


ARTICLE

‘The world was going through what we go through everyday’: The experiences of women with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) living with their partners during the COVID-19 lockdown in the United Kingdom

Tarnjit Sehmbi¹  | Alison Wearden¹ | Sarah Peters¹ | Kimberly Dienes²

¹The University of Manchester, Manchester, UK

²Swansea University, Swansea, UK

Correspondence

Tarnjit Sehmbi, The University of Manchester,
Oxford Road, Manchester M13 9PL, UK.
Email: tarnjit.sehmbi@manchester.ac.uk

Abstract

Objectives: Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is a long-term debilitating illness characterised by profound and persistent fatigue (*JAMA: The Journal of the American Medical Association*, **313**, 2015, 1101). The current study aims to explore the experiences of women with ME/CFS living with their partners during the COVID-19 pandemic in the United Kingdom.

Design: The study adopted a qualitative design comprising semi-structured interviews with participants. Interviews were analysed using thematic analysis (TA).

Methods: Participants were women with ME/CFS ($n=21$) recruited through ME/CFS support groups in the United Kingdom. All participants were in romantic relationships and lived with their partners.

Results: Data were organised into three themes: (1) lockdown disrupting routine, (2) reducing difference and (3) fear of getting COVID-19. People with ME/CFS found that lockdown disrupted their well-established routines. Although routines were disrupted by partners and increased working-from-home practices, participants found having partners at home helpful. People with ME/CFS believed that the changes induced by the pandemic reduced the differences between themselves and the outside world which, prior to lockdown, had felt prominent. They were fearful of getting COVID-19 as they believed this would make their ME/CFS worse. This meant that for people with ME/

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CFS, the lifting of the lockdown restrictions was an anxiety-provoking time, hence impacting symptoms. People with ME/CFS continued to adhere to government guidelines after national restrictions were eased.

Conclusions: This study outlines the experiences of women with ME/CFS during COVID-19, alongside the long-term impact this has had due to the changes that the pandemic imposed. These findings may have implications for those with long COVID.

KEYWORDS

chronic fatigue syndrome, COVID-19, lockdown, myalgic encephalomyelitis, pandemic, relationships, significant others

INTRODUCTION

Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is a long-term debilitating illness characterised by profound and persistent fatigue, both mentally and physically, co-existing with a range of symptoms including headaches, sleep dysfunction, difficulties with concentration, sore throat, sore lymph nodes, post-exertional malaise and muscle pain (Clayton, 2015; Fukuda et al., 1994; Sweetman et al., 2019). The defining characteristic of ME/CFS has been reported as being debilitating fatigue (Fukuda et al., 1994), which commonly results in a reduction in functioning from a pre-illness state in the patient. These symptoms are likely to impact many aspects of an individual's life, with the fluctuating nature of symptoms making daily and social activities challenging. ME/CFS symptoms also impact other aspects of life, such as career, leisure, social pursuits and self-care (Bartlett et al., 2022).

Due to the number of changes ME/CFS presents to an individual's life, people with ME/CFS encounter several stressors daily, for example, adapting to a reduced social network and changes in the dynamics of family structure (Dewa & Lin, 2000; Dickson et al., 2007; Milrad et al., 2019). These stressors were prominent for people with ME/CFS prior to the COVID-19 pandemic. In March 2020, in response to the global coronavirus pandemic, the UK government imposed significant restrictions on the circumstances in which members of the public could leave their homes. These measures were imposed to reduce the transmission of the virus. Government restrictions meant individuals would only leave the house for limited purposes, such as shopping for basic necessities, daily exercise outside the home, any medical need and travelling to work (however, only when working from home was not possible). Failure to comply with these rules could lead to arrest or a fine. When individuals did leave their home, social distancing rules were put in place, which meant they had to stay 2m away from people who were not in their 'bubble', consisting of people living in their household. These social and physical restrictions were termed 'lockdown' by the British public. The societal changes as a result of the lockdowns have been significant, including increased working from home (Day, 2020; Ogden, 2020). Although ME/CFS was not listed on the shielding patient list (SPL) created by the NHS in the United Kingdom, the Chief Medical Officer (CMO) for England suggested that patients with health conditions not listed in the SPL may still be at risk of vulnerability to COVID-19 if they had a combination of other factors associated with becoming seriously unwell with the virus. Hence, people with ME/CFS are often shielded to protect themselves from COVID-19. Furthermore, as a result of their illness, people with ME/CFS had often already encountered changes which affected everyone when the COVID-19 pandemic hit and lockdown was imposed, such as reduced social networks and unemployment.

Since the COVID-19 pandemic, comparisons have been drawn between the symptoms of long COVID and ME/CFS, with many similarities being found across the two diagnoses (Jason et al., 2021; Wostyn, 2021). Carfi et al. (2020) were among the first to report on long COVID,

reporting that 87.4% of patients who had been hospitalised due to having COVID-19 reported having at least one persistent symptom at a mean of 60.3 days following symptom onset, highlighting the high prevalence of the condition among those with a diagnosis of COVID-19 (Carfi et al., 2020; Davis et al., 2023).

People with ME/CFS may spend an increased time with their significant others due to limitations placed on them due to their symptoms. Lockdown was a unique time in that both the person with ME/CFS and their partner were often confined within their homes together. As for the rest of the population, it is plausible that the experience of relationships was different throughout lockdown due to the social and physical restrictions in place. This study aims to explore the experiences of people with ME/CFS quarantining with their partners during the COVID-19 pandemic. In this study, the term 'lockdown' refers to the different lockdowns enforced in the United Kingdom from March 2020 to July 2021.

METHODS

Ethical approval

Ethical approval was granted by The University of Manchester Research Ethics Committee prior to recruitment (Ref: 2020-10343-17120). Participant consent was given prior to any participation in this study.

Design

This study adopted a qualitative phenomenological design. We used semi-structured interviews to collect data. Using individual semi-structured interviews allows participants to share their views and experiences confidentially which is important when discussing personal experiences such as romantic relationships, compared to other qualitative data collection techniques such as focus groups or dyadic interviews (Braun & Clarke, 2006). The flexibility, as well as the confidentiality of experiences provided through individual interviews, encourages elaborative responses shared in a safe environment. Additionally, research has shown that interviews commonly generate an in-depth understanding of the research topic due to participants providing 'information rich' data (Patton, 2002).

Participants: sampling and recruitment

A convenience sample of ME/CFS individuals was recruited through study adverts from ME/CFS support groups across the North of England. The study was advertised between December 2020 and December 2022, and 12 ME/CFS support groups were contacted via email. Seven support groups responded and agreed to advertise the study on their support group page. In ME/CFS support groups which agreed to allow us to recruit, the poster adverts were shared on social media platforms by support group administrators. Individuals who were interested in taking part emailed the researcher to express their interest. Interviews were arranged over email, and all took place on Zoom ($n = 21$).

The inclusion criteria for this study comprised of age (18 years or older), a self-confirmed diagnosis of ME/CFS and relationship status (individuals in a romantic relationship of at least 6 months at the time of participation). The duration of ME/CFS ranged from 1 to 27 years. A self-confirmed diagnosis of ME/CFS was required due to participant confidentiality with regard to accessing NHS records. Participants were also required to speak English and have the capacity to provide informed consent. The exclusion criteria consisted of individuals who could not speak English, did not have the capacity to provide informed consent and did not have ME/CFS. These exclusions were applied largely due to project aims and limitations such as access to funding and the duration of the project. Data collection

took place between December 2020 and January 2023, by which point data saturation had been reached (Braun & Clarke, 2006; Malterud et al., 2016).

Data collection

We recruited 21 female participants. Participants were predominantly White British ($n=18$; 86%) with a minority of British Asian – Indian participants ($n=3$; 14%). The mean age of participants was 40.9 years (range 19–74). Of the total sample ($n=21$), 14 participants were on leave/unemployed due to ill health caused by ME/CFS, 2 participants had retired and 5 participants were either employed part-time or in full-time study ($n=1$).

All participants elected to be interviewed via Zoom ($n=21$). The lead author conducted all interviews, and all of them were audio-recorded. Interviews lasted up to 1 h. The interviewer followed a topic guide which had been piloted and explored the intended aims of the study.

Audio-recorded, semi-structured interviews were conducted on Zoom with participants between December 2020 and January 2023. This large data collection window was due to the researcher accommodating participants' flexible interview re-arrangements when required due to symptom fluctuations. A pilot interview (excluded from the dataset) was conducted to allow appropriate modifications to be made to the content and language of the guide prior to data collection. The participant of the pilot interview was also an individual with lived experience of ME/CFS. The pilot interview led to the topic guide being adapted to ensure the interview would not surpass 1 hour. The final version of the interview guide explored respondents' experiences of stress, and the impact of the COVID-19 pandemic on romantic relationships. The interviewer used open-ended questions and a non-judgemental style (Young et al., 2018). This is especially important in the ME/CFS population as patients can often feel unheard (Dickson et al., 2007). Adaptations were made to ensure the interview was suitable for people with ME/CFS, for example, providing participants with interview questions prior to the interview if they wished to know what they would be asked, and being offered regular breaks during the interview. Upon completion of the interviews, a document signposting appropriate services in the North of England was emailed to all participants.

The audio recordings were transcribed verbatim by the interviewer. Transcription being carried out by the interviewer is beneficial, as the interviewer has first-hand knowledge from involvement in the interview process. This is advantageous for data analysis as it allows the researcher to be closer to the data (Halcomb & Davidson, 2006).

Data analysis

Interviews were analysed using thematic analysis (TA). TA is a qualitative approach to identifying patterns ('themes'). These themes, which are identified without a priori assumptions about the data, are analysed and interpreted within the context of the research (Braun & Clarke, 2006). TA was appropriate due to its flexible nature (Braun & Clarke, 2006). An essentialist approach was adopted in order to tell the 'story of the data' (Braun & Clarke, 2013). An inductive form of TA, which assumes no prior themes or framework of the data, was applied to ensure themes were 'data-driven' themes (Braun & Clarke, 2006). Codes were identified on a semantic level, therefore coding 'mirrored participants' language and concepts' (Braun & Clarke, 2013). The ontological stance taken was critical realism, which is consistent with an inductive TA approach (Braun & Clarke, 2006). Critical realism holds that knowledge or 'truth' can exist and be shared by individuals, however, each individual's experience of truth will be influenced by their own construction of that truth (Robson, 2002). This stance was deemed appropriate as participants' experiences and perceptions could only be accessed through their unique perceptions. The epistemological stance taken was 'contextualism'. This perspective does not assume a single reality; instead, it recognises that knowledge emerges from

contexts (Madill et al., 2000). The six-stage data collection and analysis process includes (1) familiarising self with data; (2) coding; (3) generating themes; (4) developing and reviewing themes; (5) naming themes; and (6) production of the report (Braun & Clarke, 2006). Braun and Clarke (2006) highlight the recursive nature of data analysis 'where you move back and forth as needed, throughout the phases' (p. 16) (Braun & Clarke, 2006).

Trustworthiness and rigour

To ensure trustworthiness, the second author (SP) and AW, both experienced with qualitative methods, familiarised themselves with and coded 10% of transcripts. This is seen as a valuable strategy to ensure rigour in thematic analysis (Barbour, 2002), and research has shown that peer examination of data increases the credibility and dependability of the research (Lincoln & Guba, 1985). The coders discussed any minor disagreements until a consensus was reached. A constant comparative approach was taken, as research team members were involved in the data collection and analysis phases and the analysis was conducted in parallel with the data collection. In this way, the researchers could cycle between analysis and data generation.

Reflexivity

Reflexivity refers to the process of acknowledging the researchers' subjective experiences and how this may influence the process of data collection and analysis (Mosselson, 2010; Peters, 2010). The lead author held insider status with some participants, as she identified as Punjabi Sikh female, as well as having been a university student. Insider status refers to the researcher sharing a common ethnic and cultural background with the participants (Merton, 1972). This meant the researcher had an in-depth understanding of the traditions and norms of Sikhs and, therefore was able to understand the topics discussed with the Sikh participants ($n=3$). Additionally, for participants who were attending university at the time of participation ($n=2$), the researcher had insight into the norms and regulations that came with attending university. Furthermore, 100% of the participants identified as female, and all the authors were also female. None of the authors had lived experience of ME/CFS, however, 2 of the co-authors of this study have worked with people with ME/CFS throughout their research careers for a combined total of 40 years. A pilot interview was also undertaken to allow appropriate modifications to be made to the content and language of the topic guide prior to data collection. The researcher acknowledges this shared background and experiences may have had an impact on interpretation of the data. This was balanced by having a transcript of a South Asian participant cross-coded by a co-author, a researcher who held outsider status (Merton, 1972).

Care was taken to minimise the extent to which the researcher's insider status impacted analysis and the process of coding and theme formation was data driven. Reflection was also used in the process of data generation and analysis. The researcher kept notes following each interview and regularly debriefed with co-authors. Engaging with the research team encourages reflexivity and enables transparency in the coding process (O'Connor & Joffe, 2020). This increases the trustworthiness of the analysis.

RESULTS

Data were organised into three themes: (1) lockdown disrupting routine, (2) reducing difference and (3) fear of getting COVID-19.

Theme 1: Lockdown disrupting routine

Most participants felt that before lockdown they had developed a routine that allowed them to preserve their energy and prevent symptoms from being exacerbated; 'I had built strategies that prevent me from crashing' [p19]. Strategies participants had developed were often complex and had been developed through years of trial and error. These strategies included resting at specific times throughout the day, which they perceived allowed them to have energy for activities that were important to them, for example, spending quality time with their partner once they had finished work:

I have a lay in and potter around slowly when he [partner] goes to work so I can sit up with him and chat about his day once he comes home

[p15]

Having partners around more throughout the day elicited mixed emotions among participants. Some participants were happy to have their partner around the house more, as partners commonly provided support with daily chores such as 'making a cup of tea' and 'taking the dog out'. Although participants were happy to have their partners around to help more and spend quality time together, they also recognised that this also impacted the time they would usually use to rest. This change in routine impacted participants' health management strategy of resting at specific hours of the day:

It was nice having him [partner] here so we'd have a cup of tea together or he'd wait for me to have his lunch but he wanted his cuppa at 11am and 11am is just not a functioning hour for me it's when I sleep the best

[p13]

Despite this, participants expressed that the discomfort caused by being unable to rest during the day was 'worth it' as it meant they got to spend more time with their partner, which is something they were not able to do pre-lockdown:

I wouldn't change it because I love him being at home and having him here so I'd rather maybe be a little bit ill but to have him here

[p1]

Some participants reflected on the positive benefits that spending more time with partners during lockdown had had on their relationship, and compared this with the quality of their relationship pre-lockdown when they did not spend as much time with their partner:

If I think back before lockdown we were spending less time together and during lockdown we were able to do some nice yet quiet things so I think it was actually good for us we talked more and it was nice so yeah it was good for our relationship

[p14]

However, participants recognised that although it was a positive experience having partners around more, in terms of their health, this disrupted their well-established routines which had been maintained in order to manage their symptoms. Participants were also conscious about what their partners may think of their daily routine:

From a health perspective I am actually better when I'm on my own in the house cos when I need to rest I don't have to consider anybody else whereas I'm aware when somebody's

in the house I'm thinking oh I better not stay in bed any longer cos they'll be wondering what I'm doing

[p4]

Furthermore, participants felt as though they were burdening their partner with their health care needs during lockdown when their partner also had to do their own work. This feeling of burden impacted participants as it meant they were selective about the information they shared with their partners about their day in an attempt to minimise any additional burden for the partner:

He was at home all the time and I felt bad I don't ever like putting more burden on him cos I think he carries enough burden [...] I just say I'm okay

[p18]

Participants were glad to be able to resume the pre-lockdown routine that had worked well for them once their partners had returned to work. They reported feeling better for this: 'so my equilibrium is actually better now I'm used to him not being here I'm back into my pattern of how I kind of pace my day as it were' [p10]. However, some participants also spoke about the struggle with change when partners eventually went back to work post-lockdown, as they had made a lot of accommodations for their partners being at home which had resulted in a 'new routine':

I missed him the first couple of weeks when he went back to work I really was struggling because I'd gone from having him there all the time so when I did want to chat to somebody there was always somebody there

[p2].

Hence, it may have been further disruptive to return to their original routine. Despite this, majority of the participants reported resorting back to their pre-lockdown routine, as these were routines that had been acquired to manage symptoms over a long period of time.

Theme 2: Reducing difference

Participants explained that the COVID-19 lockdowns were similar to the restrictions that they lived their lives by because of their illness: 'you couldn't see anyone or do anything social and I do that everyday' [p7]. Due to the lockdown, activities which were 'normal' for people with ME/CFS and their partners were now considered normal for the rest of the world. They perceived that the gap between people with ME/CFS and the public became smaller: 'The difference between me and the world wasn't big at all [...] it was good' [p21].

Participants regularly spoke about the difficulties they had faced pre-pandemic due to the restrictions their illness had placed on them, such as being left out of social events and feeling as though they were missing out: 'my husband would get invited to events by our mutual friends and they just stopped asking me it was really frustrating' [p12]. During the pandemic, the restrictions meant participants were no longer 'missing out' on social events and participants felt as though the world slowed down to a suitable pace for them:

It was welcome to my world [...] people who were physically able would find it far more restricting and boring than I did because I haven't got the energy to do it so everything slowed down

[p9]

Participants engaged in activities which adhered to the COVID-19 restrictions throughout the pandemic. Examples were given of activities being undertaken at home or virtually:

Me and [partner] we used to do weekly date nights at home and sometimes I'd think ah I wish we could go out and then when lockdown hit it was actually cool to have indoor dates it was all over Instagram and I was thinking wow the tables have turned we aren't so different after all

[p9]

Furthermore, during lockdown, participants felt there was less pressure to engage in activities which could be potential triggers, such as socializing with friends and family or attending events. The pandemic allowed participants to normalize their everyday routine of resting, which they had acquired over time to manage their symptoms:

There was no pressure to go anywhere or do anything yeah things had slowed down and I enjoyed it was like the whole world had synced to my daily routine of having a slow life [...] I loved it 'cause I didn't feel as though I needed to measure up to anything

[p13]

Because the lockdown period had been a time which felt familiar and safe for participants, the lifting of lockdown was difficult for some participants. Participants expressed feeling disheartened that the lifting of the restrictions would mean people would go back to living their lives, whereas they were 'stuck in this place with the same life' [p3]. Participants hoped that the lockdown period would promote a better scientific understanding of their illness going forward among the public, as well as their family and friends due to the similarities ME/CFS has with long COVID:

One thing I think a lot of people in the ME world are hoping will come out of COVID is a better understanding of ME because long COVID is being seen as so similar in symptoms there will be a lot more research into these types of illnesses

[p17]

Although lifting the lockdown restrictions was a difficult time for some participants, participants were also able to reflect on the positives that had come out of the lockdown period. Participants expressed feeling more included and accepted, as after years of being ill, participants were able to partake in activities remotely via Zoom, as this was becoming the new norm. This was seen as a way of keeping up with the dynamic changes occurring in the world post-lockdown, in a way that was accessible to people with ME/CFS.

I think the thing that I loved the most about lockdown was everything being on Zoom and that's what I enjoy now so a lot of there's some groups I try to go to socialise and things like that and now there's the option to do it on zoom which means if I am struggling with my chronic fatigue I can still access things from bed

[p11]

Although social events were becoming more accessible due to online platforms such as Zoom, and the option for people with ME/CFS to partake in activities remotely while engaging in their daily self-management routines was welcomed, participants expressed feelings of upset when reflecting on the fact that it had taken a global pandemic to increase this level of accessibility for participants. Participants perceived the pandemic as the driving factor for these changes, which they felt highlighted the stigma present towards people with ME/CFS to this day:

Thinking about it why has it taken this to get people to include us in stuff over Zoom it's taken this pandemic for us to be able to take part which is really sad and it just shows we aren't taken seriously

[p11]

Theme 3: Fear of getting COVID-19

Although the majority of the participants reported lockdown as a positive time where they felt less different from the rest of the world, these positive aspects also came with new anxieties and fears around contracting the COVID-19 virus. Participants believed that having ME/CFS made them particularly vulnerable to having a negative experience and feared severe or long-lasting COVID symptoms or an exacerbation of ME/CFS symptoms if they got COVID-19. This perceived vulnerability was heightened due to similarities between ME/CFS and long COVID, and the potential risk of COVID progressing into long COVID:

The added stress of if I was to get COVID what an impact that would have on my ME because I believe that they think that ME was started from a viral infection that you never recover from so it's like well if I was to get COVID would that double my ME or will I get long COVID too so yeah the stress that that caused [...] like I really don't wanna get

[p11]

Participants who had COVID-19 during the lockdown period described it as a negative experience, as it meant their ME/CFS symptoms were worse and they were unable to distinguish which symptoms were COVID-19 related, and which were ME/CFS specific:

I actually got COVID which then made my symptoms much worse so that was a total disaster [p12].

Participants explained that while they had COVID-19, they were unable to engage in their daily routine, and this also exacerbated their ME/CFS symptoms following testing negative for COVID-19. It also took participants longer to recover from the virus:

It took me so long to recover and it was just horrible 'cause I didn't know whether my sore throat was COVID or my CFS so I'd have to do tests a lot [...] I crashed for weeks after

[p16].

This was worrying for some participants as it meant they were constantly anxious about having the virus. Participants described being hypervigilant during lockdown and beyond through symptom monitoring frequently throughout the day. Participants followed the lockdown guidelines set by the government, prioritising the safety of themselves and their families. This could often cause conflict within a romantic relationship. Some participants had partners who were key workers and therefore working away from home. Participants felt that if their partners had been outside, they increased their risk of contracting COVID-19, making them feel nervous. Participants also mentioned how their anxieties around getting COVID-19 impacted their physical relationship with their partners:

I really valued our hugs and physical comfort and I felt like all that stopped 'cause we were always being so careful and it made me feel nervous so that was a little upsetting actually

[p18]:

To adhere to the government guidelines, participants explained that they followed all the rules to manage their anxieties related to contracting the virus:

I've dealt with it by being very fussy about lockdowns wiping things down not to the point of obsession but quite you know quite continuously

[p16].

Of the minority of participants who said that they left the house for walks during lockdown, they explained that they only did this as the public had to wear masks and adhere to social distancing rules, therefore they perceived going out to be safe. Although ME/CFS was not on the NHS shielding list, participants perceived themselves as vulnerable to contracting the virus, and therefore were more vigilant about lockdown rules being followed:

I do understand people [public] who say sod it I'll just behave absolutely as normal because who wants to not see their friends you know but I know I'm the one of the people who is at risk so I'm sticking to the rules

[p5]

Furthermore, the easing of lockdowns was perceived as a stressful time for participants, as things were going back to 'normal': 'The harder thing for me was when we kind of for now because now we're coming out of lockdown people are getting busier' [p4]. Participants still felt heightened anxiety about contracting the virus and the potential risk of their ME/CFS symptoms getting worse, and therefore continued with following mask and social distancing guidance beyond what was recommended by the government. Adherence to the social distancing guidelines and mask wearing beyond the time recommended by the government was used as a mechanism for managing fears around contracting the virus:

Yeah I wore mine [mask] for months after I still wear it because I didn't want to catch it [COVID-19] so I am cautious

[p5].

DISCUSSION

The present study explored the experiences of women with ME/CFS living with their partners during the COVID-19 pandemic in the United Kingdom. Thematic analysis of the results showed that throughout the COVID-19 pandemic, the routine people with ME/CFS had acquired over time to manage their illness was disrupted. When lockdown restrictions were put in place in March 2020, partners were commonly working from home which disrupted this well-established routine. This meant that participants were not able to rest when they had planned, disrupting routines they had established to keep well and prevent relapses. Participants also expressed that although disruption of routine made managing their ME/CFS difficult, they appreciated the increased quality of time they had with their partner. Additionally, it was found that participants felt the lockdowns reduced the differences that were once present between themselves and the outside world. Participants had felt isolated and described being excluded from social events. However, during lockdowns, they felt that the world was able to empathize with what was routine for them. Importantly, family and friends were able to understand the limitations in which they lived on a daily basis. As a consequence of the lockdowns, participants also reported having a better relationship with family and friends due to them being able to empathize with them during the lockdowns.

Following on from this, participants expressed anxieties around the world going back to 'normal' post-pandemic, as this would mean they were getting 'left behind' again. Although lockdown being lifted meant that participants could resume their pre-lockdown routine, participants had commonly adapted to a newly established routine with their partners more present, therefore the easing of lockdown brought about new challenges. Although most participants were anxious about lockdown easing due to fears of being stuck while the world moved forward, participants did recognise that in some cases, things going back to 'normal' would allow them to go back to their old established routines which worked for managing their symptoms. These findings are in line with previous literature that has found that chronic illnesses disrupt habitual routines (Charmaz, 2002), as an

illness can force changes ranging from small changes in routine to radical changes in daily habits (Charmaz, 2002). Disrupted routines can be a shock for individuals as they can bring loss and limitations to the surface (Radley & Green, 1987). More specifically, ME/CFS demands the revision of occupational patterns and routines (Densham et al., 2016), therefore disruption of this well-established adapted routine over time is likely to cause disruption in everyday life. Fears around getting COVID-19 were also increased for people with ME/CFS as they believed they were particularly vulnerable to catching the virus and having a more severe illness. They worried that having COVID-19 would also exacerbate their ME/CFS symptoms or lead to long COVID. Symptoms of ME/CFS could also be mistaken for COVID-19, for example having a sore throat, which also worried participants and prompted them to take COVID-19 tests regularly. Because of this, the easing of lockdown restrictions was perceived as a stressful time for participants due to the loosening of restrictions that had been put in place to keep the public safe.

Research has shown that a high rate of patients with long COVID are fulfilling the criteria for ME/CFS (Jason & Dorri, 2022; Mancini et al., 2021). A large international survey found that among those with long COVID, 6 months following infection of COVID-19, core symptoms of ME/CFS such as fatigue, post-exertional malaise and cognitive dysfunction were frequently reported (Davis et al., 2021). Over 85% of participants reported relapse of symptoms such as post-exertional malaise triggered by physical exertion or psychological stress, also a key symptom of ME/CFS (Davis et al., 2021). These findings highlight the importance of ME/CFS-related research, as the symptom overlap means this research may be useful for people with long COVID and *vice versa*.

The majority of people diagnosed with ME/CFS are women (Cairns & Hotopf, 2005). Additionally, women are more likely to participate in research (Blazquez et al., 2008; Romano et al., 2009) and attend illness support groups than men (Krizek et al., 1999). To avoid bias, an all-female sample was recruited. It is important to consider the romantic relationships of all the participants. Within this study, most participants reported being in supportive relationships and were keen to share details about these relationships with the researcher. Recruiting people with less positive relationships may have identified unique challenges in managing ME/CFS for romantic couples living together in lockdowns. Furthermore, those in less positive relationships may be less likely to be willing to discuss their relationship. Schokkenbroek et al. (2021) found that during lockdown, women experienced more relationship stress than men because of conflict and diverging attitudes within their relationship (Schokkenbroek et al., 2021). Both men and women experienced more stress during the lockdown than pre-lockdown as they reported feeling restricted in their relationships (Schokkenbroek et al., 2021). During periods of crisis such as the COVID-19 pandemic, increased rates of intimate partner violence have been reported (Kourti et al., 2021; Parkinson & Zara, 2013). Research has shown that during the pandemic, rates of domestic violence increased (Usta et al., 2021). This research demonstrates the complexities involved in relationships during the pandemic. Further research is required to understand the experiences of people in less positive relationships with long-term conditions such as ME/CFS during this time.

The sample was also recruited through the COVID-19 pandemic, which was an especially difficult time for the public, as well as people with ME/CFS. Because of this, the sample is likely to be biased towards participants who felt well enough to take part during the pandemic. Participants who were severely impacted by ME/CFS are unlikely to have taken part in this study. Furthermore, participants who were more present online during the pandemic will have been more likely to participate; however, pre-COVID, several other avenues of recruitment such as on-site NHS recruitment may have been possible, recruiting a more diverse sample of ME/CFS patients. Recruiting online may have excluded ME/CFS participants with no internet access. Participants were also recruited through support groups in the United Kingdom. This could have resulted in interviews with people who are actively involved in seeking support or interested in research, or those with more long-term chronic symptoms of ME/CFS who had not responded to treatments.

Despite these limitations, in-depth interviews meant the data were rich and insightful and likely to capture an important range of views. Further research is required to investigate the experiences of those who do not have easy access to the Internet. There are likely to be individuals who did not benefit from

the Internet for study participation or social interactions, such as older adults (Nimrod, 2021; Seifert et al., 2021).

CONCLUSIONS

In conclusion, this study highlights the experiences of lockdown for women with ME/CFS living with their partners during the COVID-19 pandemic. The key findings suggest that although there was a disruption in routine due to the pandemic, for example, partners working from home, participants appreciated the increased time they had to spend with their partners despite this meaning they sometimes felt worse following this. It was also seen that the pandemic reduced the difference between people with ME/CFS and the outside world, as people with ME/CFS are part of a marginalised community who commonly face social isolation as a consequence of their illness. Having everyone else face the restrictions they faced everyday allowed them to feel less different from the rest of the world, and something that was normal for them was becoming normal for many people around the world. Because of this, it was seen that the easing of restrictions was an anxious time for people with ME/CFS. This was primarily due to fears of contracting the COVID-19 virus which was perceived to make ME/CFS symptoms worse. Due to these fears, people with ME/CFS reported being cautious during the phase when restrictions were being lifted, and once they had been lifted.

Research has suggested that there are many similarities between the symptoms of ME/CFS and long COVID (Jason et al., 2021; Murga et al., 2021; Poenaru et al., 2021). Because of this, the findings of this study have implications for those with both ME/CFS and long COVID (Komaroff & Lipkin, 2021). The findings of this research highlight the importance of routine for people with ME/CFS, as well as insight for health care professionals regarding the adaption of activities or treatment to suit those who are physically limited due to ME/CFS to minimise the gap between those with ME/CFS and those without. Furthermore, although the COVID-19 lockdowns have been lifted, it is apparent that longstanding changes have been made in society, for example, increased working-from-home practices. People with ME/CFS can attend medical appointments remotely if they prefer (Leach et al., 2023), however, participants valued social activities being made accessible during the lockdowns such as online support groups. Because of this, professionals specialising in ME/CFS should encourage online events such as online isometric yoga classes (Oka et al., 2017) which can have a social element. Being involved in social activities is something participants felt they missed out on pre-lockdown, therefore introducing online social groups for the ME/CFS population post-lockdown would allow the ME/CFS population to access social activities. Future research should follow up on any longstanding changes in routine made by the ME/CFS community to account for changes brought about by the pandemic, for example, increased partners working from home. The findings showed that participants were often conscious about resting in front of their partners, therefore it would be interesting to explore whether these feelings are longstanding and how they impact romantic relationships with working from home becoming the norm.

AUTHOR CONTRIBUTIONS

Tarnjit Sehmbi: Writing – review and editing; project administration; writing – original draft; methodology. **Alison Wearden:** Supervision; methodology; writing – review and editing. **Sarah Peters:** Supervision; writing – review and editing; methodology. **Kimberly Dienes:** Supervision; writing – review and editing; methodology.

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CONFLICT OF INTEREST STATEMENT

No conflicts of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

ORCID

Tarnjit Sehmbi  <https://orcid.org/0000-0002-7508-6115>

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