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#### Title: Activity pacing is associated with better and worse symptoms for patients

#### with long-term conditions

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# Abstract

**Background:** Activity pacing has been associated with both improved and worsened symptoms, and its role in reducing disability among patients with long-term conditions has been questioned. However, existing studies have measured pacing according to uni-dimensional subscales, and therefore the empirical evidence for pacing as a multifaceted construct remains unclear. We have developed a 26-item Activity Pacing Questionnaire (APQ-26) for chronic pain/fatigue containing five themes of pacing: activity adjustment, activity consistency, activity progression, activity planning and activity acceptance.

**Objective:** To assess the associations between the five APQ-26 pacing themes and symptoms of pain, physical fatigue, depression, avoidance and physical function.

**Methods:** Cross-sectional questionnaire design study. Data analysed using multiple regression.

**Participants:** 257 adult patients with diagnoses of chronic low back pain, chronic widespread pain, fibromyalgia and chronic fatigue syndrome/myalgic encephalomyelitis.

**Results:** Hierarchical multiple regression showed that activity adjustment was significantly associated with increased physical fatigue, depression and avoidance, but decreased physical function (**all p≤0.030**). Activity consistency was associated with decreased pain, physical fatigue, depression and avoidance but increased physical function (all p≤0.003). Activity planning was associated with reduced physical fatigue (**p=0.025**) and activity acceptance was associated with increased avoidance (**p=0.036**).

**Conclusion:** Some APQ-26 pacing themes were associated with worse symptoms and others with symptom improvement. Specifically, pacing themes involving adjusting/reducing activities were associated with worse symptoms, whereas pacing themes involving undertaking consistent activities were associated with improved symptoms. Future study will explore the causality of these associations to add clarification regarding the effects of pacing on patients' symptoms.

#### Key words

Activity pacing

Chronic pain

Chronic fatigue

Questionnaire

Multiple regression

#### Introduction

Activity pacing involves the regulation of activity to assist the management of longterm conditions.<sup>1</sup> Although pacing continues to receive support from patient groups and it is frequently cited as a facet of cognitive behavioural therapy and graded exercise therapy,<sup>1-5</sup> it remains ambiguous in terms of its interpretation and empirical evidence.<sup>1,6,7</sup> A systematic review and meta-analysis highlighted the paucity of evidence regarding the effects of pacing and the mixed findings that have emerged to date.<sup>8</sup> Pacing has been found to be ineffective, together with being associated with better and worse symptoms.<sup>7,9,10</sup>

Specifically, activity pacing has been found to be associated with improved symptoms on regression analyses: decreased physical impairment among patients with fibromyalgia;<sup>9</sup> and decreased anxiety and depression, and increased pain control among patients with chronic pain.<sup>11</sup> Conversely, pacing has been found to be insignificantly associated with disability and depression on regression analysis among people with chronic pain;<sup>7</sup> and associated with greater disability via unadjusted correlations, but not associated with disability when pain or other coping strategies were controlled among patients with fibromyalgia.<sup>12</sup> Subsequently, Karsdorp and Vlaeyen<sup>12</sup> questioned the role of pacing as a facet of pain-management programmes. The above findings measured pacing according to the existing pacing subscales of the Chronic Pain Coping Inventory (CPCI),<sup>9</sup> the Pain and Activity Relations Questionnaire (PARQ)<sup>10</sup> and the Patterns of Activity Measure-Pain (POAM-P).<sup>11</sup> However, existing pacing subscales appear to measure pacing in limited terms of predominantly reducing activities, for example, breaking down tasks/using rest breaks/going slow and steady. We suggest that such facets may be unlikely to reduce disability. Alternatively, if pacing was measured in terms of having consistent/progressive activities (as described in other pacing literature<sup>1,13</sup>), lower disability may be observed. Therefore, the full dimensions of pacing may not yet have been investigated in terms of associations with patients' symptoms.

Following on from this, we have developed a multifaceted Activity Pacing Questionnaire (APQ) using three stage mixed methodology. Thirty-eight items were

developed and reached consensus of inclusion during Stage I: The Delphi technique.<sup>14</sup> This number was reduced to 26 during Stage II: The psychometric study.<sup>15</sup> Factor analysis yielded five themes of pacing in the APQ-26: activity adjustment, activity consistency, activity progression, activity planning and activity acceptance. Activity adjustment was labelled as such due to containing 10 items that refer to adjusting the approach to activities through breaking down tasks, using rest breaks and alternating activities. Activity consistency contains four items that involve undertaking similar amounts of activity each day, including on 'good' and 'bad' days. Activity progression contains three items referring to gradually increasing activities that have previously been avoided, together with gradually increasing the duration of activities. Activity planning contains 6 items that involve assessing activity levels, and setting time limits to avoid 'overdoing' activities and setting meaningful goals. Activity acceptance contains three items that involve accepting capabilities through setting realistic goals, adapting activity targets and being able to say 'no' to some activities. Stage III explored the acceptability of the APQ via telephone interviews with patients, while also exploring their views and beliefs on the concept of pacing.<sup>16</sup>

The aim of this paper was to gain a better understanding of the APQ-26 themes of pacing by examining their associations with patients' symptoms/characteristics (that is, pain, fatigue, depression, avoidance and physical function) in more detail in their clinical context. It was hypothesised that the APQ-26 pacing theme activity adjustment may be associated with worse symptoms due to involving breaking down tasks/limiting activities. Such facets of pacing may be implemented more regularly to cope with more severe symptoms (for example, increased pain and physical fatigue);<sup>8,17,18</sup> are predicted to be associated with increased depression due to potential

reductions in activities; may accompany avoidance behaviours;<sup>7,12</sup> and may be associated with lower levels of overall physical function.<sup>8,18</sup>

In contrast, the APQ-26 pacing theme activity consistency was hypothesised to be associated with improved symptoms. Since one of the aims of activity pacing is to regulate activity levels and reduce the distressing boom-bust/overactivityunderactivity activity pattern,<sup>13,19</sup> it was predicted that patients implementing consistent activities, may report improved symptoms (for example, lower pain, fatigue, depression); lower avoidance behaviours; and overall improved physical function. The authors hypothesised that activity progression might be associated with lower pain, fatigue, depression and avoidance, and improved physical function due to both being implemented when symptoms are less severe, together with leading to selfreports of better symptom management and sense of achievement/fulfilment. Similarly, the APQ-26 theme activity planning was predicted to associate with improved symptoms due to involving pacing facets that challenge the overactivityunderactivity cycle. The APQ-26 theme activity acceptance was predicted to be associated with improved symptoms similarly to other studies that have found associations between acceptance and lower pain, depression and increased physical function.<sup>20</sup>

In addition, it was predicted that patients' pain severity may explain a large proportion of the associations with different pacing themes, and that higher pain reports may be associated with increased reports of other symptoms. Therefore, pain was considered to be both an outcome variable and a possible confounding variable when it was not an outcome. Similarly, patients' demographic characteristics were predicted to have an influence on the report of symptoms. For example, increasing age was predicted to be associated with worse symptoms such as increased fatigue and reduced function due to age-related physiological changes, lower levels of activity tolerance and the presence of co-morbidities.<sup>21-24</sup> Furthermore, the authors predicted that there may be subtle differences in symptoms according to patients' main reported condition. For example, patients with CFS/ME may report fatigue to a greater extent than patients with low back pain where pain may be the most burdensome symptom. In order to control for any other variables that may **affect** the associations between pacing themes and symptoms, other potential confounding variables such as participants' gender and duration of condition were also controlled in the regression model.

# Methods

#### **Participants**

Participants included patients referred to physiotherapy in a National Health Service Trust (United Kingdom) by a hospital consultant or general practitioner following their diagnosis of chronic low back pain, chronic widespread pain, fibromyalgia and chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME). All participants had experienced their symptoms for  $\geq$ 3 months' duration, were English literate and aged 18 years or older. **Patients were invited to participate in the study while currently awaiting/commencing physiotherapy and retrospectively (having completed treatment)** to increase recruitment opportunities and to increase the generalisability of the findings across patients at different stages of treatment. Excluded from the study were patients with evidence of a serious underlying pathology, or neurological/inflammatory conditions.

#### **Data collection**

Patients were invited to participate through both postal questionnaires and on attending physiotherapy. Reminder questionnaire booklets were sent to those not responding within three weeks of the first administration. Written informed consent was obtained from participants. Patients' identities were kept anonymous during data analysis via the allocation of study codes. Each questionnaire booklet included demographic questions, the APQ and validated measures of current pain, physical fatigue, depression, avoidance, and physical function. These validated measures were selected due to their frequent presentation and distressing impact among patients with chronic pain/fatigue, together with their alignment with the fear-avoidance model.<sup>25</sup>

# Activity Pacing Questionnaire (APQ)

Activity pacing was measured using the APQ,<sup>14</sup> which contains items referring to different facets of pacing such as breaking down tasks, setting goals and gradually increasing activities. The APQ utilises a 5-point Likert scale with categories: 0='never did this', 1='rarely did this', 2='occasionally did this', 3='frequently did this' and 4='always did this'. **Patients** rate their answers considering their physical/cognitive/social activities undertaken in the previous week. The APQ was purposively developed for patients with chronic pain and/or fatigue to increase its clinical relevance due to the frequent overlap and co-existence of these symptoms.<sup>26</sup> Patients completed the original 38-item APQ (prior to item reduction to 26). However, data analysis involved participants' answers to the 26 items of the APQ-26 in order to explore the properties of the refined APQ.<sup>15</sup> (See Table 1 for examples of APQ-26 items.)

# Pain Numerical Rating Scale (NRS)

Pain was measured using an 11-point NRS of current pain where 0= 'no pain' and 10= 'worst possible pain'.<sup>27</sup> The 11-point NRS scale is easy to complete, and is sensitive and responsive to change.<sup>28</sup>

#### Chalder Fatigue Questionnaire (CFQ)

Physical fatigue was measured using the CFQ physical fatigue subscale, containing seven items; rated as 0='better than usual', 1='no more than usual', 2='worse than usual' and 3='much worse than usual', where increased scores indicate worse fatigue.<sup>29</sup> Participants were asked to rate their fatigue over the past month. The scale has previously been found to have good reliability (Cronbach's alpha=0.89), and concurrent validity in terms of sensitivity and specificity with the Revised Clinical Interview Schedule Fatigue Question.<sup>29</sup>

#### Hospital Anxiety and Depression Scale (HADS)

Symptoms of depression were assessed via the 7-item HADS depression subscale, each item reflecting on the previous week. Items are rated on a 4-point scale (0-3); higher scores indicating greater potential depression.<sup>30</sup> The HADS has been found to have good internal consistency (mean Cronbach's alpha=0.82); and concurrent validity against other frequently used depression scales via correlation coefficients and receiver operating characteristic (ROC) curves to determine the sensitivity and specificity of cut-off scores to identify cases of depression.<sup>31</sup>

# Pain Anxiety Symptoms Scale (PASS-20)

Avoidance was measured via the Escape and Avoidance subscale of the PASS-20. The subscale contains five items, each rated on a 6-point Likert scale (0='never' to 5='always') where higher scores represent greater avoidance.<sup>32</sup> PASS-20 items referred to general behaviours rather than across a specific time frame. Reliability of the PASS-20 and convergence validity with the original PASS-40 have been demonstrated.<sup>32</sup>

#### Short-Form 12 (SF-12)

Physical function was measured using the physical component summary of the Short-Form 12 (SF-12).<sup>33</sup> For items requiring a time reference, participants were asked to answer the items reflecting on the previous week. The physical component summary is scored on a scale of 0-100 where higher scores reflected better function.<sup>34</sup> The SF-12 has demonstrated reliability and validity against the SF-36.<sup>33,35</sup>

Of note, data analysis did not include all subscales of the CFQ, HADS, PASS and SF-12 due to potential problems with collinearity in the regression model.

#### **Statistical analyses**

Data were analysed using IBM SPSS Statistics 22.<sup>1</sup> Unadjusted associations between the APQ-26 themes and symptom scores for current pain, physical fatigue, depression, avoidance, and physical function were estimated using Pearson's correlations. These were estimated separately for each symptom variable across the participants who were included in the corresponding multiple regression model, that is, those having complete data on the **13** independent variables: age, gender, three dummy variables for main condition (chronic widespread pain, fibromyalgia, CFS/ME, with back pain as the reference category), duration of condition (the natural logarithm of duration was taken to improve the symmetry of the distribution), **patient status (current or retrospective)**, current pain and the five APQ-26 pacing themes. Partial correlations were also estimated between APQ-26 themes and symptom scores adjusted for the **13** independent variables.

Five separate hierarchical (sequential) multiple regression models were fitted to estimate the adjusted associations between the APQ-26 themes for each symptom score. Potential confounding variables of participant's age, gender, main condition,

<sup>&</sup>lt;sup>1</sup> IBM SPSS Statistics Version 22: statistical software, IBM Corporation, Armonk, New York.

duration of condition **and whether the participant was a current patient** were included in the first block. Current pain was added in the second block if it was not the outcome variable for the model. In the third block, the five APQ-26 pacing theme scores were added to assess how pacing related to symptom outcome variables (Figure 1). The underlying assumptions of multiple regression (normality and homogeneity of variance of residuals, linearity and multicollinearity) were assessed for each model, and there was no evidence that the assumptions were violated.

Participants with one or more missing values for the symptom scores or independent variables were excluded from these analyses. Characteristics of participants with complete data on the **13** independent variables were compared with those with missing data to check for any potential bias. The two groups were compared using Pearson's chi-square test for dichotomous variables, and the independent-samples t-test for interval/ratio variables. Little's test for Missing Completely At Random (MCAR) was performed for this set of **13** variables, and also for this set plus each of the scores for physical fatigue, depression, avoidance and physical function in turn.

#### Results

#### **Participants**

Of the 311 participants who consented and completed the questionnaire booklet, **164** were patients currently awaiting/commencing physiotherapy and **147** had completed physiotherapy treatment; 31.8% were male and 68.2% were female; aged 18-91 years (mean=46.0 years); recruitment rate=20.3%. Participants could report more than one condition, but as their main condition low back pain was reported most frequently (65.0%), followed by chronic widespread pain (13.5%), CFS/ME (10.5%), fibromyalgia (7.9%), 'other condition' such as regional pain (3%).<sup>2</sup> One participant did not report having back pain, chronic widespread pain, fibromyalgia or CFS/ME as a main condition and was excluded from these analyses.

# **Completeness of data**

A maximum of 257 patients had complete data for an individual regression model, of whom 133 were current patients and 124 had completed physiotherapy. There was no significant difference between participants with complete data or those with missing data on 12 of the 13 independent variables. The only variable showing a statistically significant difference was activity consistency, with a higher mean among those with complete data (2.22, SD=1.00 v 1.89, SD=1.00, p=0.044). Little's MCAR test showed no evidence to reject the hypothesis that data were missing completely at random (p=0.526) over the 13 variables. Since this included the dependent variable for the regression model for current pain, participants included in this model appeared typical of the entire sample. This was also true for the other regression models (physical fatigue p=0.083, depression p=0.650, avoidance p=0.349 and physical function p=0.766).

#### **Correlation analysis**

Based on the participants who would be included in each of the regression models, Pearson's correlations between the APQ-26 and symptom scores (Table 2) showed similar findings to our previous analysis.<sup>15</sup> Activity adjustment was associated with higher levels of current pain, depression and avoidance, and lower levels of physical function. Activity consistency was associated with lower levels of physical fatigue, depression and avoidance and higher levels of physical function. Activity progression

<sup>&</sup>lt;sup>2</sup> CFS and ME were given as separate check box options to suit some patients' preferences but combined in the subsequent analyses because of the small number with ME.

was associated with higher levels of current pain. Activity planning was significantly associated with lower levels of physical fatigue, and activity acceptance was associated with higher levels of current pain and avoidance.

However, when adjusted for the other independent variables, including the other APQ-26 themes, the pattern changed (Table 2). Activity adjustment was significantly associated with higher levels of depression and avoidance and lower levels of physical function as before, but after adjustment, the association with pain was no longer significant; instead, it was significantly related to higher levels of physical fatigue. Activity consistency remained significantly associated with lower levels of physical fatigue, depression and avoidance and higher levels of physical function, but became significantly associated with lower levels of current pain. There were now no significant partial correlations between activity progression and any of the symptoms, while activity planning retained its significant association with lower levels of physical fatigue. Activity acceptance lost its significant association with current pain but retained its significant association with higher levels of avoidance.

# **Regression analysis**

In the regression models for current pain, physical fatigue, depression and physical function, the demographic variables entered in block 1 explained a significant portion of variance ( $R^2$ =13.2% to 19.6%, all p<0.001) (Table 3, Figure 2). The exception was avoidance ( $R^2$ =5.5%, p=0.066), where age, gender, main condition, duration of condition and being a current patient did not appear to be related to avoidance. Adding current pain in the models for physical fatigue, depression, avoidance and physical function always explained a further significant amount of variance ( $R^2$ =3.9% to 14.3%, all p<0.001). Adding the APQ-26 variables continued to explain a further significant amount of variance ( $R^2$ =13.4%

for avoidance, all p≤0.005). The total amount of variance explained in terms of adjusted  $R^2$  varied from 18.3% for avoidance to 38.9% for physical function. An  $R^2$  of 0.13 could be considered to be a medium sized effect and an  $R^2$  of 0.25 a large effect size from a transformation of Cohen's  $f^{2.36}$ 

In the final regression model for current pain (Table 3, Figure 2), being a current patient was a significant factor (p<0.001), with a mean pain score 1.60 points higher than that for retrospective patients. The conditions chronic widespread pain (p=0.004) and fibromyalgia (p=0.002) were also significant; participants with these conditions had mean scores that were 1.18 and 1.62 points higher (respectively) for current pain (0-10) than those with back pain, adjusted for other variables. Duration of condition was also positively associated with current pain (for log of duration, B=0.38, p=0.008). Of the APQ-26 themes, only activity consistency showed a significant association with current pain (B=-0.57, p=0.003), with higher consistency scores associated with lower pain scores.

In the final regression model for physical fatigue (Table 3, Figure 2), age was significantly associated with an increase in age of 1 year being related to an adjusted drop of 0.06 in fatigue score (p=0.003). Fibromyalgia was again significant in the final model; participants with fibromyalgia had an adjusted mean fatigue score that was increased by 1.83 points higher (p=0.037). Interestingly, CFS/ME was not significantly associated with higher levels of fatigue. Current pain was significantly associated with increased physical fatigue (B=0.46, p<0.001), as was activity adjustment (B=0.86, p=0.030). Activity planning (B=-0.90, p=0.025) and activity consistency (B=-1.02, p=0.002) were associated with decreased physical fatigue.

In the final regression model for depression (Table 3, Figure 2), being a current patient was significant (p=0.007), with current patients having a mean depression score 1.43 points higher than retrospective patients. Fibromyalgia was significantly associated with higher depression scores (p=0.011), participants with fibromyalgia having an adjusted mean depression score raised by 2.08 points. CFS/ME was significantly associated with depression too, with an adjusted mean score that was raised by 2.03 (p=0.005). Current pain was significantly associated with increased depression scores (B=0.66, p<0.001), as was activity adjustment (B=0.87, p=0.019). Activity consistency was associated with decreased depression scores (B=-1.05, p=0.001).

In the final model for avoidance (Table 3, Figure 2), the only significant associations were with **being a current patient (B=1.71, p=0.042)**, activity adjustment (**B=1.75**, p=0.004), activity acceptance (B=1.05, p=0.036) and activity consistency (B=-2.05, p<0.001), the latter being a negative association. In the final model for physical function, age **showed** a significant negative association with the outcome (B=-0.09, p=0.036). Participants with fibromyalgia (p=0.035) and CFS/ME (p<0.001) also had lower mean scores for physical function, reduced by 3.70 and 5.94 respectively. There were also negative associations with current pain (B=-1.35, p<0.001) and activity adjustment (B=-4.01, p<0.001), and a positive association with activity consistency (B=2.11, p=0.001).

# Discussion

The findings of this study drive forwards the debate surrounding the relationships between activity pacing and symptoms of chronic pain/fatigue. Activity pacing has previously been found to be associated with both better and worse symptoms of chronic pain/fatigue across different studies. Within the present individual study, mixed findings have similarly emerged. In contrast to previous studies, the present study measured pacing using a multi-dimensional scale<sup>15</sup> while previous studies implemented pacing subscales that were unidimensional.<sup>7</sup> Different themes of pacing, as found in the APQ-26, appear to be associated with better and worse symptoms. In agreement with our hypothesis, APQ-26 pacing themes that involve adjusting/limiting activities were generally associated with worse symptoms, whereas pacing themes involving having similar levels of activities each day/planning activities were associated with improved symptoms. Figure 3 shows a path diagram summarising the significant positive/negative adjusted associations between APQ pacing themes and symptoms. This illustrates that of the APQ-26 themes, activity adjustment and activity consistency have the most significant role in the associations between pacing and patients' symptoms.

Also as we hypothesised, the APQ-26 theme activity adjustment was associated with worse symptoms: increased fatigue, depression, avoidance and reduced physical function. The finding of an insignificant association between activity adjustment (involving pacing facets such as breaking down tasks) and pain opposes findings of Murphy et al.<sup>18</sup> whereby increased pacing was implemented both in reaction to increased pain (as a symptom-contingent strategy); but also, and unexpectedly, increased pain was consequential of increased pacing.<sup>18</sup> In contrast to the present study, Murphy et al.<sup>18</sup> measured pacing across regular time-intervals in the day to explore causality. Murphy et al.<sup>18</sup> described pacing in terms of breaking down tasks, but also going slowly/taking breaks and going at a steady pace; the latter two facets do not feature in the APQ-26.

On regression analysis, activity adjustment was significantly associated with worse fatigue, in concordance with some previous findings.<sup>17,18</sup> Since pain was found to be associated with fatigue, adjusting for pain may have allowed this association to emerge in the analysis. The association between activity adjustment and fatigue may in part be explained by some activity adjustment items referring to using rest breaks. Similarly, pacing has been found to be ineffective at reducing fatigue when defined predominantly in terms of reducing activities.<sup>37</sup>

Activity adjustment was significantly associated with increased depression. A similar pattern was found when pacing was measured using the POAM-P, the PARQ and the CPCI pacing subscales, but not associated with depression when pain was controlled.<sup>7</sup> It is suggested that increased utility of pacing facets that involve adjusting/limiting activities may have an effect on lowering mood due to the possible reduction in achievement of activities.<sup>7</sup>

Activity adjustment was significantly associated with higher avoidance. The PASS-20 Escape and Avoidance subscale includes items referring to going to bed during severe pain episodes, stopping and avoiding activities due to pain. This may help to explain the positive associations with activity adjustment which contains concepts of splitting up tasks, reducing duration of tasks and having rest breaks; facets that could be perceived as inferring an avoidance of activities. This concurs with the previous significant correlations between increased avoidance and increased pacing when pacing was measured using the items of the PARQ, POAM-P and CPCI.<sup>7</sup> The PARQ, POAM-P and CPCI pacing subscales appear limited in content, and refer to items of breaking down tasks and using rest breaks, most similarly to activity adjustment of the five APQ-26 pacing themes.

Activity adjustment was significantly associated with worse physical function. Similarly, Murphy et al.<sup>17</sup> found that pacing was significantly associated with lower physical activity on hierarchical linear regression after controlling for demographics, disability and other variables. Murphy et al.<sup>17</sup> measured pacing using only two modified items from the CPCI pacing subscale. Murphy et al.<sup>17</sup> concluded that the pacing facets of going slower and taking rests would logically correlate with lower physical activity. However, other studies implementing the CPCI, PARQ and POAM-P pacing subscales (also containing items referring to reducing activities) did not find that pacing was associated with disability or physical function when controlling for other covariates.<sup>7,11,12</sup>

As we hypothesised, the APQ-26 theme activity consistency was associated with improved symptoms. Activity consistency was significantly associated with lower pain and fatigue in the regression analysis. Implementing consistent activities may help to reduce the overactivity-underactivity cycle and the consequential fluctuations in pain/fatigue, whilst also promoting quota-contingent approaches to activity, rather than symptom-responsive behaviours.<sup>1,13</sup> Similarly, pacing has previously been found to be associated with reduced fatigue when defined in terms of having regulated activities.<sup>38</sup>

Activity consistency was significantly associated with lower depression, lower avoidance and increased physical function. We suggest that this association with improved mood may again be linked to reductions in fluctuating activity levels, and sense of achievement from undertaking some activity even on 'bad' days. Similarly, Cane et al.<sup>11</sup> found that the POAM-P pacing subscale was associated with lower depression (p<0.01) when avoidance and overdoing behaviours were controlled. The concept of engaging in activities on 'bad' days challenges avoidance behaviours as

described in the PASS-20 Escape and Avoidance subscale. Furthermore, this concept may share similarities with some of the features of task-contingent persistence behaviour identified by Kindermans et al.,<sup>7</sup> that is, attempting activities despite symptoms. Similarly to activity consistency, task-contingent persistence was previously found to be significantly associated with reduced disability.<sup>7</sup>

As hypothesised, the APQ-26 theme activity planning was significantly associated with some improved symptoms, that is, lower fatigue. Similarly to activity consistency, we suggest that planning activities in advance (for example, duration of activities), may assist a quota-contingent approach and the reduction of the over-activity/under-activity pattern. This in turn may result in lower fatigue levels than having an inconsistent/fluctuating approach to activities.

Contrary to our hypothesis, activity acceptance was significantly associated with some worse symptoms, specifically, increased avoidance. Activity acceptance contains items referring to saying 'no'/changing activity targets which may allude towards some avoidance of activities. This might also highlight differences between the APQ-26 theme of activity acceptance and other concepts/measures of acceptance.<sup>20</sup> Therefore, among the APQ-26 themes there are significant associations with both increased and decreased avoidance. This contrasts findings that pacing (measured using the POAM-P pacing subscale) is unrelated to avoidance and fear of movement.<sup>11</sup>

The APQ-26 pacing theme activity progression, in contrast to our hypothesis, was not significantly associated with better symptoms; nor was it significantly associated with worse symptoms in the regression model. The gradual progression of activities has been previously stated as a facet of pacing,<sup>1,13</sup> therefore its role as part of this coping strategy warrants further exploration.

As hypothesised, patients' demographic characteristics and pain severity acted as important mediators in the associations between the APQ-26 pacing themes and other symptoms, accounting for a significant proportion of the variance in the regression model among four of the five APQ-26 pacing themes. Of the reported main conditions, fibromyalgia was most frequently significantly associated with symptoms: being associated with increased pain, physical fatigue, depression and reduced physical function. Unexplainably, CFS/ME was not significantly associated with greater levels of fatigue, even when pain was controlled. More unexpected, and contrary to our predictions, were the lower reports of fatigue among patients of increasing age. It is speculated that perhaps patients with CFS/ME or increasing age accommodate to symptoms such as fatigue, and consequentially report the impact of fatigue to a lesser extent.

In agreement with our hypothesis, increased current pain was significantly associated with worsened symptoms, that is, increased fatigue, depression, avoidance and lower physical function (whilst controlling for demographic variables). Similarly, pain has previously been found to be associated with higher levels of depression and disability on regression analysis among a sample with chronic musculoskeletal pain.<sup>7</sup>

# Strengths and limitations

It cannot be assumed that these findings are transferrable for all patients, and at all times. Indeed, with emerging benefits of individually tailored pacing interventions,<sup>38-40</sup> it might be that patients with tendencies to overly persist with activities are advised to adjust/limit their activities, and implement pacing themes of activity adjustment, activity planning and activity acceptance. Conversely, patients with avoidant tendencies may benefit from setting goals, engaging in some activity on 'bad' days and gradually increasing activity levels (that is, implementing themes of activity

planning, activity consistency and activity progression).<sup>1,40</sup> Moreover, if pacing is instructed as a multifaceted construct, it allows for possible fluctuations in symptoms that arises in some long-term conditions.<sup>41</sup> The authors suggest that implementing the appropriate theme of pacing according to patients' needs at a given time, underpins the rehabilitative concept of pacing. Used in this way, a multidimensional approach to pacing could challenge previous findings that have questioned the role of pacing in rehabilitation programmes.<sup>12,37</sup>

The regression models found that the total amount of variance explained ranged from a substantial  $R^2$ =18.3% to 38.9%. However, it should be noted that the regression example, models did clinical observations (for not include detailed physiological/objective measurements). Being a current patient was associated with significantly worse scores for pain, depressive symptoms and avoidance, possibly because they were actively seeking help with their symptoms; scores on fatigue and physical function were also worse among current patients but not significantly so. It should be noted that the aim of the study was not a comparison of symptoms before and after treatment, rather correlations between pacing and symptoms at a single time point. Since the present study design was correlative and not causal, it cannot be determined whether the implementation of the five APQ-26 pacing themes led to better/worse symptoms, or whether symptoms led to the implementation of different pacing themes. Future study will implement longitudinal methods to explore the causal effects of pacing themes on symptoms, and assess changes in pacing following standardised pacing interventions.

#### Conclusion

Activity pacing is associated with both better and worse symptoms for patients with long-term conditions, and this varies according to the activity pacing themes that are implemented. Activity adjustment (breaking down tasks/using rest breaks) was associated with worse symptoms. Activity consistency (undertaking similar levels of activity) was the only APQ-26 pacing theme that was associated with improved symptoms for all dependent variables. The clinical implications of this are that activity pacing appears to be a multidimensional concept; and one that requires careful instruction for patients. Previous studies have measured pacing in terms of reducing/adjusting activities. However, different patterns of results were found in the present study when pacing was described to include other facets. If such controlled findings are replicated in longitudinal studies exploring causality, clinicians may be advised to implement activity consistency as the focus of future pacing interventions. With increasing research in this field, it is becoming apparent that the description of pacing is imperative to understanding the effects of pacing. The APQ-26 is a comprehensive scale that can be used to explore the associations between different activity pacing themes and symptoms. This would help to guide clinicians towards advocating themes of pacing with the potential to reduce disability, manage pain and improve other symptoms of long-term conditions.

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#### **Figure Legends**

Figure 1. Hierarchical (sequential) multiple regression model: five separate multiple regression models for the symptoms: current pain, physical fatigue, depression, avoidance and physical function

Figure 2. Significant associations from the hierarchical (sequential) regression analysis Figure 3. Significant adjusted associations (standardised regression coefficients) between APQ-26 pacing themes and symptoms

# Table 1. Examples of items contained within each of the five themes of activity pacing in the APQ-26

Theme	Items
Activity adjustment	I broke tasks up into periods of activity and rest
	I took a short rest from an activity so that I could complete the activity later
Activity consistency	I did a similar amount of activity on 'good' and 'bad' days
	I kept to a consistent level of activity every day
Activity	I gradually increased how long I could spend on my activities
progression	I gradually increased activities that I had been avoiding because of my
	symptoms
Activity planning	I planned in advance how long I would spend on each activity
	I set activity goals that were meaningful for me
Activity acceptance	I changed my activity targets if they were unrealistic
	I was able to say 'no' if I was unable to do an activity

Table 2. Corr	elations of APQ-2	26 scores with syn	nptoms scores for	participants inc	luded in the
regression mo	odel for each sym	ptom			

	Current	Chalder	HADS	PASS	SF-12
	pain (0-10)	physical	depression	avoidance	physical
		fatigue			component
	(n = 257)	(n = 252)	(n = 249)	(n = 240)	(n = 253)
Pearson correlations					
Activity adjustment	.176 (.005)	.066 (.300)	.135 (.033)	.239 (<.001)	337 (<.001)
Activity consistency	098 (.116)	280 (<.001)	280 (<.001)	196 (.002)	.182 (.004)
Activity progression	.123 (.050)	072 (.257)	007 (.914)	.073 (.262)	101 (.108)
Activity planning	.096 (.126)	138 (.029)	052 (.418)	.102 (.113)	113 (.074)
Activity acceptance	.142 (.023)	.011 (.867)	002 (.977)	.188 (.003)	105 (.094)
Partial correlations <sup>a</sup>			$\checkmark$		
Activity adjustment	.055 (.387)	.140 (.030)	.152 (.019)	.192 (.004)	309 (<.001)
Activity consistency	190 (.003)	202 (.002)	223 (.001)	277 (<.001)	.207 (.001)
Activity progression	.118 (.065)	050 (.441)	028 (.672)	.014 (.831)	.083 (.199)
Activity planning	003 (.964)	144 (.025)	051 (.438)	035 (.598)	021 (.750)
Activity acceptance	.075 (.243)	.087 (.177)	035 (.590)	.139 (.036)	.099 (.125)

P-values in parentheses. Significant associations ( $p \le 0.05$ ) are highlighted in bold.

APQ=Activity Pacing Questionnaire; HADS=Hospital Anxiety and Depression Scale;

PASS=Pain Anxiety Symptoms Scale; SF-12=Short-Form 12

<sup>a</sup> adjusted for age, female, main condition, duration, **current patient,** current pain (except

when dependent variable) and other APQ-26 activity scores using multiple regression.

0 /	Cur	rent pai	in (0-		Chalde	r		HADS		PAS	SS avoid	ance	SF	-12 phys	sical
		10)		phy	sical fat	tigue	d	lepressi	0 <b>n</b>				C	ompone	nt
		(n=257)	)		(n=252)	)		(n=249	)		(n=240)	)		(n=253)	)
Variable	Δ	Part	Р	Δ	Part	Р	Δ	Part	Р	Δ	Part	Р	Δ	Part	Р
s added	$\mathbf{R}^2$	ial		$\mathbf{R}^2$	ial		$\mathbf{R}^2$	ial		$\mathbb{R}^2$	ial F		$\mathbb{R}^2$	ial	
		F			F			F						F	
Block 1:	.18	8.31	<.0	.13	5.23	<.0	.19	8.38	<.0	.05	1.93	.06	.18	8.07	<.0
Age,	9		01	2		01	6		01	5		6	7		01
female,															
main															
condition															$\lor$
, log of															
duration,											$\wedge$				
current														·	
patient															
Block 2:	n/a	n/a	n/a	.07	23.5	<.0	.14	51.8	<.0	.03	9.84	.00	.13	49.1	<.0
Current	a			7	4	01	3	8	01	9		2	6	1	01
pain								X							
Block 3:	.05	3.47	.00	.08	5.54	<.0	.06	4.69	<.0	.13	7.85	<.0	.09	7.96	<.0
APQ-26	4		5	2		01	0		01	4		01	7		01
scores															
Final	β	В	95	β	В	95	β	В	95	β	В	95	β	В	95
model			%			%			%			%			%
			СІ			CI			CI			CI			CI
Age	.00	-		-	-	-	-	03	-	-	03	-	-	09*	-
(years)		.000	.02,	.18	.06**	.10,	.09		.07,	.07		.09,	.12		.17,
		1	.02			02			.01			.03			01
Female	-	51	-	-	34	-	-	53	-	-	30	-	-	38	-
	.08		1.1	.03		1.4	.05		1.6	.02		1.9	.02		2.7

Table 3.	Hierarchical multiple regression analysis of symptom scores against age,	
gender,	condition, duration, current pain and APO-26 scores	

			9,			8,			0,			9,			1,
			.18			.80			.54			1.3			1.9
												9			5
Chronic	.16	$1.18^{*}$	.38,	.07	.78	-	.04	.44	-	.08	1.36	-	-	29	-
widespre		*	1.9			.55,			.84,			.63,	.01		3.0
ad pain			8			2.1			1.7			3.3			7,
						6			1			6			2.4
															8
Fibromy	.16	1.62*	.61,	.12	1.83*	.12,	.14	$2.08^{*}$	.48,	-	-1.94	-	-	-	-
algia		*	2.6			3.5			3.6	.09		4.5	.11	3.70*	7.1
			3			4			8			7,		$\boldsymbol{\boldsymbol{\boldsymbol{\wedge}}}$	5, -
												.69			.26
CFS/ME	-	20	-	.06	.78	-	.15	2.03*	.60,	-	-1.74		_	-	-
	.03		1.1			.75,		*	3.4	.09	$\boldsymbol{\mathcal{K}}$	4.0	.19	5.94*	9.1
			3,			2.3			6			8,		**	1, -
			.73			1						.60			2.7
											/				8
Log of	.16	.38**	.10,	.03	.12	-	.00	00	-		21	-	-	15	-
duration			.66			.35,			.45,	.04		.93,	.02		1.1
						.59			.44			.50			1,
															.80
Current	.29	<b>1.60</b> *	.96,	.07	.69	-	.15	1.43*	.40,	.13	<b>1.7</b> 1 <sup>*</sup>	.06,	-	-1.69	-
patient		**	2.2			.42,		*	2.4			3.3	.08		3.9
			4			1.8			7			6			7,
						0									.58
Current	n/a	n/a	n/a	.28	.46**	.26,	.39	.66***	.47,	.12	.29	-	-	-	-
pain					*	.67		*	.86			.02,	.36	$1.35^{*}$	1.7
												.60		**	7, -
															.93
Activity	.08	.21	-	.18	.86*	.08,	.19	.87*	.14,	.27	$1.75^{*}$	.58,	-	-	-

adjustme			.26,			1.6			1.6		*	2.9	.38	$4.01^{*}$	5.5	
nt			.67			3			0			3		**	9, -	
															2.4	
															4	
Activity	-	-	-	-	-	-	-	-	-	-	-	-	.20	$2.11^{*}$	.84,	
consisten	.20	.57**	.95,	.21	$1.02^{*}$	1.6	.22	$1.05^{*}$	1.6	.31	$2.05^{*}$	2.9		**	3.3	
су			20		*	4, -		**	4, -		**	9, -			9	
						.39			.46			1.1				
												2				
Activity	.15	.36	-	-	25	-	-	13	-	.02	.10	-	.09	.85		k
progressi			.02,	.06		.88,	.03		.72,			.84,	<u>_</u>		.45,	
on			.75			.39			.46			1.0	Γ.		2.1	/
												5			4	
Activity	-	01	-	-	90*	-	-	29	-	-	32	-	-	26	-	
planning	.00		.49,	.20		1.6	.06		1.0	.05		1.5	.03		1.8	
			.47			8, -			3,			3,			6,	
						.11			.45			.88			1.3	
											•				4	
Activity	.09	.24	-	.10	.45	-	-	17	-	.17	$1.05^{*}$	.07,	.10	1.04	-	
acceptan			.16,			.21,	.04		.79,			2.0			.29,	
ce			.63			1.1			.45			2			2.3	
						1									8	
	ANC	OVA F=	6.53,	ANG	OVA F=	7.51,		ANOVA	A	ANG	OVA F=	5.12,		ANOVA	A	
	1	p<0.001			p<0.001			F=11.99	),		p<0.001	l		F=13.32	,	
								p<0.001	1					p<0.001		
	Ad	j R <sup>2</sup> =0.2	206	Ac	lj R <sup>2</sup> =0.2	252	Ac	lj R <sup>2</sup> =0.	365	Ac	lj $R^2 = 0.1$	183	Ac	lj R <sup>2</sup> =0.3	389	

HADS=Hospital Anxiety and Depression Scale; PASS=Pain Anxiety Symptoms Scale; SF-12=Short-Form 12;

 $\beta$ =standardised regression coefficient; B=unstandardised regression coefficient; \*=p $\leq 0.05$ ; \*\*=p $\leq 0.01$ ; \*\*\*=p $\leq 0.01$ ;

<sup>\*</sup>p≤0.05, <sup>\*\*</sup>p≤0.01, <sup>\*\*\*</sup>p≤0.001 <sup>a</sup> Current pain was the dependent variable

Figure 1. Hierarchical (sequential) multiple regression model: five separate multiple regression models for the symptoms: current pain,

physical fatigue, depression, avoidance and physical function.

Block 1	Block 2	Block 3	<b>Dependent variables</b> Symptoms
			Current pain
Patient demographics Age Gender Main condition	Current pain (when not the dependent variable)	APQ-26 pacing themes Activity adjustment Activity consistency Activity progression	Physical fatigue
Duration of condition Patient status		Activity planning Activity acceptance	Depression
			Avoidance
			Physical function

# Figure 2. Significant associations from the hierarchical (sequential) regression analysis



# Figure 3. Significant adjusted associations (standardised regression coefficients)



between APQ-26 pacing themes and symptoms

\*p≤0.05, \*\*p≤0.01, \*\*\*p≤0.001