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An Adaptive Pacing Intervention for Adults Living With Long COVID: A Narrative Study of Patient Experiences of Using the PaceMe app

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Abstract

Adaptive pacing (AP) is a self-management technique which seeks to balance energy and rest in individuals with chronic health conditions. Adaptive pacing can help people with myalgic encephalomyelitis/chronic fatigue syndrome learn how to manage their energy expenditure thereby reducing their risk of post-exertional malaise (PEM) and other symptoms. Given some symptom similarity, AP also has rehabilitation potential for people experiencing disability from long COVID. The purpose of this study was to explore patient experiences of an AP intervention (the "PaceMe" app) to determine its value for individuals experiencing long COVID. Twenty-five participants each took part in two narrative interviews (at intervention start point and at 3-6 months). Data were analyzed using narrative thematic analysis. Our analysis identified 4 themes relating to key benefits of the PaceMe app: (1) PEM management, (2) Support, (3) Validation, and (4) Control and Agency. By illuminating the critical facts and centring patient voices, these findings contribute a better understanding of the experiences and needs of those with long COVID and highlight the value of a digital health intervention as a vital component of rehabilitation.

Keywords

activity tracking, long COVID, mHealth, recovery, adaptive pacing, narrative research, lived experience

Introduction

Long COVID is a patient-made term describing new or ongoing signs and symptoms experienced during or after SARS-CoV-2 infection that cannot be explained by an alternative diagnosis. The term was coined during the early months of the pandemic by those who continued to experience persistent, disabling symptoms, and failed to recover in the weeks and months that followed.[1,2] Patients commonly report several debilitating symptoms, including respiratory, cardiovascular, neurological, and musculoskeletal symptoms.[3–5]

At this time, few treatment possibilities have been established for people with long COVID.[6] While several guidelines on long COVID have been published, the absence of a practical and effective means to guide patient rehabilitation has resulted in clinical practice adopting a symptom-based approach.[7] A consensus has emerged among the medical profession and researchers that long COVID research and guidelines must

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reflect patients' lived experience.[6,8] Critical to this research is a focus on patient voices to better understand the experiences and needs of those with long COVID.[9]

Adaptive pacing (AP) is a self-management technique that aims to balance energy and rest.[10] Like other self-management techniques, pacing is considered a strategy rather than a technique and is used to minimize symptoms or reduce the impact of a health condition on the individual's life.[11] At the heart of pacing is the "energy envelope" theory which proposes that in order for individuals to remain within their physical and mental limits and conserve energy, only energy within the "envelope" of perceived available energy level may be expended.[12]

Pacing is one of the principal approaches currently used to manage myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), has the largest degree of patient engagement and greatest patient-reported benefit.[11] According to the 2021 NICE guidelines for ME/CFS, pacing "helps people learn to use the amount of energy they have while reducing their risk of post-exertional malaise (PEM) or worsening their symptoms by exceeding their limits" and takes into consideration all types of activity (cognitive, physical, emotional, social) as well as overall level of activity.[11]

The utility of pacing among people with ME/CFS has prompted the study of pacing as a potential self-management strategy for adults living with long COVID to ascertain if pacing may similarly aid rehabilitation. Like ME/CFS, long COVID is an often-unpredictable illness with patterns, symptoms, and levels of severity which can fluctuate over time. Due to the novel and developing nature of the condition, little evidence exists regarding the benefits of pacing in people with long COVID; however, sufficient benefits documented elsewhere, primarily in ME/CFS[13–15] warrant further investigation. Accordingly, we respond to calls for research into long COVID rehabilitation interventions grounded in patients' lived experience,[6,8] designed by disabled people, for disabled people[16] and which generate a greater understanding of the psychosocial needs of long COVID patients.[17] Based on the potential benefits of AP for people with ME/CFS, we investigated both the self-management and psychosocial benefits of the Pace Me app and its potential in supporting patients to cope with their changed life situation.

Method

The qualitative study reported here employed narrative interviews with a subset of individuals with long COVID who were taking part in a pragmatic trial of the PaceMe app. In keeping with a narrative methodology, we consider the stories participants share to be socially constructed, shaped by both personal lived experience and the broader sociocultural setting in which the individual is immersed. We respect the grounding of participants' accounts in their own lived experience while appreciating the significance of cultural context, social perspectives, and shared beliefs.[18]

PaceMe Intervention

The intervention was provided via a bespoke support platform incorporating a wearable activity tracker (Fitbit Charge 5, Fitbit, USA), a data processing server, and a cross-platform (iOS and Android) mobile app (PaceMe). During enrolment in the study, participants were allocated time and heart rate (HR) limits of attempting to spend no more than 30 min per day above 60% of their age-predicted HRmax. Participants would receive alert notifications when they reached 50%, 75%, and 100% of their time limits. Alerts included a text notification regarding the percentage of their time limit they had reached, as well as an infographic containing a suggestion for good pacing habits curated from responses from people with ME/CFS who had been using pacing for several years.

The app also allowed participants to register when they experienced a bout of PEM. When this occurred, our server would review the 3 days prior to the bout and determine if they had exceeded their suggested pacing limits in any of those 3 days. If they had, then there would be no changes to their pacing limits, and participants would receive a notification that we had reviewed their data and that it was likely that they had experienced PEM because they had done too much. In addition to logging a bout of PEM, the app included sections that participants were requested to complete each month: a "symptom check in" (to get a view of the month-by-month symptom load of participants); a "brain-fog test" (to assess cognitive function); and a battery of items exploring neurological function, PEM, quality of life, breathlessness, self-efficacy, and pain. We also had the data server scan each participant's responses daily and send appropriate notifications to complete one of the 4 sections each week if responses were missing.

Participants and Recruitment

Following ethical approval (approved by the Health and Life Sciences SEC at the University of the West of Scotland, approval no. 17763), 25 participants (19 female, 6 male, median age 47) enrolled in the PaceMe trial were recruited to take part in the qualitative study. All participants met the inclusion criteria: adults reporting persistent symptoms which have lasted for at least 8 weeks after initial infection with COVID-19 and which interfere with day-to-day activity; recovering at home and have access to an Android or iPhone mobile phone. We used a combination of purposeful, criterion, and convenience sampling to recruit a range of participants (eg, in terms of age and sex) and to remain within the time constraints of this funded project. Potential participants were contacted by email and those who expressed interest were emailed a copy of the participant information sheet and consent form. Following receipt of a signed consent form, the first interview was scheduled.

Data Collection

Data were gathered through longitudinal narrative interviews conducted by the first author. Participants were offered the choice of in-person or online video interviews (using Microsoft Teams); all participants chose to conduct the interview via video recording. A semistructured interview guide was developed in collaboration with our Patient and Public Involvement (PPI) representative from Long COVID Scotland to explore participant experiences of their initial infection of Covid-19, the development of symptoms into long COVID, and perspectives of the PaceMe intervention. A pilot interview was conducted with our PPI representative in order to test our co-produced interview schedule and ensure the efficacy, sensitivity, and relevance of the interview questions.[19]

Interviews lasted between 40 and 75 min. Two interviews were carried out with each participant. Interview 1 was conducted at the start of the individual's involvement in the trial and focussed on supporting participants to share stories of their experience of long COVID. A follow-up interview was conducted between 3 and 6 months later and focussed on eliciting participants' stories of their experience of the intervention, specifically the effectiveness of PaceMe in managing their long COVID symptoms and bouts of PEM. The interviews were video recorded and transcribed verbatim, with field notes and observations recorded by the first author in a reflexive research diary. In accordance with ethical requirements, any identifying information was removed, and all participants names have been anonymized.

Data Analysis

Following verbatim transcription, the first and second authors immersed themselves in the data through reading and rereading transcripts, personal reflection, and collaborative dialogue.[20] Analysis and interpretation proceeded in a comparable way to Riessman's[21] description of a *thematic narrative analysis*. Initially, this involved a within-case analysis (focusing on one participant at a time) to understand and explore the events, tone, content, and arc of each participant's story. Next, a cross-case analysis was conducted to identify common themes across participants' stories. Our focus throughout was on the stories that participants shared which provided insights into the effectiveness, usefulness, value, and meaning of the PaceMe app. Through discussion of the initial themes and further dialogue between the first and second authors, 4 themes were agreed as key to the participants' experiences. Together, these themes provide a nuanced understanding of how PaceMe was experienced by participants during the intervention, and the potential of AP in the self-management of long COVID.

Results

In what follows, we present the 4 (interrelated) themes that emerged through our analysis: (1) PEM management; (2) Support; (3) Validation; (4) Control and Agency. These themes provide detail about *how* participants used the app and the *outcomes* they experienced through its use. We share excerpts from the interviews which demonstrate these themes in action, followed by a discussion of the implications of our findings for clinical practice.

Theme 1: Identification and Management of Triggers

An important value of PaceMe was the identification of PEM triggers and a clearer understanding of the appropriate amount of rest and relaxation required to manage or limit PEM. This included identifying triggers participants had not previously been aware of and establishing a personal "tipping point." The app helped increase knowledge of participants' own physiology allowing them to better understand their experience of long COVID and the complex nature of its symptoms. Anna's account offers detailed insights into the process through which PaceMe helped her manage her symptoms:

> When I started, at first, I was getting warnings every day and I think my steps were at 10 000 steps a day, and that was just wandering around the house. And then after being on the study for a couple of weeks, I stopped having them (notifications) constantly. (Before) it wasn't that I was identifying PEMs because I was living in them constantly, they were lasting for days at a time and everything that I was doing was making me feel that way … I had a constant headache, I had constant muscle aches and twinges and, you know, I was being sick all the time. Several times a day I was breathless constantly and coughing. And it would come on when I did things. I would walk out the house to go to the garage to put a wash on and be coughing the whole way over there. And so, it made me really recognize that I needed to move much more slowly all the time … It helps so much to make me stop and think, right well, actually I need to rest now.

Anna's excerpt illustrates how PaceMe facilitates a greater awareness of the balance between energy expenditure and exacerbation of symptoms, including but not limited to PEM. By providing real-time information and alerts whenever participants came close to exceeding their personal threshold, it was possible to identify what Graham refers to as "a sweet spot":

> I've been sort of working with the watch, so I've kind of, I'm trying to keep it around ten because, again, that seems to be a sweet spot where I'm not too knackered. So, that seems to be a sweet spot. So, I do try and keep an eye on my steps and if I can help it, not go too far above that 10/11 and I'm all good. So, I use that as a guide.[1]

A further value of PaceMe was how it helped participants make sense of their condition by, for example, allowing them to identify specific triggers of PEM such as incidents that cause short, sharp spikes in HR which had almost immediate consequences for energy levels and fatigue:

> Something that I hadn't actually thought of was sometimes I play in a band, and I play piano, and I sing …. I would never have considered that. But actually, I've been able to see that raises my heart rate. (Michelle)

Theme 2: Support

A second theme in participants' narratives of using the PaceMe app is support. Having received inadequate support from medical professionals and limited access to health services, many participants described how PaceMe offered the first meaningful support they had received (beyond their immediate family or partner). The app was experienced as, in one participant's words, "a crutch," that held emotional value, providing confirmation and reassurance, as well as practical support in aiding the monitoring and management of symptoms.

For example:

> I think, like, pacing, it's just hard … it's constant and it's really hard. So, it feels quite supportive to have the app, in this really user friendly way, and it's just there, in kind of black and white. (Samantha)

> It's just sort of reassuring that you're not alone, in a way, or other people were feeling the same thing … that it's not just you that feels like this or coping with it … It's almost like a crutch in a way. It's a better support than you're getting … And on the days when it doesn't sync, I would say that sometimes you feel a bit bereft. (John)

In particular, participants found that PaceMe offered support through a connection to researchers, visualization of data, and features such as the ring back request function. For some participants, simply knowing there were other people taking part in the study and therefore they were not alone, provided support in the form of shared knowledge, reassurance, and validation that there were other people coping with the same condition.

Theme 3: Validation

The third theme identified in the data analysis was validation. Many participants shared stories of how they experienced varied forms of validation through using PaceMe, often felt through the provision of confirmation or evidence for what they were experiencing. Seeing the effects of long COVID in the form of data created by the app offered participants reassurance that what they were experiencing was not, as one participant described, "all in my head." Examples of this process are evident in the following excerpt:

> I think for me it's quite nice because I do try and look at it and go "ah, that's interesting." Maybe I'm feeling like that and then it shows me what's happened those couple of days. So yeah, it's like another tool that's there to use cause sometimes you think it's in your head, but actually when you look at it, it's that reassurance that there's a connection there. (Louise)

For some participants, PaceMe was also a useful tool to provide evidence to others, for example, when they needed to rest or when they risked doing too much and exacerbating symptoms:

> It helps me feel more able to say to other people because, like, I've got it on my screen. It's not like I show it to them … (but) it helps ease the feeling of, I'm being ridiculous, what I'm physically doing isn't that much, which it wouldn't have been before I was ill or to another person. But it is for me. And seeing that alert, it's like OK, I really need to rest and it's OK to say that. (Samantha)

For one participant, the validation provided by the PaceMe app was so important to them that they became upset when discussing the end of the study and considering their lives without the intervention:

> It was a bit of a lifeline to start with because it was literally the only thing I had to help me to understand it … I had a bit of a panic because I thought it was only for three months and I was like starting to get worried … what I would do after I didn't have the app. *(Participant becomes upset)* But then I realized it's for six (months), so I've still got another wee while to go on it … So, yeah, I would be happy to stay on it or go on it again or something. It has been a bit, like, what will I do? (Anna)

Theme 4: Agency

All participants in this study described a deep sense of loss for their former selves as well as a total loss of control over their lives and futures. Our analysis shows how PaceMe supported greater autonomy and agency by helping participants regain some degree of control of their health and wellbeing. An example of how this happens is described by Samantha:

> The alerts are definitely really helpful. Yeah, I guess there's been a couple of times when I've known that I'm doing too much but there's been some sort of, like, minor work emergency or something so I've carried on. But even then, in some ways it's a bit stressful getting the alert and it telling me like "you're doing too much." I'm like, "I know that, but I'm carrying on anyway." But even still, it's really helpful because there's something about knowing that's happening and, "I'm making a choice" … Now, compared to the start of the study, I feel like I have a lot more control.

Participant accounts also revealed how the app helped them regain some degree of control or agency over other aspects of their health, such as sleep, activity, or mental health. For example:

> I feel like I have a little bit more control of my life because it gives me an idea of how I sleep … And also, I'm aware of my steps. So, I feel like I'm a little bit more in control that way. I know where I've overdone it because I actually do more steps in the house than I thought. (Ashley)

> I think I actually have taken on board quite a lot and I felt much more able to say to work and to friends like I just can't do that. If we do that, then I can't do this … With work as well, I can feel hmm, still not great with it, but better at saying I just don't have the spoons[2] to do that, and I have reasons for that, you know. So, I think pacing is definitely good for mental health, and it's a good way to think about things … like I can't do everything and that's just it. (Heather)

Discussion

This study assessed experiences of long COVID and the potential of pacing through use of the Pace Me app. Across the interviews, we were struck by the value and meaning participants attached to their use of the PaceMe app. All participants expressed the view that PaceMe had been helpful for them in some way. For some, it held great meaning and value as they considered the app to be profoundly important in their efforts to manage long COVID. For others, the app's usefulness was more modest, perhaps serving a particular functional outcome for a specific period of time.

The use of mHealth platforms such as mobile applications in improving self-efficacy of chronic illness through improved health knowledge has been well-documented.[22–25] However, a lack of clarity around long COVID and how it ought to be handled in clinical practice has generated confusion for researchers, clinicians, and patients.[26] With a clearly established case definition and symptom profile lacking, increased knowledge about long COVID and the triggers which exacerbate symptoms, especially PEM, represents an important finding of PaceMe. Research on other long-term conditions such as HIV and diabetes[27,28] has reported similar positive uses of mobile applications in supporting the monitoring of health behaviors and self-management. Crucially, we found that PaceMe increased participants' knowledge and understanding of their own experience of long COVID, in turn supporting their confidence in managing day-to-day activities to prevent triggering PEM and other long COVID symptoms.

Many people experiencing long COVID have limited access to health services and have received insufficient support from medical professionals.[29] This was also the case for most participants in our study. In this context, other forms of support are vital for people living with long COVID.[26,30] The app was experienced as "a crutch" and "lifeline" that held emotional value, providing confirmation and reassurance, as well as practical support in aiding the monitoring and management of symptoms. In a study[29] of online communities, participants expressed the importance of peer support for exchanging knowledge of recovery practices such as diet, self-help treatments, and approaches to exercise and pacing, as well as discussing research and gaining feelings of solidarity. Our findings suggest support was equally important to participants and one of the key values found in the use of PaceMe. These findings align with a growing body of research[30,31] which see support and social connectedness as a "social cure" against some of the damaging consequences of chronic illness.

The impact of long COVID stigma and its implications for self-esteem and self-efficacy have been well-documented.[31–34] Not only does stigma negatively impact quality of life but can lead to avoidance of medical help-seeking, which may exacerbate illness in the long-term and prevent recovery. While PaceMe cannot of course tackle deeply held societal beliefs which contribute to stigma, our findings suggest that it can contribute to alleviating the weight of stigma by acting as a tool for validation, reassurance, and support—human attributes that support the individuals' ability to cope with, and manage, chronic illness and disability.

Research has likewise demonstrated how chronic illness impacts individuals' agency and sense of self.[35–37] People with long COVID also commonly describe a loss of control over their own bodies, feeling that they are "strange and unfamiliar" and do not feel like their own.[32] All participants in this study described a deep sense of loss for their former selves as well as a total loss of control over their lives and futures. This aligns with research on the importance of understanding the bearing of a long-term health condition on the patient's sense of agency.[27,38] Our findings contribute to this literature by suggesting that PaceMe helps people with long COVID develop a greater sense of autonomy, agency, and a renewed sense of control.

Strengths and Limitations

All participants described their experience of using the PaceMe app in positive terms. We therefore have limited insights to share regarding potential adverse aspects of using the app. Additionally, while our study provides longitudinal insights, this is limited to the duration of the intervention. We were not resourced to conduct follow-up interviews to explore participant experience post-intervention.

Conclusion

Our findings support several conclusions which have important and groundbreaking clinical implications for the treatment and management of long COVID. First, AP—delivered through the use of mHealth strategies such as the PaceMe app—provides a range of valued uses for people managing long COVID. Second, PaceMe provided both education and a practical strategy to allow participants to better manage PEM (and other long COVID symptoms) by, for example, identifying and moderating triggers of which they were previously unaware. Third, PaceMe offered people with long COVID vital support, validation, and—crucially—a regained sense of control and agency over their lives which was lost as a result of the disruption the illness has caused. Finally, our study reinforces the importance of narrative methods in research into the design and delivery of healthcare services. Without considering nuanced accounts of patient experiences, the personal meaning and value of the PaceMe app would not have been identified.

With regard to future research, this article highlights the importance of digital resources for people with long COVID to support pacing. We therefore posit that digital resources should be developed and tested to aid energy management/pacing in other fatiguing conditions such as ME/CFS. This would negate issues of inclusivity and accessibility, given the support would be digital and remote. Furthermore, this would improve scalability of pacing/energy management rather than relying on healthcare professionals in one-to-one or group settings.

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Author Contributions

RM contributed to conceptualization of the research, conducted the interviews, carried out the analysis, and wrote the first draft. DC contributed to conceptualization of the research, oversaw the analysis and reviewed and revised the finished article. JO, LH, JM, MM, NS, and JI provided feedback on the first draft. All authors agreed to the finished article.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Ethics Approval

Our study was approved by the Health and Life Sciences SEC at the University of the West of Scotland (approval no. 17763). All participants provided written informed consent prior to enrolment in the study.

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Notes

1. By 10/11 Stuart is referring to 10-11,000 steps.
2. Reference to 'spoons theory', a term coined by Miserandino (2017) in relation to energy capacity.

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