



Exploring patients' opinions of activity pacing and a new activity pacing questionnaire for chronic pain and/or fatigue: a qualitative study

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Abstract

Objective Despite the frequent recommendation of activity pacing as a coping strategy for patients with chronic pain and/or fatigue, pacing is interpreted in different ways and there is an absence of a widely accepted pacing scale. We have developed a new Activity Pacing Questionnaire (APQ). The aims of this study were to explore patients' views and beliefs about the concept of pacing, together with the acceptability of the APQ.

Design Qualitative pragmatic study using semi-structured telephone interviews. Data were analysed using Framework analysis.

Participants 16 adult patients attending secondary care physiotherapy out-patient departments were recruited via purposive sampling. Diagnoses included chronic low back pain, chronic widespread pain, fibromyalgia and chronic fatigue syndrome/myalgic encephalomyelitis.

Findings Pacing emerged as a multifaceted concept from participants' descriptions. The implementation of pacing was influenced by participants' age, the presence of co-morbidities and participants' emotions. The APQ was found to be generally acceptable in comparison to two existing pacing subscales. Participants undertook activities using quota/symptom-contingent approaches. Four behavioural typologies emerged: Task avoidance, Task persistence, Task fluctuation (boom-bust) and Task modification (activity pacing).

Conclusions The APQ appears to be easy to complete, and acceptable to patients who are attending physiotherapy for the management of long-term conditions. It emerged that individual patients implemented different pacing facets to varying degrees, and that different behavioural typologies were apparent. The relationships between behavioural typologies and facets of pacing warrant further investigation to facilitate the development of effective tailored pacing interventions.

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Introduction

Activity pacing has been described as a pattern of activity, a behaviour and a coping strategy [1–7]. Pacing involves modifying activities to improve function and reduce disability [2,8,9]. Accordingly, pacing is frequently advised in pain management programmes for long-term conditions (LTC), such as chronic low back pain, chronic widespread

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pain/fibromyalgia and chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) [1,10,11].

The development of LTC may be associated with altered behaviours such as avoidance, which is recognised in the fear-avoidance model [1,5,12]. Unchallenged, avoidance can manifest in reduced function and altered mood (for example, depression) [12]. In contrast, confrontation behaviour involves continuing activities without fear of pain/(re)injury [12]. Confrontation or ‘persistence’ of activities has been associated with reduced disability, depression and pain [10,13]. However, excessive persistence may be unsustainable and can lead to overuse, increased symptoms and enforced rest [1,14–17]. Therefore, excessive persistence may activate the overactivity–underactivity (boom–bust) cycle [2,16,18]. This cycle involves high activity levels on ‘good’ days and consequential ‘bad’ days of low activity [16].

Activity pacing has the aim of reducing avoidance, over-exertion and fluctuations between the two [4,14,16,19]. Pacing, as a pain management strategy is believed to have been first addressed by Fordyce in 1976 [4,16]. Fordyce [20] advised undertaking activities according to time/goal quotas (rather than symptoms) to challenge underactivity/overactivity. Subsequent pacing descriptions include: activity-rest cycling, symptom-contingency/energy conservation and graded activity, without a clear consensus on one description [4,11,21].

Despite the proposed benefits of pacing, the empirical evidence is sparse and conflicting; pacing being associated with better and worsened symptoms [1,6]. This may be partly due to the absence of a widely accepted pacing scale. There are pacing subscales within the Coping with Rheumatic Stressors questionnaire (CORS) [22], the Chronic Pain Coping Inventory (CPCI) [9], the Pain and Activity Relations Questionnaire (PARQ) [5] and the Patterns of Activity Measure-Pain (POAM-P) [7]. However, existing pacing subscales appear limited in content, reflecting concepts of reducing over-exertion, but not reducing under-exertion/fluctuating activities. Furthermore, there is no validated scale for patients whose predominant symptom is fatigue. To date, the acceptability of existing subscales has not been explored. Acceptability has been defined as ‘the degree to which somebody agrees that something is good enough to use or allow’ [23]. Therefore the content of existing scales may not reflect patients’ interpretations of pacing.

We have developed an Activity Pacing Questionnaire using mixed methods (see Fig. 1). Stage I, the Delphi technique, involved 49 clinicians and 10 patients to develop the original 38 questionnaire items [24]. Stage II, the psychometric study, implemented a cross-sectional, questionnaire design study. Following factor analysis, 12 items were removed and five broad themes of pacing emerged in the APQ-26. Each theme demonstrated satisfactory internal consistency (Cronbach’s $\alpha = 0.72$ to 0.92), test–retest reliability (intraclass correlation coefficient, ICC = 0.50 to 0.78 , $P \leq 0.001$) and construct validity against the CPCI and

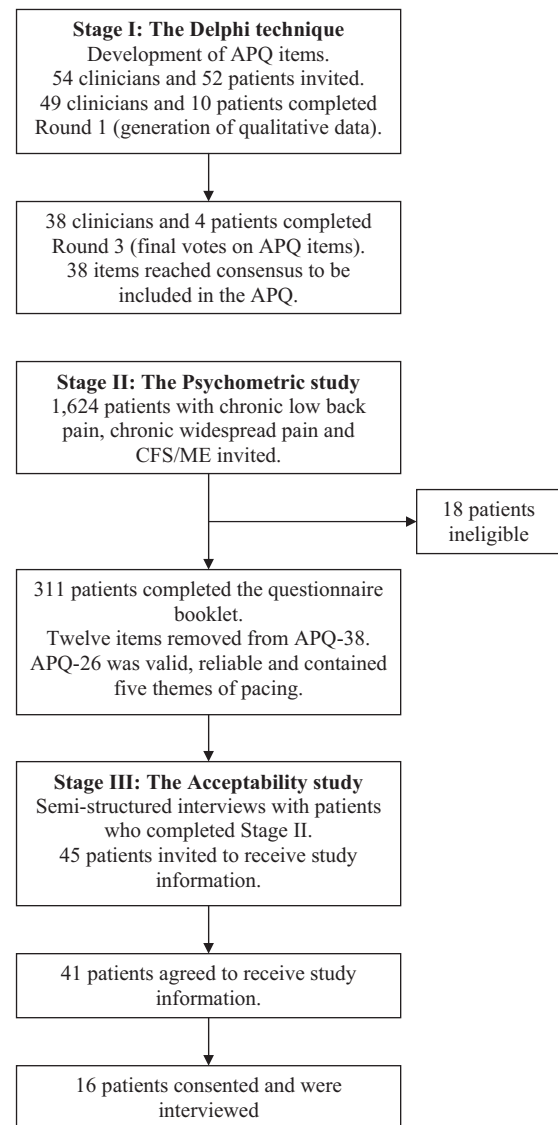


Fig. 1. Flow chart of recruitment into the mixed methods study to develop the activity pacing questionnaire (APQ).

PARQ pacing subscales [25]. This paper presents Stage III, the acceptability component. The aims of Stage III were twofold:

- (1) explore patients’ views and beliefs about the concept of pacing,
- (2) assess the acceptability of the APQ-38, and CPCI and PARQ pacing subscales.

Methods

Qualitative study design

Semi-structured telephone interviews were used to explore patients’ opinions on pacing and the acceptability of the pacing scales (see Fig. 2).

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