 2.*

10
11 “He also put me on the very lowest dose gabapentin 3x per day. I began the medication the
12 same night. The next day I had a terrible headache but something felt different. I continued
13 the meds 3x per day like directed. After 1 week I began to be able to get up and move a
14 little. I began doing dishes and light house work. My family was rejoicing. I was improving.
15 After a few weeks of being on the medication I could tell it was helping with all the pain. The
16 tremors were still there, but were farther in the background, if that makes sense? ..as if
17 they had been put on soft mute. The meds weren't stopping the tremors but calmed them I
18 guess.”
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29 7) Impact on People's Lives and Livelihood
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33 **Theme 18. Vibrations and tremors were associated with mental health effects,**
34 **including anxiety, depression, and suicidal thoughts.**
35
36

37 *Example 1.*

38
39 “The psychologist who saw me for 30 minutes gaslit me saying I need to exercise more as
40 my severe depression could be the cause of my symptoms when I called him on that he said
41 he noted in his report 'as tolerated' that my chronic fatigue syndrome could also be the
42 cause but he doesn't deal with that only psychological causes. My therapist says I am
43 clearly depressed because of my fatigue from what she has seen for a year. Being in
44 constant pain, unable to participate in life day after day, month after month is depressing.
45 Of course I feel useless. Of course I feel things might not get better. I haven't been
46 functioning for 16 months!”
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3 *Example 2.*
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5 "I could not sleep and went 15 days straight with no sleep. I was suicidal in addition to all
6 the other Covid symptoms, thus one showed up two months after my acute Covid."
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11 **Theme 19. Vibration and tremor symptoms caused disability for some people.**
12

13 *Example 1.*
14

15 "I am writing to advise that I am one of the Covid long-haulers who is experiencing hand
16 tremors. I feel them in my arms also and occasionally in my voice and breathing. The
17 tremors in my hands are so severe that I cannot grip or hold a pen for any length of time
18 before my hand writing deteriorates to chicken scratch. I have also resorted to dictating
19 many of my emails and messages because my fingers don't hit the right keys. I don't know
20 if tinnitus qualifies as internal vibration but I do have it and it is getting louder all the time.
21 It causes me great anxiety and I have not been able to discover a treatment or solution."
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31 *Example 2.*
32

33 "Since March, I have had limited mobility as my legs give way and do not have the strength
34 to walk unassisted. I have to use a chair to shower and walk with a cane. I cannot walk
35 across the room without falling into things and struggle with balance. I have felt internal
36 tremors that feel like a fizzing/bubbling that moves through my trunk and extremities. My
37 arms and legs shake and I have problems even with holding my fork still to feed myself. My
38 mind doesn't cooperate most days and I have speech issues with slurred speaking and
39 stuttering."
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50 **Theme 20. Vibrations and tremors could disturb or prevent sleep.**
51

52 *Example 1.*
53

54 "Mostly Every morning waking up, there is an electrical zap from the top of my spine to mid
55 back. Before I knew what the correct term was, I was telling doctors I buzz like a battery.
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3 This sensation happens first when I'm opening my eyes in the morning. It's the first
4 conscious feeling in the morning every day. If I try and go back to sleep the vibrations get
5 more intense and more upsetting. So the best thing to do upon waking up is just get up and
6 go on about my day. If I take a nap during the day. No problem, no vibrations. But there is
7 a limit that I can sleep at any time, so if I do nap When I wake up, I don't try and sleep
8 more. There is I feel, a component of the vibrations That affect my sleep. I am very tired
9 and feel most nights that my brains at war with itself and I don't feel refreshed when
10 waking up. Sometimes, not very often, I will get a whole body tremor feeling it's unpleasant
11 but, doesn't last very long. I would say the ones that wake me up in the morning are more
12 bothersome because I do not wake up gently or quietly. It really is internal torture."
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25 *Example 2.*

26
27 "Just when I thought I was done developing new symptoms in March this started, every
28 time I start to fall asleep I get shooting pain and immense pressure in my arms, legs and
29 spine. It wakes me up instantly. Imagine all the times you doze off a little in the day, times
30 that by 20 if you are on medications that make you sleepy and try to imagine how torturous
31 that symptom is when it happens to you 20 times a day. No one knows what this is or how
32 to stop it. I'm forced to take muscle relaxers, lyrica, and Ativan to try to get to sleep before
33 the symptom starts."
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48 **Theme 21. Vibration and tremor symptoms could prevent people from working or
49 carrying out daily life activities.**

50 *Example 1.*

51 "I am not the person I was before Covid. I used to paint, refinish furniture, hang out with
52 girlfriends, dance, golf, bike, travel, date. Now I barely have the energy to help my patient
53 which is the only reason I have a roof over my head. If I can't do it at any point, he needs
54 to replace me and I lose my place to stay. I have no income and I couldn't possibly work."
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5 *Example 2.*

6
7 "I got covid [September 2020]. I'm a nurse practitioner and cared for patients with Covid. I
8
9 tried to go back to work. And after my psych Neuro testing I was found to have cognitive
10
11 decline and severe memory recall and other memory issues. I was pulled from work
12
13 [March], and then let go [May]."

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16
17 **Theme 22. Vibration and tremor symptoms could cause financial stress, through a**
18 **combination of medical care costs and loss of income from medical leave.**

19
20
21 *Example 1.*

22
23 "Before the pandemic was looking for another part time job so could live in a better place
24
25 Now am drowning in medical debt with no relief in sight or ability to hold a job This has
26
27 devastated my life Now am stuck living in an old garage without plumbing Hauling water
28
29 back and forth from a garden hose and dumping dirty water takes what little energy have."
30
31

32
33
34 *Example 2.*

35
36 "I got Covid [September 2020] and continue to have daily debilitating symptoms that have
37
38 prevented me from going back to work. Side note: is there any government funding for
39
40 those of us who are long haulers and can't get back to work yet? My short term disability
41
42 ran out beginning of April and I've been without any income since. It's getting really tough."
43
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46 Facebook

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48 For all 450 comments combined, the 10 most frequent terms were tremors (64%),
49
50 COVID (55%), pain (51%), vibrations (43%), months (36%), burning (29%), feet (24%),
51
52 hands (22%), legs (21%), and back (20%). Two Word Clouds were generated based on
53
54 prevalent terms related to the themes found in emails.

1
2
3 The first Word Cloud (Figure 1) analyzed 288 comments in response to a post that
4 requested people experiencing tremors or internal vibrations to comment. This Word Cloud
5 revealed that the five most common words used in comments were: tremors, COVID,
6 vibrations, months, and pain. Words included also indicated that symptoms ranged in
7 presentation and severity, and vibrations were mentioned, as were seizures, shaking, and
8 twitching. This Word Cloud also included other long COVID symptoms including brain fog,
9 fatigue, and anxiety. Words indicating timing and duration of symptoms included months,
10 days, and constantly. The only medication captured was gabapentin. Finally, similarly to the
11 email responses, comments included mentions of sleep and being tired.

12
13 The second Word Cloud (Figure 2) was created based on 162 comments to a
14 Survivor Corps poll that asked respondents about vibration or buzzing sensations and
15 neuropathic pain. This Word Cloud revealed that pain, burning, COVID, legs, hands, and
16 feet were the most common terms mentioned in comments. This Word Cloud included terms
17 related to sensations such as burning and symptoms such as shingles and thrush.

18 19 20 21 22 23 24 25 26 27 28 29 30 31 32 33 **Discussion**

34
35 This study describes key themes and experiences among a group of individuals
36 reporting long COVID and a prolonged and debilitating symptom complex that prominently
37 involves internal tremors and vibrations. While symptom experiences were heterogenous—
38 in symptom timing, medical history, and initial infection, for instance—there were also
39 common themes in how individuals described these symptoms and their effects. Individuals
40 also reported how diagnostic evaluation and medical care have not yet identified possible
41 mechanisms or successful treatment for these symptoms.

42
43 Although the causal pathway remains unclear from these patient reports alone, these
44 patient experiences demonstrate the prolonged and debilitating symptom complex
45 associated with long COVID. Many of the themes identified in this analysis demonstrate
46 physical suffering, including due to severe pain (Theme 2), constancy of the tremor
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3 episodes (Theme 7), and tremors lasting for months or even over a year after initial
4 infection (Theme 10). Our findings, importantly, also demonstrate how the suffering from
5 this symptom complex invades peoples' lives, livelihood, and psychological well-being.
6
7 Themes included effects on mental health such as anxiety, depression, and suicidality
8 (Theme 18) aligning with recent studies,[5, 24-26] and effects on daily functioning including
9 inability to exercise (Theme 11), sleep deprivation (Theme 20), and even disability (Theme
10 19). The cumulative toll of these limits on daily functioning and well-being led some people
11 to have to quit or pause working and household or family responsibilities (Theme 21) and to
12 fall into subsequent debt or financial distress (Theme 22). Each individual's experience with
13 these symptoms was different, and not all experienced the most severe effects. However,
14 the reports revealed a pattern that these symptoms could cause immense pain and
15 disruption to daily lives and livelihood.
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19 This study extends the literature in several ways. Previous literature consists of case
20 series that provide preliminary reports of patients' clinical presentation, course of care, and
21 outcomes, but information on people's experience with tremors more broadly has not been
22 described in relation to long COVID.[6-13] In addition, the literature describes symptoms
23 from the point of view of healthcare providers, but not from patients. Previous case-series
24 reports included a total of 16 people previously infected with SARS-CoV-2 who suffered
25 from myoclonus-ataxia syndrome between 3 days to 6 weeks after acute, often mild, or
26 moderate, infection.⁵⁻¹² Our report attempts to add a larger, broader overview of
27 experiences of these symptoms. Our analysis expands upon the sensorimotor symptoms
28 described to date. Furthermore, we describe symptoms experienced by individuals who
29 might not have sought formal medical care.
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33 This study, although limited in scope, is an effort to channel the perspective of
34 patients for a condition that has yet to be defined. The utility of this study is that it may
35 enable more formal and structured data collection for individuals with this syndrome. These
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3 experiences should be more rigorously characterized to develop hypotheses and understand
4 mechanisms.
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7 There are several key implications of the work. First, internal vibrations and tremors
8 cause severe suffering, both physically and mentally, for a group of individuals after self-
9 reported SARS-CoV-2 infection. Second, while the overall scale of these symptoms is still
10 unknown, this group of people experiencing the symptoms have not recovered from the
11 symptoms nor have they received specific diagnoses or been given treatment that
12 completely alleviates their suffering. Third, the descriptions of feeling internal vibrations and
13 tremor symptoms were similar across this group of patients and independent of one
14 another's responses as the emails were not seen by the other participants.
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23 This study has several limitations. Respondents were a convenience sample with
24 minimal information about their demographic or clinical characteristics, including laboratory-
25 confirmed infection with COVID-19. Any information about testing is based on self-report.
26 As such, we cannot determine whether these symptoms were caused by their infection with
27 SARS-CoV-2, or whether the symptoms reported by different people were the same
28 symptom complex or of the same etiology. We also cannot determine whether the sample is
29 representative of the source population experiencing these symptoms. The data are self-
30 reported and cross-sectional; information was limited to what individuals provided in their
31 initial communication and there was no follow-up. This limited the scope of findings and
32 may have excluded information that medical professionals would have found relevant. This
33 sample may have been skewed toward individuals healthy enough to be active members of
34 a patient community (Survivor Corps) and to email a response to the group. Finally, this
35 study cannot provide information on the incidence and prevalence of these symptoms.
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50 In conclusion, some individuals report experiencing internal vibration and tremor
51 symptoms, often causing intense suffering, after a self-reported history of SARS-CoV-2
52 infection. The symptoms had some common features but there was variability in timing,
53 concomitant symptoms, and impact. Further research is needed to understand and alleviate
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this suffering by studying the extent and scope of these symptoms, possible mechanisms, and potential treatment.

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Competing Interests Statement

In the past 3 years, Dr. Krumholz reported receiving personal fees from Massachusetts Medical Society, UpToDate, Element Science, Eyedentify, and F-Prime. He is a cofounder of HugoHealth, Refactor Health, and Ensign-AI. He is associated with grants and/or contracts, through Yale New Haven Hospital, from the Centers for Medicare & Medicaid Services, and through Yale University from Johnson & Johnson Consumer, Janssen, and Pfizer. The other authors report no potential conflicts.

Contributor and Guarantor Information

Dorothy Massey (DM) and Mitsuaki Sawano (MS) served as first coauthors. DM played a key role in planning, designing, analyzing data, and drafting the manuscript. MS critically reviewed the manuscript and took charge of the major revisions after peer review, contributing significantly as a first coauthor. Other contributors, ADB, DBG, NG, SPS, LF, CBG, CC, TZ, RS, and HMK, played crucial roles in carefully evaluating the manuscript. DBG and NG were involved in designing the project and collecting data. CBG, responsible for data analysis and manuscript drafting, contributed substantially to the revision process. HMK, in addition to planning and drafting, provided valuable supervision.

Transparency Statement

DM, MS, and HK affirm that this manuscript is an honest, accurate, and transparent account of the study being reported; no important aspects of the study have been omitted; and there were no discrepancies from the study as originally planned.

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This study received no funding.

Data Sharing Statement

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Deidentified data will be shared by the corresponding author upon request.

Ethics Approval

This study involves human participants but was exempted by the Yale Institutional Review Board.

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Figure Legend:

Figure 1 - Word Cloud from comments in response to a post

Figure 2 - Word Cloud from comments on a Survivor Corps poll

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Supplement 1

To solicit emails for this study, Survivor Corps and Nick Güthe requested emails from Survivor Corps members via Facebook and an emailed newsletter that is also posted on the Survivor Corps website.

First, Nick Güthe posted the following in the Survivor Corps Facebook page [July 2021]:

"Hi, to anyone on this group. It's Nick Güthe, Heidi Ferrer's husband. A study is forming with a top doctor for Long Haulers with Neurological tremors similar to Heidi Ferrer's -- Tremors or internal vibrations. If you have these symptoms and want to be included please comment below. This isn't a clinical trial but an attempt to gather data and stories to help get funding, bring attention to these symptoms which are so destructive to any Long Haulers physical and mental health."

Nick Güthe and Diana Zicklin Berrent responded to Facebook comments on this post to ask members to email their story, writing: "Send your story to hq@survivorcorps.com."

Second, a [newsletter](#) sent to members included the following [July 2021]:

*"A study is forming for Long Haulers with Neurological tremors or internal vibrations. If you have these symptoms and want to be included, please **EMAIL** us with your details. This is not a clinical trial, but an attempt to gather data and stories to help get funding, and bring attention to these destructive symptoms that impact Long Hauler's physical and mental health."*

Supplement 2. Email Initial Code List

Below is listed the initial code list created by authors HMK and DM, prior to input from all team members and creation of the final code.

1) Symptom Perception and Location

Vibrations and tremors were described concomitantly, with descriptions of internal vibrations, visible tremors, and some people experiencing both.

Vibration or tremor site varied, from the entire body to localization in extremities, chest, abdomen and other locations.

Vibrations and tremors occurred with other symptoms of varying number.

Vibrations and tremors could cause severe pain.

2) Initial Symptom Onset

Vibration and tremor initial onset varied, from the day of initial infection to weeks later.

Vibrations and tremors occurred following or during acute COVID-19 infections that varied from mild to severe.

3) Symptom Timing

Vibration and tremor episodes could be brief, or could be prolonged, even constant.

Vibration and tremor episodes could occur constantly, daily, or only when relapses occurred.

People experienced vibrations and tremors over different time periods (even if they were episodic), and some did not have improvement in symptoms after more than a year.

4) Symptom triggers or alleviators

The vaccine was associated with both improvement in symptoms for some people, and a relapse in symptoms for others.

Exercise and activity were associated with onsets of tremors and vibrations.

A variety of self-treatment strategies, such as diet modifications and humming, were used to alleviate tremors and vibrations.

5) Change from Baseline Health Status

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2
3 People with vibrations and tremors had varying health states before their COVID-19 infection, from
4 those who were completely health to those with pre-existing conditions.
5

6) Experience with Medical Establishment

8
9 Medical testing failed to reveal the mechanism of either tremors or vibrations.
10

11 Tremor and vibration symptoms were sometimes doubted or dismissed by doctors.
12

13 Medications have been provided for tremor symptoms, with varying results.
14
15

7) Effect on People's Lives and Livelihood

17
18 Vibrations and tremors were associated with mental health effects, ranging from anxiety to suicidal
19 thoughts.
20

21 Vibration and tremor symptoms could cause disability people.
22

23
24 Vibration and tremor symptoms could cause financial stress, through a combination of medical care
25 costs and loss of income from medical leave.
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27 Vibrations and tremors could disturb or prevent sleep.
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29 Vibration and tremor symptoms could prevent people from working or carrying out daily life activities.
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Supplement 3. World Cloud Analysis Methodology

Leveraging the "quanteda" [1], "wordcloud" [2], and "tm" [3] packages in R, we constructed a Word Cloud of the most frequent words used to express some long-term effects of experiencing a COVID-19 infection among a Facebook COVID-19 survivors page. The data was converted from an xlsx to a txt file where it was then loaded as a corpus file, a specific type of file format required for Word Cloud generation, using the "Corpus" function in the "quanteda" package. To clean the corpus file, we utilized the "tm_map" function in the "tm" package to convert all text to lower case, to remove numbers, to remove punctuation and special characters, and then to collapse extra white space characters to a single blank space. Once cleaned, we built a term-document matrix which was then read into the "wordcloud" function within the "wordcloud" package. We set the minimum frequency of words to be included into the Word Cloud to 3, the maximum number of words allowed into the Word Cloud to 200, and then removed all extraneous, filler words such as "and", "comment", "view", "you." We included all adjectives, nouns, and verbs associated with COVID signs, symptoms, and experiences into the Word Cloud.

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Supplemental Table 1. Full Survivor Corps Poll for Word Cloud 2

The following poll was posted in Survivor Corps [June 2021] and was titled "Vibration/Buzzing/Pain Poll." There were 20 answer choices, each a statement relevant to vibration, tingling, buzzing, and neuropathic sensations. We have included the poll and responses for context, but for the purposes of qualitative analysis, we reviewed only the comments posted in response to this poll. These poll responses were collected as of July 16, 2021. The following text was included with the Facebook poll:

"VIBRATION / BUZZING / PAIN POLL

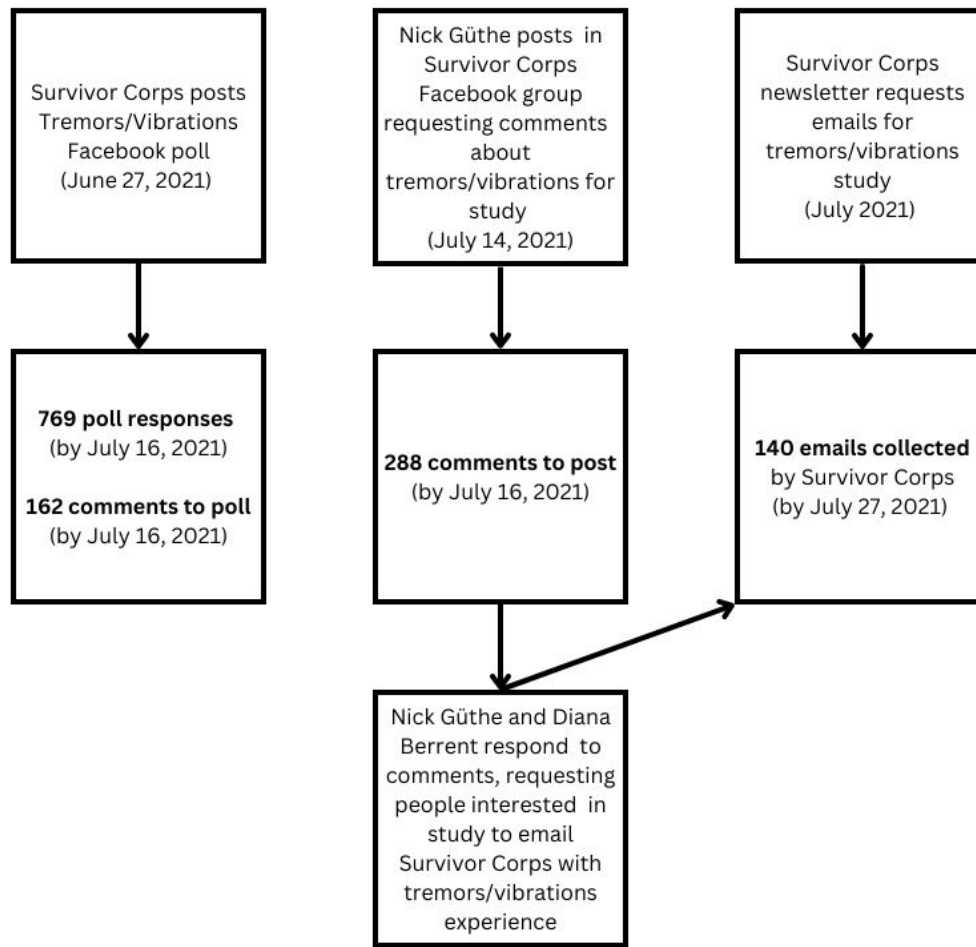
SO MANY LONG HAULERS ARE DESCRIBING A BUZZING OR VIBRATION OR

NEUROPATHIC PAIN IN THEIR BODIES AND EXTREMITIES - WE WANT TO LEARN

MORE!"

Answer Choice	Number of Votes
I am participating in this poll (please check here!)	769
I HAVE experienced new tingling / buzzing / vibrating feelings since Covid	660
These vibrating feelings come and go	590
I HAVE had neuropathic pain (burning feeling on skin) since Covid	396
These vibrations appear in different parts of my body at different times	365
The neuropathic pain (burning feeling on skin) comes and goes	345
I have these vibrating feelings mostly in my extremities	268
These vibrations bother me a great deal	252
My neuropathic pain (burning feeling on skin) has been in my hands and feet	232
The neuropathic pain (burning feeling on skin) bothers me a great deal	232
My neuropathic pain (burning feeling on skin has been all over my body)	149

1	These vibrations feel "like they are making me insane"	129
2		
3	I have NOT had neuropathic pain (burning feeling on skin) since Covid	111
4		
5	I have these vibrating feelings mostly in my chest	98
6		
7	The neuropathic pain (burning feeling on skin) is excruciating / makes me	67
8	feel "like I'm going insane"	
9		
10	I have NOT experienced any new tingling / buzzing/ vibrating feelings since	48
11	Covid	
12		
13	The neuropathic pain (burning feeling on skin) is constant	44
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15	These vibrating feelings are constant	35
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17	These vibrations don't bother me	22
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19	The neuropathic pain (burning feeling on skin) doesn't bother me very	21
20	much	
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Supplemental Figure 1. Data Collection Process

Supplemental Figure 2. Roadmap of themes and domains

Domain 1. Symptom Experience, Description, and Anatomic Location

Theme 1. Vibrations and tremors were described concomitantly, with descriptions of internal vibrations, visible tremors, and some people experiencing both.

Theme 2. Vibration or tremor site varied, from the entire body to localization in extremities, chest, abdomen, and other locations.

Theme 3. Vibrations and tremors occurred with other symptoms of varying number.

Theme 4. Vibrations and tremors could cause severe pain.

Domain 2. Initial Symptom Onset

Theme 5. Vibration and tremor initial onset varied, from the day of initial infection to weeks or even months later.

Theme 6. Vibrations and tremors occurred following or during acute COVID-19 infections that varied from mild to severe.

Domain 3. Symptom Timing

Theme 7. Vibration and tremor episodes could be brief, or could be prolonged, even constant.

Theme 8. Vibration and tremor episodes could occur constantly, daily, or only when relapses occurred.

Theme 9. Vibration and tremor symptoms could completely resolve temporarily and could return up to months later.

Theme 10. People experienced vibrations and tremors over different time periods (even if they were episodic), and some did not have improvement in symptoms after more than a year.

Domain 4. Symptom triggers or alleviators

Theme 11. Exercise and activity were associated for some with onsets of tremors and vibrations.

Theme 12. A variety of self-treatment strategies, such as diet modifications and humming, were used to alleviate tremors and vibrations.

Domain 5. Change from Baseline Health Status

Theme 13. People with vibrations and tremors had varying health states before their COVID-19 infection, from those who were completely healthy to those with pre-existing conditions.

Domain 6. Experience with Medical Establishment

Theme 14. Medical testing failed to reveal the mechanism of either tremors or vibrations.

Theme 15. Tremor and vibration symptoms were sometimes doubted or dismissed by doctors.

Theme 16. The vaccine was associated with both improvement in symptoms for some people, and a relapse in symptoms for others.

Theme 17. Medications have been provided for tremor symptoms, with varying results.

Domain 7. Impact on People's Lives and Livelihood

Theme 18. Vibrations and tremors were associated with mental health effects, including anxiety, depression, and suicidal thoughts.

Theme 19. Vibration and tremor symptoms caused disability for some people.

Theme 20. Vibrations and tremors could disturb or prevent sleep.

Theme 21. Vibration and tremor symptoms could prevent people from working or carrying out daily life activities.

Theme 22. Vibration and tremor symptoms could cause financial stress, through a combination of medical care costs and loss of income from medical leave.

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