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Fishing for Validation: Understanding Promises and Challenges of a Private Social Media Group for COVID-19 Long-Hauler Patients

ABHINAV REDDY KARRA, University of Maryland, Baltimore County, USA

RANJAN JAISWAL, University of Maryland, Baltimore County, USA

SANORITA DEY, University of Maryland, Baltimore County, USA

The COVID-19 pandemic has affected more than 301 million people worldwide so far. Many communities (such as minority communities) suffered disproportionately more difficulties throughout the pandemic. In this paper, we would like to focus on one such community: COVID-19 long-haulers community. Long-hauler community consists of people affected by Coronavirus, but their symptoms do not cure in a couple of weeks; instead, they experience lingering symptoms for months. The concerns of this community were initially ignored by health care providers primarily because of limited information. In this paper, we have analyzed the social media discussion of a private Facebook group dedicated to the long-hauler community. In addition, we interviewed the community members to investigate their motivations for joining the group and how the group has impacted their lives as long-hauler patients. Our analyses revealed the primary discussion topics of this community. It also showed how a minority community could stand by each other using social media groups during a crisis. We concluded the paper with long-term implications of our findings for health care systems, policies, and existing literature on cooperative AI.

CCS Concepts: • **Human-centered computing** → **Empirical studies in HCI**; **Empirical studies in collaborative and social computing**.

Additional Key Words and Phrases: Long-hauler, social media, medical gaslighting, lingering symptoms

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1 INTRODUCTION

The COVID-19 pandemic, a global health crisis, has infected more than 301 million people and killed more than 5.48 million globally since late January 2020 [1]. Although COVID-19 vaccines are found to be effective at protecting people against severe infection and death [28], new variants of COVID-19 virus, such as Delta and Omicron, raised concerns against the efficacy of the vaccines and the antibodies from previous infections [40]. The pandemic that has continued to spread for more than two years has no longer remained a health crisis; instead, it has become a human, economic, and social turmoil for many communities. At the time of this global crisis, it is critical to understand how social media impacts people's lives.

Authors' addresses: Abhinav Reddy Karra, University of Maryland, Baltimore County, USA; Ranjan Jaiswal, University of Maryland, Baltimore County, USA; Sanorita Dey, University of Maryland, Baltimore County, USA.

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Researchers have found that during the pandemic social media are being used to spread unapproved cures, misleading rumors, and conspiracy theories about the origin of the Coronavirus. Young social media users got overloaded with information negatively impacting their psychological well-being [50]. More than a quarter of the most viewed videos on COVID-19 on YouTube contained misleading information, representing more than 62 million views that created unnecessary health anxiety [23, 46]. However, not all information consumed from social media was harmful. Scientists and healthcare professionals used social media to circulate critical information about the pandemic and the vaccinations instantaneously to millions of people. Amid long-term social distancing, social media helped people to maintain social connections and ward off social isolation [35]. In this paper, we extend this body of work further by exploring how social media groups may become the primary source of assurance and validation for communities, especially at the time of global crisis when the basic needs and requirements are hard to fulfill.

To examine the impact of social media groups, we focused on COVID-19 long-haulers community on Facebook. Who belongs to the COVID-19 long-haulers community? Typically, mild or moderate COVID-19 symptoms last about two weeks for most people. However, some individuals experience lingering health problems even when they have recovered from the acute phase of the illness. Standard COVID tests cannot find any live Coronavirus in these patients' bodies. However, they still experience a wide range of symptoms regularly for months [21, 77] which often makes it difficult for them to go to their previous routine. People living with post-COVID symptoms for at least four weeks are identified as "COVID-19 long haulers", "long-COVID", or "post-acute sequelae of SARS-CoV-2 infection" as referred by the National Institutes of Health (NIH).

The reasons we chose the COVID-19 long-hauler community for exploring the impact of social media during the pandemic were threefold. First of all, long-hauler patients did not exist before this pandemic. Studying this community has given us a unique opportunity to understand how trust and empathy among community members can be formed entirely on social media when other forms of communication are hard to reach. Second, we expect to contribute to the emerging topic of studying the role of social media in seeking health information [24, 47]. When misinformation and disinformation on online platforms have become a primary concern while seeking health information, our study explored how social media groups may establish a sense of mutual trust and emotional dependence. Third, earlier research on long-COVID predominantly focused on identifying the wide range of symptoms reported by long-hauler patients by analyzing social media discussions and online survey responses. They applied machine learning techniques to examine the probability of suffering from a series of chronic symptoms by long-hauler patients [6, 83]. However, understanding the symptoms without considering the emotional, economic, and social challenges faced by long-hauler patients might not give us a complete story about this community. We aimed to contribute to this area by providing a more comprehensive narrative of this community.

In our study, we intended to go beyond the analysis of symptoms reported by long-hauler patients in their social-media group. We sought to learn why and how the COVID-19 long-hauler group named "COVID-19 Long Haulers Discussion Group" was formed on Facebook and its impact on the members coping with their long-hauler conditions during difficult times. We conducted a mixed-method study that took two main approaches. First, from Facebook, we collected this group's posts and comments (186,860 entries) from November 3rd, 2020, to February 8th, 2021. To identify the topics of discussion in this group, we applied a combination of qualitative annotation and LDA topic modeling. Our analysis allowed us to acquire a baseline understanding of the group's discussion topics on social media. This knowledge helped us interview the group members in the second stage. We interviewed 23 members of the group, including the admin. We asked them to reflect on their experiences of being a part of the group. More specifically, we asked them when and

why they joined the group, how they interacted with other members, and how the group impacted them throughout their journey as long-hauler patients.

Considering the outcomes of qualitative annotation and LDA topic modeling together, we identified two primary topics: 1) discussions regarding Long hauler symptoms and 2) discussions **not related to** Long hauler symptoms. These two main topics contained nine sub-topics which are discussed in detail. The discussions regarding symptoms often asked for assurance and validation from the community that their lingering, unusual symptoms were not completely unheard of by other group members. In contrast, the posts and comments that were not about symptoms often shared the journey to recovery to keep the hope up among the members of the community.

Our interviews found that the Facebook group helped its members find validation that their long-COVID symptoms were not related to any psychosomatic conditions; instead, they were caused by their physiological conditions. The group's private setting helped them feel secure and protected where no one would take advantage of them for sharing their vulnerabilities or judge them because of their unexplained conditions. The group helped them frame their questions to their doctors and primary care physicians in a way that often assisted them in diagnosing the root causes of their symptoms faster.

We learned how social media groups' intimate, private settings might serve as essential support systems for online communities. The community can stand for each other at times when regular resources, infrastructures, and even friends and family members may not be able to provide adequate support. Our findings have widespread implications for examining online community designs and functioning to better support ad-hoc groups' needs. Our results contributed to the existing literature on cooperative AI. They showed how an AI-supported social media platform like Facebook could contribute to the formation of an online community and motivate the members to cooperate to overcome emotional and physiological challenges during a crisis. We also drew attention to the limitations and complexities of such groups, which have great potential but may not serve all the needs of the communities as the communities grow bigger and older. We discussed how platform designers could adopt AI-driven approaches to overcome many of these challenges and help support groups grow on their platforms. We believe this research would stir up discussion on new avenues for public health intervention to better address the requirements of minority groups during critical times such as a global pandemic.

Ethics and Disclosure. Because we used social media data of a private group, we had to get permission from the group's admin to get this study approved by the relevant institutional review board. In addition, we took great care in how data and analyses are presented in the paper, for instance, by avoiding any personally identifiable information. We intentionally avoided including any quote in the paper from the group's social media discourse as the data was collected from a "private" group, and we wanted to ensure that the data was not traceable at all. Although one of the co-authors on the papers got infected with Coronavirus during this study, none of the co-authors have experienced any long-hauler symptoms yet. We joined the group only as HCI researchers to collect data and later process them. The admin of the group posted the call for the interview study on the group page as per the request of the authors of the paper. We recruited only those participants who responded to that call. No other member was contacted for the interview. We explained our position (a group of HCI researchers where only the interviewer had been a group member for almost a year) and described the study's goal. We collected the verbal consent of interview participants before the start of each interview session. We recognize and acknowledge the limitations of our methodological approach and our position as researchers and outsiders to this particular online community. A number of our interview participants became emotional when they explained their lingering conditions during the interview. We acknowledge that their emotional

state of mind might have some effect on their interview responses. However, we believe the effect was minimal and did not impact our main findings. We describe our limitations further in the Discussion section.

Background of the COVID-19 Long Haulers Discussion Group on Facebook. This private Facebook group was created on June 26th, 2020. The group is visible to everyone but requires approval from admins for joining. Someone can also join the group by receiving an invitation from another group member. So far, it has 14,088 members and counting. The primary objective of this group is to assist Long-hauler patients emotionally. As mentioned on their information page, “we are ... here to offer experiences and support. You are not alone. This is not anxiety. Enter with kindness and grace.” This is a global group that is represented by members from more than 100 countries. 82.9% members identified themselves as women, 16.5% as men, and 0.6% as non-binary. The top ten countries from where members joined the group are the United States, the United Kingdom, Canada, South Africa, Australia, Philippines, India, Sweden, Ireland, and Mexico. In the context of this long hauler social media community, we primarily asked the following research question:

- **RQ1** What did the long-hauler community discuss in their private social media group? What can we learn from their discourse that may have long-term implications on other online and offline platforms supporting communities created during the crisis?
- **RQ2** Why was this community created? Why was it set as a private group? How did group members come to know about the existence of the group? How did the group impact them while they were dealing with long-COVID symptoms?

2 RELATED WORK

2.1 Socio-economic Challenges during COVID

On March 11, 2020, the World Health Organization (WHO) declared COVID-19 a global pandemic. Only 118,000 confirmed cases were reported then, which has increased to 5.48 million so far, and we are still counting. Because of this rapid increase in the number of confirmed cases, COVID-19 did not remain only a common infectious disease; instead, it has impacted almost every aspect of our society. For instance, when mental health patients received counseling services through an online program, counselors found building rapport in the online environment challenging. On the other hand, mental health patients faced hardship related to finance, housing, and distance learning due to the pandemic, which often resulted in increased anxiety, stress, addiction, depression, or psychosis [56, 74].

Getting accustomed to online programs and the working environment was challenging, not only for mental health patients. Older adults also faced numerous challenges because of this change of norms. According to a 2017 Pew Research study, three-quarters of those older than 65 said they needed someone else to set up their electronic devices [4]. A third also said they were only a little or not confident in their ability to use electronics and navigate the web [19]. This problem worsened during the pandemic when older adults had to isolate themselves thoroughly as they faced a high risk of getting infected by the COVID-19 virus [58]. Like older adults, getting used to the online environment introduced many challenges for children. An initial survey has found that children could rarely interact face-to-face with their teachers due to lockdown. Some schools and families did not have any dedicated resources and facilities for participating in online programs. The problem was more grave for below-average income families as children from those families felt less strongly about their capacities to cope with online learning activities than other children [76].

Below-average income families also experienced a great deal of unemployment and layoffs during this pandemic, making it even harder for their families to survive. In Joe Pinker’s (2020) Atlantic essay entitled, “The Pandemic Will Cleave America in Two” [66], he highlighted two

distinct experiences of the pandemic. Highly educated people would be able to continue working from home and would be able to avoid public gatherings as advised by CDC. However, this was not the case for low-income jobs. Unlike high-income jobs, most low-income jobs could not be done staying at home. These people either risked their lives to continue working throughout the pandemic or lost their jobs because of downsizing. Unemployment was found to be at the core of many socio-economic challenges such as lower standard of living [12], domestic violence [44], and mental health issues [41].

Socio-economic challenges due to the pandemic affected developing countries such as India, Bangladesh, and Pakistan more severely than western countries. A recent study has predicted that the domino effect of the pandemic on health, healthcare, and nutrition might pose major setbacks to previously gained successes of National health programs in India [32]. Researchers have recommended governments of South Asian countries consider acting collectively to address their challenges and create favorable economic recovery conditions caused by the pandemic [42].

All these socio-economic challenges discussed so far have hit members of the minority communities such as Black communities, Latinos, immigrants, and sex workers even harder [80]. This paper focused on one such minority community– the COVID-19 long-hauler community. We address them as a minority community since the percentage of people experiencing long-hauler symptoms is around 10% of the total infected people infected by Coronavirus. Because of this smaller percentage, like other minority communities, the long-hauler community faced more socio-economic challenges than regular COVID patients. Until recently, even medical professionals knew very little about the conditions and challenges faced by the long-hauler community. Thus, the long-hauler community tried to comfort and assure each other by forming social media groups. In this paper, we focused our attention on one such group formed on Facebook to support COVID-19 long-hauler patients emotionally. We aimed to investigate how they extended support to each other when only a few people even believed in their concerns.

2.2 Medical Gaslighting

Apart from a long list of physiological challenges, one common experience that most of the long-hauler patients had to go through was the medical gaslighting [69]. The term gaslighting was initially coined in a movie called *Gaslight*, which tells the story of a man who pushes his new wife to doubt her sanity through manipulative tactics. The concept first gained traction as a construct in psychological literature during the 1960s. For some who have experienced it, the feeling can be worse than physical abuse [73]. Doctors and healthcare professionals often exercise gaslighting in the medical field by downplaying their patients' physiological condition as a psychological problem such as stress, anxiety, or somatic symptom disorder (a mental state when someone has excessive and unrealistic worries about their health).

Women patients experience medical gaslighting the most because of the knowledge and trust gap among healthcare providers [61]. Recently, the concept received much media attention because of the book titled "Doing Harm" [49] published by Maya Dusenbery, where she shared her own traumatic experience of medical gaslighting and discussed more largely gender bias in medicine and how it hurts women. However, medical gaslighting did not stay limited to women patients in the long-hauler community. Both men and women patients experienced it equally when they asked for solutions to their conditions.

Why were Long-hauler patients gaslit when authorities put so many initiatives to treat people infected by Coronavirus? A recent case study showed that it might not always be intentional. One primary reason could be the lack of knowledge about this new virus and how different individuals might get infected by the virus. Before much research was done on this virus, healthcare providers believed that COVID-19 would kill only a few (between 1% to 2% of the infected people), and the

rest would only face “mild” symptoms for some time. Healthcare providers strictly followed the official description of COVID-19 symptoms and relied heavily on the COVID lab-test results. No one listened carefully to those reporting unusual symptoms but tested negative for Coronavirus. They were excluded from any possible help or valid answers only because either their conditions were not found “deadly” or they were not found COVID positive by standard tests. Rita Rubin discussed medical gaslighting in her publication [69] against long-hauler patients. She explicitly talked about those long-hauler patients who were never tested for COVID — often because either their requests were denied or they did not qualify for a COVID test. Already overwhelmed medical facilities with many critical patients did not have enough resources and necessary training to address issues that Long-hauler patients had been dealing with for months. As Bruce Lee mentioned in a famous quote, “When under duress, we do not rise to our expectations but fall to our training level.”

2.3 Minority Groups on Social Media

Research studies have found a close connection between minority groups and social media in recent years. For instance, Muller et al. have shown that since the 2016 presidential primaries and President Donald Trump’s political rise, one standard deviation increase in Twitter usage increases anti-Muslim hate crimes by 32% [59]. Trump’s tweets about Islam-related topics increased in xenophobic tweets by his followers, cable news attention paid to Muslims, and hate crimes in the following days. Another form of hate message that spread across all major social media platforms during the global pandemic was Anti-Asian racial messages. About 17% of Asian Americans said they experienced severe online harassment in January 2021 compared with 11% during the same period last year. Online hate and harassment are not unique to Asians. For many years, social media users who identify as Black, Jewish, transgender, or as part of other marginalized groups have complained that Facebook and Twitter are not doing enough to stamp out hate speech, despite having rules against that type of behavior [79].

Despite the threat of spreading hate messages, misinformation, disinformation, and rumors through social media, minority communities often found social media as the only place where they could express their opinion freely and fearlessly. A 2011 national survey of LGBTQIA youth reported that this population spent more time online and was likelier to have close online friends than non-LGBTQIA youth [30]. Social media platforms enable LGBTQIA people to seek and find health information [36, 51], yet this practice can sometimes be invalidating when one’s specific identity or health concern is not represented online [51]. Tumblr has often been recognized as particularly LGBTQIA friendly [17, 18, 26, 62]. Some of Reddit’s features, such as anonymous and pseudonymous identities, enable LGBTQIA communities to form and thrive darwin2017doing, farber2017transing. Overall, studies found that social media can be a critical place for online LGBTQIA presentations due to the ability to maintain boundaries between different identities and networks, thus enabling a relatively safe space for identity exploration and transition [15, 34].

In addition to identity exploration, minority communities often relied on social media to protest discrimination against communities. In 2014, following the non-indictments of officers in the murders of Michael Brown and Eric Garner, the youth of color used hashtags such as “#AllLivesMatter” and “#BlackLivesMatter” to shape the national discourse about race in the wake of these high-profile tragedies [16]. Black Lives Matter (BLM) group frequently used social media for building connections, mobilizing participants and tangible resources, coalition building, and amplifying alternative narratives [38, 60].

Similar to the BLM group and LGBTQIA community, the long-hauler community also utilized Facebook to unite and find strength and solidarity within the group. However, unlike other minority groups, we know very little about the motivations, community norms, and expectations of the long-hauler community. Our work aims to fill this existing gap by closely examining this community.

2.4 COVID-19 and Long-Hauler Community

The concept of long-COVID was first discussed in global media in early June 2020. Ed Yong, a science journalist, published an article in *The Atlantic* on lingering symptoms of COVID-19 of nine people he interviewed. It is strongly believed that long-COVID is the first illness created through patients finding one another on social media [14]. Soon after that, the research community started focusing on long-hauler patients. In early publications, researchers documented case studies of long-COVID patients. They gathered the symptoms that long-haul patients frequently reported [43, 71]. Research publications explained how different organs of long-COVID patients might get damaged permanently as an after-effect of Coronavirus infection. For instance, Michael Marshall [52] explained how long-hauler patients might experience cardiomyopathy, heart disease in which muscles of the heart become stretched, stiff, or thickened, affecting the heart's ability to pump blood. The author suggested more follow-up studies to recognize long-term neurological and psychological consequences of COVID-19, which was also observed among SARS-CoV-2 patients.

Another critical challenge with the long-COVID condition was the lack of definition. Case studies identified that severity of the COVID infection could not explain whether someone would experience long-COVID symptoms or not. Patients who experienced mild or no symptoms during their infection also reported long-hauler symptoms after four to eight weeks of their initial infection. It was also unclear in terms of the timeline when post-COVID or long-COVID symptoms might appear among COVID patients. Fernández-de-las-Peñas et al. [27] aimed to define such factors in an attempt to provide a structured model for this concept. Dr. Nisreen A. Alwan, who herself experienced long-COVID conditions for months, wrote several articles [2, 3] to highlight how long-COVID patients were ignored at the beginning of the pandemic and the necessary steps that need to be taken in the future to avoid such negligence on a large scale.

As long-hauler patients started connecting through social media, their online discourse worked as rich resources for tracking self-reported symptoms of long-COVID patients. For instance, researchers studied posts from public online communities such as *r/covidlonghaulers* on Reddit and found that social affordances of online media such as Reddit are often critical for generating collective intelligence and storytelling during crises that crisis-impacted populations believe and find more credible than official sources [8]. Banda et al. [7] analytically analyzed the Twitter feed to identify the commonly reported symptoms and frequently consumed medications for those symptoms. Ziauddeen et al. [83], on the other hand, conducted an online survey to explore how long-COVID symptoms affected people's quality of life. These studies allowed researchers to record responses from those who could not access standard RT/PCR tests because of community policy. Such analysis can support the clinical data collection process, which often misses those patients who never get admitted to hospitals for their conditions. Our study builds on this body of work. We posit that private online spaces can provide a trusted environment for long-hauler communities to find assurance of their claims and extend reciprocity to the broader audience. Our mixed-method approach allowed us to go beyond the primary discussion topics of this group on social media platforms. It revealed the inherent motivations, dependencies, and beliefs that gave the group members the strength to endure the worst conditions.

3 STUDY DESIGN

This research aims to understand the private Facebook group “COVID-19 Long Haulers Discussion Group” explicitly created for long-hauler patients. In RQ1, we aimed to identify the primary topics that COVID-19 long-hauler community discusses on their online social media group. To this end, we started collecting the online discourse of the group and analyzed them to find their primary topics of discussion. We followed up with an online interview study. In interviews, we were able to



Fig. 1. A word cloud is showing all the major topics discussed in the COVID-19 Long-Haulers Discussion Group. We included all topics on which at least ten posts were posted on this group's page. The text size of the name of each topic is proportional to the number of posts on that topic. The list of topics includes several symptoms experienced by long hauler patients and many emotional states explaining the state of the mind of the members of this group.

ask the members to reflect on their reasons for joining the group, their expectations, the impact of the group on them, and things the group can do more for them. The findings from the interviews helped us answer RQ2. This mixed-method approach allowed us to explore the prospects and challenges of this group with minute details. We summarized our understanding and practical implications of our findings in the discussion section of this paper.

3.1 Analyzing Social Media Discourse of the Long-Hauler Community

We started by collecting the online discourse of the long-hauler community. We applied the following techniques to identify the primary discussion topics from this dataset: 1) analyzed the data using a topic modeling algorithm and 2) manually annotated the data using an interpretative qualitative analysis technique. The outcome of the topic modeling algorithm and qualitative analysis complemented each other and allowed us to investigate the discussion topics of this group more thoroughly.

3.1.1 Collecting Social Media Data shared by COVID Long Haulers' Community. The first step was to select a social media group dedicated to long-hauler patients. There are several Facebook groups and Twitter communities that could satisfy this criterion. Some notable Facebook groups for long-hauler patients are COVID-19 Long-Haulers Discussion Group, COVID-19 Long Haulers Support, Survivor Corps, and COVID-19 Longhauler Advocacy Project. We decided to focus on the "COVID-19 Long-Haulers Discussion Group" for three reasons: 1) it was one of the earliest groups for the long-hauler community on Facebook, 2) it was created explicitly for long haulers patients, as the name suggests, and 3) it was a private group. We hypothesized that a private, reasonably large social media group for long-haulers would make long-hauler patients feel more comfortable sharing their ideas, thoughts, experiences, and opinions. We acknowledge that **public** social media groups might have introduced different but equally important nuances to this study. We would

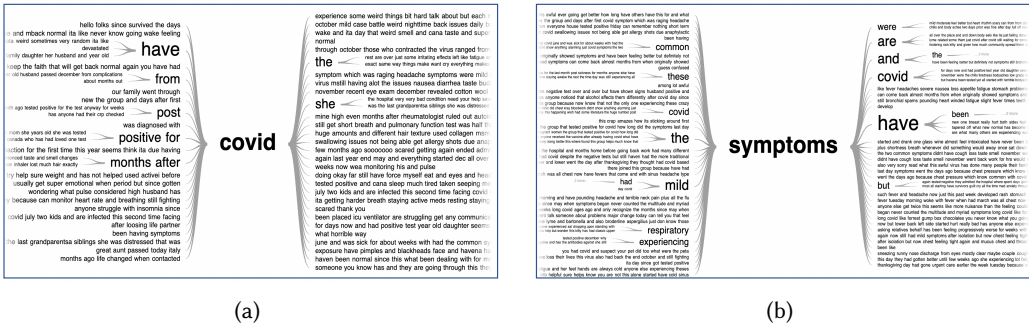


Fig. 2. Example word-trees built around “covid” and “symptoms” on snippets of Facebook posts and comments in our dataset. The font sizes are proportionate with relative occurrence.

leave it for future work. Figure 1 shows the most frequent keywords that were mentioned in posts and comments by the members of this group.

To analyze posts and comments available on this group, we manually copied all the posts made by this group daily. Some of the posts’ comments remained hidden when there were many comments under one post. It is worth mentioning that some posts received more than 200 comments in this group. We expanded all comments before copying them. We continued this process from November 1st, 2020 till February 8th, 2021. We collected 10,234 posts during this duration which contained 186,860 comments. On average, there were 18.26 comments per post. These posts were posted by 7,446 unique users (mean=1.37 posts per user). To give the reader a broad sense of our dataset, we present example word-trees in Figure 2 which show examples of post snippets of how people express “symptoms” and “covid” on this group’s page on Facebook.

3.1.2 Adopting the Latent Dirichlet Allocation (LDA) technique to identify Main Discussion topics of the Group. We began by applying standard text-processing steps such as removing special characters, hyperlinks, punctuation, digits, stop-words, and lowercasing all characters. We adopted the Latent Dirichlet Allocation (LDA) technique [11] to extract the range of discussion topics the long-hauler community contributed through posts and comments. LDA is a widely used unsupervised statistical model to discover hidden topics by analyzing the semantic structure of the documents. Each topic consists of keywords that define it, and text tokens are distributed over latent topics throughout each document. We treated each comment or post as a document and applied LDA on all of them.

The performance of the LDA model depends on the choice of hyperparameters α and β and the number of topics (k). Here, α controls the sparsity of document-topic distribution, and β determines the sparsity of topic-word distribution. A low value of α is preferred (less than 1), because it produces a sparse distribution, leading to very few topic assignments per comment. This intuitively makes sense because it is almost unlikely to mention many topics in a single Facebook post or comment. Similarly, lower values of β favor fewer words per topic. To tune the value of the hyperparameters, we followed the similar procedure proposed by Pathik et al. [11]. We considered the number of topics (k) = 20 as a seed value and ran the LDA model for a range of values of α and β . We considered all values in the range of [0.01 0.99] at regular intervals of 0.05. We ran the model and recorded the coherence score for each unique combination of α and β . Thus, we chose $\alpha = 0.01$ and $\beta = 0.11$ as the best-fitting hyperparameters for our dataset since the coherence score of the model was the highest for this combination.

Once the values of α and β were identified, we followed the same procedure to tune the number of topics (k). With $\alpha = 0.01$ and $\beta = 0.11$, we ran the model for all values in the range of [5 50] at

regular intervals of 5. We observed the highest coherence score at $k = 15$, and the score did not increase significantly after that. We also investigated the topics themselves and increasing the value of k beyond 15 resulted in the repeated appearance of the same keywords in multiple topics, which was not intended in our context. Finally, we decided to run the model for $\alpha = 0.01$, $\beta = 0.1$, and $k = 15$ and generate topics for further analysis. Once the topics were identified, two human coders familiar with the concept of social media group for COVID long haulers independently reviewed those 15 topics and the top words in each topic. Following an inductive open coding method, they individually identified the non-overlapping themes from those topics. In the process, they merged two or more topics when they were thematically overlapping. Finally, they resolved disagreements through discussions. We identified two main themes. Primarily, the topics generated by LDA can be divided into two major categories: 1) the topics where group members discussed a specific symptom or a group of symptoms that they were regularly experiencing and 2) topics that were not directly related to any symptoms. The first main topic contained six sub-topics, and the second one contained three subtopics (discussed in section 4).

3.1.3 Qualitative Annotation of Long-Hauler discussion on Facebook. To ensure that we did not miss any critical discussion topics, we performed manual annotation of a subset of our dataset. Two human coders (one of them was the first author of this paper) familiar with the COVID long hauler community and their activities on social media examined a random sample of 1000 entries from our dataset. To ensure a uniform representation, we divided our dataset into ten parts based on when a specific post/comment was posted. For instance, in part 1, we considered all posts/comments between November 1, 2020 and November 10, 2020. Part 2 contained all posts/comments between November 11, 2020 and November 20, 2020, and so on. We randomly collected 100 posts/comments for qualitative annotation from each part.

Without labeled ground-truth data, our human coders adhered to an open inductive coding approach [30]. We organized three brainstorming sessions during this coding process, where both coders discussed their preliminary thoughts. We followed an iterative process, and after multiple iterations, we identified 24 initial themes. Next, we invited five undergraduate students to avoid any bias imposed by the first author of this paper and make this annotation process more applicable. All of them had backgrounds in social media data analysis, social science, and behavioral psychology to examine another random sample of 500 comments (the same process was followed for maintaining uniform representation). This new set did not contain any comments from the previous set. To provide background on the annotation process, we conducted an hour-long information session discussing themes identified earlier along with specific example comments. All coders independently coded the new set of 500 comments following this discussion. They could either apply any theme from the existing pool of 24 themes (if applicable) or create a new theme for each comment based on their judgment. Finally, we discussed their coding experiences and received feedback about potentially ambiguous, misrepresented themes and possible new themes.

We modified, removed, and added a few themes based on the discussion with undergrad coders. Next, to assess the effect of the changes, the first author and a social science expert coded another random sample of 1000 comments (which did not include comments from any previous set). The disagreements in annotations were resolved through discussion until consensus was reached. We also combined multiple initially identified themes that were closely related to each other. Finally, we achieved a substantial agreement based on Cohen's kappa test ($K = 0.84$). Combined efforts in the three stages resulted in the same two major themes (as we identified from LDA analysis): 1) topics related to symptoms and 2) topics not related to symptoms. However, in the "topics not related to symptoms" theme, we identified four new sub-topics.

All topics and sub-topics identified through LDA analysis and qualitative annotation are discussed in section 4.

3.2 Interviewing Members of Long-Hauler Community

To understand the background and motivation of the members of this long-haulers community, we conducted a qualitative interview. The semi-structured interview protocol was designed to understand the challenges that long-hauler patients faced during the pandemic and their experience participating in this Facebook group. We asked them to describe when and why they felt the need to be a part of a support group for long-hauler patients. Our questions, in particular, addressed how they found this specific group, whether they joined any other groups for long-hauler patients, how they engaged with each group, what kind of information they posted, and how comfortable they were posting those content in the group. Further, we asked how the group assisted them throughout and how the affordances of the group's design (private vs. public, methods, regulations, and rules of administration imposed by admins and moderators) impacted their level of engagement in the group. We asked them about their strategies to verify the information shared in the group. Finally, we asked them to reflect on additional features they would like to access as a community.

3.2.1 Participants. Participants were recruited through an open call for an interview posted on the Facebook page of the group. The admin of the group posted the call as we anticipated that a post made by the admin would reach more members of the group. All members who initially responded ($N = 31$) to that call were contacted by the authors. Twenty-four members agreed to schedule interviews, and we completed 23 interviews. One participant initially planned her interview but could not attend due to her deteriorating health. The last author of the paper conducted all interviews in the fall of 2021 via voice chat or Google Meet, depending on the interviewees' preference. On average, each interview took 37 minutes to complete. They were between the ages of 16 and 72 (average 47.5 years), and all but one of them experienced long-hauler symptoms for at least six months at the time of the interview.

3.2.2 Analysis. The interviews were analyzed using elements from grounded theory [20] in particularly open qualitative coding using thematic analysis. After transcription, three researchers read through the interviews and developed themes individually based on the coded data material, which were later categorized. The themes emerged from the data rather than being prescribed from the interview guide. The researchers regularly met to iterate and converge on the broader categorization of themes. This analysis was performed to uncover participants' main concerns as long-hauler patients and how the Facebook group helped them to deal with those concerns as a community. The findings of the interviews are discussed in section 5.

4 RESULTS: ANALYSIS OF THE ONLINE DISCOURSE OF LONG-HAULER COMMUNITY

Table 1 lists the nine topics presenting the main discussions in the long-haulers' Facebook group. The table shows the percentage of posts (column 2) on each topic, along with the top five keywords. Members of the group discussed various ongoing symptoms that they experienced for months after COVID. Some notable ones were hair loss, chest pain, difficulty breathing, abnormally high or low blood pressure level, brain fog, fatigue, and loss of smell and taste. They also discussed how some of these symptoms continued for months, and on many occasions, even their doctors failed to treat those symptoms.

The topics unrelated to symptoms mainly highlighted community-wise collaboration and empathy. Members of the community expressed condolences when someone went through a tough time. They also expressed warm gratitude to the group for support during the hour of need. The timeline

of these posts and comments was just before the COVID vaccine initially became available for everyone. The members of long-haulers' group consulted each other to get additional information about the vaccines. This indicates a sense of trust among the members who were essentially ignored for a long-time by the healthcare system.

The qualitative annotation also identified all topics identified by LDA. Moreover, it identified four additional topics (not found by LDA)(listed in Table 2). All those four topics were not directly related to long-hauler symptoms; instead, they discussed the effect of long-hauler conditions on their daily life. For instance, group members mentioned getting panic attacks and nightmares in anticipation of getting their symptoms back. They also explained their financial crisis due to loss of their job and how some of them even got evicted from their apartment in the middle of the pandemic. We classified all these additional topics in the second main topic (topics not related to symptoms). Here, it is worth mentioning that we identified 523 unique users from our final dataset of 1000 posts or comments used for qualitative analysis. The percentage included in the description of the topics unique to qualitative annotation is calculated, considering 523 as the total number of users.

Overall, the main discussion topics identified by LDA show that the group members considered this space as a trusted place where they felt comfortable discussing their lingering symptoms, vulnerabilities, and challenges. They also found this group useful to gain assurance that they were not experiencing these conditions alone; rather, as a group, they were facing these conditions, which might have given them a sense of hope and courage to face these conditions as a strongly bonded group. An in-depth description of all these topics is included in Appendix 9.1.

4.1 Summary of the Analysis of the Online Discourse

In summary, combining the LDA analysis and qualitative annotation allowed us to construct a detailed and nuanced picture of the online discourse of the long-haulers' social media community. LDA analysis helped us find this group's most frequently discussed topic, whereas qualitative analysis allowed us to reflect on those topics' more subtle presentation styles. It also helped us identify some less frequently mentioned topics from the dataset. Topics unique to the qualitative annotation showed that the community members shared not only their symptoms with the group but also their challenges, everyday struggles, and despair that they could not share comfortably and confidently with their family, friends, or anyone else. The group provided them a safe platform to talk without hesitation and the fear of judgment.

In the next section, we describe the findings of our interviews with the group members. The interviews assisted us in understanding why the members decided to join the group and how the group impacted them throughout the pandemic. The interviews' findings and the discourse analysis gave us a holistic picture of this online community– their needs, expectations, fulfillment, and journey on this path of suffering and uncertainty.

5 RESULTS: ANALYSIS OF THE INTERVIEW TRANSCRIPTS

We identified four themes from the analysis of our participants' interview transcripts, which are explained in this section. Table 3 shows the details of all interview participants.

5.1 Lack of Social and Institutional Validation

In early 2020, when the novel Coronavirus started spreading worldwide, little was known about how the virus would impact the lives of infected people. The unprecedented pressure on health care facilities forced them to focus primarily on severely ill patients, such as patients who had trouble breathing. The concept of COVID long-haul condition was new to the medical community, and only a few doctors could understand or treat the various symptoms of long-hauler patients.

Table 1. LDA table with nine topics. Column 2 shows the percentage of comments in that specific category. Column 4 lists five representative words from each topic.

	Lexical Group	Percentage of Posts/Comments	Top Five Keywords
Topics related to symptoms	Symptom of Hair Loss	8.80%	"hair", "falling", "losing", "plasma", "convalescent"
	Symptoms Reappearing for Months even after negative test result	15.77%	"symptoms", "months", "still", "tested", "negative"
	Symptoms of Loosing Smell and Taste	7.33%	"smell", "feel", "taste", "back", "sinus"
	Symptom of Irregular Heart Rate and Blood Pressure	16.80%	"heart", "blood", "rate", "pressure", "low"
	Symptoms of Brain Fog	14.46%	"brain", "fog", "remember", "lost", "spelling"
	Symptoms of Pain	9.2%	"pain", "chest", "neck", "else", "cough"
Topics not related to symptoms	Seeking suggestion for vaccination	13.59%	"vaccine", "dose", "anyone", "recommendation", "received"
	Pray for loved ones recovery and offering condolences	7.90%	"family", "prayers", "god", "please", "group"
	Sharing News about Recovery and Thanking the Community	6.15%	"hospital", "home", "work", "relief", "grateful"

Table 2. List of topics identified only from qualitative annotation

Title of the Topics	Brief Description
Expressing Frustration	Expressing frustration and embarrassment for nightmares, memory loss, symptoms appearing on random days
Experiencing panic attacks	Experiencing panic attacks anticipating irreversible damages such as damages in their genetic structure
Overwhelmed with Financial Instability	Getting overwhelmed by financial challenges such as by getting laid off from existing jobs or by not being able to continue with the current job because of the lack of awareness of the employers in rural areas .
Seeking suggestions	Seeking suggestion from the community on issues such as outreach programs for COVID patients and other rarely available products and services

According to our participants, this condition created a problematic situation for long-hauler patients. They were tested COVID negative through conventional tests such as PCR test. Yet, they could never fully recover from their symptoms. For many of our participants, their primary-care physicians claimed nothing wrong with them. Everything that they were experiencing was in their

Table 3. Participants' overview

Feature	Age	Location	Profession
Participant 1	49	Florida	Employed in Family Business
Participant 2	50	Texas	Rancher
Participant 3	16	Tennessee	High-School Student
Participant 4	43	Georgia	Lawyer
Participant 5	52	Ohio	Instructor/Recruiter
Participant 6	69	Alabama	Retail Shop Employee
Participant 7	72	Tennessee	Fundraiser
Participant 8	50	North Carolina	Nurse: retired
Participant 9	52	California	Public Relationship Officer
Participant 10	68	Johannesburg, SA	Teacher
Participant 11	43	Colorado	Insurance Broker
Participant 12	49	Oregon	Aesthetician
Participant 13	20	New Jersey	Freshman Student in College
Participant 14	30	Colorado	Uber Driver
Participant 15	50	New York	Corporate director for Restaurant opera
Participant 16	54	Virginia	Nutritionist
Participant 17	39	California	Physical therapist
Participant 18	52	Florida	Swimming pool cleaner
Participant 19	54	Utah	Teacher (retired)
Participant 20	51	Minnesota	Long-term Disability from Work
Participant 21	47	Washington	Healthcare Industry
Participant 22	50	Missouri	Teacher
Participant 23	56	Connecticut	Product Manager

mind. They were just experiencing an episode of anxiety, and for several participants, their doctors even prescribed them medicines usually used to treat anxiety and depression. As P15 explained it in his interview:

Do you know what it is like to come across people who do not really believe you? It is like that Netflix show called “Manifest” where they all quote-unquote survived the plane crash and came back, and I said that is us. We survived, we are here, we have got these weirdo things that happen to us that we cannot really explain. Lab tests do not always reveal the root cause of this condition. It might not happen to us all the time, but it certainly does occur. I cannot tell you why I could be sitting on the couch watching TV and my blood pressure all of a sudden, even though I am on medication, goes to 150 over 123. I have no idea. It had never happened before. (P15)

Some participants could not even explain their condition to their family members. As P7 mentioned:

Yes, this is like a chronic illness. Family members get tired of hearing it. They expect you to get well. They expect you to do something to get well. They want you to be happy and fine because they cannot do anything about it either. (P7)

All of our participants wanted to find answers to their symptoms. They wanted to know that they were not alone in experiencing such symptoms. As P9 mentioned, they were “fishing for validation”. Mainstream media sources often explained COVID as a “do or die” situation. Once you

get infected, you will either die from a respiratory tract infection or survive. All of our participants, at some point, were clinically declared as COVID negative. Although they survived, they could not go back to their previous lifestyle. Nobody could explain why they could not recover completely. Some participants even blamed themselves for their prolonged symptoms:

I look up in the mirror and get really really angry with myself. I feel that if I had tried harder, I would have gotten myself out of this couch anyway. Right up until I got sick for the first time, I was a competitive athlete. I say myself, like every other athletic injury, I need to snap out of it and move forward. But this (long-haul symptoms) doesn't allow you to do that, which sometimes makes me feel down. (P15)

Some of our participants were admitted to the intensive care unit (ICU) for some time. When they recovered from their critical condition, they were released without further guidance. In addition to their lingering symptoms, they could not forget the fear of staying in the ICU without friends and family members. They needed someone who could listen and understand them without any judgment.

One common topic that frequently emerged in our interviews was the lack of validation in many forms. Some of our participants experienced and got treated for long-term depression in the past. Thus, they were confident that their current symptoms were not related to depression or anything similar. Yet they were frequently told that the fatigue and brain fog that they were experiencing was nothing but a side effect of their depression. Participants with Gastrointestinal (GI) symptoms were told that they should receive treatment for eating disorders. All participants in our study looked for validation of their condition from many sources. That urge was one of the main reasons why they looked for support groups similar to "Long-hauler discussion group" on social media. We now turn to more detailed accounts of how this Facebook group supported our participants through their struggle as long-hauler patients.

5.2 A group that Provided a Sense of Camaraderie and New Directions to Try for

In the US, CDC confirmed the first case of COVID-19 on January 18, 2020. Some of our interview participants mentioned that they got infected with Coronavirus sometime in March 2020, which is the same time when many states of the US started lockdown regulations. These participants started noticing their long-haul symptoms in early May, approximately two months after their first infection. In a recent trial, CDC also found that timeline consistent with a report that considered a random sample of recovered COVID-19 patients in Long Beach, California [82].

Many of our participants started looking for solutions for their symptoms during this time. However, they could not find any mainstream source explaining their conditions. So they started talking to a few people on social media. As P8, one of the few people who started the group on Facebook mentioned:

Whether there was something seriously wrong with us that we needed to look into. We were little groups of people in the beginning. In a small group, we started talking. Someone said I crashed and face-planted. I said I did that too. It just felt so much better because we could not get answers from anybody else. Doctors did not know what to do. We were told to avoid hospitals. So nobody knew what we were supposed to do about this or if it was normal. We helped each other. (P8)

A few other groups related to COVID and long-haul were created on Facebook at around the same time (June 2020). "COVID-19 Long-Haulers Discussion Group" officially started on June 26, 2020, with 50 members. Some of our participants came to know about this group from their friends, some participants learned about it from discussions in another COVID-related social media group,

and others read about the group in news articles and blog posts. A few participants actively looked for such support groups on Facebook and found them.

From the beginning, the group admin and moderators ensured that no one in the group would provide any form of medical advice or prescriptions. The group's objective was to support those who were struggling with long-haul symptoms. All participants in our interviews mentioned that the group validated their symptoms. It helped them realize that they were not alone with similar complaints. A global group like this gave them the much-needed assurance that there were hundreds of other members from all over the world who at some point experienced similar symptoms, and they were just one of them. This validation helped them to overcome self-doubts and gave them the confidence to ask for help. As P8 mentioned:

That validation really helped anchor me. I really did not know if this was something in my head. Am I just blowing things in my mind? Am I creating problems that I did not actually have? Am I exaggerating something? The group helped me realize that I actually was not. It helped me look for ways to find data to support my condition. (P8)

The sense of validation and camaraderie not only helped our participants to clear out their self-doubts but also helped them learn more about new findings and medical trials on long-hauler patients as a group. Most of our participants suffered from brain fog as long-hauler patients. They could not read scientific or news articles completely. However, when more people started joining the group, they started sharing whatever information they could gather, and that collective knowledge was beneficial for the group members. They learned proper terminologies relevant to their symptoms that helped them to seek treatments from their doctors. For instance, when someone shared about new lab tests that might assist long-hauler patients, many participants asked their doctors to run the same tests. Those tests helped their medical diagnosis, which was critical for them to recover from some of their symptoms. In another scenario, when a doctor did not agree to run those lab tests, one of our participants (P11) asked her doctor to write down this denial clearly in her medical charts. This demand eventually convinced her doctor to run those tests, which proved necessary for her diagnosis. The group's discussion helped our participants know their rights in seeking treatments from their healthcare providers. Moreover, the group helped our participants find local resources, doctors, and supporting organizations dedicated to long-hauler patients. In fact, for one of our participants, the group suggested him to avoid a local doctor who later lost his medical license because of committing medical malpractice. As P14 mentioned,

It was an extended research partnership as a lay person with no scientific training. My group helped me frame my questions better to my doctor, which is in many cases critical for getting any help from your doctor as a long-hauler patient. (P14)

Another critical element of support that emerged from this group, according to our participants, was suggestions for home remedies. The group always restricted sharing medical advice among its members. However, members often shared home remedies and supplements, which helped alleviate some of their symptoms. Our participants mentioned that those remedies and suggestions helped them immensely, especially when their doctors could not improve their condition. For example, P18 mentioned applying Vicks VapoRub on her feet and putting her socks on for her soar throat. She learned about this remedy from another member of the group, which turned out to be a great relief for her. P9 learned about probiotic yogurt from one of the group's discussion threads, which helped her manage some of her Gastrointestinal (GI) symptoms, thus enabling her to regain some weight. While our participants discussed several home remedies and herbal products that they learned from the members of this group, they also acknowledged that no one in the group could suggest any solution for some of their symptoms. Knowing that such a large group of people could

not find a solution for some specific symptoms helped them accept that some symptoms might not have an answer. As P15 described:

I had abdominal pain. Many others have it too. However, nobody knew what to do with it. Knowing that there is no solution for it is helpful. I felt that it is okay. I am not going to die for this. Let's keep going. Take Ibuprofen and move on. (P15)

Several participants in our study described long-haul as a chronic illness. Like any other chronic illness, it takes continuous medical attention. Some of our participants found it challenging to arrange support from their health insurance, especially because many of their symptoms were not widely recognized by the medical community. Members of the group, who had prior experience working in the health insurance industry, often helped others find the appropriate insurance codes to avoid billing errors and claim rejections. Some other participants, who did not have any health insurance plans, mentioned that the group helped them find various local support groups and voluntary services where they could receive medical care for free.

Last but not least, the group provided unconditional emotional support to its members. As one of the moderators mentioned in her interview:

When any long-hauler patient said she had no idea what was going on with her and she was scared, we (the group) said, come on in. You are not alone — that is the best thing we can say. Even if you do not get medical answers, you get support from others who can identify with you what you are feeling and how you are progressing or not through your illness. We are here to help each other out. That is how we, as a group, began to feel purposeful. (P8)

All participants in our interviews unequivocally admitted that the group helped them emotionally when nobody else listened to them. Fourteen participants described that they either experienced gaslighting from their doctors or their doctors completely ignored their complaints and asked them to take medication for depression and anxiety. For other participants, although their doctors wanted to help them with their symptoms, they did not know how. Thus, it has been a long journey of sufferings with much uncertainty for all of our participants. The group stayed with them through all ups and downs. The group members listened, prayed for each other, and above all, did not judge any circumstances. They helped each other to abate the feelings of loneliness and despair. Some participants explained how they went into depression when they had a highly active lifestyle before the infection, and the long-hauler condition made it impossible for them to go back to their profession. The group members gave them strength at those low points. As P19 mentioned, reading others' posts who also experienced depression for similar reasons helped her realize that it was okay to reach that edge. She should not just go for it. Other group members also helped her to calm down eventually.

5.3 Sense of Safety and Trust

One major topic that all of our participants mentioned was the sense of safety they experienced by being a member of this group. This is a private group. Members had to get approved by the moderators to join the group or receive an invitation from another member. This private setting provided a feeling of safety and comfort to all the members, which they did not experience in other public social media groups. Several participants said they were not confident sharing their health conditions on social media. Some of them felt sheepish to complain about their symptoms so broadly. They became self-conscious and never posted their conditions on their own Facebook page. Other members feared receiving hate messages and threats from their local communities, who often did not believe that COVID was real. As P11 mentioned:

I know many nurses and doctors who work at the hospital in ICU wards, and their experience has been absolutely insane here in Southern Oregon. There has been one nurse who has been bitten after she told a man that he had COVID and was getting him wheeled into the ICU ward. The man looked at her, called her filthy names, and said I do not have COVID. You are a lying sack of shit, and they beat her. That is the norm here, not the exception. (P11)

All these participants found this private Facebook group a safe place to share their concerns. The admin and moderators of the group always restricted all types of political and religious discussions. Some conservative (in the context of US politics) participants found this policy extremely helpful for sharing their thoughts without fear. They experienced constant resistance and hostility from their friends, family members, and local communities. It was almost impossible for them to talk about their long-hauler conditions in public. This Facebook group gave them that freedom and a sense of relief. The group members never judged them by their political or religious identity; instead, they treated them as someone who needed help and support.

Some other participants mentioned that although they usually care about their personal and financial security when they consider sharing something on social media, their benefits from communicating and interacting with this group were much more significant than any other concerns. They mentioned that if new members could find their symptoms less overwhelming by reading their discussions, they would consider it worth sharing irrespective of security concerns.

In the context of trust and safety, all of our participants mentioned the effort that the admin and moderators of the group took to keep this group a safe and trustworthy place for their members. Some of our participants mentioned that they had never seen any propaganda or misinformation in this group. One participant said she had seen only a few posts on controversial topics, such as using Ivermectin in treating COVID 19 in the group. However, the moderators immediately addressed those posts and permanently removed them from the group's page. Another participant remembered seeing posts discussing the risks of getting vaccinated before the vaccine became available in the USA. During our interview, the group admin mentioned that anybody, who tried to spread confusion on vaccination, received a warning immediately after their first attempt. If they continued to share such information, they were suspended or banned entirely from the group based on their prior record. A similar approach was taken against those members who tried to offer medical advice in the group. As the admin mentioned:

This group was never made to provide medical advice. We cannot do that. Organizations that do that lose their licenses. We are a support group. That is what we do: support our members when they need us the most. (P22)

Some of our participants mentioned a dual strategy they followed when receiving new information from this group. They relied on their instinct when they received suggestions for home remedies and herbal products. However, when they learned about some new medicine or treatments from this group's discussions, they consulted their doctors before taking action. P21 explained this dual strategy during her interview:

Home remedies are simple tips. Some mentioned drinking more water to get relief from lung burning symptoms. Another person suggested drinking herbal teas for GI symptoms. These are simple suggestions. These suggestions are, anyway, not harmful. So I never felt the need to verify them before trying. (P21)

However, not all of our participants believed in this strategy. Some of them mentioned that they never accepted any information directly from the discussion in the group; instead, they considered the group another source of valuable information. They verified all information from reliable sources before believing in anything. For instance, P9 considered Mayo Clinic, CDC, Johns Hopkins

hospital, and WebMD as her reliable sources to verify any information. P12 discussed observing the source of information to verify its authenticity. She mentioned that when one article or report was published by a reputed research university or scientific organization, she considered it authentic, otherwise not.

A few participants mentioned that just by reading an article or post, they could tell whether that is authentic or not. As P12 described, growing up in an evangelical cult made her aware of the languages cults often use to convince people of their propaganda. For instance, authentic articles would talk about alleviating the severity of a symptom, whereas dishonest ones will share ideas on how to cure those symptoms permanently. However, not everyone could adopt this strategy for consuming new information from this group. Two participants mentioned that they did not take immediate action on any information shared on the group's page; instead, they waited and stayed watchful. They believed that fake misinformation would not last in the group for a long time. When the information was genuine, it was posted multiple times, and many other members would comment in support of the original content. That is how they would know that the content was real, not fake. Overall, our interviews identified a wide range of strategies that the group members adopted to verify the authenticity of information produced by the group. Despite that, they all agreed that this group (moderators and admin) made an extensive effort to maintain a safe and judgment-free environment for long-hauler patients, which was critical for them to feel safe in this group.

5.4 Opportunities for Expansion

While our participants described how the Facebook group supported them, they mentioned several areas where they would like to see more initiatives and improvements. This discussion included factors related to the infrastructure provided by the group. In this discussion, participants paid equal attention to facilities and initiatives that need to be added by respective authorities both locally and countrywide.

The primary concern regarding the infrastructure of the Facebook group was the ability to find a relevant discussion from the list of all discussions shared in this group. A number of our participants described this need based on their own experiences. At different times, when our participants wanted to find an old conversation from the group's page, they either could not find it at all, or it took them a long time to find that specific conversation. Sometimes, participants wanted to find an old conversation to clarify their doubts; other times, they wanted to forward that conversation to their friends and family members. Thus they faced this challenge frequently.

The current infrastructure of the group could not solve this issue. The admin of the group mentioned that they once tried to tag each conversation with a name of a symptom, but they could not continue that initiative consistently. Many participants mentioned the need to organize these discussions more coherently and make it easier for the members to find as required. P13 said that such an organization would also make finding a specific discussion less emotionally demanding. Reading a long list of discussions to find a specific one can take a toll on the mind since many of these discussions explained the real hardships and challenges of the group members. An intuitive and user-friendly search engine for this task would be beneficial for many group members.

Most of our participants suggested creating a search engine for the group that would allow them to find old discussions based on a specific symptom. One participant added that the organization would be more efficient if we could add the context of the member who originally posted that discussion on the group's page. For instance, P6 read many discussions on the group's page where someone explained how their long-COVID symptoms disappeared after getting vaccinated. P6 found these posts highly promising and learned more about these members' experiences. Her condition did not improve after getting vaccinated; some of her symptoms worsened. She was

curious to know more about those members who recovered after vaccination. She later realized that all of those members experienced long-hauler symptoms for at most six months. None of them experienced them for more than a year, whereas she was experiencing them for more than 18 months then. She mentioned that if she could read not only those posts but also read the status of the member who posted them, it would not raise false hope for her in the first place.

While discussing various features of the group, some participants mentioned how the discussions in the group mostly provided a small snippet of someone's story, not their full story. The group primarily exposes the hardships and sufferings of its members. It often takes a toll on people who follow this group every day. As P4 mentioned:

(...) This group has useful information and feedback, but it is also emotionally overwhelming because people will share suicidal thoughts and hopelessness. I mean, on the one hand, the group is supportive, but on the other hand, it is kind of bombarded with so many people in a dark place. People have killed themselves, people are hopeless, and they are losing family members and things like that. I do not think I can handle more than one group like this, to be honest. (P4)

However, some participants mentioned that it should not always be sad and hopeless. They knew a few people who have recovered substantially over time. They wanted to know the stories of those members as well. The Facebook group does not show the entire journey and ultimately how, if at all, they have recovered. The group's page is excellent for receiving immediate feedback on an urgent crisis. However, it does not show light at the end of the tunnel. Our participants described how those stories of recovery would have given strength to others. They suggested that a section hosting such recovery stories would be a great approach to address this concern. P10 also added that some members, who have recovered to a great extent, often do not feel comfortable sharing that news in the group since almost everybody in the group is sharing incidents of their hardships. A separate section would help them get out of that discomfort and be more willing to share their recovery journey.

In our interviews, participants identified several areas where they would like to see more local and countrywide initiatives to support the long-hauler community. One such topic is the lack of post-COVID clinics for long-hauler patients. All of our participants, who live in rural communities, mentioned not being able to access any post-COVID clinics. They had to access local health care facilities for their symptoms and hence, needed to interact with doctors who were not yet fully aware of the long-COVID condition. Our participants remembered several incidents of gaslighting and ignorance during those visits. Participants from major big cities, who could physically access post-COVID clinics, were not always accepted in those clinics either because of their restrictive criteria for accepting new patients. P8 mentioned maximum acceptance of patients with pulmonary issues and breathing concerns; not easy to get accepted for neurological complaints.

Finally, most of our participants discussed the need for financial assistance for long-hauler patients. The lingering symptoms of long-COVID forced some of our participants to quit their existing professions. Others had to take a long break before considering going back to their profession. For a few participants, the severity of symptoms became extremely high every three to four months. Thus, they faced a hard time continuing with the regular schedule of their profession. All these participants expressed the need for extensive financial support for the long-hauler community. They described the long delay someone would experience if they apply for disability benefits in the USA. More initiatives are required at the state and federal levels to address these concerns sincerely. In the same context, many participants also discussed the need for medical insurance for long-hauler patients. Our participant highlighted several incidents where long-hauler patients lost their health insurance because of their financial crisis. A few members talked about rural areas

where not having a health insurance plan is not uncommon in the community. Continuing the treatment plans for long-COVID symptoms has become a constant challenge for all these people. Our participants hoped to see more government and private sector efforts to deal with this sensitive issue.

In summary, the interview study allowed us to know the challenges, struggles, and motivations of group members. Several participants in our interviews mentioned that they never posted in the group but closely followed it. The interviews allowed us to know their perspectives. It also reflected on those topics that the group's current structure could not satisfy. Overall, these interviews filled the gaps in our understanding that the social media discourse analysis could not fulfill.

6 DISCUSSION

6.1 Private Groups on Online Platforms

Groups on social media platforms allow their members to share ideas, thoughts, opinions, and challenges with same-minded people. Researchers have shown how social media groups motivated their members to share knowledge on common-interest topics where organizational knowledge-sharing infrastructure is hard to achieve [63, 65]. However, exploring *private* social media groups is still in its early stage. Prior work found that while public groups helped people to maintain weak connections with a large group of contacts, private groups provided the “strongest form of support” [54].

In our interview study, we found most of the members (21 out of 23) preferred private over public groups to share their symptoms. One primary reason for avoiding public groups was the fear of judgment. People suffering from more common chronic diseases such as type 2 diabetes often do not hesitate to share their symptoms in public groups [63]. Yet, our participants mentioned several incidents where they experienced a sense of distrust and humiliation in public groups. For instance, members of public COVID groups frequently discussed the connection between being overweight and experiencing long-COVID symptoms. Such discussions without any medical proof severely damaged the self-esteem of our participants. They started avoiding the public COVID groups on Facebook and eventually found a private group they could be a part of without any judgment. These findings are consistent with previous work where researchers observed a private social media group for early career teachers and found that the majority of the group members considered it a place where members could trust each other at the highest level [54].

Before discussing the impact of building a trusting relationship in private online groups, it is critical to reflect on the word “trust”. Different researchers across disciplines defined the concept of “trust” in many ways [5, 9, 10, 29, 45, 55]. In general, trust is considered as the central element to interpersonal [31] and commercial [57] relationship. In our work, we focused on interpersonal trust among the members of the long-hauler group on social media. We observed two forms of interpersonal trust among the members: affective and cognitive. Affective trust is based on emotional ties between two parties in a relationship that results from the mutual exhibition of care and concern [25, 53]. We observed affective trust among the group members because of their shared experience of physiological and mental challenges throughout the pandemic. On the other hand, cognitive trust refers to an instrumental evaluation by the follower of the salient personal characteristics of the leader, such as their integrity, competence, reliability, and dependability [25, 70]. The members of the long-hauler community showed cognitive trust to the admin and moderators of the group, who tirelessly worked to keep the group free from bias, misinformation, personal judgments, and attacks. Overall, the sense of trust experienced by our interview participants was a combination of both affective and cognitive trust, which helped them feel a part of this community.

Our findings indicate that to build such a strong bond of trust in a community, minority communities on social media platforms might need a private setting. Experiencing social judgment in public settings is not new to minority communities. Private groups provide individuals the affordance to express their true selves without hesitation [67]. Such an environment is also critical for people with rare and stigmatized diseases. People with rare diseases or their caretakers often suffer loneliness, social isolation, and a sense of disconnection [75] as they do not feel confident to share their challenges with their extended families, co-workers, and other social media ties in a public setting [24]. Private groups (similar to COVID-19 Long-Haulers Discussion Group) on social media can provide emotional support and become a valuable resource for reaching available resources for them.

Apart from emotional support, these support groups can temporarily fulfill the gap of the healthcare providers, especially during crisis [68]. However, despite the perceived trustworthiness of these private groups, one critical aspect to remember is that the privacy and trustworthiness of these groups would remain valid until their members remain loyal to the community. When sharing sensitive health-related information, people might need to apply a certain level of self-censorship [24]. As some of our participants mentioned being aware of the risk of sharing sensitive information on social media, they still shared that information because the benefit was higher than the risk. On the other hand, some participants decided not to share a few details about their health condition because “there are a few things which are not meant to be shared... no matter what the benefit is”. These two contrasting attitudes show that at a time of urgency and global crisis, digital privacy literacy alone might not be able to predict people’s information-sharing behavior on online platforms. This finding is inconsistent with previous work [48] where researchers observed digital privacy literacy as a strong predictor in this context. Defining the fine line of self-censorship in different contexts can be a topic of future work which might have implications for the members of private social media groups.

6.2 Support Groups on Social Media

The role of support groups formed on social media platforms has become a significant topic of discussion within the CSCW community. For instance, social media support groups for mental health patients act as constantly available tools to provide information, advice, and support [64]. Mental health patients often use these platforms as a reliable medium for honest self-disclosure, which works like a therapeutic ingredient for them [39]. In addition to managing health conditions, support groups can provide critical assistance for identity management. Britton et al. [13] found that social media support groups for new mothers become a critical infrastructure for transitioning into motherhood, avoiding the burden of social norms and normative expectations. [13].

The participants of our interview study supported many of these findings from previous work and helped us learn some new knowledge particularly relevant in their context. For instance, the private group helped our participants ensure they were not mental health patients. Many participants in their interviews mentioned that this assurance helped them manage their physical condition better. They learned that other people in the group were also going through similar symptoms, yet they survived. This assurance helped them regain their self-confidence; thus, they found the motivation to look for possible treatments for their symptoms. This is consistent with new mothers as support groups made them realize that they were not alone who were feeling depressed and exhausted at times by the responsibilities as mothers. They understood that those feelings were normal. They could still thrive as mothers and in their careers. Finding such assurance is critical in many scenarios because these studies found that even close friends and family members cannot show such compassion in specific scenarios. Social media support groups can become a lifeline in these scenarios, even for those people who are not regular users of social media platforms.

In our interview study, participants further mentioned that after suffering from chronic symptoms for months, they felt guilt and shame to talk about their condition even with their close family members. It was sometimes because they had had that same conversation many times since their symptoms started, and they did not want to repeat that conversation anymore. For other participants, it was because they had an impression of being healthy to their family members and did not want to break that impression. However, sharing those same experiences with the members of their support group did not make them feel guilty. They could post several times daily whether some symptoms were improving or deteriorating. They would always find someone else in the group with the same experience. Finding at least one other person like them helped them overcome the guilt and elevated their sense of community. In their private support group, they did not fear creating a weak self-impression because the group members were not there to judge them. These observations are similar to traditional in-person support groups such as substance abuse support groups. The online setup allowed these groups to grow globally, introducing more diversity. Online support groups are making their members more open to accepting members from culturally different backgrounds yet letting them feel the companionship.

Lastly, the support group members shared critical information, such as locations of testing centers and dedicated clinics for long-COVID symptoms and announcements about new treatments related to frequent symptoms. Most importantly, the group members helped each other frame their queries to their doctors so they could receive necessary attention and treatments. This support was beneficial for those members whose doctors did not believe in their condition as a physiological condition and ignored their complaints for months. Instead of complaining about their symptoms, the group members learned about specific laboratory tests that they should get recommended by their doctors or specialists to reach out for further consultation. Many of our participants mentioned that this process of gathering knowledge as a group helped them break the deadlock that they had experienced for a long time before joining the group. The method of gathering knowledge as a group has been studied earlier in the workplace and was found to be effective for the team's performance [33]. Further investigation of gathering knowledge as a group in the social context might add more insight into the importance of online support groups.

6.3 Theoretical Implications

This study assesses the long-hauler community and their harrowing journey through difficulties via an inexpensive and unobtrusive data source, social media data. Our findings from the interview study explain the motivations of the members for joining the group and their expectations from the group in the long run. Long hauler patients received denials and ignorance throughout the pandemic. Only recently, initiatives have been taken to establish facilities specially equipped to assist conditions related to long-hauler patients. However, gathering information from existing long-hauler patients and taking action as per the requirements would most likely take substantial time and effort. Since social media data consists of long hauler patients' self-initiated and candid opinions and experiences, this data provides us with a rich and accessible lens to examine this community, their requirements, and their complaints. This approach has clear advantages beyond traditional mechanisms — such as surveying a large group of COVID-19 patients and closely monitoring their symptoms and lingering conditions. Our analysis of the social media discourse shows the opportunities to understand the breadth of mental, physiological, and socio-economic issues the long haulers' community face throughout this global pandemic through social media data. Accessing the symptoms of the COVID-19 long-hauler patients from a global population might be helpful for designing inclusive infrastructures for the treatment and rehabilitation of the long-hauler community.

During the pandemic, social media was frequently accused of spreading fake news, misinformation, and disinformation on mask usage, vaccination safety, COVID-19 prevention measures, and treatments. In recent work, Su et al. [81] found that social media news use was associated with firmer conspiracy beliefs. Individuals who trust social media news more are more likely to believe in conspiracy theories. Our findings present an opposite side of social media where a minority community (COVID-19 long-haulers) organically gathered together and found assurance, hope, and support from each other. This private Facebook group provided a trusted place where no one was dismissive of their conditions; instead, the community made them feel visible, understood, and believed.

6.4 Practical Implications

6.4.1 Contribution to Cooperative AI. Our findings contribute to the core concept of cooperative AI by showing how an AI-supported social platform like Facebook can provide a trusting place for enhancing collaboration between long-COVID patients during difficult times. Besides our current findings, our study discovered several areas where the platform lacks necessary features for facilitating human-human cooperation among the group members. We envision having more cooperative AI driven approaches on social platforms for engaging online groups. One such area that would be useful for the long-hauler community is the functionality of searching past conversations from the group's page regarding a specific symptom. Many participants explained not having any functionality for advanced semantic search queries on Facebook's private groups' pages. Including an AI-powered search feature for semantic search queries could be a useful addition for group members who often need to revisit such information for themselves and their friends and family members. Advanced search that can process online conversations and produce results by understanding the user's intent through the query's contextual meaning will provide more opportunities for group members to find critical information when needed. This feature could be a less stressful approach for long-hauler patients, especially when someone is not in the mindset to go through a bunch of emotionally draining posts and comments to find the intended information. Advanced AI-powered search engine can also be an excellent resource for systematically tracking the continuous change of symptoms of a diverse group of patients who are hard to access in any physical location.

Another concern was the task of finding peers in the group who had similar concerns or had experienced similar concerns in the past. One of the moderators and some earlier members of the group mentioned taking time every day to reply to as many posts as possible. They felt a form of responsibility to respond because they were in the group from the beginning, and they had seen conversations on most of the concerns that any member in the group might experience. They felt the obligation to promptly address all members' concerns because they did not want them going through the same anxiety that they experienced when no one was there to address them. Although their intention was noble, continuously monitoring the group's conversation was tiring, and this voluntary task took a lot of time and energy. One possible solution to his stressful task can be using an AI-based match-making tool that would recommend to users about potential peers who had gone through similar experiences in the past and would be willing to have a conversation. This functionality would release the mental pressure on moderators and senior members of the group to constantly monitor queries on the group page. They will get a notification from the AI engine if they are the best match for specific queries. This feature will not remove the existing rights of group members to participate freely in any post of their choice. Instead, this will ensure that no members' queries would go unnoticed even when moderators and senior members are not vigilantly monitoring.

Users sharing information on private social media groups expect their conversation to stay within the boundary of the group. This concern makes it harder for the admin and moderators of the group to organize information as they do not feel comfortable using external tools or platforms (such as Google Doc) to organize information. Introducing cooperative AI driven solutions within the platform would be the most desirable and convenient approach in this context. In the future, it would be interesting to examine the practical challenges of including these proposed solutions in existing social media platforms.

6.4.2 Monitoring the Existing Symptoms and their Continuous Changes over Time. The challenges and discrimination against minority groups such as COVID long haulers' community are often difficult to assess at a finer granularity. Although long hauler patients did not experience denials and negligence for a long time (as in other minority communities such as LGBTQIA community), many of them had to go through physiological and mental challenges that they had no prior experience with. They had no way to prepare for these challenges beforehand. Existing health care facilities often did not have the resources to assist long-hauler patients. Realizing these challenges, a Facebook group called "Survivor CORPS" has recently created a live guideline on establishing and operating a multi-disciplinary Post-COVID Care Center [22] based on published practices of established centers from around the world. Our findings can provide valuable insights for such organizations, allowing a richer and nuanced understanding of long-haulers' physiological and mental conditions.

6.4.3 Developing Infrastructure for Long-Hauler Rehabilitation. Moreover, the symptoms experienced by long hauler patients often continue for a few weeks to several months. Our results have shown that lingering symptoms not only impact the physiological and mental conditions of the patients but also affect their overall lifestyle. Individuals going through such conditions often become temporarily incapable of continuing their existing jobs. Members from the long-haulers' community also shared incidents where they had to quit their job because of some chronic condition such as ME/CFS (Myalgic encephalomyelitis/chronic fatigue syndrome), which can develop as an aftereffect of COVID-19 infection [37]. Since COVID long-hauler research is still very early, it is hard to predict how fast long-hauler patients would recover from this condition. In fact, the logic behind traditional physiological and cognitive therapy for ME/CFS has also received massive criticism. We believe our findings from posts not related to symptoms will provide initial insights for establishing rehabilitation facilities appropriate for long-hauler patients. Future work could adapt our approach to looking at more nuanced conceptualizations of long-term socio-economic challenges of long hauler patients that can be used to develop a concrete structure of rehabilitation program for them.

6.5 Policy and Social Implication

Pandemic generally occurs infrequently. The last major pandemic in the United States was H1N1 flu, commonly known as swine flu. It was detected in 2009, and 12,469 individuals died from the infection. In comparison to swine flu, we have seen 850 K deaths in the USA because of COVID-19, which is approximately 68 times higher than swine flu. Preparing for such a significant pandemic is always challenging but not entirely impossible. Some notable examples are Singapore, Japan, Hong Kong, Taiwan, and South Korea. These countries severely suffered from SARS-COV-2 in 2003 and swine flu in 2009. However, they applied lessons learned from those outbreaks to revise their public health systems so that they could handle COVID-19 much better than the United States, some European countries such as Italy, and India [78].

Some of these statistics mentioned above might sound demoralizing, but we can still learn from this pandemic. World Health Organization (WHO) has shown that infectious disease outbreaks are

emerging alarmingly regularly over the last 30 years [72] and we cannot deal with them just by luck. We need to significantly reorganize our public health care system in the USA to be better prepared for the next pandemic. Our findings reveal that medical gaslighting might not happen only to women, black people, and Latinos. Without careful monitoring and a well-structured public health care system, this kind of discrimination can happen to anybody. A pandemic similar to COVID-19 can worsen such a condition, especially when the health care system is not prepared in advance. We believe our work will provide data-driven insights for informed policy decisions and aid in building backup facilities even for people whose conditions are not initially well-defined by medical science. Layered, people-oriented, and citizen-science-based health care divisions might become a more effective solution in these scenarios. Our findings have shown that social media discourse can be an excellent resource for monitoring these issues closely. Early detection of such conditions might be more manageable through regular social media data monitoring where people from diverse communities are organically gathering together to share their experiences. To this end, we recognize that some of the alarms raised on social media can turn out to be false alarms, and prompt actions against those alarms can be wasteful. Therefore, we suggest carefully constructed layered infrastructure that can filter false alarms raised on social media (if any) and pursue further actions only on legitimate cases.

From a methodological perspective, we further recognize the ethical complexities associated with automatically monitoring people's social media data for making critical decisions in the public health care sector. The concern becomes stronger when discussing private social media groups whose content should not be accessible to non-members of the group. The factors that motivate users to express their opinion on social media and enable their candid self-disclosure may be confounded by their perceptions of being monitored. Moreover, people may have a reservation about who uses the results of such analysis — they may not be comfortable having government officials assess their social media data, as it can raise questions surrounding the privacy of social media data. If such a monitoring system is set without careful consideration of the privacy of social media data, users of such groups might get discouraged and uncomfortable sharing their personal, sensitive information in the group.

7 LIMITATIONS AND FUTURE DIRECTIONS

We acknowledge that our work has limitations, many of which suggest exciting directions for future research. We do not make any population-centric assessments because the Facebook group in our work cannot be considered for wholesome online discussions of the long-hauler community. Instead, our work should be seen as a proof-of-concept study to examine the long-hauler community on social media. Future work that makes population-centric assessments associated with long-hauler patients should consider the caveats concerning missingness and quality of social media datasets. It is also worth mentioning that the dataset that we considered for discourse analysis contained data for 100 days. Thus, our findings might not reflect all critical topics discussed in this long-hauler group from the inception of the group till now. Future work for building platforms and infrastructures might consider analyzing the entire dataset of social media discourse of the community for clarity and completeness.

Our work inherently suffers from self-selection biases. It only works in the language of the individuals who self-selected to express themselves in online communities, particularly those who did not feel shy to share their experiences on social media. Relatedly, we only study the language on social media. Incorporating other behavioral and communicative signals like frequency of posting, the topic of interest, and the support-seeking or support-giving nature of posting can help us comprehensively understand the long-hauler community on social media. Future work can further investigate this community across other mediums and social media platforms. In addition,

our interview study recruited only English-speaking users, and all but one participant were US citizens. Conducting a future interview study with the non-English-speaking population of this community might reveal new aspects of the community which we could not capture in our findings. Furthermore, the average age of our interview participants was 47.5 years. We had 16 out of 23 (70%) participants in the 40 - 64 age group. Although the medical community did not find the patient's age as a deciding factor for long-COVID symptoms, we acknowledge that our participant pool was not equally distributed among all age groups. A future study explicitly focusing on long-COVID patients in other age groups (16 and younger, 17 - 39, 65 and older) might uncover a more holistic picture of long-hauler patients.

8 CONCLUSION

This paper studied the long-hauler community from the discussion of their private social media group and an interview study. Adopting a combined qualitative and computational approach, this paper makes three primary contributions. First, we identified two main themes that broadly summarize all the discussion topics of the COVID-19 long-haulers' group on Facebook. Second, our interview revealed how a minority community could build a trusted environment on social media, especially during a global crisis when traditional resources are hard to reach. Finally, we discussed our contribution to cooperative AI literature and building infrastructures for the long-hauler community. We believe our work bears the potential to better understand the long-hauler community from an honest point of view, especially when the community was ignored initially by health care providers. Our work also supports tailored public health intervention and policy change to better address the requirements of minority groups during critical times such as a global pandemic.

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9 APPENDICES

9.1 Description of the topics identified through LDA and Qualitative Annotation

9.1.1 Discussion on Hair Loss Symptom. One common symptom discussed in this community is hair loss. Members often shared their experiences of massive hair loss as part of their long-hauler condition. In most cases, members explained how they were shocked when they had to go through a spell of massive hair loss. It affected them emotionally and made them depressed to see patches on their scalp. Some members found this incident so embarrassing that they decided to shave their heads completely. To absorb the initial shock, they often avoid going outside altogether. In response to these posts, many members shared their experiences of losing hair too and let the member (who posted initially about hair loss) know that "you are not alone". Some members felt relieved by sharing their hair loss experiences in the comment section because they initially did not dare to share their own stories with the group. In the comment section, some members assured others that most like their hair would come back in a few months as others discussed before that COVID hair

loss might be a temporary condition, not a permanent one. Among all these shocking experiences, a few members mentioned that their hair returned after a few months; however, some got a new hair type that they did not have before. In one post, someone mentioned that they were going through a transition phase to adjust their identity with their new hair type.

9.1.2 Discussion on Reappearing Symptoms. Members of the group anticipated two different reasons for their reappearing symptoms. In some posts, members mentioned that their symptoms reappeared for no known triggers after a few months. New COVID patients reported the most when they reported that after their infection, they recovered completely; however, all their symptoms came back after two to three months of their first infection. Some members took the COVID test with reappearing symptoms, but the result was negative. Members who consulted physicians with reappearing symptoms often found no solutions or treatments for their symptoms and asked for help and suggestions from the community.

Another set of discussions in this category mentioned the possibility of getting reinfected by COVID. Members complained about receiving false assurance from their doctors that they could not get reinfected by COVID. Some noted that their doctors even suggested they take no precautions (such as mask and social distancing), assuming they would have antibodies for COVID-19 and antibodies would protect them from reinfection. However, many comments in this category denied that assurance and claimed that antibodies might only remain active for around three months. They also suggested that others seriously follow the mandates of masks and social distancing as they anticipated that different variants of COVID might occur to the same patients; thus, reinfection would not be a hoax but a brutal reality.

9.1.3 Discussion on Loss of Smell and Taste. Losing the sense of taste and smell has been reported frequently by the members of this group. Some members mentioned phantom odors (such as a burnt cigarette or dog's urine). Members who got burning smells often described it as an exhausting experience. They kept looking for the source of the smell everywhere, only to realize that it was nothing but a phantom smell. Others described smelling all food and drinks as rotten.

Many members mentioned in the comments section about partially getting back their sense of taste and smell in three to six months. In one post, a member explained how it is common to lose the sense of taste and smell after a viral attack. She explained how this could happen due to the damage to the olfactory nerves. She also described that most people could regenerate olfactory nerves and regain their sense of smell over time. There were a few posts in this category where members expressed their fear that they would not notice a house fire on time because of their inability to smell anything. Some members mentioned that to avoid any accident due to this symptom, they installed a fire alarm system in their house or asked their neighbors to call the fire department immediately if they noticed something unusual.

9.1.4 Discussion on Irregular Heart Rate. One of the highly discussed topics in the group is heart issues. Members discussed heart-related problems such as irregular heart rates, heart palpitations, sudden chest pain, inability to walk or jog, and high blood pressure. Because of these symptoms, members of this group had to consult cardiologists, and they often shared their experiences visiting their cardiologists with the group. Members diagnosed with significant heart issues explained their difficulties due to their heart condition. However, many members expressed frustration and despair when regular tests such as Echocardiogram, Electrocardiogram, MRI, and Holter Monitor test could not explain their heart condition.

In one post, a member expressed a mixed feelings when her cardiologist could not find any reason for her heart palpitation. On one end, she was grateful that no significant damage was found in her heart. However, she also felt helpless because the doctor could not provide any solution to

her current heart issues. The doctor also suggested she exercise and lose weight condescendingly, which, ironically, she could not do in the first place because of her heart palpitation. Some members complained that their cardiologists often labeled the cause of certain heart conditions such as Tachycardia as anxiety and prescribed anxiety medication without further examining their heart for any internal damage or irregularity. Overall, posts and comments in this category expressed frustration and irritation for not being able to make appointments with cardiologists, for the lack of care, sincerity, and arrogance of cardiologists, and for their tendency to blame overweight patients for their weight without any empathy and respect.

9.1.5 Discussion on Brain Fog. Experiencing brain fog is another common symptom that the long-hauler community frequently discussed in the group. Many posts/comments in this category mentioned that they started experiencing brain fog symptoms two to three months after their initial infection, which considerably impacted their regular lifestyle. Some members had difficulties doing simple tasks like operating the TV remote, ordering food, or writing a weekly grocery list. Another common sign of the start of the brain fog was forgetting the spelling of familiar words or names, and many posts/comments shared these experiences with the group. Members described their frustration and helplessness to the group because of failing to complete simple tasks. A few posts also told how frightening this symptom could be by explaining how their brain fog almost resulted in a car accident. They cautioned other members with brain fog conditions to avoid interstate driving at least for some time.

One striking difference between posts/comments in this category and other categories was humor and fun. Members mentioned funny incidents related to their brain fog condition in some posts. For instance, incidents like how they tried to start their car with a mobile phone charger, how they ended up wearing three pants to their work, how they put their novel in the freezer and their glass of water in the pantry, and so on. Although we are uncertain, these posts might have eased off some of the tension and anxiety group members experienced throughout the pandemic.

9.1.6 Discussion on Pain. We found posts and comments on pain experienced by long-hauler patients in this category at various parts of their bodies. Some frequently mentioned topics in this category were muscle pain, back pain, chest pain, joint pain, and sharp stabbing pain all over the body. Members also posted videos of their thigh or calf muscles twitching continuously for hours. In the comments section, others suggested remedies to alleviate pain. For example, members mentioned various supplements such as zinc, potassium, magnesium, and B12. In other comments, members suggested trying essential oil, consulting a chiropractor, or therapy machines to get relief from pain symptoms. In some cases, members explained in their posts that they were not generally pain adverse before describing their current condition. One possibility for that explanation could be the stigma around chronic pain. They might have explained their general pain tolerance level to avoid getting judgmental comments in response to their posts. In this category, members also suggested other Facebook groups dedicated to pain symptoms, such as “COVID: Joint/Muscle Pain Long Hauler” to those unable to find any solution to their condition.

9.1.7 Seeking Suggestion on Vaccination. The dataset we analyzed covered a timeline when COVID vaccines were still unavailable until many members at least received their first dose of COVID vaccine, and a few received their second dose. Discussion in this category initially focused on whether it was safe to get vaccinated. Most of the posts discussed this topic from the perspective of the people who already had COVID. Members were concerned about getting the vaccine because vaccines were not tested on previous COVID patients before approval. In one post, someone also showed skepticism about dividing the vaccine into two doses claiming that pharmaceutical companies split the vaccine into two doses because of the scarcity of the raw material.

However, the discussion on vaccination skepticism slowly moved into the phase where we observed more posts on the after-effects of getting the vaccine. Many members shared their experiences (both good and bad) of getting the vaccine. People with serious side effects asked others to watch such critical side effects when considering getting their shots. Some members claimed that people who had COVID before would have more side effects from the first dose and fewer side effects from the second dose. Some other members described how their long-hauler symptoms partially alleviated after the vaccine. One notable factor in this category is that the number of comments posted by the group's admin and moderators was significantly higher than in any other category. In many comments, the admin asked members not to raise any controversy about the vaccine as the group was not created as an anti-vax community.

9.1.8 Asking for Prayers. Posts in this category asked for prayers from the community. Members often explained their own, another family member, or close friend's critical condition and asked for prayer from the group. Most comments in this category acknowledged the call and sent prayers in response. Some members suggested remedies for alleviating symptoms. For instance, when someone described getting lung cancer after a COVID infection, someone in the comment section suggested getting a second opinion since she had previously heard from another resource that COVID-related lung damage could be confused with cancer cells. Members often mentioned their friends and family members who had experienced similar conditions before but later recovered fully. These comments were intended to strengthen the post's writer during her difficult times. Members who lost their loved ones also asked for prayers from the group. They asked for strength and comfort from the group so their family could recover from the shock.

9.1.9 Sharing Recovery News and Thanking the Community. Although the number of posts sharing the recovery story was not as high as in other categories, we still found such posts in our dataset. In some posts, members mentioned that they recovered fully after a certain period. They thanked the group for being with them through their tough times and hoped others would find strength from their recovery stories. Not all posts in this category described their state as fully recovered. Some members also mentioned how they have partially recovered from their acute symptoms and hoped to fully recover in the near future. A few members also explained how they thought they had fully recovered in the past, but in a few weeks, all of their old symptoms returned with the same severity level. So they shared their second recovery story hoping their symptoms would not return. Member not only thanked the group when they fully recovered but also thanked the group for listening to them with empathy and for believing in their conditions. Members often expressed their suicidal thoughts in the group. The group always tried to extend help to those members by sending prayers, cards, or personal messages and calling them to check their status. The writer of such posts also returned to say thank you to the group. They described that the group helped them at a time when no one else believed in them.

9.1.10 Expressing Frustration and Embarrassment for Nightmares, Memory Loss, Experiencing Symptoms on Some Random Days. (This topic is unique to qualitative annotation)

Other than reporting physiological symptoms, some members of this group discussed having vividly realistic nightmares regularly (N=43, 8.22%). On some occasions, members of this group claimed that they had gotten over all other symptoms but had harrowing nightmares almost every night, making them even scared to go to sleep. Those nightmares were frequently about getting infected with the COVID-19 virus again. Many members felt embarrassed to share this condition with their primary care physicians, assuming they would make fun of them or would not take their condition seriously. Another primary reason for such an emotional outbreak was temporary memory loss (N = 106, 20.26%). Someone described that he forgot what he was talking about in the

middle of a phone call, and out of embarrassment, he had to hang up the phone with his best friend. Finally, many members of this group got frustrated since their symptoms returned on random days, and on other days, they were perfectly normal. Not anticipating how the next day or next week would look like made them frustrated and helpless. Overall, comments and posts in this category could not be marked as COVID long-hauler symptoms (at least those who described these experiences felt like that), but these experiences made them feel exhausted and drained regularly.

9.1.11 Experience Panic Attacks because of the Anticipation of Some Irreversible Damage. (This topic is unique to qualitative annotation)

Some group members did not talk about any specific lingering symptoms but shared their thoughts of experiencing panic attacks frequently. Some members believed that COVID-19 had changed their genetic structures irreversibly. For instance, one group member stated that even after fully recovering from COVID 10 months back, she could never be as active and energetic as she was before. She believed that COVID had affected her genes. Although she had no symptoms and tested negative, she felt that her quality of life had degraded significantly because of the infection. Other members (N=35, 6.69%) also suspected the change in genetic structure. They claimed that they had constant panic attacks, thinking they would be more likely to experience chronic illnesses such as diabetes, high blood pressure, and autoimmune diseases. A few community members (N=55, 10.51%) shared their experiences of seeing close family members going through extreme conditions because of COVID. They claimed that they had panic attacks, thinking that their family members were critically ill because of certain properties of their genes. If somehow they get infected by the COVID virus, their condition would be critical because they all have similar genetic structures.

9.1.12 Overwhelmed with the Financial Instability. (This topic is unique to qualitative annotation)

Concerns about financial instability were another topic discussed in this group frequently. Many group members (N = 150, 28.68%) reported being laid off from their jobs because of their lingering symptoms. Some of them (N=39, 7.45%) were tensed because they felt that their getting laid off would always be in their professional record, which could be considered a negative point when applying for new jobs. Some members (N=59, 11.28%) expressed their fear that they would not perform like they used to do before COVID because they could not recover as much as they expected. Long hauler patients were also deeply concerned that their employer would not believe in their lingering symptoms because they did not have any medical records to prove their symptoms were legit. Some members even mentioned that they hid their sufferings from everybody in their workplace as much as possible. This is because they were afraid that their employer and co-workers might think that their conditions were all psychosomatic symptoms, and that thought might impact their future promotions and salary raises in the company.

9.1.13 Seeking Suggestions. (This topic is unique to qualitative annotation)

Members of this social media group trusted each other, and thus, they asked for suggestions from the group members on various topics. LDA technique identified posts and comments where the group members sought suggestions on vaccination, its effectiveness, the risk factors, and so on. Although vaccination was one of the most popular topics for seeking tips, that was not the only topic people asked for suggestions from each other. Another popular topic was outreach programs for COVID-19 patients or especially for COVID-19 long-hauler patients. Other popular topics in this category were cures for unusual symptoms, various information related to health care facilities, accessibility of certain products which were hard to find during the initial stage of the pandemic, and reference for specialist doctors and support groups in their county.

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