Public Perspectives on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: A Twitter Thematic and Sentiment Analysis

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Abstract

Background: Myalgic encephalomyelitis (ME), also referred to as chronic fatigue syndrome (CFS), is a complex illness that typically presents with disabling fatigue, cognitive dysfunction, and functional impairment. The etiology and management of ME/CFS remain contentious and patients often describe their experiences through social media.

Objective: We explored public discourse on Twitter/X to understand the concerns and priorities of individuals living with ME/CFS.

Methods: We used the Twitter application programming interface to collect tweets related to ME/CFS posted between January 1st, 2010, and January 30th, 2024. Tweets were sorted into three chronological time periods (pre-COVID-19, post-COVID-19, and post-UK NICE Guidelines). A Robustly Optimized BERT Pretraining Approach language processing model was used to categorize the sentiment of tweets as positive, negative, or neutral.

We constructed word clouds for all tweets in the three pre-specified time periods and identified tweets that mentioned COVID, the UK NICE guidelines, and key themes that were prevalent among the word clouds (i.e., fibromyalgia, research, physicians). We sampled 1,000 random tweets from each theme, which were independently reviewed in duplicate to identify subthemes and representative quotes.

Results: We retrieved 905,718 tweets, of which 53% were neutral, 38% were negative, and 9% were positive. Word clouds highlighted patients' symptoms and shifted from fibromyalgia being mentioned pre-COVID to long COVID mentioned after the onset of the COVID-19 pandemic. Tweets mentioning fibromyalgia acknowledged the similarities with ME/CFS, stigmatization associated with both disorders, and lack of effective treatments. Physician-related tweets often described frustration with ME/CFS labelled as mental illness, dismissal of complaints by healthcare providers, and the need to seek out 'good doctors' who viewed ME/CFS as a physical disorder. Tweets on research typically praised studies of biomarkers and biomedical therapies, called for greater investment in biomedical research, and expressed frustration with studies that suggested a biopsychosocial etiology for ME/CFS or those supporting management with psychotherapy or graduated activity.

Tweets about the UK NICE guidelines expressed frustration with the 2007 version that recommended cognitive behavioral therapy (CBT) and graded exercise therapy (GET), and a prolonged campaign by advocacy organizations to influence subsequent versions. Tweets showed very high acceptance of the 2021 UK NICE guideline which was seen to validate ME/CFS as a biomedical disease and removed recommendations in favor of CBT and GET. Tweets about COVID-19 typically proposed overlaps between long COVID and ME/CFS, including claims of a common biological pathway, and advised there was no cure for either condition.

Conclusions: Our findings suggest that public discourse on Twitter regarding ME/CFS highlights stigmatization and dismissal by physicians; frustration with management approaches focused on activity and psychotherapy; a desire for research that validates a biomedical model of etiology and effective treatments for ME/CFS; and an overlap between fibromyalgia, long COVID, and ME/CFS.

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Abstract

Background: Myalgic encephalomyelitis (ME), also referred to as chronic fatigue syndrome (CFS), is a complex illness that typically presents with disabling fatigue, cognitive dysfunction, and functional impairment. The etiology and management of ME/CFS remain contentious and patients often describe their experiences through social media.

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We constructed word clouds for all tweets in the three pre-specified time periods and identified tweets that mentioned COVID, the UK NICE guidelines, and key themes that were prevalent among the word clouds (i.e., fibromyalgia, research, physicians). We sampled 1,000 random tweets from each theme, which were independently reviewed in duplicate to identify subthemes and representative quotes.

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Key words: Myalgic encephalomyelitis; chronic fatigue syndrome; Twitter; sentiment analysis; Long COVID

Introduction

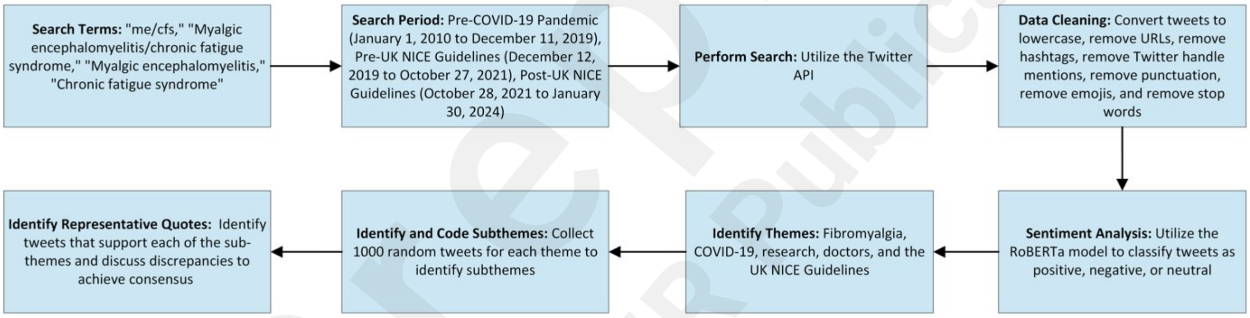
Myalgic encephalomyelitis (ME), also known as chronic fatigue syndrome (CFS), is an often debilitating multisystemic disorder [1]. Though it lacks a universally accepted definition, ME/CFS is often characterized by persistent fatigue, cognitive dysfunction, and impaired daily functioning [2]. The global prevalence of ME/CFS has been estimated at 0.89% (95%CI 0.6% to 1.33%) and is more common among women in their 40s and 50s [3]. Despite the prevalence and debilitating nature of ME/CFS, it remains poorly understood due to uncertain pathophysiology, nonspecific symptoms, and limited education and acceptance by the medical community [4].

Lived experiences are invaluable sources of information for guiding research [5]. People living with ME/CFS report higher levels of online activity compared with other patient groups [6, 7], and social media is highly valued among individuals with ME/CFS as a way to connect with other patients [8]. We examined the public discourse on Twitter (rebranded as “X” in July 2023) to understand the sentiments, concerns, and priorities of individuals living with ME/CFS and associated stakeholders.

Methods

We conducted a retrospective observational study of tweets. Our research approach consisted of seven steps: (1) developing Twitter search terms, (2) establishing a time period from which tweets would be collected, (3) utilizing the Twitter Application Programming Interface (API) to collect tweets within the defined search period, (4) processing tweets to enhance the accuracy of data analyses, (5) performing sentiment analysis using a Robustly Optimized BERT Pretraining Approach (RoBERTa), (6) identifying themes in the tweets through word frequency, and (7) collecting and further analyzing 1000 random tweets for each theme to identify sub-themes and representative quotes [9] (Figure 1).

Figure 1: Flowchart summarizing the methodology used to conduct sentiment analysis and identify representative themes.



Data Collection

The search terms used to collect tweets were "me/cfs”, "myalgic encephalomyelitis/chronic fatigue syndrome”, "myalgic encephalomyelitis”, and "chronic fatigue syndrome”. Exclusion criteria included non-English tweets and retweets.

The search period for tweet collection was January 1, 2010 to January 30, 2024. The full-archive search endpoint from the Twitter API allows users to retrieve publicly available tweets posted since March 2006 [10] which covered our timeframe. We were aware of two key events relevant to ME/CFS during our search period: the onset of the COVID-19 pandemic and subsequent recognition of long COVID (which has substantial overlap with ME/CFS) [11], and the release of the 2021 UK

National Institute for Health and Care Excellent (NICE) guidelines for the diagnosis and management of ME/CFS[12]. As such, we grouped retrieved tweets into three time periods for development of word clouds and sentiment analysis: (1) pre-COVID-19 pandemic (January 1, 2010 to December 11, 2019), (2) post-COVID-19 pandemic (December 12, 2019 to October 27, 2021), and (3) post-UK NICE guidelines (October 28, 2021 to January 30, 3024). December 11, 2019 was chosen as the "last day" of the pre-COVID-19 time period since the first report of the SARS-CoV-2 virus was on December 12, 2019 [13]. Likewise, October 28, 2021 was chosen as the "first day" to begin collecting tweets for the post-UK NICE guidelines dataset since the new guidelines were originally announced on that day, though they were officially published on October 29, 2021 [14].

Data Cleaning

Tweets were preprocessed to enhance the accuracy of the sentiment analysis. Modifications to tweets included conversion to lowercase form, removal of URLs, hashtags, Twitter handle mentions, punctuation, emojis, and common English stop words (e.g. don't, weren't, it, do). Stop words were removed using the Natural Language Toolkit (NTLK) [15].

Sentiment Analysis

We employed the natural language processing (NLP) capabilities of RoBERTa to conduct sentiment analysis of the cleaned tweets. RoBERTa, an iteration of BERT (Bidirectional Encoder Representations from Transformers) was selected over its predecessor due to its robust performance and notable effectiveness in understanding short-text formats, such as tweets RoBERTa was trained on approximately 58 million tweets and fine-tuned for sentiment analysis with the TweetEval benchmark [16]. RoBERTa generated probability scores for each tweet and categorized them into three distinct sentiment classes: negative, neutral, or positive.

Word Cloud Development

Following collection and cleaning of tweets, a word cloud was constructed for each of the three time periods using the *matplotlib* library in Python. Words that were included as search terms during data collection (i.e. “me/cfs”) were excluded from the word cloud. Words had to be mentioned at least 100 times to be represented in a word cloud, and the size of each word was proportionate to the number of mentions it received.

Identification of Tweet Themes

Based on key events during the search period, our research question, and the most frequent terms identified in the word clouds, we identified themes to explore in the retrieved tweets. For each theme, the corresponding tweets were each assigned a unique number and a random number generator (Excel Version 2406) was used to select a random sample of 1000 tweets. The original versions of the tweets were manually reviewed by two independent reviewers to identify sub-themes and representative tweets. The reviewers discussed naming and coding of subthemes that emerged to ensure consistent understanding; subthemes represented in fewer than 20 tweets were discarded. Reviewers discussed any discrepancies to achieve consensus

Ethical Considerations

This study ensured anonymity and confidentiality of Twitter users by removing the Twitter handles associated with all representative tweets reported. The requirement for ethics review was waived by the Hamilton Integrated Research Ethics Board at McMaster University since all tweets were publicly available.

Results

Characteristics of the Dataset

Twitter API retrieved 905,718 tweets relevant to ME/CFS during our search period. This included 570,136 tweets spanning from January 1, 2010 to December 11, 2019 (Pre-COVID group); 139,449 tweets spanning from December 12, 2019 to October 27, 2021 (Post-COVID group); and 196,133 tweets spanning from October 28, 2021 to January 30, 2024 (Post-UK NICE guidelines group).

Word Clouds

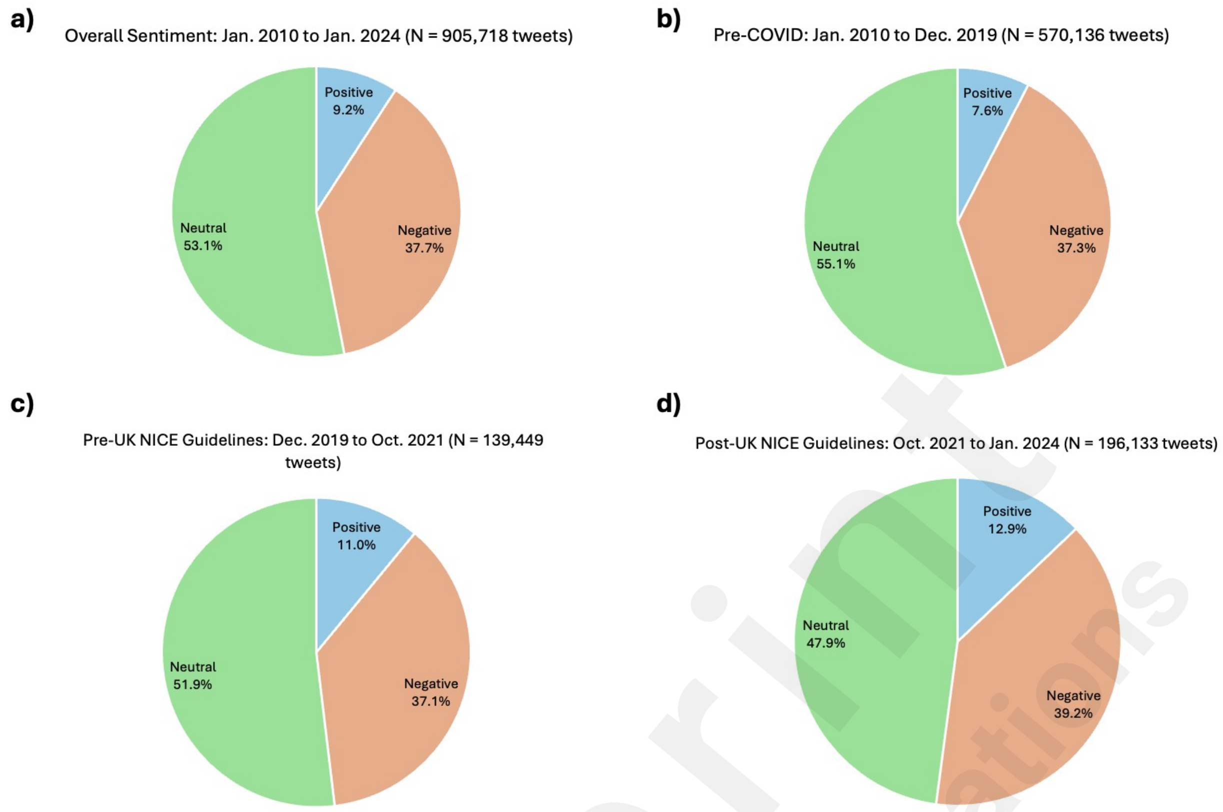
Word clouds for each time period consistently highlighted symptom-related terms (e.g., always tired, crash, pain), research, and doctors. The pre-COVID period found ‘fibromyalgia’ was a dominant term appearing in tweets, whereas from the COVID-19 pandemic onwards ‘long COVID’ was commonly mentioned. Word clouds from the post-COVID and post-UK NICE guideline were very similar, but the terms ‘PEM’ (referring to post exertional malaise) and ‘POTS’ (referring to postural orthostatic tachycardia syndrome) appeared only after publication of the guideline (Figures 2a-2c).

Figure 2. Word clouds depicting the top 100 most common words mentioned in ME/CFS tweets retrieved between (a) January 1, 2010 to December 11, 2019 (pre-COVID-19), (b) December 12, 2019 to October 27, 2021 (post-COVID-19), and (c) October 28, 2021 to January 30, 2024 (Post-UK NICE ME/CFS Guidelines).

Sentiment Analysis

Overall, tweets related to ME/CFS were predominantly neutral (53.1%, n=480,642) or negative (37.7%, n=341,336) in their sentiments, with only 9.2% (n=83,740) tweets classified as conveying positive sentiments. When considering the three time periods of interest, we found that the proportion of negative tweets remained largely the same (range of 37.1% to 39.2%), but the proportion of neutral tweets decreased over each period (from 55.1% to 47.9%) with corresponding increases in positive tweets from 7.6% pre-COVID, to 11.0% post-COVID, to 12.9% post-UK NICE guidelines (Figure 3).

Figure 3. a) Overall sentiment (January 1, 2010 to January 30, 2024), b) Pre-COVID-19 (January 1, 2010 to December 11, 2019), c) Post-COVID-19 (December 12, 2019 to October 27, 2021), and d) Post-UK NICE Guidelines (October 28, 2021 to January 30, 2024).



Twitter Thematic Analysis

Based on the research question and word clouds, the following five themes were identified: (1) fibromyalgia, (2) physicians, (3) ME/CFS research, (4) UK NICE guidelines for diagnosis and management of ME/CFS, and (5) long COVID. We retrieved 23,477 tweets that mentioned fibromyalgia; 16,112 tweets about physicians; 37,915 tweets about research; 2,234 tweets that discussed the UK NICE guidelines for diagnosis and management of ME/CFS; and 80,685 tweets pertaining to COVID. Notably, tweets could fit within multiple of these themes.

Theme 1: Fibromyalgia

Fibromyalgia was a dominant term in the pre-COVID word cloud, and our review of representative tweets identified six subthemes. The first two subthemes centered around patient’s frustration with the dismissal of ME/CFS and fibromyalgia as psychological or psychosomatic illnesses and disappointment with the care they received. Many tweets under these themes involved negative personal experiences with friends, family, or healthcare providers, including dismissal of ME/CFS and fibromyalgia-related symptoms.

> *"I can't even count how many conversations I overheard between my parents during the 90s about how chronic fatigue syndrome and fibromyalgia were fake diseases for depressed, lazy, overweight, listless women with no other conflicts in their lives."*

> *"Doctors are so afraid of patients who have symptoms of FMG (fibromyalgia) or CFS (chronic fatigue syndrome) because they have no clue what are causes or how to treat. I now believe years of shots may be part of the causes."*

> *"That's one thing I'm dealing with. One doctor said fibromyalgia. Another said fibromyalgia and chronic fatigue syndrome. Others look at me like I'm crazy. All I know is, I hurt all the time and I'm always tired. I'm just sick of them not listening."*

The third subtheme focused on the dissemination of research investigating ME/CFS and fibromyalgia. Some tweets simply shared links to research articles in the field of ME/CFS and fibromyalgia. Others lamented the lack of research towards ME/CFS and fibromyalgia.

> *"I think you are all on the back foot as researchers for long Covid as the similarities to the extremely underfunded chronic fatigue syndrome and related fibromyalgia conditions are completely inadequately diagnosed and treated. You have a long long way to go to understanding."*

The fourth subtheme specifically related to individuals sharing their personal experiences with ME/CFS and fibromyalgia, whereas the fifth subtheme highlighted online support groups or educational resources for individuals with these conditions.

> *"Jump ahead five years, I had lost over 50 pounds, was almost completely bedridden, and was too weak to sit up, talk, or feed myself. I was diagnosed with fibromyalgia and myalgic encephalomyelitis/chronic fatigue syndrome, two illnesses that we still know very little about."*

> *"I got ME/CFS in the '90s, and it turned into fibromyalgia in 2002. (Fibro is like ME/CFS with a lot more pain.) I stopped having severe pain that required opiates several years ago, but I'm still not healthy. I wouldn't wish it on my worst enemy."*

> *"Check out FibroFlutters - an informal 'patient-led' support group based in Sunderland for people with Fibromyalgia, ME/CFS, chronic illness."*

The sixth subtheme focused on recommended treatments for fibromyalgia and ME/CFS symptom management. Tweets would often reference news articles supporting the claims being discussed, with many recommending unconventional treatment modalities.

> *"Could Green Light Therapy Help Fibromyalgia and ME/CFS?"*

> *"A Methylene Blue Boost? Could a Blue Dye Help with ME/CFS, Long COVID and Fibromyalgia?"*

Theme 2: Physicians

Four subthemes were identified on the topic of ME/CFS and the role of doctors in diagnosis and treatment. The first subtheme was that most doctors are misinformed and/or do more harm than good. Many tweets expressed frustration with the fact that doctors typically lacked sufficient knowledge and experience to handle the complex, multifaceted symptomology associated with ME/CFS.

> *"It's because regular doctors have no clue what post viral fatigue or ME/CFS is. Exercise can be harmful even if organs are fine."*

> *"I just LOVE idiot doctors who think they know more about ME/CFS than I do. None of them understand PEM, and always think I'm exaggerating. I have 40 years of experience with this, and they're all morons.*"

The second, related, subtheme centered around physicians mislabeling ME/CFS as mental illness. Some tweets relayed experiences of doctors ascribing ME/CFS symptoms to major depressive disorder rather than acknowledging the existence of the illness. Other explanations offered by doctors included anxiety disorders or simply stating that the symptoms were psychological.

> *"I got ME/CFS after a seriously bad case of tonsillitis at 20. My doctors thought it was depression and increased my antidepressants. Surprise! That didn't help."*

> *"I've had ME/CFS for over twenty years. Doctors generally don't care to hear about illnesses they don't know how to treat. I've been told I'm perfectly fine, my illness is just in my head."*

> *"I have ME/CFS myself. This is a neurological disease. Since most doctors are not familiar with it, we sufferers are often labeled as mentally ill, although the symptoms are purely*

> *physical."*

The third subtheme was dismissal of patients' concerns by doctors. One commonly cited reason for this was because of the poorly understood pathophysiology of ME/CFS. Several Twitter users relayed experiences of not being believed by healthcare providers.

> *"Example number 579 why the Golden Girls were light years ahead of its time: the episode where Dorothy has Chronic Fatigue Syndrome. The dismissing of her legitimate medical complaints as simple aging or lack of social life by doctors who can't find an easy diagnosis is spot on!"*

> *"I developed ME/CFS 8 years ago. It has absolutely devastated my life & the real kicker is NO Duke doctors I've seen have a clue how to treat/support me or don't believe in it at all. Being disabled is extremely hard but to be gaslit & dismissed makes it so much worse."*

The fourth subtheme focused on the need for patient self-advocacy to find 'good' doctors or to receive appropriate treatment. Within this theme, some Twitter users advocated withholding their diagnosis of ME/CFS from their doctors to receive adequate care.

> *"Most doctors are not your friend if you have ME/CFS. Don't see them for that. See them for symptoms, never mention ME/CFS. They cannot help with that."*

> *"However, I'm super relieved (in disbelief) that after seeing a dozen+ doctors/specialists, I've found one who's actually assessing my ME/CFS and POTS! Like looking at my symptoms, considering possible diagnoses and causes, and starting me on an initial treatment - *jaw on*

> *the floor*."*

Theme 3: Research

Three subthemes were identified among tweets discussing research. The first centered around the dissemination of research, with Twitter users sharing links to articles or citing recent literature. Tweets typically focused on research supporting physical causes of ME/CFS, and medical treatments, with some suggesting evidence supporting a biomedical model of ME/CFS was vulnerable to suppression:

> *"New research linking chronic fatigue syndrome to retrovirus is released after being held by journal."*

The second theme focused on criticism of research, particularly studies that found support for management of ME/CFS with psychotherapy or graduated exercise. Further, some Twitter users speculated that some ME/CFS researchers were involved in manipulating research output.

> *"The #PACE study claimed that graded exercise training (GET) and cognitive behavioral therapy (CBT) were effective in treating Myalgic Encephalomyelitis. There were so many things wrong with this study that it's being used as an example of how NOT to do research."*

> *"That man I have permanently blocked. He claims to be an ME/CFS researcher. Almost all of them are corrupt and get paid to keep ME/CFS patients from finding out they likely are vaccine injured or sick as a result of a post-infectious gain of function virus."*

The third theme involved calls for increased funding for ME/CFS research. Some Twitter users compared the relatively small amounts of funding allocated to ME/CFS versus other conditions to underscore the need for increased funding.

> *“We need massive research programmes into both long Covid and ME/CFS, coupled with better information for doctors. But above all, we need something that currently seems a long way off. A government that gives a damn.”*

> *“ME/CFS research is severely underfunded. Current NIH Funding: ME/CFS has $13 million in active NIH awards. HIV/AIDS has $3294 million in active NIH awards.”*

Theme 4: UK NICE Guidelines for Diagnosis and Management of ME/CFS

We identified six subthemes that discussed different aspects of UK NICE guidelines for ME/CFS. The first theme focused on perceived problems with research used to inform the initial 2007 NICE guidelines. Much of this criticism focused on the PACE trial (Pacing, graded Activity, and Cognitive behaviour therapy; a randomised Evaluation), which randomised 641 patients diagnosed with ME/CFS to either pacing, CBT, GET, or specialist medical care, and found that CBT and GET were more effective than pacing or specialist medical care for reducing fatigue and improving physical functioning.[17]

“the PACE trial which has subsequently informed NICE guidelines on treatment for ME/CFS is a great example of completely ignoring the patient voice, as well as dubious research ethics (yet is still up on the Lancet).”

“The problem is the broad definition of ME/CFS in PACE. It makes results fairly meaningless. NICE guidelines are the problem. They treat PACE as more powerful evidence than it is. Let’s fight to

change NICE in light of new evidence. A warning for GET.”

The second theme focused on comments that changes to the UK NICE guideline were the result of prolonged efforts by the ME/CFS community. Specifically, how the guideline was changed to remove recommendations in favor of GET and CBT after pressure from patient advocacy groups.

> *“Many thanks to everyone who signed this petition below re removal of GET & CBT from NICE Guidelines. We’ve reached 10,000, let’s keep it going and get to 15,000.”*
>
> *“The updated NICE guidelines for ME/CFS are out. GET is gone (which is an absolute triumph) and CBT is now a coping strategy not a treatment. I'll take that as a win*.”
>
> *“We worked with ForwardME to ensure this guideline was led by #pwme*.”
>
> *“The new NICE guidelines on ME/CFS that recommend patients stay active within their safe limits was generally welcomed by patients and a petition in support of its publication received 23,000 signatures*.”

The third sub-theme was comprised of tweets advising that the 2021 UK NICE guidelines now recognized ME/CFS as a biological disease. There were several references to the 2007 NICE guideline that was perceived as supporting ME/CFS as a psychological condition, and that the 2021 update had reversed this position.

“ME/CFS is placed under the Neurological Conditions section on the NICE guideline.”

“The recent NICE guidelines have reversed previous statements about [ME/CFS] being psychological and now acknowledge that it is physiological.”

The fourth sub-theme focused on how the 2021 NICE guideline now recommended against GET and CBT as a management option for individuals with ME/CFS.

> *“Current NICE guidelines: The results show clearly that cognitive behavioural therapy and graded exercise therapy are unsuitable treatments or management approaches for ME/CFS.”*

> *“The 2021 NICE guidelines for #MECFS have a severity box that outlines the situation…"People with severe ME/CFS are unable to do any activity for themselves or can carry out minimal daily tasks only (such as face washing or cleaning teeth)."*

> *“The newly released NICE guidelines for ME/CFS is very firm about rejecting hysteria-based GET, CBT & The Lightening Process.”*

The fifth theme focused on the need to promote and defend the 2021 NICE ME/CFS guideline. Several comments acknowledged that there was competing evidence regarding the role of CBT and GET and advised that promotion of the 2021 NICE guideline was critical to ensure these interventions were not offered to patients.

> *“The people who built their careers on disabling, torturing ... even killing ME/CFS patients are extremely powerful in the UK and were not going to accept this [the new NICE guidelines] because they would have to admit their fraud. So they have decided to play dirty.”*

> *"I just bloody knew it. Medical professionals are going to ignore nice guidelines and rebrand GET, CBT, to try to continue pushing us down the wrong road. Be careful everyone with #ME/CFS. WATCH OUT for anything like, improving activities, gradual activity increase etc."*

> *"The @MEAssociation has been contacting NHS trusts that still recommend CBT and GET as treatments for #MECFS, in contradiction to the 2021 NICE guideline."*

The sixth subtheme included tweets advocating that the 2021 NICE ME/CFS guideline would also benefit individuals with long COVID. Specifically, many tweets discussed how the new guideline should be used to avoid CBT and GET for individuals with long COVID.

> *"Let's hope the recent NICE guidelines changes on ME/CFS protect those with Long Covid from going through the hell that people with ME/CFS have gone through in terms of gaslighting and medical abuse."*

> *"I am sure the CBT/GET services and researchers are worried about losing ME/CFS patients with the review of the NICE guidelines on ME/CFS. They will look to the #longcovid patients to mitigate the loss."*

Theme 5: Long COVID

The fifth theme that emerged was the association between ME/CFS and long COVID, within which six further subthemes were identified. The first subtheme focused on a common biological cause between long COVID and ME/CFS, although hypotheses were highly variable ranging from immunopathology, micro clots, brain stem malfunction, chronic inflammation, respiratory muscle dysfunction, and mitochondrial aberrations, among others. Relatedly, the second subtheme focused on the erroneous attribution of long COVID and ME/CFS symptoms to psychological causes.

> *"The inner lining of blood vessels (the endothelium) plays a crucial role in maintaining cardiovascular health. A recent study found that individuals with ME/CFS and those with long COVID had significantly impaired endothelial function."*

> *"QUACK psychiatrists who have been harming patients for decades. Stop this, just stop it. Haven't you harmed enough myalgic encephalomyelitis patients? Do you need to damage more people who have Long Covid with the same garbage psychobabble?"*

> *"In terms of Long Covid and ME/CFS, there's definitely a concerted effort on the part of some powerful people to deny, minimise and psychologise. Which allows people to believe that recovery is possible, if you have the right attitude."*

The third theme included tweets focused on the notion that if more research had been pursued for ME/CFS, we would now have effective treatments for long COVID. The fourth subtheme related to beliefs that the current attention given to long COVID would likely benefit patients with ME/CFS, given the substantial overlap between these conditions.

> *"If governments around the world had allocated more than a pittance to biomedical ME/CFS research over decades, the Long COVID fallout might not have been so severe."*

> *"There's a huge overlap between ME/CFS and Long COVID. If only people had cared*

> *decades ago to look into ME/CFS we might have had answers for Long COVID people.*"

> "*I hate to say it...but long covid is kind of a gift for us with me/cfs, because it has increased funding.*"

The fifth subtheme referred to warnings to avoid exercise and psychotherapy for the management of long COVID and ME/CFS. Several tweets relied on the 2021 NICE guidelines for support.

> *"Unless you have ME/CFS or Long Covid, in which case exercise can take you into total incapacity with severe intractable pain lasting for decades. Minimise exertion, rest, rest, rest."*

> "*Walking and running do not treat the underlying issue with ME/CFS or Long Covid. See NICE warning about graded exercise for LC patients and draft guidelines which say exercise should not be prescribed to ME/CFS sufferers.*"

The sixth subtheme was comprised of tweets that advised there was no cure for long COVID or ME/CFS.

> *"If what you have is Long Covid going on to ME/CFS, stay at home and rest, take care of yourself. There is no effective medical treatment, nothing that a doctor can give you that can make you better."*

> "*I've been existing with ME/CFS for the past 29 years. It's a post-viral disease I got from Epstein Barr Virus (Mono). It's a living death. I've now had Long COVID since March of*

2020. It's also a post-viral ME/CFS-like disease. There's no treatments nor cures.”

Discussion

We found Twitter to be an active forum for discussions regarding ME/CFS, with most tweets being either neutral or negative in their sentiments. Increases in positive tweets occurred after release of the 2021 NICE guidelines for the diagnosis and management of ME/CFS and after the onset of the COVID-19 pandemic. Tweets posted after the pandemic also showed a high frequency of mentioning long COVID. Our thematic analysis identified acknowledgement of considerable overlap in symptoms between fibromyalgia, ME/CFS and long COVID; frustration with dismissal by physicians and labelling of these conditions as psychological; and a desire for research that identified physical causes and biomedical treatments for ME/CFS. Further, there was considerable enthusiasm for the 2021 NICE guideline that reversed prior recommendations in favor of CBT and GET, claims that these changes were the result of patient advocacy efforts, and that both ME/CFS and long COVID were lifelong conditions without effective treatments or cures.

This is the first study to analyze public sentiment regarding ME/CFS on Twitter. People living with ME/CFS go online up to ten-fold more often than individuals living with other chronic conditions in order to connect with other patients and share experiences [18]. Prior studies have confirmed the overlap in symptoms between people living with fibromyalgia and those diagnosed with ME/CFS [19], with some investigators suggesting that labels assigned to patients may be largely an artefact of medical specialization [20].

Unfortunately, several studies have found that, due to a lack of objective diagnostic markers, people living with ME/CFS often perceive stigmatization and experience delegitimizing practices by physicians [21, 22]. These experiences may have clinical implications, as a recent systematic review found stigma is associated with increased pain intensity, disability, and depression among people living with chronic pain [23]. Conversely, physician empathy has been associated with improved outcomes [24, 25]. People living with ME/CFS typically report low satisfaction with physician encounters [25-27], often due to the perception that physicians are inadequately trained to manage their complaints and often attribute symptoms to psychological issues [28]. These experiences are consistent with studies of physicians reporting that one third to half of general practitioners do not accept ME/CFS as a genuine clinical entity and, among those who do, many lack confidence in diagnosis and management [29].

ME/CFS research is a contentious topic as, despite four decades of study since case definitions of ME and CFS were published in the mid-to-late 1980s [30], a biomedical cause or biomarkers of disease remain elusive. Prospective studies that control for ascertainment bias have failed to show an association between acute infection and development of ME/CFS [31]. Alternately, several studies have found associations between the onset of ME/CFS and elevated pre-morbid stress, psychopathology, severe life events or difficulties [32-34]. These findings should not be construed as evidence that symptoms associated with ME/CFS are not real, but as support that the central nervous' systems response to biological, psychological, and social factors may be more likely to explain symptoms versus a specific disease process [35]. Our findings, however, suggest this paradigm may be unacceptable to many people living with ME/CFS.

Similar issues appear to have complicated the acceptance of interventional studies and the development of clinical practice guidelines. The largest randomized controlled trial to explore management of ME/CFS is the PACE trial [17]; however, the finding that CBT and GET provided benefits for fatigue and physical function at both 1 and 2-year follow-up [36] is contentious for many patients and advocacy groups [37]. The ME Association recommended that NICE withdraw their recommendation for GET and that CBT should not be a primary intervention for ME/CFS, and a petition to retract the PACE trial received over 10,000 signatures from patients [38]. Our analysis of tweets also found several mentions of a prolonged campaign to pressure the UK NICE guideline authors to remove recommendations in favor of CBT and GET, which did occur in the 2nd version released in 2021.

The updated NICE guidance justified the recommendations against CBT and GET for four reasons. First, by downgrading the evidence for indirectness because trials that provided supporting evidence did not require patients to screen positive for post-exertional malaise (PEM), even though treatment effects were similar across patients with different diagnostic criteria (including those with PEM). This may also explain why PEM was introduced in our word clouds of tweets after the 2021 NICE guideline was published. Second, they rejected evidence from randomized trials that found GET was not harmful in favor of anecdotal reports by patients that GET worsened their symptoms. Third, they considered outcomes at the longest follow-up reported, which in the case of the PACE trial meant results were confounded by cross-over. Finally, the guideline panel rejected evidence from Cochrane reviews because they did not report on mortality – an outcome that review authors did not view as relevant for trials of CBT or GET [39].

Our analysis suggests the updated NICE guidelines were well-received by patients and could explain the increase in positive tweets at this time. However, four members of the 2021 NICE guideline development committee resigned in protest [40], representatives of seven UK medical groups (including the Royal College of Physicians) signed a joint statement relaying concerns with the guideline [41], and more than 50 international specialists analyzed the guidelines and concluded: “The consequences of this are that patients may be denied helpful treatments and therefore risk persistent ill health and disability” [42]. At present, there are at least two ongoing campaigns by ME/CFS advocacy groups to have other publications they disagree with retracted: A Cochrane review that found GET was helpful for ME/CFS [43], and a deep phenotyping study of ME/CFS patients that found limitations were due to "altered effort preference" [44].

Mention of long COVID in tweets made after the onset of the pandemic aligns with studies that have shown large overlap in symptoms between this condition and ME/CFS [11]. Interest by patients with ME/CFS may also be driven by the renewed attention to post-infectious fatigue syndromes that long COVID has generated and the resulting new investments in research. For example, the US National Institutes of Health (NIH) recently committed $1 billion to fund long

COVID research [45]. Patients with a diagnosis of long COVID face similar issues as ME/CFS patients. Female sex and psychological factors are risk factors for developing long COVID [46-48], infection with COVID-19 may not be required to manifest symptoms of long COVID [49], and CBT [50] and graduated exercise [51, 52] are emerging as promising therapies.

The notion that recovery from ME/CFS is not possible is inconsistent with the evidence. Whereas only 5% of patients experience full recovery without targeted intervention [53], there are entire organizations dedicated to recovered patients, such as Recovery Norge[54] Interviews with patients who have fully recovered from ME/CFS reveal a consistent pattern of engagement with graduated exercise and psychotherapy to increase self-agency [55, 56]. Further, recovery from ME/CFS is associated with not attributing illness to a physical cause and a greater sense of control over symptoms [53]. Patients who achieve recovery, however, report conflicts with patients who have not, and skepticism about whether they actually had ME/CFS. As a result, once patients recover from ME/CFS they are less likely to remain engaged with online support groups [57].

Strengths and Limitations

Strengths of our study include a large dataset of almost 1 million tweets. Additionally, we performed sentiment analysis with a RoBERTa model which has previously been trained on 58 million tweets. Finally, we ensured that representative subthemes were identified by independent raters, which increases confidence in the reliability of our findings.

Our study also had several limitations. The method of tweet collection relied on a list of search terms that may have missed some relevant tweets and NLP models can misinterpret the sentiment of tweets, particularly when sarcasm is employed [58]. As NLP methods evolve, it may become possible to harness the power of the Generative Pre-trained Transformer (GPT) models to facilitate more accurate sentiment, emotional, and thematic analyses. Additionally, discussions surrounding long COVID in the post-UK NICE dataset may have suffered from some confounding with the post-COVID dataset due to the overlap in dates, particularly since long COVID was identified relatively late into the pandemic.

Future Directions

Twitter appears to be an important source of information and communication for people living with ME/CFS. The degree to which advice is credible and consistent with current best evidence is therefore important. Our findings suggest that people living with ME/CFS that post on Twitter believe that GET is harmful, CBT is ineffective, and recovery is not possible. Efforts should be made to promote dissemination of evidence-based information on Twitter and assist patients in assessing the credibility of statements made on social media. Removing hope of improvement or recovery from ME/CFS can have dire consequences for some sufferers.[59-62]

A survey of members of the Canadian Association of Medical Assistance in Dying (MAID) Assessors and Providers found ME/CFS was the 2nd most common non-fatal condition for which MAID was requested. [63]

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Conflicts of Interest

The authors declare no conflict of interest.

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