RESEARCH ARTICLE

An Analysis of Self-reported Long COVID-19 Symptoms on Twitter

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Abstract

Objectives: A majority of patients suffering from acute coronavirus disease 2019 (COVID-19) are expected to recover symptomatically and functionally. However, there are reports that some people continue to experience symptoms even beyond the stage of acute infection. This phenomenon has been called long COVID-19. This study attempted to analyze symptoms reported by users on Twitter self-identifying as long COVID-19.

Materials and methods: The search was carried out using the Twitter public streaming application programming interface using a relevant search term.

Analysis and results: We could identify 89 users with usable data in the tweets posted by them. Most users described multiple symptoms, the most common of which were fatigue, shortness of breath, pain, and brain fog/concentration difficulties. The most common course of symptoms was episodic.

Conclusion: Given the public health importance of this issue, the study suggests that there is a need to better study postacute COVID-19 symptoms.

Keywords: Coronavirus disease 2019, Long coronavirus disease 2019, Long-hauler, Persistent symptoms, Twitter analysis.

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Introduction

The COVID-19 pandemic has affected millions of people across the world. It is expected that most of the patients with COVID-19 will recover from infection.[1] However, there are reports that many of these people continue to experience symptoms and disability.[2] In English-speaking countries, the term "long COVID-19" or "long-haulers" has been used to describe this phenomenon and the people suffering from it, respectively.[3,4] There are various anecdotal reports, discussions on online forums and social media, and patient-led research regarding the experiences of people who self-identify as suffering from long COVID-19.[5] Social media such as Twitter has been used to mine data regarding patient accounts of symptomatology in the COVID-19 pandemic.[6] Given the public health importance of this issue and the paucity of information from conventional sources, this study was undertaken to analyze symptoms associated with long COVID-19 reported by users on Twitter.

Materials and Methods

Tweets were collected using the retweet package in RStudio software from the Twitter public streaming application programming interface. Given the millions of tweets on COVID-19, the search protocol was restricted to the term "long COVID-19," tweets in the English language, and retweets were excluded. The retry on rate limit function was set to true to retrieve as many tweets as possible. Once the tweets were retrieved, they were manually read. Tweets that were not in English or by users who did not identify themselves as having long COVID-19 symptoms or having symptoms due to another disorder such as Lyme disease or chronic fatigue syndrome/myalgic encephalomyelitis, tweets about long COVID-19 in general but not self-experienced symptoms were excluded. The tweets included in the final analysis were in English by users, who identified themselves as having long COVID-19, and the content of the tweets pertained to the symptoms experienced them.

The initial search retrieved 3449 tweets from 190 different tweeters from 20th to 29th July 2020. After manually reading the tweets and applying the inclusion criteria, 165 tweets from 89 users were included in the final analysis. Multiple tweets from single users were collapsed into one text block and repeat or similar symptoms were deleted so that symptoms referred to in more than one tweet were counted only once per person.

Results

A total of 240 symptoms were mentioned by all the users. On analysis, these were grouped into 94 different symptoms. The most common symptoms with >1 mention are presented in Table 1.

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Table 1: Symptoms with >1 mention in tweets

Serial number	*Symptoms*	*Prevalence number (%)*
1	Fatigue	42 (47.19)
2	Shortness of breath	23 (25.84)
3	Brain fog	15 (16.85)
4	Exercise intolerance	13 (14.60)
5	Pain in the whole body	9 (10.11)
6	Altered smell	7 (7.86)
7	Headache	7 (7.86)
8	Tachycardia	6 (6.74)
9	Altered taste	6 (6.74)
10	Pain chest	5 (5.61)
11	Dizziness	3 (3.37)
12	Pain abdomen	3 (3.37)
13	Fever	3 (3.37)
14	Nausea	3 (3.37)
15	Cough	3 (3.37)
16	Weakness	3 (3.37)
17	Altered appetite	2 (2.24)
18	Pain (location not specified)	2 (2.24)
19	Chest tightness	2 (2.24)
20	Numbness	2 (2.24)
21	COVID-19 symptoms	2 (2.24)
22	Tinnitus	2 (2.24)
23	Altered sleep	2 (2.24)
24	Pain in ear	2 (2.24)
25	Pain in muscles	2 (2.24)
26	Irritability	2 (2.24)
27	Tachycardia on exertion	2 (2.24)

Around 47 users mentioned the time period of symptoms, and these ranged from 3 to 42 weeks (16–20 weeks by 32 users). There was no association between nature and the number of symptoms reported and the duration of illness. A total of 29 users mentioned the course of their symptoms. The most common pattern described was one of episodes or relapses ($n = 16$), followed by a continuous course ($n = 9$), of which some described fluctuations in the course of symptoms (n = 3) and four users described continuous symptoms with added on symptoms during exacerbations. The common precipitating factors for exacerbations were physical activity ($n = 3$), trauma ($n = 1$), and heat ($n = 1$). A total of 53 users (59.55%) reported more than one symptom. Unique hashtags associated with long COVID-19 included "long-haulers" and "No End In Sight Void."

Discussion

Twitter data mining has been used as a means for analysis of symptom profiles in various disorders, including COVID-19.[6] There are anecdotal reports, online content and some evidence to suggest that a proportion of patients who have recovered from acute COVID-19 continue to have some symptoms.[2,7] Considering the millions of people who have been infected and recovered from acute COVID-19, persistent symptoms and presumably disability and impairment in quality of life may pose a significant public health challenge. The results of this analysis show that the signal-to-noise ratio with regard to patient-driven data in COVID-19 is very high, as has been observed earlier.[6] This may reflect the interest generated by COVID-19; it also observed that long COVID-19-related content also attracted users identifying with Lyme disease, myalgic encephalomyelitis/chronic fatigue syndrome, fibromyalgia communities who offered support and identified symptoms reported as long COVID-19 to be similar to theirs.

In keeping with the limited data available, this analysis shows that most of the users reported multiple symptoms (>1) at varying durations of illness (3–42 weeks with a majority at 16–20 weeks). This was like that reported in another study even though the average duration of postacute assessment was at 60 days (~9 weeks).[6] The most common symptoms reported were also similar (fatigue, shortness of breath, brain fog/concentration difficulties, pain, cough, disturbances in smell, taste, appetite, chest discomfort, and headache etc.). In addition, users described different courses of symptoms, with most describing an episodic or relapsing course usually brought about by some precipitant.

Chronic persistence of symptoms in postacute severe acute respiratory syndrome infection has been described earlier with somewhat symptomatologies.[8] Some have speculated that these could be due to immunological mechanisms.[7] Similarly, postviral fatigue syndromes have been described due to a variety of etiologies which are often associated with chronicity and development of chronic fatigue syndrome.[9]

There are various limitations in analyzing nonexperimental Twitter-derived data, including incomplete data, the self-selection of users, lack of objective validations of reported symptoms, inexact reporting of variables such as sociodemographic data and nonexact definitions of symptomatology.[10] Twitter allows only limited characters, so there is a possibility of missing other details. There is also the possibility of relevant data being missed or being available on other social media platforms. Our data set also suffers from these limitations. In addition, we did not have any information regarding the symptom severity of the initial disease and treatment details. Self-reported symptoms may be erroneous and require thorough evaluation.[11] There is high heterogeneity of symptoms which further requires study using standard case definitions in a representative population.[12]

On the contrary, studies such as these also represent subjective and experiential accounts that may otherwise be missed. These are also useful methods of generating data from groups of individuals who may otherwise not be able to access formal healthcare facilities.

Conclusion

The result of this Twitter analysis suggests that some patients who have recovered from acute COVID-19 seem to have multiple prolonged symptoms (as described above) with varying courses and outcomes. There is a need to better characterize post-COVID-19 symptomatology and elucidate the mediating variables through rigorous scientific studies. If present in significant numbers of people, the prevention and management of these symptoms should be incorporated into treatment protocols.

Disclosure

The preprint of this paper is deposited in the MedrXiv preprint platform. The DOI of the preprint paper is https://doi.org/10.1101/2020.08.14.20175059 and the link is https://www.medrxiv.org/content/10.1101/2020.08.14.20175059v1.

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