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Mixed methods study of views and experience of non-hospitalised individuals with long COVID of using pacing interventions

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Long COVID is highly prevalent and debilitating, with key symptoms including fatigue, breathlessness, and brain fog. Pacing is an approach to energy conservation used to help people with chronic conditions like ME/CFS manage the impact of their condition, and could be a useful strategy for people with Long COVID. The aim of this study was to explore the views and experiences of non-hospitalised adults with Long COVID of pacing as an intervention. This mixed methods study is part of the Therapies for Long COVID (TLC) Feasibility trial. A feasibility questionnaire was developed for participants. In addition, semi-structured interviews were conducted with a sub-sample of participants at the end of the study and these interviews were analysed using the reflexive thematic analysis approach. 28 participants completed the feasibility questionnaire and 19 participants took part in a qualitative interview. Participants found that pacing helped improve motivation and activity planning. Concerns included challenges due to time constraints, complexity of the intervention, and limited instructions. Pacing for Long COVID may offer potential benefits and is feasible but further research is required to demonstrate its benefits. Overall, research on pacing in the context of Long COVID has the potential to enhance our understanding of symptom management and rehabilitation strategies for this emerging population.

Keywords Pacing, Qualitative, Long Covid, Mixed methods

Long COVID, or Post-COVID-19 condition, is defined as "the continuation or development of new symptoms three months after the initial Severe Acute Respiratory Syndrome Coronavirus 2 (SARS-CoV-2) infection, with these symptoms lasting for at least two months with no other explanation."[1] Although COVID-19 is no longer a public health emergency of concern[2], many people experience the long-term sequalae of SARS CoV-2 infection. It is estimated that one in 10 people suffering from COVID-19 will develop Long COVID symptoms[3]. The UK Office for National Statistics estimates that there are around 1.9 million (6.2%) of cases in the UK[4]. Long COVID is characterised by the experience of a wide range of symptoms, including fatigue, breathlessness and brain fog, 12 or more weeks following SARS CoV-2 infection[5,6]. These symptoms often have significant impacts on health, quality of life and work capability[7].

Despite the significant disease burden, there is currently a lack of treatments for Long COVID[8,9] mainly because of the complex nature of the condition and the fact that key randomised controlled trials have not

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published their results yet[10]. Therefore, people experiencing Long COVID have to learn to manage to live with their symptoms and adapt their daily life accordingly[11]. One of the approaches used by people with Long COVID to manage their symptoms is pacing[12–14].

Pacing is an approach to energy conservation that is widely advocated by people with lived experience of chronic fatigue, such as those with chronic fatigue syndrome (CFS) and myalgic encephalomyelitis (ME)[15–17], as well as other chronic conditions, including multiple sclerosis[18], rheumatoid arthritis[19], and more recently Long COVID[12–14,20]. It is defined as "energy management, with the aim of maximising cognitive and physical activity, while avoiding setbacks/relapses due to overexertion"[21]. In other words, it involves reducing activity levels to manageable levels and planning daily activities to prevent the "boom and bust" cycle whereby overdoing activities is followed by extreme fatigue that can last from hours to days[13,17].

Pacing exercises can take different forms[18]. For example, for the co-production of a feasibility trial of pacing interventions led by the current research team, a list of 35 pacing resources for Long COVID and other conditions in various formats was compiled and included books, videos, written guidance, mobile phone applications, and smartwatches[13].

Although the impact of pacing on people with chronic conditions, such as ME, has been documented and suggests that pacing might have a beneficial effect on fatigue management and fatigue reduction[18], research on acceptability of pacing activities in the context of Long COVID is scarce.

This study addresses this gap by exploring the views and experience of non-hospitalised individuals with Long COVID of using pacing interventions.

Methods and analysis

Ethics

Ethical approval for this study was granted by the West Midlands – Solihull Research Ethics Committee (21/WM/0203). All participants provided written informed consent. This research has been conducted in accordance with the Declaration of Helsinki.

Study design

This mixed methods study was a sub-study of the NIHR funded Therapies for Long COVID (TLC) feasibility trial, a UK-based decentralised four parallel arm open label randomised trial[22,23]. The TLC feasibility trial aimed to assess the feasibility and acceptability of using pacing interventions on a digital platform (Aparito Atom5™) with a 12-week follow-up period. Three pacing interventions were included: a pacing app, a pacing book, and a pacing video. Links to the pacing app and the pacing videos were included in the Atom5™ digital platform while the pacing book was sent to participants through the post. Participants were only given brief instructions as to how to use the interventions and were advised to use the interventions as often as they wished. Further description of these pacing interventions can be found in Additional file 1. Qualitative evaluation and economic evaluation studies were also conducted[23]. Detailed information on recruitment methods, sample size and randomisation used in the TLC feasibility trial have been published elsewhere[22] and can be found in Additional file 2.

This paper reports the views of the study participants on pacing and their experiences of using the pacing interventions during the TLC feasibility trial.

Data collection

Feasibility questionnaire

The study team designed a bespoke feasibility questionnaire with members of the study's Patient and Public Involvement and Engagement (PPIE) group (referred to as 'patient partners' in this paper). The feasibility questionnaire was administered via the study's electronic platform Atom5™ at the end of the follow-up period (Week 12). The feasibility questionnaire consisted of both multiple choice and open-ended questions on the use of the pacing interventions.

Qualitative evaluation

Participants who took part in the feasibility trial were invited to take part in semi-structured, one-to-one interviews at Week 12 to ensure they had enough time to use the pacing interventions and be able to reflect on them. In addition, participants who formally withdrew and individuals who consented but did not take part in the study were also invited for a qualitative interview. Interviews were conducted online (via Zoom/Microsoft Teams using University of Birmingham secure accounts) by a member of the research team (CM). Semi-structured topic guides (tailored to the different participant groups) were used to ensure key topics, including topics identified through the feasibility questionnaire, were consistently covered. The topic guides remained flexible and evolved based on findings.

The researcher offered participants breaks during the interview. The participants were able to request breaks when they wish to do so or to reschedule a follow up interview if they became tired.

Interviews were audio recorded using an encrypted digital recorder or on Zoom, except during the breaks. Recordings were transcribed verbatim automatically in Zoom and checked by the researcher for accuracy. The transcripts were anonymised and assigned a unique identification number.

Participants who agreed to take part in a qualitative interview received a £10 Amazon voucher.

All TLC participants who were randomised to one of the intervention groups were invited to complete the Feasibility questionnaire. All TLC participants, regardless of whether they completed the Feasibility questionnaire or not, were invited to take part in a qualitative interview (including the ones who did not complete the Feasibility questionnaire). As a result, not all participants who were interviewed had completed the Feasibility questionnaire, nor had used the interventions.

Data analysis

Quantitative data (feasibility questionnaire)
Simple descriptive statistics were used including frequencies and percentages presented for each feasibility outcome measure (e.g. number and percentage of participants randomised to each intervention arm, number and percentage of participants using pacing interventions).

Qualitative evaluation (open-ended questions from feasibility questionnaire and qualitative interviews)
Computer-Aided Qualitative Data Analysis software NVivo12 was used to manage, sort, and code the transcribed data from the qualitative interviews and the responses to the open-ended questions from the Feasibility questionnaire. Reflexive thematic analysis (RTA)[24,25] of the data was conducted with the aim of exploring and developing the main themes found in the data. RTA is a flexible, interpretative and systematic approach to qualitative data analysis which emphasises researcher subjectivity as a resource for research[24]. It involves a six-phase process which helps the researcher to systematically explore, interpret, and report a theme-based analysis from a qualitative dataset[24,25].

Two researchers independently coded a subset of the transcripts ($n=2$) to cross check the coding strategy and data interpretation. Data analysis was carried out simultaneously with data collection.

Consent for publication

Written consent for publication was obtained from all participants.

Results

1. Study participants

A total of 85 people was randomised to one of the four arms of the feasibility trial, of whom 35 participated in this mixed methods part of the study. 27 participants (77.1%) were female and 33 (94.2%) were of white ethnicity. The mean age was 46 years (range = 27–67). Further participant characteristics can be found in Table 1.

Participants were recruited to the study from October 2022 to November 2022 through several routes (Additional file 2)[26].

Out of the 35 participants were included in this study, 28 participants completed the feasibility questionnaire and 19 participants took part in a qualitative interview. Further details can be found in Tables 2 and 3.

2. Quantitative data (Feasibility questionnaire, n = 28)

This section reports the findings from the feasibility questionnaire, which was completed at the end of the study (Week 12) by 28 participants who had been randomised to one of the pacing interventions (43.7%).

(a) Previous use of pacing interventions

Most of the respondents who completed follow up ($n=25$, 89.2%) had not previously used the pacing interventions selected for this study. However, 21 (75%) had used other pacing interventions before taking part in our study (Table 4). Other pacing interventions used included the Internet (NHS website, ME website, general pacing advice, Spoon theory, YouTube videos), apps (Visible), private fatigue management training, peer support (Long COVID support group), physiotherapy advice, HOPE programme.

(b) Use of pacing interventions during feasibility trial

Of the 28 participants who completed the feasibility questionnaire, use of the allocated pacing intervention was 100% (10/10) for the video, 90% (9/10) for the book and 62.5% (5/8) for the app.

The pacing book was used three times or more by eight of the 10 participants over a period of two weeks or more. The participants who used the video ($n=10$) used it for over a period of two weeks or more ($n=3$) and watched it on average 1.8 times. The pacing app was used daily for three months by four of the five participants who had used it (Table 5).

Reasons for not using the allocated intervention included not receiving it (pacing book) and already using an alternative pacing app. Amongst the nine participants who had used the pacing book, one used it only partly because of a lack of time and social circumstances, as shown in their open-ended comment:

"Don't think pacing is working for me because of my job and living alone." (Participant 61 - book)

(c) Impact of pacing interventions on daily activities

When asked about the potential impact of the pacing interventions, 18 participants (64.2%) believed that the intervention helped them understand how to pace their usual activities (strongly agree/agree). In addition, 26 participants (92.8%) tried pacing after using the intervention (Table 6). Out of these 26 participants, 13 (50%) reported being able to pace their daily activities (strongly agree/agree) whereas five (19.2%) reported not being able to pace their daily activities (strongly disagree/disagree).

Reasons for not trying pacing after using the pacing intervention included lack of time due to work and family commitments and believing they were pacing already and not perceiving any additional benefit from the pacing app:

"I work full time and have 3 children. Pacing is not possible" (Participant 274 - book)

Number of participants	Total (*n* = 35)	Pacing video (*n* = 10)	Pacing app (*n* = 11)	Pacing book (*n* = 10)	Usual care (*n* = 4)
Age					
Age [Mean(SD)]	46.0 (10.6)	47.9 (10.5)	46.6 (10.1)	43.4 (10.9)	46.0 (14.4)
Sex, n (%)					
Male	8 (22.9)	2 (25.0)	4 (50.0)	0 (0)	2 (25.0)
Female	27 (77.1)	8 (29.6)	7 (25.9)	10 (37.0)	2 (7.5)
Ethnicity, n (%)					
White	33 (94.2)	10 (30.3)	10 (30.3)	9 (27.2)	4 (12.1)
Asian or Asian British-Indian	1 (2.9)	0	0	1 (100.0)	0
Any other Mixed/Multiple ethnic background	1 (2.9)	0	1 (100.0)	0	0
Other ethnic groups	0	0	0	0	0
Smoking status, n (%)					
Never smoked	27 (77.1)	8 (29.7)	7 (25.9)	9 (33.3)	3 (11.1)
Ex-smoker	5 (14.3)	2 (40.0)	2 (40.0)	0	1 (20.0)
Current smoker	1 (2.9)	0	1 (100.0)	0	0
Currently vaping	2 (5.8)	0	1 (50.0)	1 (50.0)	0
SARS CoV-2 vaccination status, n (%)					
Unvaccinated	2 (5.7)	1 (50.0)	1 (50.0)	0	0
One dose	2 (2.4)	0	0	1 (50.0)	1 (50.0)
Two doses	4 (4.8)	0	3 (75.0)	1 (25.0)	0
Three doses	27 (77.1)	9 (33.3)	7 (25.9)	8 (29.7)	3 (11.1)
Employment, n (%)					
Unemployed	3 (8.6)	1 (33.3)	1 (33.3)	1 (33.3)	0
Employed but stopped working because of illness	15 (42.3)	4 (26.7)	5 (33.3)	4 (26.7)	2 (13.3)
Employed	14 (40.0)	3 (21.4)	4 (28.6)	5 (35.7)	2 (14.3)
Self-employed	3 (8.6)	2 (66.6)	1 (33.3)	0	0
Retired	0	0	0	0	0
Voluntary work	0	0	0	0	0
Work/Education, n (%)					
Stopped working or education	14 (40.0)	5 (35.7)	3 (21.4)	4 (28.6)	2 (14.3)
Working/education time decreased	10 (28.6)	4 (40.0)	4 (40.0)	1 (10.0)	1 (10.0)
Working/education time increased	2 (5.7)	1 (50.0)	0	1 (50.0)	0
N/A	9 (25.7)	0	4 (44.4)	4 (44.4)	1 (11.1)

Table 1. Participant characteristics.

"I pace well enough already and the Spoonie app doesn't help me anymore than what I already do. Also has a silly name!" (Participant 48 - app)

2. Open-ended comments from Feasibility questionnaire and Qualitative evaluation

Participants' previous experience of pacing and their use of pacing interventions during the trial were mentioned in the Feasibility questionnaire's open-ended comments and were also explored during the qualitative interviews.

(a) Previous experience of pacing

Most of the interviewees had heard of pacing before and appreciated its value. Several participants had tried to pace before. Some reported that they thought they knew what pacing was prior to the study but realised, after using the trial's pacing interventions, that they had misunderstood what it was. Most of the interviewees reported using the interventions in the early parts of the study (first 2 to 3 weeks). One of the interviewees (randomised to the pacing book intervention) reported using it before each follow up timepoint.

(b) Experience of using pacing interventions during trial

Participant ID	Intervention	Feasibility questionnaire	Qualitative interview
1	App		✓
6	Book	✓	✓
18	Video	✓	✓
20	Video	✓	✓
21	Usual care		✓
25	App	✓	
30	App	✓	✓
33	Usual care		✓
38	Book	✓	
48	App	✓	
52	Book	✓	
58	App	✓	
59	Video	✓	✓
60	Video	✓	✓
61	Book	✓	
67	Video	✓	
74	Usual care		✓
76	Video	✓	✓
87	App		✓
92	Book	✓	✓
95	Book	✓	
105	App	✓	✓
117	Book	✓	
118	Video	✓	✓
133	Video	✓	
136	Book	✓	✓
252	App		✓
257	Book	✓	
264	App	✓	
274	Book	✓	
278	Video	✓	
295	App	✓	
297	Video	✓	
321	App	✓	✓
324	Usual care		✓
Total		28	19

Table 2. Breakdown of data collection per participant.

	Book	Video	App	Usual care	*N*/A	Total
Participants who completed the trial	2	4	3	1		10
Participants who had not completed the feasibility trial but had not formally withdrawn	1	2	2	3		8
Participants who had formally withdrawn from the feasibility study			1			1
Participants who had consented but had not been randomised					2*	2
TOTAL	3	6	6	4	2	19

Table 3. Number of interviewees per intervention arm and interviewee type. *In addition to the two interviews, nine emailed responses were received.

Positive experience

Interviewees generally reported a positive experience from the pacing interventions. Their positive experience of using the pacing interventions included easiness to understand them, helping with planning activities, being recognised as a Long COVID sufferer, helping with staying motivated, helping others to understand Long COVID symptoms.

		Pacing Book ($n=10$)	Pacing Video ($n=10$)	Pacing App ($n=8$)
Previous use of allocated study intervention	Yes	1 (10%)	2 (20%)	0 (0%)
	No	9 (90%)	8 (80%)	8 (100%)
Previous use of other pacing interventions	Yes	6 (60%)	8 (80%)	7 (87.5%)
	No	4 (40%)	2 (20%)	1 (12.5%)

Table 4. Previous use of the feasibility trial's and other pacing interventions ($N=28$).

	N (%) that used the intervention at least once	Frequency and duration of intervention use
Book ($n=10$)	9 (90%)	Read the whole book for ≥ 2 weeks (80%) Partly read it (10%)
Video ($n=10$)	10 (100%)	30% (> 2 weeks)
		0% (6–7 days)
		30% (4–5 days)
		10% (2–3 days)
		30% (1 day)
		1.8 times (mean)
App ($n=8$)	5 (62.5%)	Used app daily for 3 months (80%)
		Used the app daily for 1 month (20%)

Table 5. Summary of pacing intervention use during the feasibility trial.

		Pacing Book	Pacing Video	Pacing App
Did the intervention help you understand how to pace your usual activities?	Strongly Agree	3 (30%)	0 (0%)	2 (25%)
	Agree	2 (20%)	7 (70%)	2 (25%)
	Neutral	2 (20%)	3 (30%)	0 (0%)
	Disagree	1 (10%)	0 (0%)	1 (12.5%)
	NA	2 (20%)	0 (0%)	3 (37.5%)
Did you try pacing after using this intervention?	Yes	9 (90%)	10 (100%)	7 (87.5%)
	No	1 (10%)	0 (0%)	1 (12.5%)
Were you able to pace your daily activities?	Strongly Agree	1 (10%)	0 (0%)	1 (12.5%)
	Agree	2 (20%)	6 (60%)	3 (37.5%)
	Neutral	3 (30%)	3 (30%)	2 (25%)
	Disagree	2 (20%)	1 (10%)	0 (0%)
	Strongly disagree	1 (10%)	0 (0%)	1 (12.5%)
	NA	1 (10%)	0 (0%)	1 (12.5%)

Table 6. Impact of pacing interventions on daily activities.

Easy to understand

Interviewees found both the pacing book and the pacing video useful and easy to understand. They particularly liked the simplicity of the book (pictures and text).

Help with planning activities/energy

Some interviewees reported that the study pacing interventions were helpful to plan their day, allocate the correct amount of energy to their activities, stay calm, and feel better:

> *"Particularly useful for how to manage good vs bad days (i.e., you don't have to keep up the same level of activity on bad days). Helps to stay calm when symptoms flare and just lean on what you've planned for a bad day" (Participant 38 – book)*
>
> *"Very useful as I was trying to push myself into recovery previously and just kept crashing. Pacing is helping me feel better" (Participant 59 – video)*
>
> *"Using the app has enabled me to visualise my daily activity a lot better and pace myself better. I definitely feel an improvement in my overall health since using it" (Participant 58 – app)*
>
> *"App was useful for thinking through how much energy individual activities use" (Participant 321 – app)*

Being recognised as a long COVID sufferer
One particular interviewee mentioned that the video focused specifically on Long COVID rather than ME. This gave them a sense of recognition:

> *"I watched the video a few times, I loved the fact there were people who had experienced Long COVID. It was the same as me. I liked the fact that it was about Long COVID and not ME" (Participant 59 – video)*

Help with staying motivated and focused
Some participants found that the pacing book and the pacing app helped motivate themselves, stay focused and keep pacing:

> *"I learned new things, it helped me remotivate me" (Participant 42 – book)*

> *"I used it consistently throughout the trial period. I used it every day, it gave me a focus. It had a degree of flexibility in itself, it was useful […] I pace, I am still fatigued, I try not to crash, I am careful to not overdo it. It's not getting any worse. I am better than I was at first. When I climb stairs, I do feel tired but less out of breath, I don't have to sit down after climbing stairs. My headaches have improved" (Participant 321 – app)*

> *"I recognise the signs. I have a 10 mins break between activities and a proper 45 min break, due to the video. I am feeling a bit better. Resting before was just having a cup of tea" (Participant 59 - video)*

Help others to understand long COVID symptoms
Several interviewees believed that both the pacing book and the pacing video could also have an impact on their family members' understanding of living with Long COVID and what pacing is:

> *"It would also help friends and families to understand what I'm going through" (Participant 95 – book)*

> *"It helped me with communicating to other people about pacing, it helps others understand what I go through, that it's not "all in my head"… I now have a mission to pace, it helps me pace, it increased my awareness, it developed over time. I didn't really get it at the beginning. After a while [2 months], I got it" (Participant 59 – video)*

Concerns about pacing interventions

Despite the positive comments, participants had some concerns about using the pacing interventions, mainly because of family/work commitments, the Long COVID symptoms, the lack of instructions and advice on pacing, content not relevant enough to pacing, and mobile app fatigue (feeling of exhaustion experienced by users after having/using many apps on their digital device).

Family demands, work commitments
While several participants acknowledged that pacing was useful in theory, they also highlighted the fact that the pressures of everyday life (work, family, and unexpected events) made pacing difficult and they struggled to commit to it:

> *"I have mixed success with pacing due to family demands" (Participant 67 – video)*

> *"No one can pace their whole life… there are still unexpected events, deadlines to be met (e.g., tax, accounts) and family demands" (Participant 118 – video)*

> *"Pacing is great in theory however life is demanding and there are lots of pressures such as work, parental responsibility, managing symptoms and extreme fatigue" (Participant 264 – app)*

Impact of long COVID symptoms
Some participants reported that their Long COVID symptoms impacted how they used the pacing book:

> *"It is a lot of information and difficult to apply with brain fog and around work" (Participant 117 – book)*

Similarly, some participants commented on the time it took them to watch the video, especially when suffering from fatigue.

Limited instructions/advice on pacing
Although most understood the instructions included with each intervention, some of the participants who used the Spoonie Day app felt that there were not enough instructions on how to use it:

> *"There weren't many instructions – I wasn't sure what to do and the number of spoons did not match how I felt" (Participant 30 - app)*

> *"I found it very difficult to figure out the correct pacing just with the booklet. I would have appreciated a face-to-face explanation by someone who is experienced" (Participant 257 – book)*

> *"The video does not give enough simple practical advice on pacing. I have been trying to pace my activity, which is low (I can't work) and with a lot of resting but I am still crashing with my symptoms without a real understanding of why (sometimes I do more and don't crash, sometimes I do crash, sometimes I crash for a day or two, sometimes for more than a week). The video is not in enough depth for me to deal with this sufficiently and learn more" (Participant 278 – video)*

Content not relevant enough to fatigue
Several interviewees admitted not using the Spoonie Day app much or not at all because they felt it was not relevant enough to fatigue:

> *"I didn't use the app much, I designed my own spreadsheet and made it more about fatigue" (Participant 105 – app)*

Not a mobile app user
Some participants admitted not using mobile app:

> *"I realised I had used this app before, I didn't like it, I I'm not a huge app fan anyway" (Participant 87 – app)*

Discussion

This study aimed to describe the views and experience of using pacing interventions in non-hospitalised individuals with Long COVID.

Many participants had used pacing methods before taking part in our study, such as online resources, apps, private training, and peer support. While some found the study pacing interventions helpful in understanding and practicing pacing, as described in the feasibility questionnaire, others, during the qualitative interviews, reported challenges such as lack of time and complexity of the interventions. Feedback on the pacing interventions was mixed, with some participants acknowledging their effectiveness in helping plan activities, while others found them difficult to understand. Despite familiarity with the concept of pacing, some participants realised their misconceptions of what pacing actually was after engaging with the interventions. The pacing app was used slightly less by participants than the video and the book. However, participants who used the app used it for longer. Participants who used the pacing video reported slightly more impact on their understanding of how to pace.

Overall, most participants reported a positive experience with the interventions, though some found certain aspects burdensome or lacking in clarity.

Findings in relation to existing literature

Our study has shown that even if most study participants were positive about the concept of pacing[27], they sometimes struggled to use the pacing interventions, especially when fatigued[28]. This is perhaps due to the fact that although many of our participants had heard and tried pacing before our study, some of them admitted that they had misunderstood what it was. This is also reflected in existing literature[29,30] and it is reinforced by the fact that some of our participants believed that there were not enough instructions provided with the study pacing interventions. This is further complicated by the unpredictable nature of Long COVID symptoms[7], making it more difficult to concentrate and focus on the task. The brief instructions given to the participants could also explain the attrition rate described in our feasibility manuscript published recently[22].

Delivering the feasibility trial's interventions remotely had its limitations. For example, some of the participants suggested including more human communication[22] and this could explain the fact that all the participants randomised to the pacing video used it during the trial and found that it helped them understand how to pace. This has been highlighted in recommendations published recently[31].

Mobile app fatigue is becoming a real concern[32] and could be one of the reasons why participants randomised to the pacing app used it less than participants randomised to the pacing video and the pacing book.

Considerations for delivery of pacing interventions in the context of long COVID
Therefore, there is a number of considerations which could improve the users' knowledge of pacing and what it involves. Firstly, adding more instructions on how to use the pacing interventions would help individuals with Long COVID plan and prioritise their daily activities[29] as well as increase engagement of participants with pacing interventions. Secondly, developing formal guidance around the definition and use of pacing in the context of Long COVID[33], would increase knowledge of pacing of participants and their family/carers. Finally, adding tailored support mechanisms would facilitate the integration of pacing strategies into the daily lives of affected individuals and would also, as one of our participant noted, contribute to giving individuals with Long COVID the recognition they are seeking for[34]. Despite the similarities between ME/CFS and Long COVID, individuals with Long COVID are eager to make the distinction between them in order to have their own identity[28].

Reflexivity

CM conducted and analysed the qualitative interviews. CM is an experienced female qualitative researcher. In addition to conducting and analysing the interviews, CM led parts of the main study (TLC study) PPIE work and met with the PPIE group every week before and during the feasibility study. As a result, she had some knowledge around living with Long COVID and this helped her refine the qualitative interview topic guide. Although it is difficult to accurately measure the researcher's subjectivity, the Long COVID knowledge gained through the meetings with the PPIE group contributed to reducing any potential prior assumptions and ensured the validity and reliability of the data analysis.

Strengths and limitations

The main strength of our study is its mixed methods design. The feasibility questionnaire allowed to identify issues that were discussed in more detail during the qualitative interviews, which allows for a more comprehensive understanding of the concept of pacing in the context of Long COVID.

Our study is not without limitations and these include the small number of participants ($n = 28$) who completed the feasibility questionnaire. However, the fact that this is complemented by 19 qualitative interviews provides a more detailed picture of participants' views and experiences of pacing and using the pacing interventions.

In addition, most participants were white and female. Although this reflects to some extent the wider Long COVID population, this has also an impact on our ability to generalise our findings.

Implications for research

Our feasibility study shows that the exploration of pacing within the context of Long COVID can have implications for research and clinical practice. Firstly, further investigation into the effectiveness of pacing strategies in managing Long COVID symptoms is needed. Existing studies have shown a lack of effectiveness in managing pain and fatigue, albeit in a different condition to Long COVID[35], and it would be interesting to assess the impact of pacing on Long COVID. This would also contribute to a better understanding of the long-term impact of pacing on symptom management, quality of life, and functional recovery among individuals with Long COVID. It is anticipated that such research could also contribute to the development of evidence-based guidelines and interventions tailored to this population.

Secondly, research should focus on exploring the factors that influence feasibility and adherence to pacing interventions, considering the diverse sociodemographic, cultural, and psychosocial contexts in which individuals with Long COVID navigate their recovery journey.

Conclusion

Pacing is an important component of symptom management for Long COVID. However, the challenges arising from the lack of detailed knowledge around pacing, familial and work commitments, and the impact of Long COVID symptoms, need to be addressed in order to optimise its effectiveness.

Overall, research on pacing in the context of Long COVID may have the potential to enhance our understanding of symptom management and rehabilitation strategies for this emerging population, which will ultimately be improving clinical outcomes and quality of life.

Data availability

The datasets used and analysed during the current study are available from the corresponding author on reasonable request.

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References

1. WHO. Post COVID-19 condition (Long COVID). https://www.who.int/europe/news-room/fact-sheets/item/post-covid-19-condition#:~:text=It%20is%20defined%20as%20the,months%20with%20no%20other%20explanation (2022).
2. Statement on the fifteenth meeting of the International Health Regulations (2005) emergency committee regarding the coronavirus disease (COVID-19) pandemic11/04/2024]. https://www.who.int/news/item/05-05-2023-statement-on-the-fifteenth-meeting-of-the-international-health-regulations-(2005)-emergency-committee-regarding-the-coronavirus-disease-(covid-19)-pandemic?adgroupsurvey=%7Badgroupsurvey%7D&gclid=EAIaIQobChMI4Ojtsdbe_gIVjQRyCh07igt4EAAYASACEgJ9pfD_BwE&fbclid=IwAR2M8EAyiSrAodhK9p-X582nHkP2AigpSX8pYIsLsPwqYh4SG26RGokGe7E (2023).
3. Davis, H. E. et al. Long COVID: major findings, mechanisms and recommendations. *Nat. Rev. Microbiol.* **21**(3), 133–146 (2023).
4. ONS. *Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK* (2022).
5. Subramanian, A. et al. Symptoms and risk factors for long COVID in non-hospitalized adults. *Nat. Med.* **28**(8), 1706–1714 (2022).
6. Davis, H. E. et al. Characterizing long COVID in an international cohort: 7 months of symptoms and their impact. *EClinicalMedicine* **38**, 101019 (2021).
7. Aiyegbusi, O. L. et al. Symptoms, complications and management of long COVID: a review. *J. R Soc. Med.* **114**(9), 428–442 (2021).
8. Brown, K. et al. Long COVID and self-management. *Lancet* **399**(10322), 355 (2022).
9. Ledford, H. Long-COVID treatments: why the world is still waiting. *Nature* **608**(7922), 258–260 (2022).
10. Fairbank, R. Long COVID still has no cure—so these patients are turning to research. *Nature* **628**(8006), 26–28 (2024).
11. Hossain, M. M. et al. Living with long COVID: A systematic review and meta-synthesis of qualitative evidence. *PLoS One*. **18**(2), e0281884 (2023).
12. Parker, M. et al. Effect of using a structured pacing protocol on post-exertional symptom exacerbation and health status in a longitudinal cohort with the post-COVID-19 syndrome. *J. Med. Virol.* **95**(1), e28373 (2023).
13. Turner, G. M. et al. Co-production of a feasibility trial of pacing interventions for long COVID. *Res. Involv. Engagem.* **9**(1), 18 (2023).
14. Ghali, A. et al. The relevance of pacing strategies in managing symptoms of post-COVID-19 syndrome. *J. Transl Med.* **21**(1), 375 (2023).
15. Jason, L. A. et al. Energy conservation/envelope theory interventions to help patients with myalgic encephalomyelitis/chronic fatigue syndrome. *Fatigue* **1**(1–2), 27–42 (2013).
16. Jason, L., Muldowney, K. & Torres-Harding, S. The energy envelope theory and myalgic encephalomyelitis/chronic fatigue syndrome. *AAOHN J.* **56**(5), 189 –195 (2008).
17. Goudsmit, E. M. et al. Pacing as a strategy to improve energy management in myalgic encephalomyelitis/chronic fatigue syndrome: a consensus document. *Disabil. Rehabil.* **34**(13), 1140–1147 (2012).
18. Abonie, U. S. et al. Effects of activity pacing in patients with chronic conditions associated with fatigue complaints: a meta-analysis. *Disabil. Rehabil.* **42**(5), 613–622 (2020).
19. Furst, G. P. et al. A program for improving energy conservation behaviors in adults with rheumatoid arthritis. *Am. J. Occup. Ther.* **41**(2), 102–111 (1987).
20. Garner, P., Jarte, H. I. & Calder, L. H. Long covid and self-help pacing groups—getting by with a little help from our friends. *BMJ Opin.* (2020).
21. Pacing for people with ME. 2019: Action for ME (2019).
22. McMullan, C. et al. Key considerations for digital decentralised clinical trials from a feasibility study assessing pacing interventions for long COVID. *Sci. Rep.* **14**(1), 22083 (2024).

23. Haroon, S. et al. Therapies for long COVID in non-hospitalised individuals: from symptoms, patient-reported outcomes and immunology to targeted therapies (The TLC Study). *BMJ Open.* **12**(4), e060413 (2022).
24. Braun, V. & Clarke, V. Toward good practice in thematic analysis: avoiding common problems and be(com)ing a knowing researcher. *Int. J. Transgend Health*. **24**(1), 1–6 (2023).
25. Braun, V. *Thematic Analysis: A Practical Guide* (Sage, 2022).
26. McMullan, C. et al. *Key Considerations for Digital Decentralised Clinical Trials From a Feasibility Study Assessing Pacing Interventions for Long COVID* (Scientific Reports,2024).
27. Geraghty, K., Hann, M. & Kurtev, S. Myalgic encephalomyelitis/chronic fatigue syndrome patients' reports of symptom changes following cognitive behavioural therapy, graded exercise therapy and pacing treatments: analysis of a primary survey compared with secondary surveys. *J. Health Psychol.* **24**(10), 1318–1333 (2019).
28. Humphreys, H. et al. Long COVID and the role of physical activity: a qualitative study. *BMJ Open.* **11**(3), e047632 (2021).
29. Antcliff, D. et al. Exploring patients' opinions of activity pacing and a new activity pacing questionnaire for chronic pain and/or fatigue: a qualitative study. *Physiotherapy* **102**(3), 300–307 (2016).
30. Nielson, W. R. et al. Activity pacing in chronic pain: concepts, evidence, and future directions. *Clin. J. Pain*. **29**(5), 461–468 (2013).
31. Aiyegbusi, O. L. et al. Recommendations to promote equity, diversity and inclusion in decentralized clinical trials. *Nat. Med.* **30**(11), 3075–3084 (2024).
32. Pang, H. & Shao, Q. Unpacking the potential influence of life satisfaction on network heterogeneity, emotional exhaustion and mobile app fatigue: a Stressor-Strain-Outcome approach. *Int. J. Environ. Res. Public. Health* **20**, 4 (2023).
33. Kingstone, T. et al. Finding the 'right' GP: a qualitative study of the experiences of people with long-COVID. *BJGP Open.*, **4**, 5 (2020).
34. Roth, P. H. & Gadebusch-Bondio, M. The contested meaning of long COVID—Patients, Doctors, and the politics of subjective evidence. *Soc. Sci. Med.* **292**, 114619 (2022).
35. Murphy, S. L. et al. Brief time-based activity pacing instruction as a singular behavioral intervention was not effective in participants with symptomatic osteoarthritis. *Pain* **157**(7), 1563–1573 (2016).

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Author contributions

FJ, AC, LB and DS are patient partners who were involved at all stages of the study.CM, SH, GT, OLA, SEH and MC designed the study.CM collected, analysed and interpreted the data. AS, LJ, NG and SF contributed to the data analysis. SH, MC and SF contributed to the data interpretation.EHD and CF were involved in the set up and maintenance of the Atom5TM platformCM drafted the manuscript. SH, GT, OLA and MC contributed to drafting the manuscript. All authors read and reviewed the manuscript.

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Competing interests

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Additional information

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