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An international survey of experiences and attitudes towards pacing using a heart rate monitor for people with myalgic encephalomyelitis/chronic fatigue syndrome

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Abstract.
BACKGROUND: Myalgic encephalomyelitis (ME) is a complex, multi-system neurological condition. The defining feature of ME is post-exertional malaise (PEM) with over 30 symptoms triggered by physical, cognitive, emotional and social activity. The cause of PEM is unclear but one area of research using cardio-pulmonary exercise tests show a reduced ventilatory anaerobic threshold (VAT) with repeated tests leading to PEM. Pacing with heart rate monitoring (HRM) provides feedback to maintain activity intensity below the VAT. There is only one piece of research investigating the use of HRM although a number of guidelines recommend it.
OBJECTIVE: To identify the experiences and attitudes of people with ME towards HRM.
METHODS: A 40 question online survey was devised and released on ME websites, Twitter and Facebook pages. People with ME read the information sheet and followed an online link to the survey. The survey was open for three weeks and all answers were anonymous.
RESULTS: 488 people with ME completed the survey. Most participants were female, 35-50 years and with a reported illness of greater than 5 years. Over 100 types of HR monitor used. Over 30 benefits and over 30 negatives identified. HRM reduced severity of ME and severity and duration of PEM.
CONCLUSION: Although there are limitations, HRM has many benefits including helping PwME to understand and manage their PEM and support them to increase their activities, including work. There is a need for more research and education of healthcare professionals in the safe use of HRM.

Keywords: Surveys and questionnaires, therapeutics, neurology

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1. Introduction

Myalgic encephalomyelitis (ME) is a "complex, acquired multi-systemic disease with 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]. The defining feature of ME is post-exertional malaise (PEM), the worsening of symptoms following physical, cognitive, emotional and social activity with a prolonged recovery period. There are over 30 symptoms of PEM [2] including cognitive impairment, muscle pain, fatigue, flu-like symptoms, difficulty sleeping etc. There is a delay between a triggering activity and the onset of PEM usually 2-7 days after but this may vary [2]. Symptoms usually last days to weeks, but again can vary [2]. The variability in onset delay and duration of PEM makes planning daily activities difficult, raising the importance of interventions to improve the predictability of symptoms as a strategy to enhance health-related quality of life in people with ME (PwME).

It is unclear what causes PEM. One area of research using cardiopulmonary exercise testing (CPET) has shown that PwME have a reduced ventilatory anaerobic threshold (VAT) especially when the test is repeated on a second consecutive day [3]. The VAT or lactate threshold is the point at which a person switches from aerobic to anaerobic metabolism, and there is an increased production of lactate as a by-product [4]. PwME have been shown to reach this threshold more quickly than healthy people, and it is theorised that this could be due to inefficient and damaged aerobic metabolic processes causing the symptoms of PEM. The early production of lactate [5] during activity or inefficient production of adenosine triphosphate (ATP) [6] could explain the symptoms of PEM such as muscle and joint pain, cognitive dysfunction and fatigue in PwME. In addition, decreased oxygen extraction in a subset of PwME [7] suggests ME involves a problem of oxygen utilization rather than bioavailability. This phenomenon may be responsible for observed maladaptation in autonomic function, including orthostatic [8] and chronotropic intolerances [9].

It follows from findings of physiological studies that pacing activity intensities and durations may help PwME to stabilize symptoms and functioning. General frameworks for pacing are available, such as energy envelope theory [10, 11] and 'spoon theory' [12]. However, these general frameworks lack the specificity necessary for PwME to make moment-to-moment and day-to-day decisions about energy expenditure and corresponding future potential to do daily activities. Physiological findings suggest that maintaining activity intensities and durations below the VAT may provide the potential for useful real-time feedback. Heart rate is a common cardiovascular parameter measured by commercially available biometric devices, so they may be useful tools to help PwME maintain activities at intensities below VAT.

An energy management strategy incorporating heart rate monitoring (HRM), first developed by the Workwell Foundation in 2010, has been incorporated into a number of consensus and guidance documents [13–17], and is considered a reliably effective intervention among PwME. This energy management strategy suggests identifying the average resting heart rate over seven days and then setting a limit of 15 beats above that resting heart rate (HR) using HRM to reduce activity above that limit. However, there is only one piece of scholarship about the effectiveness of this intervention. Stevens et al. [18] conducted a case study using HRM and a pragmatic flexibility and strengthening programme. After one year the participant was able to complete daily activities without symptoms with improvements in maximum oxygen consumption (VO_2) and maximum minute ventilation (VE) on a cardiopulmonary exercise test (CPET).

Despite the popularity of pacing strategies among PwME, preliminary evidence of effectiveness and integration of pacing recommendations into clinical consensus and guidance documents, little is known about the specific current practices of PwME. Elucidation of current practices would allow for the identification of potential patient-derived best practices that would be the subject of future study, in addition to establishing potential learning needs among PwME who do and do not use heart rate monitoring. The present study, therefore, aimed to identify the experiences and attitudes of PwME towards HRM.

2. Methods

Ethical approval was obtained from the University of Leicester (#31983). This survey was conducted in accord with the ethical standards of the Committee on Human Experimentation of the University of Liverpool and in accord with the Declaration of Helsinki of 1964 and its later amendments. An online survey was developed by members of ME/CFS Pacing with

a Heart Rate Monitor #2 Facebook group and Physios for ME. 40 questions were devised (Table 1) with tick boxes to reduce the energy requirement needed to answer, and open questions to allow expansion if required. The survey was advertised on the Physios for ME website (www.physiosforme.com) with a participant information sheet that was read before the participants clicked on a link for the survey. The link to the Physios for ME website was provided on various sites on Facebook and Twitter. The inclusion criteria were PwME (self-reported) who had used or were using HRM. The survey was open for three weeks and all data collected was anonymous. Consent was assumed if the participant clicked on the link after reading the information sheet.

Descriptive and inferential statistics were used for the quantitative data. The data were coded and entered into IBM SPSS (version 25.0). Participants were separated into mild, moderate, severe and very severe ME (self-reported) before and after using HRM, the data were then analysed to see if there were any differences between the groups after HRM. Differences were calculated between these groups in the severity of their PEM and recovery time and the type of HRM device using Wilcoxon Signed-Ranks test. Finally, the qualitative responses were analysed with content analysis [19], however, a more detailed analysis of the qualitative results will be presented in a separate article with results from follow-up interviews.

Table 1
List of questions

1. Are you completing the questionnaire for yourself or as a carer of someone with ME/CFS?
2. What is your gender?
3. What is your age?
4. How long have you had symptoms of ME/CFS in years?
5. Please select any diagnoses that apply to you
6. If you received CBT could you tell us if it was effective for your symptoms
7. If you received GET could you tell us if it was effective for your symptoms
8. In which broad world region were you diagnosed?
9. With regards to ME/CFS, how has your care and support by the NHS been? (If in UK)
10. How did you find out about HRM pacing?
11. What appealed to you about HRM pacing when you first learned of it?
12. Has your opinion changed about HRM pacing?
13. Thinking about your preferred or most recent Heart Rate Monitoring Device. What make and model is it?
14. Do you use the above watch as a stand-alone wrist device using its optical sensor or with a paired chest-strap?
15. What are your favourite features?
16. How long have you been pacing using a heart rate monitor in years?
17. Thinking about how you set your alert or limit. Which method have you found to give the best results?
18. How do you find HRM pacing?
19. How do you pace using your HRM device?
20. Do you measure HRV? If so how do you measure your HRV?
21. What equipment do you use to measure your HRV?
22. What platform are you using to measure HRV?
23. What would you class your severity of ME before HRM pacing?
24. Before HRM pacing, how severe was your Post Exertional Malaise (PEM)?
25. Before HRM pacing, how long did it take to recover from PEM to baseline?
26. How would you describe your severity of ME after HRM pacing?
27. What course has your ME/CFS been taking?
28. How long does it now take to recover from PEM to baseline?
29. If/when you suffer from PEM, how severe is it?
30. What are the benefits of HRM pacing?
31. Is there anything you can do since HRM pacing that your illness had prevented you from doing before HRM pacing?
32. What are the negatives of HRM pacing?
33. Is there anything you'd want to tell someone who is new to HRM pacing?
34. I feel my illness is now – better/improved/no change/worse
35. I am able to do – more/the same/less
36. Do you think you have been harmed directly by HRM pacing?
37. How have your family and friends responded to you doing HRM pacing?
38. How have carers, physiotherapists, medical professionals responded to you doing HRM pacing?
39. Please use this page to tell us anything else you think would be useful
40. If you are happy to be interviewed about your experiences please email . . .

3. Results

3.1. Demographics

515 PwME completed the survey, however 27 responses were excluded due to not having a diagnosis of ME/chronic fatigue syndrome (CFS) (Table 2). Most participants were between the ages of 35-50 years (49.2%), from the United Kingdom (56.2%), with a reported illness of greater than 5 years (82.4%). Half of participants had been using heart rate monitoring for less than 1 year at the time of the survey. The most commonly reported comorbidities were postural orthostatic tachycardia syndrome (48%) and fibromyalgia (32.4%).

3.2. Types of heart rate monitors

Over 100 different types of HR monitors were reported as being used. Table 3 lists the main types of heart rate monitors. Most frequently reported devices

Table 2
Demographics of the survey population

Demographic	Percentage of participants
Age group (years)	
Below 18 (completed by carer)	0.8%
19 – 34	17%
35 – 50	49.2%
51 – 70	32%
71 – 90	1%
Sex (female)	87%
Country of origin	
UK including NI	56.2%
Europe	18%
North America excluding Canada	11.5%
Australasia and Oceania	8.6%
Canada	5.1%
Central America	0.2%
Asia	0.2%
Africa	0.2%
Length of time with ME in years	
0 – 4	17.6%
5 – 9	26.6%
10 – 20	29.1%
>20	26.6%
Length of time using HR monitoring in years	
0 – 1	50%
2 – 3	29%
4 – 5	15%
>6	6%
Severity before using HR monitoring (A number of people selected 2 options)	
Mild	14%
Moderate	56%
Severe	38%
Very severe	3%
Severity after using HR monitoring	
Mild	18%
Moderate	53%
Severe	28%
Very severe	1%
Comorbidities	
Postural orthostatic tachycardia syndrome/orthostatic intolerance	48%
Fibromyalgia	32.4%
Dysautonomia/small fibre neuropathy	14.3%
Mast cell activation syndrome	11.9%
Ehlers-danlos syndrome	9.6%
Any psychiatric disorder	9%
Orthostatic hypotension	8.6%
Attention deficit hyperactivity disorder	5.1%
Long Covid	5%
Autism spectrum disorder	4.9%
Functional neurological disorder	4.9%
Endocrine/thyroid/diabetes/adrenal/hormonal	0.5%
IBS/coeliac/diverticulitis/crohns/gastroparesis	0.5%

included Apple Watch (15.5%), Fitbit Charge 2 (11.0%), and Garmin Vivoactive 4 S (10.6%). 83.5% of participants used standalone wrist devices, 12.3% paired the chest strap with wrist devices, with ipad 0.4% or with phone 0.6%. Combining a chest strap

Table 3
Types of heart rate monitors

Types of HR monitor	Percentage of participants
Apple Watch	15.5%
Fitbit Charge 2	11.0%
Garmin Vivoactive 4S	10.6%
Polar A370	7.6%
Fitbit Versa	5.4%
Polar M430	4.0%
Garmin Venu Sq	4.3%
Garmin Vivo Smart	3.7%
Mio Alpha	3.4%
Fitbit Sense	2.9%
Samsung Galaxy	2.7%
Oura Ring	1%
Fitbit Ionic	0.7%
Other Garmin models	14%
Other Fitbit models	10%
Other Polar models	6%

with the wrist monitor/phone/ipad was often difficult due to cognitive issues and some people found the chest straps uncomfortable and too costly. Table 4 shows that there were significant improvements in the rate of recovery, the severity of PEM and the level of severity of ME after using HRM, independent of whether they used a chest strap or no chest strap.

3.3. *Level of severity, amount of PEM and rate of recovery*

The level of severity of participants were compared before and after HRM (see Table 4). Although the median was apparently similar (Mdn = 2.00), a Wilcoxon Signed-Ranks test indicated a statistically significant reduction in their severity of ME after HRM pacing (z=–5.07, $p < 0.001$, $n = 330$). The severity of participants' PEM was compared before and after HRM. On average, PEM severity was lessened after HRM (Mdn = 2.00) when compared to PEM severity before HRM (Mdn = 3.00). A Wilcoxon Signed-Ranks test indicated a statistically significant difference in favour of HRM (z=–11.11, $p < 0.001$, $n = 377$). The duration taken for (rate of) recovery from PEM were compared before and after HRM. On average, recovery from PEM was faster after HRM (Mdn = 2.00) when compared to recovery from PEM before HRM (Mdn = 3.00). A Wilcoxon Signed-Ranks test indicated a statistically significant difference in favour of HRM (z=–9.54, $p < 0.001$, $n = 300$).

Table 4
Perceived changes severity of ME, severity of PEM, and in period of recovery from PEM after HR monitoring across multiple variables

Variable	Severity of ME				Severity of PEM				Period of recovery from PEM			
	N^	Mdn before	Mdn after	z	N^	Mdn before	Mdn after	z	N^	Mdn before	Mdn after	z
Types of HR monitor												
Apple Watch	42	2	2	–1.29	45	3	2	–3.95***	38	3	2	–3.97***
Polar A370	12	3	2	–.45	17	3	2	–2.66**	12	3	2	–2.65*
Polar M430	9	2.5	3	.00	9	3	2	–2.37*	5	4	2	–2.03*
FitBit Charge 2	25	2	2	–1.63	28	2	2	–3.05**	26	3	2	–1.94
Fitbit Versa	12	2	2	.00	14	2	2	–2.12*	14	2	2	–1.34
Fitbit Ionic	3	2	2	–1.00	2	4	2.5	–1.00	1	5	–	–
Fitbit Sense	9	2	2	–1.00	10	2.5	2	–1.86	8	2	2	–1.41
Garmin Vivoactive 4S	20	2	2	–2.12*	33	2	2	–3.12**	26	3	2	–3.17*
Garmin Venu Sq	15	2	2	.00	14	3	2	–2.89**	12	2.5	2	–2.26*
Samsung Galaxy	6	3	2.5	–1.00	6	3	2	–1.89	7	3	2	–2.12*
Other	118	2	2	–3.35**	134	3	2	–6.73***	95	3	2	–4.60***
Multiple devices used	29	2	2	–1.27	31	3	2	–2.35*	26	3	2	–2.23*
Use of chest strap												
Paired to Polar H7 or H10 chest strap	25	2.5	2	–2.83**	32	3	2	–4.13***	26	3	2	–3.71***
As a stand-alone optical wrist sensor	248	2	2	–4.70***	278	3	2	–9.21***	234	3	2	–8.35***
Other	27	2.5	2	–.91	32	3	2	–3.48**	17	3.5	2	–2.20*
Multiple responses	23	2	2.5	–.30	27	3	2	–3.31**	16	4	2	–2.59*

*$P < 0.05$; **$P < 0.01$; ***$P < 0.001$. ^Number of participants who did not have missing data. A drop in value indicates an improvement in the symptom. Mdn = Median.

3.4. Using heart rate monitoring

51% of PwME had been using HRM for 0 to 1 years, 28% for 2 to 3 years, 15% for 4 to 5 years and 6% for more than 6 years. Table 5 shows the different methods used to set a heart rate limit. Some people were using heart rate monitoring inappropriately, for instance "*I haven't set an alert, I'm now thinking I don't know what HRM pacing is . . .* " and "*Using zone system – minutes in zone 2 – monitor if can manage to get into zone 3 (Maximum Heart Rate 180, zone 2 103-119bpm, zone 3 120-136bpm) I was told about 220-age × 50% and so far haven't reached it*" and were receiving inappropriate advice "*My doctor suggested 75% of MHR and I tried to stay below that limit (142 bpm).*"

There were difficulties identified due to Postural Orthostatic Tachycardia Syndrome (POTS) "*With pretty bad POTS in the mix, staying under anything is basically impossible, even with a range of medications*" and variations due to menstrual cycle "*My level of physical functioning changes with my cycle, and my resting HRM in the fitbit can vary with as much as 15 from ovulation to menses – and also where my limit should be*". In addition, some people felt that they needed help to work it out "*I'd love to be able to use HRM properly as I think it would be useful, but I'm struggling to do this on my own with no help. I'm not very technical*". 50% found HRM easy to moderate to use, but 5.2% found it too difficult to continue with one person saying, "*I'm constantly over my suggested hr limit when I move*".

Table 5
Different methods for setting heart rate limits

Method	Percentage of participants
Still searching for the limit	31.4%
Maximum Heart Rate (MHR) (220 – age) x 60%	19%
Resting Heart Rate (RHR) plus 15bpm	13.4%
MHR (220 – age) x 50%	11.9%
It's too soon to say	10.8%
MHR (220 – age) x 55%	10.6%
2 day CPET results	3.2%
Other – Less than 100bpm	1.4%
2-day CPET results minus a predetermined value provided by my medical professional	0.8%
Other – Use hrv	0.8%
Other – Resting heart rate plus 35/30/25	0.6%
Other – Use zones	0.6%
Other – MHR (220 – age) x 70%	0.2%
Other – Less than 110bpm	0.2%
Other – Less than 120bpm	0.2%
Other – Less than 125bpm	0.2%
Other – Don't set limit just minimise time	0.2%

Some people selected more than one choice. Other – additional responses from participants.

Table 6
List of benefits identified

Benefit	Percentage of participants
Helped them understand PEM triggers better	72%
Real-time feedback on effects of current or prior activity	69%
Helps stop boom/bust or push-crash cycle	64%
Helps minimise PEM	57%
Discovering PEM triggers	55%
Help find more energy efficient ways of doing things	53%
Raising awareness for those around you of the effects of activity on heart rate	52%
Identifying that POTS or other OI may be a comorbidity that can be treated	49%
Slowing or stopping deterioration	46%
Improving quality of life	39%
Feeling generally better overall	31%
Improving function	26%
Too soon to say	8%
No benefits	3%

Table 7
Functional changes after using pacing with a heart rate monitor

Functional benefit	Percentage of participants
Improved ability to be able to do any activities of daily living or self-care	31%
Able to enjoy a hobby or interest	24%
Improved physical capability, eg sitting up in bed, able to stand, able to walk or work	23%
Increased time with family or friends	23%
Improved sensory tolerance, eg to light, sound, touch, etc.	22%
Improved sleep	21%
Improved ability to speak or have a conversation	19%
Improved ability to listen to music or watch a television programme, etc.	19%
Increased time with hobbies or interests	19%
Increased ability to walk	19%
Shower or bathe	16%
Increased time in work or education	9%
Return to exercise	5%
Chewing, swallowing, eating	3%

3.5. Benefits of pacing with a heart rate monitor

Although there were benefits outlined in Table 6, fewer PwME found that this translated into functional improvements (see Table 7). 31% had improved their ability to be able to do any activities of daily living or self-care, 24% were able to enjoy a hobby or interest and 23% improved physical capability, e.g., sitting up in bed, stand, walk or work. These functional changes are outlined in Table 7. Although 5% returned to exercise one PwME stated that "*By exercise I mean recumbent exercise on a pilates reformer using a physiotherapist versed in HR pacing to guide me*". It is important to note, as one PwME explained that "*pacing (even with a HRM) is only one factor linked to improvements. It helps but has to sit within a wider set of interventions and support*".

3.6. Negatives of pacing with a heart rate monitor

57% felt the main negative was the lack of support from carers or medical professionals with one PwME saying "*I wouldn't dream of mentioning it to my GP – I just do the best I can by myself. I long for the day when I can do this in conjunction with a knowledgeable medic*". 43% felt that one of the negatives of HRM was financial, i.e., budget limitations and the cost of device and 43% identified a negative as the initial restrictions imposed by staying below the threshold or limit. Table 8 outlines the negatives expressed towards HRM.

Table 8
Negatives of pacing with a heart rate monitor

Negative	Percentage of participants
Lack of support from carers or medical professionals	57%
Financial, i.e., budget limitations and the cost of device	43%
Initial restrictions imposed by staying below the threshold or limit	43%
There is no "one size fits all" with regards to HRM pacing guidance	35%
Mental, e.g., "cog fog", setting up alerts, syncing data, etc.	34%
Alerts continually being triggered	31%
Physical, e.g., optical sensor irritating the skin, metal allergy, etc.	31%
Frustration at the length of time it takes to stabilise	30%
Battery life – does it last as long as I need it to?	28%
Complex to begin with	27%
Alerts can be stressful	27%
Accuracy of device	26%
Comfort, e.g., allodynia	15%
Limitations of my phone, laptop, tablet or computer	13%
Lack of support from family members	9%
Water-resistance – does it suit my lifestyle?	7%
Electrical sensitivity, e.g., WiFi or Bluetooth sensitivity	7%
Skin colour or tattoos – hard to find one that works for me	0.2%

In addition, a number of PwME identified that "*HRM does not give info on time spent doing cognitive stuff*". Another comment related to the fact that these devices are designed for healthy people "*HR*

watch not made for sick people, it assumes I'm working out and stuff". In addition, a number of people expressed frustration with the lack of research stating that there is a "*lack of research and integration into 'mainstream' medicine*".

2.2% stated they felt they had been harmed by HRM and 4.1% stated that they felt they may have been harmed. However, when asked to expand on their replies only 12 people expanded on their answers. Four felt that the reduced activity had led to deconditioning, two people felt it affected their mental health, one felt it may have made their orthostatic intolerance worse, one felt it made them "*stiff and sore in their muscles*" but continued to say "*but I'm convinced I would be in much more pain if I pushed like I did before*", one felt "*a little perhaps through a false sense of confidence and trusting imprecise data*", one felt it led to "*having 6 months of unnecessary cardiology investigations all for nothing because the commercially available HRMs cannot detect PVCs (ectopic heartbeats)*", another said "*staying under heart rate determined by 2-day CPET still causes PEM*" and finally one was using the HRM incorrectly leading to harm "*when I used the 60% of max HR threshold to do recumbent cycling I really messed myself up – I was very unwell*".

3.7. Support from family and healthcare professionals

48% of participants said that family members were supportive about them using HRM, 24% were mixed and 27% were indifferent with 5% being not supportive. One participant said:

> "*The objective information from the Heart Rate Monitor meant my husband was immediately more able to understand my limits and was more sympathetic to me and the constraints I have to live within. This was a huge step forward*" and another on the same lines stated that "*It helps to give you data*".

Whereas another said "*Mostly they don't care a lot*" or that family think they are overanxious or over reporting "*Family and friends with ME, supportive, but friends without ME think I am making a fuss*" and "*Easier for my kids to see to understand, however lots of comments about how monitoring your heart rate increases it, makes you a hypochondriac*".

In comparison 14% of healthcare professionals were supportive about HRM, 19% mixed, 34% indifferent and 18% not supportive. One participant said:

> "*No National Health Service professionals have shown any interest or relevance & even give the impression it's a bit over the top. Private ME specialist physio has been so helpful*".

Another said: "*My specialist ME OT had never heard of it and didn't seem interested when I tried to talk about it, even though it had been the most useful management technique I've found*".

And "*good medical professionals take the HR-readings seriously, allow me to lay down, etc., arrogant doctors think a high HR is = stress or fear or panic*".

A lot of people said that they do not talk to their health professionals about it or "*I no longer consult medical professionals unless I absolutely have to*".

A number of the participants stated that they felt healthcare professionals including occupational therapists, physiotherapists and other clinicians should be trained in the use of pacing with a HR monitor and heart rate monitors should be available on the NHS.

3.8. Additional comments and advice for PwME

Some respondents highlighted the use of heart rate variability monitoring to enhance their HRM. Heart rate variability is the fluctuation in the time intervals between consecutive heartbeats [20]. 53.7% used heart rate variability monitoring to help guide their management and one person said "*monitoring HRV data eliminated my rolling PEM and I even managed to increase some functionality without crashing*", however, some found no correlation with their symptoms: "*I did take HRV readings and tracked in my 3 month spreadsheet and found zero correlation to symptoms*" and some felt HRM was challenging enough, "*I couldn't even begin to understand HRV. It was challenging enough just trying to monitor HR*".

Some respondents also gave advice for PwME who were about to start HRM:

- "*Use it as a support to living, not as a restriction*"
- "*Stick with it, it can take months, it's not an overnight solution, stick to it for at least 6 months*"
- "*Join a support group*"
- "*Be prepared to be shocked at how little you can do at first*"
- "*Take care with cognitive activities*"
- "*Get help with set-ups*"
- "*If it's causing too much stress, then it might not be the right strategy for you*"

4. Discussion

This study aimed to identify the experiences and attitudes of PwME towards HRM. As the survey participants were mainly female between the ages of 30 – 50 this reflects the larger ME population [1]. Approximately 40% of the survey participants described themselves as having severe or very severe ME indicating that the survey results provide experiences of more people with this higher level of severity of ME. As it is thought that approximately 25% of the ME population have severe or very severe ME [21] this survey therefore over represents the experiences of severe and very severe PwME. Over 50% of the participants were from the UK so it is not clear if more people in the UK are using HRM or that the survey did not reach many of the ME populations in the USA, Canada and Australia. In future surveys, the survey link would need to be shared with more ME organisations in these countries. The results of this survey therefore reflect the experiences of people mainly in the UK and Europe.

Although the use of HRM has been encouraged since 2010 [18] for people with ME, the majority of the survey participants had only been using it for the last three years despite most of the participants having ME for over five years. There appears to be a lack of knowledge related to the use of HRM and certainly a lack of research exploring the efficacy of its use in people with ME. The variety of methods used to calculate the estimated VAT demonstrates the lack of knowledge and understanding of how to calculate it. The use of the CPET test to calculate an individual's VAT is seen as the gold standard, however, Moore et al. [22] identified that up to 7% of people with ME who undertook CPET took up to 10 weeks to recover and 1% did not recover after one year. Outside of the USA there is also a lack of CPET testing. So an alternative, valid and reliable way of calculating the VAT needs to be found as many countries will not have access to CPET testing.

The concerning aspect of the use of the HRM was that some participants were using too high a level of estimated VAT or were attempting to use zones when working with the heart rate monitor. There is a clear need for PwME and healthcare professionals advising them to know how to use these devices specifically for ME. Healthcare professionals are perhaps familiar with the use of heart rate monitors for cardiac rehabilitation where people with cardiac conditions are encouraged to work at 60% of their maximum heart rate [23] and maintain that level of aerobic activity for 20 minutes in order to improve cardiovascular fitness. Unfortunately for PwME, their anaerobic threshold is lower [24] so if they were to work at 60% of their maximum heart rate this is likely to exceed their VAT and cause significant PEM. The survey showed not just the lack of knowledge but also the lack of support that PwME have received from healthcare professionals, and this reflects two meta-syntheses that highlighted that PwME are not taken seriously by physicians and that "there is general scepticism and minimization of ME" [25, 26]. HRM has the potential to show carers, family members and healthcare professionals that the person with ME has a physiological problem that requires recognition and validation.

The survey identified that over 100 devices were used for HRM with the most popular being the Apple watch, followed by Garmin, Fitbit and Polar devices. The results show that all the devices have the potential to improve the level of severity of ME, the severity of PEM and rate of recovery from PEM, independent of whether a chest strap is used. However, a number of people highlighted that all the devices on the market are designed for people without a chronic condition. There is a need for a more bespoke device that is easy to use with functions designed for PwME, for example rather than setting zones and targets to exceed [27] there would be the option to set an alert to stay below a target. It was also clear that heart rate devices do not have the capacity to monitor the energy used during cognitive, social and emotional activities. A device that could do that would be very beneficial for PwME.

The survey also highlighted that some PwME were using heart rate variability to enhance HRM although this was not without its challenges. HRV is the fluctuation in the time intervals between consecutive heartbeats [20] and can be used to estimate autonomic nervous system health. It can potentially suggest whether there is imbalance in the sympathetic and parasympathetic drives that may produce symptoms of dysautonomia and PEM. This may be an area for future research.

A number of negatives were identified with HRM, the main ones being lack of support, financial cost and too restrictive. Lack of support has already been discussed, however as well as educating healthcare professionals perhaps financial support to provide these devices would be beneficial for PwME to manage their condition, considering people with diabetes are provided with blood sugar monitors by the NHS in the UK [28] and insurance companies in the USA and Canada. In relation to the negative responses about

HRM causing restrictions to activity and potentially leading to deconditioning, this highlights the need for individualised care and the importance of support for PwME while trying these devices. Assistance would be beneficial in relation to: setting up the device, learning to pace with the device, and social support so that they can rest and reduce their activity while still managing their everyday commitments. Ultimately by finding their baseline and allowing their body to rest there maybe the potential to improve their activity levels [29].

Nearly all the participants found benefits with HRM but less than a third found that these benefits translated into increased functional activity. In fact, HRM often resulted in reduced functional activity to stay under their VAT. However, it is encouraging to see the potential for HRM to increase capacity to work or to increase the time at work. As many as 1 : 250 of the working population have ME [29] and as ME affects mainly working age adults [1, 30] any approach that has the potential to help people continue in work is beneficial. It is important to recognise that HRM is a management tool that needs to be used in conjunction with many other management strategies such as rest, prioritising, and planning [31, 32]. HRM is not a cure for ME, but it can be used as a management tool with the potential to help most PwME.

4.1. Limitations

- It is recognised that it was not possible to check that people filling out this survey had an official diagnosis of ME, although the patient information sheet and all literature related to the study identified that part of the inclusion criteria was a diagnosis of ME. In future surveys, the ICC will be part of the participant information leaflet so participants can check that they fit the criteria for ME.
- The statistical analyses are limited by the numbers of respondents in some of the groups and it is recognised that an intervention study is needed to truly establish the differences between different devices and the impact on disease and symptom severity and PEM symptoms.

5. Conclusion

This survey aimed to identify the experiences and attitudes of PwME towards HRM. Although there are limitations due to the range of the sample, it has highlighted that HRM has many benefits including helping PwME to understand and manage their PEM and support them to increase their activities, including work. It is recognised that one of the negatives is the potential to reduce physical function although this may only be in the initial stages of HRM. It has also highlighted the need for more research and education of healthcare professionals in the safe use of HRM.

Ethical approval

Ethical approval was obtained from the University of Leicester (31983).

Informed consent

Consent was assumed if the participant clicked on the survey link after reading the information sheet.

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Conflict of interest

The authors declare that they have no conflict of interest.

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