**Living with Chronic Fatigue Syndrome during Lockdown and a Global Pandemic**

G. Brewer a\* and K. Stratton a

aDepartment of Psychology, University of Liverpool, Liverpool, United Kingdom

\*Corresponding author, Dr Gayle Brewer, Department of Psychology, University of Liverpool, Liverpool, United Kingdom, L69 7ZA, Gayle.Brewer@liverpool.ac.uk

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Objective: Chronic Fatigue Syndrome, a condition characterised by extreme fatigue that is not explained by other medical conditions, places individuals at greater risk of COVID-19. The condition is also associated with a lack of social support and social isolation. These individuals may, therefore, have a unique experience of lockdown and the pandemic. The present study investigates the experiences of those with Chronic Fatigue Syndrome during the COVID-19 pandemic. Design: In the present study, we identified fifty online forum (Reddit) posts, discussing the personal lived experience of Chronic Fatigue Syndrome during lockdown and the global pandemic. These posts were subject to inductive thematic analysis. Results: Four themes were extracted from the data. These were (i) Symptom Change, (ii) Social Interactions, (iii) Comparing Experiences, and (iv) Positive Consequences. Themes highlighted both positive and negative experiences of the COVID-19 pandemic. For example, whilst some people reported more severe symptoms, lockdown also provided more accessible opportunities to interact (i.e., online videocalls). Conclusion: Chronic Fatigue Syndrome influenced physical, psychological, and social pandemic experiences, with both positive and negative outcomes of the lockdown and pandemic apparent. Findings have the potential to support those with Chronic Fatigue Syndrome and those who experience post-COVID-19 fatigue.

Keywords: CFS/ME; Chronic Fatigue Syndrome; COVID-19; Online Forums; Pandemic

Word count: 5598

# Introduction

The impact of the COVID-19 pandemic extends far beyond those who have personally contracted the coronavirus. For example, people may experience the loss of loved ones, take on additional caring responsibilities, or be affected by the wider economic crisis that has followed. For those with health conditions that pre-date the pandemic, additional short and long-term concerns may also be apparent (e.g., increased susceptibility to COVID-19 and reduced access to medical care). The pandemic also has the potential to raise awareness of important issues, however, and improve provision for those who are disabled or socially isolated. In the present study, we investigate the lived experience of those with Chronic Fatigue Syndrome during the COVID-19 pandemic, a sector of the population who are at increased risk of COVID-19 and more likely to be socially isolated prior to lockdown.

Chronic Fatigue Syndrome (CFS) also known as Myalgic Encephalomyelitis (ME) is a chronic illness characterised by extreme fatigue that is not explained by other medical conditions or alleviated by rest or sleep. Other prominent symptoms include musculoskeletal pain, concentration and memory difficulties (often referred to as ‘brain fog’), exhaustion in response to minimal cognitive or physical effort, and headaches [1]. The initial cause of Chronic Fatigue Syndrome remains unclear and the focus of current medical intervention is on management of the condition rather than cure. Difficulties experienced by those with Chronic Fatigue Syndrome are exacerbated by social stigma and questions relating to the legitimacy of the condition [2,3]. In part this reflects the extent to which the condition has often been historically ignored, belittled, and misunderstood, for example, when labelled in the media as ‘yuppie flu’ [4,5].

Isolation in the form of lockdown and quarantine has formed an integral part of government responses to COVID-19 [6]. The mental and physical health consequences of social isolation and loneliness are well-established [7] and there are concerns that lockdown and quarantine will increase incidence of loneliness, stress, anxiety and depression [8]. Those experiencing longer periods of isolation or and those that are more fearful of infection are most likely to report negative psychological effects of lockdown and quarantine [9]. Of course, the extent to which individuals are socially connected (in normal circumstances) varies widely, with some groups relatively isolated prior to the pandemic. For example, those with Chronic Fatigue Syndrome are less likely to be employed outside the home or engage in regular physical and social activities than those without the condition. Therefore, social isolation and a sense of personal loss are more common in those with Chronic Fatigue Syndrome [10,11,12]. It is possible that those who already experience a degree of isolation are less impacted by COVID-19 related lockdowns or more prepared to cope with them.

The COVID-19 pandemic may reduce access to medical care for those with pre-existing conditions if resources are diverted to the testing and treatment of COVID-19 from other conditions, or if the treatment of coronavirus patients that do not have pre-existing conditions is prioritized. Indeed, recognising the potential for limited health care resources to be preferentially allocated to non-disabled patients, disability activists have sought to raise awareness of disability and the potential de-valuation of disabled lives [13,14,15]. The pandemic may also negatively impact health and wellbeing if people are unwilling to attend medical appointments due to fear of contamination [16,17]. Such concerns may be particularly prominent in those with Chronic Fatigue Syndrome, which is associated with increased health anxiety [18] and attentional bias toward health-threat information [19].

It has been suggested, however that, on a long-term basis, the COVID-19 pandemic may raise awareness of chronic health conditions and the ability to provide accommodations to support those with disabilities. For example, there may be a greater willingness to support flexible or home working and host events online [20,21]. In addition, those who recover from COVID-19 may experience a range of long-term symptoms, including fatigue [22]. As a consequence, the pandemic may increase attempts to support and accommodate those experiencing severe fatigue. The present study aimed to qualitatively understand the lived experiences of Chronic Fatigue Syndrome during the COVID-19 pandemic. Online discussion forums were utilised, which provide an opportunity to discuss sensitive subjects in a supportive and anonymous environment. These personal accounts highlight the issues of importance to those contributing to online discussions without prompting from researchers and have the potential to improve future provision. We consider,

RQ1) How has the pandemic impacted on the symptoms and health anxieties experienced by those with Chronic Fatigue Syndrome.

RQ2) To what extent has COVID-19 impacted on the social isolation or connectedness experienced by those with Chronic Fatigue Syndrome.

RQ3) Are experiences of lockdown and the global pandemic qualitatively different for those who do and do not have Chronic Fatigue Syndrome.

# Methods

## Selection of forum posts

The present study utilised Reddit, a popular online discussion forum platform. The platform contains over 10,000 user-generated online communities i.e., ‘subreddits’, united by common interests [23]. The anonymity and online nature of the forums supports contributions from those who are unable to meet face to face and encourages individuals to discuss sensitive issues that may be difficult to discuss more openly. Hence, Reddit provides users with an opportunity to share experiences and gain support for a range of health conditions, and especially those that are stigmatised or misunderstood. Online forum posts have been used to investigate a range of issues including chronic disease [24] and mental health [25,26]. Those with specific health conditions may use Reddit to obtain health related information or increase their understanding of the condition, e.g., interpretation of symptoms, diagnosis, and condition management [27]. Therefore, examination of these discussions provides a valuable understanding of the patient experience such as those issues impacting on wellbeing and quality of life or patient engagement with professional services.

We searched Reddit for relevant i.e., Chronic Fatigue Syndrome focused subreddits and within the subreddits searched for relevant posts using words such as ‘COVID, coronavirus, lockdown, and pandemic’. For inclusion, the posts had to discuss *personal* experiences of Chronic Fatigue Syndrome during the COVID-19 pandemic. Posts that talked about the experiences of someone else, gave advice or asked a question without sharing experiences, or did not mention COVID-19 were excluded. Data were collected during May and June 2020 and the first fifty Reddit posts (with unique usernames) meeting this inclusion criteria were analysed. None of the participants reported a personal diagnosis of COVID-19 and the search and extraction of all forum posts was conducted manually on Reddit.

## Data analysis

Both researchers independently analysed the datafile using inductive thematic analysis [28]. This analytical method has been applied to discussion forum posts [e.g., 29,30], and was deemed as the most appropriate for understanding personal stories within the context of the COVID-19 pandemic. We read the stories several times and established initial codes independent from each other. Codes were organised into broader themes in order to establish an initial thematic framework. The final themes were agreed after checking analytical interpretations for any discrepancies.

## Ethical issues

The research used publicly available information. Therefore, the study did not require review by the Institutional Review Board. However, we adopted additional steps in order to protect the anonymity of the Reddit users further. In this study the usernames are not revealed, any quotes used from the posts are slightly altered, and we are not reporting the names of the subreddits that we analysed.

# Results

We identified a number of themes relating to experiences of Chronic Fatigue Syndrome during the COVID-19 pandemic. Many forum posts also contained non-COVID-19 information (e.g., describing the onset or course of the condition); these themes are not reported here if they did not directly relate to the COVID-19 pandemic. The four themes extracted from the data were (i) Symptom Change, (ii) Social Interactions, (iii) Comparing Experiences, and (iv) Positive Consequences.

## Symptom Change

Forum posts often commented on the impact of COVID-19 on Chronic Fatigue Syndrome symptoms. For some participants, symptoms were significantly worse during the pandemic. For example, ‘Something about lockdown has caused a relapse after over a decade of remission’ (participant 41) and ‘Every day I wake up feeling like I've been hit by a bus. I've not had symptoms this bad for a couple of years’ (participant 21). This change in symptoms was often attributed to ‘becoming less conditioned to doing things’ (participant 12) or practical issues such as ‘no school, daycare… the ‘new normal’ has set off every flare’(participant 33). Participants also reported difficulty determining whether the exhaustion experienced was due to a standard symptom flare or sign of COVID-19 infection, which caused considerable anxiety.

As described by participant 27:

Whether it's the cold, flu, whatever, I always get really fatigued right after being exposed to someone and before any symptoms show up…the past couple of days have been some of the most extreme fatigue I've had in a long time. Because of where I live, there's a (very small) chance it could be COVID-19. I doubt it, but I can’t help worrying.

Other participants reported that their symptoms had improved during lockdown and this was generally attributed to fewer demands on their time and energy. As summarised by participant 7:

The CFS is significantly better since everyone went into lockdown. I think it is because having to go places was incredibly draining for me. Now I don't have to go out to eat, I don't have to visit anyone. I don't have to go to church, I don't even go to the grocery store. Even just driving was incredibly exhausting but now I don't have to drive anywhere.

## Social Interactions

Forum posts often discussed the impact of COVID-19 on social interactions. Specifically, participants with Chronic Fatigue Syndrome reported that the pandemic had provided opportunities to interact with loved ones online where face to face meetings would not be feasible. For example, ‘Everyone has downloaded zoom or houseparty. I'm having great catch ups with people I rarely get to see and it's awesome’ (participant 44) and ‘I’m in touch with so many friends and even family that I haven’t been able to talk to much because I can’t travel to see anyone anymore.’ (participant 19) As summarised by participant 16:

Lockdown now means comfy group chats on the sofa in my PJs. I miss seeing them in-person, but I'm interacting with them so much more frequently virtually and in a way that is so much less physically demanding. It feels like a win for me.

Participants benefited both from not engaging in face to face meetings and also because they no longer needed to feel anxious or guilty when turning down invitations or cancelling plans. As reported by one participant ‘The best part is I also don’t feel constant guilt and worthlessness because this lifestyle is “acceptable” and encouraged now’ (participant 8). However, some forum posts acknowledged that online interactions were also tiring. It is important to note that those with Chronic Fatigue Syndrome hoped that the use of video calls would continue but recognised that this change in interaction styles was likely to be temporary. For example:

I hope things will change after it is over, but I worry that those who are really stir crazy will be out the house even more after this, traveling and spending time with one another, while I stay in my little bubble at home. (participant 19)

Similarly, participant 44 commented:

I'm sure it won't last. Everyone is getting a taste of the isolation we experience every day but once it's over I doubt they'll keep up with the video calls. It's hard to realise that we don't need to be as socially isolated as we are.

## Comparing Experiences

A common discussion theme involved comparing the pandemic or lockdown experiences of those with and without Chronic Fatigue Syndrome. In particular, participants compared the temporary lockdown experience of the general population with the long-term isolation experienced by those with Chronic Fatigue Syndrome. For example, ‘People are worried that COVID-19 will cause them to be quarantined for two weeks. People with CFS are like, “two weeks?”’ (participant 28) and ‘I've just done 2 weeks without leaving my flat, I call this “the average February”’ (participant 29). As a consequence, those with Chronic Fatigue Syndrome recognized that ‘we have these learned skills healthy people do not have’. Participant 18 summarised:

When people were freaking out over getting food, I thought “But that's been my life for so long! I have to be prepared to stay at home for an indefinite period”. I'll admit that I felt a certain amount of schadenfreude at the people who were wailing about not being able to socialise, dance, go on exciting holidays, etc.

Participants also highlighted the COVID specific anxieties experienced by those with existing health conditions. For example, participant 3 stated ‘Dealing with COVID-19 is difficult for everyone. For those who are more at risk, it is harder and scarier…So many able-bodied people are unaware of the privilege they have and it has intensified during this ordeal’. Forum users reported ‘struggling not being able to go outside because people can’t be trusted to maintain social distance’ (participant 25). In one account, participant 25 described:

Lots of young people with no masks on, who walked right toward us as if there was no reason to keep distance. I really started to panic… I was so freaked out that I got angry and chastised them for not giving people space, they are young and healthy but not everyone is… It has really triggered some of my past struggles with being isolated, and frustration with the ignorance of others not being aware of invisible illnesses.

## Positive Consequences

Many participants discussed COVID-19 as a potential catalyst for long-term societal change and greater awareness and inclusion of disability. In part, this reflected greater interest in fatigue as a long-term outcome of COVID-19. For example, participant 40 commented:

The pandemic might be one of the best things to happen to CFS patients…suddenly journalists and doctors are paying attention to and taking CFS seriously because it is very similar to what people with COVID are describing. Politicians are now demanding that both conditions be studied. The National Institutes of Health have set up a study and will be able to observe patients very closely while they recover or develop CFS…It might allow them to figure out why some get CFS and don't recover.

Other participants recognised the long-term implications of COVID-19 for those with Chronic Fatigue Syndrome in another context. As described by participant 42, ‘For those of us well enough to be able to work a little, and lucky enough to have a job that can be done remotely, the pandemic has firmly established remote work as something that is here to stay.’

# Discussion

The present study investigated the lived experience of those with Chronic Fatigue Syndrome during COVID-19 using online forum posts. Four themes were extracted from the data. These were (i) Symptom Change, (ii) Social Interactions, (iii) Comparing Experiences, and (iv) Positive Consequences.

Forum posts often focused on the extent to which symptoms had changed during the pandemic. For some people, symptoms had worsened (i.e., a flare or relapse), whereas for other forum users, symptoms had improved. In part, this reflected the individual circumstances of each person. For example, while some forum users found it difficult to cope with additional childcare responsibilities others benefited from the move to home working. Regardless of individual circumstances, however, the stress, anxiety, and uncertainty associated with a global pandemic appeared to impact on those with Chronic Fatigue Syndrome. Previous research has documented the negative impact of stress on Chronic Fatigue Syndrome symptoms [31] and stress management interventions may reduce Chronic Fatigue Syndrome symptom severity [32]. It is important, therefore, that healthcare professionals support those with Chronic Fatigue Syndrome during global or national crises and recognise the issues that may impact on their illness experience. Of course, reflecting the stigma and contested nature of the Chronic Fatigue Syndrome diagnosis, many people favour personal responsibility and self-reliance rather than dependence on medical professionals [33], therefore self-help tools may be particularly benefitical.

Those with Chronic Fatigue Syndrome often experience social isolation and poor-quality social support [34]. It is important to address this issue as social support quality is associated with the maintenance of fatigue severity and functional impairment in those with Chronic Fatigue Syndrome [35]. In part, social isolation reflects difficulties attending social events in-person [36]. Therefore, online interaction (e.g., social media) may provide some opportunities for social interaction and support. In the present study, forum users reported that online platforms such as Zoom allowed them to meet loved ones in a more accessible format. This was not as demanding (with regard to physical and mental energy) as face to face meetings.

Previous research has explored the potential for technological innovation (e.g., the use of avatars in online platforms) to reduce social isolation in these populations [e.g., 37] though the specific approaches taken in these studies (i.e., moving around a virtual world) can lead to disorientation and nausea. Further research addressing the use of online platforms such as Zoom or Microsoft Teams to promote a more naturalistic interaction is required. Despite the clear benefits of online interaction, those with Chronic Fatigue Syndrome often expressed concern that the socialising would return to ‘normal’ after COVID-19, i.e., that those who were healthy would abandon online meetings in favour of face to face socialising. Therefore, the value of online interactions for those who are unable to meet face to face should be more widely discussed in order to encourage continued participation and reduce social isolation in vulnerable groups.

A common subject of discussion within the online forums was the different approach to lockdown (and the wider pandemic) taken by those with and without Chronic Fatigue Syndrome. In particular, those with Chronic Fatigue Syndrome often likened their own experience to a more permanent lockdown, where they were unable to leave the house or engage in the activities desired. Indeed, the reduction in activity is a core feature of Chronic Fatigue Syndrome and has a considerable impact on quality of life [38,39]. The general population, and indeed health professionals, may not fully understand the issues experienced by those with chronic illness, which may have wider ramifications for approaches taken to health and social care. Lockdown and the COVID-19 pandemic may have provided a shared experience and common language to facilitate discussion between those who do and do not experience chronic illness.

Those with Chronic Fatigue Syndrome report a desire to promote an understanding and acceptance of the condition amongst both general and professional audiences [40]. Further engagement with the Chronic Fatigue community and exploration of the issues raised in the present study may support the development and delivery of public health campaigns intended to promote empathy and understanding of Chronic Fatigue Syndrome. Additional interventions are especially required to highlight the impact of chronic illness on individuals and their families to promote compassion and support. Forum users also expressed concern that other people (particularly ‘young, healthy people’) were not taking appropriate precautions such as social distancing. This caused considerable anxiety and further limited activity outside the home. It is important that public health messages emphasise that measures such as social distancing and mask wearing are especially important for the protection of vulnerable people. Greater understanding of invisible illnesses (i.e., those that are not immediately apparent to others) would, in general, also be beneficial.

Forum posts often speculated that there may be long-term positive outcomes of COVID-19 for those with Chronic Fatigue Syndrome. For those requiring long-term post-COVID-19 recovery support, severe fatigue is expected to be a major issue, contributing to poor physical and mental wellbeing and this is consistent with historical epidemics [22,41]. The post-infection symptoms of viruses such as SARS, dengue, and Ebola (such as severe fatigue, pain, and sleep disturbance) have been likened to Chronic Fatigue Syndrome [42,43,44]. Indeed, studies investigating the long-term impact of SARS and the West Nile virus indicate that a significant number of patients qualified for a diagnosis of Chronic Fatigue Syndrome or Myalgic Encephalomyelitis [45,46]. Indeed, it has been argued that “Chronic Fatigue Syndrome (CFS) is a specific mechanism for explaining the symptoms of covid-19, which should be used as a basis for treatment strategies.” [47, p.4]. Forum posters were hopeful that increased medical interest in fatigue would prompt research in this area.

In response to COVID-19, a considerable proportion of the global workforce has moved to remote working [48]. Though research has begun to emerge evaluating the experience of those moving to remote work during the pandemic [e.g., 49] this does not differentiate between those who are or are not disabled and those who do or do not have a preference for regular routine working. In the present study those with Chronic Fatigue Syndrome discussed (pre-COVID) difficulty convincing employers to sanction home working and the hope that the use of remote working by such a large sector of the population would support future claims for remote working. Research indicates that control over working conditions is associated with lower levels of disability retirement [50]. Employers should, therefore, apply the experience of supporting remote working during COVID-19 to employees who wish to spend more time working from home to support disabled employees.

## Limitations and Future Research

In the present study, online forum posts were analysed. These posts were initiated by those experiencing Chronic Fatigue Syndrome and therefore were not prompted by the assumptions or priorities of the researcher. This approach was also preferable as it did not require those who already suffer from fatigue to engage in potentially tiring questionnaires or interviews. Future research may, however, conduct individual interviews or focus groups to further explore issues identified. In addition, the present study does not have demographic data (e.g., age, gender, marital status or living arrangements) for those posting in the online forums and it is not possible to determine the extent to which these participants are representative of the wider Chronic Fatigue community or are comparable to those using other online discussion forum platforms. However, the sample is unlikely to be diverse (e.g., all information was posted in English) and both Reddit users and those seeking health information online tend to be younger and more educated than the general population [51,52]. Hence, future studies should address this issue and, for example, compare the experiences of those who are able to work and those who are not or those who live alone and those with family or partners present in the home.

To conclude, the current study investigated the lived experience of those with Chronic Fatigue Syndrome during the COVID-19 pandemic. Online (Reddit) forum posts were analysed, revealing four themes. These were Symptom Change; Social Interactions; Comparing Experiences; and Positive Consequences. Findings demonstrate the impact of the COVID-19 pandemic and lockdown on the symptoms, health anxieties, and social isolation experienced by those with Chronic Fatigue Syndrome. Our research highlights both the positive and negative consequences of the pandemic and the diversity of COVID-19 experiences. This information should be used to enhance the support provided to those with Chronic Fatigue Syndrome. Findings may also have wider implications, for example to support those with post-COVID fatigue.

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