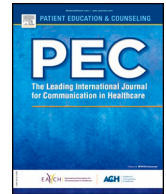




Since January 2020 Elsevier has created a COVID-19 resource centre with free information in English and Mandarin on the novel coronavirus COVID-19. The COVID-19 resource centre is hosted on Elsevier Connect, the company's public news and information website.

Elsevier hereby grants permission to make all its COVID-19-related research that is available on the COVID-19 resource centre - including this research content - immediately available in PubMed Central and other publicly funded repositories, such as the WHO COVID database with rights for unrestricted research re-use and analyses in any form or by any means with acknowledgement of the original source. These permissions are granted for free by Elsevier for as long as the COVID-19 resource centre remains active.



Using crowdsourced medicine to manage uncertainty on Reddit: The case of COVID-19 long-haulers

Charee M. Thompson^{a,*}, Kayla B. Rhidenour^b, Kate G. Blackburn^c, Ashley K. Barrett^b, Sara Babu^a

^a Department of Communication, University of Illinois, Urbana-Champaign, IL, USA

^b Department of Communication, Baylor University, TX, USA

^c Department of Psychology, University of Texas at Austin, TX, USA

ARTICLE INFO

Article history:

Received 21 April 2021

Received in revised form 18 June 2021

Accepted 7 July 2021

Keywords:

COVID-19

Crowdsourcing

Uncertainty management

Social media

ABSTRACT

Objective: Causes of and treatments for long-COVID syndrome remain unknown. Drawing on uncertainty management theory (UMT), this study elucidates the communicative nature of crowdsourced medicine as a means by which COVID “long-haulers” respond to their poorly understood illness.

Methods: 31,892 posts on the long-haulers subreddit (r/covidlonghaulers) were analyzed, starting with its creation date, July 24th, 2020, until January 7, 2021. The Meaning Extraction Method was used to identify clusters of words that mathematically group together across the text observations.

Results: Analyses yielded 16 distinct factors of words, which we thematized based on their composition, the data, and UMT. The 16 themes encompassed symptoms (e.g., pain, respiratory, sensory), diagnostic concerns (testing, diagnosis), broad health concerns (immunity, physical activity, diet), chronicity, support, identity, and anxiety.

Conclusion: Findings provide a succinct, yet robust set of themes reflecting the information-seeking (i.e., “This is happening to me”) and support-seeking functions of long-haulers’ talk (i.e., “Is this happening to you?”). Findings have implications for collective uncertainty management, online crowdsourcing, and patient advocacy.

Practice implications: We recommend that health care providers employ sensitivity when addressing the anxiety that long-haulers are experiencing while also validating that their physical symptoms are real. Online communities help long-haulers manage their uncertainty.

© 2021 Elsevier B.V. All rights reserved.

1. Introduction

As of June 2021, over 170 million people across the globe have contracted COVID-19 and more than 3.7 million have died from the disease [1]. As vaccinations increase, hospitalizations decrease in many places, and treatments improve concerns about mortality, there is now growing uncertainty about COVID-19’s lingering effects and associated chronic illnesses, known as “long-COVID” [2]. Long-COVID is characterized by relapsing or persistent symptoms, the most common of which is fatigue [3]. According to Dr. Fauci, director of the National Institute of Allergy and Infectious Diseases (NIAID) and chief medical advisor to President Joe Biden, “Anywhere from 25% to 35%—or more—have lingering symptoms. Fatigue, shortness of

breath, muscle aches, dysautonomia, sleep disturbances and what people refer to as brain fog” [4]. Some research estimates that 50–80% of people who have had COVID-19 experience symptoms up to three months after contracting the virus [5]. People suffering from long-COVID refer to themselves as “long-haulers” [6].

Recognition of “long-COVID” from the larger medical community has been slow and episodic. Dr. Fauci suggested there may be a post-COVID syndrome in July of 2020 [7]. In December of 2020, growing attention motivated a two-day workshop dedicated to long-COVID, sponsored by the National Institutes of Health. During the workshop, there was wider acknowledgment from public health officials and medical researchers that the condition needed to be deemed a syndrome with an official name to legitimate the seriousness of long-haulers’ experiences. Dr. Fauci referred to the “phenomenon” as “really quite real and quite extensive” [8]. Finally, on February 24th, 2021, Dr. Fauci announced during a press conference that long-

* Correspondence to: 702 S. Wright St./Lincoln Hall 4002, Urbana, IL 61801, USA.
E-mail address: charee@illinois.edu (C.M. Thompson).

COVID had been given a name: post-acute sequelae of SARS-CoV-2 infection, or PASC [9].

Despite increased visibility, causes of and treatments for post-COVID syndrome remain unknown, and long-haulers are turning to one another to manage their uncertainty through crowdsourcing, or “aggregating crowd wisdom to solve a problem” [10]. Social networking sites are essential for understanding crowdsourcing because of their social affordances, health information, and social support functions [11]. We focus on the social media site Reddit because it is a global, widely-accessible discussion forum. Its dependence on member contributions and discussions makes it one of the world’s largest crowdsourcing websites. As such, Reddit has been a fruitful source of information about long-haulers’ experiences and concerns [12]. Next, we discuss Uncertainty Management Theory [13] as a lens to portray the communicative nature of crowdsourced medicine in the case of COVID-19 long-haulers.

1.1. Managing health uncertainty through crowdsourcing

Uncertainty Management Theory (UMT) explains people’s responses to uncertainty, including how they *experience* uncertainty; how they *appraise* uncertainty and the emotions accompanying appraisals; and the *strategies* that they engage to manage their uncertainty [13]. Uncertainty exists “when details of situations are ambiguous, complex, unpredictable, or probabilistic; when information is unavailable or inconsistent; and when people feel insecure in their own state of knowledge or the state of knowledge in general” [13]. COVID-19 long-haulers are confronted with multiple, connected layers of uncertainty, first as patients of COVID-19 and then as patients of long-COVID. As a new emergent virus, general knowledge and understanding of COVID-19 is continually shifting and changing [14]. For those who have had COVID-19 and now live with long-COVID, uncertainty is heightened due to concerns about permanent organ damage, lost senses, chronic fatigue and concentration issues, and generally, whether full recovery is possible [15,16].

Uncertainty experiences may be appraised negatively, positively, or neutrally [13]. Appraisals are central to uncertainty management as they are associated with affective responses that guide behaviors. Negative appraisals are often accompanied by fear and anxiety, positive appraisals with hope, and neutral appraisals with indifference. Presently, the nature of COVID-19 and long-COVID and the (lack of) knowledge surrounding them means that long-haulers are likely appraising their uncertainty negatively. Frequent reminders of COVID-19 morbidity and mortality rates increase uncertainty and the overall emotional distress individuals feel as they worry about the well-being of both themselves and their families [17]. Moreover, reduced access to face-to-face social support due to social distancing, conflicting stories about COVID-19 treatments, and a lack of information on the long-term effects of COVID-19 on the respiratory system and body may further increase uncertainty and anxiety [18,19]. Long-haulers frequently feel uncertainty and anxiety connected to their fluctuating and cyclical symptoms, protracted illness, and ambiguity surrounding causes and treatment [15,16].

People manage uncertainty in four primary ways: avoiding and seeking information, seeking social support, adapting to chronic uncertainty, and controlling the management [13]. UMT posits that strategy selection hinges on appraisals and emotions such that negative appraisals of uncertainty tend to motivate people to seek information that can reduce uncertainty, and to avoid information that might increase uncertainty. Conversely, positive appraisals tend to be associated with strategies that maintain uncertainty, including avoiding information that jeopardizes hope [13]. Previous research illustrates how seeking information for uncertainty reduction is particularly salient among individuals who have recently received a

new health diagnosis [20]. Seeking health information online can help to alleviate uncertainty in two key ways: first by providing greater details of their specific health condition, and second by offering social support experienced after finding other individuals who also share the diagnosis [21]. For example, the “#Covid-19 Patient Needs Help” hashtag in China became a means for information seeking via Twitter because physicians, nurses, and other hospital staff were too overwhelmed taking care of hospitalized patients to answer questions about symptoms, mitigation efforts, or transmission for those not hospitalized [22]. Similarly, as discussed below, COVID long-haulers are turning to fellow sufferers for information and social support through crowdsourcing.

1.2. Crowdsourcing and COVID-19

Crowdsourcing, a combination of the words “crowd” and “outsourcing” coined by Howe [23] is defined as a large group of people collectively sharing information to solve a problem or complete a task for an individual or an organization. Although the study of crowdsourcing developed in the information technology field, it has great promise in health, and particularly in global health, given it comprises a rapid, low-cost strategy for reducing uncertainty by openly sharing and analyzing (what can be) endless amounts of information from an indefinite number of people [24]. Specifically, Wazny [25] provides a review of the many health applications of crowdsourcing, including surveillance (e.g. using smartphone geospatial and participant self-report data to measure disease outbreak monitoring), psychology (e.g. using Amazon Mechanical Turk to collect advice from the general public for people with autism), and diagnosis (e.g., submitting “mystery” disease questions to an outline platform where medical experts can submit their diagnostic answers).

Diagnosis has been identified as the most common usage for medicine crowdsourcing and is the most germane to this study. Diagnosis commonly surfaces as information-seekers posting their health questions on Facebook, or a similar wide-distribution and open-authorship app, in hopes online community members can provide answers [25]. Recent research at the intersection of crowdsourcing and COVID-19 has focused on how crowds can be used to identify and further understand the disease spectrum, risk factors, case presentations, and ways to optimize treatment strategies [26]. Despite impressive numbers of COVID-19 publications, most scientific studies have been small and limited in their clinical scope, fostering more questions than answers [26]. Thus, a need has surfaced for larger, community-led projects to pinpoint and inform the main clinical challenges associated with COVID-19. Physicians and medical groups across various specialties have sparked crowdsourcing projects to better serve their patient communities. Some, like the American Association of Clinical Oncology (ASCO) Survey on COVID-19, collect and analyze data directly from COVID-19 cancer patients, inquiring into and measuring the effectiveness of cancer treatments and patient outcomes post COVID-19 contraction. These community-led initiatives will fill key knowledge gaps that help tackle crucial clinical questions on the complexities of COVID-19 infections. Vermicelli et al. [27] conclude that regardless of their sources or goals, crowds and online communities represent an effective COVID-19 response strategy because they provide original, actionable, quick, and low-cost solutions to the health and economic crises spurred by the pandemic.

In sum, research on crowdsourcing and COVID-19 emphasizes the critical role that online spaces play in enabling people to share and provide COVID information and support, specifically those enduring great health uncertainty, such as COVID long-haulers. To explore how COVID-19 long-haulers manage uncertainty by engaging in crowdsourcing, we asked:

RQ. What linguistic features and functions characterize COVID-19 long-haulers' communication and information-seeking on Reddit as facets of their uncertainty management?

2. Methods

As part of a larger study of COVID-19 long-haulers on Reddit, a topic modeling text analysis approach called the Meaning Extraction Method [28] was used to identify groups of words that mathematically group together across a number of text observations Reddit. Similar to other topic modeling approaches, such as Latent Dirichlet Allocation (LDA), researchers have used the MEM to glean information about people's communication patterns [29,30], romantic relationships [31], health behaviors [32] and psychological health [33]. Given that technology is providing researchers access to large amounts of organic textual data, a software system called the Meaning Extraction Helper program was created as an automated companion tool for MEM [34] and we used it to perform topic modeling analyses on natural language extracted from the Reddit community (i.e., subreddit) r/covidlonghaulers. The MEM first identifies the most common content (e.g., nouns, verbs) words across a corpus per user while simultaneously removing low-frequency words and stop words (i.e., function words, low base rate words) [30]. A percentage of use score is calculated for each text observation by dividing the number of times an n-gram appears in their text divided by total word count [34]. Once this use score is calculated, the MEH generates an output file for use with statistical software (e.g., R, SPSS) to run a Principal Component Analysis (PCA) with varimax rotation and to extract factors composed of common word clusters used within that corpus. The factors produced by the PCA represent clusters appearing in the data set.

This study used Reddit's open source application programming interface (API) to extract the entire textual history of the newly formed long-hauler subreddit, starting with its creation date, July 24th, 2020, until January 7, 2021. These dates correspond to the origin of the subreddit through the end of the year, including a week in January. For this approximately five-month time period, a total of 48,525 text observations were extracted. After standard cleaning procedures, which included a word count criterion (WC >= 20 words), the final data set consisted of 31,892 text observations that contained 78.82 (SD = 86.93) words on average. Table 1 contains the most frequent words appearing on the r/covidlonghaulers subreddit that were included in the analysis. "Symptoms," "covid," and "day" were the most frequently used words by long-haulers to describe their experiences.

Meaning extraction analyses yielded 16 groups of words that were thematized using the textual data. Table 2 contains results for the MEH analysis, including the factors and loadings for words within the factors. To develop labels or themes for each factor, we followed Tracy's [35] iterative approach and simultaneously engaged the MEH results, the text observations, and relevant literature. We first read through the factors and the data independently, beginning with observations loading highest onto the factor. Then we met as a group to discuss potential themes. During our discussions we drew upon the tenants of UMT [13] and the motivations for health crowdsourcing [25] to label the factors in ways that were grounded in the data and conceptually consistent with the literature. For example, the grouping for words "life, health, and anxiety" initially suggested uncertainty (i.e., anxiety as a result of uncertainty about life and health). However, after reading the text observations, we had conversations about how this theme was really about anxiety as a mental health issue. Similarly, words "long, hauler, haul, and term" suggested a labeling function. However, through reading the data and group discussions, we determined a deeper self-referent or identity function of this language use.

Table 1
50 Most frequent words for r/covidlonghaulers.

Word	Frequency	Word	Frequency
symptom	11,663	chest	2831
covid	10,996	virus	2796
day	10,941	post	2787
month	9626	blood	2783
time	8530	year	2722
week	7152	sure	2703
test	7114	right	2694
long	6867	give	2675
start	6000	worse	2596
better	5739	eat	2540
doctor	5534	look	2356
pain	5474	high	2321
people	5410	happen	2223
work	5128	rest	2193
issue	4557	exercise	2179
heart	4474	anxiety	2176
see	4107	recover	2125
body	3766	said	2124
fatigue	3394	positive	2103
normal	3377	relapse	2089
hope	3328	hard	2086
sick	3314	walk	2077
experience	3272	find	2059
brain	3185	march	2024
sleep	2833	fog	2013

3. Results

The 16 factors included symptoms (e.g., *pain, respiratory, sensory*), diagnostic concerns (*testing, diagnosis*), broad health concerns (*immunity, physical activity, diet*), *chronicity, support, identity*, and *anxiety*. Table 3 contains textual examples for each of the factors. The largest grouping of factors centered on symptoms, including *respiratory* (e.g., shortness of breath), *cognitive* (e.g., brain fog and fatigue), *sensory* (e.g., loss of smell and taste), *cardiac* (e.g. tachycardia), *pain* (e.g., aches in various locations), *sleep* (e.g., less sleep and interrupted sleep cycles), and *blood pressure* (e.g., head and back of the eyes). As illustrated in Table 3, symptom language often took the form of long-haulers' sharing their own symptoms with the community.

The second group of factors were diagnostic concerns and included the factors *testing* and *diagnosis*. For *testing*, long-haulers generally spoke about their test results, including when they tested positive for COVID-19, subsequent positive and negative test results, and antibody results. Long-haulers used diagnostic language in two ways: first to seek diagnosis, and second to compare possible diagnoses. Long-haulers posed questions and hypotheses to the group about potential diagnoses, with their "post-viral" syndrome often being compared to Chronic Fatigue Syndrome (CFS).

The third group of factors focused on broad health concerns, including *immunity, physical activity*, and *diet*. *Immunity* words manifested as explanations for long-COVID, including an overactive immune response, as well as discussions about immune functioning with long-COVID and immune system recovery. Long-haulers used *physical activity* language to articulate a dilemma between exercising for health and recovery and exercising worsening their symptoms. They use *diet* words to describe how they have changed their diet during their long-COVID journey and to share dietary options with one another.

The factor *chronicity* includes temporal words. Long-haulers often segmented time beginning with their positive COVID-19 test results and subsequent negative test results. They also marked the beginning and duration of their long-COVID illness, including periods of specific symptoms. The factor *support* included a cluster of words—i.e., hope, share, glad, thanks, hear, better, thank—all

Table 2
r/covidlonghaulers MEH analysis.

Factors	1	2	3	4	5	6	7	8							
Eigenvalue	2.57	2.24	2.00	1.93	1.87	1.85	1.77	1.73							
Variance %	1.45	0.99	0.89	0.85	0.83	0.82	0.79	0.76							
M (SD)	0.10 (0.35)	0.05 (0.20)	0.24 (0.34)	0.09 (0.33)	0.03 (0.18)	0.09 (0.14)	0.10 (0.31)	0.06 (0.16)							
Testing		Respiratory	Chronicity	Cognitive	Sensory	Cardiac	Identity	Pain							
test	0.75	breath	0.85	march	0.36	fog	0.89	smell	0.77	heart	0.76	long	0.87	pain	0.52
negative	0.62	shortness	0.83	month	0.33	brain	0.89	taste	0.75	rate	0.75	hauler	0.65	side	0.41
positive	0.59	lung	0.30	sick	0.32	fatigue	0.27	sense	0.52	high	0.29	haul	0.50	left	0.39
antibody	0.58	breathe	0.26	week	0.31	symptom	0.27	lost	0.44			Term	0.30	muscle	0.33
														chest	0.33
														ache	0.31
														leg	0.31
														nerve	0.25
														16	

Factors	9	10	11	12	13	14	15	16							
Eigenvalue	1.66	1.62	1.58	1.52	1.48	1.47	1.43	1.41							
Variance %	0.74	0.72	0.70	0.67	0.66	0.65	0.63	0.62							
M (SD)	0.14 (0.30)	0.06 (0.27)	0.05 (0.19)	0.06 (0.19)	0.05 (0.19)	0.09 (0.20)	0.14 (0.18)	0.06 (0.22)							
Diagnosis		Immunity	Sleep	Physical Activity	Diet	Support	Anxiety	Blood Pressure							
covid	0.36	immune	0.77	night	0.52	walk	0.43	eat	0.56	hope	-0.38	life	-0.30	pressure	0.57
cf	0.36	system	0.76	wake	0.50	exercise	0.39	food	0.52	share	-0.36	health	-0.26	blood	0.44
post	0.33	virus	0.41	sleep	0.47	rest	0.28	diet	0.44	glad	-0.36	anxiety	-0.26	head	0.31
viral	0.30			morning	0.34	push	0.25	healthy	0.27	thanks	-0.34	hear	-0.32	eye	0.30
				hour	0.34			drink	0.25	thank	-0.31	thank	-0.31		
										better	-0.27				

Note: The Kaiser-Meyer-Olkin measure was.572, and Bartlett's Test of Sphericity reached statistical significance, which supports the components the correlation matrix.

pointing to the supportive characteristics of the community. Many observations having high frequencies of *support* words began with permutations of: “Thanks for sharing!” “Thanks for responding” and “Glad to hear things are better.” As such, support words functioned to: (a) express gratitude for other long-haulers’ contributions, (b) offer appreciation for support received from others, (c) provide encouragement to others, and (d) validate others’ experiences.

The factor *identity* included the self-referents “long” and “hauler.” Long-haulers used identity language when referring to themselves—“I am a long-hauler”—and the community at large—“We long-haulers.” It seemed that long-haulers were “trying on” the label as an identity for themselves and for the group. Referring to the larger community as long-haulers also appeared to provide validation to others and to signal membership in the group. Finally, the factor *anxiety* manifested within long-haulers’ experiences as (a) their own emergent anxiety or existing anxiety that has been exacerbated by long-COVID, and (b) their doctors’ beliefs that anxiety is driving their physical symptoms. For the former, long-haulers described worsening anxiety because of long-COVID (e.g., “anxiety loops”), and they wondered if their anxiety was a symptom of long-COVID. For the latter, long-haulers expressed frustration and feelings of invalidation. They were upset that their long-COVID symptoms were invalidated, psychologized, or dismissed as anxiety.

Table 4 contains means and standard deviations for the factors at monthly intervals. There are three noteworthy aspects of these results. First, some factors occur with greater frequency than others across time. While the means of most factors were below.10, means for *diagnosis* (range.13–0.15), *testing* (range.10–0.12) and *chronicity* (range.23–0.28) were consistently.10 and above. Second, the *identity* factor changes slightly over time. At the very least, this increase may indicate the community has become more developed or may even represent a solidified identity among long-haulers. Third, the means of the factors were relatively stable across the five months. This suggests that the factors we identified represent long-haulers’ enduring concerns and experiences.

4. Discussion and conclusion

4.1. Discussion

The purpose of this study was to explore how individuals engage in crowdsourced medicine as a means of managing their uncertainty about long-COVID. Due to the stay-at-home orders and recommended quarantines associated with COVID-19, the pandemic made traditional access to healthcare more difficult, ultimately contributing to the growth of internet crowdsourced medicine [28]. Principally, our findings provide a succinct, yet robust set of themes reflecting long-haulers’ attentional foci. By distilling nearly 32,000 text observations according to patterns of language usage, we provide a window into the uncertainty management functions of long-haulers’ talk, namely seeking information and seeking support [13]. Seeking information manifested as long-haulers’ engaging in “problem presentation” as they would to a doctor, evidenced by the preponderance of symptom-centered language that took the form of, “This is happening to me.” This is perhaps not surprising given the uncertainty surrounding long-COVID; yet it is consistent with research finding that “symptoms and treatment” are the most frequently searched COVID-19 topics online [36] and that diagnostic uncertainty is the most common medical crowdsourcing topic [25].

At the same time, the findings of this study suggest that the primary benefit of crowdsourced medicine in this study was not receiving a definitive diagnosis from fellow long-haulers—many long-haulers encouraged each other to seek doctors for medical care—but having symptoms validated and receiving emotional support. Indeed, seeking social support from fellow long-haulers often displayed as advice, information, encouragement, and validation. Identity-referents and supportive words in particular point to the community-building function of their language use. In this way, support-focused language complemented informational talk with, “Is this happening to you?” As social identity theory [37] suggests, group identity may be particularly important to uncertainty management, especially as the community continues to grow and

Table 3
Textual examples of MEH factor themes for r/covidlonghauers.

Themes	Text examples
Testing	<p>“...My first relapse felt a little worse than the initial infection and I did test negative at that time.”</p> <p>“Positive PCR test in mid-April, and NEGATIVE antibody test in November. So yes, definitely possible you had it even though your antibody test came back negative!”</p> <p>“I brought these same symptoms to my primary care last month and she had no idea how to respond especially when I tested negative for antibody”</p>
Respiratory	<p>“. A persistent dull ache in the left side of my chest is my main remaining symptom (I've had shortness of breath on and off, but this is generally much better now).”</p> <p>“. Currently having a bad flare 5 months in that makes it feel like I'm not breathing air at all. A lot of the shortness of breath I feel now feels like the issue is in my throat not my lungs (hard to explain)”</p> <p>“Just shortness of breath mostly. Im worried I have permanent lung damage since every single other symptom has mostly gone away for me”</p>
Chronicity	<p>“...I'm curious about your fevers as I am on a similar timeline and still get several low-grade fevers every week, but luckily not every day anymore. What are yours like? For me they usually come in the late afternoon but are gone by late evening and are somewhere between 99.0 and 99.9. I haven't broken 100 since I was very sick months ago, but the slight fever multiple days is confusing and worrisome. Is it similar for you?”</p> <p>“Not to be negative, but Ive been hearing X months since the beginning. 2 weeks, 2 months, 4 months, 6 months, etc. wake me up in 18 months!”</p> <p>“Got sick in March and first few months were only lung and neuro symptoms. Felt lucky that I escaped the long-term inflammation symptoms. 4 months later pretty sure I got infected again and the inflammation symptoms hit hard that first day and have stayed. Hopefully will slowly improve”</p>
Cognitive	<p>“I have been suffering from brain fog on and off for around 2 months now, even before exposure to covid on 9/3. For me, covid had seemed to affect me mentally and neurologically the most with my first symptom being an extreme depressive episode followed by multiple days of artificial anxiety that became extremely overwhelming. Right afterwards the tangible symptoms hit: low grade fever, fatigue, brain fog, and loss of taste and smell. Even after the sick symptoms had gone away, my brain was fogged to the point of completely being unable to study...”</p> <p>“I got sick back in March and my remaining issues are Fatigue, Brain fog (Cognitive Issues), Heavy, Restless and Achy legs. Last 2 months I feel like my brain fog and fatigue faded a little bit, but it's still far from good. When my fatigue faded a level last month, I noticed the brain fog also faded - for me, it seems to me like these two symptoms are connected. This also gives me hope regarding getting back to a normal state one day. My current brain fog issues are: “brain-fatigue” of voice conversations, problems multi-tasking, focus issues, and memory issues.”</p> <p>“I vape CBD flower on the daily to help with the fog. Without it, brain fog and it feels like my brain is swelling”</p>
Sensory	<p>“...I had a very easy going case with just no taste/smell, congestion (which I always am congested so it wasn't too new), and extreme tiredness. Like two weeks later, I thought I was in the clear. My taste and smell were slowly returning, but out of nowhere in early June (my taste and smell were like 60% back), a lot of foods I love smelt like garbage and tasted worse. Things like mint, some sweets, chocolate, citrus (specifically orange), all of them tasted horrible. Still little to no improvement now”</p> <p>“I have had no problems with my taste and smell. Mine is hearing and eyesight. I have had one smell issue and that is the smell of soda. It smells like rubber to me. I am not sure why, but it is annoying. It turns me away from it and makes me sad. My eyesight goes in and out with pain behind them and hearing issues where I hear nothing but grasshoppers and static. For some reason I am the only one”</p> <p>“...I also have lost my appetite and my sense of smell and taste is limited to sweet and salty but I cant discern any flavor after that”</p>
Cardiac	<p>“Recurrent bike for 30 min (plus 10 min warmup and cooldown) 3x/week. My sweet spot for heart rate is 105–110. If I push past 120, I'll get a flare for the next 1–2 days”</p> <p>“...A nurse recommended to me a pulse oximeter to monitor heart rate and oxygen”</p> <p>“Hey, so its not a magic fix. It seems to stabilize my heart the most right after I take it and for a few hours– my standing heart rate goes down to 80ish rather than 90–100, but still higher than it used to be. I'm taking it twice a day as a result. I still get lightheaded throughout the day, and further away from the niacin dose my heart rate will go to 90–100 when I'm standing (first it skyrockets to like 120 and then settles back down)”</p>
Identity	<p>“Just something to consider, as a long hauler myself staying up on what's what is important due to us not even being a year or so into initial infections. As we all know many doctors don't even recognize long haulers as a thing, im lucky to live near the Cleveland Clinic and my last ER visit gave me relief knowing doctors here are at the forefront against covid/long covid. But they had nothing for me treatment wise which is why I'm apart of this subreddit and posted this link...”</p> <p>It will be! I am still practically in bed as a long hauler approaching three months. I wonder when it will be safe for us long haulers with all of our multi system issues to get a flu shot this season.</p> <p>“a lot of long haulers are testing negative for antibodies. could imply that the lack of antibodies is causing long hauling. therefore either the vaccine could help or maybe same reason we long haul, we wont develop any antibodies from vaccine”</p>
Pain	<p>“GI issues, fever, diarrhea, body aches, fatigue, body pains, palpitations, nausea, eye pain/burning, metallic taste, smokey smells, inner nostrils swelling, loss of appetite and lost weight, shortness of breath, constipation, chest/heart pains, lack of sleep, headaches, acid reflux/heartburn, strange realistic dreams/nightmares, body twitches, brain fog”</p> <p>“I haven't had the tingling/burning but I did have headaches for the first couple months that felt like veins pulsating all the way down into the neck. I do get a chest pain sometimes that feels like it's originating from the bones of the chest, like a sharp hard stabbing. It's similar to voluntarily cracking the chest (like cracking knuckles) only this is not voluntary, and it is actually painful. It seems worse in the morning, as does a spongy feeling in the chest. Also, not so much pain, but I have had a consistent discomfort of the chest that feels like a ball is in it (near the bottom, like above the stomach) which seems to restrict my voice and makes it painful to talk”</p> <p>“Everything is worse on my left side. Tingling in my left arm, mostly left side back and abdominal pain, and my left armpit aches. Heck I even have a new thyroid nodule on my left side. Had subacute thyroiditis that caused hyperthyroid symptoms and terrible left sided head and neck pain. Most of my issues seemed to have resolved except for the pain in my arm pit and occasional back and abdominal pain, but still it was weird that effected my left side more”</p>
Diagnosis	<p>“The good news that could emerge from Covid-19 is that there would be more seriousness and scientific rigor in understanding and researching CFS. I dont think anyone can cure virus once it is in the host, but at least there could be some viral load medication similar to delaying HIV infection progressing into AIDS (4 years vs. ~25 years)”</p> <p>“I'm confused as to why it says the etiology of ME/CFS and LC are different. ME/CFS is oftrn triggered by a viral infection such as glandular fever or even chicken pox. LC has been triggered by the Covid virus, so the etiology sounds quite similar to me. And my symptoms are absolutely textbook post viral fatigue/CF”</p> <p>“...It's a general discussion over what we know about how viral infections can persist and whether long-term post-COVID-19 illness is driven by viruses that hide in the body or an immune reaction gone wild”</p>
Immunity	<p>“...I've read that the vaccines can induce varying degrees of immune system response so perhaps it can teach the body to make more antibodies then it currently does and make that final push. Maybe it will cause another huge wave and fuck us up more. Or maybe the body will just say yeah thanks for the info I already know and we just need to add another virus/infection that our bodies will be burdened with the rest of our lives. Guess well be finding out. Keep fighting brothers and sisters”</p> <p>“The way the immune system works is all about snippets. A macrophage eats an antigen, partially digests it, then starts handing out snippets to other immune agents, who communicate with each other through cytokines and produce more immune agent clones, who produce more cytokines. In case of a dire situation, the agents start killing each other, spilling out all the partially digested content, triggering a bigger immune resurgence.</p>

(continued on next page)

Table 3 (continued)

Themes	Text examples
Sleep	<p>The contents of the immune cells aren't viable. It's just a slurry of protein chains that are eventually going to be broken down to simple amino acids and rebuilt into muscle, hair, stem cells, etc."</p> <p>"The virus has passed through their system but their immune system is still on overload. The inflammation the entire body is experiencing is like irritating a wound"</p> <p>"I was having horrible insomnia for weeks in addition to the fatigue. Then one day it stopped and I started sleeping like ten hours a night. No idea what changed, but maybe the same thing will happen to you. If not then try acetaminophen, in my experience inflammation causes insomnia. Or low iron, but for long haulers probably inflammation. Acetaminophen knocks me out and I sleep amazing"</p> <p>"I'm 5+ months in. I've had dry mouth here and there since May. Usually at night when im trying to sleep or in the morning when i wake up. I mean it gets so dry that my tongue feels like sandpaper"</p> <p>TLDR: sleep has changed since COVID. Constantly waking up, bizarre dreams, sleep paralysis-like experiences, and waking up nauseous. I got COVID in July. I usually sleep soundly for 7–9 hours nominally. However lately, I have been waking up most nights after a couple hour with absolutely bizzare dreams. I usually cannot go back to sleep right away or I keep falling into this half sleep half not state (similar to sleep paralysis). After walking around or looking at my phone for a few minutes I can go back to sleep and usually sleep for a few more hours. When I wake up I tend to be a bit nauseous. This sleep cycle usually repeats for a couple of days and then one or two nights I get a solid, consistent sleep</p>
Physical Activity	<p>"Yes, recently started having really significant muscle weakness and aching. My legs ache just walking across the house, like I've been running around all day. I wobble sometimes when walking and have difficulty doing little things. I haven't decreased my activity level significantly up until this happened, so not due to less use for me. I'm at 5 months after onset of illness, and I've continued for the most part with regular activities, despite fatigue. I would rest more if I could, but I have a toddler. Rest has helped though when I am able to rest"</p> <p>"Hey, what are your thoughts on exercise/ exertion? I know it seems to make most people feel worse– my heart rate goes way too high personally and then I'm dizzy the rest of the day after a walk– and that for post-viral CFS people are advised to avoid exercise. However, POTS patients are advised to try to exercise to stabilize their heart rate. I, like many others here, have POTS symptoms. Should we push through the fatigue to try to exercise to avoid everything that triggers symptoms?"</p> <p>Quit the exercise immediately. I triggered a very bad relapse by exercising too hard. Rest like your life depends on it. I know it's debilitating, but you have to</p>
Diet	<p>"Im very glad some diets are working for some people. I've been trying to eliminate all kinds of food to see where Im going wrong to the point that my calorie count is becoming low. Plus I get stressed over what I'm eating or what the food will do to me. About 3 weeks ago I had 2 days that looked like I was coming around for the good, and the week leading up to that I wasn't on any kind of special diet. In fact I was drinking surgery smoothie king shakes, Campbells soup, and instant grits among other stuff. The two days was short lived. I do have gastritis so I know I have to watch out for foods with a lot of acid and certain fats. I'm not saying diet doesn't play a certain role in this, I just wonder if its a lot different for different people. I have POTS like symptoms so a doctor might tell me to eat more salt. I definitely think having a healthier diet helps. If anyone is getting better because of a strict diet change by all means stick with it. Maybe I will find my perfect diet but until then I can't stress about food and my weight loss"</p> <p>"...When I did eat sugars and breads, I felt really horrible. The meats I eat are organic, and I do try to get some organ meat in once every week or so minimum. I don't drink alcohol, don't smoke and limit caffeine now. I'm 8 months in, never had significant respiratory symptoms toms."</p> <p>"That's a pretty good plan so far! What I might add to that is ketogenic diet and keep yourself relatively deep in ketosis. If you are cutting out sugar and processed food anyway it shouldn't be too hard. You could also forgo breakfast and lunch. Eating one meal a day to improve productivity sounds counter intuitive but you'll have more energy"</p>
Support	<p>"That's a good thing to hear that its nothing to worry about, hope you recover quickly, take care. But consider buying a pulse oximeter its very helpful."</p> <p>"Thanks for replying. Glad to hear it got better, the dizziness is soo annoying. Does your HR also increase a lot when doing any activity?"</p> <p>"That last statement really resonated with me deeply. I have a very similar experience, in that it is the smallest things that restore my heart and soul throughout all of this. Congratulations on being able to walk several miles at a time. This is so awesome to hear, and gives so many of us the hope we need"</p> <p>"Glad to hear you are slowly improving and sorry about the relapse, I know how disheartening it can be. Thank you for checking back in and I hope you continue to feel better"</p>
Anxiety	<p>"It infuriates me that doctors are once again blaming what they dont know on anxiety. Keep advocating for yourself. If someone tells you its just anxiety, get up and walk out. No need to waste your time on ignorant doctors."</p> <p>"Yeah, all doctors say anxiety. *They* pick and choose the symptoms that can be anxiety related and seemingly ignore all the other ones"</p> <p>"Dont forget that COVID can mess with your brain. Anxiety and depression seem to be common post-COVID effects. My anxiety is majorly heightened now"</p> <p>"Well it's really hard to control anxiety and thoughts in our state with all our symptoms and I'm pretty sure most if not all of us have had it at some point, maybe even for the entirety of the illness. You know what they say "healthy mind, healthy body" it applies both ways"</p>
Blood Pressure	<p>"My blood pressure is usually low normal, but after getting sick my blood pressure was high. It fluctuated a lot but could get up to more than 160/90 for quite some time. My doctor was concerned enough to put me on a beta blocker that helped getting my heart rate to get lower but did nothing for my blood pressure. An Ace inhibitor (lisinopril) was prescribed later and it worked wonders for me. Got my blood pressure under control and surprisingly all my other symptoms disappeared other than my GI issues shortly after starting it"</p> <p>"Yes! I went to eye a couple weeks ago - and was convinced I had optic nerve inflammation and high eye pressure/glaucoma. All was good! My symptoms have since eased a little but include: eye pressure, eye strain with headaches, floaters and the scariest was eye flashes."</p> <p>"My headache was gone for days. Now it feels like someone is sitting on top of my head. My sinuses feel inflamed and when I close my eyes I feel like my head is going to explode. Its not even comparable to a headache.there is just a constant pressure in my head. I can hardly focus with it and I feel so fogged out. Did anyone have these headaches at one point and they eventually went away? I would do anything to get rid of this head pressure and dizziness. Ughhhhhh"</p>

members internalize their long-hauler identification as an aspect of their self-concept. Our findings are similar to Southwick et al.'s [12] analysis of the /covidlonghaulers subreddit from an earlier time frame and using a different textual analysis method, latent dirichlet allocation (LDA). They identified 21 word cluster themes, many of which overlap with our findings: support, physical activity and fatigue, taste and smell, time, immune system, pain, COVID-19 testing, and mental health. Together, our findings and Southwick et al.'s [12] findings portray the communicative functions of crowdsourced medicine in the context of emergent illnesses that are not well understood by medicine, such as long-COVID.

The findings of this study contribute to the literature in at least two ways. First, this study adds to a robust literature on how individuals seek health information and social support in online spaces and social networks such as Reddit [11], particularly concerning COVID-19 [38]. As related examples, studies find that social support in shared, online spaces is an active process that involves asking for support rather than passively reading support messages [39]. Research also reveals how open-authorship platforms like Facebook generate timely resources of collective intelligence and storytelling during crises that crisis-impacted populations believe and find more credible than official sources [40]. Second, as

Table 4
Descriptives for each factor across time.

Theme	Month 1	Month 2	Month 3	Month 4	Month 5
Testing	0.12(0.37)	0.12(0.38)	0.10(0.31)	0.12(0.39)	0.10(0.34)
Respiratory	0.06(0.22)	0.06(0.21)	0.04(0.17)	0.05(0.20)	0.05(0.21)
Chronicity	0.27(0.36)	0.28(0.36)	0.25(0.35)	0.23(0.33)	0.24(0.35)
Cognitive	0.09(0.30)	0.10(0.32)	0.11(0.36)	0.08(0.28)	0.10(0.34)
Sensory	0.05(0.24)	0.03(0.17)	0.03(0.18)	0.03(0.18)	0.03(0.17)
Cardiac	0.07(0.26)	0.09(0.31)	0.10(0.34)	0.10(0.31)	0.10(0.33)
Identity	0.07(0.24)	0.08(0.26)	0.08(0.27)	0.12(0.34)	0.12(0.35)
Pain	0.07(0.18)	0.06(0.16)	0.07(0.18)	0.06(0.17)	0.06(0.16)
Diagnosis	0.14(0.32)	0.13(0.27)	0.14(0.31)	0.15(0.31)	0.14(0.31)
Immunity	0.07(0.26)	0.08(0.29)	0.07(0.27)	0.08(0.33)	0.06(0.27)
Sleep	0.06(0.22)	0.06(0.20)	0.05(0.19)	0.05(0.18)	0.06(0.20)
Physical Activity	0.05(0.17)	0.07(0.20)	0.06(0.18)	0.06(0.20)	0.06(0.19)
Diet	0.05(0.17)	0.07(0.23)	0.06(0.21)	0.05(0.19)	0.05(0.18)
Support	0.09(0.19)	0.09(0.18)	0.10(0.21)	0.09(0.20)	0.10(0.21)
Anxiety	0.04(0.16)	0.06(0.19)	0.04(0.17)	0.05(0.18)	0.05(0.17)
Blood Pressure	0.07(0.23)	0.06(0.19)	0.08(0.26)	0.07(0.23)	0.06(0.23)

Note: Means with standard deviations in parentheses.

information seeking and support seeking are primary means of managing uncertainty, our research also demonstrates how the social affordances of sites such as Reddit enable crowdsourced medicine as a means of collective uncertainty management—often with geographically distant strangers. Typically, research utilizing uncertainty management theory centers on individuals and close relationships [41,42]. Indeed, contributors on the long-haulers subreddit are likely motivated to manage their individual uncertainty needs, for example, posting initially to ask a question pertaining to their own symptoms. However, as individuals’ share information, they also become part of and contribute to a larger community. Collective uncertainty management then becomes a way that individuals are able to adapt to their chronic uncertainty over time.

The notion of collective uncertainty management has several implications for theory and future research. First, health knowledge sourced from the “crowd” is not necessarily knowledge that exists and need only be discovered. Instead, in the case of long-haulers, crowdsourced medicine is generative; it is: (a) knowledge about long-COVID that may not be available through other credible sources, namely, health care professionals; (b) health information that is increasingly recognized as credible and valid; (c) a source of legitimacy for long-haulers, who until recently did not have a label for their health condition; and (d) a mechanism for long-haulers to advocate for their needs. Indeed, a parallel phenomenon to crowdsourced medicine is the notion of “citizen scientist” [43]. COVID long-haulers as amateur scientists have been engaged in “patient-led research” studies since the early stages of the pandemic [15]. These studies and other social media grassroots organizing are credited for making long-COVID visible [44]. It is likely that such organizing will continue to be a means of patient advocacy. It will be interesting to see what becomes of these patient-led studies in the future and how they are received and adopted by various stakeholders, including long-haulers and academic and medical institutions. There are also ethical implications to consider [25]: while crowdsourced medicine can help solve medical mysteries, social media can be used to proliferate misinformation and disinformation that may negatively impact personal and public health. We anticipate that issues of false information will continue to gain attention as researchers, practitioners, and even social media platforms such as Facebook contend with the health implications of false content shared online (e.g., vaccine hesitancy). The appropriateness of the crowd and its intentions are important considerations for future research and application [25].

Consequently, a second implication of this research is that crowdsourced medicine raises important questions about epistemic authority. On one hand, products of crowdsourced medicine and

patient-led research might be welcomed as ways to draw upon diverse knowledge to solve pressing and perplexing health problems such as long-COVID [45]. Within the patient-provider interaction, research indicates that physicians respond to patients’ online health information seeking in ways that enhance the relationship [46,47]. Moreover, patients collectively seeking health information online—labeled “e-patients”—often come into patient-provider encounters with more informed questions, are better able to participate in shared decision-making, and demand that providers use a patient-centered approach [48]. On the other hand, crowdsourced medicine may further exacerbate tensions between expert and lay expertise. For example, some research on “informed patients” and e-patients suggests that conflict arises between patients and providers when providers perceive their authority being challenged or when patients are misled by the health information they find online [49]. It is likely that both patients and providers will continue to negotiate both the benefits and drawbacks of gaining information online via crowdsourced medicine. Future research may consider how crowdsourced medicine can impact interactions with providers who ultimately control access to treatments and other services.

Furthermore, although our study highlights how COVID long-haulers engage in crowdsourcing on Reddit to manage their uncertainty, Reddit crowdsourcing could also have the opposite effect, instead exaggerating or increasing long haulers’ anxiety regarding their condition and/or symptoms. Research demonstrates that crowdsourcing can lead to increased noise, making it difficult for participants to identify credible diagnostic solutions from a large pool of recommendations [50]. Sometimes growth in crowdsourcing participation can result in problems with self-efficacy, response efficacy, and/or accuracy of information. Therefore, future research should also consider the points at which crowdsourced medicine becomes detrimental to uncertainty navigation and management, as compared to beneficial.

This study’s contributions should be considered alongside its limitations. First, Reddit posts are completely anonymous. We cannot collect information beyond what users choose to disclose in their posts, making it difficult to possess consistent user demographics. According to Barthel et al. [51], 4% of U.S. adults use Reddit, a population that is more likely to be young, male, and liberal in comparison to the general public. The scope of the study is also somewhat limited by observing exchanges among long-haulers on Reddit alone. Future research should collect data from multiple platforms in order to achieve a more representative sample. Second, while our data set is robust, and we were intentional in our selection of text observations, we acknowledge that COVID long-haulers are an evolving community.

4.2. Conclusion

Our study is a snapshot of an emerging narrative surrounding long-COVID, one that we hope future studies will further illuminate. As long-hauler communities grow and more long-COVID research is conducted, it will be useful to understand how the health concerns we have identified endure, and what new issues may emerge. Some health concerns, such as diet and physical activity, may steadily increase as people recover. Other health issues, such as pain and cardiac issues, as well as mental health issues, may be more persistent. As time carries on and more people are vaccinated, we will need to consider the impact of chronic health issues, access to social support, and new medical insights on long-haulers' uncertainty management.

4.3. Practice implications

This research has implications for medical professionals of long-COVID patients. First, identifying their symptoms and needs over time can inform care and support services for these individuals. Our findings validate the prevalence and persistence of physical symptoms within this community, including respiratory, cardiac, and cognitive issues. Our findings also point to the complexity of mental health issues, namely, anxiety. Long-haulers talked about anxiety exacerbated or brought on by post-COVID illness. Long-haulers also described feeling dismissed by medical providers who believed their symptoms were psychosomatic [15]. Based on our study results, we recommend that health care providers employ sensitivity when addressing the anxiety that long-haulers are experiencing while also validating that their physical symptoms are real. Our findings indicate that breakdowns between long-haulers and their healthcare providers may result in unmet informational and support needs that long-haulers seek to satisfy in online communities [20].

A second implication of this research for medical professionals caring for long-COVID patients is that it reveals opportunities to address long-haulers' uncertainty and to correct potential misinformation and disinformation. For example, the factor *potential diagnosis*, suggests that long-haulers are searching for a label for their experiences and "trying on" potential labels for their illness. As diagnoses are not only meaning-making tools but also guides for medical care [52], medical providers should be aware of how long-haulers' health behaviors are affected by what illnesses they think they might have.

CRedit authorship contribution statement

Charee M. Thompson: Conceptualization, Formal analysis, Supervision, Project administration, Writing – original draft, Writing – review & editing. **Kayla B. Rhidenour:** Conceptualization, Formal analysis, Writing – original draft, Writing – review & editing. **Kate G. Blackburn:** Methodology, Formal analysis, Data curation, Writing – original draft, Writing – review & editing. **Ashley K. Barrett:** Writing – original draft, Writing – review & editing. **Sara Babu:** Writing – review & editing.

Competing interest statement

The authors have no competing interests to declare.

References

- [1] World Health Organization. WHO Coronavirus (COVID-19) Dashboard|WHO Coronavirus (COVID-19) Dashboard With Vaccination Data; 2021. <https://covid19.who.int/> (Accessed 10 June 2021).
- [2] Doughton S. Many of the earliest COVID "long-haulers" still suffer; Seattle researchers are trying to figure out why|The Seattle Times; 2021. <https://www.seattletimes.com/seattle-news/health/nearly-a-year-on-many-of-the-earliest-covid-19-long-haulers-are-still-not-back-to-normal/> (Accessed 19 April 2021).
- [3] Nabavi N. Long covid: how to define it and how to manage it. *BMJ* 2020;370:3489. <https://doi.org/10.1136/bmj.m3489>
- [4] Strazewski L. Dr. Fauci offers 2021 forecast on COVID-19 vaccines, treatments|American Medical Association; 2020. <https://www.ama-assn.org/delivering-care/public-health/dr-fauci-offers-2021-forecast-covid-19-vaccines-treatments> (Accessed 19 April 2021).
- [5] Komaroff A. The tragedy of long COVID 2020 Harvard Health Blog – Harvard Health Publishing; 2020. <https://www.health.harvard.edu/blog/the-tragedy-of-the-post-covid-long-haulers-2020101521173> (Accessed 19 April 2021).
- [6] Rubin R. As their numbers grow, COVID-19 "long haulers" stump experts. *J Am Med Assoc* 2020;324:1381–3. <https://doi.org/10.1001/jama.2020.17709>
- [7] Fox M. Coronavirus may cause fatigue syndrome, Fauci says; 2020. https://edition.cnn.com/world/live-news/coronavirus-pandemic-07-09-20-intl/h_5125152a01f8c98d362cf15d6860ab37 (Accessed 19 April 2021).
- [8] Belluck P. Covid "long-haulers" need medical attention, experts urge 2020. The New York Times; 2020. <https://www.nytimes.com/2020/12/04/health/covid-long-term-symptoms.html> (Accessed 19 April 2021).
- [9] U.S. Office of the Press Secretary. Press Briefing by White House COVID-19 Response Team and Public Health Officials, The White House; 2021. <https://www.whitehouse.gov/briefing-room/press-briefings/2021/02/24/press-briefing-by-white-house-covid-19-response-team-and-public-health-officials-7/> (Accessed 19 April 2021).
- [10] Tucker JD, Day S, Tang W, Bayus B. Crowdsourcing in medical research: concepts and applications. *PeerJ* 2019;7:6762. <https://doi.org/10.7717/peerj.6762>
- [11] Park A, Conway M, Chen AT. Examining thematic similarity, difference, and membership in three online mental health communities from reddit: a text mining and visualization approach. *Comput Hum Behav* 2018;78:98–112. <https://doi.org/10.1016/j.chb.2017.09.001>
- [12] Southwick L, Guntuku SC, Klinger EV, Pelullo A, McCalpin H, Merchant RM. The role of digital health technologies in COVID-19 surveillance and recovery: a specific case of long haulers. *Int Rev Psychiatry* 2021;1–12. <https://doi.org/10.1080/09540261.2020.1854195>
- [13] Brashers DE. Communication and uncertainty management. *J Commun* 2001;51:477–97. <https://doi.org/10.1111/j.1460-2466.2001.tb02892.x>
- [14] Vraga EK, Bode L. Defining misinformation and understanding its bounded nature: using expertise and evidence for describing misinformation. *Polit Commun* 2020;37:136–44. <https://doi.org/10.1080/10584609.2020.1716500>
- [15] Assaf G, Davis H, McCorkell L, Wei H, O'Neill B, Akrami A et al. Report: what does COVID-19 recovery actually look like? – Patient-Led Research Collaborative; 2020. <https://patientresearchcovid19.com/research/report-1/> (Accessed 19 April 2021).
- [16] Del Rio C, Collins LF, Malani P. Long-term health consequences of COVID-19. *J Am Med Assoc* 2020;324:1723–4. <https://doi.org/10.1001/jama.2020.19719>
- [17] Fiorillo A, Gorwood P. The consequences of the COVID-19 pandemic on mental health and implications for clinical practice. *Eur Psychiatry* 2020;63:32. <https://doi.org/10.1192/j.eurpsy.2020.35>
- [18] Asmundson GJG, Taylor S. Coronaphobia: fear and the 2019-nCoV outbreak. *J Anxiety Disord* 2020;70:102196. <https://doi.org/10.1016/j.janxdis.2020.102196>
- [19] Yazdany J, Kim AHJ. Use of hydroxychloroquine and chloroquine during the COVID-19 pandemic: what every clinician should know. *Ann Intern Med* 2020;172:754–5. <https://doi.org/10.7326/M20-1334>
- [20] Lee SY, Hawkins R. Why do patients seek an alternative channel? The effects of unmet needs on patients' health-related internet use. *J Health Commun* 2010;15:152–66. <https://doi.org/10.1080/10810730903528033>
- [21] Donovan EE, LeFebvre L, Tardif S, Brown LE, Love B. Patterns of social support communicated in response to expressions of uncertainty in an online community of young adults with cancer. *J Appl Commun Res* 2014;42:432–55. <https://doi.org/10.1080/00909882.2014.929725>
- [22] Zhao X, Fan J, Basnyat I, Hu B. Online health information seeking using "#COVID-19 Patient Seeking Help" on Weibo in Wuhan, China: descriptive study. *J Med Internet Res* 2020;22:22910. <https://doi.org/10.2196/22910>
- [23] Howe J. The Rise of Crowdsourcing|WIRED; 2006. <https://www.wired.com/2006/06/crowds/> (Accessed 19 April 2021).
- [24] Ranard BL, Ha YP, Meisel ZF, Asch DA, Hill SS, Becker LB, et al. Crowdsourcing—harnessing the masses to advance health and medicine, a systematic review. *J Gen Intern Med* 2014;29:187–203. <https://doi.org/10.1007/s11606-013-2536-8>
- [25] Wazny K. Applications of crowdsourcing in health: an overview. *J Glob Health* 2018;8:010502. <https://doi.org/10.7178/jogh.08.010502>
- [26] Desai A, Warner J, Kuderer N, Thompson M, Painter C, Lyman G, et al. Crowdsourcing a crisis response for COVID-19 in oncology. *Nat Cancer* 2020;1:473–6. <https://doi.org/10.1038/s43018-020-0065-z>
- [27] Vermicelli S, Cricelli L, Grimaldi M. How can crowdsourcing help tackle the COVID-19 pandemic? An explorative overview of innovative collaborative practices. *RD Manag* 2021;51:183–94. <https://doi.org/10.1111/radm.12443>
- [28] Chung CK, Pennebaker JW. Revealing dimensions of thinking in open-ended self-descriptions: an automated meaning extraction method for natural language. *J Res Pers* 2008;42:96–132. <https://doi.org/10.1016/j.jrp.2007.04.006>
- [29] Barrett A, Murphy M, Blackburn K. "Playing hooky" health messages: apprehension, impression management, and deception. *Health Commun* 2018;33:326–37. <https://doi.org/10.1080/10410236.2016.1266578>
- [30] Markowitz DM. The meaning extraction method: an approach to evaluate content patterns from large-scale language data. *Front Commun* 2021;6:13. <https://doi.org/10.3389/fcomm.2021.588823>
- [31] Olivarez O, Hardie R, Blackburn KG. The language of romance: an open vocabulary analysis of the highest rated words used in romance novels. *J Lang Soc Psychol* 2018;37:680–91. <https://doi.org/10.1177/0261927X18793976>

- [32] Rhidenour KB, Blackburn K, Barrett AK, Taylor S. Mediating medical marijuana: exploring how veterans discuss their stigmatized substance use on Reddit. *Health Commun* 2021;1–11. <https://doi.org/10.1080/10410236.2021.1886411>
- [33] Blackburn KG, Wang W, Pedler R, Thompson R, Gonzales D. Linguistic markers in women's discussions on miscarriage and abortion illustrate psychological responses to their experiences. *J Lang Soc Psychol* 2020. <https://doi.org/10.1177/0261927X20965643>
- [34] Boyd RL. Meaning Extraction Helper|A program to help with text analysis, topic modeling, and language exploration; 2021. <https://www.ryanboyd.io/software/meh/> (Accessed 19 April 2021).
- [35] Tracy SJ. *Qualitative Research Methods: Collecting Evidence, Crafting Analysis, Communicating Impact*. second ed. Malden, MA: Wiley; 2019.
- [36] Bento AI, Nguyen T, Wing C, Lozano-Rojas F, Ahn YY, Simon K. Evidence from internet search data shows information-seeking responses to news of local COVID-19 cases. *Proc Natl Acad Sci USA* 2020;117:11220–2. <https://doi.org/10.1073/pnas.2005335117>
- [37] Tajfel H, Turner JC. An integrative theory of intergroup conflict. In: Austin WG, Worchel S, editors. *The Social Psychology of Intergroup Relations*. Monterey, CA: Brooks/Cole Publishing Company; 1979. p. 33–47.
- [38] Seiter CR, Brophy NS. Social support and aggressive communication on social network sites during the COVID-19 pandemic. *Health Commun* 2021;1–10. <https://doi.org/10.1080/10410236.2021.1886399>
- [39] Myrick JG, Holton AE, Himelboim I, Love B. #Stupidcancer: exploring a typology of social support and the role of emotional expression in a social media community. *Health Commun* 2016;31:596–605. <https://doi.org/10.1080/10410236.2014.981664>
- [40] Barrett AK. Digital storytelling using new technology affordances to organize during high uncertainty. *Narrat Inq* 2019;29:213–43. <https://doi.org/10.1075/ni.18017.bar>
- [41] Hernandez RA, Colaner C. "This is not the hill to die on. Even if we literally could die on this hill": examining communication ecologies of uncertainty and family communication about COVID-19. *Am Behav Sci* 2021;65:956–75. <https://doi.org/10.1177/0002764221992840>
- [42] Romo LK, Thompson CM, Ben-Israel P. An examination of how people appraise and manage health-related financial uncertainty. *Health Commun* 2021;1–9. <https://doi.org/10.1080/10410236.2021.1876813>
- [43] Guerrini CJ, Majumder MA, Lewellyn MJ, McGuire AL. Citizen science, public policy. *Science* 2018;361:134–6. <https://doi.org/10.1126/science.aar8379>
- [44] Callard F, Perego E. How and why patients made Long Covid. *Soc Sci Med* 2021;268:113426. <https://doi.org/10.1016/j.socscimed.2020.113426>
- [45] Provenzi L, Barelo S. The science of the future: establishing a citizen-scientist collaborative agenda after COVID-19. *Front Public Health* 2020;8:282. <https://doi.org/10.3389/fpubh.2020.00282>
- [46] Caiata-Zufferey M, Schulz PJ. Physicians' communicative strategies in interacting with internet-informed patients: results from a qualitative study. *Health Commun* 2012;27:738–49. <https://doi.org/10.1080/10410236.2011.636478>
- [47] Masters K, Loda T, Johannink J, Al-Abri R, Herrmann-Werner A. Surgeons' interactions with and attitudes toward E-patients: questionnaire study in Germany and Oman. *J Med Internet Res* 2020;22:e14646. <https://doi.org/10.2196/14646>
- [48] Tan SSL, Goonawardene N. Internet health information seeking and the patient-physician relationship: a systematic review. *J Med Internet Res* 2017;19:9. <https://doi.org/10.2196/jmir.5729>
- [49] Moick M, Terlutter R. Physicians' motives for professional internet use and differences in attitudes toward the internet-informed patient, physician-patient communication, and prescribing behavior. *Med* 2012;1:2. <https://doi.org/10.2196/med20.1996>
- [50] Dissanayake I, Nerur S, Singh R, Lee Y. Medical crowdsourcing: harnessing the "wisdom of the crowd" to solve medical mysteries. *J AIS* 2019;20:4. <https://doi.org/10.17705/1jais.00579>
- [51] Barthel M, Stocking G, Holcomb J, Mitchell A. Seven-in-ten Reddit users get news on the site, Pew Research Center; 2016. <https://www.journalism.org/2016/02/25/seven-in-ten-reddit-users-get-news-on-the-site/> (Accessed 19 April 2021).
- [52] Jutel A. Sociology of diagnosis: a preliminary review. *Sociol Heal Illn* 2009;31:278–99. <https://doi.org/10.1111/j.1467-9566.2008.01152.x>