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ARTICLE

The role of digital health technologies in COVID-19 surveillance and recovery: a specific case of long haulers

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ABSTRACT

Digital health and technologies are essential to curbing the novel coronavirus 2019 (COVID-19) pandemic especially with shelter-in-place and social distancing orders. Epidemiologists and public health officials are tapping into frequently used technologies like wearables, digital devices, digital and social media data to detect and validate COVID-19 symptoms throughout the pandemic, especially during early stages when symptoms were evolving. In this article, we review how digital technologies and social media platforms can identify and inform our understanding of COVID-19 pandemic surveillance and recovery efforts. We analyze Reddit narrative posts and comments on r/covidlonghaulers to demonstrate how social media can be used to better understand COVID-19 pandemic. Using Reddit data, we highlight long haulers' patient journeys and shed light on potential consequences of their condition. We identified 21 themes, of which the following were significantly associated with valence: COVID-19 Symptoms ($r = -0.037$), medical advice ($r = -0.030$), medical system ($r = -0.029$), bodily processes ($r = -0.020$), questions ($r = 0.024$), physical activity ($r = 0.033$), self-differentials and negations ($r = 0.040$) and supplements ($r = 0.025$). Our brief literature review and analysis of r/covidlonghaulers narrative posts demonstrate the value of digital technologies and social media platforms as they act as modern avenues for public health, safety, and well-being.

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COVID-19; digital health; long haulers; long covid

Introduction

When the transmission of COVID-19 began to escalate (Wang et al., 2020; Vogels, 2020), many countries implemented quarantine orders and social distancing guidelines to slow the spread. Since these orders encourage individuals to stay at home, there has been a substantial increase, by as much as 20%, in the use of online platforms and other digital technologies (Vogels, 2020). In the United States, a Pew Research Centre survey of U.S. adults found that over half (53%) reported that the 'internet has been essential for them personally'. The pandemic has caused a paradigm shift, moving many commercial and social activities online (Vogels, Perrin, Rainie, & Anderson, 2020). Due to this shift, health care professionals and researchers are exploring how wearables, digital devices and digital and social media data can advance our understanding of the pandemic. Whitelaw et al. (2020) identified how digital technologies can be applied to 'pandemic planning, surveillance, testing, contact tracing, quarantine, and health care'. (Whitelaw et al., 2020) Most notably, countries with flattened COVID-19 incidence curves (e.g. South Korea, Taiwan, Singapore) and who maintained low mortality rates, adopted the aforementioned digital technologies. Fagherazzi et al. (2020) highlight how social media listening, digital support tools, smartphone-based tracking, virtual hospitals, remote patient monitoring, and chatbots for screening triage are key mechanisms for a 'COVID-19 digital health ecosystem'. In this article, we discuss the ways in which digital health and technologies, including wearable devices and digital and social media platforms, identify, inform and support our understanding of

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Supplemental data for this article can be accessed here.

COVID-19 pandemic surveillance and recovery efforts.

Technology's role in COVID-19 surveillance and recovery

Identify

Emerging symptoms

During the early stages of the pandemic when the pathology of the virus was unclear, the U.S. Centres for Disease Control and Prevention (CDC) symptom list was evolving each week. The CDC's Morbidity and Mortality Weekly Report (MMWR) noted that fever, cough or shortness of breath are the most common symptoms, however, COVID-19 patients can experience a range of symptoms, including gastrointestinal symptoms, chills, myalgia, headache and prolonged fatigue (Burke et al., 2020). The scientific and digital data communities alike employed online and social media platforms for supplemental information. Digital exhaust, defined as information and/or consumer data created by using digital platforms or devices, can be used to identify COVID-19 latent symptoms and cases to better predict and prevent further spread (McNeil, 2020). Twitter released a 100% COVID-19 stream to enable 'developers and researchers to be able to study the conversation about COVID-19 in real-time'. (Twitter Developer, 2020) Researchers found that Twitter users discuss their symptoms and test results on the platform. Another group identified 1002 COVID-19 symptoms that used 668 unique expressions across COVID-19 positive Twitter users (Sarker et al., 2020). Similarly, the COVID-19 Twitter stream was used to characterize anxiety, loneliness and positive language trends throughout the pandemic (Chandra Guntuku et al., 2020). Collectively, this work is leveraged to identify emerging symptoms but also to better predict and prevent further spread.

Population trends

Digital health and technologies have the potential to identify COVID-19 symptoms and cases at the population level. For profit companies' digital tracking products like Oura rings, Fitbits and Apple Watches were able to identify some COVID-19 symptoms, such as fever and heart measurements (Fowler, 2020), whereas digital thermometers showed a population-level temperature increase during the early phases of the pandemic (Fagherazzi et al., 2020). Even one's voice has potential to identify latent cases. U.S. university, Massachusetts Institute of Technology (MIT) collected voice and cough samples from over 5000 individuals with and without COVID-19 to identify a potential footprint and distinct vocal biomarkers (Laguarta et al., 2020). As shown with Google search data and influenza hotspots, one's online searches may reveal population trends (Li et al., 2020). Chinese researchers conducted a retrospective analysis of the search terms, 'coronavirus' and 'pneumonia' with China's published COVID-19 incidence data and suspected cases and found increased searches over one week ahead of published data. Correlating search trends with China's published COVID-19 incidence data and suspected cases, they found increased searches roughly 10–14 days prior to the published dataset. They also observed a lag, with a 'maximum correlation at 8–12 days for laboratory-confirmed cases and 6–8 days for suspected cases' (Li et al., 2020). Lastly, passively collected data from social media platforms and cell phone activity have been used to understand population-level movement trends (COVID-19 Mobility Data Network, 2020; Sehra et al., 2020). A recent study used cell phone location data to better understand movement in the U.S. They found a direct relationship between counties where activity declined at workplaces and increased at home to produce lower COVID-19 infection rates (Sehra et al., 2020). As we approach the second wave, digital health technologies will further define how we identify and understand COVID-19 symptoms and cases.

Inform

Public, opinion, concerns and health habits

Paramount to identifying cases, much work has been done on capturing public opinion, health habits, safety measures and digital health literacy. Researchers are using ubiquitous digital data and social media platforms to delve into the human experience, track surges in COVID-19 searches and related health topics. Previous work explored positive and negative language markers from six social media platforms: Twitter, YouTube, Facebook, PushSquare.com, Archinect.com and LiveScience.com. 47 million COVID-19-related comments were mined and using a random sample of 1 million selected comments, they identified 20 positive and 34 negative language markers. Most prominent negative markers were death, die, fight, bad, kill and lose, while positive markers included help, hope, protect, love, support, good, share, care and stay safe (Oyebode et al., 2020). This work signals how social media data can be used to capture the public perspective of the pandemic.

Similarly, others used Reddit, a digital platform where users can share information and discuss topics anonymously, to capture public priorities and concerns. Analysing over 90,000 posts, they found temporal trends of COVID-19 related questions like public health measures, how COVID-19 impacted daily life and the severity of the pandemic. For instance, in mid-March 2020, there was an increase of questions regarding how to 'safely spend time outdoors' pre-dating the CDC's official guidelines in early April (Stokes et al., 2020). This work signals how social media data can be used to capture the public perspective of the pandemic.

A burgeoning field of study explores how social media activity is positively correlated with COVID-19 misinformation, such as, the belief that taking vitamin C prevents COVID-19 infection (Jamieson & Albarracín, 2020). In addition to misinformation, social media platforms are used to intervene in prevailing public health safety and political ideologies. Researchers observed how Twitter bot accounts used #COVID-19 to promote ideological hashtags typically associated with the U.S.'s alt-right values (Ferrara, 2020). Emerging research in digital health literacy education is one solution to not only combat misinformation but also encourage patients to confidently navigate the vast world of online health information (van der Vaart & Drossaert, 2017). Positive correlations have been found between health status and digital health literacy skills, warranting the need for literacy tools that are more widely accessible. Conard (2019) highlights best practices in digital health literacy; they include the need for more personalized technologies and the incorporation of interactive tools encouraging an action-oriented experience for consumers. Social media and digital technologies provide further understanding of public opinion, combat misinformation, and can be leveraged for real-time and health literate public health interventions (Sehra et al., 2020).

Support

Health care access and connectivity

In the era of COVID-19, most health care encounters and experiences occur online. In the United States, there was a 154% increase in telehealth visits during the last week of March 2020, compared with the same period in 2019 (Koonin et al., 2020). Similar trends are seen globally. Slomski (2020) comments that within the American healthcare system 'the COVID-19 pandemic has created a new-normal health care landscape characterized by telemedicine and temporary out-of-state medical licences for physicians with geographically dispersed patients'. However, the 'COVID-19 digital health ecosystem' is not inclusive to all types of citizens. A new term, telehealth literacy, defined as 'the capacity to understand and have personal and technical comfort with the receipt of health care through technology' underscores how low telehealth literacy adversely impact older adults (65 years and older), individuals with low health literacy levels and limited, infrequent access to the internet, and subgroups such as individuals with lower socioeconomic status. This rapid shift is leaving behind vulnerable populations without such digital resources or literacy and exacerbating health disparities (Gray et al., 2020, Krelle et al., 2020). In response, Gray et al. (2020) outline five strategies: expanding broadband access, having accommodations for language, literacy, and disability, offering telehealth literacy training, engaging Community Health Workers, and teaching 'digital empathy' and 'webside manner' in medical and health care curriculums. Incorporating these strategies could address the digital divide and improve health care access (Gray et al., 2020).

Nevertheless, social media and digital platforms offer new ways to generate novel insights (Murray et al., 2020). They enable connectivity and psychological first aid (Merchant et al., 2011); they are critical avenues for social connection and support while simultaneously exchanging health information and experiences. Social media support groups foster personal empowerment for individuals experiencing emotional and medical distress (Barak et al., 2008, Chung, 2013). Pre-COVID-19, Reddit threads were used for awareness-raising and support-seeking for health-related concerns like mental health (Choudhury & De, 2014). During the pandemic, patients and doctors alike turned to digital and social media platforms to share their experiences.

Case study: long haulers

An emerging group of COVID-19 survivors with lasting and debilitating effects of the infection created an online grassroots, patient-driven community using the hashtag, #covidlonghaulers to discuss and share experiences, symptoms, and social support (Mahase, 2020). COVID-19 survivors, also known as long haulers, are described as individuals 'who have either recovered from COVID-19 but are still reporting lasting effects of the infection or have had the usual symptoms for far longer than would be expected' (Mahase, 2020; Taquet et al., 2020). A CDC MMWR

report found that 35% of COVID-19 survivors had not returned to their usual state of health when interviewed 2–3 weeks after testing. Young adults, persons aged 18–34 years with no chronic medical conditions, have higher rates of prolonged symptoms. Moreover, one in five have yet to return to their usual state of health (IVY Network Investigators, 2020).

Objective

We aim to explore and characterize how #covidlonghaulers is used on Reddit, a popular digital platform, to explore what long haulers post about and the language they use. We will measure word and phrase frequency and language valence to highlight themes. This study seeks to highlight the voices of long haulers and shed light on the potential consequences of their condition that might warrant further research.

Methods

Data collection

This study was considered exempt by the University of Pennsylvania Institutional Review Board as it involves the analysis of publicly available data. We collected publicly available Reddit posts and comments (collectively called posts hereafter) from *r/covidlonghaulers* using the Pushshift and PRAW APIs (Boe, n.d.; Baumgartner et al., 2020) and grouped them together for all analyses. All results presented are shortened and redacted in order to preserve Reddit user anonymity.

Processing posts

From all posts, we extracted the relative frequency of single words and phrases (consisting of two or three consecutive words). We generated 25 latent dirichlet allocation (LDA) topics from all posts using the MALLET implementation (Blei & Ng Mijjbe, 2003). LDA uses an unsupervised dimension reduction procedure to identify latent topics in large quantities of text. Each topic is represented by a list of words that tend to cluster together. This list of words along with the top 20 posts was used to identify latent topics. The distribution of LDA topics was extracted from each post. Themes were categorized by independent review of research team members. Thematic coding of the data was carried out through an iterative open coding process.

Measuring valence

Valence of every post was estimated using the Affective Norms for English Words (ANEW) lexicon (Bradley & Lang, 1999). The ANEW lexicon draws on a dictionary of words with pre-assigned meanings and assigns a positive or negative rating. The model takes as inputs the counts of the words which we automatically extract from the posts to obtain an estimate of valence for each message. This lexicon has been shown to work well on multiple social media platforms (Twitter, Reddit, etc.) for tasks ranging from sentiment analysis to mental health identification (Nielsen, 2011; Gaur et al., 2018).

Statistical analysis

Using ordinary least squares regression, we identified words, phrases and topics significantly associated with valence and effect size was measured using Pearson's r with the DLATK library (Schwartz et al., 2017). We used Benjamini–Hochberg p-correction and $p < 0.05$ for indicating meaningful correlations.

Results

Posts were collected for a duration of 2 months from the beginning of the subreddit on July 24 through November 10, 2020. A total of 33,519 posts were obtained from 1762 unique users. We identified 21 distinct sub-themes from *r/covidlonghaulers* narrative posts. Statistically significant themes associated with valence were: COVID-19 Symptoms ($r = -0.037$), medical advice ($r = -0.030$), medical system ($r = -0.029$), bodily processes ($r = -0.020$), questions ($r = 0.024$), physical activity ($r = 0.033$), self-differentials and negations ($r = 0.040$) and supplements ($r = 0.025$). Table 1 displays themes, correlation values with valence, and illustrative narrative posts. Please note that posts were edited and identifiers were redacted to preserve anonymity.

We also identified language associated with the positive and negative valence of posts. Among positive valence, words in the support thematic area are most prominent (Figure 1). For example, in the theme of Support, listed words include hope, good luck, people, sleep and health. Whereas the most common negative valence words include sick, pain, infection, chest_pain; these words were found most in the Pain theme.

Relative font size represents a stronger correlation with positive or negative valence and colour represents the relative frequency of word usage. All words

Table 1. Statistical insights on differential LDA topics across positive and negative valence posts.

Theme	Top Words	Pearson r (95% CI)	Illustrative Post(s)
Topics associated with positive valence			
Support	thanks, hope, good, keep, sharing, comments, hear, soon, posted, interesting, i'll, great, sounds	0.218 (0.2, 0.237)***	Thank you for your theory. I'll keep that with a positive mind set. Sorry that you're going through that. I thought I was in the clear. Got sick back in March mostly gastro symptoms, with rapid resting heart beat, shortness of breath, headache etc. a day or two ago I started having a lingering headache. Now I'm feeling the gastro stuff kicking back in. It seems more mild than in March thankfully. But it's def the same type of symptoms. Of course it's not anxiety. You'll get better again, then relapse, then get better again etc. Don't be disheartened, look at the big picture - and I bet the overall trend on the graph is upwards. Also, see if you can isolate any relapse triggers … This long covid thing seems to reward caution and patience.Good luck!
Taste and Smell	diet, eat/eating, water, sugar, food(s), drink/drinking, tea, lot, coffee, try, alcohol, inflammation	0.148 (0.128, 0.167)***	Search Google for Inflammatory foods.Sugar (including drinks), Trans or heavily Saturated Fats, Carbohydrates, Alcohol, packaged Meat, are some of the nastier things you can feed your body while under Covid LH. For me Caffeine and Dairy products are also on the list. My smell is very distorted. It's also incredibly weak. All perfume scents and shampoo smell the same to me.
Sharing Stories	we, us, who, work, our, need, care, able, their, health, can't, doctors, someone, trying, doesn't	0.136 (0.116, 0.155)***	Wow your story sounds so similar to mine. I also got sick in March and had pretty much all of the symptoms you described, and along a similar timeline. I know exactly what you mean by your fading out episode. The same thing happened to me except I actually fainted.
Sleep	up, when, sleep, heart, down, night, rate, sleeping, oxygen, while, breath, air, wake, low, hours	0.082 (0.063, 0.102)***	Gasping for air? Hello to those who have been suffering for a long period of time. I am now 5 months into this s**t and I am very worried about the gasping of air I get while sleeping … If anyone else has gotten this please message me! I am starting to become suicidal. Thank you!
Self-Differentials and Negations	i'm, it's, i've, don't, think, sure, can't, that's, haven't, i'll, seem/seems, worse, i'd, around	0.04 (0.021, 0.06)***	I worry about my health and getting sleep everyday and I don't even know if I'm gonna be able to sleep today cause I feel like I'm struggling to breathe and feels like something is sitting on my chest. I also been having other issues which I don't even wanna mention cause I don't want to hear about how t might be a serious condition because no one is asking me seriously. Everyone thinks my symptoms are due to anxiety even though I know it's not. I'm so f***ing done
Physical Activity and Fatigue	brain, fog, exercise, fatigue, started, relapse, walk, helped, physical, walking, hard, slow, activity, relapses	0.033 (0.013, 0.052)**	Anti-inflammatory diet and gentle exercise (walking and pilates) helped me a lot. B12 may help with exhaustion and brain fog.
Supple-ments	taking/take, help/helps/helped, nac, started, try, supplements, magnesium, breathing, steroids, sleep, vitamin, oil	0.025 (0.005, 0.045)*	Glutamine, bcaa, ashwaganda-66, Adderall, DLPA, fish oil, B12, daily vitamin, zinc. NACCBD Sambucus Multivitamin Iron pill Vitamin C Milk Thistle occasionallyTCM herbs given by a practitioner
Frustrat-ions	cfs, covid, post, don't, people, know, research, evidence, want, advice, disease	0.024 (0.005, 0.044)*	I consistently see people with cfs posting in covid subs where they have no business being. As someone with ME/CFS who is also a COVID long hauler I have every business being in this sub. You ignore the evidence provided to you then continue to ask for evidence. You admit to being negatively biased against a community that has been unfairly maligned for many years, and insist on refusing to use the appropriate name for the disease.
Lifestyle Changes	work, sick, over, felt, off, hours, went, while, able, home, myself, working, where	0.024 (0.005, 0.044)*	Physical therapist assistant here. Start of symptoms June 12, went back to work after 2.5 weeks of sick time … I went on disability due to increased fatigue and other symptoms. Still not working, at 7 weeks now, not looking like I can go back anytime soon.

(*continued*)

Table 1. Continued.

Theme	Top Words	Pearson r (95% CI)	Illustrative Post(s)
Support Groups	people, there, who, many, medical, their, illness, those, patients, chronic, cfs, studies, research, sars, group	0 (-0.02, 0.020)○	r/covid19stack And join body politic slack to get more support. This is a live survey of the top 100 symptoms experienced by long term sufferers on FB. Shows what are the common ones and how many unusual ones there are too.
Topics associated with negative valence			
Long Haulers Symptoms	pain, chest, eyes, pressure, head, throat, eye, sometimes, feels, vision, headaches, legs, right, left, muscle	−0.246 (-0.264, -0.227)***	Just wondering if this pain could be muscle strain related from coughing, I've seen it mentioned often enough. waves of difficulty breathing, light pneumonia symptoms, fatigue, brain fog, headache, strange pressure in spots across my forehead, red blotchy skin, congestion, muscle twitching, clumsiness
COVID-19 Testing	test/tested/tests, positive, negative, covid, sick, antibody, infection, virus, antibodies, early, march	−0.182 (-0.201, -0.163)***	I just got tested positive again for antibodies and the infection was in early March! Well I'm just over 2 weeks in, and mostly recovered at this point. For the last few days, the inflated high blood pressure feeling and related soreness was the main issue … I went back to the doctor and my PCR test was negative.
Time	days, weeks, week, months, better, after, got, felt, day, sick, fatigue, first, month, last	−0.177 (-0.196, -0.158)***	5 1/2 months of fever (100.5-101.1, varies) every day. Got sick March 4th.
Pain	pain, issues, having, reflux, acid, muscle, thyroid, inflammation, tests, gi, joint	−0.165 (-0.184, -0.146)***	Im almost 6 months in. Still dealing with POTS, acid reflux, sinus issues, body aches, headaches, trouble getting sleep, can barely eat anything without causing a flare up, the smallest activities exhaust me and make my heart race, very real dreams/ nightmares.Of all the symptoms, the POTS is the worst. I could live with everything else. The heart issues still really suck and can be scary at times. F***anyone who says this is just anxiety or allergies
Medical Procedures	heart, chest, normal, blood, cardiologist, breath, test/tests, lung/lungs, issues, mri, said, shortness	−0.062 (-0.082, -0.043)***	I developed ectopic heart beats with dysautonomia. It feels like my heart flutters, but it's apparently harmless.
COVID-19 Symptoms	smell, taste, same, lost, never, weird, times, almost, sense, thought, cold	−0.037 (-0.057, -0.018)***	Did you "recover" and feel back to normal or is this something thats continued.
Peer Medical Support	virus, cells, immune, however, histamine, cell, certain, syndrome, covid19, treatment, response	−0.03 (-0.049, -0.010)**	Like a probiotic? Any specific recommendations for a product to use?
Medical System	she/her, doctor(s)/doc, told, said, he, care, er, went, appointment	−0.029 (-0.048, -0.009)**	Anything new from the lung doctor visit? No lol, she repeated what she saw on my xray and told me to get a ct scan that I cant afford
Bodily Processes*	blood, could, cause, inflammation, clotting, might, vitamin, type, insulin, look, clots, high, use, bleeding	−0.02 (-0.039, 0)^	The virus messes with insulin production if it attacks the pancreas. Insulin is a master hormone that influences the sex hormones. If you have dysregulation of sex hormones toward high androgen, you can develop benign ovarian cysts, which could upstream be the source of bleeding. Get an ultrasound?
Immune System	immune, system, dr, cytokines, patients, video, steroids, il-6, cytokine, phase, drug, elevated, theory, steroid	−0.009 (-0.028, 0.011)^	Yes. My doctor is doing lots of testing for autoimmune disorders. I've had random autoimmune markers and symptoms, plus a family history before covid. I think that I was a likely candidate for the long covid because my immune system was already wonky.
Mental Health	hair, stress, anxiety, definitely, loss, probably, new, panic, issue, diagnosis, attacks, mental, own	−0.002 (-0.022, 0.018)^	You're not alone. Also, I've been to five doctors (if you count one ER doc and one telehealth doc) and they all seem to think I'm a hypochondriac because "my tests are fine." Just suffering one day at a time and hoping it improves someday. I miss not thinking about breathing (being able to take a full, deep breath, and not feeling pain when I breathe), and taking it for granted. Ugh. Will I return to pre-Covid? I'm worried so much … Hey guys, Today is my 14th day since initial symptoms and I worry to death if I can ever get back to my pre-covid life. Could anyone please advise me to see if I can get better?

Pearson r $>$ 0 indicates association with positive valence and Pearson r $<$ 0 indicates association with negative valence. Significance was measured using paired, two-tailed t-test with Benjamini-Hochberg p-correction.
*p <.05, **$p < 0.01$, ***$p < 0.001$, ^$p >= 0.05$

and phrases in the word clouds are significant, tested using paired, two-tailed *t*-test with Benjamini–Hochberg *p*-correction ($p < 0.05$).

Discussion

Data from digital platforms can provide information about how affected populations are experiencing symptoms, seeking support and accessing resources, information that would otherwise be harder to track in real time. Social media platforms like Reddit and Twitter present complementary real-time data sources to bolster identification efforts (Chandra Guntuku et al., 2020). Our analysis found COVID-19 long haulers use Reddit to document their patient experiences and concerns. Our analysis highlighted the multiple areas of long haulers' daily lives that have changed, including how they eat, sleep, and move. We identified 21 themes that encompass the various topics and priorities that matter most to individuals still recovering from COVID-19. Our analysis highlighted the multiple areas of long haulers' daily lives that have changed, including how they eat, sleep and move. From their early symptom indicators like loss of smell and body pains (Table 1). This dataset could be leveraged to inform the long hauler COVID-19 symptom list, similar to Twitter analysis conducted early in the pandemic. Users also expressed their frustrations with testing and the medical system primarily in Themes of Medical Advice ($r = -0.030$), medical system ($r = -0.029$), bodily processes ($r = -0.020$) and questions ($r = 0.024$). In the Medical System theme, users shared stories about their interactions with various doctors. Users were looking for shared experiences, advice and support through this subreddit and other online platforms. The themes Peer Medical Advice and Support Groups included recommendations on symptom management and for other social media and online support groups like the Body Politic slack group. Connecting online is especially important to curb the spread but also to combat loneliness and social isolation throughout the pandemic. Although these themes were not statistically significant, it sheds light on the informational and emotional support long haulers are utilizing.

Although not statistically significant, our study found Mental Health, Support and Sleep themes (Table 1) to be striking. When discussing one's mental health status, our analysis found the following words most often used: 'stress, anxiety, definitely, loss, probably, new, panic, issue, diagnosis, attacks, mental and own'. These select words are a window to how long haulers' mental health may be adversely impacted. Recently, the Lancet Psychiatry journal published a groundbreaking study using 69 million U.S. electronic health records, of which more than 62,000 cases of COVID-19. They created propensity score matched cohorts of patients with and without a COVID-19 diagnosis to investigate whether a diagnosis of 'COVID-19 compared with other health events was associated with increased rates of subsequent psychiatric diagnoses' (Taquet et al., 2020). They found that 'COVID-19 survivors have a significantly higher rate of psychiatric disorders, dementia, and insomnia [and] that a previous psychiatric illness is independently associated with an increased risk of being diagnosed with COVID-19' (Taquet et al., 2020). Our sample used self-differentials and negations like, 'can't, don't, didn't, doesn't, haven't'. Previous research found that depressed individuals use more first-person singular pronouns and more negative valence language (Guntuku et al., 2019). In addition to psychiatric conditions, researchers suggest additional research focussing on the long-term adverse effects of COVID-19 including pulmonary sequelae, sleep patterns, and neurocognitive and neuropsychiatric impairments. Interestingly, our sample did not discuss stigma and discrimination which are two themes prevalent in the existing literature among COVID-19 patients and long haulers (Villa et al., 2020). Long haulers' mental health is receiving more attention. Currently, groups are exploring the incidence of depression, anxiety, posttraumatic stress disorder (PTSD), and substance use disorder, cardiovascular, pulmonary, neurological disease among COVID-19 survivors, signalling additional attention and funding to assess psychopathology and monitor changes as they recover (del Rio et al., 2020; Gennaro et al., 2020).

As the pandemic continues, scientific and medical advice and evidence is evolving. The World Health Organization (WHO) coined a new term, infodemic, defined as, 'an overabundance of information—some accurate and some not—that makes it hard for people to find trustworthy sources and reliable guidance when they need it' (Zarocostas, 2020) and cautioned users about misinformation (Dubey et al., 2020). Our analysis captures the variety of information found on the *r/covidlonghaulers*. It includes academic, peer-reviewed manuscripts, YouTube videos, Facebook, and personal blogs. In this digital age, it is challenging to establish a source's credibility and validity. Table 1 demonstrates that many Reddit users provided their peer's medical advice such as taking

Figure 1. Language associated with positive and negative valence of Reddit r/covid long haulers posts.

certain vitamins and supplements such as, 'Glutamine, bcaa, ashwaganda-66, Adderall, DLPA, fish oil, B12, daily vitamin, zinc' and 'NACCBD Sambucus Multivitamin Iron pill Vitamin C Milk Thistle occasionally TCM herbs given by a practitioner'. Little is known about supplements and vitamins for COVID-19 patients. The exchange of medical information and advice on social media and digital platforms is important for the medical and public health communities. Nearly one-fifth of U.S. adults use social media as their primary news outlet, compared to television, radio and newspaper (Jurkowitz & Mitchell, 2020). Now more than ever, researchers and public health officials focus on protecting medical and scientific value on digital and social media platforms (Merchant & Asch, 2018). A large body of research demonstrates medical misinformation can have direct health consequences as seen with the anti-vaccination movement (Hussain et al., 2018). Exploring how and what types of COVID-19 related themes and types of information the general public and subgroups are discussing in real-time is essential to advance our understanding and to proactively plan large scale interventions.

The scientific community must be equipped to properly and appropriately care for such patients. Within the last six months, two longitudinal studies, the Post-hospitalization COVID-19 Study (PHOSP-COVID) in the United Kingdom and the Survivor Corps study in the United States funded by the Chan Zuckerberg Initiative are major efforts in this space (PHOSP-COVID, 2020; RecoveryCorps.org, 2020). Both aim to better understand the differences between how individuals recover from COVID-19 infection and to improve the health outcomes of those with confirmed or suspected COVID-19. There is much to be learned from the 2003 severe acute respiratory syndrome (SARS) outbreak in that SARS outbreak survivors reported similar prolonged symptoms. A case–control study found chronic and widespread musculoskeletal pain, fatigue, depression and disordered sleep among patients with chronic post-SARS syndrome (Moldofsky & Patcai, 2011). A report published New England Journal of Medicine longitudinally followed acute respiratory distress syndrome survivors for a year and found 'persistent functional disability' extrapulmonary conditions, with muscle wasting and weakness as the most prominent (Herridge et al., 2003). In the Support Group theme, users commonly used 'sars' in their dialogue. Although this theme was not statistically significant it demonstrates that long hauliers gleaning best practices from the SARS outbreak. Similarly, nuanced understandings of testing, recovery, and stigma can be learned from the U.S. National HIV/AIDS Strategy (Holtgrave et al., 2020).

Implications

Merchant and Asch (2018) note how social media and digital platforms present emerging threats to effective scientific communication. However, these same platforms can also offer solutions to: (1) combat misinformation and (2) increase research attention. In effort to combat misinformation, several platforms enacted expert and crowd-sourced solutions. For example, throughout the COVID-19 pandemic, Reddit hosts American Medical Association (AMA) to provide timely and accurate scientific and medical information. Twitter and Facebook note misinformation warnings and include a credible website associated with the misleading content. TikTok added a 'misleading information' category in the app where users can report videos that may violate its

misinformation policies. In addition to posting and moderating content, digital platforms can be incredible recruitment sites for new studies. Most prominently, the 'Patient-Led Research for COVID-19'25 is a patient-created group founded on Slack, a messaging platform that includes topic-related chat rooms, private group messaging, and direct messaging. The Patient-Led Research for COVID-19 (Patient Led Research, n.d.) was one of the first reports on long haulers' in-depth recovery experience. From their user-generated social support group, they were able to collect diverse information on long haulers, such as respondent demographics, medical background, lifestyle variables, symptoms experienced, satisfaction with care delivery, and if they experienced stigma. Interestingly, they asked respondents if they shared their patient journey on social media. They found that approximately 50% of respondents shared their COVID-19 experience more publicly on social media, blogs or other platforms'. (Patient Led Research, n.d.) This grassroots effort was one of the first studies on long haulers providing key insights for future work and spurring academic research collaborations since their second survey is sponsored by University College London, UK. If social media and digital platforms are used collaboratively among users and scientists, they can be harnessed for effective scientific communication and innovative research studies.

Limitations

Limitations of this study include retrospective design, selection and responder bias. We only identified content on one subreddit thread and potentially other threads might yield different themes and sub-themes. The study sample consists of social media users and is not representative of the general population. An estimated 5% of US adults use Reddit, who are between the ages of 18 and 29 (Stokes et al., 2020), so our analysis is skewed towards younger individuals. Due to the nature of the data, we do not have any demographic information on the users included in this analysis. A recent study found that U.S. COVID-19 survivors' mean age is 49.3 years, more than half (55.4%) are female, half (51.0%) are White, nearly one-quarter (23.6%) are Black, and over one-third (36.6%) reside in the Northeast (Taquet et al., 2020). We posit our sample is similar in terms of sociodemographics. We also only collected posts in the English language, non-English posts could yield different themes. Additionally, social media posts do not verify one's medical status or medical credentials. Social media platforms do use proprietary software to filter inappropriate, invalid or inaccurate medical diagnoses or other health-related information. Long haulers may use other subreddits such as r/longcovid to document their patient journey and concerns. Despite these limitations, social media platforms provide an unstructured and accessible venue for patients to share their experiences and potentially to inform research efforts and health care delivery.

Conclusion

As the pandemic progresses, more digital and social media analyses and interventions are needed to investigate and support COVID-19 patients and survivors and especially long haulers. As we plan for the second wave, digital platforms and interventions will be the primary mode in which individual connect and health care professionals intervene. We expect more epidemiological surveillance efforts that use social media datasets and machine learning procedures and rapid case identification and interruption of community transmission (e.g. sensors and smartphone GPS) to bolster contact tracing efforts. In an effort to combat misinformation, social media and digital technologies can be used to finetune real-time personalized insights and prioritize information for public communication (Budd et al., 2020). However, to implement population-level interventions, there are several ethical questions around efficacy, privacy, and algorithm transparency (Barnett & Torous, 2019). How do public health professionals engage with social media companies? As a community, how can we build clear guidelines and action-steps to scaffold algorithmic assessment decision-making? How do we prevent and protect from unintended misuse, manipulation, and propagation of misinformation? How might we consider the impact of misclassifications and how derived mental health indicators can be responsibly integrated into systems of health care? Discussions around these issues should include public health professionals, clinicians, computer scientists, lawyers, ethicists, policymakers, and social media users from diverse socioeconomic and cultural backgrounds. Looking to the future, there is a need for rigorous scientific studies to evaluate the role of social media and digital technologies' role in long-term public health research and interventions (Barnett & Torous, 2019; Abroms, 2019; Torous & Walker, 2019). To curb COVID-19's spread and plan for future pandemics, it has become necessary to embrace these platforms as they act as modern avenues for public health, safety, and well-being.

Disclosure statement

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