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ORIGINAL PAPER

Long Haul COVID-19 Videos on YouTube: Implications for Health Communication

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Abstract
The term COVID-19 "long haul" originated on social media and was later studied by the scientific community. This study describes content related to persistent COVID-19 symptoms on YouTube. The 100 most viewed English-language videos identified with the keywords "COVID-19 long haul" were assessed for video origin, engagement, and content related to COVID-19 long-haul. The findings indicate that the majority of videos were uploaded by television or internet news (56%), followed by consumers (members of the public, 32%), health professionals (only 9%), and lastly by entertainment TV (non-news programs, 3%). Videos originating from entertainment TV were significantly more likely to be "liked" than videos from other sources. The most commonly mentioned long-haul symptoms in the videos were physical (fatigue, 73%; difficulty breathing/shortness of breath, 56%; and joint or muscle pain, 49%) and cognitive (difficulty thinking or concentrating; 69%). The case of COVID-19 long haul demonstrates that social media are significant fora whereon the public identify health concerns. It is necessary for healthcare professionals to assume an active and responsible role in social media.

Keywords Long haul · Long COVID · Health communication · COVID-19 · YouTube

Introduction

The COVID-19 pandemic has caused a global public health crisis [1, 2] and those who are afflicted experience a wide range of symptoms of varied severity. The onset of the pandemic brought an urgent need for the scientific community to provide clear recommendations to the public [3]. However, in the early phases of the pandemic, news and social media coverage of COVID-19 were mixed with political and economic discourse [4]. The emerging information meant that guidelines kept shifting, and the fragmented public health infrastructure caused many to feel hesitancy in following the advice of the scientific community [4, 5]. Professional organizations have information on their websites for their members, on the communication and cognitive symptoms of COVID-19 long haul, but this information is not typically accessed by the public [6–8].

COVID-19 survivors found each other on social media [9] and began to discover that they shared prolonged symptoms, being the first to indicate that COVID-19 could lead to protracted illness in the post-recovery phase [1]. Given that half of COVID-19 survivors experience prolonged symptoms [10], many survivors found solace in social media groups [11]. Before the phenomenon of persistent COVID-19 symptoms was well-documented, social media discussions validated the presence of lingering symptoms, while medical professionals may have been dismissive [9, 11]. As a result of these discussions, COVID-19 survivors with persistent symptoms [12] colloquially became known as "long haulers," a term coined by COVID-19 survivors on social media [13].

As COVID-19 continues to evolve, the scientific community continues to learn more about the virus' long-term health effects [14, 15]. The long-term sequelae of COVID-19 vary from person to person [16–20]. Through self-reports and diagnostic assessments [21], health professionals saw a disruption of nearly every organ system [15, 20, 22–27], including a high incidence of cognitive dysfunction, stroke,

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and other neuropathologies. There were additional physical problems, including weight loss, critical illness weakness, severe pressure ulcers, renal failure, vascular problems, and significant psychological effects. Intervention should ideally be provided by a rehabilitation team (which includes speech language pathologists), who are urged to treat this novel situation as they would any population with neurocognitive and communication disorders [24].

For many experiencing COVID-19 long haul the social support provided by online communities has been essential [28]. At the same time, information garnered online served as a valuable tool for researchers seeking to understand and improve public health outcomes. The novel way in which long term effects of COVID-19 were identified and defined, i.e., through social media, points to an intersection between scientific research and the use of social media by the public to discuss health issues.

Considering that 4.48 billion people use social media worldwide [29], these platforms provide real-time opportunities to track, evaluate, and gain insight into emerging diseases [30]. YouTube, a well-known social media platform, has 122 million visits per day globally [31]. Viewers spend on average 18 min on YouTube per day, totaling more than a billion hours of content viewing per day [31]. While the chronic symptoms experienced by many people who recovered from COVID-19 are not well understood [32], no identified research to date has investigated the presence of this information on YouTube. Thus, the purpose of this study was to describe the content of videos related to COVID-19 long-haul on YouTube, with a view to a better synergy between the scientific community and the public seeking information on social media.

Methods

The methodology for this study is based on that of an earlier study of COVID-19 long-haul news coverage [33]. The data were collected in December of 2021. The videos were identified on YouTube (via Google Chrome) by searching with the keywords "COVID-19 long-haul." They were then filtered by the number of views. The first 100 videos with the highest view counts were included. Thirty-three videos were excluded due to exceeding 45 min in length or failing to be relevant to long-haul COVID-19. They were then replaced with the next 33 videos on the view-count list. The source of the video was put into one of the following categories: (1) consumer, (2) professional, (3) television or internet-based news, (4) entertainment TV.

The metadata for each video were then identified. This included the URL, number of views, upload date, length in minutes and the number of likes/dislikes. The study used the following content categories: the length of time symptoms persisted, tiredness and/or fatigue, brain fog or memory loss, ear ringing, sleep disturbance, stroke, fear and/or worry, hair loss, headache/sinus pain, loss of smell or taste, dizziness, heart palpitations, chest pain, difficulty breathing and/or shortness of breath, lack of mobility, joint or muscle pain, depression or anxiety, fever, diarrhea, symptoms getting worse after physical or mental activities, multisystem inflammatory syndrome (MIS), post-intensive care syndrome (PICS), post-traumatic stress disorder (PTSD), difficulty getting help, available treatment, symptoms being worse in women, symptoms being worse in older populations, job loss/inability to work, other related life issues related to long haul symptoms, waves of symptoms, relief after vaccine, other symptoms. Responses were coded as "yes"/1 if the categories were included in the video or "no"/0 if they were not. Additional written information was added to the "other symptoms" column as this category required further specification.

Statistical analyses were performed using IBM SPSS Statistics for Windows (version 23, Armonk, NY) [31]. A value of $p < 0.05$ was used to determine statistical significance. Descriptive statistics were generated for categorical variables. The number of "likes" and the length of YouTube Videos by the origin of the video uploads were analyzed using one-way ANOVA.

Since this study did not involve research with human subjects, the Institutional Review Board (IRB) at William Paterson University determined the study did not require ethics review.

Results

Data from 100 YouTube videos based on the highest number of views were analyzed. The 100 YouTube videos had been watched a cumulative total of 15,319,997 times. The videos were uploaded in the 18 month period from July 2020 to December 2021. The highest number of videos was uploaded in both March 2021 (8%) and July (8%) 2021.

Origin: The origin of upload of the videos fell in the following categories: television or internet-based news, consumer (i.e., the general public), medical professionals, and entertainment television. Television or internet-based news videos accounted for 56%, consumer-created video accounted for 32%, professional video accounted for 9%, and entertainment TV created video accounted for 3%.

Engagement: The number of "likes" in each video origin was significantly different ($p < 0.001$). The mean number of "likes" for videos uploaded by entertainment TV was 16,108 [226–47,000], compared with 9,236 [0–58,000] for videos uploaded by professionals, compared with 1,715 [21–26,000] for videos uploaded by television or internet-based news, and compared with 963 [1–6,000] for videos

uploaded by consumers. The mean length of YouTube videos was not significantly differentiated by the origin of video upload ($p = 0.17$); 691.3 [506.9–875.5] seconds for videos uploaded by consumers, 644.0 [323.7–964.3] seconds for videos uploaded by medical professionals, 484.2 [379.2–589.2] seconds for videos uploaded by television or internet-based news, 680.7 [155.3–1206.1] seconds for videos uploaded by entertainment TV.

Content: 56% of the YouTube videos report the length of time that COVID-19 long haul symptoms persist. The length of time was reported to range from one month to about one year. The YouTube video reports included the following COVID-19 long-haul symptoms: tiredness or fatigue (73 cases; 73%), difficulty thinking or concentrating (69 cases; 69%), difficulty breathing or shortness of breath (56 cases; 56%), joint or muscle pain (49 cases; 49%), symptoms that get worse after physical or mental activities (37 cases; 37%), headache/sinus pain (33 cases; 33%), other related life issues related to long haul symptoms (33 cases; 33%) treatment available (30 cases; 30%), chest pain (26 cases; 26%), waves of symptoms (26 cases; 26%), fast beating or pounding heart (25 cases, 25%), loss of smell or taste (24 cases; 24%), sleep disturbances (24 cases; 24%), depression or anxiety (17 cases, 17%), fever (15 cases; 15%), job loss/inability to work (15 cases; 15%), dizziness (15 cases; 15%), difficulty getting help (14 cases; 14%), relief after vaccine (14 cases; 14%), hair loss (10 cases; 10%), fear or worry (10 cases; 10%), diarrhea (5 cases; 5%), autoimmune conditions (5 cases; 5%), ear ringing (4 cases; 4%), stroke (4 cases; 4%), worse in women (4 cases; 4%), worse in older population (4 cases; 4%), post-intensive care syndrome (2 cases; 2%), post-traumatic stress disorders involving long-term reactions to a very stressful event (2 cases; 2%). A summary is shown in Table 1.

Table 1 Content regarding Long-Haul COVID-19 symptoms on YouTube videos (N = 100)

Contents	Number of cases	Percent (%) of total
Tiredness or fatigue	73	73
Difficulty thinking or concentrating	69	69
Difficulty breathing or shortness of breath	56	56
Joint or muscle pain	49	49
Symptoms that get worse after physical or mental activities	37	37
Headache or sinus pain	33	33
Life issues related to long haul symptoms	33	33
Treatment availability	30	30
Chest pain	26	26
Waves of long-haul symptoms	26	26
Fast beating or pounding heart	25	25
Loss of smell or taste	24	24
Sleep disturbances	24	24
Depression or anxiety	17	17
Fever	15	15
Job loss or inability to work	15	15
Dizziness on standing	15	15
Difficulty getting help	14	14
Relief after vaccine	14	14
Hair loss	10	10
Fear and/or worry	10	10
Diarrhea	5	5
Autoimmune conditions	5	5
Ear ringing	4	4
Stroke	4	4
Worse symptoms in women	4	4
Worse symptoms in older populations	4	4
Post-intensive care syndrome	2	2
Post-traumatic stress disorders involving long-term reactions to a very stressful event	2	2

Discussion

In the aftermath of the first wave of the COVID-19 pandemic, lingering physical and psychological health problems among survivors were widely reported on social media [34]. Meanwhile, various cognitive, emotional, and other neuropsychiatric persistent symptoms began to also be noted in COVID-19 survivors [35]. In this study we examined the information conveyed via YouTube videos in terms of who uploaded videos, how much the public reacted to them, and the breadth of coverage regarding long COVID. Our analysis focused on the most widely viewed 100 YouTube videos uploaded from July 2020 to December 2021. During this period, medical professionals have been learning how to improve the care of patients with COVID-19 [36]. The findings of this study indicate that videos developed by TV/internet-based news sources and consumers accounted for the majority of the highly-viewed videos. In contrast, videos developed by health professionals represented a minority of the referenced sample (9%). It appears that health professionals continue to miss opportunities to fill information gaps and connect with the public on issues that align with their specialties and the public's health concerns.

In terms of the content covered by the videos, the findings of the present study indicate that cognitive problems were the second most reported symptom, mentioned in 69% of the videos we sampled, along with a report that general symptoms get worse after physical or mental activities (37%). In addition, psychological distress persists long into the post-recovery phase of COVID-19. Mental health and well-being in the forms of sleep disturbances, depression or anxiety, fear or worry, and post-traumatic disorder were reported in a combined 53% of complaints. Hence, there is a need to prioritize knowledge of the impact of long haul COVID-19 on cognitive and mental health. Our findings suggest that COVID-19 infection may serve as a predictor of long-term psychological distress and cognitive challenges. The mental health implications brought on by the pandemic necessitate that healthcare professionals integrate psychosocial support into the general physical pandemic care. Furthermore, raising awareness of the likely impending, long-term cognitive and mental health problems associated with COVID-19 may better prepare health professionals to monitor, direct services, and support patients. Similarly, it may help patients recognize such symptoms and prepare for the relevant services that they may need. The physical symptoms reported in the videos included a variety of non-respiratory problems ranging from fatigue (73%), joint or muscle pain (49%), headache or sinus pain (33%), chest pain (26%), to tinnitus and stroke (4% for each). The content of the videos also included a number of social issues, such as life issues related to long haul symptoms (33%), availability of treatment (30%), and job loss (15%). Symptoms were reported to be worse in women (4%) and in older persons (4%). Clearly, much and varied information is contained in these videos on YouTube.

Given that the public discussion regarding COVID-19 long haul on social media was the impetus for getting the medical community to examine the condition, it is not surprising that the public, non-professionals, are driving the conversations on YouTube. Further, our findings suggest that COVID-19 long-haul is extensively discussed on YouTube: the videos in this study had garnered more than 15 million views. It is important that health professionals have a more prominent and responsible place on the platform.

Lastly, it is interesting that COVID-19 long haul, as an illness, was initially rejected by the medical community [37], while social media became the outlets where survivors reported their conditions. Social media reports on COVID-19 long haul started a movement [37, 38] that expanded the known symptomatology to include protracted illness [39] and directed the spotlight on the sequelae of the disease. According to Callard and Perego [9], COVID-19 long haul "has a strong claim to be considered the first illness to be collectively made by patients finding one another through Twitter and other social media" (p. 4). The digital era facilitated the interconnectedness of long haulers to communicate and share their experiences within the larger, global community [19, 38, 40]. Researchers have studied COVID-19 long-haul conversations on Twitter and Reddit [9, 19, 40, 41], but to our knowledge, this is the first study to address this topic on YouTube.

The limitations of this study, methodological and inherent to YouTube, include a cross-sectional design, which does not represent changes over time. Second, YouTube is a popular video sharing platform and the findings of this study may not apply to other social media platforms with different intent and features. Third, new videos with evolving content are uploaded at a high rate. This could influence which videos are most popular at different points in time. Fourth, the most popular views are filtered by view count and the extent to which YouTube's algorithms influenced this are not accounted for. Fifth, this study was limited to English language videos despite there being considerable content in other languages on this topic on YouTube. Sixth, one set of keywords was used in this study, so a variety of related keywords could influence the yield.

The collective experiences shared by patients in online communities led to shifts in the recognition of "long COVID" and subsequent support in health, media, and policy channels [37, 38]. After the initial mapping of patients suffering from COVID-19 long haul [9], the mining of social media datasets to understand the clinical course and

symptomatology of COVID-19 long haul has become prevalent [9, 19, 41]. At the same time, medical and immunologic evidence presented by scientists continues to emerge [42–46]. In addition to the medical literature, health professionals should recognize the importance of social media and social listening to learn about patients' quality of life and functioning after contracting COVID-19. These insights can potentially inform educational efforts for patients and healthcare providers on the challenges and services necessary for COVID-19 long-haul patients.

Author Contributions BK, CHB and ETJ conceptualized the study. EB collected the data, EP conducted the data analysis. All authors contributed to the manuscript production.

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Declarations

Conflict of interest Not applicable.

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Ethical Approval Since this study did not involve research with human subjects, the Institutional Review Board (IRB) at William Paterson University determined the study did not require ethics review.

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