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Pacing with a heart rate monitor for people with myalgic encephalomyelitis/chronic fatigue syndrome and long COVID: a feasibility study

N. Clague-Baker[a,b], T. E. Davenport[c], B. Wickens[d], H. Leeming[e], K. Dickinson[f], E. McBurney[a], K. Leslie[b], M. Bull[b] and N. Hilliard[b]

[a]Physiotherapy Department, University of Liverpool, Liverpool, UK; [b]Physios for ME, Liverpool, UK; [c]Department of Physical Therapy, University of the Pacific, Stockton, CA, USA; [d]Stockport ME group, Manchester, UK; [e]Visible Health, Sheffield, UK; [f]Facebook groups – HRM4Pacing, ME/CFS – Pacing with a Heart Monitor #2, London, UK

ABSTRACT

Background: People living with ME/CFS and LC frequently live with post-exertional malaise (PEM), which is associated with impairments in aerobic metabolism. They often use pacing with a heart rate monitor (HRM) to minimize time spent above the anaerobic threshold; however, there is limited research on the feasibility and efficacy.

Objective: To establish the acceptability, adherence, outcomes, and adverse events associated with pacing with an HRM for a future definitive study.

Methods: After informed consent and baseline measurements (including 10 min stand test, 5 questionnaires, accelerometry, heart rate variability, and lactate), participants were randomized into a control or intervention group using simple randomization and sealed envelopes. The intervention group used a heart rate monitor with weekly online HRM pacing advice (how to use the HRM, problem solving), and the control group received weekly online pacing advice (how to pace, problem solving). Follow-up measures were repeated, and semi-structured interviews were conducted at two and six months post-enrolment.

Results: 47 participants were recruited; however, recruiting people with LC was difficult due to wanting to use/already using HR monitoring. The interviews identified that the procedure was acceptable, and the majority of the participants completed the outcome measures. There were some changes from baseline to follow-up in all the outcome measures except the 10-minute stand test and accelerometry. There were no serious adverse events. Follow-up interviews identified 89% continued using HRM at 8 weeks and 66% after 6 months.

Conclusions: Studies of HRM are feasible and acceptable for ME/CFS and LC, although recruitment strategies should be reviewed for LC.

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CONTACT N. Clague-Baker Nicola.Baker@liverpool.ac.uk Physiotherapy Department, School of Allied Health Professions and Nursing, Institute of Population Health, University of Liverpool, j128 Johnston Building, The Quadrangle, Brownlow Hill, Liverpool L69 3GB, UK

Introduction

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) has been defined as a profound dysfunction/dysregulation of the neurological control system, resulting in faulty communication and interaction between the central nervous system and major body systems [1]. Symptoms include Post-exertional malaise (PEM); Neurological abnormalities, such as sleep, autonomic, and sensory disturbances, headaches, pain and cognitive disturbances; Immune, Gastrointestinal, and Genitourinary impairments, such as flu-like symptoms and sensitivities to food or medications and Energy metabolism/Ion transportation impairments, such as orthostatic intolerances and temperature intolerances [1]. ME/CFS is identified based on clinical findings consistent with one of several established contemporary case definition criteria [1–3]. The World Health Organization has classified ME/CFS as a neurological health condition in 1969 [4], but the complex pathophysiology of this disease process is known to affect multiple body systems. ME/CFS most frequently occurs after an illness [5,6]. The most recent systematic review by Lim et al. [7] summarized literature published before the beginning of the SARS-COV-2 global public health emergency, establishing an average prevalence of 1.4% of the population worldwide. A recent cohort study indicates approximately 5% of people with 'Long COVID' meet contemporary clinical criteria for ME/CFS [8].

Long COVID (LC) is defined as 'the presence of signs and symptoms that develop during or following an infection consistent with SARS-COV-2, which continue for 12 weeks or more and are not explained by an alternative diagnosis [9]. Symptoms include Respiratory symptoms; Cardiovascular symptoms; Fatigue; Fever; Pain; Neurological symptoms, such as cognitive impairments, Headache, Sleep disturbance, Peripheral neuropathy symptoms, Dizziness, Delirium, Mobility impairment, Visual disturbance; Gastrointestinal symptoms; Musculoskeletal symptoms; Ear, nose, and throat symptoms; Dermatological symptoms; Psychological/psychiatric symptoms [9]. A subset of people with LC develop post-exertional malaise (PEM) or post-exertional neuroimmune exhaustion (PENE) [1], which is the defining feature of ME/CFS. This means that, like people with ME/CFS, if they exert themselves physically, mentally, emotionally, or socially, they have an exacerbation of symptoms or develop new symptoms immediately and delayed for up to 24 and even 48 h [1].

Key commonalities in case definition criteria involving PEM include an inappropriate loss of physical and/or mental stamina, rapid physical and/or mental fatiguability, a tendency for other associated symptoms within the individual's cluster of symptoms to worsen, and progressive loss of functional baseline [3,10,11]. There also must be a pathological length of time to recover of >24 h or more [3], and other conditions potentially explaining the pattern of symptoms must be excluded [1,3,12–14]. PEM results in substantially impaired health-related quality of life compared to normative data [15–19], healthy matched control participants [20,21], and individuals with other fatigue-related health conditions [17,21]. PEM-related signs, symptoms, and disablement appear related to impaired aerobic metabolism [22–25], resulting in abnormalities in physiological recovery from acute exertion [24,26–29].

The two-day cardiopulmonary exercise test (CPET) serves as key objective evidence of PEM in people with ME/CFS [30]. People with ME/CFS have an abnormal decrease in the volume of oxygen consumed (VO_2) and work rate, especially at the ventilatory anaerobic threshold (VAT), on the second day of a two-day CPET [28]. The ventilatory anaerobic threshold (VAT) is the point at which ventilation starts to increase at a faster ratecompared to oxygen consumption [22]. This observation in people with ME/CFS is different from sedentary matched controls, who reproduce these values reliably between the two days [22,24]. Ventilatory findings of early onset of anaerobiosis have been corroborated by studies, indicating excess lactate production in people with ME/CFS but not matched deconditioned controls on CPET [31] and during daily functional activities [32]. These physiological findings align with an unfavourable response to traditional exercise prescription in people with ME/CFS [33], suggesting the need for alternative approaches that can optimize functioning with respect to signs and symptoms of PEM.

Pacing is the intentional act of balancing activity and rest, which is a managed approach to avoid aerobic energy system impairments underlying PEM. A recent systematic review [34] of five studies with 1317 people with ME/CFS found that there was insufficient evidence that pacing had a positive effect on physical function and pain, although it may have an effect on fatigue. They concluded that further studies with larger sample sizes and improved quality were needed. One method of pacing involves the use of a person's heart rate as a form of biofeedback. The theory and practice of pacing with a heart rate monitor (HRM) was devised by the Workwell Foundation in the United States [35]. Anecdotally, people living with ME/CFS and LC frequently use pacing with an HRM, but it has been the subject of little formal scholarship [36]. An ME/CFS case study showed improvement in oxygen consumption (VO_2) after one year of pacing with an HRM [37]. A large international survey documented that pacing with an HRM is beneficial for most people with ME/CFS, leading to a better understanding of the condition and even more activity for some individuals [36]. Interviews of participants with LC in a pacing study indicated HRM can improve the sense of support, validation, and agency or control in people living with PEM [38]. A case series with people with LC demonstrated positive aspects of using pacing with an HRM, such as managing fatigue and knowing when to rest [39]. A recent observational longitudinal study with people with complex chronic illness indicated that an HRM can be used to predict PEM exacerbations and worsening of fatigue and cognitive dysfunction [40]. However, to date, no controlled studies of pacing with an HRM have been conducted in the ME/CFS population, and one ongoing study associated with the interview study above [37] with the LC population is yet to be published.

The literature is replete with promising preliminary findings of case studies and cross-sectional research into pacing using an HRM, which now require verification through larger randomized trials that are designed to establish causation. These large trials often rest on the findings of earlier feasibility studies that begin to explore critical issues in design, implementation, and analysis, such as recruitment, acceptability of clinical measures, and adverse events. Therefore, the aim of this study was to determine the feasibility of a randomized trial to establish clinical outcomes and satisfaction associated with pacing using an HRM. Issues of interest in this study included acceptability of the intervention and endpoint measures, rates of recruitment and retention, preliminary data on outcomes, and potential adverse events. These data will be used to design a more definitive future study to investigate the effectiveness of pacing with an HRM in people with ME/CFS and LC.

Method

Study design

This study was a mixed-methods approach as the aims required both quantitative and qualitative methodologies. The recruitment strategy, incidence of adverse events, and suitability of outcome measures were measured using quantitative measures, that is, record of numbers screened and recruited; record of reported adverse events; successful completion of all questionnaires; and physical outcome measures. Acceptability was measured with qualitative methods, that is, via semi-structured interviews. As the interview data were collected after the intervention, the mixed-method design is a sequential explanatory design, meaning that the quantitative data were collected first and analysed, followed by the collection and analysis of the qualitative data, leading to a holistic interpretation of the entire dataset [41]. The study protocol was approved by the University of Liverpool ethics committee (Reference 11,373).

Participants

People living with ME/CFS and LC were recruited via the Stockport ME/CFS and LC support group and online ME/CFS and LC forums (e.g. Twitter/X and Facebook). All the participants with ME/CFS had to meet the International Consensus Criteria for Myalgic Encephalomyelitis (ICC) for the diagnosis of ME/CFS [1]. People with different severities of ME/CFS were recruited, ranging from mild to moderate/severe ME/CFS [42]. Participants with LC had to have PEM. All participants were over 18 years old (mean age (SD) 46.4 (10.9)), all ethnicities and both males ($n = 7$) and females ($n = 40$) included. Exclusion criteria were people with very severe ME/CFS and LC, people who were already using pacing with an HRM and people with LC without PEM. As this was a feasibility study, a power calculation was not completed. The aim was to recruit 25 people with ME/CFS and 25 people with LC over eight months, as this was considered a large enough sample to fulfil the study aims.

Materials

Outcome measures included:

(1) A 10-minute stand test [43,44], which involves lying supine for five minutes and then standing still for ten minutes without leaning on any support. During this test, blood pressure, heart rate, and oxygen levels are measured at baseline, after five minutes lying, at two minutes, five minutes, and ten minutes of standing. All symptoms are recorded during the test. Blood pressure is measured with a handheld automatic sphygmomanometer cuff on the arm (OMRON M2Basic), and pulse and oxygen saturation are measured with a finger pulse oximeter (OxiPro 2).
(2) Patient-Reported Outcomes Measurement Information System (PROMIS) Fatigue and Physical Function Tools [45,46]. The PROMIS tools were designed by HealthMeasures in the USA (funded by the National Institutes of Health) to provide free validated measures for a number of variables, including fatigue and physical function. The PROMIS Fatigue measure has been validated in the ME/CFS population and shown

to be valid and reliable [47]. The Physical Function measure has not been validated in the ME/CFS or LC populations, but has been shown to have strong construct validity and test-retest reliability in a similar population of people with chronic heart failure and back pain [48]. These measures were chosen to measure fatigue and physical function in this study due to their ease of use and thorough process of development.

(3) DePaul Symptom Questionnaire Short Form [49]. The Depaul Symptom Questionnaire Short Form was designed to measure common symptoms of ME/CFS and was adapted from the long version so that people with ME/CFS only had 14 questions to complete rather than 99 questions. It is an effective screening tool for symptoms of ME/CFS and was used in this study to determine the effectiveness of the screening process.
(4) 36-Item Short Form Survey (SF-36) [50]. The SF-36 is a quality of life (QOL) measure that has been shown to be valid and reliable for people with ME/CFS [51] and, therefore, was chosen to be used in the present study to measure QOL before and after the intervention.
(5) Good Day/Bad Day Questionnaire [52]. The Good Day/Bad Day Questionnaire was devised by the Bateman Horne Center in the USA, which is a specialist centre for ME/CFS, LC, and fibromyalgia. The validity of the measure has not been tested in these populations, but has been shown to be valid and sensitive for a population with orthostatic intolerance [53]. As orthostatic intolerance is a particular issue for many people with ME/CFS and LC, this instrument was used during the study.
(6) The ActiGraph wGT3X-BT26 [54] accelerometer measures activity levels using a triaxial device worn over the right hip during waking hours. The total activity recorded was divided into percentage time in stationary behaviour, light, moderate, vigorous activity, and moderate-to-vigorous activity (MVPA), indicating activity that could provide a cardiovascular benefit.
(7) The FirstBeat bodyguard 2 [55] uses heart rate, breathing frequency, heart rate variability, and oxygen uptake to identify periods of 'physiological stress' (suggesting sympathetic nervous system dominance), 'recovery' (parasympathetic nervous system dominance), and physical activity. The FirstBeat bodyguard 2 calculates the percentage of time the user is in 'physiological stress' and the percentage of time the user is in 'recovery'. The FirstBeat bodyguard 2 has demonstrated validity for healthy participants when compared with electrocardiogram recordings during everyday activity [56]; however, the validity of the measure has not been documented in people with ME/CFS or LC.
(8) The Cosmed Lactate Pro 2 [57] measures the presence of lactate, and levels above 4 are an indication of higher levels of anaerobic metabolism, that is, energy produced without oxygen [58]. Normal lactate values range between 0.5 and 2.2 mmol/L during submaximal activities [58].
(9) Interview schedule included questions related to *Your life with ME/CFS or Long COVID, If you were part of the control group what were your experiences of the study or If you were part of the intervention group what were your experiences of the study*.

Procedure

An invitation post was advertised on Physios for ME Twitter/X page, website and Facebook page, Long COVID Physio Twitter/X page, and the ME Association Twitter/X pages and Facebook pages. An invitation email was sent to the Stockport support group administration team, who then sent the email out to the support group. If a potential participant was interested in the study, they emailed the principal investigator (PI), who then sent the information sheet and asked them to email if they were still interested after reading the information sheet. At least 48 h were provided to consider participation. The potential participants were then followed up with a screening phone call or Zoom chat, depending on the preference of the person with ME/CFS or LC, to discuss the study and identify suitability for the study.

On the day of assessment, the PI arranged to complete the assessment in the participants' homes. After obtaining written consent, the following information was recorded from the participant: details about their ME/CFS or LC; past medical history, drug, and social history. The following baseline assessments were also undertaken: all participants undertook the ten-minute stand test [43,44], and then the participants filled out five questionnaires, including the Patient-Reported Outcomes Measurement Information System (PROMIS) Fatigue and Physical function tools [45,46], DePaul Symptom Questionnaire Short Form [49], 36-Item Short Form Survey (SF-36) [50], and Good Day/Bad Day Questionnaire [52]. These questionnaires were left with the participants to complete over the following five days, so they did not over-exert themselves on the day of testing. Also, over the following five days, all the participants were asked to wear an accelerometer, ActiGraph wGT3X-BT (ActiGraph, Pensacola, FL, USA) [54], to measure their activity levels for a week before starting the programme.

In addition, some participants in each group wore a first-beat heart rate variability (HRV) monitor (FirstBeat) [55], and some participants in each group took their lactate using a handheld device (Cosmed Lactate Pro 2) [57] to analyse a finger prick blood sample on waking, once during the day and before going to bed. Not all participants wore an HRV monitor (FirstBeat) or measured their lactate levels due to the limitations of funding. During this follow-up week, they were asked to record their activity levels and any PEM they had during that week. At the end of that week, the PI returned, allocated them to their randomized group and took the diary, questionnaires, and equipment away.

After the five days of baseline measures, the PI allocated the participants into a control group or an intervention group. Randomization was achieved using simple randomization using random number tables and sealed envelopes, separate randomization and sealed envelopes for those with ME/CFS and those with LC. Those in the intervention group received either a Garmin® wrist-based device (Garmin® Vivosmart 3) or a Polar® Verity Sense arm band paired with the Visible software app. The PI provided the HRM and written and video instructions about how to set up the device and how to calculate their heart rate limit. They were then advised to keep their heart rate below that level during everyday activity.

For the Garmin® device, instructions were given and advice was provided about calculating the heart rate limit by either (i) (208–70% of age) × 0.55 or (ii) Resting HR plus 15 bpm based on the Workwell Foundation advice [35]. The second method provides a lower, more restrictive limit, so participants had the choice of either this lower limit or the higher limit provided by the first calculation. For the Visible device, separate instructions were provided. Once the participant entered their age into the Visible device, it automatically calculated their limit based on the following calculation: (220-Age) × 0.6.

Both devices allowed an alarm or alert to be set to notify participants when they went over their chosen HR limit.

During the study, all participants recorded PEM symptoms and episodes of PEM and activity in a written diary. The control group did not have an HRM for eight weeks. All groups attended 30-minute online pacing sessions every week for four weeks, moderated by the research team. Those using an HRM had sessions related to pacing with an HRM, and those not using an HRM had sessions related to general pacing advice. These sessions were at the same time and on the same day each week, based on the availability of the research team. They were informal discussion sessions that provided additional support and answered any questions about pacing. At the end of the eight weeks, the PI returned to repeat the baseline measures. The control group then received an HRM to try, and the intervention group had the choice of continuing to use the HRM or to stop using it.

Finally, the participants were asked to take part in an online interview to discuss their experiences of the study and of using the HRM if they had used them after the eight-week intervention. If they had not used the HRM, they were asked their thoughts on the pacing advice. Interviews were conducted online by the PI and audio-recorded. In addition, interviews were conducted six months after the initial interviews to discuss all participants' experiences of pacing with an HRM.

Data analysis

All quantitative data were analysed using descriptive statistics. As this was a pilot feasibility study, no inferential tests were performed on the data, but trends in the data were noted qualitatively. The size of the study limits the power of the study to infer a significant statistical difference. If inferential tests were conducted on these data, there would be a risk of a Type I or Type II error. The record of the number of participants screened and recruited provided the feasibility of recruitment. The record of adverse events identified the incidence of adverse events, and the ability to complete all of the questionnaires and physical outcome measures identified the suitability and acceptability of the outcome measures. Acceptability of the outcome measures and procedures was also discussed during the semi-structured interviews. All qualitative data from the interviews were analysed by the PI and a master's student using a phenomenological approach and interpretive thematic analysis[59]. Themes were identified related to using pacing with an HRM and will be reported in a separate article. Data related to acceptability and ongoing use of the HRMs are reported in this article.

Results

Forty-seven participants (40 female) were recruited, including 32 people living with ME/CFS and 15 people living with LC (see Table 1 and Figure 1). In total, 22 (15 ME/CFS and 7 LC) participants were randomized into the control group and 25 (17 ME/CFS and 8 LC) into the intervention group. The mean age (standard deviation; SD) of people with ME/CFS was 46.7 (11.7), and LC 45.7 (9.6) and 98% of all participants were white Caucasian. The average length of time with ME/CFS was 13.7 (10.7) years, and LC was 2.1 (0.9) years.

Table 1. Participant demographics.

	Total = 47	ME/CFS = 32	LC = 15
Randomized group allocation	C:22 I:25	C:15 I:17	C:7 I:8
Age, mean (SD)	46.4 (10.9)	46.7 (11.7)	45.7 (9.6)
Gender M:F	7:40	5:27	2:13
Ethnicity C:A*	Ca: 46, A:1	Ca:31, A:1	Ca:15, A:0
Length of time with ME/LC in years, mean (SD)	9.9 (10.3)	13.7 (10.7)	2.1 (0.9)
Severity CFIDS disability scale [18]**			
Median (range)	40 (20–80) (moderate)	35 (20–80) (moderate to severe)	45 (30–60) (Moderate)
Severity grouped			
Mild no. (%)	1 (2)	1 (3)	0 (0)
Moderate no. (%)	24 (51)	14 (44)	10 (67)
Moderate to severe no. (%)	22 (47)	17 (53)	5 (33)
No. of co-morbidities			
Median (range)	3 (0–5)	3 (0–5)	2 (1–3)
Type of co-morbidities			
Cardiovascular	6	5	1
Respiratory	8	8	0
Neurological (including dysautonomias)	21	18	3
Musculoskeletal (including fibro and hypermobility)	23	18	5
Gynaecological	8	6	2
Cancer	2	2	0
Gastrointestinal	15	11	4
Endocrine (including hypothyroid and diabetes)	9	8	1
Urinary	2	2	0
Allergies (including skin, hayfever, sinuses)	7	6	1
Sleep apnoea	5	4	1
Mental health (including anxiety, depression)	15	12	3
Autism	2	1	1
Total	123	101	22

Note: Key: M: Male, F: Female. C: Control, I: Intervention. Ca: Caucasian, A: Asian. ME: Myalgic Encephalomyelitis, LC: Long COVID.
**CFIDS – lower score = greater disability.

Thirty (94%) people with ME/CFS stated their trigger was viral. The participants with ME/CFS were screened at the beginning using the ICC criteria. The DSQ-SF also uses the Fukuda [60], Canadian [61], and IOM criteria [62], and this is self-reported. 24 out of 32 participants with ME/CFS fitted all criteria at baseline and follow-up. Two people with ME/CFS met all criteria at baseline but did not meet the Canadian or IOM criteria at follow-up. One person with ME/CFS was screened as fitting the ICC but did not meet the Canadian and IOM criteria when they filled out the form independently. Four forms had incomplete data. Of the participants with LC, eight met the ME/CFS criteria at baseline and on follow-up, three met the criteria at baseline but not at follow-up, and one did not meet the criteria at baseline or follow-up. Other baseline demographic data are shown in Table 1.

Participant recruitment

One hundred and seven participants were screened, and 81 were eligible for recruitment; 47 (44%) consented over a six-month period, providing an actual recruitment rate of 7 per month (Figure 1). There was a relative over-recruitment of people with ME/CFS and a relative under-recruitment of people with LC compared to initial targets. Reasons for

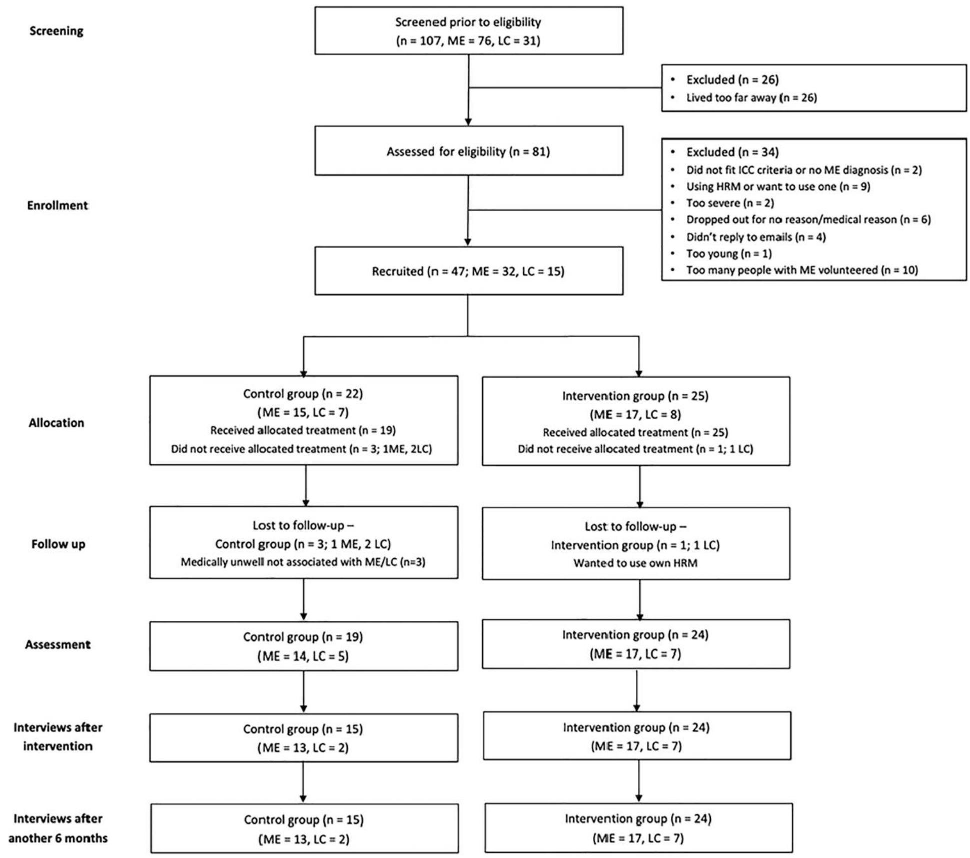

Figure 1. CONSORT diagram.

non-participation were people with ME/CFS did not fit the ICC criteria or no ME/CFS diagnosis (*n* = 2), people with LC already using HRM or wanted to use one (so did not want to be in the control group) (*n* = 9), too severe (*n* = 2) (after discussion they felt they could not manage the requirements of the study), dropped out before recruitment due to medical reason or not providing a reason (*n* = 6), didn't reply to emails (*n* = 4), too young (*n* = 1) and too many people with ME/CFS volunteered (*n* = 10). Ethical approval did not permit recruitment from National Health Service ME/CFS or LC clinics, but recruitment of people with LC was snowballed through word of mouth via support groups and online forums.

Acceptability of the testing procedure

All participants found the outcome measure testing procedure acceptable, although five participants (5 ME/CFS) could not complete the ten-minute stand test due to severe symptoms. The follow-up measurements with the accelerometer, lactate measurements, and/or heart rate variability were all acceptable to the participants. Filling out the questionnaires was acceptable, and having the questionnaires over a week made it easier for them to fill out.

Acceptability of the intervention

All participants reported struggling to fill out a written diary for the two months during the intervention period. Participants who were in the intervention group chose which HRM they wanted to wear, either a wrist-based Garmin® device or an arm-based strap with the Visible app. Among those who used the Garmin® device, some found it difficult to read due to the screen being small, and some found it hard to set up. Those using the arm-based device found it difficult to always have the mobile phone with them. The personal support they received from members of the study team was viewed positively by all participants.

Participants in the control group accepted that they would not use an HRM because they knew they would receive a device when the intervention period ended. All participants took part in online pacing sessions. These were well-received, although not everyone was able to attend the sessions due to the timing of synchronous sessions or energy levels.

Adherence and drop-outs

Adherence was not formally recorded but based on self-report, five people with ME/CFS in the intervention group did not use the HRM for the whole eight weeks of the intervention due to difficulties with the HRM ($n = 1$), unable to stay under the heart rate limit due to POTS ($n = 1$), medically unwell ($n = 1$), and found it too difficult/did not find it helpful ($n = 2$). In relation to drop-outs, of the 47 who were recruited, three in the control group (1 ME/CFS and 2 LC – due to medical issues unrelated to the study) and one in the intervention group (1 LC – due to wanting to use own HRM) dropped out after the two-month intervention phase and therefore had no follow-up data included in the intention-to-treat analysis.

Ten-minute stand test/active stand test (10MST)

All but five participants ($n = 5$ with ME/CFS) completed the ten-minute stand test. Two of these five participants had a significant reaction indicating POTS, that is, they had a sustained increase in heart rate over 30 bpm within 10 min of standing [63]. This had not been previously diagnosed in these participants; in addition, these two participants had significant postural hypertension. Their general practitioner was informed. There were no discernible changes in the blood pressure, heart rate, and oxygen saturation measures before and after the intervention.

Accelerometry

All participants were able to wear the accelerometer around their waist during the day between four and six days at baseline and at follow-up. The results are shown in Table 2. Both groups showed no discernible change in stationary behaviour or light behaviour from baseline to post-intervention. However, both groups had a slight increase in moderate activity behaviour and moderate to vigorous physical activity from baseline to post-intervention.

Table 2. Accelerometer and FirstBeat data.

	Accelerometer data									
	% time in stat base	% time in stat after	% time in light base	% time in light after	% time in mod base	% time in mod after	% time in vig base	% time in vig after	% time in MVPA base	% time in MVPA after
I ($n = 25$)	82.4	82.4	15.2	15.3	2.3	2.6	0.03	0.04	2.4	2.7
C ($n = 22$)	80.2	80.0	17.4	17.4	2.3	2.6	0.07	0.07	2.4	2.7
	FirstBeat data									
	% recovery baseline	% recovery follow-up	% stress baseline	% stress follow-up						
Intervention ($n = 16$)	10	10	73	66						
Control ($n = 14$)	14	15	64	65						

Note: Key: I: Intervention, C: Control. Stat: stationary behaviour, base: baseline, after: after intervention, light: light activity, mod: moderate activity, vig: vigorous activity, MVPA: moderate-to-vigorous activity.

Lactate measurements

Twenty-two participants ($n = 14$ control group and $n = 8$ intervention group) measured their lactate levels between four and six days. All participants had measures over 4.0 at baseline. One person in each group recorded all lactate levels below 4.0 at the follow-up measurements. Two intervention participants ($n = 1$ with ME/CFS and $n = 1$ with LC) and one control participant (LC) had an average lactate score over 6.0 at baseline, which dropped to 3.9 and 2.6, respectively, at follow-up. Both the control (3.7–2.7) and intervention groups (3.7–2.9) demonstrated qualitative decreases in their average lactate levels from baseline to follow-up.

Heart rate variability/physiological stress and recovery

Thirty participants ($n = 14$ control group and $n = 16$ intervention group) wore an HRV/First-Beat monitor on average 4.7 days at baseline and 4.4 days after the intervention period. Three participants had incomplete data due to the monitor not recording the data, possibly due to problems with the chest attachments. The control group demonstrated a 1% (14–15%) increase in per cent recovery from baseline to post-intervention compared to 0% (10–10%) per cent recovery in the intervention group. However, the intervention group saw a 7% (73–66%) decrease in physiological stress compared to a 1% (64–65%) increase in physiological stress in the control group. Two people in the intervention group ($n = 2$ with ME/CFS) and two people in the control group ($n = 2$ with ME/CFS) always had over 90% physiological stress at baseline and follow-up and one person in the intervention group ($n = 1$ with ME/CFS) and two people ($n = 2$ with ME/CFS) in the control group had 0% recovery at all times at baseline and follow-up.

36-item short form survey (SF-36)

The participants reported that the SF-36 [50] took a long time to complete and that the data were incomplete. For the control group, eight forms were incomplete, as well as the three dropouts, and for the intervention group, seven forms were incomplete, as well as one dropout. Table 3 shows a decrease in physical function from baseline to follow-up for both groups; however, both groups showed a positive increase in physical health, emotional health, and energy levels, with the intervention group showing greater changes. Both groups showed a positive increase in emotional well-being, with the control group greater than the intervention and the control group had a greater reduction in pain. The intervention group demonstrated a positive change in social functioning compared to the control group. Both groups showed a positive change in general health.

PROMIS – physical function and fatigue (PPF and PF)

The PROMIS physical function and fatigue questionnaires were the quickest and easiest of the questionnaires to complete, although there were four missing values in addition to the dropout missing data. The intervention group showed no change in physical function but a decrease in fatigue, whereas the control group showed an increase in physical function but no change in fatigue (see Table 4).

Table 3. SF36 results.

	Intervention ($n = 25$)	Control ($n = 22$)
Physical Functioning (PF) baseline	275	292
Physical Functioning (PF) follow-up	270	269
Change	**−5**	**−23**
Role limitations due to PH (PH) baseline	8	10
Role limitations due to PH (PH) follow-up	41	15
Change	**+33**	**+5**
Role limitations due to EmP (EmP) baseline	158	150
Role limitations due to EmP (EmP) follow-up	173	156
Change	**+15**	**+6**
Fatigue/energy (E) baseline	47	43
Fatigue/energy (E) follow-up	67	44
Change	**+20**	**+1**
Emotional well-being (EmW) baseline	299	280
Emotional well-being (EmW) follow-up	310	300
Change	**+11**	**+20**
Social functioning (SF) baseline	50	50
Social functioning (SF) follow-up	75	43
Change	**+25**	**−7**
Pain (*P*) baseline	84	81
Pain (*P*) follow-up	87	64
Change	**+3**	**−17**
General Health (GH) baseline	108	90
General Health (GH) follow-up	139	121
Change	**+31**	**+31**

Note: PF – higher score better; PH – higher score better; EmP – higher score better; E – higher score better; EmW – higher score better; SF – higher score better; *P* – higher score worse; GH – higher score better.

Good day/bad day questionnaire (GDBDQ)

The participants reported that this measure was difficult to quantify as it relies on self-report and recall over the last month, that is, how many good days do you average in a month, how many bad days in a month. Also, the instrument asks how many hours of upright activity on a good day and how many hours of non-upright activity in 24 h on a bad day, which proved to be difficult for the participants to calculate. As a result, data were missing on eight control questionnaires and six intervention questionnaires. The results can be seen in Table 4, showing variable responses. The intervention group showed a reduction in good days but an increase in upright hours on good days, compared to the control group which reported an increase in good days but a reduction in upright hours on good days. Both groups showed a reduction in bad days, but a decrease in upright hours on bad days.

Adverse events

No serious adverse events were reported over the course of the study. The five ME/CFS participants who did not complete the ten-minute stand test reported PEM immediately after the test as well as delayed symptoms.

Participant perspectives from the interview

A separate article will be published outlining the in-depth thematic analysis from the interviews immediately after the intervention and six months after the end of the

Table 4. PROMIS and Good Day/Bad Day questionnaire results.

	PROMIS data			
	Physical Function baseline	Physical Function follow-up	Fatigue baseline	Fatigue follow-up
Intervention ($n = 25$)	25	25	32	30
Control ($n = 22$)	24	25	34	34

	Good Day/Bad Day data							
	Good days before	Good days after	Bad days before	Bad days after	Hours upright before – good day	Hours upright after – good day	Hours upright before – bad day	Hours upright after – bad day
Intervention ($n = 25$)	12.7	11.5	12.8	10.1	5.3	5.9	2.7	2.3
Control ($n = 22$)	8.4	11.2	16.6	15.2	7.6	6.6	2.8	2.3

Note: Physical function – higher score = better physical function, Fatigue – higher score = more fatigue.

intervention. It was not possible to interview the people who dropped out due to medical issues ($n = 4$, 1ME/CFS, 3LC) and four other participants (3LC, 1ME/CFS) did not respond to the request for interviews. Therefore, thirty-nine participants were interviewed immediately after the intervention and six months after the intervention. 89% of the intervention group planned to continue using pacing with an HRM immediately after the intervention, and at six months, 66% of all interviewees planned to continue using an HRM. Most people who were not going to continue using pacing with an HRM were people with ME/CFS ($n = 11$, i.e. 37% of people with ME/CFS) for reasons including skin reactions to the Garmin® strap, connectivity issues with Visible, cognitive issues, the strap broke on Garmin®, difficulties due to POTS and general health got worse. One person with LC stopped using the device as it made him anxious, and another person with LC stopped using it as much as they were much improved.

Two people changed their HRM device to Fitbit®, one to Apple Watch®, and two to another Garmin® device, but all who changed devices continued to use an HRM. Most people with ME/CFS stated that they wished they had known about pacing with an HRM when they were first diagnosed with ME/CFS, as they felt it was a useful tool to learn how to pace. As most people with ME/CFS had a disease duration of over five years, they already had learned how to pace using other strategies.

Discussion

The findings of the study indicate that it is feasible to conduct a randomized controlled trial investigating the use of an HRM in people with ME/CFS. The percentage of males to females in the study for people with ME/CFS (18%) and LC (15%) was lower than reported in the larger ME/CFS and LC populations [64,65]. In addition, the ethnicity of the study population was not representative of the UK population [66], although more research is needed to understand the true range of ethnicity in the ME/CFS and LC populations, as previously highlighted [67]. The level of disability for the ME/CFS participants was greater than that of the LC participants, but the study population represents the 'moderate' and 'moderate/severe' groups in both populations, with only one person classified as 'mild'. This demonstrates the feasibility of recruiting people with a range of disease severities if the study is designed to support them, following the recommendations for patient inclusion made by Professor Tyson [68].

Feasibility was assessed in relation to the ability to recruit, how acceptable the study was to the participants, the suitability of the outcome measures, and preliminary evidence of adverse events. Using social media and local support groups to recruit, over 50 people had contacted the study team within 24 h. However, most people who wanted to get involved were people with ME/CFS. In addition, it can be seen from the testing that although the team used the ICC [1] for screening for people with ME/CFS and only recruited people who had been diagnosed with ME/CFS, when the participants self-reported their symptoms using the DePaul symptom questionnaire [49], three did not meet the criteria for ME/CFS using the Fukuda [60], Canadian Consensus [61], and IOM criteria [62] either at baseline or follow-up. This observation highlights the difficulty in diagnosing ME/CFS and the subsequent problems when trying to identify the effectiveness of an intervention, which must be considered in designing a definitive trial investigating pacing with an HRM.

When recruiting people with LC with PEM, it was very difficult to recruit through social media and local support groups. It appeared that people with LC were reluctant to get involved, either because they were already using an HRM or they wanted to use it and, therefore, did not want to be randomized into a control group. Since this study was conducted, Visible has further developed its app and device and published data reporting data on over 25,000 people who are now using them worldwide [69]. This means finding people with LC and ME/CFS who are not using an HRM may become more difficult over time, especially recruiting through social media. One way to recruit people with LC who have not yet tried an HRM could be to recruit from LC clinics, because these individuals are new to living with the disease and may not yet be aware of all the options available. However, these clinics do not exist in Northern Ireland and Scotland and are not being recommissioned in other areas of the UK. In addition, the lack of testing for SARS-COV-2 may limit our ability to identify people with LC to recruit for future studies.

The procedures were acceptable to all participants, although keeping the written diary was difficult for the participants to complete for two months during the intervention period. The diaries provided limited information related to the aim of the study, so in subsequent studies, collecting these data would not be recommended. Some participants had difficulty setting up the devices and setting the HR limit despite video and written information, so individualized support was required and must be considered for any future study. Some participants had difficulty using the HRM devices. Findings from a previous survey study of people with ME/CFS established that they used over 100 different types of devices for HRM [36]. Selecting a specific device for a definitive study may be difficult due to the wide range of patient preferences. Devices also have been developed allowing participants to use HRV rather than setting heart rate limits to monitor their progress and manage their symptoms [69]. HRV may require consideration alongside HR to manage symptoms and activity limitations from PEM.

Adherence was not formally measured, but some participants stated that they were unable to use the HRM devices due to practical issues, such as difficulties with the strap and screen or were unable to stay under the heart rate limit due to POTS. Using HRV might be more successful for people with difficulties such as POTS, so that they do not have to remain under an HR limit when their HR is already high, but this idea needs further investigation. Four people dropped out; three due to medical issues unrelated to the study and one due to wanting to use their own HRM device. Care must be taken in future studies to ensure participants are fully aware of which devices are being used for the study. While there were no serious adverse events, five people developed PEM after the testing, so this must be considered in selecting and implementing outcome measures for a future definitive study.

All physical outcome measures were completed by the participants, although five people with ME/CFS were not able to complete the 10-minute stand test and met the criteria for POTS. In a future study, the use of the 10-minute stand test might be reviewed, although this study highlights the importance of carrying out simple clinical tests for POTS, such as the 10-minute stand test, as POTS is a condition that can be moderated with conservative measures and medication [44]. It is disappointing that five people (16%) with ME/CFS in the study had not been tested for POTS previously, despite having had ME/CFS for between 10 and 36 years.

Lactate and Firstbeat measurements showed changes over time, although the sample size was not large enough to establish a significant difference. These measures could be continued into the definitive study to help determine if HRM can impact lactate levels and physiological stress, both of which have been shown to be increased in people with ME/CFS. In addition, interestingly, the accelerometer data showed that there was no significant drop in activity levels with the introduction of HRM. One common criticism of HRM for people with ME/CFS is that it will lead to a reduction in activity levels as people with ME/CFS become more cautious. The present study appeared to contradict this assertion, but more research is needed. An additional criticism of pacing with an HRM is that it will lead to an increase in anxiety and symptom monitoring, as was observed in people with atrial fibrillation [70]. However, only one person with LC reported anxiety with the HR limits and alarms.

Using questionnaires to measure the effect of pacing with an HRM proved to be difficult for participants. The SF-36 and the GDBDQ were difficult for the participants to complete and showed limited changes over time. The PROMIS questionnaires were simpler to complete and did show some change over time, so they could potentially be used in a definitive study. Since the completion of this study, more questionnaires have been specifically designed for people with ME/CFS, such as the Functional Capacity in Myalgic Encephalopathy/Chronic Fatigue Syndrome survey [71], PEM/PESE Activity Questionnaire [72], or clinical assessment toolkit [73]. These might be more appropriate for a future definitive study. Measuring change in people with ME /CFS and LC is difficult due to the fluctuating nature of the condition [74,75]. Lessons from research in other fluctuating conditions, like human immunodeficiency virus, which highlight the importance of patient-reported measures [76] and the need to measure health utility alongside the physical, psychological and social impacts of an intervention [77].

Measurements and interventions were all carried out in the participants' homes, therefore reducing the need for the participants to travel. However, this involved the researcher visiting the participants four times. In a future study, it may be possible to reduce the burden on both the researchers and participants by removing the follow-up visits to collect equipment and instead asking the participants to return the measurement tools by post, where able to do so. This study has helped to rationalize some of the physical and questionnaire-based measures in order to inform a future study and minimise the burden on future participants.

Limitations

The study has several limitations. As this was a feasibility study. The sample size was small and recruitment was limited to those within a specific geographical area. Other studies related to pacing with an HRM and LC have used postal services to distribute the HRM devices and outcome measures; however, this approach has additional limitations as it provides limited support for the participants, especially those who have cognitive difficulties.

Participants were asked during the screening process whether they had had a formal diagnosis of ME/CFS or LC. This was part of the inclusion criteria; however, this was not confirmed with a review of their medical notes. This, therefore, could be seen as a limitation of this study.

Other confounding variables were not controlled, such as medication use or other interventions over the eight months of the study. This would need to be considered for a definitive study. Finally, not all physiological measures were recorded by all the participants, and the measures were not taken at the six-month follow-up stage due to funding limitations. It would be beneficial to determine the longer-term effects of pacing with an HRM in a definitive study.

Conclusions

Findings from this study support the feasibility of conducting a study using an HRM for people with ME/CFS and LC, although recruitment strategies need to be reviewed for LC. Measuring the effect of pacing with an HRM requires a combination of physical and questionnaire-based measures, as well as interview methods to ensure a comprehensive understanding of any effect. People with ME/CFS and LC continue to use an HRM after the end of the study, which suggests they find it beneficial.

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Notes on contributors

Dr. Nicola Clague-Baker is a chartered physiotherapist with over 35 years of clinical experience and currently teaches neurological physiotherapy and research at the University of Liverpool. Her ME/CFS research relates to physiological measurements in everyday activity and management techniques, such as heart rate monitoring and transcutaneous auricular vagus nerve stimulation. She is inspired by her close friend, who has had ME/CFS for over 35 years. She is a co-founder of Physios for ME and co-wrote 'A physiotherapist's guide to understanding and managing ME/CFS'.

Dr Todd E. Davenport is Professor and Chair in the Department of Physical Therapy at the University of the Pacific in Stockton, California. Dr. Davenport is a scientific advisor to the Workwell Foundation and current Chair of Long Covid Physio. His research involves the systems-level physiology and clinical recognition of myalgic encephalomyelitis (ME) and ME-like conditions, such as Long COVID. Dr. Davenport is grateful to all people with lived experience with ME and ME-like conditions, which have informed, supported, and challenged his line of scholarly work throughout his career.

Ben Wickens has ME/CFS and Long COVID and is an active user of Heart Rate Monitoring as a self-management tool. He has been the co-chair of the Stockport ME group charity for over a decade and is actively involved in both ME/CFS and Long COVID communities. He has supported many people in setting up devices for HRM purposes as well as troubleshooting issues they may have.

He has delivered training to community groups, NHS staff on Heart Rate Monitoring for ME/CFS, and Long COVID.

Harry Leeming is the founder of Visible, a healthtech company focused on helping people manage complex chronic illnesses, such as Long Covid and ME/CFS, through wearable technology. Visible integrates biometrics with symptom tracking to deliver personalized self-management strategies. The company actively collaborates with academic institutions, clinicians, and patient organizations to conduct real-world research and generate novel insights into post-viral and neuro-immune conditions.

Kathryn Dickinson is a patient representative with 40 years of lived experience with ME/CFS, following a post-viral illness. She co-founded the ME/CFS – Pacing with a Heart Monitor #2 Facebook group and the HRM4Pacing website, which supports over 1500 individuals – many of whom are severely affected. These platforms guide the use of heart rate and heart rate variability (HRV) data to support pacing and energy management, as ME/CFS is an energy-limiting condition. Drawing on independent research and community collaboration, Kathryn's work promotes accessible, data-informed, practical self-management strategies to aid energy conservation, apply biofeedback techniques, and reduce the frequency and severity of post-exertional malaise (PEM) and post-exertional symptom exacerbation (PESE).

Emily McBurney is a chartered physiotherapist and, at the time of this study, was a Pre-registration Master's Physiotherapy student at the University of Liverpool.

Karen Leslie is a chartered physiotherapist specializing in neurological rehabilitation. She works in private practice with people who have disorders or damage to the brain, spinal cord or nervous system and developed an interest in ME/CFS through her clinical work. Karen is a co-founder of Physios for ME and co-wrote A physiotherapist's guide to understanding and managing ME/CFS.

Dr. Michelle Bull has worked in clinical and non-clinical roles with an emphasis on supported self-management of long-term conditions, including cardiac rehabilitation, cancer rehabilitation, physical activity promotion, and, more recently, Long COVID. She has extensive knowledge and experience of ME/CFS due to the condition affecting family members. She is a co-founder of Physio for ME and co-wrote A physiotherapist's guide to understanding and managing ME/CFS.

Natalie Hilliard works clinically as a chartered physiotherapist in private practice, covering musculoskeletal and neurological conditions and specializing in the management of ME/CFS and Long COVID. Natalie was inspired by her close friend, who has post-viral severe ME, and it is through knowing her friend that Natalie has learnt so much more about this illness. She is a co-founder of Physios for ME and co-wrote 'A physiotherapist's guide to understanding and managing ME/CFS'.

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