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Title: Long COVID, the lived experience from a cohort observation in the United Kingdom through hand-written diaries.

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ABSTRACT

Background: Long COVID is a rapidly evolving global health crisis requiring interdisciplinary support strategies that incorporate the lived experience of patients. Currently, there is a paucity of research documenting the day-to-day experiences of patients living with Long COVID.

Objective: To explore the lived experience of Long COVID patients.

Study design: Longitudinal cohort observation.

Setting: An inductive, data-driven, qualitative approach was used to evaluate hand-written diaries obtained from individuals who had been referred to a Derbyshire Long COVID clinic.

Participants: 12 participants (11 females, age 49 ± 10 years, 11 Caucasians) were recruited. Participants were included if they had confirmed or suspected COVID-19 infection, >18 years old, understood the study requirements and provided informed consent.

Method: Participants were directed to complete self-report diaries over 16 weeks. Responses were transcribed verbatim and analysed using thematic analysis.

Results: Three key themes were highlighted; (1) a need to further understand symptoms and symptom management, (2) the impact upon the quality of life and health status, and (3) the persistence and episodic nature of symptoms affecting physical, mental, and emotional wellbeing.

Conclusions: The novel challenges presented by Long COVID are complex with varying interrelated factors that are broadly impacting quality of life. In our quest to develop efficacious support mechanisms we must incorporate the lived experiences and foster true collaborations between health professionals, researchers, and service providers to improve patient quality of life.

Future research: Research must engage a representative demographic to ensure that support services are appropriate and accessible.

Trial registration: NCT04649957.

STRENGTHS AND LIMITATIONS OF THE STUDY

- Diaries are flexible and adaptable tools which allowed participants to record their lived experiences at their convenience.
- The diaries allowed participants to open up and reveal nuanced details that, in the presence of a researcher, may not have been documented.
- Participants were instructed to use the diaries freely and so entries were not made every day by some participants.

INTRODUCTION

International efforts have been predominantly focused on addressing acute infection associated with Coronavirus disease 2019 (COVID-19). Efforts to restore social and economic areas of activity are ongoing, however, we are still very much amid a global pandemic that threatens a lasting impact on global health[1]. Despite widespread community transmission, there has been little acknowledgement from policymakers and governments to either reinstate previously effective mitigation strategies[2] or develop integrative approaches aimed at controlling the pandemic through risk assessment and containment measures postulated to be more successful long-term (i.e., effective testing and monitoring, safeguarding healthcare staff, and sufficient medical resources)[3]. The development and rollout of efficacious vaccines have undoubtedly reduced the severity of acute infections, observed by a reduction in hospitalisations and mortality[4, 5]. However, vaccines only offer partial protection against the development of Long COVID and current data estimates that 1 in 10 positive COVID-19 infections will experience long-term illness, accordingly, sustained transmission will inevitably lead to an increase in Long COVID prevalence[1]. Long COVID is a patient-made term[6] and is currently defined by the World Health Organisation as individuals with probable or confirmed COVID-19 diagnosis presenting symptoms 3 months after symptom onset, and symptoms lasting at least 2 months that cannot be explained by an alternative diagnosis[7], whilst there are various definitions it generally describes a persistent and often complex symptom profile that broadly impacts quality of life (QoL).

Recent statistics estimate that >2 million people in the United Kingdom (UK)[8] and 144.7 million globally[9] are living with long-term and debilitating symptom profiles of Long COVID. The Office for National Statistics demonstrates a broad incidence of Long COVID in females aged 35-69 years old, and those from lower socioeconomic backgrounds, further evidence of a widening health-inequalities gap[8, 10, 11]. The complex and episodic symptom profile is at the front of mechanistic investigations to increase pathological insight but the lived experience of patients has thus far received little attention[12]. The need to obtain a mechanistic understanding is unquestionable to inform the design and development of appropriate support services and pharmacological interventions that can address patient complaints. However, even in the wake of future treatment approaches, the longstanding impact on physical health and mental well-being will require comprehensive support mechanisms to restore pre-COVID-19 functional status and QoL.

Although limited longitudinal investigations exist, reports of physical, cognitive, and psychosocial symptoms (i.e., fatigue, brain fog, and anxiety) that impact multiple physiological systems (i.e., cardiovascular, respiratory, and pulmonary system) are becoming well documented[13-15]. Davis et al.[13] identified three symptom clusters that have distinct temporal profiles, cluster 1 identified early symptoms that peak and then diminish (i.e., runny nose, loss of appetite, fever), cluster 2 represented stable symptoms (i.e., nausea, chest tightness, fatigue), meanwhile cluster 3 represented symptoms that initially increase sharply than either plateau or slightly increase or decrease over the following months (i.e., palpitations, brain fog, post-exertional malaise)[13]. Unpredictable symptom profiles could partly explain why individuals with Long COVID have struggled to access the support that is needed to help them manage/improve their condition.

Another aspect reported via an online survey of Long COVID is the episodic nature of symptoms[16] with 86% of participants (n= 3,252, 95% Confidence Interval (CI), 84.8% to 87.0%) having symptoms triggered or exacerbated by physical or mental activities[13]. Despite a call for the lived experience to be key in the design and implementation within research[17], there is a lack of detail and studies that provide qualitative accounts of patients. Callan et al.[18] recognised the relapsing-remitting time course of Long COVID as an ‘episodic disability’ whereby participants reported brain fog that aligned with the unpredictable wellness and illness previously described in HIV-positive patients. However, the focus groups were followed up 4-6 months later by email and similarly provide a snapshot summary to that of online surveys. Witvliet[19] retrospectively revealed the details of her personal Long COVID journey which revealed nuanced details that would not be captured in clinical pathways. This detail could provide important insight to support clinical decision making but also in the development of Long COVID support pathways that are relevant, accepted and lead to improved patient outcomes.

Patient diaries have previously been used in intensive care units (ICU) and are useful tools to document patients' lived experiences[20, 21]. Diaries are flexible and adaptable tools that can be used anytime and away from face-to-face research and clinical settings[21] which can bridge the gap in communication between patients and healthcare providers[22]. However, the use of diaries in documenting the day-to-day lived experience of individuals with Long COVID is not commonplace and there is a paucity of data obtained that documents the lived experience which is important in the design and development of specific support mechanisms[17]. Accordingly, this study sought to capture the lived experience of individuals with Long COVID taking part in a 16-week cohort observation study collected via hand-written diaries.

METHODS

Following NHS research ethics approval (IRAS ID: 292920) and informed consent, qualitative accounts of the lived experience of 12 Long COVID participants (1 male, age 49 ± 10 years) were recorded via diaries over 16 weeks. The diaries formed part of a larger cohort observation of individuals recovering in community settings from a COVID-19 infection. Participants were recruited following a referral from an established Long COVID clinic and directed to use the diaries freely to capture information that they deemed appropriate as part of their post-COVID-19 journey. This exploratory approach was appropriate given the lack of understanding of the lived Long COVID experiences, and a greater need to inform the development of bespoke support mechanisms.

Researcher characteristics

The researchers had bimonthly contact with participants, and this did influence diary entries, with multiple accounts of site visits and their impact upon symptoms. Researchers in contact with participants had not previously worked with hand-written diaries however given participants were instructed to use diaries freely, this should have had limited impact on how they were used.

Patient and public involvement (PPI) statement

PPI was a crucial part of the research design, implementation of the project and interpretation of the resulting data reported here. Participants were instructed to freely create their own data that was relevant to their lived experience of COVID-19. Participants were involved in raising awareness of our research to recruit participants in their Long COVID networks and will also be involved in the dissemination of the results by sharing the findings with their support groups and networks.

Data analysis

Extracts were transcribed verbatim and coded using the qualitative software NVIVO 12 Pro (Version 12.7, QSR International, Doncaster, Australia). An inductive, data-driven approach was adopted to code the data into descriptive terms which were collated to produce 12 themes and 82 sub-themes. Themes and sub-themes were grouped to generate three overarching themes, (1) Understanding symptom management (2) QoL status and (3) Emotions. Theme coverage was also reported and denoted the percentage reporting of the theme across all the diaries. A sample of the data was shared with the trial steering group to check for accuracy and avoidance of interpretational bias.

RESULTS

Participant characteristics are detailed in Table 1 and are skewed in representation towards white, middle-aged females, and are consistent with research in this area[23].

Table 1: Pooled participant pre-COVID, baseline and 16-week post-baseline measures (Mean ± SD).

	Pre-COVID	Baseline	16-weeks	*P* values
Overall health (AU)	2 ± 0.9	4 ± 0.6	3 ± 0.8	< 0.001
COVID-19 Symptom rating (AU)	-	8 ± 1	7 ± 2	0.324
PCFS (AU)	-	3 ± 0.4	2 ± 0.8	0.054
Dyspnoea (AU)	-	3 ± 0.7	3 ± 0.8	1.000
EQ5D-5L (AU)	-	13 ± 3	13 ± 5	0.575
EQ5D-5L VAS (AU)	-	46 ± 16	47 ± 22	0.691

Overall health score: 1-5 scale (1 = very good and 5 = very bad). COVID-19 Symptom score: 0–10 rating of symptom effect on daily life (0 = no impact / symptoms and 10 = symptom/s have had a big effect). PCFS: 0–4 scale of functional status (0 = no limitations and 4 = severe limitations). Dyspnoea: 1-5 scale of breathlessness (1 = breathless only with strenuous exercise and 5 = too breathless to leave the house). EQ5D-5L involves rating subcategories of mobility, self-care, usual activities, pain/discomfort, and anxiety/depression on a 1-5 scale (1 = no problems and 5 = extreme problems or inability). EQ5D-5L VAS: 0-100 scale of perceived overall health (0 = worst health they can imagine and 100 the best health they can imagine). Overall health data only for retrospective pre-COVID evaluation. AU, Arbitrary Unit, PCFS, Post COVID Functional Status, VAS, Visual Analogue Score. *P* values are derived from paired samples t-tests.

Theme 1: Understanding symptom management

Symptom management received 66% coverage with 2,089/2911 references made to Long COVID symptoms. Furthermore, the broad and cyclical nature of symptoms highlights the day-to-day challenges associated with COVID-19 recovery:

> *"… headache (lighter), aches/ pains in muscles/ joints, pains/ aches in chest, shortness of breath, brain pulsating, light ringing in ears. Thought I'd put the alarm on and I hadn't, internal vibrations/pain in upper arms… kept losing focus in online training."*

> *"… went out for a meal with work for a couple of hours - felt good. Got home - symptoms returned intensely."*

> *"Pins and needles went yesterday evening. Arms feel wonderful again. No pins and needles in hand. Made such a difference to my mood today… Every day is a new day."*

Nine out of the twelve diaries made references relating to the awareness and availability of healthcare support to help participants cope with the challenges of living with Long COVID. There were regular suggestions that the services were unhelpful, underdeveloped, and slow:

> *"…neurology appointment came away disappointed and angry at lack of understanding…"*

> *"Felt the doctor (as in GP) needs awareness raising more to Long COVID."*

> *"Chased Long COVID clinic been waiting since 25th June. Still, 2.5 months to wait at least!!"*

In response to frustration at a lack of services, participants reported opting to try self-treatment methods with mixed results. These include self-prescribed vitamin supplementation or changes to diet:

> *"Can feel the benefits of B 12 – less fatigue."*

> *"Still feel antihistamines and low histamine diet do help."*

Other instances highlight that these experimental treatments resulted in symptom exacerbation:

> *"…went to… oxygen centre for an intense therapy trial. Had to stop procedure after 15 minutes due to intensifying chest pain and blurred vision"*

> *"Oxygen therapy. extremely tired, confusion + brain"*

Despite this frustration, there was recognition that care services to appropriately support their needs are developing:

> *"Occupational therapist through LC clinic really supportive/ helpful."*

> *"Now seen CF [Chronic fatigue] clinic and improving pacing"*

Furthermore, a doctor within an established Long COVID clinic was able to identify symptoms associated with a pulmonary embolism and was able to make a referral for further examination.

> *"Very good referrals to fatigue clinic, breathing clinic, vocational rehab, blood tests, eye checks. Go to A&E for blood clot check."*

The role of the family as part of the lived experience was also repeatedly noted. However, akin to healthcare support services, the data provided mixed findings. For example, some participants were very dependent on family and the support provided was crucial to everyday life and functional activity:

> *"In a lot of pain after the walk, not comfortable going out without my wife support."*

> *"Totally exhausted and hardly able to do anything, my husband is looking after me."*

The diaries also revealed that participants played an important role in supporting their families, usually in the form of some sort of task or responsibility. Unsurprisingly, this served to exacerbate symptoms and/or have negative outcomes:

> *"Saw son + his girlfriend so cooked lunch for them - was fab to see them but wiped me out - everything ached and was shattered!!"*

> *"Stayed at sons for night to look after his dogs, flooded kitchen, (forgot I'd left tap on)."*

Theme 2: Quality of Life status

Symptoms were closely associated with QoL (29% coverage). This theme not only identified the impact on functional status and ability of participants to be physically active but also the numerous times they needed to recover and manage symptoms accordingly. Commonly reported symptoms of tiredness, fatigue, and exhaustion were often managed with recovery periods:

"…visit to see my Auntie. An exhausting day… genuine chest pain and tightness so sat down… my chest problems are worsening… exhausted so went upstairs straight away."

"Went to a church service, walked but it was very slow, tiring and cause chest tightness. Went and lay on the bed all of the afternoon. Couldn't remember how long I slept."

Regardless of whether recovery was acute (i.e., a quick nap on the sofa) or prolonged (i.e., resting all day in bed), symptoms were not consistently alleviated, and it was commonplace for symptoms to persist and often become exacerbated:

"Rested from 5pm - After a couple of hours symptoms intensified again. Had conversation with a friend and kept forgetting simple words."

"Rested all afternoon. Made tea / struggled to walk my dog. All symptoms intensified, unable to do anything else, pains in muscles/joints particularly fingers/hands, forearms and elbows. Light headedness."

Persistent symptomology also impacted routine functional activities that pre-COVID-19 infection would have likely taken less time and energy to complete. This ranged from difficulty to concentrate during a task, as well as prolonging the length of time to complete that activity:

"…writing Christmas cards out of my mind. Completed them but it took three hours. It took me three times longer than before I had Long COVID. "

"Took all day to Hoover and Polish"

The ability to exercise had also changed, with a few accounts of low volume cycling, or light cross-trainer or treadmill activities reported. In most instances, targeted exercise for participants was intolerable:

"The physios want me to continue the exercises at home but that is impossible for me to do."

"Exercise but everything seems like one step forward and two steps [back]"

There was a determination from participants to engage in physical activities. Walking was frequently reported however was consistently linked with an exacerbation of symptoms:

"Try taking my dog for a walk… This was hard as my legs felt heavy and tired to move."

> *"Physios want me to continue the exercises at home but that is impossible for me to do. No strength at all."*

Return to work was affected by Long COVID symptoms and some participants did not feel prepared to resume their careers due to the physical and mental challenges of work:

> *"I am signed off work… still feel I would be unable to return to work at present (feel concerned whether I will ever be able to [return to] my job as a community nurse as it is a mentally and physically demanding role)."*

However, participants who returned to work described the experience as a "*fight*", while having to manage the challenges of their symptoms alongside the financial pressures of having had an extensive period of leave from work:

> *"Having to fight for every step as well as being ill."*

> *"Grief from work - half pay without notice."*

A key facet in all activities was the role of pacing. Participants were often keen to be functional and active, and pacing strategies helped them manage these activities:

> *"Very tired this evening but know I would be so tea out the freezer. Getting better on these days. I'm not superhuman. I can pace."*

> *"Very tiring week… paced myself each day."*

For some, advice was sought from other individuals recovering from COVID-19 infection. Specifically, sharing of experiences helped participants pace and manage activities in their own lives:

> *"Interesting interview on Lorraine with Nick Knowles TV presenter. after having COVID and wanting to get back into shape he returned to the gym and found exercised knocked him back with recovery. Quite interesting I think, since I've eased off with my morning gym sessions, I think it may be helping my recovery?"*

Another interesting finding was that participants could pace their activities feeling ok until they stopped, thereafter symptoms were unbearable:

> *"Helped install CCTV system, wanted to do something normal [to] see how I got on. Lots of breaks, pace myself, painkillers. Was OK until I stopped. Symptoms intensified immensely,*

> *nine out of 10"*

Therefore, it does seem that there is a limit of tolerance on the extent to which pacing can help during a particular activity, with education on the cumulative activity load across a time needing to be established:

> *"Went to horse again and a walked at a steady pace with regular stops to get some fresh air. Left ear still blocked, whooshing and earache, left arm still weak and unable to lift for long without getting a cramping pain. Pain in feet and internal vibrations at night, still coughing phlegm up and a cough…"*

The symptom exacerbation following activities was widely reported, however, participants chose to still engage with certain activities despite knowing that symptoms would occur during or afterwards:

> *"Went to a family wedding at 1:00pm. Very hard to make the effort but enjoyed seeing my nephew getting married. Had to leave early, was totally exhausted and went to bed at 7:00pm."*

> *"Went to meet a friend for coffee, exhausted after and needed to rest."*

Socialising did not always reap the preconceived benefits and, on some occasions, served to make participants feel worse. This did not just exacerbate physical symptoms, but also presented mental and emotionally difficulties:

> *"Taken to coffee but taking part in 1960s quiz very physically and mentally exhausted… failed miserably at quiz due to total brain fog… Went to bed again in the afternoon feeling very frustrated…"*

Theme 3: Emotions

Another pillar on which our codes were structured was through the emotions and thoughts of our participants (5% coverage). A range of negative emotions accompanied changes in symptomology and functional capacity:

> *"Came home and had a soak in the bath which took an hour to get over after getting out muscles and joints aching. By late afternoon muscles and joints nerve aching from head to toe… I was sobbing with the pain."*

> *"Had bad night sleep, feeling anxious + teary this morning. Feel unable to attend study appointment due to feeling unwell so have rescheduled."*

Emotions were accompanied with comparisons to healthy individuals around them which frequently led to negative sentiments and feelings of despair:

> *"Was taken to church in the morning followed by a fund-raising coffee morning for Macmillan Cancer Research. It made me aware of how I am still physically and mentally "disabled" due to how quickly other non-Long COVID people moved about."*

> *"Sitting on the side-lines watching everyone else live."*

Furthermore, participants would also compare themselves to their pre-infection state…:

> *"Worried whether I will ever get back to pre Long COVID state."*

> *"Still ever present - the failing/knowledge that, without the sertraline, I would be in a little ball of depression. When will this end. Will I ever get my life back."*

…with changes in identity and emotional sensitivity since infection also reported:

> *"I was made aware that I now have very little compassion or empathy- I'm not the same person."*

> *"I just know I'm not me anymore."*

4. Theme undulation

An area that underpinned all themes was the undulating nature of the post-COVID-19 journey and the interconnectivity of all themes. Participants often revealed that it was commonplace to experience a period of improvement followed by worsening of symptoms, day-by-day in some cases. However, this was often accompanied by comments regarding a correlated change in their QoL status and emotional state:

> *"…sadly looks like another corner turned ☹. Energy levels even more. Craved carbs and chocolate."*

> *"Every day is a new day."*

DISCUSSION

To the best of our knowledge, this is the first study to provide a detailed qualitative account of the day-to-day experiences of individuals living with Long COVID. The data highlights three key themes relating to: (1) understanding symptom management and the presentation of a broad symptom profile, (2) the impact upon QoL, health status and the role of pacing in managing functional tasks, (3) turbulent and episodic symptom profiles with changes in physical, mental, and emotional status.

Arguably the biggest challenge associated with Long COVID is its broad symptom profile[15]. Our work aligns with previous research that has identified the most prevalent symptom profiles associated with Long COVID[1, 13, 24, 25]. However, data here recognises the integration of the symptoms with factors such as QoL status, and comparisons with healthy others and previous self, rather than considering these in isolation. For many participants, symptoms were managed by rest or sleep, which impacts their ability to undertake activities of daily life (e.g., completing the school run or engaging in social activities). It was reported that when participants did attempt activities that are deemed low intensity this would exacerbate symptoms and lead to an extended period of convalescence. Accordingly, attempting to live with Long COVID requires considered support mechanisms that aim to help individuals understand changes in their physical, mental, and emotional health which is in line with an episodic symptom profile that is prone to exacerbation. A further consideration is to understand the episodic nature of Long COVID. Participants here reported perceived improvements in symptom severity, often referring to '*turning a corner',* however, this could change instantaneously and without any provocation in some cases, a finding that has been recognised in other studies[13, 18, 19, 26]. It is well known that patients with chronic diseases will increase activities when they feel able but with little consideration of the consequences[27]. As such, further research is required to document changes in symptom profile relative to increased volume and intensity of activity.

Data here supports that of Davis et al.[13], who highlighted disparate recovery profiles that failed to reach a resolution 7 months post-infection, thus highlighting the individual nature and the need for tailored approaches[14]. The broad and complex symptom profile of Long COVID makes it hard for health workers, family and friends to fully understand the realities of living with a debilitating and unpredictable condition[16]. Our data extend this understanding by demonstrating that multiple stakeholders are often involved in the Long COVID journey, which is representative of the multidimensional and complex presentation of this condition. Boix et al.[28] reported that many people with Long COVID have unfortunately struggled to have their condition recognised. Patients have therefore felt isolated and resulted to self-treatment methods given the lack of knowledge, understanding, and bespoke treatments available for their condition and, in some instances, this has served to deteriorate, rather than ameliorate, their health[29, 30].

Following critical illness such as a severe COVID-19 infection, it can be commonplace to experience a range of difficult emotions and periods of stress which can manifest in the form of feeling tearful, lack of appetite, and difficulty sleeping[31]. Houben-Wilke and colleagues[32] demonstrate that negative emotions (i.e., post-traumatic stress disorder, anxiety, and depression) persist in some Long COVID patients 3 and 6 months after the onset of COVID-19 symptoms, with a prevalence comparable between hospitalised and non-hospitalised patients. Our data indicates in a non-hospitalised cohort that these emotions are frequently borne out of symptomology, however, comparisons to healthy individuals and pre-infection states are centred at the heart of these thought processes. Houben-Wilke et al.[32] cited a lack of care and unmet needs as factors that contribute to negative emotions, however, future support services also need to consider helping Long COVID patients accept their new baseline health to avoid unhelpful comparisons. There is a need to further this understanding with more research concerning the clear need for physical, mental, and emotional support.

The body of research surrounding the treatment and management of Long COVID is of international interest, however, there is a need to develop bespoke, adaptive, flexible, and interdisciplinary resources to support individuals with Long COVID[33-35]. This is in keeping with one of our main findings which was the broad and undulating symptom profile reported by participants. Macpherson and colleagues[36] suggest services to support patients could take the form of 'one-stop' clinics in hospitals to treat patients holistically alongside established multidisciplinary departments. However, time to access support presented one of the biggest challenges to our participants, and if 'one-stop' clinics cannot support demand then patients may refer to potentially harmful self-treatment methods that will exacerbate symptoms. Therefore, whilst 'one-stop' multidisciplinary approaches offer a potential solution, the complex clinical presentation with patient settings may be better suited to a detailed and expansive service that is underpinned by a comprehensive screening process that directs patients to the required services which act in a 'buffet style system' where patients can access (in both volume and intensity) services they require to positively influence clinical outcomes.

Multidisciplinary collaboration has been suggested as an approach to provide Long COVID support[1, 11]. However, given the nature of multidisciplinary teams (i.e., lack of interaction and unison between members), it is postulated that this would have limited patient benefit[1]. Alternatively, Faghy and colleagues[1] suggest an interdisciplinary approach embedded in systems science may better help identify key stakeholders that can assist in the design, delivery and evaluation of support services. This will be vital given the prevalence of Long COVID[9] combined with a chronically under-resourced and understaffed NHS[37]. One group of stakeholders that may help ease this growing clinical burden are sports and exercise medical professionals whose expertise can help design and deliver holistic rehabilitative programmes. For example, these professionals could supervise patients' volume and intensity selection process for their directed activities, which importantly does not necessarily need to include physical activity (i.e., diaphragmatic/box breathing)[33, 35]. Furthermore, the resources of this sector (i.e., physiological laboratories as testing facilities) may also help ease the burden on primary healthcare settings. However, it is important the lived experience is incorporated into the entirety of the process to ensure the co-design and delivery of services address patient needs, are safe and are accepted by Long COVID patients[38]. For example, it is widely acknowledged that key triggers (physical, cognitive and emotional) can lead to provoke a relapse or worsening of symptoms[13], and this may explain why previous attempts to re-purpose existing clinical interventions for Long COVID services have not been accepted and in some cases have been damaging (i.e., the prescription of physical activity and graded exercise therapy)[39-41]. Early indications of the effectiveness of a personalised approach have been positive[42], however, these lack the involvement of the lived patient experience in the design and testing process and so also risk rejection if not suitable in the applied setting. Gorna et al.[17] propose that an approach involving an individualised physical assessment by physicians with medical expertise to identify organ and multisystem dysfunction is needed. This could then inform individualised and wider rehabilitation plans that will also be inclusive of other key stakeholders (i.e., employers when employees are returning to work). However, broad representation must be a key consideration in future work to ensure robust advice is provided, and the inclusion of the lived experience of minority groups with Long COVID also needs to be better understood.

A limitation of COVID-19 research, inclusive of our work, is the lack of ethnic diversity, male representation and small sample sizes[13, 26, 36, 43-45]. Long COVID has a tendency to present more commonly in females than males[46], however, ethnic minorities have been disproportionately affected by the COVID-19 pandemic[47-49]. A recent report by the National Institute for Health Research showed that the latter group constituted only 9% of cohorts in COVID-19 studies conducted in the UK. This is despite ethnic minorities constituting 14% of the general population in the UK[50]. Current barriers to taking part in COVID-19 research have been postulated to include access to health services, language, and mistrust[43-45, 51, 52]. Gopal and colleagues[52] explain that existing equality and diversity recommendations to tackle these barriers (i.e., cultural competency training) have the potential to do more harm than good through ethnocentrism and stereotyping. Instead, they recommend that a Cultural Safety approach engrained within a deep medicine ideology would be most appropriate. By focusing on the individual experience of care, staff self-reflexivity, and structural reflexivity, Gopal et al.[52] postulate deep medicine would help overcome barriers such as mistrust and, subsequently, may help facilitate researcher-participant relationships in future research[53, 54]. Developing rapport by establishing and aligning with key principles valued by patients and reflecting with peers that challenge our own biases are just a couple of key examples of how future studies may look to develop trust and provide a safe, reassuring environment for ethnic minorities. This would be especially valuable in observational studies such as our own that require participant engagement over a prolonged period.

CONCLUSIONS

This study has added to a growing body of literature in sharing the lived experience of Long COVID from the perspective of the patients. Over 16 weeks, our work recognised the broad, disabling, and episodic symptom profile of people living with Long COVID. It is vital more is done to support an already isolated group in a manner that not only provides validation to the Long COVID patient, but also a specific and adaptive support system that addresses the milieu of symptoms and undulating nature synonymous with Long COVID.

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Data sharing statement: Anonymised data can be made available on request.

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APPENDICES

Apendix A – Theme 1 additional quotes:

"Struggled to get up/ fatigue. Short of breath. Tinnitus horrendous every day. sore throat. Cannot sleep. Lymph nodes swollen Clavicle/ underarm. Aching like I have the flu."

"Feeling exhausted had a steady day out with my hubby and he did all of the driving."

"Felt really drained and lacking energy again. Slept for a short time at lunchtime. Cried because I was so tired, I didn't have the energy to drive to hospital to visit husband. Got son to take me."

"Sunday funday. Cinema with son. It was the best day of his life. Mean so very much to hear and see him enjoy himself. Had to be up early to get there so slept in car on way home in traffic."

Appendix B – Theme 2 additional quotes:

"Attended university research programme… Pretty exhausting mentally… Lay on the bed all afternoon and retired at 9:00pm - so very tired with no energy."

"Had a rest day still having muscle pain and nerve pain and muscle twitches."

"Great effort required to climb stairs. Legs painful and like Jelly."

"Short of breath for most of the journey. How can be sitting as a passenger in the car be so tiring."

"Rested the rest of the day - headache increased"

"Took my dog for a slow short walk - very difficult to do and took twice as long."

"Walked 50 metres… very tiring and struggled with breathing on return journey."

"Anxiety - through the roof at times but that due to work, money issues."

Appendix C – Theme 3 additional quotes:

"Heart pounding today for most of day. Emotionally very angry today (for no reason). Did very little today - watched TV and visited family. poor appetite today."

"Make me feel down when I go out and see how fast other people move about or is it just that I am so slow."

Appendix D – Theme 4 additional quotes:

"Everything seems like one step forward and two steps back"

ID bmjopen-2020-041038 SRQR Checklist

	Item	Page
Title	Item 1. Title: Concise description of the nature and topic of the study. Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended.	page 1
Abstract	Item 2. Abstract: Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions.	page 2
Problem Formulation	Item 3. Problem Formulation: Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement.	pages 3-5
Purpose or research question	Item 4. Purpose or research question: Purpose of the study and specific objectives or questions.	page 5
	Item 5. Qualitative approach and research paradigm: Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., post-positivist, constructivist/interpretivist) is also recommended; rationale	pages 2, 5 & 6
	Item 6. Researcher characteristics and reflexivity: Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results and/or transferability.	page 5
Context	Item 7. Context: Setting/site and salient contextual factors; rationale.	pages 2 & 5
Sampling strategy	Item 8. Sampling strategy: How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale.	page 5
Ethical issues pertaining to human subjects	Item 9. Ethical issues pertaining to human subjects: Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues.	page 5

	Item 10. Data collection methods: Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale.	page 5
Data collection instruments and technologies	Item 11. Data collection instruments and technologies: Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study.	page 5
Units of study	Item 12. Units of study: Number and relevant characteristics of participants, documents, or events included in the study; level of participation.	pages 5 & 6
Data processing	Item 13. Data processing: Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding and anonymization / de-identification of excerpts.	page 6
Data analysis	Item 14. Data analysis: Process by which inferences, themes, etc. were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale.	page 6
Techniques to enhance trustworthiness	Item 15. Techniques to enhance trustworthiness: Techniques to enhance trustworthiness and credibility of data analysis,(e.g., member checking, triangulation, audit trail); rationale	page 6
Synthesis and interpretation	Item 16. Synthesis and interpretation: Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory.	pages 6 & 13
Links to empirical data	Item 17. Links to empirical data: Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings.	pages 13 - 16
	Item 18. Integration with prior work, implications, transferability, and contribution(s) to the field: Short summary of main findings, explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field.	pages 13 -16
Limitations	Item 19. Limitations: Trustworthiness and limitations of findings	pages 3, 15 & 16

Gilbert AW, *et al. BMJ Open* 2021; 11:e041038. doi: 10.1136/bmjopen-2020-041038

Conflicts of interest	Item 20. Conflicts of interest: Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed.	page 17
Funding	Item 21. Funding: Sources of funding and other support; role of funders in data collection, interpretation, and reporting.	page 17

Long COVID, the lived experience of patients from a cohort observation in the UK.

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Title: Long COVID, the lived experience of patients from a cohort observation in the UK.

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Key Words: Lived experience, COVID-19, Long COVID, Health and Wellbeing

ABSTRACT

Background: Long COVID is a rapidly evolving global health crisis requiring interdisciplinary support strategies that incorporate the lived experience of patients. Currently, there is a paucity of research documenting the day-to-day experiences of patients living with Long COVID.

Objective: To explore the lived experience of Long COVID patients.

Study design: Longitudinal qualitative cohort observation.

Setting: An inductive, data-driven, qualitative approach was used to evaluate hand-written diaries obtained from individuals who had been referred to a Derbyshire Long COVID clinic.

Participants: 12 participants (11 females, age 49 ± 10 years, 11 Caucasians) were recruited. Participants were included if they had a previous confirmed or suspected COVID-19 infection with ongoing recovery, >18 years old, understood the study requirements and provided informed consent.

Method: Participants were directed to complete self-report diaries over 16 weeks. Responses were transcribed verbatim and analysed using thematic analysis.

Results: Three key themes were highlighted; (1) a need to further understand symptoms and symptom management, (2) the impact upon the quality of life and health status, and (3) the effect of turbulent and episodic symptom profiles on personal identity and recovery.

Conclusions: The novel challenges presented by Long COVID are complex with varying interrelated factors that are broadly impacting functional status and quality of life. Support mechanisms must incorporate the lived experiences and foster true collaborations between health professionals, patients, and researchers to improve patient outcomes.

Trial registration: NCT04649957.

STRENGTHS AND LIMITATIONS OF THE STUDY

- Self-report diaries are flexible and adaptable methods that allow participants to record their feelings and lived experiences at their convenience.
- The diaries allowed participants to open up and reveal nuanced details that, in the presence of a researcher, may not have been documented.
- The diaries allowed participants to document their experiences over time rather than at predetermined moments where they may not have been prepared physically or emotionally to answer.
- Participants were instructed to use the diaries freely and so entries were not made every day by some participants.

INTRODUCTION

Over the time-course of the Coronavirus pandemic 2019 (COVID-19), international attention has predominantly focused on addressing the impact of acute infection. Thanks to effective and widespread vaccination this has undoubtedly reduced the severity of acute infections, observed by a reduction in hospitalisations and mortality[1, 2]. As such the focus has now shifted to restoring social and economic activities. Despite a shift in focus, we are still very much amid a pandemic that is demonstrating a lasting impact on public health[3]. Whilst vaccines reduce the likelihood of severe patient outcomes, it is established that vaccines do not prevent transmission or infection with SARS-COV-2 and they offer minimal protection against post-viral issues and symptom profiles, commonly referred to as Long COVID.

Defined by the World Health Organisation as '*individuals with probable or confirmed COVID-19 diagnosis presenting symptoms 3 months after symptom onset, and symptoms lasting at least 2 months that cannot be explained by an alternative diagnosis*'[4]. Recent statistics estimate that >2 million people in the United Kingdom (UK)[5] and 144.7 million globally[6] are living with long-term and debilitating symptom profiles of Long COVID[7]. The complex and episodic symptom profile is at the forefront of mechanistic investigations to increase pathological insight. Reports highlight the extent of physical, cognitive, and psychosocial symptoms (i.e., fatigue, brain fog, and anxiety) and the impact upon multiple bodily systems (i.e., cardiovascular, respiratory, and pulmonary system) that is becoming established[8-10] Davis et al.[8] identified three symptom clusters that have distinct temporal profiles, cluster 1 identified early symptoms that peak and then diminish (i.e., runny nose, loss of appetite, fever), cluster 2 represented stable symptoms (i.e., nausea, chest tightness, fatigue), meanwhile cluster

3 represented symptoms that initially increase sharply then either plateau or slightly increase or decrease over the following months (i.e., palpitations, brain fog, post-exertional malaise)[8]. Another aspect reported via an online survey of Long COVID is the episodic nature of symptoms[11] with 86% of participants (n= 3,252, 95% Confidence Interval (CI), 84.8% to 87.0%) having symptoms triggered or exacerbated by physical or mental activities[8].

Recent data suggest that 1 in 10 positive SARS-CoV-2 infections will go on to experience long-term illness[8]. There is an unquestionable need to increase the pathological understanding to inform the design and development of bespoke and safe support services and pharmacological interventions for Long COVID patients. However, given the unique nature of COVID-19 and Long COVID, there is a need to engage the intended stakeholders and learn from the experiences of those living with this condition. Despite repeated calls from patients to incorporate the lived experience as a prominent feature in the design and implementation of research[12], there remains a lack of detail that provides thorough longitudinal insight from patients. Callan et al.[13] recognised the relapsing-remitting time course of Long COVID as an ‘episodic disability’ whereby participants reported brain fog that aligned with the unpredictable wellness and illness previously described in HIV-positive patients. However, the focus groups were followed up 4-6 months later by email and similarly provide a snapshot summary to that of online surveys. Witvliet[14] retrospectively revealed the details of her personal Long COVID journey which included nuanced details that would not be captured in clinical pathways. This detail could provide important insight to support clinical decision making but also in the development of Long COVID support pathways that are relevant, accepted, and lead to improved patient outcomes. Patient diaries have previously been used in intensive care units (ICU) and are useful tools to document patients’ lived experiences[15, 16]. Diaries are flexible and adaptable tools that can be used anytime and away from face-to-face research and clinical settings[16] which can bridge the gap in communication between patients and healthcare providers[17]. Diaries can allow Long COVID patients to remember their experiences independent of recall bias and without eliciting emotional difficulty that is brought about with an in-person consultation. However, the use of diaries in documenting the day-to-day lived experience of individuals with Long COVID is not commonplace and there is a paucity of data obtained that documents the longitudinal lived experience which is important in the design and development of specific support mechanisms[12]. Accordingly, this study sought to capture the lived experience of individuals with Long COVID taking part in a 16-week cohort observation study collected via hand-written diaries.

METHODS

Following NHS research ethics approval (IRAS ID: 292920) and informed consent, qualitative accounts of the lived experience of 12 Long COVID participants were recorded via diaries over 16 weeks. Previous post-viral research and the paucity of SARS-CoV-2 infection recovery information influenced the study design rationale of 16 weeks; however, we acknowledge current recovery time extends beyond this significantly. The diaries formed part of a larger cohort observation powered by sample analysis techniques of individuals recovering at home from a SARS-CoV-2 infection. The sample presented here was a sub-sample of patients that completed the study. Data from the diaries were monitored continuously and analysed until saturation. Participants were recruited following a referral from an established Long COVID clinic where a participant information sheet and contact details were provided to obtain any further detail/clarifications. Following the request to participate in the study, participants were passed onto the research team for consenting. As part of the study procedures listed entirely at clinicaltrials.gov (NCT04649957), participants were provided with and directed to freely use a self-report diary, that was returned and photocopied monthly, to capture information that they deemed appropriate as part of their post-COVID-19 journey. This exploratory approach was appropriate given the lack of understanding of the lived Long COVID experiences, and a greater need to inform the development of bespoke support mechanisms.

Researcher characteristics

Researchers from the University of Derby had bimonthly contact with participants and instructed them to use diaries freely; this should have had limited impact on how they were used. A member of the research team (CT) transcribed, coded, and thematically analysed all the diaries, and then uploaded completed transcriptions to a secure OneDrive file. Alongside regular meetings, diaries in this file were checked for accuracy by other members of the research team (MAF, REA, RO, JY, and FVF). CT had previous experience with interview transcription.

Patient and Public Involvement and Engagement (PPIE) statement

PPIE was a crucial part of the research design, implementation of the project, and interpretation of the resulting data reported in this manuscript. Previous research team experiences with pneumonia patients informed the data collection materials repurposed for this study. Participants were involved in raising awareness of our research to recruit participants in their

Long COVID networks and will also be involved in the dissemination of the results by sharing the findings with their support groups and networks.

Data analysis

Full diaries were transcribed verbatim and coded using the qualitative software NVIVO 12 Pro (Version 12.7, QSR International, Doncaster, Australia). An inductive, data-driven approach was adopted to code the data into descriptive terms which were collated to produce 12 themes and 82 sub-themes. Themes and sub-themes were grouped to generate three overarching themes, (1) a need to further understand symptoms and symptom management, (2) the impact upon the quality of life and health status, and (3) the effect of turbulent and episodic symptom profiles on personal identity and recovery. Theme coverage was also reported and denoted the percentage reporting of the theme across all the diaries. A sample of the data was shared with the trial steering group to check for accuracy and avoidance of interpretational bias.

RESULTS

Participant characteristics are detailed in Table 1 and are coincidentally skewed in representation towards white, middle-aged females, and are consistent with research in this area[18].

Table 1: Pooled participant pre-COVID, baseline and 16-week post-baseline measures (Mean ± SD).

Demographic Profile		Mean (± SD)		
Age (years)		49 ± 10		
Sex		Male (N=1) Female (N=11)		
Ethnicity		White British (N=11)		
Occupational Status		Employed Full Time (N=3) Illness absence from work (N=8) Retired (N=1)		
Index of Multiple Deprivation (IMD) Decile		7 ± 3		
Performance Status	Pre-COVID	Baseline	16-weeks	*P* values

Overall health (AU)	2 ± 0.9	4 ± 0.6	3 ± 0.8	< 0.001
COVID-19 Symptom rating (AU)	-	8 ± 1	7 ± 2	0.324
PCFS (AU)	-	3 ± 0.4	2 ± 0.8	0.054
Dyspnoea (AU)	-	3 ± 0.7	3 ± 0.8	1.000
EQ5D-5L (AU)	-	13 ± 3	13 ± 5	0.575
EQ5D-5L VAS (AU)	-	46 ± 16	47 ± 22	0.691

Overall health score: 1-5 scale (1 = very good and 5 = very bad). COVID-19 Symptom score: 0–10 rating of symptom effect on daily life (0 = no impact / symptoms and 10 = symptom/s have had a big effect). PCFS: 0–4 scale of functional status (0 = no limitations and 4 = severe limitations). Dyspnoea: 1-5 scale of breathlessness (1 = breathless only with strenuous exercise and 5 = too breathless to leave the house). EQ5D-5L involves rating subcategories of mobility, self-care, usual activities, pain/discomfort, and anxiety/depression on a 1-5 scale (1 = no problems and 5 = extreme problems or inability). EQ5D-5L VAS: 0-100 scale of perceived overall health (0 = worst health they can imagine and 100 the best health they can imagine). Overall health data only for retrospective pre-COVID evaluation. AU, Arbitrary Unit, PCFS, Post COVID Functional Status, VAS, Visual Analogue Score. *P* values are derived from paired samples t-tests.

Theme 1: Understanding symptom management

Symptom management received 66% coverage with 2,089/2911 references made to Long COVID symptoms. Furthermore, the broad and cyclical nature of symptoms highlights the day-to-day challenges associated with COVID-19 recovery:

> *"… headache (lighter), aches/ pains in muscles/ joints, pains/ aches in chest, shortness of breath, brain pulsating, light ringing in ears. Thought I'd put the alarm on and I hadn't, internal vibrations/pain in upper arms… kept losing focus in online training."*

> *"… went out for a meal with work for a couple of hours - felt good. Got home - symptoms returned intensely."*

> *"Pins and needles went yesterday evening. Arms feel wonderful again. No pins and needles in hand. Made such a difference to my mood today… Every day is a new day."*

Nine out of the twelve diaries made references relating to the awareness and availability of healthcare support to help participants cope with the challenges of living with Long COVID. There were regular suggestions that the services were unhelpful, underdeveloped, and slow:

> *"…neurology appointment came away disappointed and angry at lack of understanding…"*

"Felt the doctor (as in GP) needs awareness raising more to Long COVID."

"Chased Long COVID clinic been waiting since 25th June. Still, 2.5 months to wait at least!!"

In response to frustration at a lack of services, participants reported opting to try self-treatment methods with mixed results. These include self-prescribed vitamin supplementation or changes to diet:

"Can feel the benefits of B 12 – less fatigue."

"Still feel antihistamines and low histamine diet do help."

Other instances highlight that some experimental treatments resulted in symptom exacerbation:

"…went to… oxygen centre for an intense therapy trial. Had to stop procedure after 15 minutes due to intensifying chest pain and blurred vision"

"Oxygen therapy. extremely tired, confusion + brain"

Despite this frustration, there was recognition that care services to appropriately support their needs are developing:

"Occupational therapist through LC clinic really supportive/ helpful."

"Now seen CF [Chronic fatigue] clinic and improving pacing"

Furthermore, a doctor within an established Long COVID clinic was able to identify symptoms associated with a pulmonary embolism and was able to make a referral for further examination.

"Very good referrals to fatigue clinic, breathing clinic, vocational rehab, blood tests, eye checks. Go to A&E for blood clot check."

The role of the family as part of the lived experience was also repeatedly noted. However, akin to healthcare support services, the data provided mixed findings. For example, some participants were very dependent on family and the support provided was crucial to everyday life and functional activity:

"In a lot of pain after the walk, not comfortable going out without my wife support."

"Totally exhausted and hardly able to do anything, my husband is looking after me."

The diaries also revealed that participants played an important role in supporting their families, usually in the form of some sort of task or responsibility. This commonly served to exacerbate symptoms such as brain fog which had negative outcomes:

> *"Saw son + his girlfriend so cooked lunch for them - was fab to see them but wiped me out - everything ached and was shattered!!"*

> *"Stayed at sons for night to look after his dogs, flooded kitchen, (forgot I'd left tap on)."*

Theme 2: Quality of Life status

Symptoms were closely associated with QoL (29% coverage). This theme not only identified the impact on functional status and ability of participants to be physically active but also the numerous times they needed to recover and manage symptoms accordingly. Commonly reported symptoms of tiredness, fatigue, and exhaustion were often managed with recovery periods:

> *"…visit to see my Auntie. An exhausting day… genuine chest pain and tightness so sat down… my chest problems are worsening… exhausted so went upstairs straight away."*

> *"Went to a church service, walked but it was very slow, tiring and cause chest tightness. Went and lay on the bed all of the afternoon. Couldn't remember how long I slept."*

Regardless of whether recovery was acute (i.e., a quick nap on the sofa) or prolonged (i.e., resting all day in bed), symptoms were not consistently alleviated, and it was commonplace for symptoms to persist and often become exacerbated:

> *"Rested from 5pm - After a couple of hours symptoms intensified again. Had conversation with a friend and kept forgetting simple words."*

> *"Rested all afternoon. Made tea / struggled to walk my dog. All symptoms intensified, unable to do anything else, pains in muscles/joints particularly fingers/hands, forearms and elbows. Light headedness."*

Persistent symptomology also impacted routine functional activities that pre-COVID-19 infection would have likely taken less time and energy to complete. This ranged from difficulty to concentrate during a task, as well as prolonging the length of time to complete that activity:

> *"…writing Christmas cards out of my mind. Completed them but it took three hours. It took*

me three times longer than before I had Long COVID. "

"Took all day to Hoover and Polish"

The ability to exercise had also changed, with a few accounts of low volume cycling, or light cross-trainer or treadmill activities reported. In most instances, targeted exercise for participants was intolerable:

"The physios want me to continue the exercises at home but that is impossible for me to do."

"Exercise but everything seems like one step forward and two steps [back]"

There was a determination from participants to engage in physical activities. Walking was frequently reported however was consistently linked with an exacerbation of symptoms:

"Try taking my dog for a walk… This was hard as my legs felt heavy and tired to move."

"Walked 50 metres… very tiring and struggled with breathing on return journey."

Return to work was affected by Long COVID symptoms and some participants did not feel prepared to resume their careers due to the physical and mental challenges of work:

"I am signed off work… still feel I would be unable to return to work at present (feel concerned whether I will ever be able to [return to] my job as a community nurse as it is a mentally and physically demanding role)."

However, participants who returned to work described the experience as a "*fight*", while having to manage the challenges of their symptoms alongside the financial pressures of having had an extensive period of leave from work:

"Having to fight for every step as well as being ill."

"Grief from work - half pay without notice."

A key facet in all activities was the role of pacing. Participants were often keen to be functional and active, and pacing strategies helped them manage these activities:

"Very tired this evening but know I would be so tea out the freezer. Getting better on these days. I'm not superhuman. I can pace."

"Very tiring week… paced myself each day."

Specifically, advice from other people sharing their experiences helped participants pace and manage activities in their own lives:

> *"Interesting interview on Lorraine with Nick Knowles TV presenter. after having COVID and wanting to get back into shape he returned to the gym and found exercised knocked him back with recovery. Quite interesting I think, since I've eased off with my morning gym sessions, I think it may be helping my recovery?"*

Another finding was that participants could pace their activities feeling ok until they stopped, thereafter symptoms were unbearable:

> *"Helped install CCTV system, wanted to do something normal [to] see how I got on. Lots of breaks, pace myself, painkillers. Was OK until I stopped. Symptoms intensified immensely, nine out of 10"*

Therefore, it does seem that there is a limit of tolerance on the extent to which pacing can help during a particular activity, with education on the cumulative activity load across a time needing to be established:

> *"Went to horse again and a walked at a steady pace with regular stops to get some fresh air. Left ear still blocked, whooshing and earache, left arm still weak and unable to lift for long without getting a cramping pain. Pain in feet and internal vibrations at night, still coughing phlegm up and a cough…"*

The symptom exacerbation following activities was widely reported, however, participants chose to still engage with certain activities despite knowing that symptoms would occur during or afterwards:

> *"Went to a family wedding at 1:00pm. Very hard to make the effort but enjoyed seeing my nephew getting married. Had to leave early, was totally exhausted and went to bed at 7:00pm."*

> *"Went to meet a friend for coffee, exhausted after and needed to rest."*

Socialising did not always reap the preconceived benefits and, on some occasions, served to make participants feel worse. This did not just exacerbate physical symptoms, but also presented mental and emotionally difficulties:

> *"Taken to coffee but taking part in 1960s quiz very physically and mentally exhausted… failed miserably at quiz due to total brain fog… Went to bed again in the afternoon feeling very frustrated…"*

Theme 3: Emotional Impact of Long COVID Symptoms on Personal Identity and Recovery

Another theme that came from the analysis was the emotions and thoughts of our participants, and the impact of this on their personal identity and long-term recovery (5% coverage). A range of negative emotions accompanied changes in symptomology and functional capacity:

> *"Came home and had a soak in the bath which took an hour to get over after getting out muscles and joints aching. By late afternoon muscles and joints nerve aching from head to toe… I was sobbing with the pain."*

> *"Had bad night sleep, feeling anxious + teary this morning. Feel unable to attend study appointment due to feeling unwell so have rescheduled."*

Emotions were accompanied with comparisons to healthy individuals around them which frequently led to negative sentiments and feelings of despair:

> *"Was taken to church in the morning followed by a fund-raising coffee morning for Macmillan Cancer Research. It made me aware of how I am still physically and mentally "disabled" due to how quickly other non-Long COVID people moved about."*

> *"Sitting on the side-lines watching everyone else live."*

Furthermore, participants would also compare themselves to their pre-infection state…:

> *"Worried whether I will ever get back to pre Long COVID state."*

> *"Still ever present - the failing/knowledge that, without the sertraline, I would be in a little ball of depression. When will this end. Will I ever get my life back."*

…with changes in identity and emotional sensitivity since infection also reported:

> *"I was made aware that I now have very little compassion or empathy- I'm not the same person."*

> *"I just know I'm not me anymore."*

4. Episodic and Undulating Nature of Long COVID

An area that underpinned all themes was the undulating nature of the post-COVID-19 journey and the interconnectivity of all themes. Participants often revealed that it was commonplace to experience a period of improvement followed by worsening of symptoms, day-by-day in some cases. However, this was often accompanied by comments regarding a correlated change in their QoL status and emotional state:

> *"…sadly looks like another corner turned ☹. Energy levels even more. Craved carbs and chocolate."*

> *"Every day is a new day."*

This was consistent across the 16-week period despite patients implementing management strategies, and it did not seem that patients became more expert at managing their condition.

However, the extended study period did reveal how seasonal weather changes may be somewhat, but not entirely, responsible for the episodic nature of the above themes:

> *"Housebound [can't breathe cold air - Hurts] due to cold. Muscle and bones hurting a lot. Can't regulate body temperature. In a lot of pain"*

> *"Feeling a lot better with it getting warmer but my body is aching."*

DISCUSSION

To our knowledge, this is the first study to gather qualitative accounts over a longitudinal basis which highlights the day-to-day experiences of individuals living with Long COVID. The data highlights three key themes relating to: (1) understanding symptom management and the presentation of a broad symptom profile, (2) the impact upon QoL, health status and the role of pacing in managing functional tasks, (3) the effect of turbulent and episodic symptom profiles on personal identity and recovery.

Evidently, the biggest challenge associated with Long COVID is a broad and debilitating symptom profile[10]. Our work aligns with previous research that has identified the most prevalent symptom profiles associated with Long COVID[3, 8, 19, 20]. However, data here further outlines the integration of the symptoms with factors such as QoL status, and comparisons with healthy others and previous self, rather than considering these in isolation. For many participants, symptoms were managed by rest or sleep, which impacts their ability to undertake activities of daily life (i.e., completing the school run or engaging in social activities). It was reported that when participants did attempt activities that are deemed low intensity this would exacerbate symptoms and lead to an extended period of convalescence. Accordingly, attempting to live with Long COVID requires considered support mechanisms that aim to help individuals understand changes in their physical, mental, and emotional health which is in line with an episodic symptom profile that is prone to exacerbation. A further consideration is to understand the episodic nature of Long COVID. Participants here reported perceived improvements in symptom severity, often referring to '*turning a corner',* however, this could change instantaneously and without any provocation in some cases, a finding that has been recognised in other studies[8, 13, 14, 21]. It has been suggested that patients with chronic diseases will increase activities when they feel able but with little consideration of the consequences[22]. However, this does not align with our data which is better associated with the findings of Humphreys et al.[23] who report that Long COVID patients prioritise a sense of normality and control over relapse. Our findings indicate that pacing advice of activities seems to have become more widespread and useful through Long COVID clinics and television programmes since this work, yet specific guidelines are still scarce. As such, further research is required to document changes in symptom profile relative to increased volume and intensity of activity.

Data here supports that of Davis et al.[8], who highlighted disparate recovery profiles that failed to reach a resolution 7 months post-infection, thus highlighting the individual nature and the need for tailored approaches[9]. The broad and complex symptom profile of Long COVID makes it hard for health workers, family, and friends to fully understand the realities of living with a debilitating and unpredictable condition[11]. Our data extend this understanding by demonstrating that multiple stakeholders are often involved in the Long COVID journey, which is representative of the multidimensional and complex presentation of this condition. Boix et al.[24] reported that many people with Long COVID have unfortunately struggled to have their condition recognised. Patients have therefore felt isolated and resulted to self-treatment methods given the lack of knowledge, understanding, and bespoke treatments available for their condition and, in some instances, this has served to deteriorate, rather than ameliorate, their health[25, 26].

Following critical illness, it can be commonplace to experience a range of difficult emotions and periods of stress which can manifest in the form of feeling tearful, lack of appetite, and difficulty sleeping[27]. Houben-Wilke and colleagues[28] demonstrate that negative emotions (i.e., post-traumatic stress disorder, anxiety, and depression) persist in some Long COVID patients 3 and 6 months after the onset of COVID-19 symptoms, with a prevalence comparable between hospitalised and non-hospitalised patients. Our data indicates in a non-hospitalised cohort that these emotions are frequently borne out of symptomology, however, comparisons to healthy individuals and pre-infection states are centred at the heart of these thought processes. Houben-Wilke et al.[28] cited a lack of care and unmet needs as factors that contribute to negative emotions, however, future support services must incorporate methods to support grief due to loss of identity and purpose which is prominent amongst Long COVID patients. For example, meaning development, art therapies, and journaling advanced by the Four Phase Model[29] are proposed to be especially useful in grief management for ME/CFS patients. Further research is needed to deepen the understanding and integration between physical, mental, and emotional support mechanisms.

Research surrounding the treatment and management of Long COVID is of international interest, however, there is limited evidence that repurposing existing clinical interventions has efficacy in addressing the unique and complex pathological mechanisms that underpin Long COVID. Therefore, bespoke, adaptive, flexible, interdisciplinary, and patient centred approaches are needed to support individuals with Long COVID[30-32]. This is in keeping with one of our main findings which was the broad and undulating symptom profile reported by participants. Macpherson et al.[33] suggest services to support patients could take the form of 'one-stop' clinics in hospitals to treat patients holistically alongside established multidisciplinary departments. However, time to access support presented one of the biggest challenges to our participants, and if 'one-stop' clinics cannot support demand then patients may refer to potentially harmful self-treatment methods that will exacerbate symptoms. Therefore, whilst 'one-stop' multidisciplinary approaches offer a potential solution, the complex clinical presentation with patient settings may be better suited to a detailed and expansive service that is underpinned by a comprehensive screening process that directs patients to the required services which act in a 'buffet style system' where patients can access (in both volume and intensity) services they require to positively influence clinical outcomes.

Multidisciplinary collaboration has been recommended as an approach for Long COVID support[3, 34], and recent NHS policy[35] has set out to drive multi-disciplinary team working for those living with chronic health conditions which been effective in significantly improving cancer care[36]. However, given the nature of multidisciplinary teams (i.e., lack of interaction and unison between members), it is postulated that this would have limited patient benefit[3].

Alternatively, Tremblay et al.[37] found that cancer patients under the care of teams working with a greater interdisciplinary intensity reported four times greater access to care compared to lower intensity teams; access which our participants reported as a major difficulty. Furthermore, Veronese et al.[38] found improvements in surgery waiting times through interdisciplinary teamwork even when factoring in socioeconomic barriers in upper-middle income countries. Therefore, facilitating access through a 'buffet-style' approach in an interdisciplinary manner should ensure greater access to, and equity of, care.

Faghy and colleagues[3] suggest an interdisciplinary approach embedded in systems science may better help identify key stakeholders that can assist in the design, delivery and evaluation of support services. This will be vital given the prevalence of Long COVID[6] combined with a chronically under-resourced and understaffed NHS[39]. A group of stakeholders that could ease a growing clinical burden is clinical exercise specialists whose expertise can design and deliver holistic support programmes that recognises the individual and broad symptom profile. These professionals can develop and implement holistic support mechanisms that are tailored to the individual and whose expertise is not limited to the prescription of physical activity and exercise[30, 32]. Furthermore, working in an interdisciplinary manner with a broad spectrum of other rehabilitation experts inclusive of physical, lifestyle, behavioural, and wellbeing practitioners would ensure other patient care needs are effectively supported. However, to be effective, it is important the lived experience is captured and incorporated into the entirety of the process to ensure the co-design and delivery of services address patient needs, are safe, and are accepted by Long COVID patients[40]. For example, it is widely acknowledged that key triggers (physical, cognitive, and emotional) can prompt post-exertional symptom exacerbation and/or relapse[8], which could explain why previous attempts to re-purpose existing clinical interventions for Long COVID services have not been accepted and in some cases have been damaging (i.e., the prescription of physical activity and graded exercise therapy)[41-43]. Early indications of the effectiveness of a personalised approach have been positive[44], however, these lack the involvement of the patient experiences in the design and testing process and so also risk rejection if not suitable in the applied setting. Gorna et al.[12] propose that an approach involving an individualised physical assessment by physicians with medical expertise to identify organ and multisystem dysfunction is also needed. This could then inform individualised and wider rehabilitation/support plans that will also be inclusive of other key stakeholders (i.e., employers when employees are returning to work). However, broad representation must be a key consideration in future work to ensure robust advice is provided, and the inclusion of the lived experience of minority groups with Long COVID also needs to be better understood.

A limitation of COVID-19 research, inclusive of our work, is the lack of ethnic diversity, male representation, young people, low socioeconomic groups, and small sample sizes[8, 21, 33, 45-47]. Long COVID has a tendency to present more commonly in females than males[48], however, ethnic minorities have been disproportionately affected by the COVID-19 pandemic[49-51]. A recent report by the National Institute for Health Research showed that the latter group constituted only 9% of cohorts in COVID-19 studies conducted in the UK. This is despite ethnic minorities constituting 14% of the general population in the UK[52]. Current barriers to taking part in COVID-19 research have been postulated to include access to health services, language, and mistrust[45-47, 53, 54]. Gopal and colleagues[54] explain that existing equality and diversity recommendations to tackle these barriers (i.e., cultural competency training) have the potential to do more harm than good through ethnocentrism and stereotyping. Instead, they recommend that a Cultural Safety approach engrained within a deep medicine ideology would be most appropriate. By focusing on the individual experience of care, staff self-reflexivity, and structural reflexivity, Gopal et al.[54] postulate deep medicine would help overcome barriers such as mistrust and, subsequently, may help facilitate researcher-participant relationships in future research[55, 56]. Developing rapport by establishing and aligning with key principles valued by patients and reflecting with peers that challenge our own biases are just a couple of key examples of how future studies may look to develop trust and provide a safe, reassuring environment for ethnic minorities. This would be especially valuable in observational studies such as our own that require participant engagement over a prolonged period.

A merit of using diary methodology was how it enabled participants to reveal nuance experiences of their lives that, in the presence of a researcher, may not be easily recalled. For example, one participant reported crying as she did not have the energy to see her husband in hospital (Appendix A.) The emotional cost of reliving a new way of living at a predetermined moment in-person may have been substantial where other energy requirements such as travel, conversation, and sustained questioning may drain participant energy levels; unlike diary entries which could be completed at any time that was convenient to participants. However, quotes alike to this one lacked important detail which otherwise may have been explored with other research methodologies. For example, interviews would have been better suited to explore the source of self-treatment options.

CONCLUSIONS

This study has added to a growing body of literature in sharing the lived experience of Long COVID from the perspective of the patients. Over 16 weeks, our work recognised the broad, disabling, and episodic symptom profile of people living with Long COVID. It is vital more is done to support an already isolated group in a manner that not only provides validation to the Long COVID patient, but also a specific and adaptive support system that addresses the milieu of symptoms and undulating nature synonymous with Long COVID.

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APPENDICES

Apendix A – Theme 1 additional quotes:

"Struggled to get up/ fatigue. Short of breath. Tinnitus horrendous every day. sore throat. Cannot sleep. Lymph nodes swollen Clavicle/ underarm. Aching like I have the flu."

"Feeling exhausted had a steady day out with my hubby and he did all of the driving."

"Felt really drained and lacking energy again. Slept for a short time at lunchtime. Cried because I was so tired, I didn't have the energy to drive to hospital to visit husband. Got son to take me."

"Sunday funday. Cinema with son. It was the best day of his life. Mean so very much to hear and see him enjoy himself. Had to be up early to get there so slept in car on way home in traffic."

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	Item	**Page**
Title	Item 1. Title: Concise description of the nature and topic of the study. Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended.	page 1
Abstract	Item 2. Abstract: Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions.	page 2
Problem Formulation	Item 3. Problem Formulation: Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement.	pages 3-4
Purpose or research question	Item 4. Purpose or research question: Purpose of the study and specific objectives or questions.	page 4
	Item 5. Qualitative approach and research paradigm: Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., post-positivist, constructivist/interpretivist) is also recommended; rationale	pages 2, & 6
	Item 6. Researcher characteristics and reflexivity: Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results and/or transferability.	page 5
Context	Item 7. Context: Setting/site and salient contextual factors; rationale.	pages 2 & 5
Sampling strategy	Item 8. Sampling strategy: How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale.	page 5
Ethical issues pertaining to human subjects	Item 9. Ethical issues pertaining to human subjects: Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues.	page 5

	Item 10. Data collection methods: Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale.	page 5
Data collection instruments and technologies	Item 11. Data collection instruments and technologies: Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study.	page 5
Units of study	Item 12. Units of study: Number and relevant characteristics of participants, documents, or events included in the study; level of participation.	pages 5, 6 & 7.
Data processing	Item 13. Data processing: Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding and anonymization / de-identification of excerpts.	page 5 & 6.
Data analysis	Item 14. Data analysis: Process by which inferences, themes, etc. were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale.	page 6
Techniques to enhance trustworthiness	Item 15. Techniques to enhance trustworthiness: Techniques to enhance trustworthiness and credibility of data analysis,(e.g., member checking, triangulation, audit trail); rationale	page 5 & 6
Synthesis and interpretation	Item 16. Synthesis and interpretation: Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory.	pages 2, 6 & 13.
Links to empirical data	Item 17. Links to empirical data: Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings.	pages 7 – 13.
	Item 18. Integration with prior work, implications, transferability, and contribution(s) to the field: Short summary of main findings, explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field.	pages 13 -17.

Limitations	Item 19. Limitations: Trustworthiness and limitations of findings	pages 3 & 17.
Conflicts of interest	Item 20. Conflicts of interest: Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed.	page 18.
Funding	Item 21. Funding: Sources of funding and other support; role of funders in data collection, interpretation, and reporting.	page 18.

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Title: The lived experience of patients with Long COVID: a qualitative study in the UK.

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Key Words: Lived experience, COVID-19, Long COVID, Health and Wellbeing

ABSTRACT

Background: Long COVID is a rapidly evolving global health crisis requiring interdisciplinary support strategies that incorporate the lived experience of patients. Currently, there is a paucity of research documenting the day-to-day experiences of patients living with Long COVID.

Objective: To explore the lived experience of Long COVID patients.

Study design: Longitudinal, observation study.

Setting: An inductive, data-driven, qualitative approach was used to evaluate hand-written diaries obtained from individuals who had been referred to a Derbyshire Long COVID clinic.

Participants: 12 participants (11 females, age 49 ± 10 years, 11 Caucasians) were recruited. Participants were included if they had a previous confirmed or suspected COVID-19 infection with ongoing recovery, >18 years old, understood the study requirements and provided informed consent.

Method: Participants were directed to complete self-report diaries over 16 weeks. Responses were transcribed verbatim and analysed using thematic analysis.

Results: Three key themes were highlighted; (1) understanding who helps patients manage symptoms, (2) daily activities and the impact upon quality of life and health status, and (3) the effect of turbulent and episodic symptom profiles on personal identity and recovery.

Conclusions: The novel challenges presented by Long COVID are complex with varying interrelated factors that are broadly impacting functional status and quality of life. Support mechanisms must incorporate the lived experiences and foster true collaborations between health professionals, patients, and researchers to improve patient outcomes.

Trial registration: NCT04649957.

STRENGTHS AND LIMITATIONS OF THE STUDY

- Self-report diaries are flexible and adaptable methods that allow participants to record their feelings and lived experiences at their convenience.
- The diaries allowed participants to open up and reveal nuanced details that, in the presence of a researcher, may not have been documented.
- The diaries allowed participants to document their experiences over time rather than at predetermined moments where they may not have been prepared physically or emotionally to answer.
- Participants were instructed to use the diaries freely and so entries were not made every day by some participants.

INTRODUCTION

Over the time-course of the Coronavirus pandemic 2019 (COVID-19), international attention has predominantly focused on addressing the impact of acute infection. Thanks to effective and widespread vaccination this has undoubtedly reduced the severity of acute infections, observed by a reduction in hospitalisations and mortality[1, 2]. As such the focus has now shifted to restoring social and economic activities. Despite a shift in focus, we are still very much amid a pandemic that is demonstrating a lasting impact on public health[3]. Whilst vaccines reduce the likelihood of severe patient outcomes, it is established that vaccines do not prevent transmission or infection with SARS-COV-2 and they offer minimal protection against post-viral issues and symptom profiles, commonly referred to as Long COVID.

Defined by the World Health Organisation as '*individuals with probable or confirmed COVID-19 diagnosis presenting symptoms 3 months after symptom onset, and symptoms lasting at least 2 months that cannot be explained by an alternative diagnosis'*[4]. Recent statistics estimate that >2 million people in the United Kingdom (UK)[5] and 144.7 million globally[6] are living with long-term and debilitating symptom profiles of Long COVID[7]. The complex and episodic symptom profile is at the forefront of mechanistic investigations to increase pathological insight. Reports highlight the extent of physical, cognitive, and psychosocial symptoms (i.e., fatigue, brain fog, and anxiety) and the impact upon multiple bodily systems (i.e., cardiovascular, respiratory, and pulmonary system) that is becoming established[8-10] Davis et al.[8] identified three symptom clusters that have distinct temporal profiles, cluster 1 identified early symptoms that peak and then diminish (i.e., runny nose, loss of appetite, fever), cluster 2 represented stable symptoms (i.e., nausea, chest tightness, fatigue), meanwhile cluster

3 represented symptoms that initially increase sharply then either plateau or slightly increase or decrease over the following months (i.e., palpitations, brain fog, post-exertional malaise)[8]. Another aspect reported via an online survey of Long COVID is the episodic nature of symptoms[11] with 86% of participants (n= 3,252, 95% Confidence Interval (CI), 84.8% to 87.0%) having symptoms triggered or exacerbated by physical or mental activities[8].

Recent data suggest that 1 in 10 positive SARS-CoV-2 infections will go on to experience long-term illness[8]. There is an unquestionable need to increase the pathological understanding to inform the design and development of bespoke and safe support services and pharmacological interventions for Long COVID patients. However, given the unique nature of COVID-19 and Long COVID, there is a need to engage the intended stakeholders and learn from the experiences of those living with this condition. Despite repeated calls from patients to incorporate the lived experience as a prominent feature in the design and implementation of research[12], there remains a lack of detail that provides thorough longitudinal insight from patients. Callan et al.[13] recognised the relapsing-remitting time course of Long COVID as an 'episodic disability' whereby participants reported brain fog that aligned with the unpredictable wellness and illness previously described in HIV-positive patients. However, the focus groups were followed up 4-6 months later by email and similarly provide a snapshot summary to that of online surveys. Witvliet[14] retrospectively revealed the details of her personal Long COVID journey which included nuanced details that would not be captured in clinical pathways. This detail could provide important insight to support clinical decision making but also in the development of Long COVID support pathways that are relevant, accepted, and lead to improved patient outcomes. Patient diaries have previously been used in intensive care units (ICU) and are useful tools to document patients' lived experiences[15, 16]. Diaries are flexible and adaptable tools that can be used anytime and away from face-to-face research and clinical settings[16] which can bridge the gap in communication between patients and healthcare providers[17]. Diaries can allow Long COVID patients to remember their experiences independent of recall bias and without eliciting emotional difficulty that is brought about with an in-person consultation. However, the use of diaries in documenting the day-to-day lived experience of individuals with Long COVID is not commonplace and there is a paucity of data obtained that documents the longitudinal lived experience which is important in the design and development of specific support mechanisms[12]. Accordingly, this study sought to capture the lived experience of individuals with Long COVID taking part in a 16-week observational study collected via hand-written diaries.

METHODS

Following NHS research ethics approval (IRAS ID: 292920) and informed consent, qualitative accounts of the lived experience of 12 Long COVID participants were recorded via diaries over 16 weeks. Previous post-viral research and the paucity of SARS-CoV-2 infection recovery information influenced the study design rationale of 16 weeks; however, we acknowledge current recovery time extends beyond this significantly. The diaries formed part of a larger observational study powered by sample analysis techniques of individuals recovering at home from a SARS-CoV-2 infection. The sample presented here was a sub-sample of patients that completed the study. Data from the diaries were monitored continuously and analysed until saturation[18]. At saturation, 17 participants had completed their involvement with 5 participants choosing not to fill out their diaries. Reasoning for non-completion included memory loss, energy prioritisation, and depressive feelings towards diary use. Participants were recruited following a referral from an established Long COVID clinic where a participant information sheet and contact details were provided to obtain any further detail/clarifications. No time-limit was placed on participation decision. Following the request to participate in the study, participants were passed onto the research team for consenting. As part of the study procedures listed entirely at clinicaltrials.gov (NCT04649957), participants were provided with and directed to freely use a self-report diary, that was returned and photocopied monthly, to capture information that they deemed appropriate as part of their post-COVID-19 journey. This exploratory approach was appropriate given the lack of understanding of the lived Long COVID experiences, and a greater need to inform the development of bespoke support mechanisms.

Researcher characteristics

Researchers from the University of Derby had bimonthly contact with participants and instructed them to use diaries freely; this should have had limited impact on how they were used. All researchers had experience in their respective field of working with clinical populations with chronic conditions.

Patient and Public Involvement and Engagement (PPIE) statement

PPIE was a crucial part of the research design, implementation of the project, and interpretation of the resulting data reported in this manuscript. Previous research team experiences with pneumonia patients informed the data collection materials repurposed for this study. Participants were involved in raising awareness of our research to recruit participants in their

Long COVID networks and will also be involved in the dissemination of the results by sharing the findings with their support groups and networks.

Data analysis

One researcher (CT, who a had previous experience with interview transcriptions) transcribed verbatim, coded, and thematically analysed full diaries using the qualitative software NVIVO 12 Pro (Version 12.7, QSR International, Doncaster, Australia). Alongside regular meetings, diary transcriptions were checked for accuracy by other members of the research team (MAF, REA, RO, JY, and FVF). An inductive, data-driven approach was adopted to code the data into descriptive terms which were collated to produce 12 themes and 82 sub-themes and grouped to generate three overarching themes. Two researchers (RO & JY, both with previous qualitative research experience) then reviewed 50% of the transcripts each with the generated themes and met with CT to confirm whether these were reflective of the presented data. These findings were then shared with the remainder of the research team (MAF, REA, and FVF) and with two patient representatives for review; no adjustments were requested, and the themes were deemed reflective of the transcripts. Theme coverage was also generated by CT and denoted the percentage reporting of the theme across all the diaries.

RESULTS

Participant characteristics are detailed in Table 1 and are coincidentally skewed in representation towards white, middle-aged females, and are consistent with research in this area[19]. Three key themes were identified: *(1) understanding who helps patients manage symptoms, (2) daily activities and the impact upon quality of life and health status, and (3) the effect of turbulent and episodic symptom profiles on personal identity and recovery.*

Table 1: Pooled participant pre-COVID, baseline and 16-week post-baseline measures (Mean ± SD).

Demographic Profile	Mean (± SD)
Age (years)	49 ± 10
Sex	Male (N=1) Female (N=11)
Ethnicity	White British (N=11)

Occupational Status	Employed Full Time (N=3) Illness absence from work (N=8) Retired (N=1)
Index of Multiple Deprivation (IMD) Decile	7 ± 3

Performance Status	Pre-COVID	Baseline	16-weeks	*P* values
Overall health (AU)	2 ± 0.9	4 ± 0.6	3 ± 0.8	< 0.001
COVID-19 Symptom rating (AU)	-	8 ± 1	7 ± 2	0.324
PCFS (AU)	-	3 ± 0.4	2 ± 0.8	0.054
Dyspnoea (AU)	-	3 ± 0.7	3 ± 0.8	1.000
EQ5D-5L (AU)	-	13 ± 3	13 ± 5	0.575
EQ5D-5L VAS (AU)	-	46 ± 16	47 ± 22	0.691

Overall health score: 1-5 scale (1 = very good and 5 = very bad). COVID-19 Symptom score: 0–10 rating of symptom effect on daily life (0 = no impact / symptoms and 10 = symptom/s have had a big effect). PCFS: 0–4 scale of functional status (0 = no limitations and 4 = severe limitations). Dyspnoea: 1-5 scale of breathlessness (1 = breathless only with strenuous exercise and 5 = too breathless to leave the house). EQ5D-5L involves rating subcategories of mobility, self-care, usual activities, pain/discomfort, and anxiety/depression on a 1-5 scale (1 = no problems and 5 = extreme problems or inability). EQ5D-5L VAS: 0-100 scale of perceived overall health (0 = worst health they can imagine and 100 the best health they can imagine). Overall health data only for retrospective pre-COVID evaluation. AU, Arbitrary Unit, PCFS, Post COVID Functional Status, VAS, Visual Analogue Score. *P* values are derived from paired samples t-tests.

Theme 1: Understanding who helps Long COVID patients with symptom management

Symptom management received 66% coverage with 2,089/2911 references made to Long COVID symptoms. Furthermore, the broad and cyclical nature of symptoms highlights the day-to-day challenges associated with COVID-19 recovery:

> *"… headache (lighter), aches/ pains in muscles/ joints, pains/ aches in chest, shortness of breath, brain pulsating, light ringing in ears. Thought I'd put the alarm on and I hadn't, internal vibrations/pain in upper arms… kept losing focus in online training."*

> *"… went out for a meal with work for a couple of hours - felt good. Got home - symptoms returned intensely."*

> *"Pins and needles went yesterday evening. Arms feel wonderful again. No pins and needles in hand. Made such a difference to my mood today… Every day is a new day."*

Available support options

Nine out of the twelve diaries made references relating to the awareness and availability of healthcare support to help participants cope with the challenges of living with Long COVID. There were regular suggestions that the services were unhelpful, underdeveloped, and slow:

> *"…neurology appointment came away disappointed and angry at lack of understanding…"*

> *"Felt the doctor (as in GP) needs awareness raising more to Long COVID."*

> *"Chased Long COVID clinic been waiting since 25th June. Still, 2.5 months to wait at least!!"*

In response to frustration at a lack of services, participants reported opting to try self-treatment methods with mixed results. These include self-prescribed vitamin supplementation or changes to diet:

> *"Can feel the benefits of B 12 – less fatigue."*

> *"Still feel antihistamines and low histamine diet do help."*

Other instances highlight that some experimental treatments resulted in symptom exacerbation:

> *"…went to… oxygen centre for an intense therapy trial. Had to stop procedure after 15 minutes due to intensifying chest pain and blurred vision"*

> *"Oxygen therapy. extremely tired, confusion + brain"*

Despite this frustration, there was recognition that care services to appropriately support their needs are developing:

> *"Occupational therapist through LC clinic really supportive/ helpful."*

> *"Now seen CF [Chronic fatigue] clinic and improving pacing"*

Furthermore, a doctor within an established Long COVID clinic was able to identify symptoms associated with a pulmonary embolism and was able to make a referral for further examination.

> *"Very good referrals to fatigue clinic, breathing clinic, vocational rehab, blood tests, eye checks. Go to A&E for blood clot check."*

Family interdependence

The role of the family as part of the lived experience was also repeatedly noted. However, akin to healthcare support services, the data provided mixed findings. For example, some participants were very dependent on family and the support provided was crucial to everyday life and functional activity:

> *"In a lot of pain after the walk, not comfortable going out without my wife support."*

> *"Totally exhausted and hardly able to do anything, my husband is looking after me."*

The diaries also revealed that participants played an important role in supporting their families, usually in the form of some sort of task or responsibility. This commonly served to exacerbate symptoms such as brain fog which had negative outcomes:

> *"Saw son + his girlfriend so cooked lunch for them - was fab to see them but wiped me out - everything ached and was shattered!!"*

> *"Stayed at sons for night to look after his dogs, flooded kitchen, (forgot I'd left tap on)."*

Theme 2: Daily activities and the impact upon quality of life

Symptoms were closely associated with QoL (29% coverage). This theme not only identified the impact on functional status and ability of participants to be physically active but also the numerous times they needed to recover and manage symptoms accordingly. Commonly reported symptoms of tiredness, fatigue, and exhaustion were often managed with recovery periods:

> *"…visit to see my Auntie. An exhausting day… genuine chest pain and tightness so sat down… my chest problems are worsening… exhausted so went upstairs straight away."*

> *"Went to a church service, walked but it was very slow, tiring and cause chest tightness. Went and lay on the bed all of the afternoon. Couldn't remember how long I slept."*

Regardless of whether recovery was acute (i.e., a quick nap on the sofa) or prolonged (i.e., resting all day in bed), symptoms were not consistently alleviated, and it was commonplace for symptoms to persist and often become exacerbated:

"Rested from 5pm - After a couple of hours symptoms intensified again. Had conversation with a friend and kept forgetting simple words."

"Rested all afternoon. Made tea / struggled to walk my dog. All symptoms intensified, unable to do anything else, pains in muscles/joints particularly fingers/hands, forearms and elbows. Light headedness."

Changes in functional ability and physical activity

Persistent symptomology also impacted routine functional activities that pre-COVID-19 infection would have likely taken less time and energy to complete. This ranged from difficulty to concentrate during a task, as well as prolonging the length of time to complete that activity:

"…writing Christmas cards out of my mind. Completed them but it took three hours. It took me three times longer than before I had Long COVID. "

"Took all day to Hoover and Polish"

The ability to exercise had also changed, with a few accounts of low volume cycling, or light cross-trainer or treadmill activities reported. In most instances, targeted exercise for participants was intolerable:

"The physios want me to continue the exercises at home but that is impossible for me to do."

"Exercise but everything seems like one step forward and two steps [back]"

There was a determination from participants to engage in physical activities. Walking was frequently reported however was consistently linked with an exacerbation of symptoms:

"Try taking my dog for a walk… This was hard as my legs felt heavy and tired to move."

"Walked 50 metres… very tiring and struggled with breathing on return journey."

Return to work was affected by Long COVID symptoms and some participants did not feel prepared to resume their careers due to the physical and mental challenges of work:

"I am signed off work… still feel I would be unable to return to work at present (feel concerned whether I will ever be able to [return to] my job as a community nurse as it is a mentally and physically demanding role)."

However, participants who returned to work described the experience as a "*fight",* while having to manage the challenges of their symptoms alongside the financial pressures of having had an extensive period of leave from work:

"Having to fight for every step as well as being ill."

"Grief from work - half pay without notice."

Pacing as an activity management strategy

A key facet in all activities was the role of pacing. Participants were often keen to be functional and active, and pacing strategies helped them manage these activities:

"Very tired this evening but know I would be so tea out the freezer. Getting better on these days. I'm not superhuman. I can pace."

"Very tiring week… paced myself each day."

Specifically, advice from other people sharing their experiences helped participants pace and manage activities in their own lives:

"Interesting interview on Lorraine with Nick Knowles TV presenter. after having COVID and wanting to get back into shape he returned to the gym and found exercised knocked him back with recovery. Quite interesting I think, since I've eased off with my morning gym sessions, I think it may be helping my recovery?"

Another finding was that participants could pace their activities feeling ok until they stopped, thereafter symptoms were unbearable:

"Helped install CCTV system, wanted to do something normal [to] see how I got on. Lots of breaks, pace myself, painkillers. Was OK until I stopped. Symptoms intensified immensely, nine out of 10"

Therefore, it does seem that there is a limit of tolerance on the extent to which pacing can help during a particular activity, with education on the cumulative activity load across a time needing to be established:

"Went to horse again and a walked at a steady pace with regular stops to get some fresh air. Left ear still blocked, whooshing and earache, left arm still weak and unable to lift for long without getting a cramping pain. Pain in feet and internal vibrations at night, still coughing phlegm up and a cough…"

Post-exertional symptom exacerbation

The symptom exacerbation following activities was widely reported; however, participants chose to still engage with certain activities despite knowing that symptoms would occur during or afterwards:

> *"Went to a family wedding at 1:00pm. Very hard to make the effort but enjoyed seeing my nephew getting married. Had to leave early, was totally exhausted and went to bed at 7:00pm."*

> *"Went to meet a friend for coffee, exhausted after and needed to rest."*

Socialising did not always reap the preconceived benefits and, on some occasions, served to make participants feel worse. This did not just exacerbate physical symptoms, but also presented mental and emotionally difficulties:

> *"Taken to coffee but taking part in 1960s quiz very physically and mentally exhausted… failed miserably at quiz due to total brain fog… Went to bed again in the afternoon feeling very frustrated…"*

Theme 3: Emotional impact of Long COVID symptoms on personal identity and recovery

Another theme that came from the analysis was the emotions and thoughts of our participants, and the impact of this on their personal identity and long-term recovery (5% coverage). A range of negative emotions accompanied changes in symptomology and functional capacity:

> *"Came home and had a soak in the bath which took an hour to get over after getting out muscles and joints aching. By late afternoon muscles and joints nerve aching from head to toe… I was sobbing with the pain."*

> *"Had bad night sleep, feeling anxious + teary this morning. Feel unable to attend study appointment due to feeling unwell so have rescheduled."*

Emotions were accompanied with comparisons to healthy individuals around them which frequently led to negative sentiments and feelings of despair:

"Was taken to church in the morning followed by a fund-raising coffee morning for Macmillan Cancer Research. It made me aware of how I am still physically and mentally "disabled" due to how quickly other non-Long COVID people moved about."

"Sitting on the side-lines watching everyone else live."

Furthermore, participants would also compare themselves to their pre-infection state…:

"Worried whether I will ever get back to pre Long COVID state."

"Still ever present - the failing/knowledge that, without the sertraline, I would be in a little ball of depression. When will this end. Will I ever get my life back."

…with changes in identity and emotional sensitivity since infection also reported:

"I was made aware that I now have very little compassion or empathy- I'm not the same person."

"I just know I'm not me anymore."

4. Episodic and Undulating Nature of Long COVID

An area that underpinned all themes was the undulating nature of the post-COVID-19 journey and the interconnectivity of all themes. Participants often revealed that it was commonplace to experience a period of improvement followed by worsening of symptoms, day-by-day in some cases. However, this was often accompanied by comments regarding a correlated change in their QoL status and emotional state:

"…sadly looks like another corner turned ☹. Energy levels even more. Craved carbs and chocolate."

"Every day is a new day."

This was consistent across the 16-week period despite patients implementing management strategies, and it did not seem that patients became more expert at managing their condition.

However, the extended study period did reveal how seasonal weather changes may be somewhat, but not entirely, responsible for the episodic nature of the above themes:

> *"Housebound [can't breathe cold air - Hurts] due to cold. Muscle and bones hurting a lot. Can't regulate body temperature. In a lot of pain"*

> *"Feeling a lot better with it getting warmer but my body is aching."*

DISCUSSION

To our knowledge, this is the first study to gather qualitative accounts over a longitudinal basis which highlights the day-to-day experiences of individuals living with Long COVID. The data highlights three key themes relating to: (1) understanding who helps patients manage symptoms, (2) daily activities and the impact upon QoL, health status, and the role of pacing in managing functional tasks, (3) the effect of turbulent and episodic symptom profiles on personal identity and recovery.

Evidently, the biggest challenge associated with Long COVID is a broad and debilitating symptom profile[10]. Our work aligns with previous research that has identified the most prevalent symptom profiles associated with Long COVID[3, 8, 20, 21]. However, the diaries further outline the integration of symptoms with factors such as QoL status, and comparisons with healthy others and previous self, rather than considering these in isolation. For many participants, symptoms were managed by rest or sleep, and the diaries allowed participants to think more deeply about how this impacted their ability to undertake activities of daily life (i.e., completing the school run or engaging in social activities). It was reported that when participants did attempt activities that are deemed low intensity this would exacerbate symptoms and lead to an extended period of convalescence. Accordingly, attempting to live with Long COVID requires considered support mechanisms that aim to help individuals understand changes in their physical, mental, and emotional health which is in line with an episodic symptom profile that is prone to exacerbation. A further consideration is to understand the episodic nature of Long COVID. Participants here reported perceived improvements in symptom severity, often referring to '*turning a corner*'; however, this could change instantaneously and without any provocation in some cases, a finding that has been recognised in other studies[8, 13, 14, 22]. It has been suggested that patients with chronic diseases will increase activities when they feel able but with little consideration of the consequences[23]. However, this does not align with our data which is better associated with the findings of Humphreys et al.[24] who report that Long COVID patients prioritise a sense of normality and control over relapse. Our findings indicate that pacing advice seems to have become more widespread and useful through Long COVID clinics and television programmes since this work. However, specific guidelines are still scarce and the diaries reveal detailed examples of how even sensible pacing strategies can result in ineffective outcomes. As such, further research is required to document changes in symptom profile relative to increased volume and intensity of activity to help better inform pacing advice.

Our data supports that of Davis et al.[8], who highlighted disparate recovery profiles that failed to reach a resolution 7 months post-infection, thus highlighting the individual nature and the need for tailored approaches[9]. The broad and complex symptom profile of Long COVID makes it hard for health workers, family, and friends to fully understand the realities of living with a debilitating and unpredictable condition[11]. Our data reaffirm this understanding by demonstrating that multiple stakeholders are often involved in the Long COVID journey, which is representative of the multidimensional and complex presentation of this condition. Boix et al.[25] reported that many people with Long COVID have unfortunately struggled to have their condition recognised. Patients have therefore felt isolated and resulted to self-treatment methods given the lack of knowledge, understanding, and bespoke treatments available for their condition and, in some instances, our data reaffirms the notion that this can deteriorate, rather than ameliorate, their health[26, 27].

Following critical illness, it can be commonplace to experience a range of difficult emotions and periods of stress which can manifest in the form of feeling tearful, lack of appetite, and difficulty sleeping[28]. Houben-Wilke and colleagues[29] demonstrate that negative emotions (i.e., post-traumatic stress disorder, anxiety, and depression) persist in some Long COVID patients 3 and 6 months after the onset of COVID-19 symptoms, with a prevalence comparable between hospitalised and non-hospitalised patients. Our data indicates in non-hospitalised participants that these emotions are frequently borne out of symptomology; however, the diaries were able to reveal real-time, daily examples of how comparisons to healthy individuals and pre-infection states are centred at the heart of these thought processes. Houben-Wilke et al.[29] cited a lack of care and unmet needs as factors that contribute to negative emotions; however, future support services must incorporate methods to support grief due to loss of identity and purpose which is prominent amongst Long COVID patients. For example, meaning development, art therapies, and journaling advanced by the Four Phase Model[30] are proposed to be especially useful in grief management for ME/CFS patients. Further research is needed to deepen the understanding and integration between physical, mental, and emotional support mechanisms.

Research surrounding the treatment and management of Long COVID is of international interest; however, there is limited evidence that repurposing existing clinical interventions has efficacy in addressing the unique and complex pathological mechanisms that underpin Long COVID. Therefore, bespoke, adaptive, flexible, interdisciplinary, and patient centred approaches are needed to support individuals with Long COVID[31-33]. This is in keeping with one of our main findings which was the broad and undulating symptom profile reported by participants. Macpherson et al.[34] suggest services to support patients could take the form of 'one-stop' clinics in hospitals to treat patients holistically alongside established multidisciplinary departments. However, the diaries enabled participants to reflect on some of the biggest challenges associated with support services, which mainly included time to access support alongside GP understanding of Long COVID. As such, if 'one-stop' clinics cannot support demand nor validate patient concerns, then patients may refer to potentially harmful self-treatment methods that will exacerbate symptoms. Therefore, whilst 'one-stop' multidisciplinary approaches offer a potential solution, the complex clinical presentation with patient settings may be better suited to a detailed and expansive service that is underpinned by a comprehensive screening process that directs patients to the required services which act in a 'buffet style system' where patients can access (in both volume and intensity) services they require to positively influence clinical outcomes.

Multidisciplinary collaboration has been recommended as an approach for Long COVID support[3, 35], and recent NHS policy[36] has set out to drive multi-disciplinary team working for those living with chronic health conditions which has been effective in significantly improving cancer care[37]. However, given the nature of multidisciplinary teams (i.e., lack of interaction and unison between members), it is postulated that this would have limited patient benefit[3]. Alternatively, Tremblay et al.[38] found that cancer patients under the care of teams working with a greater interdisciplinary intensity reported four times greater access to care compared to lower intensity teams; access which our participants reported as a major difficulty. Furthermore, Veronese et al.[39] found improvements in surgery waiting times through interdisciplinary teamwork even when factoring in socioeconomic barriers in upper-middle income countries. Therefore, facilitating access through a 'buffet-style' approach in an interdisciplinary manner should ensure greater access to, and equity of, care.

Faghy and colleagues[3] suggest an interdisciplinary approach embedded in systems science may better help identify key stakeholders that can assist in the design, delivery and evaluation of support services. This will be vital given the prevalence of Long COVID[6] combined with a chronically under-resourced and understaffed NHS[40]. A group of stakeholders that could ease a growing clinical burden is clinical exercise specialists whose expertise can design and deliver holistic support programmes that recognises the individual and broad symptom profile. These professionals can develop and implement holistic support mechanisms that are tailored to the individual and whose expertise is not limited to the prescription of physical activity and exercise[31, 33]. Furthermore, working in an interdisciplinary manner with a broad spectrum of other rehabilitation experts inclusive of physical, lifestyle, behavioural, and wellbeing practitioners would ensure other patient care needs are effectively supported. However, to be effective, it is important the lived experience is captured and incorporated into the entirety of the process to ensure the co-design and delivery of services address patient needs, are safe, and are accepted by Long COVID patients[41]. For example, it is widely acknowledged that key triggers (physical, cognitive, and emotional) can prompt post-exertional symptom exacerbation and/or relapse[8], which could explain why previous attempts to re-purpose existing clinical interventions for Long COVID services have not been accepted and in some cases have been damaging (i.e., the prescription of physical activity and graded exercise therapy)[42-44]. Early indications of the effectiveness of a personalised approach have been positive[45]; however, these lack the involvement of the patient experiences in the design and testing process and so also risk rejection if not suitable in the applied setting. Gorna et al.[12] propose that an approach involving an individualised physical assessment by physicians with medical expertise to identify organ and multisystem dysfunction is also needed. If this approach was combined with further work inclusive of diary methodology, which this study has identified as useful in providing real-world, personalised post-exertional symptom exacerbation experiences, then this could then inform individualised and wider rehabilitation/support plans that could also be inclusive of other key stakeholders (i.e., employers when employees are returning to work). However, broad representation must be a key consideration in future work to ensure robust advice is provided, and the inclusion of the lived experience of minority groups with Long COVID also needs to be better understood.

A limitation of COVID-19 research, inclusive of our work, is the lack of ethnic diversity, male representation, young people, low socioeconomic groups, and small sample sizes[8, 22, 34, 46-48]. Long COVID has a tendency to present more commonly in females than males[49]; however, ethnic minorities have been disproportionately affected by the COVID-19 pandemic[50-52]. A recent report by the National Institute for Health Research showed that the latter group constituted only 9% of cohorts in COVID-19 studies conducted in the UK. This is despite ethnic minorities constituting 14% of the general population in the UK[53]. Current barriers to taking part in COVID-19 research have been postulated to include access to health services, language, and mistrust[46-48, 54, 55]. Gopal and colleagues[55] explain that existing equality and diversity recommendations to tackle these barriers (i.e., cultural competency training) have the potential to do more harm than good through ethnocentrism and stereotyping. Instead, they recommend that a Cultural Safety approach engrained within a deep medicine ideology would be most appropriate. By focusing on the individual experience of care, staff self-reflexivity, and structural reflexivity, Gopal et al.[55] postulate deep medicine would help overcome barriers such as mistrust and, subsequently, may help facilitate researcher-participant relationships in future research[56, 57]. Developing rapport by establishing and aligning with key principles valued by patients and reflecting with peers that challenge our own biases are just a couple of key examples of how future studies may look to develop trust and provide a safe, reassuring environment for ethnic minorities. This would be especially valuable in observational studies such as our own that require participant engagement over a prolonged period.

A merit of using diary methodology was how it enabled participants to reveal nuance experiences of their lives that, in the presence of a researcher, may not be easily recalled. For example, one participant reported crying as she did not have the energy to see her husband in hospital (Appendix A.) The emotional cost of reliving a new way of living at a predetermined moment in-person may have been substantial where other energy requirements such as travel, conversation, and sustained questioning may drain participant energy levels; unlike diary entries which could be completed at any time that was convenient to participants. However, quotes alike to this one lacked important detail which otherwise may have been explored with other research methodologies. For example, interviews would have been better suited to explore the source of self-treatment options.

CONCLUSIONS

This study has added to a growing body of literature in sharing the lived experience of Long COVID from the perspective of the patients. Over 16 weeks, our work recognised the broad, disabling, and episodic symptom profile of people living with Long COVID. It is vital more is done to support an already isolated group in a manner that not only provides validation to the Long COVID patient, but also a specific and adaptive support system that addresses the milieu of symptoms and undulating nature synonymous with Long COVID.

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Data sharing statement: Anonymised data can be made available on request.

Ethics Approval Statement: Ethical approval (IRAS ID: 292920) was granted by the Health Research Authority (HRA) and Health and Care Research Wales (HCRW).

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APPENDICES

Apendix A – Theme 1 additional quotes:

“Struggled to get up/ fatigue. Short of breath. Tinnitus horrendous every day. sore throat. Cannot sleep. Lymph nodes swollen Clavicle/ underarm. Aching like I have the flu.”

“Feeling exhausted had a steady day out with my hubby and he did all of the driving.”

“Felt really drained and lacking energy again. Slept for a short time at lunchtime. Cried because I was so tired, I didn't have the energy to drive to hospital to visit husband. Got son to take me.”

“Sunday funday. Cinema with son. It was the best day of his life. Mean so very much to hear and see him enjoy himself. Had to be up early to get there so slept in car on way home in traffic.”

ID bmjopen-2020-041038 SRQR Checklist

	Item	Page
Title	Item 1. Title: Concise description of the nature and topic of the study. Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended.	page 1
Abstract	Item 2. Abstract: Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions.	page 2
Problem Formulation	Item 3. Problem Formulation: Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement.	pages 3-4
Purpose or research question	Item 4. Purpose or research question: Purpose of the study and specific objectives or questions.	page 4
	Item 5. Qualitative approach and research paradigm: Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., post-positivist, constructivist/interpretivist) is also recommended; rationale	pages 2 & 6
	Item 6. Researcher characteristics and reflexivity: Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results and/or transferability.	Pages 5 & 6.
Context	Item 7. Context: Setting/site and salient contextual factors; rationale.	pages 2 & 5
Sampling strategy	Item 8. Sampling strategy: How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale.	page 5
Ethical issues pertaining to human subjects	Item 9. Ethical issues pertaining to human subjects: Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues.	page 5

	Item 10. Data collection methods: Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale.	page 5
Data collection instruments and technologies	Item 11. Data collection instruments and technologies: Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study.	page 5
Units of study	Item 12. Units of study: Number and relevant characteristics of participants, documents, or events included in the study; level of participation.	pages 5, 6 & 7.
Data processing	Item 13. Data processing: Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding and anonymization / de-identification of excerpts.	pages 5 & 6.
Data analysis	Item 14. Data analysis: Process by which inferences, themes, etc. were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale.	page 6
Techniques to enhance trustworthiness	Item 15. Techniques to enhance trustworthiness: Techniques to enhance trustworthiness and credibility of data analysis,(e.g., member checking, triangulation, audit trail); rationale	page 6
Synthesis and interpretation	Item 16. Synthesis and interpretation: Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory.	pages 2, 6 & 14.
Links to empirical data	Item 17. Links to empirical data: Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings.	pages 7 – 14.
	Item 18. Integration with prior work, implications, transferability, and contribution(s) to the field: Short summary of main findings, explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field.	pages 14 -18.

Limitations	Item 19. Limitations: Trustworthiness and limitations of findings	Pages 3 & 18.
Conflicts of interest	Item 20. Conflicts of interest: Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed.	page 19.
Funding	Item 21. Funding: Sources of funding and other support; role of funders in data collection, interpretation, and reporting.	page 19.

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