

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

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

6) Experience with Medical Establishment

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

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

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

7) Effect on People's Lives and Livelihood

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

Vibration and tremor symptoms could cause disability people.

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

Vibrations and tremors could disturb or prevent sleep.

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

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.

Works Cited

- [1] K. Benoit, K. Watanabe, H. Wang, P. Nulty, A. Obeng, S. Muller and A. Matsuo, "quanteda: An R package for the quantitative analysis of textual data," *Journal of Open Source Software*, vol. 3, no. 30, p. 774, 2018.
- [2] I. Fellows, "wordcloud: Word Clouds. R package version 2.6," 2018. [Online]. Available: <https://CRAN.R-project.org/package=wordcloud>.
- [3] I. Feinerer and K. Hornik, "Text Mining Infrastructure in R. R package version 0.8-8," *Journal of Statistical Software*, vol. 25, no. 5, pp. 1-54, 2008.

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

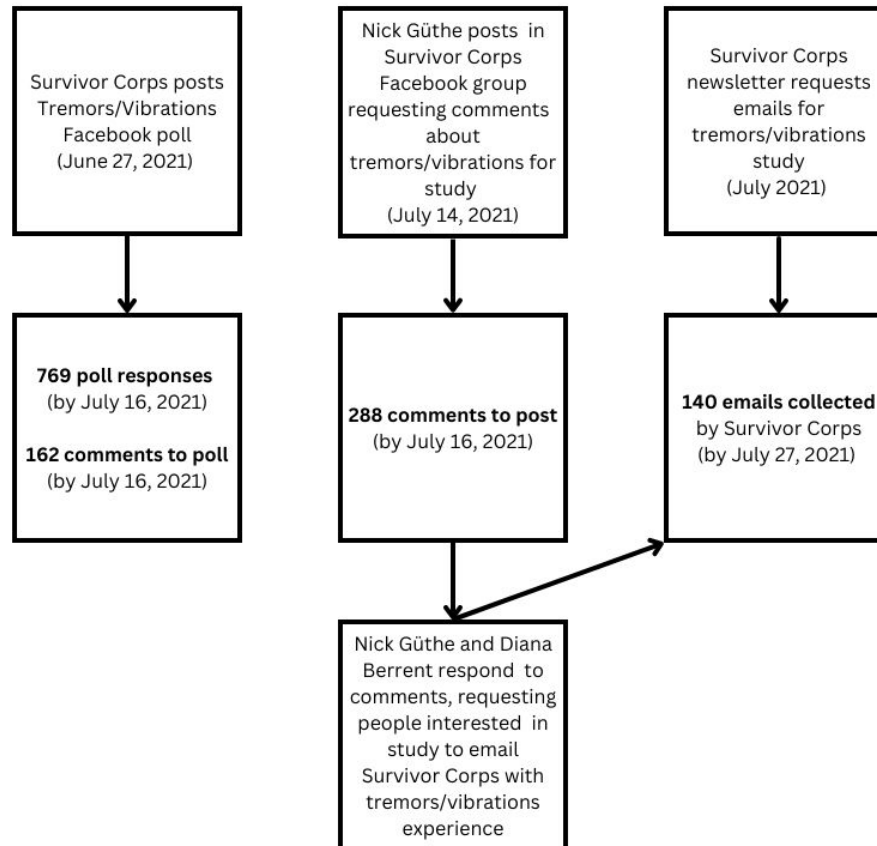
The following poll was posted in Survivor Corps [June 2021] and was titled "Vibration/Buzzing/Pain Poll." There were 20 answer choices, each a statement relevant to vibration, tingling, buzzing, and neuropathic sensations. We have included the poll and responses for context, but for the purposes of qualitative 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.