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Title: “Welcome to my world”: A thematic analysis of the lived experiences of people with Myalgic Encephalomyelitis during the UK COVID-19 lockdown

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Abstract

Objectives: We explore the experiences of people with Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (pwME/CFS) during the first UK COVID-19 lockdown period. We specifically probe perceived commonalities and departures in experience between government- and health-imposed lockdowns, application of coping strategies for social isolation, and predictions for inclusion of the chronically ill in post-pandemic society.

Methods and Measures: Thirty semi-structured interviews were conducted in pwME/CFS between June – July, 2020. Responses were qualitatively analysed using an experiential, thematic framework.

Results: While participants reported enhancements in digital accessibility during lockdown, they perceived this as an unintentional benefit from changes designed to cater universally. Similarly, their expectation was that the general population's limited experience of restriction would not engender greater understanding for those who would continue to experience health-imposed lockdowns, post-pandemic. Participants described numerous strategies for coping with restriction and isolation, developed during prior health-imposed lockdowns and applied to this novel circumstance, highlighting the presence of acceptance and resilience in the sample.

Conclusions: Our findings suggest that future work may fruitfully examine whether our participant's predictions for post-pandemic societal inclusion have been met, and how resilience and acceptance might be developed and nurtured in chronically ill populations through times of adversity.

Keywords: Myalgic Encephalomyelitis; Chronic Fatigue Syndrome; COVID-19; Lockdown; Coping; Social Isolation.

Introduction

Myalgic encephalomyelitis (ME), also known as Chronic Fatigue Syndrome (CFS)¹, is a multisystem, neuroinflammatory disease with a heterogeneous, fluctuating and chronic course. Alongside post-exertional malaise (PEM; a temporary and disproportionate exacerbation of symptoms in response to physical and/or cognitive exertion), impaired functioning is seen across neurological, immunological, gastrointestinal and energy metabolism systems (Carruthers et al., 2011). With no clearly established biomarkers and lack of taxonomical consensus (Lim & Son, 2020), diagnosis is typically lengthy and dependent on elimination of other conditions (Conroy et al., 2022). People with ME/CFS (henceforth “pwME/CFS”) face societal stigma shared by other chronic illness communities (Dickson et al., 2008), yet also attract scepticism and delegitimization within the medical arena (Geraghty, 2020; Pheby et al., 2020). The traumatising nature of such confrontations, alongside symptom load, mean that pwME/CFS are often deeply isolated (Larun & Malterud, 2007). While grieving their previous lives, the loss of function, independence, relationships, social and occupational identity also threaten aspects of personhood (Åsbring, 2001).

As treatment options are limited (Vink & Vink-Niese, 2022), interventions may instead aim to improve quality of life in the presence of symptoms (Pinxsterhuis et al., 2015). Acceptance and Commitment Therapy and underpinning concepts, such as psychological flexibility (Hayes et al., 2011), position acceptance of the condition and its limitations as a necessary first step. Once achieved, acceptance may generate a sense of agency, allowing

¹ Terminology within this field is fiercely debated as it relates to varying aetiological perspectives (e.g., Lim & Son, 2020). ME is more frequently aligned with a biomedical model than is CFS, and is preferred by the patient community and by the present authors. Nevertheless, this paper uses “ME/CFS” and “pwME/CFS” to include individuals who, given the interchangeable use of these terms, could have received either diagnosis.

pwME/CFS to develop and adapt to a flexible structure that accommodates their symptom fluctuations, whilst allowing crucial pursuit of identity-preserving value-driven activity (Åsbring, 2001; Dickson et al., 2008). Whether naturally-observed or intervention-led, preliminary evidence suggests that lifestyle adjustments congruent with this approach can be beneficial for quality of life and psychosocial outcomes and also support development of problem- and emotion-focused coping strategies (Chapman et al., 2019; Densham et al., 2016; Jonsjö et al., 2019). Crucially, this approach complements and encourages empirically-supported pacing strategies for activity management (Brown et al., 2013; Jason et al., 2013). However, condition acceptance is conceived of as a challenging, ongoing, and shifting process (Pinxsterhuis et al., 2015), understandably less prevalent in those recently diagnosed (Brown et al., 2010; Jason et al., 1999). Flexibility-induced benefits may also be more difficult to attain for those who have severe forms of ME/CFS or those experiencing transient symptom flares (Jonsjö et al., 2019; Strassheim et al., 2021), who may need to strictly limit their routines until their symptoms sufficiently improve to support implementation of further coping strategies (Jason et al., 1999, 2013). For these individuals, and pwME/CFS more widely, the internet may present an alternative or additional coping tool. The platform provides and supports comparatively low-energy and flexible options for entertainment, social contact, and self-education (Lian & Nettleton, 2015). Virtual access to peer-led support groups may facilitate the development of social capital, as seen in other patient populations (Berard & Smith, 2019), allowing users to derive both a sense of community and improvements to wellbeing.

The outbreak of COVID-19 was a historic landmark where, suddenly, being house-bound became the norm, with associated losses of routine activities and social contact affecting the mental health of millions (Robinson et al., 2022). Consistent with pandemic-enhanced social, financial, psychological and health disadvantages experienced by disabled

people (Shakespeare et al., 2022), some pwME/CFS reportedly experienced symptom flares, exacerbated by difficulties in booking medical appointments and maintaining self-care routines amid heightened fears of contracting the virus (Brewer & Stratton, 2020; Moncorps et al., 2022). Accordingly, one study found that pwME/CFS found their illness harder to cope with during the pandemic (Moncorps et al., 2022), which the authors linked to less social support seeking and lower engagement in problem-focused coping, suggesting that lockdown compounded their isolation. In contrast, Brewer and Stratton's (2020) qualitative analysis found that challenges were experienced in parallel with several unexpectedly positive outcomes. Interestingly, as connecting online became the primary means of preserving social contact and protecting wellbeing for the general population (Kluck et al., 2021), participants benefited from enhanced opportunities to participate in society, allowing avoidance of pre-pandemic anxieties and guilt related to attending or cancelling face-to-face activities. Some also considered themselves better placed to deal with the circumstances of lockdown, having already developed specific coping skills for managing social isolation and restricted activity (Brewer & Stratton, 2020). Similar sentiments were also evident in accounts of ME/CFS bloggers and advocates during 2020, who highlighted the ableist undertones in the normative assumption that "everybody" was both experiencing and struggling with the restrictions imposed by lockdown (Hunt, 2020; Radenkova, 2020). Arguably then, previous health-imposed 'lockdowns' and the uncertainty intrinsic to chronic illness (Mishel, 1999) may confer transferable resilience to other forms of adversity (Poli et al., 2021).

The present study sought to provide an experiential account of pwME/CFS during the government-imposed lockdown. We specifically probe two questions posed by one blogger/advocate in June 2020 (Whittingham, 2020a): i) "What is a pandemic like when being housebound and isolated is your norm; when freedom is something that was lost long ago?" and ii) "Do many years of experience make the current situation easier or harder to

bear?”. In examining the coping strategies and experiences of “lockdown experts”, we asked about their comparative perceptions of the general public’s experience and whether they thought these temporary shared circumstances of restriction might help to tackle the stigma and lack of empathy that typically result in societal exclusion of the chronically ill.

Method

Participants and recruitment

In May 2020 we advertised for British participants, either formally diagnosed with ME/CFS or symptomatic for the past two years (Lim & Son, 2020), on Facebook and Reddit community groups. The advertisement explained our focus on coping strategies, perceptions of societal inclusion prior to the pandemic, and predictions of the same post-pandemic.

Forty-five people responded to study advertisements, and thirty completed the full study procedure ($M^{age} = 38.93$, $SD^{age} = 12.72$; 27 female, 2 male, 1 non-binary). While three participants described their ethnic background as White European, White Italian and White Finnish, all others described themselves as White British. Half of the sample had completed an undergraduate degree or above. Fifteen participants lived with a partner (two with children); nine with family members and seven lived alone (one with children). **Three participants were employed either part- or full-time at the time of the study; all worked from home during the pandemic, a situation which reflected the flexible work arrangements they already held with their employers.** Twenty-three participants self-reported their current ME/CFS severity level, without reference to recognised taxonomies (see *discussion*): two classified themselves as mild, two as mild-to-moderate, three as moderate, eight as moderate-to-severe, six as severe, and two as very severe. Twenty-eight participants reported their year of diagnosis revealing that the sample had an average illness duration of 8.89 years ($SD = 7.81$, range = 2 – 32 years), with participants reporting an average delay of 5.07 years

between symptom onset and diagnosis ($SD = 4.06$, range = 1 – 27 years). Twenty-seven of the thirty participants also self-reported between 1 and 15 additional physical and/or psychiatric diagnoses (most commonly fibromyalgia, Postural Orthostatic Tachycardia Syndrome, Hypermobility Spectrum Disorders, anxiety and depression). Five participants also reported neurodevelopmental diagnoses, including autism and dyslexia.

Materials and procedures

Our semi-structured interview schedule was developed using emerging literature on the psychosocial impact of COVID-19 for people with and without chronic illness (e.g., Goggin & Ellis, 2020; Ryan, 2020a; Umucu & Lee, 2020), and bloggers and advocates with ME/CFS (Hunt, 2020; Whittingham, 2020a). It comprised three sections: initial questions to establish participant history of chronic illness and societal isolation, an examination of experiences during the COVID-19 lockdown period (both their own and their perceptions of the same for the general population); and an exploration of perceived differences between participants' prior experiences of health-imposed lockdowns and the COVID-19 lockdown. We also probed coping strategy utilisation and perceptions about potential impact of the pandemic on future societal treatment of people with chronic illnesses and disabilities.

Ethical approval was granted by Bournemouth University's Science, Technology and Health Research Ethics Panel (Approval code: 32426; Approval date: 02/06/2020).

Participants were directed to a Qualtrics landing page, where they could read and download the study information sheet, provide written consent and demographic details, as described above. Upon completion, participants were emailed to schedule an interview. Each participant was allocated a single researcher throughout for purposes of rapport development. To assist this, the researchers provided brief personalised introductions which explained their positioning in relation to the study. This was important as we hail from a psychological

discipline which has historically contributed to the stigma and delegitimization surrounding ME/CFS (Geraghty, 2020).

The interview process was flexible to manage participant's potential for PEM. Participants were encouraged to choose an interview time which suited their fluctuating symptom load and could complete in one sitting (24 participants) or in multiple, short sessions (six participants). Involvement of caregivers to facilitate participation was permitted; in two instances, a caregiver managed the audio-visual technology. Twelve participants chose an audio-visual format (Skype/Zoom) and 18 requested a telephone call. All interviews were audio-recorded using Audacity® software. Recordings comprised the interview schedule only, omitting a verbal restatement of the participant information and debrief sheets (both already accessible to the participant in paper form) and researcher responses to any questions the participant had ahead of interview. Audio recordings were initially transcribed using an automated service and then manually checked for accuracy by the fifth author. Audio-recordings were securely deleted after transcriptions had been finalised.

Participants were sent the interview questions before the interview, to avoid anticipatory anxiety and allow extra thinking time if needed, and afterwards, to provide further comments via email, if desired. Interviews were conducted between June-July 2020; 17 by the first author and 13 by the second author. Interviews lasted between 25 to 73 minutes ($M = 38$ minutes). All participants completed the interview schedule in full, with no attrition attributed to symptom flares. While we may assume that fluctuations in interview duration were participant-driven, with longer interviews reflecting further elaboration in response to the questions posed, we cannot rule out the possibility that participants self-regulated interview duration according to their individual pacing requirements. Rights to withdraw and reschedule were reiterated throughout the session. Participants were compensated with gift vouchers for their time.

Analysis

Data were analysed through inductive thematic analysis (e.g., Guest et al., 2011). The third and sixth authors independently performed initial coding of the transcripts and compared codes for similarity; most of the initial codes were overlapping, signifying appropriate inter-rater reliability between the researchers (e.g., McCormack & Wignall, 2017). These codes were then combined and condensed into more focused codes, with the potential for these to become sub-themes and themes (Joffe, 2011). Potential sub-themes were discussed with the first and second authors, who conducted the interviews, with labels and descriptions adjusted to ensure the inductive analysis aligned with the interviewer's understandings of the data, which helped to form overarching themes (Clarke & Braun, 2013; Wignall & Driscoll, 2020). All authors cross-checked final themes and sub-themes against the raw interview transcripts, as well as previous research, as a final form of reliability (e.g., Jaspal, 2020).

Reflexive statement

The research team comprised of people with multiple identities and experiences. One member of the research team is a pwME/CFS and another has a close relationship to a pwME/CFS. While these individuals were not viewed as experts, their knowledge and experiences were particularly drawn upon both when constructing the interview schedule and assessing the practicalities of conducting interviews within this population (e.g., offering multiple formats of completion). These researchers conducted all interviews, the structured nature of which minimised their ability to introduce their own interpretation of responses and were open about their own positionality to the topic to emphasise transparency and to enhance rapport building with participants.

Due to the closeness of the topic for some of the research team, it was especially necessary to consider our own positionality at the various stages of data analysis. To mitigate potential bias and experience-based interpretation, initial coding of the data was undertaken by members of the research team who had not conducted the interviews, nor compiled the interview schedule. Once these themes had been suitably condensed through discussion, the interviewers (and remaining, naïve members of the research team) were called upon to verify those themes and subthemes against the transcript data, ensuring that they mirrored their interpretation of the participant's intended meaning. This staggered, but collaborative approach, ensured that the final identified themes were rooted within the data.

Results

Four themes were identified: the shared experience of lockdown; distinctive experiences of lockdown; coping with lockdowns and future pandemic-driven societal change. Preliminary quote-to-theme mappings, organised by participant, are available within our supplementary materials.

The Shared Experience of Lockdown

The first theme explores how participants' experiences of the government-imposed lockdown were perceived to be similar to those of the general population and identified two subthemes: *collective experience* acted to increase the perception of societal *inclusivity* (albeit *unintentionally*) and some participants wondered if this could exact some degree of future understanding for the continued restricted circumstances faced by the chronically ill.

Lockdown as a Collective Experience

All participants described how some aspects of lockdown were experienced collectively by those in society. The resultant sense of community, largely built and maintained online, reduced feelings of alienation e.g., "at the beginning of lockdown, it was lovely. I didn't feel like the odd one out, I feel like everybody was in the same situation... it's like we

reconnected to the basic things in life.”; “It’s kind of, quite weird in a way, because everyone is in that position that you were in... just having everyone in the same boat just makes a big difference.” One participant, who is bedbound and predominantly socialised online pre-pandemic, said, “It’s become easier to speak with my friends... they were forced into the digital domain to socialise... I’ve taken part in quizzes which I’ve never had the opportunity to do before.” Facebook was identified by 16 participants as being particularly useful for facilitating interactions with both chronically ill and healthy individuals. For example, one participant said, “I have a huge group of people on Facebook that I've got support from” with another commenting similarly:

I’m part of a Facebook group of people with chronic illness who are shielding.

They’ve all been sharing tips with each other and there's been a lot of advice on how to cope with illness and about how to cope in lockdown. It’s been really useful.

Unintentional Inclusivity

As opportunities for work and leisure progressively moved online, 23 participants described being able to partially reclaim their place in society. For example, one participant said, “my church has all moved online now... I’ve also contributed to [online] worship, which I haven’t done before” with another similarly commenting that “The whole world is online... It’s been really nice, but emotional because it’s like the world is suddenly being brought to your doorstep... things I wanted to do is something I can do now.” Another participant also expressed a sense of relief in now being able to participate on their own terms:

With ME, I have been balancing going out with massive a rest before and after.

People say, “she looks okay”, but they don’t see me when I’m at home when I’ve got no energy to cross the room or whatever. You sort of feel guilty... I think lockdown suited me better.

However, 13 participants expressed varying levels of frustration and/or resentment that these opportunities had not previously existed to support those isolated by their health, feeling like unintended beneficiaries of enhancements designed for the wider population. For example, one participant commented, “The world has come to me a bit more... there's lots of stuff suddenly available online. I think, why wasn't it available before? It's all suddenly online, so lots of this stuff is pre-recorded.” Likewise, another participant stated, “everything is falling at the feet of able-bodied people to help them through lockdown, but we haven't had that; no one's been helping us for decades; people are becoming more and more marginalised and more bed-bound and more disconnected.” They added that “society has been hypocritical – things I've needed in the past, like virtual hospital appointments, have been blocked for me; now they're more common”. Another participant echoed this observation:

I think one thing that I found that was really frustrating was that, not frustrating I was glad for it, but I was just like why did it take healthy people being in a lockdown for chronically ill people to have access to certain things?

Distinctive Experiences of Lockdown

Theme two presents participant-identified incompatibilities between government-imposed and health-imposed lockdowns, **an observation made by all participants, with many** particularly highlighting differences in longevity and potential for activity engagement.

Addressing the first component, one participant said, “with [the general population], they know that they've got an end to [lockdown]. With chronically ill people, we don't have an end date”, with another adding, “[the general population] know [lockdown] will end, they know it is only short term.” Another participant linked these two components, saying, “Lockdowns are similar in the sense that there are restrictions, but it's completely different in the sense that the general population can do what they want, and they know that there's an end.” Elaborating on how the types of restriction vary in their intensity, and thus govern

possible activity, a further participant said, “the public can at least go for a walk or the shops; I couldn't even get out of bed for a lot of the time” with another similarly commenting, “I can't suddenly take up exercising, I can't suddenly find new channels for energy, because I must spend a lot of my time resting and my freedoms are so restrictive.”

Many participants suggested that there were possible differences in how lockdowns were perceived by the general population compared to chronically ill people. One participant said, “It's a novelty to [the general population] because they don't have to go into work. They've been furloughed or reduced their workdays or are enjoying the space. [Health-imposed lockdown] is something I struggle with.” Thus, while believing some of the general population were able to use the government-imposed lockdown as a time for rest and self-improvement, some pwME/CFS necessarily adopted a ‘business as usual’ approach, with a further participant saying, “this is my life. I don't get to go outside.”

Relatedly, some participants expressed frustrations about the general population's experienced difficulties in adapting to lockdown restrictions. One participant described complaints about face masks and other lockdown restrictions as “hilarious”: “It just made me think, people complaining about the restrictions being put in place because they just don't get it”, while another stated:

I know it's a very selfish point of view because it was a new experience for everybody else and it was quite shocking. But for me, I wanted to kind of shout, “I've been living like this for the last bloody five years, and I've been feeling ill through most of it.”

When some people are struggling to cope, part of me felt like “you all need to just get over it”... I did feel a bit like “well, welcome to my world.”

To alleviate such frustrations, a participant said they, “end up switching off social media because I read stories on Facebook of able-bodied and health-privileged people moaning about not going to the gym or the pub.”

Coping with Lockdowns

The third theme explores participants' strategies for coping with lockdowns. These originated in our participant's previously experienced health-imposed lockdowns but were also deemed applicable to government-imposed lockdowns. While these strategies might benefit the general population, whose experience of restriction was novel, pwME/CFS felt *apprehension* around sharing them.

Strategies for Coping with Lockdown

Participants described three strategies for coping with lockdown. These were: having flexibility in routines and structure, having a social support network, and the importance of identifying and pursuing small pleasures.

Routines and structure provided participants with feelings of accomplishment whilst reducing the respective cognitive and physical load associated with spontaneous planning and implementation of activity. **This was the most common coping strategy, mentioned by 29 participants.** For example, one participant said, "I think it's essential to keep a routine because in lockdown you lose that, so getting up, making sure you have breakfast at regular time, going to bed at a certain time." Another said, "Have an aim of the day, even if it's something very small so that you feel like you've achieved something." Similarly, a further participant said, "You need to structure your day, keeping a routine. I know I shouldn't sit in one room all day, so I'll move to different areas of the house. I'll try to change what kinds of activities I do throughout the day." Flexibility in routines were heavily emphasised, with another participant saying, "I think for me it would be to make a list or a schedule – it doesn't mean the schedule has to be followed exactly... I've got sort of my routine generally."

Social support was regarded as the second most important coping strategy, often occurring digitally, and was mentioned by 27 participants. For example, one participant said, "It's important to try to stay connected... Facebook messenger is useful to keep in contact."

Similarly, another said, “speaking to somebody outside the family everyday... sometimes you’re just not well enough, but even just a quick phone call...I just think it's just a really good idea.” Quotes also emphasised the need to balance desire for social connection with available energy levels: “I tend to dip in and out of Facebook because I can find it a bit overwhelming, but at the same time it's that social connection, especially with other people in the same boat that I find that really helps.”

Participants suggested that acceptance of limitations and appreciating small pleasures was seen as key for maintaining good mental health; **this strategy was mentioned by 21 participants**. For example:

I always try and give myself something to look forward to, like an episode of TV to watch - It's tiny, tiny things, like the nice dinner I have planned for tomorrow. Just little things and it is about taking pleasure in the small things and really noticing them.

I am so grateful.

Regarding adaptation to and acceptance of restrictions, **mentioned by 20 participants**, one participant said, “I think the main thing is changing your mindset and almost coming to terms with it; appreciating the little things as much as you can and living in the moment maybe more than you would’ve before (restrictions).” Linking the importance of social support and small, daily pleasures, another participant said, “I would focus on the things I enjoy doing and focus on the people that I love and care about.”

Apprehension about Sharing Strategies

While **several** participants indicated that they had already used social media and blogs to share their strategies to benefit the general population, they expressed uncertainty about whether this advice would be acknowledged and appreciated. For example: “I think that we’ve got loads of tips and tricks that we could share, but whether people would listen is a totally different ballgame.”; “[the general population] aren’t listening to the people who

really know the territory of lockdowns, that have been living with it for decades. They are not really looking into those people”. A further participant supported these views and suggested that the wider implications of their advice might be overlooked:

I probably would share coping strategies, but I'd also want the public to understand the reason we have these strategies... try to get them to increase their understanding that at the same time that they can go back to work and do normal stuff, there are still a lot of people that can't. We'll help you, but a little bit more understanding when lockdown is finished for you would also be really nice.

Future Pandemic-Driven Societal Change

The final theme addresses participant predictions about whether the temporary experience of lockdown for the general population would promote a better understanding of continued restrictions, with the potential for catalysing societal change. Earlier themes suggest that participants perceived the general population to have little understanding of health-imposed lockdowns, which would impede development of future awareness. Indeed, one participant noted that newer, accessible home-food delivery services were disbanded even prior to the end of lockdown, saying, “Once lockdown started to ease, and people got into their routine and whatever, they all drifted off. It didn't last very long... you go back to feeling well, ‘I'm invisible again.’”

Reiterating predictions for reinstated alienation, another participant said, “When lockdown is eased and things return to normal, those who are able, I think their focus is going to shift to being able to do things again... there should be reminders that for some people, this is normal.” A similar outcome was expected by a further participant, who focused instead on practical and economic barriers:

Realistically is it sustainable going forward... why would anybody want to go and visit the museum when you can do it online... you wouldn't spend money in the gift

shop... I think economically, a lot of the things that have been given away for free will just go back to normal.

While the predictions made by other participants were more positive, they still emphasised uncertainty:

[It's about] trying to get the message out that some people are [under lockdown] the whole time and hopefully people will gradually try and make things to be more inclusive because they've experienced a little bit of that. I don't know how much that will actually happen. But, hopefully.

Discussion

The present study sought to elicit an experiential account from pwME/CFS during the first UK COVID-19 lockdown. Using semi-structured interviews we identified four themes around shared experiences, unique perceptions, coping strategies, and predictions regarding societal change.

Relating to Whittingham's (2020a) initial enquiry, those with prior experience of health-imposed isolation both continued to embrace and perhaps found it easier to adapt to new technology-mediated methods for maintaining social connectedness. For example, while within-community support groups were still used for advice sharing, the online environment also now supported reconnection with friends and non-immediate family members.

Facilitating the latter exchanges, participants noted that a sense of community pervaded early lockdown experience, which may have reduced the negativity that sometimes previously characterised such interactions (Dickson et al., 2008; Larun & Malterud, 2007). Similar observations of this new "shared ground" and its associated benefits have been made by people with other chronic illnesses and disabilities (Colas et al., 2021; Simpson et al., 2021).

As in Brewer and Stratton (2020), some participants noted that adaptations, previously possible but unimplemented, now existed to support digital participation in formerly inaccessible activities and communities (e.g., religious services, art exhibitions, pub quizzes). **Paradoxically then, greater freedoms were sometimes afforded by the circumstances that accompanied government-imposed (versus health-imposed) lockdowns.** Indeed, some participants, who had occasionally been able to participate in outdoor activities, felt relief that they could now engage in a way that placed fewer demands on their limited energy reserves. Pre-pandemic literature linked symptom exacerbation to (often unavoidable) in-person activity attendance (Brown et al., 2013; Jason et al., 2013), such that online social activities might have provided a beneficial, less taxing alternative for pwME/CFS. This is consistent with reports from other chronic illness communities who likewise noted that lockdown facilitated activity pacing and prioritisation of health (Colas et al., 2021; Poli et al., 2021; Simpson et al., 2021). These accounts from our and previous studies present a departure from the disproportionately negative psychosocial outcomes reported amongst disabled communities during lockdown, largely attributed to disruption of face-to-face activities and barriers that prevented transfer of social interaction to the digital environment (Cho & Kim, 2022; Jesus et al., 2021; Shakespeare et al., 2022). Such factors are less applicable to our participants; **the specific energy-limiting nature of their condition may have encouraged earlier adaptation to technology-mediated communication, making the required transition somewhat easier (e.g., Whittingham, 2020a).** Indeed, all spoke about current and past use of online platforms for socialising, and many commented that their routines, disproportionately centred around the home, had remained comparatively untouched by lockdown restrictions. These observations emphasise the importance of considering disability type and pre-pandemic routine when assessing the impact of lockdown (Holm et al., 2022; Lau et al., 2021).

In conditions with poor prognosis, differences in coping may critically mediate wellbeing (Densham et al., 2016; Pinxsterhuis et al., 2015). Exploring suggestions that past adversity may inform future problem-solving attempts (Mishel, 1999; Poli et al., 2021; see also Whittingham, 2020a), our participants were asked to describe the coping strategies already at their disposal which they deemed generalisable to new sources of restriction. Several strategies were identified, which mirrored advice offered by community bloggers (Radenkova, 2021; Whittingham, 2021) such as seeking and maintaining social support, acceptance of the situation, imposing a flexible structure, and mindfully integrating small daily pleasures. Interestingly, these participant-identified strategies are well-reflected in the synergistic components of Acceptance and Commitment Therapy (Hayes et al., 2011).

Reflecting the wider applicability of our sample's suggestions, higher levels of psychological flexibility within the general population have been linked to lower depression, anxiety, catastrophising and stressor rumination when measured longitudinally across lockdown (Landi et al., 2022; Prudenzi et al., 2021). This relationship was particularly evident for trait-level psychological flexibility, which may be built through prior exposure to adverse circumstances (Cheng, 2003). In accord with other researchers, we suggest that some people with chronic illness may have been better-equipped than the general population to cope with the government-imposed lockdown via enhanced resilience (Lau et al., 2021; Poli et al., 2021) and the application of specific and previously developed strategies (Simpson et al., 2021). This appears consistent with the coping resources of participants from Brewer and Stratton (2020), but initially seem to diverge from Moncorps et al. (2022), whose ME/CFS sample struggled more than usual with their illness during the pandemic and appeared less likely to draw on social support and problem-focused coping styles. However, those two findings – of increased illness-related difficulties, and of different coping strategies – were not related; furthermore, they derived from responses to adapted, reductive single-item

measures. Consequently, they cannot inform us as to whether coping strategies of pwME/CFS, which were assumed to be less adaptive through an able-bodied, normative lens, were effective for these individuals at this specific time.

While Whittingham's (2020a) initial enquiry appears to suggest commonality in the freedoms lost across both health- and government-imposed lockdowns, our participants noted several important departures. Firstly, a degree of uncertainty was common to both, but there were different expectancies about the duration of this uncertainty. While uncertainty of any duration can negatively impact an individual's sense of control and self-efficacy (Taylor et al., 2000), long-term uncertainty, as seen in the situation of pwME/CFS, may result in negative mental health outcomes and slow development of acceptance and adaptive coping strategies (Åsbring & Närvänen, 2002; Brown et al., 2010). Further, while mitigation of viral transmission was the clear and universal goal of pandemic restrictions, health-imposed lockdowns were instead accompanied by self-imposed restrictions, specifically tailored to manage that individual's symptom load (Jason et al., 1999). These differing motivations had implications for the types and intensity of activity that our participants could engage in at home and further impacted their interpretation of the general population's perceptions of lockdown. While our participants did not view lockdown as a novelty or opportunity for self-improvement, they thought that some of the general population may have felt this way. Participants noted with frustration and resentment that these departures in experience went seemingly unacknowledged by the wider population, which understandably coloured their predictions for the post-pandemic future. Like community bloggers (Whittingham, 2020a, 2020b), they reiterated that they had unintentionally benefitted from enhanced inclusivity and accessibility in the digital domain and that these opportunities were likely to diminish as the general population returned to their normal lives. These findings have implications for millions joining the post-viral community as a direct result of COVID-19 infection (Alwan,

2020; Office for National Statistics, 2022). Long-COVID bears striking resemblance to ME/CFS (Wong & Weitzer, 2021) and it is conservatively estimated that 10% of those still experiencing symptoms 12-weeks after infection will meet ME/CFS diagnostic criteria at six months (Komaroff & Bateman, 2021).

Addressing the predictions of our sample, both academic literature and community blog posts document progressive losses in digital access post-July 2021, impeding the leisure and occupational pursuits of disabled communities (Brown et al., 2021; Holland, 2021; Whittingham, 2021, 2022). These changes parallel the emergence of a utilitarian agenda, which holds vulnerable individuals responsible for their own safety from viral transmission (Hunt et al., 2022; Linke, 2022). The resulting climate has led to avoidable job losses (Holland, 2021; Ryan, 2020b), further barriers to engagement in value-driven activity and social interaction (Whittingham, 2020b, 2022), and perceived stigmatisation toward members of the disabled community who continue to take viral precautions (Goggin & Ellis, 2020; Linke, 2022).

Limitations and future directions

There are several limitations of the current study. Firstly, the sample followed diagnostic trends in being predominantly female (Conroy et al., 2022), lacking male, non-binary, and transgender voices. The sample also exhibited high levels of comorbidity, which may complicate our ability to specifically contextualise our participant's experiences through the lens of ME/CFS. While we tried to be inclusive of people with differing illness severity, the nature of the study likely precluded participation by some severely or very severely ill individuals, who might struggle to speak, listen, or process sensory input over prolonged periods (Strassheim et al., 2021). ME/CFS severity classification systems show wide variation (Lim & Son, 2020), thus we allowed participants to optionally self-report their current symptom severity without providing standardised categorical definitions. Several

participants omitted to report, and others described fluctuating patterns of functionality over time, making categorical inferences difficult. As such, we cannot ratify self-categorisations in accordance with standardised NICE (2021) or other criteria (e.g., The ME Association, 2022).

Our recruitment approach necessarily targeted individuals already belonging to online support groups. Unlike other disabled populations who reported barriers to online participation during lockdown (Cho & Kim, 2022; Jesus et al., 2021), our participants may have been more proficient users of technology for communicative and other purposes pre-pandemic. Further, given that some pwME/CFS might be attracted to these groups due to societal stigma (Lian & Nettleton, 2015), these past experiences may have understandably influenced their perceptions and predictions. Similarly, these online spaces may be less populated by the recently diagnosed or those who were satisfied and engaged with local in-person treatment and activity offerings pre-pandemic; now negatively impacted by their loss. Cultural representativeness is however suggested by the similarity between these findings and those of a previous UK sample of pwME/CFS (Brewer & Stratton, 2020), despite methodological differences.

Future work may more fully examine whether the post-pandemic predictions of our sample have been met for this and other disabled groups. We recommend a longitudinal approach given that fluctuations in case numbers and governmental guidance may appreciably impact perceptions of societal response to viruses and post-viral illness. Addressing limitations of representativeness, follow-up work should seek to ensure that pwME/CFS of differing severity are accommodated.

We present two further important findings regarding coping strategy development in pwME/CFS. Firstly, acceptance, which is commonly regarded as slow and inconsistent to develop in pwME/CFS (Chapman et al., 2019; Jason et al., 1999), emerged as a coping

theme, despite the considerable variation in illness duration within the sample. Secondly, our participants emphasised the identification and pursuance of small pleasures, which may reflect the process of benefit-finding; a positive marker indicative of resilience and post-traumatic growth (Taylor et al., 2000). Benefit-finding is inconsistently found in pwME/CFS (Arrol & Howard, 2013; Åsbring & Närvänen, 2001; McInnis et al., 2015) and future work might re-assess the prevalence and development of such coping strategies in this population.

In response to Whittingham's (2020a) initial enquiry, some findings from our sample appear to suggest similarities in their experience of health- and government-imposed lockdowns. Importantly then pwME/CFS may have found it easier to adapt to some aspects of lockdown, readily applying previously-developed coping strategies to a new source of restriction. As such, future research may further examine both strategy type and how strategy application both supports and reflects the development of acceptance and resilience in chronically ill populations. However, our sample noted that their ability to adapt to the circumstances of the government-imposed lockdown were, in some ways, a lucky coincidence; while past experience left them well-equipped to embrace digital innovations, enhanced accessibility in this domain was primarily designed to cater for the many, not the few. They also noted that the general population both failed to acknowledge the parallels between health- and government-imposed lockdown and how aspects of the latter might be experienced differently by the chronically ill, which inspired pessimistic predictions around continued societal inclusion and enhanced understanding post-pandemic.

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